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## The Experience of Older Women Living with Loneliness and Chronic Conditions in Appalachia

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### Abstract

This phenomenological qualitative study explored the experience of living with loneliness and multiple chronic conditions for rural older women in Appalachia. The study took place in 2012 in Northern West Virginia. Participants were 14 older women who were chronically ill, community dwelling, and lonely (Score of 40 or higher on the Revised 20-item UCLA Loneliness Scale). Thematic content analysis revealed four categories that contained thirteen themes: (a) negative emotions of loneliness, which included themes of sadness, disconnection, fear, anger, and worry; (b) positive emotions when not lonely, which included themes of joy with others and pride in self; (c) loss of independence and loneliness, which included themes of functional decline contributes to loneliness, burden, and gratitude for help; and (d) ways of managing loneliness, which included remembering holidays and happier moments, staying busy, and getting out. The study contributes new knowledge about the experience of anger, fear, and worry when lonely. These emotions have not extensively been identified as significant to loneliness. Future studies exploring the links between loneliness and anger, fear, worry, and negative physical health outcomes could enhance knowledge of mechanisms by which loneliness contributes to health decline. Additionally, knowing that positive emotions such as joy are described as being linked to less lonely times could inform future work that aims to diminish loneliness and enhance positive emotional states. Finally, understanding that functional impairment is described as contributing to loneliness in this population reinforces the need to assess for and address functional limitations.

### Keywords

Loneliness; Rural; Appalachia; Chronic Conditions; Older Adults

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Globally, the prevalence of loneliness in older adult samples has been reported to be as high as 38% (Holmen, Ericsson, Andersson, & Winblad, 1992). For U.S. adults over age 65, the prevalence of loneliness has been reported to be 19% (Theeke, 2009). Loneliness is internally perceived as a deficiency (Perlman, 1982) that is experienced within the relational system of subjective individual need, mutual acceptance in relationships, and social

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integration. One quantitative study on loneliness reported that loneliness was a unique construct, different from (but predictive of) depression (Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006). This is an indicator that loneliness may have its own unique emotional and psychosocial characteristics.

For over a decade, it has been believed that loneliness negatively influences physical health through neuroimmunological pathways (Cacioppo et al., 2002; Hackett, Hamer, Endrighi, Brydon, & Steptoe, 2012; Hawkley & Cacioppo, 2003; Steptoe, Owen, Kunz-Ebrecht, & Brydon, 2004). Chronic illness is reported to be present in 6.6% - 9.5% of people (Shiovitz-Ezra & Ayalon, 2010). Loneliness has been linked to multiple chronic conditions including hypertension (Hawkley, Masi, Berry, & Cacioppo, 2006), coronary artery disease (Thurston & Kubzansky, 2009), metabolic syndrome (Whisman, 2010), diabetes (Tomaka, Thompson, & Palacios, 2006), and lung disease (Keele-Card, Foxall, & Barron, 1993). In addition, loneliness has been identified as an independent predictor of functional decline (Perissinotto, Stijacic Cenzer, & Covinsky, 2012) and mortality in samples of older adult populations (Luo, Hawkley, Waite, & Cacioppo, 2012). Older adults who are chronically lonely may have a higher risk of mortality compared to those with situational loneliness, and both groups may have higher risk for mortality compared to those who are not lonely (Shiovitz-Ezra & Ayalon, 2010).

It may be that lonely persons are less likely to engage in positive health behaviors that would positively influence function or chronic illness control. Loneliness has been reported to be a negative influence on positive health practices (Yarcheski, Mahon, Yarcheski, & Cannella, 2004), and has been linked to negative health behaviors (Theeke, 2010), such as smoking and less physical activity. For older adults and their caregivers, loneliness has been identified as the most important factor predicting lower quality of life (Ekwall, Sivberg, & Hallberg, 2005).

A limited number of qualitative studies have described experiential themes of loneliness in samples of older women (Ballin & Balandin, 2007; Dong, Chang, Wong, & Simon, 2012; Letvak, 1997; Lou & Ng, 2012; Smith, 2012). In these prior studies, participants identified disrupted meaningful engagement (Smith, 2012) and functional losses as important to loneliness. Themes identified in past research that describe negative emotional states have included “emotional isolation” (Dong et al., 2012) “not belonging” (Rokach, 1989) and “creating anxiety” (McInnis & White, 2001). Other studies identified themes related to the social aspects of loneliness including “lack of communication and social networks” (Ballin & Balandin, 2007), “need for connection” (Letvak, 1997), and “perceived absence of relationships” (McInnis & White, 2001).

Although these studies have contributed to a broad understanding of the experience of loneliness, a knowledge gap still exists when seeking to comprehensively understand the emotional experiences of lonely persons, and the structure of meaning in the experience as it relates to chronic conditions. There is a critical need to understand the spectrum of emotions experienced with loneliness because negative emotions elicit the physiological stress response (McCain, Gray, Walter, & Robins, 2005) that has been linked to poorer health outcomes in multiple chronic conditions. In addition, because loneliness is linked to cultural

experiences and influences (Del Barrio et al., 2010), it is important to study loneliness within the cultural context of the population. Older adults living in Appalachia experience health disparities (Gobble, 2009) and multiple predictors of loneliness such as poverty (Mullins, Elston, & Gutkowski, 1996), rurality (Kivett, 1979), and multiple chronic conditions (Theeke, 2010). Ascertaining the meaning of loneliness in this population brings a deeper understanding of what cultural, emotional, and health issues matter most to persons living with loneliness and chronic conditions in rural Appalachia. Therefore, the research question was: What is the structure of meaning for older people who are living with loneliness and chronic conditions in Appalachia?

## Theoretical Framework

The qualitative methodology was guided by two theoretical frameworks; story theory (Liehr & Smith, 2008) and phenomenology (Van Manen, 1997). Story theory assumes that persons (a) change in multidimensional ways as they interrelate with their world, (b) live in a present that incorporates their past and expected future events, and (c) experience meaning as a form of unfolding of human potential (Liehr & Smith, 2008). Three interrelated concepts of story theory guided the story gathering process: (a) intentional dialogue, (b) connecting with self-in-relation, and (c) creating ease (Liehr & Smith, 2008). Story theory has been used to enhance understanding of other chronic physical conditions such as hypertension (Liehr et al., 2006).

Intentional dialogue is defined by Liehr and Smith (2008, p. 209) as “purposeful engagement with another to summon the story of a complicating health challenge.” The point of intentional dialogue is to engage with another person in a trusting relationship that allows the other person to fully tell the story of a health experience while trying to discern the significant meaning of the health experience. The storyteller is encouraged to delve deeper into the personal health experience, which in this study was loneliness. In the framework of story theory, the concept of “intentional dialogue” is described as being derived from previous work by Carl Rogers (1951) that emphasized the importance of the listener conveying to the storyteller that the speaker is sharing an experience worth hearing and therefore is being given the undivided attention of the listener (Rogers, 1951).

Connecting with self-in-relation is a process where the storyteller “recognizes self as related with others in a story plot” (Liehr & Smith, 2008, p. 210). This concept in story theory was derived from the work of Hall and Allan (1994) and Surrey (1991), all of whom described self-in-relation as a concept that is important to nursing practice. Liehr and Smith (2008) described “connecting with self-in-relation” as the integration of one’s own history with a reflective awareness about that history. When exploring “connecting with self-in-relation,” it is key to acknowledge that the story of an experience is a recollection that may have meanings that are unique to an individual and that subtle differences in the recollection can hold significant meaning. It is posited by Liehr & Smith (2008) that when one tells the story of a health experience and reflects on that experience, the story teller and the story gatherer may come to new insights about the meaning of the health experience.

The third concept of story theory, “creating ease,” is defined as “an energizing release experienced as the story comes together in movement” (Liehr & Smith, 2008, p. 212). Creating ease is described by Liehr and Smith (2008) as having two dimensions; “remembering disjointed story moments” and “flow in the midst of anchoring” (p. 212). These two dimensions of creating ease are derived from the literature on understanding (Polanyi, 1958) and flow (Czikszentimihalyi, 1990). The authors of these foundational works emphasize that finding meaning in a personal story of a health challenge can lead to a renewed sense of purpose and is, therefore, a situation that creates ease and facilitates healing.

The phenomenology framework was important to the project in that it guided the overall perspective of the study team as we attempted to understand the very essence of loneliness as experienced by the participants. The analysis process was guided by thematic content analysis methods, which are described as part of the descriptive phenomenology research process (Vaismoradi, Turunen, & Bondas, 2013). This method has been recommended as being appropriate for the complex psychosocial phenomena that are often encountered by nurses (Elo & Kyngäs, 2008).

## Methods

### Data Collection

The setting was the Robert C. Byrd Health Sciences Center of West Virginia University, a large land grant state university located in the city of Morgantown, West Virginia. Morgantown is approximately 75 miles from a large urban area. Participants were recruited from Northern West Virginia, which sits wholly in the Appalachian region. The economy of the area is based largely on industry and the university. After ethical approval was obtained through the West Virginia University Institutional Review Board for the use of human subjects to conduct this research, a convenience sample was recruited using two different methods. First, advertisements were placed in the community and at a primary care clinic located within the Health Sciences Center. Second, notifications were mailed to participants of past studies who had previously agreed to be contacted regarding new studies being conducted by the research team.

Twenty-two women and no men volunteered to participate. When potential participants called, they were given additional information about the study and screened for the inclusion criteria, which were: community dwelling, diagnosis of at least one chronic condition, score of 40 or greater on the 20-item UCLA Revised Loneliness Scale (Russell, Peplau, & Cutrona, 1980), and ability to participate fully in conversation during an interview. Once inclusion criteria were met, no instruments were used and a mutually agreed upon time for data collection was scheduled. After arriving for the study interview, participants signed an informed consent prior to the interview. All interviews were conducted by the principal investigator (PI), occurred face to face, and lasted between 2 and 3 hours.

During each interview, the PI was purposefully engaged with the participant to hear each story of loneliness. The structure of the interviews was accomplished by applying the concepts of story theory. The interviews began by asking participants what it was like to live

with loneliness. Participants were encouraged, through open ended questions, to expand on descriptions of what mattered most about loneliness, recognition of the role of self in one's own story of loneliness, challenges related to loneliness, and what worked to diminish or cope with loneliness. Appendix A provides a summary of talking points that were used to facilitate open discussion during the interviews. The recorded interviews were transcribed verbatim by a member of the research team and the participants were assigned a participant number and corresponding pseudonym. Pseudonyms were Amy, Betty, Carol, Debra, Ella, Faye, Gail, Haley, Ida, Jane, Kate, Laurel, Mary, and Nancy. No personal identifiers remained after transcription occurred and all transcriptions were assigned a number code to maintain confidentiality. Data collection ceased after interviewing 14 participants because the study team determined that data saturation had been achieved.

### Author Bias

The authors of this manuscript had various levels of knowledge about and experience with loneliness. The principal investigator is an expert on loneliness, with extensive knowledge of loneliness, having completed multiple quantitative studies of loneliness and health. Co-investigators balanced the investigative team because they were not knowledgeable about loneliness and did not have preconceptions about loneliness as an experienced health phenomenon. This was the first qualitative study of loneliness conducted by this team so there were no assumptions about the positive or negative emotional experiences that would be described by study participants. None of the authors had personal relationships with study participants. The qualitative analysis process included analysis by researchers who were not present in the room with the participants during the interviews. The study team approached the analysis objectively without bias toward any specific theme.

### Data Analysis

Thematic content analysis was conducted on 238 double-spaced pages of transcriptions of stories of loneliness. First, the research team verified transcriptions by listening to the audiotapes of the interviews while reviewing the transcript word by word. Second, the team engaged in reading the transcripts multiple times to become familiar with the story data. Third, after completing the preparation phase of becoming familiar with the data, the team engaged in an organizing phase through a process of open coding to identify categories of themes that mattered most to participants. In order to be considered a category for a theme, the team agreed that at least four participants had to make some mention of the potential theme in their descriptions of their experience of loneliness. Fourth, similarities identified in stories were grouped into themes. This involved identifying trends of words being used, evaluating frequency of word use, and examining the relationships of the words being used. Fifth, the grouped stories under each theme were considered and compared to each other and the entire data set for similarities and discrepancies. Although it was not the goal of the study to have participants reach resolution of loneliness, the transcriptions were explored for descriptions of positive coping with loneliness. During the final reporting phase, interactions between the investigators included scholarly discussions about the study results until a consensus was reached about the themes.

## Sample Description

The sample included 14 female participants (mean age 74.4 [SD 5.8]). Overall, participants had a mean loneliness score of 47.18 (SD 7.88, Range 40-69) on the UCLA Revised Loneliness Scale (Russell et al., 1980), indicating moderate to high loneliness. Five participants were married, five were separated or divorced, three were widowed, and one was never married. The participants all said they completed high school education and six participants reported earning a college degree, with four of the six earning Masters degrees. Overall, household income was relatively low, with 10 participants reporting annual household incomes of less than \$40,000. Nine participants lived with a spouse, three lived alone, and two lived with other relatives. Twelve participants reported being retired and two were still working. Study participants had multiple chronic conditions (mean was 2.8 chronic conditions [SD 2.1, Range 1-8]). Eight participants reported having hypertension (57%), five had diabetes (36%), five had arthritis (36%), four had heart disease (29%), three had cancer (21%), three had lung disease (21%), and one participant had a stroke (7%).

## Results

Thematic content analysis revealed four categories that included 13 themes. The first category was identified as “Negative Emotions of Loneliness.” In this category, five themes of Sadness, Disconnection, Fear, Anger, and Worry were explicated. The second thematic category of “Positive Emotions when not Lonely” includes two themes of Joy with Others and Pride in Self. The third thematic category was identified as “Loss of Independence and Loneliness” and included three themes of Functional Decline Contributes to Loneliness, Burden, and Gratitude for Help. The fourth thematic category was “Ways of Managing Loneliness,” which included three themes of Remembering Holidays and Happier Moments, Staying Busy, and Getting Out.

### Negative Emotions and Loneliness

Participants frequently described negative emotional states including sadness, disconnection, fear, anger, and worry. As we have noted below, a variety of factors could trigger these negative emotions such as: antagonistic relationships, distrust in healthcare providers, declining physical and functional status, loss of loved ones, seasonal changes, divorce, and becoming the primary caregiver for a loved one. The negative emotional experiences of loneliness were prevalent, with the particular emotional state of sadness and disconnection being mentioned by all participants.

**Sadness**—In the transcriptions, the word “sad” was used 171 times and was observed in the transcriptions from all 14 participants. Participants referred to a deep sadness many times during the interviews. Examples are presented from Gail and Ida. Gail mentioned sadness 19 times during her interview. She said:

All of my relationships have made me sad...the people I was close to...they are all gone which is another reason I am lonely and pathetically sad...I never found the [right] guy to spend my life with and actually, I never found anybody....that is pretty sad, isn't it? It's hard for me to try to figure out about loneliness. Sometimes



it's just like a wave that, that comes over me.....I'll start crying and sometimes I even start crying, not realizing what I'm thinking about.

Ida also described a sadness that came with loneliness.

Well you know that it really hurts. I have to take care of [Buddy]. Last week I had to give up my game of bridge because I couldn't find somebody to help me. I am losing my friendships and that makes me very, very sad.

**Disconnection**—A sense of being disconnected from other people was described 34 times and at least one time by all 14 participants. Betty described how she missed connection with others.

I feel like nobody cares. I have nobody to confide in really. I just feel like there is really nobody who loves me or talks to me. One of things that surprised me... you know if I don't go around and talk to people, they don't necessarily come to me and talk to me. I've just had to reason through it and say, "you know they're busy and they're interested in their own lives and you know we are not living in a day in which people really care about other people."

Jane similarly described disconnection:

Well, loneliness I think feels like desperation for people. You just feel like you have absolutely nobody. I think about the things I did wrong and I try not to dwell on that but when I'm home alone and when I go to bed I start thinking about all these things. Like what if I had done this or that or what if I had tried harder in this area. It feels like you're a non-entity and it feels like there is nothing within you that gives someone else a reason to want to know you.

**Fear**—The words "fear" and "afraid" were used 110 times by seven participants to describe emotions with loneliness. Debra talked about the fear associated with possibly having to relocate to meet her healthcare needs while she was already lonely. She said, "The biggest fear I have is, where will I go from here? If I have my knee operated on, I would have to go probably to a rehabilitation center." Mary mentioned fear seven times and described it as:

I think all those fears would just trap you. There was like a fog on my mind...being afraid of what would happen...it isn't selfishness...you are just scared. You can't be like Chicken Little and always think the sky is falling. You have to make a list of things to do so you don't think about it...you know...we can just die at any moment.

**Anger**—The emotion of anger was identified 42 times in the transcriptions, with a total of six participants mentioning being angry or mad. Ella discussed anger over how people superficially listen but do not really understand, leaving her feeling like she did not have the opportunity to get her words out. She stated, "I want to take that phone and throw it about 50 yards." Betty spoke of anger with her healthcare provider by stating, "I have a lot of anger towards my doctor...he kind of just looks off in the distance when I talk to him." Ida described feeling alone and being angry at others for not meeting her needs:

My granddaughter came in and did some things but she had other things to do too. I was getting to the point where I was angry. When my daughter and her husband came in, I cut their neck off because I was angry. Here they come 16 hours in and I was fussing because I was angry and mad.

**Worry**—The experience of worry was described 19 times by four participants. Ella discussed worry five different times during her interview. She mentioned worrying about children, but also not wanting her children to worry about her. She said, “I worry about her because she will be my daughter forever but I didn’t want her to worry about me...and you know what...now she doesn’t.” Faye mentioned worry 11 times in quotes such as, “I worry about myself...my breathing is bad and I have to limit what I do.” Betty said, “I worry that they will do things... that the hospital or doctor will do things that they shouldn’t be doing.”

### Positive Emotions when Less Lonely

Participants consistently highlighted positive emotions that were enjoyed when they were not experiencing loneliness. The positive emotions were described in the context of being with family or self-accomplishments and, therefore, the themes were identified as joy with others and pride in self.

**Joy with others**—Overall, the experience of joy when interacting with others was described 208 times (44 comments about the significance of relationships with grandchildren and 164 comments about the importance of friend relationships) by 12 participants. Ella described positive emotions in relation to time spent with children and grandchildren, stating, “Oh, I love it! My blood pressure was down the whole time I was there” and “I think grandchildren are the best thing that God ever created. They bring me joy.” Haley described her enjoyment in maintaining relationships with long-term friends. She said, “I literally view my old friends, and I’m talking old like back to high school, kind of like jewels. They tell me they love me and they worry about me. That’s very important.”

**Pride in self**—Pride in personal accomplishments was mentioned 12 times by five participants. Nancy stated, “By going to the day hospital I get to, along with a group, talk about the things that have happened and the things I’ve improved myself in, where I had been at one time or another by being depressed.” Statements from Carol such as, “I get to bowl on Fridays....my world is shrinking you know but I can definitely still go to the store and go bowling. On Tuesdays I go to the VA and call appointment reminders too...I can still do these types of things” reveal the importance of maintaining pride in self by participating and contributing to social and community activities.

### Loss of Independence and Loneliness

All participants regularly spoke of the link between loss of function and loneliness, which was described as directional - with functional impairment being a contributor to loneliness. In addition, the experience of being perceived as “burden” to others was noted. Finally, participants conveyed feelings of gratitude for help that is available or was offered.



**Functional decline contributes to loneliness**—Loss of function or inability to do things that could be done in the past was mentioned 159 times by all 14 participants. The participants described functional decline as limitations in physical mobility, cognitive function, finances, or independent transportation. Amy reflected on her loss of independence with statements such as, “I cried every time I moved with my back. I can’t move and I have to go to the bathroom but I know it’s going to hurt” and “I think it’s just been since I have been unable to walk and get out that it’s more like a trap. Like I’m inside my body and I can’t get out.” Financial limitations discussed by participants led to the eventual loss of property or automobiles, thus limiting their transportation. Others concluded that losing their ability to drive would negatively affect their overall well-being and health. Similarly, individuals who were able to maintain their independence expressed feelings of anxiety and fear over someday losing their functional abilities. Ida stated, “I wonder what’s going to happen when I’m not able to work. I worry about that.”

**Burden**—The perception of feeling like a burden was described 21 times by four participants. Amy discussed her concerns of potentially burdening others with actions as simple as phone calls. She said, “I don’t even call my friends anymore because I feel they’ve got a life and, you know, [I] don’t want to interrupt if they are busy.” Gail spoke of other people being too busy and not wanting to bother them. She said, “It’s just busyness, and they talk to other people because they have a need to...Whereas they don’t have a need to talk to me.”

**Gratitude for help**—Four participants described being grateful for help they received in coping with their limitations. Jane spoke about her inability to drive a car and expressed gratitude about a neighbor who helps her out. She said, “She takes me in to the doctor, you know, because you have to have a driver. I hate to ask her but I really appreciate it”. Gail described how she was financially limited and could no longer easily get to the grocery store. She spoke of how she appreciated others who helped her make up for this specific functional deficit. She said, “They will deliberately shoot a deer for me. They brought me a deer already cut up and frozen so that all I have to do is put it in the freezer.” Haley mentioned the kindness of people who are nearby as being important and appreciated. She identified help from the maintenance man by describing how he helped her when she fell in her apartment. She said,

He came and picked me up the other day...he put me back in the chair. I didn’t have any britches on and he just said that he wouldn’t look. That was really nice. I really needed help. I was really glad for that.

### Ways of Managing Loneliness

Study participants described how they were able to manage their loneliness. They emphasized that it was very important to remember traditional events like holidays or times of happiness and to keep oneself busy, explaining that being busy provided a distraction from loneliness. Planning ways to get out of the home was described as an important way to cope with loneliness, even if the plan was simply to get out to do routine activities.

**Remembering holidays and happier moments**—Remembering traditional holidays and happier times from the past was mentioned 79 times by all 14 participants with specific holidays being mentioned 30 times (Christmas was identified 17 times, Easter seven times, and Thanksgiving six times). Participants spoke of how happy memories of holidays and other times were important to diminishing their current experience of loneliness. For example, Betty talked about how she looks forward to the holidays because her memories are happy. She said, “Like Christmas and Thanksgiving...I live for that...happy times for the family. Really keeps me going because those are times when I am so busy.” Mary spoke of the importance of the holidays, “You know, and I keep saying, as long as I’m alive and able to cook Christmas and Thanksgiving.... I will do it. You know, because I love having them [family members visiting]...it is the best part of my year.” Ella noted the effects of having memories of happier times on her current situation of loneliness, stating, “The happiness [experienced] in your life removes so many barriers that you didn’t even know that were there.”

**Staying busy**—The importance of staying busy was described 48 times by nine participants. Sharing feelings among a group with similar problems, social outings, gardening, reading, helping others, maintaining a daily routine, staying connected with friends, participating in educational and creative arts classes, working, praying, and spending time with pets were all described as ways that participants added structure to their days to stave off loneliness. Jane said, “You don’t have time to dwell on it if you’re busy, so plan things in your calendar” and Faye explained that, “staying busy with church keeps me going” as she described how prayer gave her motivation to continue on while experiencing loneliness.

**Getting out**—The ability to get out as a way of diminishing loneliness was mentioned 20 times by eight study participants. Laurel talked about getting out five times during her interview. She commented, “For me, getting out was a major [help] this winter. It is nice to get out with people and work together on something. Nice not to be cooped up in the house.” Kate emphasized the importance of getting out to do routine things. She said,

I gave a car to George because he drives me in the winter. It was good because he drives me to the store or to my appointments and we needed a good car so we could get out. For safety reasons, I thought it was a good thing for us.

Jane provided advice on getting out. She noted strategies such as, “try to surround yourself with some friends or anybody so that you are not isolated. Make sure that you have a way to get out.”

## Discussion

Story theory was a useful theoretical framework for elucidating the meaning of the psychological concept of loneliness. Liehr and Smith (2008) emphasized that the theory can be used to gather stories of a health phenomenon so that knowledge can be developed about the story path of that issue. In this study, use of the theory as a framework to gather the qualitative data facilitated understanding of the path of each story of loneliness. Learning the

past and present experiences of lonely participants as they deal with loneliness contributes to a deeper understanding of loneliness as a psychological construct that influences health.

### **Negative Emotions and Loneliness**

The negative emotional concepts identified in this study -- sadness, disconnection, fear, anger, and worry -- are described as integral to the loneliness experience. This is a new finding because these emotional states have not been studied as directly related to loneliness in past studies. Because loneliness has been determined to be a major predictor for anxiety and depression (Bekhet & Zauszniewski, 2012; Cacioppo et al., 2006), it may be that the emotional experience of anger, fear, and disconnection while lonely are contributing to these behavioral health conditions, in addition to sadness and worry. Therefore, addressing the negative emotional states experienced while lonely could potentially prevent anxiety and depression. This would be significant because these conditions are prevalent across populations and impact the healthcare system in a variety of ways (Cacioppo et al., 2006).

Fear has been seldom reported as related to loneliness in quantitative studies of older adults. However, older adults who experience both fear and loneliness have reported lower quality of life (Jakobsson & Hallberg, 2005). One study of community dwelling older adults reported that loneliness and lack of participation in social activities was associated with higher levels of fear of crime (De Donder, Verté, & Messelis, 2005). Discerning the relationship between fear and loneliness could contribute new knowledge that may be clinically relevant since it is unknown if loneliness contributes to fear or if fear, itself, contributes to self-isolating behaviors

Although anger has been described as co-existing with loneliness in studies of specific populations such as persons with cancer (Sahin & Tan, 2012), it has not been described as an emotion that is usually associated with loneliness. Anger is known to activate the neuroimmunological stress response described by McCain and colleagues (2005), and has been linked to both hypertension (Mushtaq & Najam, 2014) and depression in older adults (Havva, 2013). Because loneliness has been described as being related to hypertension for many years in quantitative studies (Hawkey et al., 2006; Momtaz et al., 2012; Thurston & Kubzansky, 2009), understanding the relationship between anger and loneliness could elucidate new areas for intervention. Given that one study reported that anger may be protective against cardiovascular events in some cases (Nakamura et al., 2013), it cannot necessarily be assumed that the coexistence of loneliness and anger would lead to future negative health outcomes or illness.

Worry rarely has been examined with loneliness. The only study of older men and women investigating both loneliness and worry found gender differences, with women reporting more worrying, even though women had more diverse social networks. (Stevens & Westerhof, 2006). Because the present study sample was entirely older women, the prominence of worry expressed could be related to the gender of participants. Given that loneliness has been associated with anxiety disorders in this population (Theeke & Mallow, 2013), understanding the connection between worry and loneliness is important.

### **Positive Emotions and Loneliness**

The two themes that were identified in this study as being related to positive emotions were joy with others and pride in self. Our findings describe the importance of relationships with family, particularly children and grandchildren. This is similar to the findings of Lou and Ng (2012), who studied a sample of older Chinese adults and identified the importance of family relations and daily planned social activities. Dong and colleagues (2012) also studied a sample of Chicago-based Chinese older adults and reported results that are congruent with our results because they valued intergenerational relationships and social activities. Our finding about pride could be useful in future work, potentially contributing to the design of interventions that facilitate the accomplishment of meaningful personal goals that could, subsequently, enhance pride and diminish loneliness.

### **Loneliness and Loss of Independence**

The themes that related to loneliness and loss of independence were functional decline, burden, and gratitude for help. The findings about the importance of functional ability are similar to Smith (2012), who identified that age-related functional changes can contribute to less meaningful interactions with others. In addition, our results about the importance of transportation are similar to Smith's (2012) finding that loss of transportation can be related to loneliness. In contrast to some past studies that reported a unidirectional relationship with loneliness contributing to functional decline (Perissinotto et al., 2012) and even mortality (Luo et al., 2012), participants in the current study described the relationship as cyclical, with functional decline also contributing to negative emotions and loneliness. Although there is an extensive literature exploring the relationships between functional decline and loneliness, there is a gap related to the experience of burden and feelings of gratitude for help while lonely.

### **Ways of Managing Loneliness**

Participants identified multiple effective ways to cope with, or at least diminish, their loneliness, including remembering holidays and happier moments, staying busy, and getting out. Coping mechanisms identified in this study were similar to findings from other qualitative studies. Smith (2012) emphasized that older adults cope with loneliness if they stayed connected with others, performed meaningful service, or found value in companionship with pets. Although the study participants emphasized the importance of getting out, they did not describe rurality as a specific problem in doing so. Rather, the findings of this study are similar to experiences of loneliness for older adults living non-rurally or in retirement communities (Bekhet & Zauszniewski, 2012). It is possible that because the rural environment was the norm for the participants, it was not viewed as problematic.

### **Limitations**

It is important to note that these findings cannot be generalized to men, other age groups, urban populations, communities that have access to community resources, or people without chronic illness. The lack of male participants and age of this study sample limit the generalizability of the study results to men or younger populations. Further, it is possible

that the experience of loneliness would differ for those who are not experiencing illness or who are in settings rich in resources. This study aimed to specifically understand emotions equated with loneliness in the context of chronic illness in a rural, underserved Appalachian population and thus, findings may not be similar in urban areas. In addition, the research team was based solely in the discipline of nursing and the analysis of the data was dependent on the perceptions of this team. Every attempt was made to maintain rigor to study design and analysis but the possibility always exists for error. These findings do not make it possible to quantitatively establish a definitive relationship between loneliness and the described emotions.

## Implications

The results of this study provide insight into the experience of living with loneliness and chronic conditions in this population. Knowing that older adults who are lonely in Appalachia experience significant negative emotions, including sadness, anger, fear, and worry, may mean that older adults in other situations may be having similar experiences. Professionals who work with this population should assess older adults for loneliness and for the negative emotions and functional decline described as being related to loneliness in this study. Additionally, these findings support the conclusion that loneliness is a complex experience that could impact psychological and physical health outcomes. Assessing for loneliness could lead to active care planning which could improve the quality of life of older adults with chronic conditions.

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## **Appendix A: Talking Points Used to Facilitate Semi-structured Interviews**

### **A. What matters most about loneliness?**

1. Talk to me about times in your life when you feel lonely.
2. Talk to me about your deep feelings and loneliness.
3. Tell me about your loneliness and the chronic conditions that you experience.
4. Talk to me about times in your day when you feel you belong
5. Tell me about times in your day when you feel you do not belong
6. Tell me about how belonging gives you purpose in your life
7. Talk to me about something that has meaning to you regarding relationships.

### **B. Loneliness and recognizing the role of self in one's own story of loneliness**

1. Tell me about the person closest to you
2. Tell me about people with whom you have relationships but not as closely.
3. Talk to me about people with whom you have distant relationships.
4. Talk to me about someone with whom you have an antagonistic relationship.
5. What makes you want to stay in?
6. What makes you want to get out?
7. Tell me about how getting out or staying in impacts your experience of loneliness?

### **C. Challenges related to loneliness**

1. Tell me about a turning point in the past year.
2. Tell me about a high point in the past year.
3. Talk to me about your lowest point in the last year

### **D. What works for you to diminish or cope with your loneliness**

1. Tell me about what your life lesson or message would be about loneliness