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## Using communication to manage uncertainty about cervical cancer screening guideline adherence among Appalachian women

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### Abstract

Changes to the United States Preventive Services Task Force (USPSTF) recommendations for cervical cancer preventive services have led to patient confusion, especially in medically underserved populations. We investigated how patient uncertainty concerning cervical cancer screening guidelines is appraised and managed through communication with healthcare providers by conducting in-depth, face-to-face interviews with 24 adult women between the ages of 24 and 65 ( $m = 41$ ,  $SD = 14$ ) living in Appalachia Kentucky. In general, participants expressed a high degree of uncertainty about the updated cervical cancer screening guidelines and appraised this uncertainty as both a danger and an opportunity. Communication with healthcare providers served both to exacerbate and to mitigate patient uncertainty. The study identifies how health care providers may use the change in USPSTF guidelines as a ‘teachable moment’ to productively counsel patients on the importance of timely screening, the typical progression of certain types of high-risk HPV infection to cervical cancer, and the importance of follow-up care.

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Recent changes to the United States Preventive Services Task Force (USPSTF) recommendations for preventive services have led to patient and provider confusion and inconsistent guideline diffusion (Franco, Cuzick, Hildesheim, & Sanjose, 2006; Nelson, Moser, Gaffey, & Waldron, 2009). In 2012, the USPSTF updated its 2003 recommended guidelines for the timeliness and appropriateness of cervical cancer screening (Table 1 compares the 2003 and updated 2012 guidelines). Of all the organizations that provide cancer screening guidelines, such as the American Cancer Society (ACS) and the American College of Obstetricians and Gynecologists (ACOG), the USPSTF guidelines are particularly important because, under the Affordable Care Act, new private insurance plans

and Medicare are required to cover USPSTF-recommended preventive services without patient cost sharing (Karjane & Chelmow, 2013).

Screening guidelines are particularly important in the context of cervical cancer prevention as research indicates nearly all cervical cancer deaths could be prevented if women adhered to preventive screening recommendations and treatment plans (U.S. Department of Health and Human Services, 2013; American Cancer Society, 2013). All major medical organizations (including the ACS, ACOG, and USPSTF) recommend papanicolaou smear cytologies (PAP smears), which test for cell changes on the cervix that could become cancerous if untreated, as the primary screening test for cervical cancer (U.S. Department of Health and Human Services, 2013). Other recommended services include human papillomavirus (HPV) vaccination and co-testing for women in specific age groups. Despite the importance of these screening guidelines, research investigations suggest that the public remains fairly unaware of evidence-based guidelines and of how providers may interpret these guidelines in communicating clinical recommendations (e.g., MacLaughlin et al., 2011). It is also clear that some prevention services are delivered without attention to patient appropriateness, including provision of Pap tests on young adolescents (Moyer, 2012) and HPV vaccination in adult women with abnormal Pap histories (Vetter & Geller, 2007). Some research suggests that the frequently changing guidelines for cancer screening have contributed to increased patient uncertainty with regard to the timing and appropriateness of cervical cancer screening (Karjane & Chelmow, 2013). Furthermore, it is unclear from extant work to what extent people living in rural and medically underserved areas are aware of screening guidelines (in previous or updated form). The purpose of the present study was to investigate patient uncertainty concerning cervical cancer screening guidelines among women living in Appalachian communities and to examine how this uncertainty is appraised and managed through communication with healthcare providers.

## Cervical Cancer Prevention in Appalachia

If caught early through appropriate screening, cervical cancer can be treated. Proper treatment and screening is associated with a survival rate of approximately 91% for localized cervical cancer (American Cancer Society, 2013), and national screening rates are high: Since 2005 researchers have found that over 87% of women between the ages of 25 and 44 and 81% of woman between the ages of 45 and 64 have been screened for cervical cancer in the last three years (Nelson et al., 2009). However, despite these positive screening statistics, cervical cancer screening goals currently are not being met in the United States (Rimer, Briss, Zeller, Chan, & Woof, 2004). Every year, cervical cancer affects approximately 12,000 women in the United States, resulting in death for an estimated 4,000 women (American Cancer Society, 2013). These rates are higher in medically underserved regions of the country, such as rural and Appalachian areas (Kentucky Cancer Registry, 2014). Appalachian women have a lower prevalence of Pap testing and higher rate of invasive cervical cancer than women in other parts of the United States (Hopenhayn, King, Christian, Huang, & Christian, 2008). Analysis of data from 2001 to 2003 in central Appalachian areas found the rate of cervical cancer to be 35% higher than the national average (Wingo et al., 2008). More recent analyses suggest that Appalachian Kentucky has

an invasive cervical cancer incidence rate approximately 67% above the national average (Hatcher, Studts, Dignan, Turner, & Schoenberg, 2011).

In Kentucky, free and low-cost screening is available to all 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. Yet, the factors associated with low cervical cancer screening rates are highest in rural and Appalachian areas (Hall, Uhler, Coughlin, & Miller, 2002). Known explanations for inadequate screening in Appalachia include a belief that cervical cancer has symptoms, personal factors motivated by uncertainties and fears related to screening procedures, not having a regular source of medical care, and competing demands on time or income (Head & Cohen, 2012; Schoenberg, Kruger, Bardach, & Howell, 2013; Studts, Tarasenko, & Schoenberg, 2013).

The unequal diffusion of cervical prevention services in medically underserved populations threatens to further exacerbate health inequities, undermining the potential benefit of screening for Appalachian populations most in need (Hatcher, et al., 2011; Schoenberg, et al. 2013). Indeed, a recent study of rarely and never screened Appalachian women show that the "only significant reinforcing factor distinguishing the rarely- or never-screened group from those more recently screened was the reported implication of a physician's recommendation for screening on one's decision to be screened or not" (Hatcher, et al., 2011, p. 191). Effective communication between healthcare providers and patients is essential to facilitate more appropriate screening practices, but we know little about how providers and patients interpret and talk about new screening guidelines, especially in medically underserved communities, where inappropriate screening services could potentially cause harm or have indeterminate benefits (Rimer et al., 2004). In medically underserved regions, patient-centered communication is critical to blunt potential misunderstanding and misapplication of changing USPSTF guidelines for cervical cancer screening (Schoenberg et al., 2005). Without communication intervention, changes in USPSTF guidelines may disproportionately affect medically underserved populations most vulnerable to knowledge/practice gaps.

## Managing Uncertainty about Screening Guidelines

Although new USPSTF guidelines recommend that "fewer lifetime screenings" may be appropriate for all women (to reduce the burden of cervical biopsies due to abnormal Pap test cytology of undetermined significance), the question remains how patients will understand and act on these changing recommendations. In general, patient uncertainty has been shown to significantly and negatively affect cervical cancer screening and follow-up behavior (Cohen, Scott, White & Dignan, 2013). For example, patients who have logistical, personal, or relational uncertainty related to follow-up care after receiving an abnormal Pap test result are often less likely to receive appropriate follow-up treatment. Cervical cancer-related uncertainty has been investigated with regard to risk perceptions (Garcés-Palacio & Scarinci, 2012), pre-diagnosis abnormalities (Juraskova, Butow, Sharpe, & Campion, 2007), and post-diagnosis (Cohen et al., 2013); however, to date no research has explored patient understanding and uncertainty related to cervical cancer screening guidelines.

Given our focus on patient uncertainty, the theory of communication and uncertainty management (Brashers, 2001, 2007) represents a fruitful perspective for framing our investigation of how uncertainty shapes patients' interpretations of and communication about cervical cancer screening guidelines. Broadly, uncertainty management theory can help explain patient's communicative behaviors in coping with new information and uncertain situations (Scott et al., 2012). Despite common findings of the need for uncertainty management across various chronic conditions, sources of uncertainty are also inherent to the screening, diagnostic, and treatment process, and may be unique to the particular illness or disease to be prevented or treated. Importantly, uncertainty management theory is an appropriate framework for our investigation of cancer prevention given that researchers have not identified the ways in which individuals appraise uncertainty related to new cancer screening guidelines.

Extending the framework of uncertainty in the illness experience (e.g., Mishel, 1988, 1990; Brashers, et al., 2003) to the context of screening and prevention services is important, as it can provide insight into the array of uncertainties individuals encounter in the screening process beyond issues related to diagnosis, treatment, and follow-up care. Even in the absence of an explication of uncertainty in the literature, the appearance of uncertainty—and need for uncertainty management—is a common theme in research on patient-provider communication and lay understanding of cancer screening (Cohen et al., 2013). Not surprisingly, the reduction of uncertainty is frequently a goal of knowledge-based screening awareness campaigns and patient navigator programs to promote cancer screening. Although identifying uncertainty appears to be important in this context, previous work has not accounted for the unique demands or features of uncertainty in the context of changing clinical recommendations.

In considering uncertainty management in the context of cancer prevention services research, this investigation will attempt to refine and better explain processes related to the screening experience and meaning of uncertainty, the role of appraisal in uncertainty management, and the role of behavioral responses to uncertainty. According to Brashers (2001), people can manage their health-related uncertainty by seeking to reduce, maintain, increase, or adapt to their uncertainty. The way that people manage their uncertainty is related to the way they appraise that uncertainty. When people find uncertainty threatening, they usually want to reduce it. When uncertainty allows people to maintain hope, they may want to maintain or increase it. When people acknowledge that their uncertainty will persist over an extended period of time, they can adapt to the uncertainty by learning to tolerate or even value it. A direct examination of how patient's perceive uncertainty related to changing screening guidelines can address this shortcoming by providing a grounded account of the way individuals from medically underserved communities appraise uncertainty in the context of receiving cervical cancer prevention services. Thus, the first two research questions in the present study inquired about the experience and appraisal of patient uncertainty related to cervical cancer screening guidelines:

RQ1: To what extent are women living in Appalachian communities uncertain about the USPSTF cervical cancer screening guidelines?

RQ2: How do these women appraise their uncertainty about screening guidelines?

In order to better understand the communicative process of uncertainty management, Brashers (2007) called for further investigation of more and less adaptive ways of managing uncertainty through communication. The current study answers this call by exploring the positive and negative potential of provider communication in helping to manage patient uncertainty about screening in ways that are meaningfully linked to screening behavior. In terms of practice, in order to improve cervical cancer screening rates and manage patient uncertainty about screening, we must focus on risk factors that are associated with higher screening rates (Hatcher, et al., 2011; Nelson et al., 2009). One modifiable risk factor that is feasible for intervention for producing more immediate outcomes is provider communication (Cohen, et al., 2013). In the context of new screening guidelines, new information can help patients manage uncertainty (Barbour, Ritamaki, Ramsey, & Brashers, 2012; Brashers et al., 2000) even if it fails to reduce the ambiguity of its outcome. Theoretically, however, the relationship between information provision and uncertainty management is “not straightforward” (Hogan & Brashers, 2009, p. 48). The final two research questions focus on how patients discuss cervical cancer screening guidelines with their providers and how this might affect their uncertainty:

RQ3: How do patients living in Appalachian communities report what their healthcare providers have said to them about cervical cancer screening guidelines?

RQ4: How does this communication serve to help patients manage their uncertainty about cervical cancer screening?

## Method

As part of the Rural Cancer Prevention Center’s multi-method, multi-year effort to improve cervical cancer prevention communication among medically underserved Appalachian women, the current study utilized in-depth, face-to-face interviews with Appalachia Kentucky adult women to gather patient stories about cervical cancer screening knowledge, attitudes, and practices.

## Participants

We recruited participants through local clinics and health departments in the target Appalachian region. To be eligible to participate, women had to be between the ages of 18 and 65 (because 65 is the recommended cutoff age for cervical cancer screening by the USPSTF). Twenty-four women between the ages of 24 and 65 were recruited to participate in this study. All women were white, which is reflective of the region’s population where ethnic minorities comprise less than 1% of the population (U.S. Census, 2010). The average age of the participants was 41 years old ( $SD = 14$  years; range = 24 – 65 years).

## Procedure

An advanced registered practice nurse who is a local resident of the catchment region conducted the interviews. The nurse was trained by the lead author to conduct interviews so that she could also navigate individuals to appropriate screening or care, and answer any medical questions participants had related to cancer prevention services.

Interviews occurred at the location of the participant's choosing. We used a semi-structured interview protocol that included questions about cervical cancer screening behaviors (e.g., "How old were you when you got your first Pap test?"), knowledge about cervical cancer screening guidelines (e.g., "What do you know about the current recommendations for cervical cancer prevention?"), and communication with providers about screening (e.g., "Can you tell me about the last conversation you had with your provider about getting a Pap test?"). After listening to participants' broad knowledge of cervical cancer prevention services and stories about recent provider visits, the research nurse then provided the participants with information about the 2012 USPSTF recommended guidelines for cervical cancer screening and asked participants to share their initial thoughts and feelings about the updated guidelines (e.g., "What are your initial thoughts about this guideline?") and probed to gain additional understanding regarding uncertainty. Participants were then asked to share personal stories about how their healthcare providers have talked about cervical cancer screening guidelines with them during previous visits. Finally, participants were asked about their expectations for future conversations with their providers and their intentions for changing their screening behavior in any way in the future.<sup>1</sup> The interviews lasted between 10 and 35 minutes (average length of 20 minutes). After completing the interview session, each participant received a \$30 gift card. All interviews were audio recorded and transcribed verbatim by the authors.

### Data Analysis

All four authors analyzed the interview transcripts using the core elements of the framework analysis methodology, a qualitative method of sequential inductive data analysis tailored for applied research (Ritchie & Spencer, 2002). Framework analysis is a flexible analysis wherein the analysis stage data is sifted, charted, and sorted in accordance with key issues or problems (Ritchie & Spencer, 1994). First, to familiarize ourselves with the data, the first four authors independently read the transcripts. We then met to discuss key ideas and recurring themes in participant responses to the protocol questions. After this initial meeting, we developed a thematic framework for organizing participant responses based on prior research examining antecedents to cervical cancer screening and prevention practices consistent USPSTF guidelines. In the context of understanding the implications for cervical cancer guidelines, framework analysis methodology suggests researchers consider the qualitative dimensions of attitudes and nature of people's experiences, the factors that underlie particular perceptions, what affects delivery of services, and how strategies can be improved. The framework here included how women managed uncertainties related to cervical cancer prevention service guideline changes with respect to broad concepts of their knowledge, prevention behaviors, and attitude. The researchers discussed operational definitions for the categories and considered the interrelationships among them (i.e., whether there were distinct constructs or subthemes presented from the data). Using these categorical constructs, all four researchers independently annotated the transcripts by theme. Key focal constructs were clarified, and the annotated transcripts were reexamined by noting divergent themes or unique findings. Finally, one researcher placed *in-vivo* quotations culled by all four authors into a master outline containing all identified themes. A second researcher reviewed the charting and, where disagreements were found, negotiated the placement of *in-vivo* quotations (Lindlof & Taylor, 2002) with the full research team until we reached

consensus about the primary data-driven themes. The results presented here reflect this consensus. Examples that appear in this report were selected by author discussion; all names used in this report are pseudonyms.

## Findings

In general, we found that women expressed a high degree of uncertainty about the updated cervical cancer screening guidelines. The women appraised this uncertainty as both a danger and an opportunity, which led them to endorse screening practices that highlighted the divergence between knowledge, attitudes, and behavior. We also found that communication with healthcare providers had the potential to exacerbate or to mitigate patient uncertainty.

### Uncertainty about cervical cancer screening guidelines

Women reported a lack of knowledge regarding the updated cervical cancer screening guidelines provided by professional associations and government agencies. In fact, most of the women ( $n = 18$ , 75%) reported that they thought the current recommendation was to screen annually for cervical cancer, and for many, this was based on their previous experience of receiving annual Pap tests. Emily's response typified this finding: "I was always told that you had a Pap smear every year. And if you had any problems or anything come up that was abnormal, if you've been sexually active or whatever, then to go in and get checked." Even women who reported knowing that the past guidelines had changed did not know the details of the changes, as Della illustrates:

I know that the Pap smear, as far as Paps and things like that, I know it's changed. The time that you're supposed to do it. I think it was supposed to be once every year, I think it changed too didn't it? I don't remember.

Once women learned about the updated guidelines, many expressed feeling uncertain about the recommendations, as Addie did:

I feel like the fact that there are different guidelines and that some places recommend two years and some places recommend three years in between Pap smears, that creates a huge uncertainty in my mind. Because in my opinion, I feel like health care standards and guidelines should be the same all the way across the board.

For Addie, the perceived inconsistency between the previous and updated guidelines raised questions about the credibility of the professional standards represented by those guidelines.

Women also reported varied knowledge about the conditions under which or at what age screening should stop. Although women with a family member who had had a hysterectomy often knew that screening stopped after a hysterectomy, many women did not understand that a hysterectomy eliminated the cervix and the uterus, and along with it a woman's risk for cervical cancer. In general, women thought the potential lifetime risk of cervical cancer meant that all women should continue screening indefinitely. As Lily said, "Now that I'm thinking about it, I don't – is there like a certain age that you would stop having cervical cancer? Probably not. So maybe you should keep on having them [Pap tests]." Carol went so far as to say that she found the updated guideline to be insulting to older women: "If you

stop at 65, it's like saying you're no longer important if you die. If you turn up with cervical cancer, oh well, you know, you're just over the hill, you're not as important anymore.” Carol's comment illustrates how the updated screening guidelines caused uncertainty about whether the guidelines serve the best interest of the patient.

Thus, in short, the answer to our first research question was that many women reported a relatively high degree of uncertainty about the content and credibility of the updated cervical cancer screening guidelines.

### Complex appraisals of uncertainty

The women in the present study appraised their uncertainty about the USPSTF guidelines in complex ways. In one sense, many women appraised their uncertainty about the guidelines as a danger. In the face of uncertainty about screening, participants often retained the heuristic that all screening is good and thus that more screening is better screening. The women felt that the previous guidelines provided them with the assurance that they were staying on top of their reproductive health. Consequently, the updated guidelines (which recommend less frequent screening and retain the recommendation to stop screening at age 65 or after a hysterectomy) posed an unwanted risk to their health. As Shelby expressed,

I think it's a good thing to always get checked. As you can tell, I'm pro on going to get checked and everything of that nature. The reason is, just because you've not had it in the past and you've been healthy, you can still get it at 65.

Lily asked, “You know, a hysterectomy doesn't eliminate your risk for cervical cancer, correct? Seems like better safe than sorry would apply in that whole thing here.” Some women, including Charlotte, explained their belief that, even after the cervix is removed, the “concern is finding the cancer cells in the vaginal walls, even though there's not anything in there, you know. I still have a concern for that, so they should continue 'em [Pap tests].” Hope's remark as she processed through her uncertainty about the changes in the guidelines illustrates how her uncertainty about the guidelines led her to err on the side of favoring over-screening: “There are different—people say there are different things that you should do, different protocols to follow. Yeah, I don't know what they are. I thought it was once a year. I feel like you should do it every year.” Collectively, these comments demonstrate how some women's over-screening bias heightened their uncertainty in the face of the updated cervical cancer screening guidelines.

For many, this over-screening bias was fueled by their knowledge about their peers' sexual behavior. When asked about when young women should start screening, women expressed their belief that Pap tests should begin with sexual activity, which, in their estimation, was typically earlier than the age of 21 in their community. Hope said, “I think there's probably young girls who need it younger than 21. Because there's a lot of girls that are having babies at 13 and 14, and if they're doing that, then they're not playing safe habits.” When asked “How do you feel about the recommendation that young women don't have a Pap, don't begin screening, until they are 21?” Caroline responded, “Oh wow. Kinda shocking to me,” and Della said that she found the USPSTF guidelines to be “alarming. Very.” For each of these participants, their uncertainty was based on their perception that women were sexually active at a much younger age than 21 years old.

Women in this Appalachian community also expressed concern that length between screenings would place young, sexually active women at higher risk of cancer. Shelby argued that delays would hinder early detection and treatment:

I actually think three years is too long. I think it should be once a year mandated. That's my opinion. Because if you go and get checked and two or three months later there's something, but you wait two or three more years to get checked again, it's likely going to be too late. I think the way society currently is, with teenagers being more sexually active than they were several years ago, I think it would be recommended to have it younger. I would even start at 16 or 18. 'Cause I do know that with more sexual activity, you have a higher chance you can get cervical cancer starting at an earlier age.

Carol also expressed uncertainty about the screening guidelines by sharing her incredulity about the perceived public health risk assumed by starting cervical cancer screening later:

So, even if you're sexually active as a teenager, you're not screened? That doesn't sound very smart. You know, it doesn't reflect a lot of wisdom, in my opinion, for public health. If someone is sexually active, I don't see why they, for any reason, you would not screen them. It just doesn't make sense.

Furthermore, the women's perceptions about sexual activity and its connection to HPV imbued the screening guidelines with a sense of certainty that gave the women a feeling of control over their reproductive health. However, this lay understanding of screening does not allow for the possibility that HPV testing is unnecessary if Pap testing is performed. When women learned or were knowledgeable about the guidelines and understood the causal link between HPV and cervical cancer, they did not understand why HPV testing was not recommended in women younger than 30 years old. Della spoke frankly: "I think that's crazy. Plain. That's just crazy. That's [HPV is] the most common factor in cervical cancer." The women's uncertainty about the appropriateness of the screening guidelines given the sexual norms in their community and their own sexual behavior led some women to question the credibility of the organizations that provide the recommendations. Susannah put it this way:

Are the same people that write this stuff the same people that do the national statistics for other medically related issues? Because the national statistic for a female's first time – with sexual intercourse, not just sexual interaction or oral sex or any of that, but sexual intercourse – the national average on a female is 11 years old. There's a lot of time between looking at that 11-year-old little girl and that 30-year-old woman that they test for the first time. My first, I wouldn't necessarily say STD, but my first infection happened at 19. I would see big problems with that [recommended first screening at 21 years old].

Whereas some women appraised their uncertainty about the cervical cancer screening guidelines negatively, other women appraised their uncertainty more positively because they had not been receiving regular screening, and the updated guidelines reflected their previous screening behavior. In fact, 10 (42%) of the same women who expressed unwanted uncertainty at the lower frequency of the updated screening guidelines were the same

women who later admitted to not actually getting Pap tests according to the previously recommended screening timetable. For example, when asked how long it had been since her last Pap test, Caroline (who at first said that the new guidelines were “shocking”) admitted “three plus [years] actually.” Susannah, who said that she saw “big problems” with the updated screening guidelines, later shared that she had Pap tests only “when necessary – every five to ten years.” This illustrates a clear disconnection between participants’ knowledge of and attitudes toward screening and their enacted screening practice. The knowledge/practice gap also raises questions about the extent to which the updated cervical cancer screening guidelines might affect actual practice given the apparent lack of connection between the previous guidelines, provider recommendations and women’s reported screening behavior.

In short, the answer to our second research question was that women engaged in complex appraisals of their screening guideline-related uncertainty. Some participants appraised the uncertainty negatively to the extent that the updated guidelines contradicted their knowledge and attitudes toward screening (i.e., more screening is better), but they appraised the uncertainty positively to the extent that it reinforced their previous screening behavior (which was often less frequent than previously recommended).

### **Managing uncertainty through communication with providers**

Finally, we asked participants how their healthcare providers have talked to them about cervical cancer screening guidelines and examined the potential for communication between healthcare providers and patients to address the gap between knowledge, attitudes, and behavior related to cervical cancer screening. We found that women reported being heavily influenced by conversations with their healthcare providers about cervical cancer screening behavior. Laverne explained that she would privilege her doctor’s recommendations over the USPSTF guidelines:

I probably will continue as long as my doctor thinks it’ll be beneficial to have the screenings done. But I can understand as you get older, probably your chances of developing cervical cancer are gonna decrease. But personally, I will probably continue as long as my doctor recommends that I have them done.

Addie also said that, if faced with conflicting information about the appropriate timing of screening from the organization’s guidelines and her provider’s guidelines, she would adhere to what her doctor recommended:

I know over the past few times I’ve been to my provider, I’ve noticed that the requirements for time in between Pap smears and things such as that have varied. That would make me begin to wonder and also make me lean toward wanting to go the shorter amount of time between Paps because, you know, obviously there’s some sort of reason. But at the same time I really trust my provider, so ultimately I guess I would go with what she said.

For several women, their interaction with their providers helped mitigate their uncertainty related to cervical cancer screening guidelines by releasing them from having to know the specifics about the guidelines. Caroline shared:

I kind of just, I trusted them. And what their recommendation was, I just thought that'd be okay. If there was a concern, I felt like they were being cautious enough that they would catch something if something was going wrong. I guess, I thought they were covering the risk, I trusted them. So I guess it wasn't really about what I wanted. I assumed it was my needs that they were looking out for.

Similarly, Cora said, "I trust them more than I trust myself," indicating that, absent personal knowledge about guidelines for cervical cancer screening, she trusted her provider's recommendations for Pap testing and follow-up care.

Some women reported having helpful conversations with their providers where they reached a shared decision about best screening practice. Addie shared her experience talking about cervical cancer screening recommendations with her doctor:

We actually did discuss it the last time because I had not had a Pap since I had switched to her as my provider. I couldn't remember exactly what the date was. We were discussing whether or not it was best for me to go ahead and have one or not, and she was kind of teeter-tottering. It was close enough to her guideline of three years in between, that she decided ultimately it wasn't going to hurt anything, and she wanted to establish care with her and make sure that everything was okay. So we went ahead and did it then, and she told them that I wouldn't have to do it again for another three years.

These experiences suggest that provider communication about cervical cancer screening holds great potential for ensuring timely and appropriate screening for women in Appalachian communities by leveraging the provider's credibility to help women manage their uncertainty about screening guidelines. However, in some cases, providers may contradict the updated screening recommendations in order to lessen patients' uncertainty. For instance, Bonnie appreciated how her doctor offered to continue the previous screening pattern if she wanted to be screened more frequently as a way to manage her uncertainty about developing cervical cancer:

We used to do them once a year, but if you've had three negatives then it's every three years or something like that. But then one doctor, the doctor I was seeing, said, "If you don't feel comfortable with that, then you can still come in and have it done every year."

Although at times communication with providers served to mitigate patient worry, we also found that communication with providers posed a number of challenges to patients managing uncertainty about cervical cancer screening guidelines. Participants described how they had experienced poor communication with their providers and how that had inhibited their ability to manage their uncertainty. Susannah suggested that even when providers may be providing appropriate screening care, the lack of communication about the guidelines left her with questions:

I was thinking back about my experiences with any of the OBs or GYNs, whichever way you want to look at it. I don't think any of them have really been patient-centered. It's always been a more or less "This is the way we do things, and

this is the way it happens.” It feels more like a routine for them, but I was always left with questions afterwards.

Other women reported that their providers did not communicate with them at all about cervical cancer screening guidelines, forcing them to request screening. Sadie explained: “There wasn’t really talk about the guidelines. Just, ‘We’ll let you know if anything’s abnormal, we’ll send you a letter.’ And there was no follow up. I had to ask to get one [Pap].” Cora also shared that, in the absence of discussing screening recommendations with her doctor, she was the one to initiate her screening practice: “Sometimes I go two, three years and then I’d have one. I’d skip. I wouldn’t have it done every year. I went on my own intuition.”

Many of the women reported feeling that they do not have power in the medical encounter, and that guidelines empower them to get the screening they want without having to be proactive. Hope described the dynamic this way:

I don’t have as much power. You know, like I want this kind of testing. I want to find out what this is, can you just give me, you know. You don’t have any kind of say. I know I’m trying to get what you want. I’m trying to think about those things that you said—there’s so many [guidelines] to remember. But I don’t have a lot of power or say in what happens. I do make a point to tell them my concerns, and most of the time I leave feeling better about it. But still in the back of my mind I have, “Well, we didn’t check about this thing, you know, we kind of put that one to the side and only focused on one area that I’m concerned about.”

Given that patients often engage in complex appraisals of uncertainty as both positive and negative, Hope’s comment illustrates how communication with healthcare providers can simultaneously serve as a facilitator and an inhibitor of uncertainty management. Thus, the answer to our last two research questions were that when providers engage in more patient-centered communication, uncertainty about cervical cancer screening guidelines was helpfully managed, but when providers engaged in poor or no communication about the screening guidelines, patients experienced unwanted uncertainty about best screening practices. When providers engage in patient-centered communication participants identified their ability to cope with uncertainty and communicate with their provider to manage their concerns about cervical cancer prevention.

## Discussion

The present study was designed to identify the extent to which women from the Appalachian region experience uncertainty concerning cervical cancer screening guidelines, how they appraise this uncertainty, and how their interaction with healthcare providers affects their management of this uncertainty. We found that women appraised their uncertainty in complex ways, which highlighted the gap between their knowledge, attitudes, and behavior related to cervical cancer screening. We also found that communication with providers simultaneously exacerbated and mitigated patient uncertainty. These findings have important implications for theory as well as practice.

### **Theoretical implications for the theory of communication and uncertainty management**

Research utilizing the theory of communication and uncertainty management has primarily focused on various communication strategies (e.g., social support, information seeking or avoiding) people use to manage their uncertainty in various illness contexts, including HIV and AIDS (Brashers et al., 2000), cancer (Mishel et al., 2003), organ transplantation (Scott, et al., 2011), genetic testing for breast cancer (Bylund et al., 2012) and screening for cystic fibrosis (Dillard & Carson, 2005). The current investigation is one of the first to examine uncertainty management in the context of cervical cancer screening, bolstering the growing evidence for the utility of uncertainty management theory in examining uncertainty related to health behavior (i.e., screening) rather than only in relation to a particular illness. Consistent with Brasher's (2001, 2007) call for research in this area, patients report engaging in communication behaviors with providers to both manage and negotiate uncertainty, as opposed to simply reduce uncertainty.

Furthermore, although many communication scholars agree that uncertainty can be appraised both positively and negatively, very little research has examined uncertainty appraisal processes and how appraisal is linked to uncertainty management of health behavior. We found that women in Appalachia appraised uncertainty about cervical cancer screening guidelines unfavorably insofar as the guidelines contradicted their preference for earlier and more frequent screening, but they appraised the uncertainty favorably insofar as the uncertainty reinforced their screening behavior, which typically occurred less frequently than they believed it should. This finding reinforces one of the fundamental assumptions of the theory of communication and uncertainty management, namely that uncertainty itself is neither positive nor negative, but rather it is the appraisal of the uncertainty that informs how people respond (Brashers, 2007). Moreover, in his conceptualization of uncertainty appraisal, Brashers (2001, 2007) often categorizes the appraisal as positive or negative, but not both. Our findings, however, expand Brashers's conceptualization of uncertainty appraisal by demonstrating that the very same uncertainty can be simultaneously appraised positively and negatively. This suggests that uncertainty appraisal is a complex process and that future investigations should account for the possibility of positively and negatively appraising the same uncertainty in linking uncertainty to health behavior.

### **Practical implications for communication about screening guidelines**

In the present study, we sought to identify the ways in which women residing in the medically underserved region of Appalachia Kentucky understand changes in cervical cancer screening guidelines. In so doing, we discovered the heuristics women rely on when appraising the benefits and risks associated with cervical cancer screening, and we gained insight into how uncertainty management goals may explain knowledge/practice gaps in women's willingness to adhere to recommended cervical cancer screening guidelines.

There are several practical implications for patient-provider communication from this research. First, there are clear implications for how providers can more effectively communicate with patients about screening recommendations. This study found that the uncertainty produced by changes to cervical cancer screening protocol was a resource that women often used to reaffirm their prior behavior that departed from clinical

recommendations. Health care providers may use the change in guidelines as a “teachable moment” to productively counsel patients on the importance of timely screening, the typical progression of certain types of high-risk HPV infection to cervical cancer, and the importance of follow-up care.

Importantly, because providers do not know which HPV infections will clear on their own and which will require treatment, they also need to help patients manage the uncertainty related to screening outcomes, including a positive HPV test or abnormal Pap test. All women in our sample articulated their expectation that their healthcare providers were responsible for ensuring that the patient is appropriately screened, but we found that fewer women in our sample were encouraged by healthcare providers to think about their unique screening history and whether less frequent Pap testing was appropriate for them. Concerns about failures in detecting HPV early and in treating abnormalities were perceived by participants to be the serious consequence of under-screening. In the cases where individual beliefs about Pap testing annually are uncertain or ambiguous due to conflicting or non-converging messages, an atmosphere of fear and confusion can lead individuals to avoid taking action to protect against risk or to take excessive action to protect against risk. In fact, there are a number of risks inherent in over-screening, including the cost-effectiveness of false positives and occurrence of side effects (Saslow et al., 2012). Unless their healthcare providers help to reframe their thinking and practice about cervical cancer screening, some women do not have a good reason to give up their heuristic based on past screening behavior or over-screening bias. This underscores the potential for communication with healthcare providers to significantly influence women’s screening behavior by explicitly addressing the risks that accompany over-screening for cervical cancer.

Second, given the variety of uncertainties inherent to the process of cervical cancer screening outcomes, there is a clear implication that provider provision of more knowledge, alone, will not help patients manage uncertainties that may be barriers to pursuing appropriate cervical cancer prevention strategies. Many researchers have assumed that the most critical barrier to equitable patient outcomes in cervical cancer is the gap between knowledge and practice in the diffusion of USPSTF guidelines (Avis-Williams, Khoury, Lisovicz, & Graham-Kresge, 2009; Tessaro, Herman, Shaw, & Giese, 1996). However, previous research demonstrates that knowledge and awareness of screening benefits is not a significant independent predictor of adherence to cervical cancer screening timeliness recommendations. The current research is consistent with this finding: Even when women had some knowledge that cervical cancer screening guidelines had recently changed, there was still a gap between the women’s knowledge about the guidelines and their screening behavior. This suggests that knowledge-based interventions may not be sufficient to prompt appropriate screening. Rather, healthcare providers should focus their attention on the uncertainty that thrives in the gap between knowledge and behavior. In discussing cervical cancer screening guidelines, it may be important to account for the possibility of an over-screening bias that also does not align with patient behavior. That is, patients may report the heuristic that more screening “can’t hurt,” and use screening as a means of lessening unwanted uncertainty about maintaining control over reproductive health in light of women’s sexual behavior. However, despite these intentions, the evidence in this study suggests that despite the heuristic that more screening “can’t hurt,” these good screening

intentions do not necessarily lead to regular screening behavior; concerns over making appointments, accessing appropriate follow-up care, and having a medical ‘home’ are significant barriers to women’s acting on their intention to screen frequently. By assessing a patient’s uncertainty about cervical cancer prevention (including history of abnormal Pap smears, HPV vaccination status, among other factors), providers can tailor their explanations of the potential disadvantages to excessive screening or the inconsistency between the updated guidelines and the women’s screening behavior.

Third, there is evidence that patients may use changing guidelines to discount the consequences of not screening in a timely manner; women in this population reported putting their healthcare needs behind others in their family, cancelling appointment or simply “putting off” screening because the outcomes were often uncertain, or they were certain that it would be an uncomfortable (and embarrassing) process they simply would rather go through less often. It is clear that women trust and rely on health care providers to reinforce the importance of women staying on top of their reproductive health with appropriate HPV vaccination, timely screening, and follow-up care. Focusing on uncertainty management with patients rather than knowledge transfer can enable healthcare providers to use information to help align women’s knowledge and intended screening behavior so that there is less room for unproductive uncertainty to grow in the gap between patients’ screening knowledge and behavior.

### Limitations and future research

The current study was designed as a first step to guide targeted message development to improve cervical cancer guideline communication in this special population. We do not yet know to what extent the findings from this study would apply to women of a similar age drawn from a different medically underserved population, and their strategies for managing uncertainties. In addition, although representative of the focal geographic region for this particular investigation, participants in the present study were relatively homogenous in terms of basic demographic characteristics. Additional research is needed to examine the transferability of these findings to more heterogeneous groups of women in terms of ethnicity, socio-economic status, and geographic location who may have similar or different concerns with respect to how they communicate about changing cervical cancer guidelines.

Identifying knowledge/practice gaps is important for understanding diffusion of evidence-based cancer prevention services. The current data suggest those researchers’ efforts to educate the public about HPV and cervical cancer may be important but insufficient when perceived knowledge and attitudes regarding the need for the preventive innovation conflict with the desired outcome (i.e., certainty of diagnosis and treatment). Using qualitative interviews with women who have experienced recent Pap tests as well as women who have not adhered to recommended guidelines allowed us to identify a range of cervical cancer-related knowledge, social influences, and risk perceptions about the disease (as well as HPV), which in turn has implications for effective communication from health care providers. Rather than designing knowledge-centric interventions to enhance screening uptake, the present results suggest that future efforts should focus on accounting for

patients' uncertainty to effectively accelerate women's understanding of evidence-based cervical cancer prevention service guidelines.

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**Table 1**

Comparing 2003 and 2012 United States Preventive Services Task Force Recommended Guidelines for Cervical Cancer Screening

2003 Recommendations <sup>i</sup>	2012 Recommendations <sup>ii</sup>
<p>Women should begin screening within three years of becoming sexually active or when they turn age 21.</p> <p>Once women begin screening, they should screen at least every three years.</p> <p>Women older than 65 who have had adequate previous screening and are not otherwise at risk should not continue screening.</p> <p>Women who have had a total hysterectomy with removal of the cervix for benign reasons should not continue screening.</p>	<p>Women should not screen for cervical cancer before the age of 21.</p> <p>Women between the ages of 21 and 65 should screen every three years. Women under the age of 30 do not need to test for HPV. Women between the ages of 31 and 65 who have had adequate screening with at least the last three tests negative can extend their screening to every five years, screening with HPV testing and cytology.</p> <p>Women older than 65 who have had adequate previous screening and are not otherwise at risk should not continue screening.</p> <p>Women who have had a total hysterectomy with removal of the cervix for benign reasons should not continue screening.</p>

<sup>i</sup> Information retrieved from USPSTF (2003)

<sup>ii</sup> Information retrieved from Moyer (2012)