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Evaluation of Patient Needs and Patient Navigator Communication about Cervical Cancer Prevention in Appalachian Kentucky

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Abstract

Few studies describe the way patient navigation processes may address disparities in treatment and follow-up care for medically underserved populations. Using a social ecological framework, we analyzed survey assessments of 519 patients completing a randomized navigation trial in Appalachia Kentucky to examine patient-reported barriers to follow-up cervical cancer care. We also analyzed in-depth interview transcripts with four lay patient navigators in the trial to identify barriers to follow-up care and to learn what communication strategies navigators use to successfully (or unsuccessfully) help patients navigate around those barriers. Our analysis provides insight into how patient navigation may improve adherence to follow-up care through assisted uncertainty management. We also discuss opportunities for improving navigator training to address disparities in clinical outcomes.

Keywords

Appalachian; cervical cancer; patient navigation; prevention; social support

In 2010, over 4,000 women in the United States died from invasive cervical cancer, a disease that is preventable and treatable (American Cancer Society, 2012). Well-documented disparities based on socio-economic status, race, ethnicity, and quality of health insurance are associated with inequalities in cervical cancer detection and care (Freeman, 2006; Hopenhayn, Bush, Christian, & Shelton, 2005; Wingo et al., 2008). Despite the availability of free coverage for Papanicolaou (Pap) test screening and follow-up care, many women do not return for follow-up care after abnormal cytology findings and thus risk developing cervical cancer.

Women in medically underserved communities, including women in rural Appalachia, are less likely than women in more medically advantaged areas to receive the benefits from available care (Freeman & Wingrove, 2005). In Appalachian Kentucky, women are more likely to die from cervical cancer than women residing elsewhere in the United States (Hopenhayn, King, Christian, Huang, & Christian, 2008). From 2005–2009, Appalachian women, a predominantly White population, had significantly higher age-adjusted invasive cervical cancer (ICC) incidence rates (9.85/100,000 people) than non-Hispanic White

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women in the United States (7.1/100,000 people; Kentucky Cancer Registry, 2012; Howlander, Noone, Krapcho, et al., 2012). The same pattern held for mortality over the 2005–209 time period: Appalachian Kentucky women had a cervical cancer mortality rate of 3.5 per 100,000, whereas mortality rate among non-Hispanic White women was 2.1 per 100,000 (Kentucky Cancer Registry, 2012; Howlander, Noone, Krapcho, et al., 2012). This disparity can be explained, in part, by lack of appropriate follow-up treatment after an abnormal Pap test and more late-stage ICC diagnosis in Appalachian Kentucky (Schoenberg, Baltisberger, Bardach, & Dignan, 2010).

As one method of improving patient follow-up care outcomes, the National Cancer Institute has supported the introduction of lay patient navigation programs in medically underserved areas to provide guidance and support to an individual with abnormal cancer screening results or with a cancer diagnosis. Although variations in definitions of patient navigation exist (Dohan & Schrag, 2005; Freeman, 2006), in the present research, patient navigation involves a trained lay navigator helping individual patients surmount barriers to health care, such as barriers related to insurance or finances, accessing or understanding information, or coordination of care. In the current study, the goal of the patient navigation program was to help patients secure appropriate and timely care from screening (i.e., evaluating an abnormal Pap test) until resolution of treatment.

Kentucky provides access to breast and cervical cancer screening for low-income women through the Kentucky Women’s Cancer Screening Program, funded by the Centers for Disease Control and Prevention’s Breast and Cervical Cancer Early Detection Program. For women participating in the program, the mechanism for receiving treatment and follow-up care requires that women receive cancer screening from a local health department. Results of Pap testing are not immediate, requiring women whose test results indicate abnormal cytology to return for follow-up assessment. This follow-up often involves referral to outside providers for OB/GYN screening and appropriate treatment, and this external referral often is a barrier to further care. It is at this point of referral that patients may be advantaged by the opportunity to connect with a lay navigator to help guide them through the follow-up process, ideally through treatment and back to routine care from the health department or the specialist provider.

A number of barriers to appropriate and timely care have been identified as factors that exacerbate health inequality (Epstein, 2004; Fremont et al., 2003). In the case of individuals diagnosed with an abnormal Pap test, barriers related to work-family demands, emotional stress, lack of transportation and childcare may be particularly pronounced for low-income patients residing in medically underserved communities. Additionally, sociocultural beliefs (e.g., medical mistrust) may account for barriers to care in certain subpopulations, including Appalachians (Freeman, 2004). Research has demonstrated that patient navigation is an effective method to reduce disparities in cancer care for poor and minority populations by helping them overcome barriers to access care (Dohan & Schrag, 2005; Freeman, 2004, 2006). Navigators can provide personal advocacy, local knowledge, and assistance from the lay perspective to help patients access health services that they need and overcome barriers to obtaining follow-up care (Eggleston, Coker, Das, Cordray, & Luchok, 2007; Jean-Pierre, Fiscella et al., 2011; Jean-Pierre, Hendren et al., 2011).

Previous research on medically underserved populations has used a social ecological perspective to explain barriers to women's receipt of follow-up cervical cancer care (Schoenberg, Hatcher, & Dignan, 2008; Schoenberg et al., 2010). According to the social ecological model, it is the dynamic interaction among multiple levels of factors, including individual, interpersonal, organizational, community, and cultural factors, that contributes to the health of a population (Bronfenbrenner, 1977). Research by Schoenberg and colleagues (2010) has identified patient-level determinants of follow-up to abnormal Pap tests and has found that lack of follow-up care has been associated with being young, having a low education level, lacking insurance, fearing cancer, being embarrassed, and lacking knowledge about the need for or process of follow-up care. This line of research also has detailed a number of organizational factors that are associated with a lack of follow-up care, including inadequate medical record documentation, inaccessible location, and poorly developed systems for tracking follow-up care (Schoenberg et al., 2010). Finally, some research has identified community- and cultural-level factors affecting follow-up to abnormal Pap tests, such as rural residence in Appalachia, which often entails resource scarcity and strong kinship ties (see Schoenberg et al., 2010).

Although previous work has examined factors at the individual, organizational, community, and cultural levels, less attention has been paid to the interpersonal level of influence on women's cervical cancer follow-up care and how interpersonal processes may help women overcome socio-ecological barriers to follow-up care. In particular, the interpersonal influence of social support remains understudied in the context of patient navigation (Breitkopf, Catero, & Berenson, 2004). This is surprising given that one of the key features of patient navigation programs is the provision of social support to patients, including assistance with information management, tangible needs, and emotional validation (Jean-Pierre, Hendren et al., 2011).

Navigation programs assume that lay support strategies can improve health equity for medically underserved populations (Wells et al., 2008). However, research is needed to examine the potential benefits and limitations of navigation support practices in addressing barriers to care. Thus, in the present study, we focus on the role of patient navigator communication in addressing barriers to patients' receipt of follow-up appropriate cervical cancer care and prevention services. Specifically, we asked the following research questions: What factors do Appalachian patients receiving abnormal Pap test results identify as barriers to appropriate follow-up care? To what extent do navigators acknowledge and address the barriers identified by patients? What communication strategies do navigators use to help patients address those barriers? What additional barriers to follow-up care do navigators identify, and how do they report addressing them?

Method

Field Sites

We conducted the current research in two Appalachian Kentucky Area Development Districts, which included 13 of Kentucky's 54 Appalachian counties. The counties were generally representative of the region: They were highly rural and had low population density, families with low socioeconomic status, and a shortage of health care provider and

OB/GYN services (see Kentucky Health Facts, 2012). In Kentucky, local health departments are charged with providing low-cost or free cervical cancer screening services as part of the Kentucky Women's Cancer Screening Program. Given the high rates of poverty and un- or under-insurance, residents heavily rely on state-funded medical care programs. The local health departments were thus an ideal venue in which to conduct research on health disparities.

Samples

In the present research, we used a purposive sampling strategy to recruit patients into the navigation intervention program and to select navigators to interview for the study. For the patient participants, eligible women had received an abnormal Pap test result (which indicates the presence of abnormal cells but does not provide a diagnosis of cancer or dysplasia, a pre-cancerous condition), were residents of Appalachia Kentucky, and were able and willing to participate in the study, which entailed completing a baseline survey administered in person by a patient navigator at the time of enrollment. Health department patients who received an abnormal Pap result from September 2008 to April 2010 were eligible to participate in the study. We contacted 656 patients by phone or in person when the nurse case manager and navigator team found abnormal Pap results during record review. These women were offered enrollment in the project; 41 (6%) women refused, and 96 (15%) women were considered passive refusals (i.e., women who initially agreed to participate but could not be reached again for enrollment). This resulted in a sample of 519 enrolled patients, ranging in age from 18 to 72 years old (*M* = 29 years, *SD* = 11 years).

As the demographic information in Table 1 indicates, the sample was predominantly White and was characterized by relatively low levels of education, household income, and insurance coverage. The patient follow-up care needs at the time of intake are also reported in Table 1. Although one in ten Pap tests indicates some abnormality, most cases are not serious. Follow-up recommendations for further evaluation were based on a protocol established by the Kentucky Women's Cancer Screening Program. About half of the patients reported that they had decided to follow their provider's recommendation for follow-up care (*n* = 259, 49.9%).

We also conducted in-depth face-to-face interviews with patient navigators who were currently working with patients completing the navigation intervention. The navigator participants were adult female residents of Appalachia Kentucky. Due to the embedded nature of the navigators as part of a broader community-based research project identified by a federal funding number, we have withheld navigators' demographic information to ensure confidentiality (and we do not use pseudonyms to prevent inferences being drawn from names). All available patient navigator staff (*N* = 4) at the close of study enrollment agreed to be interviewed as part of summative evaluation activities. (Over the course of the study period, many navigators were offered permanent positions in the health department or received other full-time employment offers, necessitating ongoing recruitment of new navigators to enroll patients. A total of 11 navigators enrolled patients in the intervention, with between 4 and 6 navigators recruiting participants at any given time.)

Survey Protocol

The present research was part of a larger clinic-randomized navigation project examining cervical cancer prevention in Appalachian Kentucky. A research protocol was established between each nurse case manager and patient navigator, in which patient navigators would review clinic records to identify potentially eligible patients for the research study. All patients with an abnormal Pap result were referred for navigation by nurse case managers as part of the standard of care provided by the health departments. Although each nurse case manager/navigator team had its own approach, navigators followed a general script for study enrollment (and phone recruitment if first contact was not made by personal introduction after a visit with a nurse in the health department). When possible, navigators spoke with patients immediately following a nurse's disclosure of an abnormal Pap test to inform them about the research study (including the $25 gift card incentive) and invite them to participate.

After a patient provided informed consent, the navigator asked the patient questions using a structured survey protocol and recorded patient responses in real time. Patients were asked to provide demographic information and to identify barriers to follow-up care (using a yes/no response) from a predetermined list of barriers elicited from prior research (Schoenberg et al., 2010). In addition, patients reported whether they had decided at baseline (i.e., before receiving navigation services at the close of the meeting) to follow their provider's recommendation for follow-up care. The survey, which took 20–30 minutes to complete, was part of the initial navigation meeting, which typically lasted one hour. The survey protocol was designed as a formative assessment to allow the navigators to determine the most significant barriers to follow-up care; the latter portion of the meeting involved the navigator providing informational, logistical, or emotional support to help overcome patient barriers to appropriate care. All patients (regardless of clinical trial participation) were offered the full range of navigation assistance.

Quantitative Data Analysis

Before developing our in-depth interview protocol for navigators, we analyzed the patient survey data using descriptive statistics to explain the nature of the population served by the navigation program, and we used inferential statistics to explore the associations between population characteristics, patients' decisions (at baseline) to receive appropriate follow-up care, and patient-perceived barriers to follow-up care.

In analyzing the patient survey data, we computed the frequencies of the patient-reported barriers to receiving follow-up care, which are presented in Table 2. The most frequently cited barriers were lack of insurance and cost, followed by fear of the results and fear of pain. Given the availability of low-cost or free follow-up care in Kentucky, the frequency with which cost was cited as a barrier to follow-up care evidences the patients' uncertainty about access to this care. Furthermore, the high frequency of fear of the results and fear of pain (from treatment procedures) as barriers to follow-up care is an important finding. Because HPV infections can lead to uncertainties regarding whether cervical abnormalities will recur, women's fear of the test results and fear of pain may be due to past experiences with treatment procedures, and the desire to avoid (by not pursuing care) additional follow-up Pap tests, diagnoses, and treatment. This fear may influence some women to maintain their uncertainty about their diagnosis and treatment (by not pursuing care) rather than reduce their uncertainty (by pursuing care). Thus, we decided to further investigate patient uncertainty experiences in the interviews with navigators.

In the second stage of quantitative analysis, we computed chi-square statistics to determine if there were any associations between patient demographic factors (see Table 3) or barriers to follow-up care (see Table 2) and whether the patient had decided to pursue appropriate follow-up care as recommended by her provider at the time of the baseline survey. There were no significant associations between appropriate follow-up care and age, education, or household income. These findings suggest that demographic factors do not significantly differentiate those patients who stated a decision to pursue appropriate follow-up care (i.e., by already having had an appointment or by scheduling one) from those who did not among women sampled in these health departments. We also found that most of the patient-reported barriers to follow-up care did not significantly distinguish between patients who reported a decision to pursue appropriate follow-up care and those who did not. In fact, the results from this analysis indicated that significantly more women who reported that clinic hours were a barrier to receiving care actually stated a decision to pursue appropriate follow-up care, and significantly more women who indicated that follow-up care was not a problem had not, at the time of baseline assessment, decided to pursue appropriate follow-up care.

These findings indicate that the logistical and procedural factors that many patient navigation programs assume are barriers to follow-up care are indeed common, but they may not necessarily be associated with the decision to receive appropriate follow-up care following an abnormal Pap test result. This suggests that there are other factors that are deterring women from receiving follow-up care. The goal of our qualitative approach was to further our understanding of these other factors. We used in-depth face-to-face interviewing to examine to what extent navigators acknowledged patient-reported barriers, to identify what additional barriers not explicitly considered in the survey were perceived by navigators as relevant to the patients' receipt of care, and to learn what communication strategies the navigators used to successfully or unsuccessfully help patients address those barriers. The use of quantitative and qualitative data collection and analysis methods allowed us to triangulate findings from these parallel protocols.

Interview Protocol

The four patient navigators were each interviewed by one of two of the authors (EC and AS) after providing informed consent. No incentive was provided for participation as the navigators participated in their role as project employees. The interviews followed a semi-structured protocol designed to elicit narratives focused on the navigator's perceptions of what helped or hindered patients in pursuing follow-up care for abnormal Pap tests. The interview protocol was based in part on the most common patient-reported barriers that influence navigation success (see Table 4). In addition, we also explored additional barriers to patient receipt of navigation and appropriate care (such as patient uncertainty), including navigators' difficulties communicating with patients (e.g., "Can you tell me about a time when a patient wasn't willing to follow up after her diagnosis and you had a hard time navigating her through the follow up process?") and the challenges to overcoming patient obstacles to follow-up care (e.g., "Can you tell me about a time when a patient did not get follow-up care no matter what you did to help?"). Finally, we explored how navigators successfully used communication to help patients overcome barriers to care (e.g., "Can you tell me about a time when a patient got follow-up care because of something you did or said to help?"). The interviews took place in each navigator's office and lasted between 55 and 80 minutes. The interviews were audio-recorded and professionally transcribed verbatim.

Qualitative Data Analysis

We analyzed the transcripts of the navigator interview data using qualitative descriptive analysis, a low-inference method designed to gain an accurate accounting of a phenomenon in the "everyday terms" of the phenomenon and an accurate understanding of the meanings participants attach to the phenomenon (Sandelowski, 2000, p. 336). Two of the authors (EC and AS) independently examined the transcripts and then met to discuss general emergent themes in the navigators' narratives about difficult and rewarding cases of navigation. After refining the themes through discussion, the two authors returned to the transcripts to code for how patient uncertainty and navigator support were related to follow-up care successes and difficulties. The authors met again to reach consensus on whether the interviews identified additional barriers to follow-up care that were not considered as part of the baseline survey and what communication strategies navigators used to help patients address barriers to follow-up care.

Results

The navigators had no difficulty recounting their successful and difficult cases navigating patients to appropriate care. Their stories confirmed patient-reported barriers to follow-up cervical cancer care and identified additional barriers faced by Appalachian women. We identified three themes in the navigators' accounts: (a) Logistical barriers to care can mask patient uncertainties about care outcomes, (b) Navigators strategically use certain and uncertain information about cervical abnormalities to motivate patients to receive appropriate follow-up care, and (c) Relational and personal value conflicts pose challenges to patient navigation.

Logistical Barriers to Care Can Mask Patient Uncertainties About Care Outcomes

Patient navigators were well-prepared to communicate with patients to resolve logistical barriers to care (i.e., barriers related to the procurement, fulfillment, and maintenance of appropriate health care). Because this was a low-income population residing in a medically underserved region with limited access to providers, all patients needed to receive follow-up care outside the known health department setting. According to the navigators, patients commonly expressed concerns about who would treat them and where they would get treatment:

> A lot of women doesn't want a female doctor, so. Yeah, a lot of women won't want a female, they'll only want a male. And then a lot of women are the opposite, they'll only want a female and not a male, and then we have one male doctor here, so that kind of makes it difficult with scheduling.…little things like that that bother

> them more than having the actual Pap, you know, it's just social issues, not knowing their way around the office there at [clinic name], that scares people because of the hallways. (Navigator 4)

Logistical barriers were issues that the navigators felt equipped to handle. They knew the terrain of the buildings that patients would visit and could provide assistance in bringing patients to their appointments and scheduling certain providers.

Other logistical barriers related to issues of cost: "They wonder how they're going to pay. They want to know how it's going to be paid for" (Navigator 4). The navigators were able not only to help patients understand how payment works so that the patients would accept free or low-cost follow-up care, but they also completed many of the tasks associated with securing payment for care, such as completing and faxing reimbursement paperwork to clinics.

Another logistical barrier to follow-up care involved scheduling (and rescheduling) appointments. The navigators often acted as the go-between for patients and their nurse case managers, who perceived missed appointments as a burden on their caseload. What appeared to be a logistical concern, however, could mask a patient barrier to follow-up care rooted in uncertain knowledge about screening outcomes. For example, navigators perceived that underlying motivations for missed appointments often included women's uncertainty related to and fear of confirming a cancer diagnosis or fear of pain (which is consistent with the patient-reported barriers to care from our quantitative analysis). Navigators believed that some patients indicated that they had scheduling barriers when the real barrier was fear of a cancer diagnosis. As one navigator recounted:

> Some get lost to follow up because they just, you know, they promise the moon. And it amazes me, I'm like, "Here you have something very treatable, you know, caught early and you'll just." It's like [patients think], "If I just don't keep the appointments, I'll just, you know, it'll go away." (Navigator 2)

Uncertainty is inevitable in the experience of women with a history of abnormal Pap tests because the course of infection in women's bodies is unpredictable. Navigators recognized this uncertainty as a barrier to care and reported feeling ill-equipped at times to help women live with the uncertainty of their diagnosis, which would necessarily persist until follow-up care was received. One navigator explained how her attempts to remove logistical barriers to care (e.g., scheduling) were unsuccessful in helping one woman get follow-up care because she still could not help the patient address the fear of confirming cancer:

> They go to the GYN and then they don't go back for other follow-ups. But I've had one woman, she come in here, she was in her 40s probably, and she came in and got her paperwork and said, you know, promised up and down she was going to go to the GYN. She missed her appointment. I scheduled it probably six or seven times. Usually we only have to schedule them three times and then we drop them, but I tried six or seven times. I even called her, you know, "If you need somebody to take you, you know, we can get you, try to find you some assistance to help take you up there," and she's, you know, with her work schedule, she said she just wasn't able…She had histories and her mom had, like, breast cancer, and she was

> just afraid that, you know. I'm like, "It was her breasts, you know, this is cervical, you know, it can turn into cancer, too." You know, you just try to tell, talk to them, but sometimes they don't want to listen. (Navigator 1)

One strategy navigators reported using to address uncertainty about a cancer diagnosis was to talk with women about the importance of prioritizing their health, particularly if they mentioned childcare, work, or lack of time as logistical barriers to follow-up care. Navigators also briefed women that the odds of survival are better for women who detect abnormalities sooner and get treated quickly to encourage them to keep their follow-up appointments. One navigator said that she would "share some personal stories with them" to emphasize the importance of early detection. For instance, she would tell the story of "a little girl that didn't come back and her Pap was one code, and then when it came back it was, you know, a lot worse.…Just to try to give them a perspective of what could happen if they didn't…keep their follow up" (Navigator 3). The navigator framed finding out about the diagnosis later rather than sooner as risky behavior because the abnormality can get worse if patients wait to follow up.

Navigators reported that occasionally they would see patients who sought to replace uncertainty related to their Pap test result with certain denial about the reliability of the Pap test or their HPV diagnosis. As one navigator explained:

> I had a lady in [county name] who refused, who just flat out refused, "No, I will not have a colpo[scopy] done"…I don't know if she didn't trust our services or if she just refused to, you know, I don't know. She didn't think ours [Pap test] was accurate….She had every reason, she qualified for a medical card, she had a part-time job working in a nursing home, she had the time, she had the month because she was qualified. I don't know. And to beat all, she was an LPN, so you would think of all people, she would understand the importance of it but she, she didn't. (Navigator 4)

By contrast, other patients sought to replace uncertainty about their Pap test results by embracing the certainty of one normal follow-up Pap test result and ignoring the need for subsequent regular follow-up Pap test over time:

> There's the protocol of how many normals, how many…normal Pap tests they've got to get….If maybe that first one's good, it's like [patients think] "Woohoo! Out of the woods, you know, I'm good." And [they] don't come back. (Navigator 2)

In summary, navigators experienced success in helping patients address logistical barriers to follow-up care, but when the logistical barriers masked deeper uncertainty about care outcomes as barriers to follow-up care, navigators experienced difficulty in helping patients secure follow-up treatment. Navigators identified thisuncertainty rooted in the fear of results and fear of pain as one potentially significant barrier to follow-up cervical cancer care. Moreover, the navigators reported that, in general, they did not have well-developed communication strategies for addressing such uncertainty as a barrier.

Navigators Strategically Use Certain and Uncertain Information about Cervical Abnormalities

Patient navigators identified a number of uncertainties about the nature of HPV infection and cervical abnormalities. Such uncertainties, which arise from patient misunderstanding of Pap tests and treatment processes, can act as barriers to care. All four navigators in the current study explained that they directed patients right back to the nurse case manager when patients had medical concerns, and each described how they were careful to not give patients medical advice. One navigator explained, “They may think I’m a nurse, and I sit back in clinics…but I am not a nurse…and I’m certainly not going to give you medical advice” (Navigator 2). However, the navigators’ lay understanding of abnormal Pap test results was critical in helping women manage uncertainties related to the nature of their personal diagnosis or treatment:

> They want to know how bad it is. Is it kind of bad or is it real bad, because if it’s kind of bad, they probably, they’re like, “Okay, I won’t worry about it.” So I always tell everybody, “It’s not bad at all if you get it treated, you know, if you work with us here.” But they want to know how, why, how and why they have it. They want to see a visual. They want to see what an abnormal Pap looks like and what a regular Pap looks like, and they want to, they want to know if it looks just like theirs or if theirs looks worse. Then it’s just, I don’t ever show them that because there’s no, there’s no way of knowing exactly what it looks like, but people like to see that visual. They ask me about what their next step is, and that’s one of the main things I do is help them to get their, go to their next step. I have some booklets and brochures on colpos and LEEPs and biopsies, and I have pictures of the tools used, pictures of what, you know, what’s going to be done, and so they like to see that, they like to look at that. (Navigator 4)

In addition to referring patients back to nurse practitioners, the navigators frequently reviewed standard brochures and booklets designed for the lay patient audience. By acting as a gatekeeper of visual information (e.g., letting patients see pictures of treatment tools but not of normal and abnormal Pap tests), navigators tried to help their patients resolve uncertainties about follow-up cervical cancer care. Reviewing these materials provided more information to patients and thus increased certainty, but this informational approach did not necessarily help patients in evaluating what the diagnosis would mean to them personally.

Although navigators were trained to show pictures or provide materials approved by the health department nurse case managers and project staff, occasionally patient navigators admitted to going “off script”:

> It’s hard for me to explain something to somebody that I’ve not went through myself….I don’t know what it’s like to be in their shoes because I’ve never had nothing like that. But, you know, I just try to talk to them, make them feel comfortable, you know. You know, I tell them they’re not going to do nothing, you know, like, if something’s painful, they’ll usually knock you out, you know. It’s not going to be that bad on you. I mean, I always tell them, you know, it’s sort of like a Pap. (Navigator 1)

This navigator’s story demonstrates how she, as a layperson, had uncertainty about the follow-up procedures because she had not experienced them herself. She tried to diminish the uncertainty about how painful follow-up procedures would be by substituting her more certain, lay knowledge about Pap tests. She “knew” that because patients do not receive anesthesia for these treatments, it was probably not “too bad.” However, this rhetorical strategy to communicate certain “lay knowledge” to manage her patients’ uncertainty resulted in her relaying misinformation. She told patients that the medical procedures are like a Pap test, which uses a small, soft brush to collect cells from the cervix and vagina and is not analogous to a cervical colposcopy and punch biopsy surgical procedure, which often include use of local anesthetic and carry some unique risks of pain and distress, particularly for young women (Moyer, 2012).

Navigators reported that many patients experienced uncertainty related to what it meant to be HPV-positive and to live with a cervical abnormality. It is important to note that HPV DNA testing is not always part of health department Pap procedure. But, given that HPV is responsible for more than 99% of cervical cancer cases (Walboomers et al., 1999), the women who received an abnormal Pap test result often asked navigators about the meaning of the Pap test and HPV diagnosis. Many women asked navigators for help understanding their test results when they didn't understand their risk factors: “You know, you have, if you have a married woman who comes in who, you know, doesn’t smoke and doesn’t, you know, has one partner, she’s concerned because she’s, you know, she’s, ‘How is this possible?’” (Navigator 4).

Several navigators reported that these uncertainties about being HPV-positive and the outcomes associated with follow-up care were linked to women’s concerns about the stigma associated with sexually-transmitted infections. One navigator reported that she tried to make women feel that they were not individually responsible for their diagnosis so that they would be more likely to pursue follow-up care:

> That’s kind of hard to deal with because you don’t know what’s going on inside their body, they don’t know what’s going on inside their body, and trying to explain it to them is kind of hard because society has put it on everybody that if you have anything wrong in that area of your body, it’s because you had too many sexual partners, basically. So they come in here and they feel ashamed and dirty that they have an abnormal Pap and that doesn’t, it doesn’t always mean, you know, it’s in your genes, it’s hereditary, your mother, your grandmother could’ve had some problems and you just didn’t know about it because they didn’t go to the doctor. (Navigator 4)

Navigators talked about the abnormal Pap test results in lay language to help women avoid stigma and reframe their abnormal Pap tests results as an opportunity for early cancer detection and treatment. In using the certainty of medical information about HPV to help patients resolve their uncertainty about what it meant to be HPV-positive, the navigators maintained strategic ambiguity about the cause of the diagnosis (sexually or genetically transmitted) to help encourage patients pursue follow-up care.

Relational Barriers and Personal Value Conflicts Pose Challenges to Navigation

Navigators reported that they experienced difficulty in helping patients manage relational barriers (i.e., barriers related to patients' relationships with others) and patients' personal values that they perceived conflicted with receipt of follow-up care. Navigators described how abnormal Pap test results could pose relationship difficulties for patients given the women's lay understanding of an abnormal Pap as resulting from a sexually transmitted infection. One navigator recounted how one of her patients said:

> "I don't know how I got this abnormal Pap….He told me it was from sitting on toilet seats."...You know, her husband accused her of sitting on a dirty toilet seat and getting an abnormal Pap because he was, you know, she thought that he was cheating and he said he wasn't. (Navigator 1)

Navigators tried to resolve this relational uncertainty by providing information about HPV:

> I tell them that, you know, I'm not a nurse but let me give you what I know about it; here's some, you know, some pamphlets on HPV….It is sexually transmitted, it is a virus, and just try to explain it to them the best that I can, and then if it that doesn't satisfy them, then I will let the nurse talk to them again about it. But there are a lot of questions that do arise about, arise about HPV….The thing that gets me the most about HPV is they want to immediately blame the person that they're with. You know, someone, it can lay dormant in your system for a long time and then show itself….I can't say that it's not them but I try to explain to them, "Hey, it could be someone else. Just don't go home and, you know, immediately start, you know, jumping on him." (Navigator 3)

Each of the navigators told similar stories, explaining that often it was personally difficult for navigators to speak with women about the relational implications of their diagnosis:

> The first thing they think is their spouse has cheated on them, they want to know who they got it from or where they got it from, and you try to explain to them it doesn't always mean that, and it's just really hard giving them that information, especially if they need to have a hysterectomy and they want more kids. It's so sad, you know. You have 25-year-olds having hysterectomies, so that's really, that's really hard for me is breaking that information to them. I don't like to be the bearer of bad news….It just breaks my heart. I get too involved personally. (Navigator 4)

Each navigator also reported cases when the responses (or perceptions of responses) of patients' loved ones were potential obstacles to follow-up care. Patients reported actual instances of stigmatizing behavior after they talked with family members about their abnormal Pap test result or HPV infection and need for treatment. In extreme cases, controlling and interfering spouses made it difficult for the navigators to ensure that women received appropriate follow-up care:

> I had a patient that, she had an abnormal Pap, and we brought her in for counseling, and it was a GYN referral. Well, we tried to schedule her appointment and she missed it….I called her…trying to reschedule it and she said that her husband wouldn't let her go. I was like…"Is there any way I can reschedule it?" And she said no. She said—at the time, "my boyfriend"— "My husband won't let me go."

> She said, “I don’t want to reschedule it this time,” and hung up the phone. (Navigator 1)

Alternatively, there were times when the patients’ husband was present during the navigation process itself, which created a difficult relational dynamic for the navigators to manage.

> And also a lot of the men, be it their husband or partner, are also involved and sit in there….They [the patients] seem more guarded in what they say and they kind of defer to the man, and I think that’s kind of, kind of sad sometimes. (Navigator 2)

Navigators expressed regret that they did not have communication strategies that they felt could help women in relationships with partners who interfered in the navigation process.

Navigators also reported difficulties addressing cases when patients had uncertainties related to how Pap testing and follow-up care fit within a patient’s faith-based value framework. Although navigators explained how a Pap test was a means of early cancer detection, some women’s religious convictions inhibited them from relying on medical treatment. One navigator told the story of her patient’s willingness to refuse traditional treatment in favor of prayer:

> I had a lady that was a big-time Christian. She had an abnormal Pap. She came in and she told us upfront she wasn’t getting no follow-up care because the Lord was going to take care of her. She thought…the Pap was it. She said she’ll come in next year for her repeat, her annual. And that was it….With that lady in particular, I got [the nurse case manager], you know, to come to me and assist me. (Navigator 1)

Although this woman’s religious convictions were not necessarily typical among patients, the story shows that the patient navigator was not comfortable addressing this barrier to care where a patient’s values conflicted and interfered with their follow-up care (and the navigator’s goals).

Discussion

We used a social ecological perspective to examine the interpersonal level of support provision by lay patient navigators in cervical cancer prevention efforts in a medically underserved region. By examining barriers to cervical cancer follow-up care after an abnormal Pap test result among women living in Appalachia Kentucky from the perspective of patients and their lay navigators, our analysis demonstrates how patient navigators provide support to women in managing their uncertainties related to their health. The navigators were well-trained to problem-solve logistical barriers to receiving follow-up care. However, the navigators encountered conversations in which they lacked accessible communication strategies to address patient uncertainties that posed barriers to getting appropriate follow-up care.

Our finding that navigators helped patients manage their uncertainties is consistent with the conceptualization of social support as assisted uncertainty management (Brashers, 2001, 2007). Consistent with previous research, our analysis found that patient navigators supported patients in managing their uncertainty by assisting in information seeking or avoiding, providing instrumental support, giving acceptance or validation, encouraging perspective shifts, and normalizing disease-related experiences (Brashers, Neidig, & Goldsmith, 2004; Scott, Martin, Stone, & Brashers, 2011). There is evidence that support from others also can interfere with uncertainty management in a variety of ways, such as by creating uncertainty about the relationship between the support provider and recipient, introducing support provider's own uncertainty as something to be managed, or carrying obligations to respond to the support in a certain manner (Scott et al., 2011).

On the basis of our findings, patient navigators appear to be uniquely positioned to offer support by providing helpful aspects of support to patients without incurring many of the costs entailed when family members or friends provide support. However, support from lay navigators is not without its own costs to the navigators, who reported experiencing frustration when they were unsuccessful in helping a patient or emotional distress when they had to deliver bad news. Furthermore, the support offered by lay navigators provides unique advantages compared to support from health care providers because the navigators (who are not medically trained) can assist the patient in receiving medical care without being responsible for the patient's diagnosis and treatment, which therefore allows navigators to play more of an advocacy role on behalf of patients (see Freeman, 2006; Steinberg et al., 2006).

Implications for Developing Patient Navigation Communication Strategies

The empirical observations from this study and relevant conceptual insights can be practically applied to suggest a number of less problematic, more helpful lay navigation communication strategies than those reported by navigators in the current research. First, to communicate effectively with their patients, health care providers must take into account the more abstract barriers to equal access to treatment options for Appalachian women beyond mere logistical considerations. Recognizing and responding to women's logistical barriers to cancer inequities requires connecting individuals from medically underserved communities with the material resources that a lay navigator can help access. The navigators in our study reported making efforts to match patients with a provider who would meet their needs or gender preferences, help them manage the paperwork to ensure adequate and timely payment for care, and provide lay explanations about the nature and meaning of an abnormal Pap test to facilitate informed follow-up care decisions. Here, the successes of navigation are abundantly clear: Navigators bridged gaps to help patients understand recommendations from health care providers, negotiate bureaucracy, improve knowledge of screening procedures, and overcome self-efficacy barriers (e.g., cost, availability, time). However, findings from the present study indicate that lay navigators may not be as well-equipped to help patients address barriers related to deeper uncertainties about cervical cancer and its treatment.

Second, effective patient navigation requires that navigators match appropriate HPV and cervical cancer information to patients' cultural understandings of disease. We found that the coping strategies navigators use to deal with particular uncertainties may exacerbate women's misunderstanding of HPV and cervical cancer treatment by perpetuating misinformation. Our data suggest that navigators would benefit from witnessing follow-up procedures before discussing the nature of those procedures with patients. If a navigator herself lacks the lay knowledge to provide sound advice, scripts might be developed with the cooperation of experienced patients and medical professionals to avoid misinformation from being relayed.

Third, we found that navigators perceived partner involvement to be a barrier to care for women in interfering and controlling relationships. Navigators easily identified cases of noncompliance and missed appointments that stemmed from these partner control tactics, but they lacked communication strategies to run interference against these tactics, indicating that lay navigation training programs would do well to include training to equip navigators to help patients talk with interfering partners.

Fourth, this analysis identifies how patient values may become barriers to follow-up care and therefore need to be addressed in the health care interaction. It would likely prove useful for lay navigators to be trained in using communication strategies that are sensitive to their patients' spiritual sensitivities. As Cohen (2009) has argued, "faith in a higher being or spirituality may be a constructive resource for individual optimism or inspiration to confront cancer fears" (p. 412), but this constructive potential can only be leveraged in patient navigation if the navigators are equipped to help frame women's spiritual values as consistent with (and not contradictory to) follow-up care.

Finally, the current research reveals that some uncertainties cannot be adequately managed by lay patient navigation. We found that the navigators helped patients evaluate their uncertainty by using certain and uncertain knowledge strategically and privileging some forms of uncertainty over others to reframe patients' abnormal Pap test results. Such navigator communication can help negotiate lay understandings of abnormal Pap testing, but this can come at the cost of medical precision. Some misinformation and miscommunication could reify inappropriate lay understandings of HPV, cervical abnormalities, and follow-up treatment processes, which could unduly burden a community already confronting health inequities. It is important to train lay navigators to defer to medical personnel and to develop lay support strategies for helping patients to manage uncertainty when they lack sufficient knowledge so that they do not resort to using certain (but incorrect or misapplied) information as their only available means for helping patients resolve unwanted uncertainty.

Limitations and Future Research

Lay patient navigation offers a promising strategy for health departments to improve the rates of patient adherence to appropriate follow-up care protocol after an abnormal Pap test result. Furthermore, patient navigators can provide timely and appropriate technical, relational, informational, and material support to medically underserved patients confronting daunting barriers to follow-up screening, diagnosis, and treatment. Clearly, the growth in support for navigation programs by the National Institutes of Health, the Health Services Research Administration, the American Cancer Society, and other organizations has resulted in a clear "first wave" of navigation research focused on logistical and procedural problems for effective navigation program adoption. As a result, navigation programs, including the one considered in the current investigation, have been developed with a focus on training lay people as community health workers who have the local cultural knowledge that gives them the expertise to identify and address patients' apparent logistical, procedural, and other practical barriers to care.

However, the present research suggests that there is another layer of barriers to appropriate follow-up cervical cancer care. Indeed, this additional layer is much less concrete than the procedural layer and will therefore be more difficult to address. Patient navigators may be able to address more abstract (i.e., uncertainty-related) barriers to care, but further research is needed to identify how to manage these uncertainty-related barriers with navigator communication skills training. Additionally, future research may consider strategies to help navigators identify women in interfering relationships earlier in the clinical context. Some health departments have adopted the practice of screening for domestic abuse and offering assistance accordingly. It is also important to consider whether using trained social workers or health care providers may improve navigation outcomes in cases where there may be relational interference.

One limitation of the study is that our findings are derived from self-report patient data and recollections from the navigators. However, the consistency between these two sources of data strengthens our interpretation of the findings. Additionally, at the time of the research study, it was a common requirement for women in the clinics to receive a Pap test before receiving birth control pill prescriptions. This is no longer a requirement given the most recent iteration of the U.S. Preventive Services Task Force guidelines for cervical cancer prevention. However, birth control is still a common motivating practice for women coming to the clinic for "well-women" visits. Clearly, that there is no similar motivation for follow-up care after abnormal Pap testing is a consideration for future research. If the effect of changing the U.S. Preventive Services Task Force guidelines results in fewer, less regular Pap tests in a medically underserved population, then women who receive those less regular Pap tests will have fewer contacts with health department personnel and fewer opportunities to be navigated to appropriate care.

From a communication perspective, patient navigation offers an important opportunity to address patient uncertainties that may contribute to health care inequities. Navigating patients to appropriate care in a medically underserved environment is critical to reducing health disparities. The present findings from quantitative and qualitative observations indicate that improved access to care alone is not a sufficient strategy to improve health equity. Successful patient navigation programs must operate with respect for the interpersonal communicative management of uncertainty that can facilitate effective adherence to provider recommendations for follow-up cervical cancer care.

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Table 1

Patient Demographics

Demographic factor	***n* (% of total *N*)**
Age	
18–29	343 (66.1%)
30–39	90 (17.3%)
40–49	52 (10.0%)
50–59	20 (3.9%)
60+	14 (2.7%)
Education	
Grade school	11 (2.1%)
Middle school	104 (20.0%)
High school	383 (73.8%)
College	17 (3.3%)
Graduate school	4 (0.8%)
Household income / year	
<$10,000	213 (41.0%)
$10,001–$20,000	151 (29.1%)
$20,001–$30,000	53 (10.2%)
$30,001–$40,000	27 (5.2%)
$40,001–$50,000	10 (1.9%)
$50,000+	18 (3.5%)
Ethnicity	
White	499 (96.2%)
Black	5 (1.0%)
Other	15 (2.9%)
Medically insured	
Yes	296 (57.0%)
No	222 (42.8%)
Follow-up care needed	
GYN referral	267 (51.5%)
Treatment (e.g., LEEP, laser)	246 (47.4%)
Colposcopy	233 (44.9%)
Repeat pap test	112 (21.6%)
Biopsy	2 (0.4%)

Note. Percentages do not add to 100% because some women received multiple recommendations for follow-up care.

Table 2

Patient-reported Barriers Were Not Associated with Decision to Pursue Follow-up Care

Patient-reported barrier to follow-up care	***n* (% of total *N*)**	**Decided not to pursue follow-up care at baseline *n* (% of total *N*)**	**Decided to pursue appropriate follow-up care at baseline *n* (% of total *N*)**	**χ^2 (df = 1)**	**Φ**
Cost	265 (51.1%)	109 (21.1%)	128 (24.8%)	2.55	.07
Lack of insurance	237 (45.7%)	129 (25.0%)	136 (26.4%)	.28	.02
Fear of results	184 (35.5%)	96 (18.6%)	88 (17.1%)	.64	−.04
Fear of pain	132 (25.4%)	66 (12.8%)	66 (12.8%)	.00	.00
Not had to follow up before	121 (23.3%)	63 (12.2%)	57 (11.1%)	.45	−.03
Embarrassment	81 (15.6%)	45 (8.7%)	36 (7.0%)	1.27	−.05
Transportation	79 (15.2%)	40 (7.8%)	39 (7.6%)	.03	−.01
Male provider	76 (14.6%)	38 (7.4%)	36 (7.0%)	.08	−.01
Time	75 (14.5%)	34 (6.6%)	40 (7.8%)	.52	.03
Lack of childcare	74 (14.3%)	34 (6.6%)	33 (6.4%)	.03	−.01
Clinic hours	67 (12.9%)	23 (4.5%)$^{-}$	53 (10.3%)$^{+}$	13.62***	.16***
Privacy	51 (9.8%)	22 (4.3%)	29 (5.6%)	1.01	.04
Lack of respect from provider	31 (6.0%)	16 (3.1%)	9 (1.7%)	2.12	−.06
Poor road conditions	28 (5.4%)	15 (2.9%)	16 (3.1%)	.03	.01
No provider	25 (4.8%)	14 (2.7%)	14 (2.7%)	.00	.00
Not important	23 (4.4%)	13 (2.5%)	10 (1.9%)	.43	−.03
Lack of knowledge	23 (4.4%)	12 (2.3%)	11 (2.1%)	.05	−.01
Physical health	22 (4.2%)	8 (1.6%)	14 (2.7%)	1.66	.06
Low literacy	18 (3.5%)	7 (1.4%)	11 (2.1%)	.89	.04
Language barrier	12 (2.3%)	7 (1.4%)	8 (1.6%)	.06	.01
Lack of trust in provider	15 (2.9%)	4 (.8%)	8 (1.6%)	1.33	.05
Place of follow-up care	10 (1.9%)	4 (.8%)	6 (1.2%)	.39	.03
Lack of family support	5 (1.0%)	1 (0.2%)	4 (0.8%)	1.79	.06
Follow-up care is not a problem	185 (35.7%)	104 (20.2%)$^{+}$	80 (15.5%)$^{-}$	5.16*	−.10*

*** $p < .001$,

* $p < .05$;

$^{+/-}$ indicates has a standardized residual value > 2 or < −2.

Note. Percentages do not add to 100% because women reported multiple barriers to follow-up care.

Table 3

Patient Demographics Were Not Associated with Decision to Pursue Follow-up Care

Demographic factor	**Decided not to pursue follow-up care at baseline** ***n*** **(% of total** ***N*****)**	**Decided to pursue appropriate follow-up care at baseline** ***n*** **(% of total** ***N*****)**	χ^2	Φ
Age			5.19	.10
18–29	174 (33.7%)	168 (32.6%)		
30–39	45 (8.7%)	45 (8.7%)		
40–49	26 (5.0%)	25 (4.8%)		
50–59	5 (1.0%)	15 (2.9%)		
60+	7 (1.4%)	6 (1.2%)		
Education			4.91	.10
Grade school	6 (1.2%)	5 (1.0%)		
Middle school	48 (9.3%)	56 (10.9%)		
High school	195 (37.8%)	186 (36.1%)		
College	8 (1.6%)	8 (1.6%)		
Graduate school	0 (0.0%)	4 (0.8%)		
Household income/year			9.25	.13
<$10,000	101 (19.6%)	111 (21.5%)		
$10,001–$20,000	70 (13.6%)	79 (15.3%)		
$20,001–$30,000	24 (4.7%)	29 (5.6%)		
$30,001–$40,000	18 (3.5%)	9 (1.7%)		
$40,001–$50,000	7 (1.4%)	3 (0.6%)		
$50,000+	9 (1.7%)	9 (1.7%)		

Table 4

Patient-reported Barriers Informed Interview Questions for Lay Patient Navigators

Patient-reported barrier to follow-up care	Interview questions for navigators
Lack of insurance Cost	What do you say or do when patients say that they're not getting follow-up care because of insurance concerns or cost?
Fear of results Fear of pain	What kinds of things do you say to a woman who is afraid that a biopsy will be painful or will reveal a problematic diagnosis?
Not had to follow up before	What kinds of questions do women typically have about the referral? How do you respond to these questions?
Embarrassment Privacy	When a woman seems embarrassed or concerned about privacy, what kinds of things do you say to her?
Transportation Clinic hours Time Male provider	How do you respond when a patient says that it would help her seek follow-up care if she had more reliable transportation, more convenient clinic hours, more time, more providers to choose from, or more reliable childcare?
Lack of childcare	
Poor road conditions	
No provider	
Place of follow-up care	
Lack of respect from provider Lack or trust in provider	Can you tell me a story about a patient who was diagnosed with an abnormal Pap but didn't believe the results? How did you respond to this patient?
Not important Lack of knowledge Low literacy Language barrier	When a woman receives a diagnosis of abnormal Pap, but doesn't understand what that means or doesn't think that follow-up care is important, what do you say to explain the diagnosis and follow-up care?
Physical health	When a woman says that she can't pursue follow-up treatment because she has other, more pressing health concerns, what do you say to her?
Lack of family support	How do you respond when a patient says that it would help her seek follow-up care if she had more family support
Follow-up care is not a problem	Can you tell me a story that sticks out in your mind about a woman who needed follow-up treatment, who you helped receive it?