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Perspectives on Pap Test Follow Up Care Among Rural Appalachian Women

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Abstract

Approximately one to three quarters of women notified of abnormal Pap test results do not receive appropriate follow up care, dramatically elevating their risk for invasive cervical cancer (ICC). We explored barriers to/facilitators of follow up care for women in two counties in Appalachian Kentucky, where ICC incidence and mortality are significantly higher than the national average. In-depth interviews were conducted among 27 Appalachian women and seven local health department personnel. Those who had been told of an atypical Pap test result tended to have one of three reactions; (1) not alarmed and generally did not obtain follow-up care; (2) alarmed and obtained follow up care; or (3) alarmed, but did not obtain care. Each of these typologies appeared to be shaped by a differing set of three categories of influences: personal factors; procedure/provider/system factors; and ecological/community factors. Recommendations to increase appropriate follow up care included pursuing research on explanations for these typologies and developing tailored interventions specific to women in each of the response types.

Keywords

abnormal findings; cancer screenings; cancer of the cervix; public health; health services

The introduction of the Papanicolaou (Pap) smear screening in the 1940s led to dramatic decreases in invasive cervical cancer (ICC) mortality in the United States; in the seven decades since the widespread dissemination of the Pap test, cervical cancer mortality rates have declined by approximately 75%. Despite this improvement, in 2009, 11,270 cases of ICC were diagnosed and 4,070 deaths occurred from ICC (National Cancer Institute, 2009).

Several segments of the U.S. population, including women in rural Appalachia, have not reaped as many of the benefits of medical advances as others (Freeman & Wingrove, 2005). Kentucky Appalachian women, the vast majority of whom are white, have ICC incidence rates nearly double (13.4/100,000) the national rate for non-Hispanic white women (7.3/100,000) (ACS,

2007; Hopenhayn, Bush, Christian, & Shelton, 2005). Through 2003, the U.S. cervical cancer mortality rate was 2.7 per 100,000 compared with Kentucky's rate of 3.2 per 100,000. Appalachian Kentucky rates tend to be significantly higher than state rates (National Cancer Institute, 2006).

The reasons for this high rate of ICC incidence and mortality are multifaceted, and include less frequent Pap test screening and receipt of follow-up care. Each year in the United States, approximately 5% of the 50 million Pap tests performed require additional examination, mainly due to low grade abnormalities (Eggleston, Coker, Luchok, & Meyer, 2007).

Recommendations for atypical Pap test follow up include repeat Pap tests within six months. If cervical cell changes do not diminish, and additional Pap tests show atypical squamous cells of undetermined significance (ASCUS) or low grade and high grade squamous intraepithelial lesions (LSIL and HSIL), colposcopy, endocervical curettage, or a biopsy may be performed. If further testing demonstrates the presence of abnormal cells likely to become cancer, further treatment, including loop electrosurgical excision procedure, cryotherapy or laser therapy or conization may be necessary (National Cancer Institute, 2009).

Of those notified about their Pap abnormality, between one-quarter and three-quarters do not receive appropriate follow up diagnosis and care (Benard, Lawson, Ehemann, Anderson, & Helsel, 2005; Marcus & Crane, 1998). It is estimated that this lack of optimal follow up is responsible for approximately 13% of ICC cases (Leyden, et al., 2005). Despite this connection between inadequate follow up care and ICC, it remains unclear why many women do not obtain appropriate diagnosis and treatment. Paralleling the literature on lack of Pap test use, it has been suggested that inadequate follow up is linked to characteristics of the person; the procedure, provider and the medical system; and the ecological or community context (English, et al., 2008; Rimer, Meissner, Breen, Legler, & Coyne, 2001).

Researchers most frequently have examined personal factors, or patient-level determinants, of follow-up to abnormal pap results. Lack of follow up has been associated with being young, African-American or Asian, living in an urban environment, smoking, having a low educational level, and lack of personal awareness of the need for follow up (Eggleston, Coker, Das, Cordray, & Luchok, 2007; McKee, Schechter, Burton, & Mulvihill, 2001). Other frequently cited personal factors include embarrassment, inadequate knowledge of follow up procedures, belief that cervical abnormalities are symptomatic, and fear of cancer (Breitkopf, Catero, Jaccard, & Berenson, 2004; Kahn, Goodman, Huang, Slap, & Emans, 2003; Khanna & Phillips, 2001; McKee, 1997; Nelson, Geiger, & Mangione, 2002; Paskett & Rimer, 1995). Patients with less severe abnormalities tend to be less adherent (Eggleston, Coker, Das, et al., 2007; Fox, Arnsberger, & Zhang, 1997), as do the uninsured (Battaglia, et al., 2010). The influence of social support remains unresolved (Breitkopf, et al., 2004; Stewart, Buchegger, Lickrish, & Sierra, 1994).

Procedure/Provider/System factors may include poor communication or inadequate care plans. Providers often fail to notify patients about their results or may not fully explain the results (Melnikow, Chan, & Stewart, 1999; Schofield, Sansonfisher, Halpin, & Redman, 1994) and many maintain inadequate medical record documentation (Poon, et al., 2004). Communication failures may stem from practice-level factors, such as less accessible location or inadequate systems for reporting abnormalities and tracking follow-up (Bastani, Yabroff, Myers, & Glenn, 2004; Battaglia, et al., 2010).

Finally, while receiving far less discussion than other determinants of follow-up to abnormal pap tests, ecological and community level factors can also play a role. Rural residence offers many challenges to population health including resource scarcity on both a personal level (i.e., lower income, less education, lower rates of health insurance) and in the supply of health

sources (health professional shortage areas). Other features of rural life, including kinship ties and health behavior, have been described as differing between rural and non rural areas (Beaver, 1986; Bowden, Shaul, & Bennett, 2004; Engelman, et al., 2005), sometimes leading to rural disadvantages and other times bolstering rural health outcomes. Community-level variables, such as the availability of social services and “culture” have been described as both hindrances and facilitators of positive health behavior (Campo, et al., 2008).

Despite the disproportionate burdens from cervical cancer experienced by Appalachian women, we have few insights on the factors and circumstances that shape pursuit of follow-up care (Eggleston, Coker, Das, et al., 2007). To rectify this deficit, we examined, from the perspective of local women who have experienced an abnormal Pap test result and from health department personnel who care for many of these women, the factors and circumstances that were related to follow up care in two Appalachian counties.

Method

Field site and conceptual framework

The study was conducted in two of Kentucky’s 54 Appalachian counties. The counties were selected, in part, because they have characteristics that generally are representative of the population of Appalachian Kentucky, including low population density, highly rural, low socioeconomic status, and health care provider shortages. Per capita income, unemployment rates, poverty rates, and educational attainment within these counties indicate disadvantage compared to Kentucky and U.S. rates (see Table 1)(Appalachian Regional Commission, 2006). With high rates of poverty and un- or under-insurance and a lack of health care provider choices, many Appalachian women receive their health care at the local health department, making this an ideal venue in which to conduct this study. Given the importance of this context, we employed a broad socio-ecologic framework to examine factors that shaped obtaining follow-up care. This framework was used to inform the interview questions (specifically, in our selection of probes that queried the influence of the health care provider, transportation, etc. on follow up care) as well as in the interpretation of our results. In this broad conceptual framework, these three intersecting circles (personal, procedure/provider/system, and ecological/community) shaped the receipt of cancer screening and were embedded in a broader socio-ecologic context that includes healthy policy and rurality (Rimer, et al., 2001).

Inclusion criteria, recruitment, and sample size

We employed a purposive sampling approach (Patton, 2002) for this qualitative design, using pre-specified criteria, including for the patients: having received an abnormal Pap test result; being a resident of rural Appalachia; and being able and willing to participate in the interview protocol. The health department’s nurse case manager compiled a list of all women who had received an atypical Pap test result from April, 2008–October 2008, irrespective of follow up status and severity (if known). We sought a broad array of characteristics (age, follow up status, insurance coverage) by reviewing the de-identified patient list and developing a targeted potential participant list. Then, the nurse case manager contacted the first 35 of these potential participants, screened all of them for eligibility, and asked about their interest in participating in the project. All of those called met the eligibility criteria, which was assessed by the following questions: What is your county of residence? In the past six months, have you been told that you had an abnormal Pap test? Would you be able and willing to participate in an interview to discuss your decisions regarding the Pap test result? Twenty-eight (83%) agreed to participate, although one individual did not show up for the interview. The nurse case manager then scheduled an appointment time and location for the interview. For the health department staff, our criteria included being a care provider or administrator for women receiving an abnormal Pap test results and being able and willing to be interviewed. Interviews

were conducted with all relevant health department staff. Of those contacted, 80% of patients and 100% of health department staff agreed to be interviewed.

Sample size was driven by meeting data redundancy (Lincoln & Guba, 1985), or the point at which no new information is retrieved. Data redundancy was reached by patient participant #24 (of 27) and #5 (of 7) for health department staff; however, because we had already scheduled the interviews sessions, we used the final five sessions to increase confidence in the findings.

Protocol

Trained local interviewers conducted twenty-seven patient and seven health department staff interviews using structured and semi-structured questionnaires. The interviewers explained the project, administered informed consent documents, requested that the interview be tape recorded, and asked the questions. The interview guide was informed by our socioecologic framework, in which interview questions, displayed in Box 1, focused on women's perceptions of those most and least likely to receive follow-up care, factors shaping the follow-up care decision, and programs that might enhance follow up care. The interviews lasted between 30–80 minutes, depending on the participants' level of detail. All participants were provided with a \$25 gift card. All study procedures were approved by our university's Institutional Review Board.

Box 1

Selected Questions for Semi-structured Interviews

Patients with atypical Pap test results

1. Research shows that many women do not get appropriate follow-up for abnormal Pap tests, why do you think this is?
2. What are the most important reasons for getting regular follow-up treatment if your Pap test results come back abnormal?(Probes: Anything about the woman's personal situation? Anything about getting medical care? Anything about follow up procedures? The doctors or care providers? Anything about this community?)
3. What are women likely to think if the result from their Pap test is abnormal (something may be wrong)?
4. Some women don't get follow-up care if their Pap test comes back abnormal. Why do you think this is?
5. Do you think women would be more likely to get follow-up care if they had someone to help them? What types of help are needed?
6. Who might be a good person to help a woman get the follow-up care she needs?
7. What kind of help would this person provide?

For key informants (providers, social and health service staff)

1. What do you see as factors/issues that influence adherence to recommended follow-up for abnormal Pap smears? (Probes: anything about the woman's personal situation? Anything about getting medical care? Anything about follow up procedures? The doctors or care providers? Anything about this community?)
 - a. Are there factors specific to Appalachian populations that make their situation better or worse?

- b. Do you think that this problem is affected by the types of services available to low-income women?
2. Now that you've identified potential adherence influencing factors, are there things that should be done in your hospital/clinic to modify factors to improve "ease of use"?
 - a. Are there services being offered that are underutilized?
3. What is missing? What services do you not or limitedly provide? How could you increase this service?

Analysis

The tape-recorded sessions were transcribed for subsequent analysis. Two trained researchers engaged in line-by-line coding, wherein a label or code was affixed to chunks of text (Strauss & Corbin, 1990). After performing this line-by-line review of several transcripts, the researchers developed a codebook, which was revised numerous times and was employed to ensure rigorous, systematic, and comparable analysis (Lincoln & Guba, 1985). We employed axial coding to connect coding categories and subcategories and selective coding to integrate the categories. Finally, we employed selective coding, the process by which researchers discussed and debated how categories and subcategories in our codebook were related to the central or core category (in this case, atypical Pap test follow up care decision determinants) (Strauss & Corbin, 1990). Subsequent to detecting three typologies of follow up care responses, we compared and detected patterns of influences according to these typologies.

To enhance rigor, we took several steps, including: adherence to a standard data collection protocol; independent co-coding by two researchers of identical text segments and resolution of disputed coding; review of the transcripts and procedures by experienced qualitative researchers outside of the research team; member checks with several patients and health department personnel; and development of an audit trail to specify data collection and analysis (Boyatzis, 1998; Patton, 2002).

Results

Sample characteristics

The 27 patients interviewed ranged in age from 18 to 54 years, with an average age of 29.2 years. The sample had relatively low levels of education, income, and insurance coverage; high levels of unemployment; a minority was married; and all reported being in good, very good, or excellent health (see Table 2). Consistent with the demographics of the region, all participants were white. The seven health department (HD) staff, all of whom were women, had the following job titles: program manager, nursing administrator, director, registered nurse, licensed practical nurse, and receptionist. Health department staff had, at minimum, an associate's degree and all were lifelong residents of the region.

We identified three types of responses to Pap test abnormalities. We identified no meaningful patterns to suggest socio-demographic or medical differences among women in the three response types. Each of these types emphasized different patterns of influences on follow up care (Table 3).

Type 1: Not alarmed and generally did not obtain follow up care (n=8)

For type 1 patients, only one of whom received follow up services, numerous personal, procedure/provider/system, and ecological/community factors converged to undermine care. Personal factors emphasized by type 1 patients included age and competing demands. Such

patients and health department staff suggested that age (being either young (<22 years) or older (>50 years)) negatively influenced follow up care. Some young women worried about the loss of fertility should they undergo further evaluation. Health department staff also suggested that young patients may decline follow-up because they need parents to accompany them to the health department. Two health department workers described their experience with younger patients, “With the teenage population-- they don’t want to get their parents involved or anyone else so that would be a problem with them” and

“The younger the person is, the harder it is to go for treatment because at a point the doctor wants a parent with the child, if she’s 14, 15, 16, 17 years old, then they want someone, an adult with them, the parent or whatever.”

Another health department administrator described the difficulty of getting women beyond age 50 years in for follow-up care.

“Those over 50 just don’t worry about that anymore, that part of health care is kind of over. No child bearing... And it’s just kind of like, well I’m not going to do that anymore; I didn’t like doing it when I was in my 20s and 30s and 40s, I’m certainly not going to do it now.”

Competing demands also shaped follow up care, with participants classified as type 1 having indicated that challenging work and home commitment schedules complicated follow-up care. “I take care of my bedridden uncle; for a while I missed my appointment.” (patient, age 32 years) “Babysitters; it’s hard to find a babysitter for your appointment or maybe they’re [the kids] sick or something like that, you know with kids anything.” (patient, age 23 years).

Within the second main category of influences-- procedure/provider/system factors--many did not recognize their susceptibility to ICC and normalized their atypical Pap test results. A 21 year old stated, “Well everybody gets bad Paps every now and then so what’s the big deal?” Additionally, many participants had experienced several abnormal Pap tests that had resolved themselves, leading them to question the rationality of disrupting work, home, and peace of mind to expend countless hours and financial resources.

“This is not my first time with this—it’s probably about the fifth bad Pap I’ve had. The first time, I was real shook up about it. I started keeping a file folder with all this information. I showed up where they told me to go—I took the day off of work to do that and that cost me a bundle. I think the worst was the worry, and going back, only to have them say that it looked ok and that I needed to come back again. I couldn’t take the day off again, so I skipped it and when I had my next check up, the problem seemed to go away anyhow. I’ll be honest, I’m here today, but I’m not gonna be in a hurry to come back soon, with all you gotta do and what you don’t really find out. (patient, age 45)”

Those who described not being particularly alarmed also did not appear to emphasize the connection between follow-up procedures and the possibility of cancer, instead thinking about more pressing issues and the overwhelming work it might take to address their abnormal result.

Finally, type 1 participants emphasized certain ecological/community barriers to pursuing follow up care and mentioned few facilitators. Cultural issues, like an emphasis on privacy and a lack of community awareness of the importance of follow up care figured prominently in their discussions. In rural communities with close-knit populations, loss of confidentiality loomed large in patients’ minds. Despite HIPAA regulations, health department staff described their patients feeling vulnerable to improper access to their confidential information. “You need to be treated for it and stuff but they don’t want no people finding out about it so they take a chance of not getting it treated.” Distrust of service providers converged with many Appalachian women’s past histories where families, lacking the means to obtain medical

services, did without formal care. As a health department nurse described, “That’s passed down from several generations. A lot of these women’s mothers, grandmothers, didn’t even go to a doctor to have a baby.”

Type 2: Alarmed, obtained follow up care (n=12)

Type 2 patients either overcame personal, procedure/provider/system, and ecological/community barriers or viewed these factors as facilitators of follow up care. All participants in this type received follow up care. In the first category of influences—personal factors—patients described many of the same challenges to receiving appropriate care as type 1 patients (competing demands, poverty) but indicated that these barriers were mitigated by psycho-emotional factors, such as motivating fear due to a personal or family health history. For example, one 34 year old woman explained that, despite not having a car, she managed to make a quick return to the doctor once she learned of her Pap test result, “I already had thyroid cancer and any abnormal Pap smear scares me.” A 38 year-old woman noted,

“Well to me cancer runs in my family real bad, and I lost my brother back in August for lung cancer... And I lost my mom in 2005 for lung cancer, and then I lost those family members that’s had female cancer and breast cancer and brain tumor; so if one of us gets a bad Pap, that’s the first thing to think about is cancer.”

Fear and knowledge of the importance of follow up care motivated many type 2 participants, as was the case for this 34 year-old woman: “Because you could get cervical cancer and if you have the proper follow up care, then it can either stop it or prevent it from turning into cervical cancer.”

Procedure/provider/system factors, most specifically the local health department, also tended to facilitate follow up care for type 2 patients. For example, although alarmed, this 24 year old was stymied in how she could arrange for a follow up appointment until she interacted with S, a provider at the health department.

“S gave me the confidence to go do it. She stayed on me, but that’s good; that’s what I needed. She’s like, you need to get in here and get these appointments ... I mean she’s the one that got me motivated to do it.”

In general, patients viewed the health department as an especially effective resource for working with follow up specialty care.

“I think if you come through the health department here, they can get you in faster because they [private physicians] cooperate with the health department for business like that but patients out on their own, when they call in like my sister had to call in and make her appointment, they made hers like a month or so down the road.” (patient age 24 years)

Finally, type 2 patients focused on how certain ecological/community factors facilitated follow up care. These factors go beyond the local health department and include national and state policies that have created the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the state Breast and Cervical Cancer Screening and Treatment program (BCCST). Although most participants were not aware of the names of the programs or their finding sources, many knew the health department offered treatment on sliding scales.

Type 3: Alarmed, but did not obtain care (n=7)

Type 3 patients tended to present ambivalent and multifaceted perspectives on each of the three main categories influencing Pap test follow up, and did not receive follow up services. Personal factors that influenced their follow up included age, competing demands, poverty, and psycho-emotional concerns, especially fear, with the latter most factors receiving the most emphasis.

Participants described how having limited income and limited or no health insurance intersected with the high cost of medical care to thwart follow-up care. Since most women indicated their employer did not provide health insurance and that they could not afford it independently, seeking services at the health department was their only option. “If I had health insurance, I would be going to my gynecologist but right now we don’t have any health insurance because it’s [the cost of health insurance] way high.” (patient, age 32 years) Even with subsidized services, the out-of-pocket expense may still be more than many Appalachian women can afford. “The health department has helped me pay some of it [the cost of the gynecologist] but I’ve still got bills out the wazoo.” (patient, age 26 years)

Additionally, many type 3 patients described psycho-emotional issues that prevented receipt of follow-up care for an abnormal Pap test result. Patients feared the unknown, having cancer, having to undergo uncomfortable and expensive medical procedures, loss of fertility, and not being able to care for others. This fear frequently led to inertia. One 22 year-old noted that she had missed several appointments because, “I’m kind of scared to see what’s wrong with me... I’m just afraid I might really have cancer or something and may not have long to live or nothing like that, and I’m still young.” A 45 year-old mother of three teenagers asked,

“Am I going to be sick enough to where I can’t take care of myself? And take care of the people that are depending on me? And whose burden you’re going to be because somebody’s going to take care of you and whose burden is that going to fall?”

Often type 3 patients intermingled this fear and resignation with concerns about the procedure, provider, or medical care system. In particular, type 3 patients emphasized insufficient availability of providers, lack of comfort with existing providers; and lack of continuity of care. Women described long waits and few available appointments. Scheduling conflicts and difficulties finding available appointments arose because of limited healthcare practitioner options. According to one 21 year-old patient, “There are a couple [doctors] here in town, but I think most of the time it’s probably 4–6 weeks before you can get an appointment.” Although clinics offer some limited extended hours, these are often not sufficient, resulting in wait times of weeks if not months.

Patients often described feeling uncomfortable with those providers who were available, both in terms of demographics and pertaining to quality of care. Many women preferred female physicians for gynecological procedures and described concerns about exposure and privacy with male physicians. Participants also suggested that many physicians in the area are older, raising concerns about whether they are using up to date knowledge and technology in their medical practice. “Some of the older doctors don’t really know... it’s not that they’re bad doctors, it’s just that’s what they was taught and the new ideas, it’s hard to get a new idea going.” (patient, 23 years)

Lack of continuity of care has become increasingly common in medically under-resourced areas, as providers fulfill the terms of their loan repayment programs or J-1 visas and then leave the area, as described by the director of a local health department, “You know it’s kind of a transit. Like they come in long enough to fulfill whatever obligation they need to fulfill to get rid of their student loans or to meet some kind of grant requirement.”

Often the need for providers has been filled with international physicians who have difficulty communicating with local patients. A health department nurse suggested

“It’s hard for folks to understand a lot of what they’re saying...hard for some of them to get down on the common folks’ level and can talk to them. I also think they’re just not here long enough to build that long-term relationship, the trust. Communication is always an issue but, but I think that the trust, that relationship is never there.”

Building rapport with a new healthcare provider each time can be an obstacle to patients returning for care, as described by this health department manager “I think people just have a tendency to not follow up because it’s not the same person. They dread seeing someone different. If you’ve got one person who sticks with you then they become sort of your advocate.”

Finally, ecological or community factors appeared to challenge type 3 women, particularly inadequate transportation and other community services as well as cultural issues. Inadequate or unreliable transportation emerged as a contributing factor in obstructing follow up care. In many Appalachian communities, the local public transportation service available to take patients to appointments is often unreliable and difficult to access. One 21 year-old patient described the arduous procedure for accessing public transportation.

“They have to get a form signed and everything stating that they was there and give it back to that guy that brings them and it’s just a big mess.... And I’ve known they’ve had to sit here and wait for them to come pick them up for an hour... Because they’d be out on other runs and stuff.”

The director of a local health department noted

“We do have a public transportation company. But you have to have a diagnosis and you have to wait here and wait there and you have to wait until the bus picks you up. And the bus may not drop you off; if your appointment’s at 10:00 and he’s got somebody else that’s coming there at 12:00, then he’s going to bring you at 12:00. And you’ve missed your appointment and the private physician’s not going to see you if you’re 15 minutes past your appointment and that’s really hard.”

Discussion

Despite the dramatic reduction in ICC mortality, a sizable portion—estimated between 25 and 75% of women continue to be vulnerable to ICC because they do not receive timely or appropriate follow up care upon detection of a Pap test abnormality (Benard, et al., 2005). Appalachian women, whose ICC incidence and mortality rate is significantly higher than the national average, are at elevated risk of inadequate follow-up (ACS, 2007; Hopenhayn, et al., 2005; Ries, et al., 2000). Data from ten health departments in Appalachia Kentucky demonstrated that over half of women diagnosed with ASCUS, LGSIL, or HSIL did not undertake or complete follow-up treatment, including colposcopy or cervical biopsy (National Cancer Institute, 2009). Our results corroborated this low level of follow-up; only 44% of our sample received services for atypical Pap results.

We found that three types of reactions to an atypical Pap test, and obtaining follow up care converged with the three broad categories laid out in our conceptual framework--personal factors; procedure/provider/system factors; and ecological/community factors (Rimer, et al., 2001). Although all response types experienced certain common influences on follow up care—poverty, competing demands, insufficient community resources- those who managed to receive follow up services leveraged other influences. For example, although fear of the follow up procedures or of a possible cancer diagnosis paralyzed type 1 and 3 participants, fear due to perceived susceptibility motivated type 2 participants to seek care (Goldman, et al., 2008).

Several research initiatives hold promise for increasing appropriate follow up care. First, efforts should be directed at determining characteristics associated with each of the three response types. Second, it is important to answer the question why, despite similar circumstances, do certain people transcend considerable barriers to obtain care while others remain in a “pre-contemplation” stage? Additionally, research should be undertaken to assess the most effective approach to overcome these barriers and encourage appropriate follow up care.

Although important to avoid type-casting or stereotyping patients, our findings suggest that it would be beneficial to pay special attention to each patient to determine factors shaping her follow up care decisions and to tailor interventions accordingly. For example, additional educational efforts should be increased for type 1 participants, many of whom suggested that the likelihood of the abnormality self-resolving renders follow up care not worth the trouble. Indeed, such a perspective is supported in the literature; 85–90% of HPV virus and associated cytological abnormalities self-resolve within a year (Gravitt & Jamshidi, 2005). However, given that the preponderance of ICC cases are preventable through early detection and, if necessary, follow up care, special and culturally appropriate educational efforts must be initiated. Type 2 participants, on the other hand, most of whom were already motivated, may simply need a reminder system (Melnikow, et al., 1999).

Type 3 patients faced considerable challenges; on the one hand, most acknowledged the need for follow up care and other the other hand, they perceived substantial obstacles in obtaining follow up care. Our findings suggest several intervention directions, including fear reduction by personal counseling and implementing creative clinical arrangements, including the use of paraprofessionals and flexible scheduling (Ell, et al., 2002). Perhaps the involvement of a lay health advisor who responds to patients' specific informational and other needs might alleviate the problems of overstretched providers and traditionally underserved patients with challenging work and home demands (Christopher, Gidley, Letiecq, Smith, & McCormick, 2008; Schoenberg, et al., 2009).

Limitations

Our modest sample size and composition, including all white participants (consistent with 98% of the counties in which this research took place) and purposive sampling limited the representativeness of the sample and thus the generalizability of our findings. Thus, we cannot extrapolate findings to other rural or even Appalachian communities. Additionally, because we sought to represent the perspectives of women who had received an abnormal Pap test result and those providers most likely to care for such women, our recruitment site was limited to local health departments. This sampling venue biased our results in favor of women seeking formal health care and had the potential of over-representing positive perspectives on local health departments.

Conclusions

To our knowledge, this is the first study to examine the perspectives on follow up care for an abnormal Pap test result among a rural, traditionally underserved population at elevated risk from ICC. Using a broad based, socioecologic framework allowed us to capture the varied competing and overlapping factors shaping receipt of follow up care and suggested productive avenues that may facilitate follow up care. A key message from this research was that even within relatively homogenous rural communities, important differences were observed in how women responded to an abnormal Pap test result, and these differences influenced receipt of recommended follow up care. Targeted interventions or improve policies are needed that appropriately addressing the variety of responses to an abnormal Pap test results. Such interventions or policies are best developed in partnership with those most affected by the condition (in this case, rural, traditionally underserved women), other community members, service providers, policymakers, and researchers. An improved understanding of the contexts in which follow up care decisions take place—from both patients and provider perspectives—will improve the provision of vital services. As the history of disease eradication or at least reduction suggests (Fisher & Brundage, 2009), employing a multi-dimensional approach (patient, procedure/provider/system, and ecological/community) is essential to a comprehensive understanding of complex health decisions. In the case of follow up care for

an atypical Pap test result, addressing the specific perspectives of the response types described in this article may hold great promise in further reducing deaths from this preventable cancer.

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Table 1

Characteristics of field sites compared to state and nation

	County A	County B	Kentucky	United States
Per capita income, 2007	\$23,252	\$26,175	\$30,824	\$38,615
Unemployment rate, 2008	6.9	6.9	6.4	5.8
Poverty rate, 2000	27.1	29.1	15.8	12.4
High school completion, 2000	58.5	58.3	74.1	80.4
College completion, 2000	7.7	8.9	17.1	24.4

Source: Appalachian Regional Commission, 2006

Table 2

Patient Demographic Characteristics (N=27)

Characteristic	n (%)	Obtained follow-up care (n=12)	Did not obtain follow-up care (n=15)
Age , range 18–54 years, mean	29.2 years		
18–21	5 (19%)	2	3
22–25	8 (30%)	5	3
26–35	8 (30%)	3	5
36+	6 (22%)	2	4
Education			
< High school	7 (26%)	3	4
High school graduate	11 (41%)	6	5
Some college	6 (22%)	2	4
College graduate	3 (11%)	1	2
Marital Status			
Married/partnered	5 (19%)	3	2
Separated/divorced	11 (41%)	5	6
Never Married	11 (41%)	4	7
Insurance			
Private/employer sponsored	5 (19%)	3	2
Medicare	1 (4%)	0	1
Medicaid/"medical card"	9 (33%)	4	5
Uninsured	12 (44%)	5	7
Occupational Categories			
Homemaker	1 (4%)	1	0
Professional (including health care)	2 (7%)	1	1
Clerical	5 (19%)	2	3
Retail/service	8 (30%)	3	5
Not currently employed	11 (41%)	5	6
Health Status			
Excellent	3 (11%)	2	1
Very good	11 (41%)	5	6
Good	13 (48%)	5	8
Annual Household Income			
<\$10,000	5 (19%)	2	3
\$10,001–15,000	11 (41%)	4	7
\$15,001–20,000	4 (15%)	2	2
\$20,001–25,000	1 (4%)	0	1
\$35,000–40,000	3 (11%)	2	1
\$40,001+	3 (11%)	2	1

Numbers may not add up to 100% due to rounding

Table 3

Summary of Key Influences on Pap Test Follow Up According to Response Type

Type 1: Not alarmed and did not obtain follow up care (n=8)	Type 2: Alarmed, obtained follow up care (n=12)	Type 3: Alarmed, but did not obtain care (n=7)
<ul style="list-style-type: none"> • personal factors: <ul style="list-style-type: none"> – age – competing demands – poverty • procedure/provider/system factors: <ul style="list-style-type: none"> – procedure features: unnecessary due to self-resolution • ecological/community factors: <ul style="list-style-type: none"> – cultural issues: – privacy – lack of community awareness 	<ul style="list-style-type: none"> • personal factors: <ul style="list-style-type: none"> – competing demands – poverty – psycho-emotional concerns – fear – personal/family history • procedure/provider/system factors: <ul style="list-style-type: none"> – good relations with HCP/LHD¹ • ecological/community factors: <ul style="list-style-type: none"> – national and state programs through LHD 	<ul style="list-style-type: none"> • personal factors: <ul style="list-style-type: none"> – poverty – psycho-emotional concerns – fear – competing demands – age • procedure/provider/system factors: <ul style="list-style-type: none"> – perceived quality of care – inadequate provider supply – lack of continuity of care • ecological/community factors: <ul style="list-style-type: none"> – transportation & community service limitations

¹ HCP = Health Care Provider, LHD=Local Health Department