Published in final edited form as:

J Prim Prev. 2015 April ; 36(2): 79–92. doi:10.1007/s10935-014-0379-7.

Cervical Cancer Worry and Screening Among Appalachian Women

Kimberly M. Kelly,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, Mary Babb Randolph Cancer Center, Robert C. Byrd Health Sciences Center, West Virginia University, PO Box 9510, Morgantown, WV 26506, USA

Nancy Schoenberg,

Behavioral Science, School of Medicine, University of Kentucky, 125 Medical Behavioral Science Building, Lexington, KY 40506, USA

Tomorrow D. Wilson,

Department of Biobehavioral Health, Department of Public Health Sciences, College of Health and Human Development, College of Medicine, The Pennsylvania State University, 114 Biobehavioral Health Building, University Park, PA 16802, USA

Elvonna Atkins,

Department of Pharmaceutical Systems and Policy, School of Pharmacy, Mary Babb Randolph Cancer Center, Robert C. Byrd Health Sciences Center, West Virginia University, PO Box 9510, Morgantown, WV 26506, USA

Stephanie Dickinson, and

Department of Statistics, Indiana Statistical Consulting Center, College of Arts and Sciences, Indiana University, 1100 East 7th Street, Room 200, Bloomington, IN 47405, USA

Electra Paskett

College of Public Health, Comprehensive Cancer Center and College of Medicine, Ohio State University, Suite 525, 1590 N High Street, Columbus, OH 43210, USA

Kimberly M. Kelly: kmkelly@hsc.wvu.edu

Abstract

Although many have sought to understand cervical cancer screening (CCS) behavior, little research has examined worry about cervical cancer and its relationship to CCS, particularly in the underserved, predominantly rural Appalachian region. Our mixed method investigation aimed to obtain a more complete and theoretically-informed understanding of the role of cancer worry in CCS among Appalachian women, using the Self-Regulation Model (SRM). Our quantitative analysis indicated that the perception of being at higher risk of cervical cancer and having greater distress about cancer were both associated with greater worry about cancer. In our qualitative analysis, we found that, consistent with the SRM, negative affect had a largely concrete-

experiential component, with many women having first-hand experience of the physical consequences of cervical cancer. Based on the results of this manuscript, we describe a number of approaches to lessen the fear associated with CCS. Intervention in this elevated risk community is merited and may focus on decreasing feelings of worry about cervical cancer and increasing communication of objective risk and need for screening. From a policy perspective, increasing the quantity and quality of care may also improve CCS rates and decrease the burden of cancer in Appalachia.

Keywords

Cervical cancer; Cancer screening; Appalachia; Psychosocial impact

Introduction

Appalachia is a mountainous, geopolitically-designated region, including 13 states from New York to Mississippi, along the eastern coast of the United States [Appalachian Regional Commission (ARC), 2013]. It is medically underserved, has higher rates of poverty, and has less educational attainment than the United States as a whole (ARC, 2013; Behringer & Friedell, 2006). Culturally, the central Appalachian region (parts of Kentucky, North Carolina, Ohio, Tennessee, Virginia and all of West Virginia) is noted to have elevated religiosity (Kosmin, Mayer, & Keysar, 2008; Leonard, 1999), and, psychologically, greater worry about cancer (Kelly, Ferketich, Ruffin, Tatum, & Paskett, 2012). In spite of achievements in the battle against cervical cancer (CC) (American Cancer Society, 2013), the central Appalachia region remains highly burdened by this disease (Hall, Uhler, Coughlin, & Miller, 2002; Ohio Department of Health, 2007). Cervical cancer screening (CCS) can prevent this type of cancer through the removal of abnormal cells, and research has explicated factors associated with lower CCS rates in Appalachia, such as structural barriers (e.g., transportation, health insurance) and fear of pain and embarrassment (Behringer & Friedell, 2006; Lyttle & Stadelman, 2006; Schoenberg, Hopenhayn, Christian, Knight, & Rubio, 2005). Despite efforts to understand CCS behavior in Appalachia, little research has examined worry about CC and its relationship to CCS.

Demographic factors such as lack of health insurance or transportation, lack of knowledge, and inability to pay have been linked to inadequate CCS (Scarinci, Beech, Kovach, & Bailey, 2003; Schoenberg, Hopenhayn, Christian, Knight, & Rubio, 2005). Negative affect also plays an important role in women's engagement in screening services. Many women have mentioned embarrassment or modesty as a deterrent to receiving CCSs, such as exposing one's body to medical providers (particularly male) due to modesty, religious sanctions, and being a known member of the community (Azaiza & Cohen, 2008; Holroyd, Taylor-Piliae, & Twinn, 2003; Markovic, Kesic, Topic, & Matejic, 2005). Guilt and anxiety associated with sexually transmitted disease and anxiety associated with having a family history of cancer are also important contributors to lower rates of CCS (Maissi et al., 2004; Philips, Johnson, Avis, & Whyne, 2003; Walsh, 2006). Fear (of pain, judgment by the provider because of their weight, or gossip) has also been noted to detract from CCS (Azaiza

& Cohen, 2008; Holroyd et al., 2003; Markovic et al., 2005). However, we currently lack extensive insights about CCS among Appalachian women.

Cancer distress and negative affect, which may include depression, anxiety, worry, panic and isolation (National Cancer Institute, 2013; Deimling, Bowman, Sterns, Wagner, & Kahan, 2006), have been reported in other populations at risk for cervical cancer (Korfage et al., 2014; Vigod, Kurdyak, Stewart, Gnam, & Goering, 2011). Cancer worry, defined as an affective reaction to perceived and real threat of the disease, has been found both to deter and encourage participation in CCS (Hay, Buckley, & Ostroff, 2005). A limited number of studies in varying cultural groups have found that women worry about being diagnosed, about losing intimacy and the ability to complete maternal or spousal duties if diagnosed, and fear that little could be done to treat CC if diagnosed (Ackerson & Gretebeck, 2007; Azaiza & Cohen, 2008; Hay et al., 2005). Considering equivocal findings in the literature (Hay et al., 2005), additional research is needed about the role of worry and its relationship with CCS.

A number of theoretical models include negative affect as a key predictor of behavior, and these have been applied to screening behavior (Hay et al., 2005). The Self-Regulation Model (SRM), with its focus on the interaction of self and social factors with affect and health behavior, is uniquely suited to the context of CCS in Appalachia. The SRM posits that when presented with a health threat (e.g., CC) an individual forms an affective representation of the health threat and engages in behaviors to manage it (e.g., CCS). This representation includes feelings about both the threat of and response to the disease (Cameron, 2003). The affective representation of a health threat, mainly negative affect or distress, is routed in the neural substrates of the behavioral avoidance/inhibition system in the septo-hippocampal region and in the right anterior cortex (Cameron, 2003; Sutton & Davidson, 1997). Thus, this negative affect (e.g., worry, distress) can serve to inhibit behavior when affect is allowed to run amok, in the absence of contextual cues and clear health behaviors to manage the health threat.

In addition, the cognitive representation is the individual's own understanding of the health threat and is intimately connected with its affective representation, reflecting the common neural pathways of emotion and memory in the amygdala (Cameron, 2003; Metcalfe & Jacobs, 1998). Affective representations tend to operate at the concrete-experiential level, meaning that the individual may call upon her own experience or imagine herself in the situation, rather than abstractly relating knowledge of the disease (Cameron & Leventhal, 2003). For example, individuals who do not feel personally at risk for the disease are less likely to worry about it (Leventhal, Kelly, & Leventhal, 1999). Further, the relationship of the affective representation to the self-system (i.e., innate factors such as biology and external factors such as access, culture, and religiosity) is important as contextual cues set the stage for behavior; yet this relationship has received less attention. Further, the SRM provides little detail on features of the health behavior itself that may evoke negative affect and be unappealing or may serve as barriers to appropriate utilization, which is particularly relevant to CCS behavior.

The purpose of this mixed method investigation was to obtain a more complete and theoretically-informed understanding of the role of cancer worry in CCS among Appalachian women, including the role of distress (affective representation), perceived risk (cognitive representation), and religiosity (self-system factor). Further, we paid special attention to the patient experience with cancer and screening, given that screening is thought to play a key role in the unequal burden of CC in Appalachia (Hall et al., 2002).

Methods

To better understand cancer worry in Appalachian women, our study comprised both quantitative and qualitative components. We collected data over a 3-year period, at a transitional point where an Appalachian county health department was establishing a federally-qualified health clinic. Qualitative interviews were initiated first to pilot survey questions but were completed after the quantitative survey to add richness to our understanding of cervical cancer worry and screening in an underserved population. Qualitative interviews described the components of cancer worry. The qualitative study began with in-person interviews of women from an existing data collection effort, the CARE study (Paskett et al., 2010). These Appalachian women were recruited through primary care offices, and thus were less reflective of the underserved population desired for the study. To complement the CARE study, we established a relationship with a county health department in rural Appalachian Ohio and began recruitment for the qualitative study there.

While we were conducting qualitative interviews, we began our quantitative study. This study used surveys to quantify cancer worry and examine its predictors, employing a multi-method approach that included mailed and in-person surveys. We utilized county health department medical records to identify individuals for our mailed survey, as the health department clinic was becoming less involved in routine patient care. We then augmented the mailed survey with in-person recruitment, due to low response rate, through the larger and newly-established federally qualified health clinic. However, as the clinic had recently begun operation, scant medical record data were available for review, resulting in lower documentation of CCS rates from medical records and greater reliance on self-report data.

Using both qualitative and quantitative approaches allows for: methodological triangulation and complementarity to get a better understanding of a research question both in terms of depth and convergence of results; further development of study design, such as in development of surveys; initiation to help answer questions or contradictions from one approach; and expansion to extend the types of questions that can be asked (Greene, Caracelli, & Graham, 1989; Hesse-Biber, 2010). It also allows for iteration in the development of research questions, conduct of the study, and data analysis (Hesse-Biber, 2010). Our longitudinal approach is reflective of applied clinical anthropology (Denzin & Lincoln, 2000) as described by Miller and Crabtree (2000), and shares characteristics of traditional ethnographic research (Creswell, 1998).

Quantitative Study

We sought to assess the association of negative affect and CCS by quantifying their relationship, using the SRM to explore self-system factors associated with cancer worry (Fig. 1).

Participants—We recruited women 18 years of age and older through a central Appalachian rural county health department clinic. We randomly selected and reviewed medical records to identify an equal number of women who were within CCS guidelines (within the last 13 months) or not within CCS guidelines (more than 36 months prior to medical record review), consistent with risk-appropriate guidelines [United States Preventive Services Task Force (USPSTF), 2012]. We conducted a second medical record review approximately 6 months later to identify additional eligible individuals. In addition, we added a sample of women from the associated federally-qualified clinic through in-person clinic recruitment.

Three-hundred-twenty-nine women were identified based on medical record review from a county health department clinic. Of these, we did not have valid contact information for 123 women; thus, we used a people search to identify additional addresses and telephone numbers. We identified new addresses for 84 people, resulting in 281 potentially eligible individuals. Several women ($n = 17$) had only one identified address; however, one woman may have had as many as 12. Surveys returned as a result of people searches were checked to confirm that the identity of potential participant matched medical record data (e.g., age, name, Appalachian status). Our mailed survey sample ($n = 73$), reflected a minimal response rate of 26 %. We recruited an additional sample from the clinic ($n = 64$), reflecting a participation rate of (92 %). Our final sample ($n = 137$), reflected a minimal response rate of 38.6 % but was likely higher, as we may not have had a valid address for 123 women.

Procedure—The study proceeded with institutional review board approval. The PI and research assistants randomly selected medical records from the health department clinic. A letter was mailed from the health department allowing women to ‘opt out’ of the study by mailing a postcard to the first author. For the mailings, we used an online Internet search (e.g., Intelius People Search) to find recent contact information for women whose initial mailing was returned to sender. If the individual did not opt out, we mailed the individual a packet with a letter from the health department, consent form, HIPAA form, survey, and reimbursement form. The questionnaire included information about demographics and worry. Participants were compensated \$10 for completing the survey. Research assistants made a follow-up telephone call to non-respondents. Participants had the option of completing the survey over the telephone or a second survey, 2–3 weeks later. As none of the women requested a telephone interview, we mailed a second survey packet to them. In addition, we conducted in-person surveys to improve participation rates and assist those who may have had literacy challenges.

Measures—We assessed self-system factors including age, education, race, household income, marital status, type of insurance, and length of residence in Appalachian county. Religiosity was assessed with the Religious Commitment Inventory-10 (RCI-10). The

RCI-10 is a brief screening assessment of religious motivational and behavioral commitment to a religious value system (McCullough, Worthington, Maxey, & Rachal, 1997; Worthington et al., 2003), which includes two sub-scales: the Interpersonal (6 items, eigenvalue = 6.2, Coefficient α = .92) and the Intrapersonal (4 items, eigenvalue = 1.0, Coefficient α = .87). The Religious Commitment Inventory has a 1–5 response range (not at all to totally true of me). To assess the representation of affect, we utilized the Cancer Worry Scale (CWS), made specific to CC. This four-item measure of worry about developing cancer has a 1–4 response range (not at all to almost all the time, Coefficient α = .70) (Lerman et al., 1991; Lerman, Daly, Masny, & Balschem, 1994). In addition, we used a CC-specific distress scale based on the profile of mood states (POMS; Kelly et al., 2004, 2005). We utilized six items from the POMS focusing on negative affect (depression and anxiety), modified to be specific to CC, as well as three additional items included concern about pain, worried about disfigurement, and fear of dying. Responses ranged from 1 to 5 (not at all to very much, coefficient α = .90). Finally, two comparative risk items assessed perceived risk to determine if women felt their risk of CC was higher, the same, or lower than other women their age (Kelly et al., 2005), and if women felt their lifetime risk of CC was 1 = much below average to 5 = much above average (Kelly et al., 2012). After rescaling the former item, we computed a mean of these two items to assess perceived comparative risk.

Self-report Versus Medical Record Review of Cervical Cancer Screening—

Despite the importance of accurate measurement of CCS, the best source of screening behavior data remains unclear, and findings vary in part due to type of data collected (i.e., self-report, medical record review, and administrative data), resulting in low levels of agreement between patient self-report of cancer screening and medical record review (Ferrante et al., 2008; Howard, Agarwal, & Lytw, 2009). The agreement among these measures is further complicated by patients who frequently move from one place to another, decreasing the likelihood that they have a consistent source of care and making it difficult to contact them to keep accurate documentation. In addition, our study faced the challenge of transition of care from the county health department to the newly-established, federally-qualified health clinic, which led to a delay in recruitment while patients transitioned to the new facility, and new physicians joined the practice decreasing the likelihood of available CCS documentation.

Data Analysis—We computed relevant scales as well as descriptive statistics to describe the data and determine the appropriateness of parametric tests (Table 1). First, we explored factors derived from the SRM thought to influence cancer worry, including demographics, family history, religiosity, and perceived risk. We then used stepwise linear regression to identify factors related to cancer worry. Because cancer worry was skewed, we log-transformed the variable to create a more normal distribution for regression.

Next, we used a stepwise logistic regression to identify predictors for the match (yes/no) between self-reported CCS and medical records (Table 2). We coded the outcome variable as 1 if self-reported CCS was consistent with medical records [i.e., both indicated in guidelines ($n = 16$) or both indicated not in guidelines ($n = 18$)]. We coded the outcome variable as 0 if there was a mismatch (i.e., self-report indicated in guidelines but medical

record did not ($n = 20$); or medical record indicated in guidelines, but self-report did not ($n = 1$). We excluded women with missing data on self-reported CCS ($n = 13$), with missing data from medical record review ($n = 64$), or who self-reported a date of last CCS from 1 to 3 years ago ($n = 25$) in this analysis.

We performed logistic regression to determine the factors predictive of a woman being screened within guidelines according to self-report. We coded the outcome variable as 1 for women who reported a CCS in the last year ($n = 73$) and 0 for women reporting not having a CCS within the last 3 years ($n = 24$). Finally, due to the amount of missing data from self-reported CCS, we chose to use self-report data augmented with medical record data and used logistic regression to examine predictors of cancer screening within guidelines (<1 year, $n = 80$) or not in guidelines (more than 3 years, $n = 34$). Those screening within 1–3 years were of uncertain screening status, as we did not have information from the medical records about prior abnormal CCS or DNA testing. As the results of the augmented medical record data increased the significance level of the findings, the logistic regression for self-report alone is not reported here.

Qualitative Study

This study expanded upon the findings in the quantitative study to explore the role for affect in CC and CCS behavior in lower income Appalachian women. We utilized the SRM and endeavored to understand factors underlying negative affect in the population.

Participants—We conducted in-depth, semi-structured face-to-face interviews with women ($N = 24$) recruited through primary care clinics in Appalachian Ohio. Eligibility included residing in an Appalachian county (ARC, 2013), being over 18 years of age, and having no prior history of CC. We selected a roughly equivalent number of women who were within CCS guidelines (within the last 13 months) or not within guidelines (more than 36 months ago), which is consistent with risk-appropriate guidelines (USPSTF, 2012). Table 3 summarizes the participants in the qualitative study.

Procedures—We recruited women from two sources. First, we identified women from the CARE study, a larger study of Appalachian women recruited through primary care clinics (Paskett et al., 2010). We randomly selected women from among those who were both within and not within guidelines. We then mailed eligible women a letter describing the study that included a self-addressed, stamped postcard. Those not wishing to participate could mail the postcard to the researcher. Two weeks later, we telephoned individuals continuing in the study to schedule an interview. Second, we recruited participants from an Appalachian rural county health department clinic. In most cases, a nurse working in the clinic screened for participants, and the interviewer confirmed eligibility. Each interview began with administration of informed consent documents and was followed by a brief questionnaire including CC worry and religiosity. The first author conducted the semi-structured interviews to assess patients' feelings about CC and CCS. These sessions were audio-recorded and transcribed. Participants completed surveys in 1–1.5 h and were compensated \$20 for participation.

Measures—Consistent with the qualitative study, we measured self-system factors (i.e., demographics and RCI-10) and the representation of affect (CWS). In addition, we asked participants open-ended questions: “What kinds of feelings come to mind when you think about cervical cancer?” and “What kinds of feelings come to mind when you think about cervical cancer screening?” These questions were accompanied by probes to explore feelings more fully.

Data Analysis—Demographic information, religious commitment and CC worry were summarized with descriptive statistics (Table 2). Survey reports of cancer worry were on the lower end of the scale, averaging between “not at all” and “a little bit,” indicating that participants did not express a great deal of cancer worry. To collect and analyze data, we used an Immersion/Crystallization approach that is uniquely suited to the health care context (Borkan, 1999; Miller & Crabtree, 2000; Janesick, 2000). In this approach, which is generally conducted upon completion of data collection, researchers go through a process of immersion (delving into the data to understand its meaning) and crystallization (reflecting upon the overall content, trying to identify patterns). Immersion is a very intense process where concentrated energy is focused on review of the data collected, often for days or weeks (Borkan, 1999). Crystallization can be sought through a variety of means (Borkan, 1999), but for the purpose of this study, distancing (taking time away from the data) was used.

Immersion/Crystallization has the added benefit of being useful with pre-existing theory (Borkan, 1999). Although some caution against utilizing pre-existing theory in qualitative research (e.g., Huberman & Miles, 1998), others believe that looking to pre-existing theory can inform and improve their research endeavor (Borkan, 1999; Hesse-Biber, 2010). We used thematic coding to understand affective representations of CC in Appalachian women. The SRM served as a tentative theoretical framework (Leventhal et al., 1997) for the development of research questions. Although iterative refinement of probes and analysis continued throughout the course of the study, a more formal analysis of the transcripts occurred upon completion at the end of the study. We developed codes and iteratively reviewed them for consistency. Codes were then examined in the context of the larger SRM for their thematic content, but codes and themes were not constrained by the SRM. We selected compelling, representative quotations for each code and theme. These were then reviewed in the larger interview and with background data as a check of the context from which the quote was taken. We used a number of methods to enhance the transferability and rigor of the study (Borkan, 1999; Merriam, 2002). The first author shared a preliminary draft of the analysis with the second and then other authors, who further refined the analysis (i.e., through informal peer review). In addition, a faithful reporting of participant responses through audio-recordings [i.e., accuracy (McCullough et al., 1997)] and attention to context [i.e., thick description (Merriam, 2002)] added to the validity of findings.

Results

Quantitative Study

Associations with Cancer Worry—Overall, cancer worry was on the lower end of the scale, averaging between “not at all” and “a little bit,” as assessed by our survey, indicating that participants did not express a great deal of cancer worry. The linear regression (Table 4) on the log-transformed cancer worry scale indicated two significant predictors of cancer worry: CC comparative risk ($b = 0.06$, $SE = 0.01$, $p < .001$) and CC distress ($b = 0.06$, $SE = 0.01$, $p < .001$). Higher comparative risk and greater distress were associated with greater cancer worry, such that a one unit increase on the comparative risk or distress scale was associated with a .06 unit increase on the log10 scale of worry. For example, this represents an increase of 1–1.15 on the low end or 3–3.5 on the higher end of the original 4-point worry scale.

Associations With Screening—Marital status was significantly related to the consistency between self-reported CCS and the medical record [$\chi^2(2) = 6.53$, $p = .04$], where participants who were divorced, separated, or widowed showed the highest consistency compared to those who were single [$OR\ 4.64$, 95 % CI (0.95, 23.30), $p = .06$], holding all else constant. In addition, a trend emerged, such that participants with higher level of interpersonal religious commitment were more likely to show higher likelihood of consistency between self-reported CCS and medical records [$OR\ 1.78$, 95 % CI (0.95, 3.33), $p = .07$].

Three independent variables were significantly related to screening as defined by self-report augmented with medical-records; namely, inter-religious commitment, comparative risk, and cancer worry. Both interpersonal religious commitment [$OR\ 0.65$, 95 % CI (0.43, 0.99), $p = .046$] and cancer worry [$OR\ 0.41$, 95 % CI (0.19, 0.88), $p = .02$] were negatively related to the likelihood of frequent CCS, while participants with higher perceived comparative risk were more likely to have a CCS within guidelines [$OR\ 2.41$, 95 % CI (1.18, 4.91), $p = .017$].

Qualitative Study

Cervical Cancer: Affective Representation—Most women reported that they would be extremely upset and depressed if they were told they had CC. Two women discussed their experience of being diagnosed with dysplasia, which was extremely difficult because they were teenagers and all alone in new towns. Some women tried not to think about CC and did not want to be told if they had it. Another reaction to a potential diagnosis was resignation to terminal cancer, particularly if treatments were unlikely to prolong life.

In contrast to these more dire perspectives, one woman noted, “It’s not always as bleak as it sounds. I think it scares a lot of people, the word ‘cancer,’ because they think cancer is terminal. But if caught early on, it doesn’t have to be.” Despite her perspectives, this participant fell outside of the CCS guidelines, making it less likely that she would be able to catch CC early. One woman within CCS guidelines was even more positive:

I would wonder why. But then, on another hand, I would think, ‘Well maybe I have served my purpose in this time,’ although it would be short. And if I would get

cancer then God's found another purpose, and that we would go that distance. And we would go help people. And I would accept that, and be prepared to help people.

So, although worry and fear were universal, some were able to imagine a potential benefit by helping others in similar circumstances.

Experience of Cervical Cancer Screening: Potential Emotional Barriers—Even though within guidelines for CCS, some women noted elements of the CCS experience that they did not like, indicating that CCS was “a necessary evil.” Many women reported that one's “modesty goes right out the window.” Along with getting weighed and putting on “your little gown and exposing yourself,” having other assistants in the room can add to the embarrassment:

I don't like the nurse in there. I mean it's bad enough that he is there... It would be alright, but most of them like to stand at the bottom there and hand him things. ‘Stand at the top where you're not looking!’ That would be a little more comfortable but it seems they don't do that. So, it's like I would rather you go out if you're not... I think that is a personal thing and some people don't care, but I think most people do.

Modesty can be even more challenging in small communities such as those in Appalachia:

The last time I went, the person performing the exam was a girl I went to school with...I'm thinking, ‘I don't know how I know her,’ and then after we're done, she's talking, and I'm like, ‘How do I know you?’ and she tells me and I'm like, ‘Oh my God!’

The close knit communities pose problems for private matters, such as CCS. Although some women noted only minor annoyances with the CCS, some were quite serious, considering the CCS “an invasion of the body.”

A number of women related particularly bad experiences, with one woman describing a physician that made crude sexual comments while giving her CCS when she was a young woman. A problematic technique led one woman not only to discontinue CCS but also not to have children:

Forty years ago. It made me not want to ever go back. It really took that child bearing issue right the hell out of my head... The doctor that gave me the CCS was not a doctor that had a good bedside manner. He was heavy handed, and he hurt me. And therefore I chose never to go back.

Beyond the unpleasant nature of the procedure, the CCS made some women feel victimized and vulnerable. Unfortunately, due to health care shortages in the Appalachia, some women felt they had no other alternatives for health care providers.

Cervical Cancer Screening: Facilitators—Some women noted that CCS got easier with age, with repeated testing and finding the right physician. One woman who kept up-to-date with CCS explained that the particular physician did not matter to her, “not because I have no modesty, I do, but I feel like that person's a professional, that person's doing their

job... I've seen strangers who ain't never going to see me again, but who cares?" In this case, anonymity was helpful to encourage screening, along with the perceived credentials of the healthcare professional conducting the screening procedure. Her feelings of anonymity may have been greater than most women because she had lived outside of the Appalachian region for some time. Some women noted that having an established relationship with their physicians and the coping procedures they used were helpful:

The doctor talks me down some, or nurse will hold my hand or something... I have to tell 'em, 'You have to tell me what you're doing because you're freaking me out.' I said, 'That's my body down there you know; I wanna know what you're doing.'

This communication required a certain level of comfort with their physician, and some did not feel they could communicate with their physician.

Discussion and Conclusion

Guided by the SRM, we explored worry and its association with CCS among predominantly lower-income Appalachian women. Overall, participants indicated only modest levels of cancer worry on our quantitative survey. The perception of being at higher risk of CC and having greater distress about cancer were associated with greater worry about cancer. Selected largely from a county health department, socioeconomic status did not appear to play a role in this worry, but inclusion of a higher socioeconomic status sample may help to further elucidate this finding. As the risk of cancer decreases in the Appalachian population, worry may be decreased. In the meantime, interventions may be needed to decrease CC-related worry. Along with improving the mental health of the Appalachian community, such interventions may be helpful in improving cancer screening rates, as those with elevated worry were less likely to have had a CCS. Thus, our study adds to those studies finding that worry inhibits screening behavior (Hay et al., 2005).

Although empirical data have been equivocal (Kelly et al., 2005), perceived risk was associated with screening behavior consistent with a number of theoretical models (e.g., Becker, 1974), such that those feeling that their risk of CC was higher than others were more likely to have CCS. As indicated in a previous paper, cancer risk perceptions are largely inaccurate (Kelly et al., 2005, 2012) and, due to their level of objective risk, women in Appalachia should be screened regardless of their own perceptions of risk. To further support this previous work, it is possible that women in Appalachia do not understand that their risk is increased (Reiter et al., 2013), as most women in our study did not believe they were Appalachian. Thus, there appears to be a disconnect between the federal government's definition of Appalachian and the self-identity of being Appalachian (Reiter, Katz, Ferketich, Ruffin, & Paskett, 2009), meriting future study.

Reflecting the transient nature of the county clinic population, self-report and medical record data were not consistent. Married women may have been more likely to benefit from health insurance or higher income, which may have enabled them to see a private physician, thus decreasing the accuracy of medical record reports. One rather surprising finding was the statistical trend for the role of interpersonal religious commitment in accuracy. As religion

features prominently in Appalachian culture, its role in self-report of CCS is important. Those with higher interpersonal religious commitment manifested more consistency between self-report and medical record report of screening, but this finding was likely fueled by their lower level of CCS overall. Appalachians tend to be publicly demonstrative of their religion (Leonard, 1999; Worthington et al., 2003). Our finding that those with higher interpersonal religious commitment were less likely to be screened (and thus have greater consistency between self-report and medical record report) may reflect an underlying social impression management. Appalachian women may not want to be seen having CCS. It is also possible that these women were not sexually active or may have received CCS elsewhere. Future research may clarify the role of interpersonal religious commitment and impression management on CCS.

Consistent with the SRM, negative affect had a largely concrete-experiential component. Many women had first-hand experience—either through their own experiences of cervical dysplasia or through CC in close relations—of the physical consequences of CC. These experiences were difficult emotionally, and many women did not feel that they had adequate support to manage them, a particular concern in an area with an elevated morbidity and mortality related to CC. In addition to those who had experienced dysplasia, all women believed that fear and avoidance would likely be their response to a CC diagnosis. Thus, the earlier quantitative assessment of cancer worry belies their descriptions of fear and worry in qualitative interviews, and additional research is needed to understand this seemingly contradictory finding. In contrast to other studies (Holroyd et al., 2003; Kahn et al., 2007; Kim et al., 2004), guilt and anxiety were not mentioned. Consistent with others' suggestions contesting Appalachians as fatalistic (Drew & Schoenberg, 2011), other women did not view a CC diagnosis as dire and used their relationship with God to help them cope in positive ways. Such benefit-finding has been documented in other cancers, and studies have found that individuals with cancer do cope with the condition as well as or better than other stressors (Tomich & Helgeson, 2004).

The SRM provides less detail about the features of the health behavior (i.e., pain, part of the body, person conducting the procedure) that may elicit fear. Rather, interventions with the SRM typically rely on creating fear of the disease that can surmount any concerns about procedures (Leventhal et al., 1997). Some concerns might be more easily overcome. For example, patients gave details about the aspects of the CCS that they found problematic, mostly focusing on procedural aspects that challenged modesty norms, such as observation by others in the room, as well as the lack of anonymity, reflecting the challenges of living in close-knit communities. However, some interviews revealed more troublesome behaviors on the part of physicians such as inappropriate comments and unnecessarily harsh techniques. Due to a lack of available physicians in rural regions, some participants also felt that their only alternative to avoid such treatment was to stop having screening.

Other participants indicated that physician behaviors had improved the experience, such as telling patients the progress of the procedure and helping them to relax, and having a longer-term, trusting relationship with their health provider helped. These behaviors may suggest methods for intervention to improve the experience of CCS. Indeed, the SRM indicates that having a clear action plan can help to facilitate screening (Leventhal et al., 1997), and

encouraging patients to more effectively communicate their needs to physicians may improve their uptake and experience of CCS.

We note several limitations to the current study. First, the cross-sectional nature of the study does not allow for causal inferences; thus we cannot conclude that worry causes lower screening rates. Second, our response rate of 30 % may not be reflective of the larger population of Appalachian women, decreasing the generalizability of our results. Third, this study draws largely on a select clinic-based sample, and thus our data may not be reflective of women in the clinic or the larger community who do not seek health care. In addition, this study has a relatively small sample size, which may have been responsible for our wide confidence intervals.

Conclusion

Although less frequently reported in quantitative surveys, Appalachian women reported worry and fear about CC in their qualitative interviews, perhaps indicating a discrepancy in the two methods. Further, worry resulted in lower levels of CCS. Those who had higher perceptions of risk were more likely to be screened, as were those with lower interpersonal religious commitment. Intervention in this elevated risk community is merited and may focus on decreasing feelings of worry about CC and increasing communication of objective risk and need for screening. From a policy perspective, increasing the quantity and quality of care may also improve CCS rates and decrease the burden of cancer in Appalachia.

Acknowledgments

This manuscript was supported by a Supplement to Support Diversity in Research from the National Cancer Institute (5P50-CA105632-02). We would also like to acknowledge Victoria White, M.D. for her assistance with the manuscript.

References

- Ackerson K, Gretebeck K. Factors influencing cancer screening practices of underserved women. *Journal of the American Academy of Nurse Practitioners*. 2007; 19(11):591–601. [PubMed: 17970859]
- American Cancer Society. Cancer facts and figures: 2013. 2013 <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-036845.pdf>.
- Appalachian Regional Commission. The Appalachian region: 2013. 2013 http://www.arc.gov/appalachian_region/TheAppalachianRegion.asp.
- Azaiza F, Cohen M. Between traditional and modern perceptions of breast and cervical cancer screenings: A qualitative study of Arab women in Israel. *Psycho-Oncology*. 2008; 17(1):34–41. [PubMed: 17352007]
- Becker MH. The health belief model and personal health behavior. *Health Education Monographs*. 1974; 2:324–508.
- Behringer B, Friedell GH. Appalachian: Where place matters in health. *Preventing Chronic Disease*. 2006; 3(4):A113. [PubMed: 16978488]
- Borkan, J. Immersion/crystallization. In: Crabtree, BF.; Miller, WL., editors. *Doing qualitative research*. 2nd ed.. Thousand Oaks, CA: Sage; 1999. p. 179-194.
- Cameron, LD. Anxiety, cognition, and responses to health threats. In: Cameron, LD.; Leventhal, H., editors. *Self-regulation of health and illness behavior*. New York, NY: Routledge; 2003. p. 157-183.

- Cameron, LD.; Leventhal, H. Self-regulation, health and illness: An overview. In: Cameron, LD.; Leventhal, H., editors. Self-regulation of health and illness behavior. New York, NY: Routledge; 2003. p. 1-13.
- Creswell, JW. Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, CA: Sage; 1998.
- Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahan B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology*. 2006; 15:306–320. [PubMed: 16041841]
- Denzin, NK.; Lincoln, YS. Strategies of inquiry. In: Denzin, NK.; Lincoln, YS., editors. Handbook of qualitative research. Thousand Oaks, CA: Sage; 2000. p. 366-378.
- Drew EM, Schoenberg N. Deconstructing fatalism: Ethnographic perspectives on women's decision making about cancer prevention and treatment. *Medical Anthropology Quarterly*. 2011; 25(2): 164–182. [PubMed: 21834356]
- Ferrante JM, Ohman-Strickland P, Hahn KA, Hudson SV, Shaw EK, Crosson JC, Crabtree BF. Self-report versus medical records for assessing cancer-preventive services delivery. *Cancer Epidemiology, Biomarkers and Prevention*. 2008; 17(11):2987–2994.
- Greene JC, Caracelli VJ, Graham WF. Toward a conceptual framework for mixed-method evaluation design. *Educational Evaluation and Policy Analysis*. 1989; 11:255–274.
- Hall HI, Uhler RJ, Coughlin SS, Miller DS. Breast and cervical cancer screening among Appalachian women. *Cancer Epidemiology, Biomarkers and Prevention*. 2002; 11(1):137–142.
- Hay JL, Buckley TR, Ostroff JS. The role of cancer worry in cancer screening: A theoretical and empirical review of the literature. *Psycho-Oncology*. 2005; 14(7):517–534. [PubMed: 15490428]
- Hesse-Biber, SN. Mixed methods research: Merging theory with practice. New York: Guilford Press; 2010.
- Holroyd EA, Taylor-Piliae RE, Twinn SF. Investigating Hong Kong's Filipino domestic workers' healthcare behavior, knowledge, beliefs and attitudes towards cervical cancer and cervical screening. *Women and Health*. 2003; 38(1):69–82. [PubMed: 14535607]
- Howard M, Agarwal G, Lytwyn A. Accuracy of self-reports of Pap and mammography screening compared to medical record: A meta-analysis. *Cancer Causes and Control*. 2009; 20(1):1–13. [PubMed: 18802779]
- Huberman, AM.; Miles, M. Data management and analysis methods. In: Denzin, N.; Lincoln, Y., editors; Denzin, NK., editor. Collecting and interpreting qualitative materials. Thousand Oaks, CA: Sage; 1998.
- Janesick, VJ. Handbook of qualitative research. Thousand Oaks, CA: Sage; 2000. The choreography of qualitative research design: Minuets, improvisations, and crystallization; p. 366-378.
- Kahn JA, Slap GB, Bernstein DI, Tissot AM, Kollar LM, Hilliard PA, Rosenthal SL. Personal meaning of human papillomavirus and Pap test results in adolescent and young adult women. *Health Psychology*. 2007; 26(2):192–200. [PubMed: 17385971]
- Kelly KM, Ferketich AK, Ruffin MT, Tatum C, Paskett ED. Perceived risk of cervical cancer in Appalachian women. *American Journal of Health Behavior*. 2012; 36(6):849–859. [PubMed: 23026042]
- Kelly K, Leventhal H, Andrykowski M, Toppmeyer D, Much J, Dermody J, Schwalb M. The decision to test in women receiving genetic counseling for BRCA1 and BRCA2 mutations. *Journal of Genetic Counseling*. 2004; 13(3):237–257. [PubMed: 15604634]
- Kelly K, Leventhal H, Andrykowski M, Toppmeyer D, Much J, Dermody J, Schwalb M. Using the Common Sense Model to understand perceived cancer risk in individuals testing for BRCA1/2 mutations. *Psycho-Oncology*. 2005; 14(1):34–48. [PubMed: 15386791]
- Kim H, Lee KJ, Lee SO, Kim S. Cervical cancer screening in Korean American women: Findings from focus group interviews. *Taehan Kanho Hakhoe Chi*. 2004; 34(4):617–624. [PubMed: 15502427]
- Korfage IJ, Essink-Bot M, Westenburg S, Helmerhorst T, Habbema DF, van Ballegooijen M. How distressing is referral to colposcopy in cervical screening? A prospective quality of life study. *Gynecologic Oncology*. 2014; 132(1):142–148. [PubMed: 24219984]

- Kosmin, B.; Mayer, E.; Keysar, A. American religious identification survey. New York: The Graduate Center of the City of New York; 2008.
- Leonard, BJ., editor. Christianity in Appalachia: Profiles in regional pluralism. Knoxville, TN: University of Tennessee Press; 1999.
- Lerman C, Daly M, Masny A, Balschem A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *Journal of Clinical Oncology*. 1994; 12(4):843–850. [PubMed: 8151327]
- Lerman C, Trock B, Rimer BK, Jepson C, Brody D, Boyce A. Psychological side effects of breast cancer screening. *Health Psychology*. 1991; 10(4):259–267. [PubMed: 1915212]
- Leventhal, H.; Benyamini, Y.; Brownlee, S.; Diefenbach, M.; Leventhal, EA.; Patrick-Miller, L. Illness representation: Theoretical foundations. In: Weinman, J.; Petrie, K., editors. *Perceptions of health and illness*. London: Harwood; 1997. p. 19-45.
- Leventhal H, Kelly K, Leventhal EA. Population risk, perceived risk, and cancer control: A discussion. *Journal of the National Cancer Institute Monographs*. 1999; 25:81–85. [PubMed: 10854461]
- Lyttle NL, Stadelman K. Assessing awareness and knowledge of breast and cervical cancer among Appalachian women. *Preventing Chronic Disease*. 2006; 3(4):1–9.
- Maissi E, Marteau TM, Hankins M, Moss S, Legood R, Gray A. Psychological impact of human papillomavirus testing in women with borderline or mildly dyskaryotic cervical smear test results: Cross sectional questionnaire study. *British Medical Journal*. 2004; 328(7451):1293. [PubMed: 15166066]
- Markovic M, Kesic V, Topic L, Matejic B. Barriers to cervical cancer screening: A qualitative study with women in Serbia. *Social Science and Medicine*. 2005; 61(12):2528–2535. [PubMed: 15953668]
- McCullough ME, Worthington EL, Maxey J, Rachal KC. Gender in the context of supportive and challenging religious counseling interventions. *Journal of Counseling Psychology*. 1997; 44(1): 80–88.
- Merriam, SB. Assessing and evaluating qualitative research. In: Associates, MA., editor. *Qualitative research in practice: Examples for discussion and analysis*. San Francisco, CA: Jossey-Bass; 2002. p. 18-33.
- Metcalfe, J.; Jacobs, WJ. Emotional memory: The effects of stress on “cool” and “hot” memory systems. In: Medin, DL., editor. *The psychology of learning and motivation*. Vol. 38. San Diego, CA: Academic Press; 1998. p. 187-222.
- Miller, WL.; Crabtree, BF. Clinical Research. In: Denzin, NK.; Lincoln, YS., editors. *Handbook of qualitative research*. Thousand Oaks, CA: Sage; 2000. p. 366-378.
- National Cancer Institute. [Accessed 1 Feb, 2014] Adjustment to cancer: Anxiety and distress (PDQ). 2013. <http://www.cancer.gov/cancertopics/pdq/supportivecare/adjustment/Patient/page1/AllPages>.
- Ohio Department of Health. Cervical cancer in Ohio: 2000–2004. Columbus: Ohio Department of Health, Ohio Cancer Incidence Surveillance System (OCISS); 2007.
- Paskett ED, McLaughlin JM, Reiter PL, Lehman AM, Rhoda DA, Katz ML, Ruffin MT. Psychosocial predictors of adherence to risk-appropriate cervical cancer screening guidelines: A cross sectional study of women in Ohio Appalachia participating in the Community Awareness Resources and Education (CARE) project. *Preventive Medicine*. 2010; 50(1–2):74–80. [PubMed: 19744509]
- Philips Z, Johnson S, Avis M, Whynes DK. Human papillomavirus and the value of screening: Young women’s knowledge of cervical cancer. *Health Education Research*. 2003; 18(3):318–328. [PubMed: 12828233]
- Reiter PL, Katz ML, Ferketich AK, Ruffin MT, Paskett ED. Appalachian self-identity among women in Ohio Appalachia. *Journal of Rural Community Psychology*, E12(1). 2009 <http://www.marshall.edu/jrcp/VE12%20N1/Reiter%20JRCP.pdf>.
- Reiter PL, Katz ML, Ruffin MT, Hade EM, DeGraffenreid CR, Patel DA, Unger ER. HPV prevalence among women from Appalachia: Results from the CARE project. *PLoS One*. 2013; 8(8):e74276. [PubMed: 24023700]
- Scarinci IC, Beech BM, Kovach KW, Bailey TL. An examination of sociocultural factors associated with cervical cancer screening among low-income Latina immigrants of reproductive age. *Journal of Immigrant Health*. 2003; 5(3):119–128. [PubMed: 14512766]

- Schoenberg NE, Hopenhayn C, Christian A, Knight EA, Rubio A. An in-depth and updated perspective on determinants of cervical cancer screening among central Appalachian women. *Women and Health*. 2005; 42(2):89–105. [PubMed: 16537302]
- Sutton SK, Davidson RJ. Prefrontal brain symmetry: A biological substrate of the behavioral approach and inhibition systems. *Psychological Science*. 1997; 8:204–210.
- Tomich PL, Helgeson VS. Is finding something good in the bad always good? Benefit finding among women with breast cancer? *Health Psychology*. 2004; 23(1):16–23. [PubMed: 14756599]
- United States Preventive Services Task Force. Screening for cervical cancer. 2012 <http://www.uspreventiveservicestaskforce.org/uspstf/uspscerv.htm>.
- Vigod SN, Kurdyak PA, Stewart DE, Gnam WH, Goering PN. Depressive symptoms as a determinant of breast and cervical cancer screening in women: A population-based study in Ontario, Canada. *Archives of Women's Mental Health*. 2011; 14(2):159–168.
- Walsh JC. The impact of knowledge, perceived barriers and perceptions of risk on attendance for a routine cervical smear. *European Journal of Contraception and Reproductive Health Care*. 2006; 11(4):291–296. [PubMed: 17484195]
- Worthington EL, Wade NG, Hight ME, Berry JT, Ripley JS, Berry JW, O'Connor L. The Religious Commitment Inventory-10: Development, refinement, and validation of a brief scale for research and counseling. *Journal of Counseling Psychology*. 2003; 50(1):84–96.

Fig. 1.
Self-regulation model: representation of affect

Table 1Descriptive statistics ($N = 137$) of the quantitative sample

	<i>n</i>	%
Age (in years) ^a		
19–28 years old	28	22
29–38 years old	32	25
39–49 years old	33	26
50+ years old	34	27
Race		
Non-White	16	12
White	121	88
Marital status ^b		
Divorced/separated/widowed	55	40
Married/couple	45	33
Single, never married	36	26
Annual income		
\$10,000	66	48
\$10,001–\$20,000	40	29
\$20,001–\$35,000	18	13
\$35,001 or more	13	9
Education		
Less than high school	24	18
High school	42	31
GED	13	9
Some technical/college	33	24
Technical/associates degree	21	15
Bachelors/masters degree	4	3
Type of insurance ^c		
Employer sponsored	23	17
Medicare/medicaid (governmental)	77	57
Self-pay	34	25
Consider herself Appalachian ^d		
Yes	35	27
No	93	73
Lived in same place whole life ^e		
Yes	61	45
No	74	55
Church attendance ^f		
Never	50	37
Only occasionally	44	32
Once a month	10	7

	<i>n</i>	%
Once a week	20	15
More than once a week	12	9
Interpersonal religious commitment (5 items) (1 = not at all true of me to 5 = totally true of me)	$M = 2.1, SD = 1.2$	
Intrapersonal religious commitment (5 items) (1 = not at all true of me to 5 = totally true of me)	$M = 2.5, SD = 1.3$	
Comparative risk of cervical cancer (2 items) (1 = much below average to 5 = much above average)	$M = 3.1, SD = 0.8$	
Cervical cancer distress (9 items) (1 = not at all to 5 = very much)	$M = 2.6, SD = 1.2$	
Cancer worry (4 items) (1 = not at all to 4 = a lot)	$M = 1.5, SD = 0.6$	

^aTen subjects are missing data for age

^bOne is missing data for marital status

^cThree are missing for Insurance

^dNine did not indicate Appalachian status

^eTwo did not report if they lived in the same place their whole life

^fOne is missing for Church attendance

Table 2

A comparison of the number of cervical cancer screeners in self-reported pap utilization versus medical record

		Medical record cervical cancer screening			Total
		Missing data	Not in guidelines	Within guidelines	
Self-reported	Missing data	10	2	1	13
cervical	<1 year	39	20	16	75
cancer	1–3 years	10	9	6	25
screening	>3	5	18	1	24
Total		64	49	24	137

Table 3Descriptive statistics ($N = 24$) of the qualitative sample

	<i>n</i>	%
Age (in years)		
22–28 years old	3	13
29–38 years old	3	13
39–49 years old	13	54
50+ years old	5	20
Race ^a		
Non-White	1	4
White	12	96
Marital status		
Divorced/separated/widowed	10	40
Married/couple	11	47
Single, never married	3	13
Annual income		
\$10,000	6	25
\$10,001–\$20,000	4	17
\$20,001–\$35,000	7	29
\$35,001 or more	7	29
Education		
Less than high school	2	8
High school	11	46
GED	1	4
Some technical/college	5	21
Technical/associates degree	4	17
Bachelors/masters degree	1	4
Type of insurance ^b		
Employer sponsored	6	26
Medicare/medicaid (governmental)	7	30
Self-pay	11	44
Consider herself Appalachian		
Yes	8	33
No	16	67
Length of residence in county (in years)	$M = 29$ (range 1–61)	
Church attendance		
Never	5	22
Only occasionally	7	30
Once a month	1	6
Once a week	7	28
More than once a week	4	17
Within cervical cancer screening guidelines ^b		

	<i>n</i>	%
Within guidelines	14	58
Not within guidelines	10	42
Comparative risk of cervical cancer (2 items) (1 = much below average to 5 = much above average)	$M = 2.6, SD = 1.1$	
Cervical cancer distress (9 items) (1 = not at all to 5 = very much)	$M = 1.6, SD = 0.8$	
Cancer worry (4 items) (1 = not at all to 4 = a lot)	$M = 1.3, SD = 0.6$	

^a Reflective of the demographics for this region

^b Insurance status and being within cervical cancer screening guidelines were not associated in non-parametric and correlative statistical analyses

Author Manuscript

Author Manuscript
$$***p < 0.001$$