LONELINESS AS EXPERIENCED BY WOMEN

LIVING WITH CHRONIC ILLNESS IN RURAL AREAS

by

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DEDICATION PAGE

To my husband, Chris, who has provided me with unconditional love, support and encouragement throughout this undertaking, I love you. To my children Abigail, Jack and Matthew, my greatest treasures, who brought a smile to my face each day, when I didn't feel like smiling. To my mother-in law Elaine, sister-in-law Elaine Mary, and my nieces Amanda and Makayla who logged endless hours caring for my children. I'm so grateful to have such a wonderful extended family. To my mother, father, sister and grandfather who have also stayed the course with me, they are the people behind the scenes whose support helped me find the courage and self-confidence to undertake this venture into the unknown. To my friend Jeannie who I met during graduate school, she was my rock and the one person who truly could relate to the emotional roller coaster this process has been. Finally, to my dear friend Gina who helped keep me grounded and to remember that my faith in God would see me through.

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ABSTRACT

Chronic illness is often accompanied by multiple life altering challenges for individuals especially those living in rural locations. Rural dwellers generally do not have readily accessible healthcare resources; as a result, there is a risk for poor heath related outcomes. Loneliness is one such outcome. The purpose of this study was to contribute to the existing body of knowledge related to loneliness as experienced by women living with chronic illnesses in rural areas. This was accomplished by identifying and exploring factors related to loneliness. The aims of this study were to: **(**a) to describe the levels of loneliness, depression, stress, and social support for a group of rural women with a chronic illness; (b) identify the factors associated with loneliness; and (c) explore participants' shared conversations to gain further insight into the rural chronically-ill woman's experience of loneliness.

This study was conducted as a secondary analysis of data previously collected by the Women to Women (WTW) research team at Montana State University. The WTW study provided rural women with chronic illnesses computer training and support through an online forum. The data for the secondary analysis were generated by 57 women. The key concepts were: loneliness, depression, stress, and social support. Age, education, degree of rurality, employment status, and length of chronic illness were the demographic characteristics of interest. Degree of rurality was assigned using the MSU Rurality Index. These characteristics and the key concepts were analyzed using bivariate and multivariate analytic techniques.

Content analysis was the method used to analyze the women's conversations in the online forum. The data were obtained from 12 women who were identified as the most vulnerable to loneliness. Three categories were defined using this method: longing for loved ones, "listening" from the background, and changing relationships.

Results of this study supported previous researchers' findings of correlations between loneliness and depression, social support and stress. There was no significant relationship between loneliness and degree of rurality; however, length of chronic illness was significant. Level of education was identified as an area of interest for further nursing research.

INTRODUCTION

The feeling of loneliness is often associated with the physical state of being alone. Its deeper meaning, however, is a much more complex phenomenon. A universal definition of loneliness has not been agreed upon in the literature; rather, loneliness is seen as being multi-faceted with various types and causes (Murphy, 2006). Simply put, loneliness is a deficit in needed or wanted human intimacy (Carnevali, 1986). A person may feel lonely when no one else is present, when a particular person is absent, when partners treat him or her differently than desired, or when aspects of the situation make the person feel alienated (Peplau & Perlman, 1977). Loneliness may result in personal suffering characterized by feelings of abandonment, emptiness, dissatisfaction, anxiety, and depression (Carnevali, 1986).

A significant amount of research on loneliness was conducted in the 1970s and 1980s. In more recent years, research on loneliness has declined for unknown reasons. Heinrich and Gullone (2006) speculated that loneliness might have been taken for granted and overshadowed by other conditions.

Loneliness is one of several psychosocial issues that a chronically-ill person may face (Kara & Mirici, 2004). Chronic illness is a condition that is long standing, usually permanent and progressive (Ohman, Soderberg & Lundman, 2003). According to national statistics, it is the major health problem facing Americans (Corbin & Strauss, 1988). In the United States, more than 90 million people live with a chronic illness.

Those illnesses, account for more than 75% of all U.S. healthcare expenditures (Mitka, 2006). Although many infectious diseases have significantly decreased or have even been eradicated over the past century thanks to biotechnical advances, vaccines, and antibiotics (Amara, Bodenhorn, Cain, Cypress, Dempsy & Everry, et al., 2000), there has unfortunately been a simultaneous increase in the incidence of chronic diseases. One explanation for this increase is the greater life expectancy enjoyed by many Americans. When people live longer, they are more likely to be affected by one or more chronic illnesses (Amara, et al., 2000). Currently, there are no accurate measures of the social costs and human suffering associated with chronic illnesses (Corbin & Strauss, 1988).

The biomedical model of healthcare focuses on a single causative agent and is primarily concerned with finding a cure for a disease; while this is necessary, it is insufficient for the chronically ill (Amara, et al., 2000). Individuals with chronic illness cannot be regarded as merely in need of medical treatment. They need much more than short-term medical-technical assistance. Because of the unending duration of a long-term condition, individuals with a chronic illness are likely to require counsel on deeply personal matters (Corbin & Strauss, 1988). Effective health management and disease-prevention programs for the chronically ill require a comprehensive approach (Amara, et al., 2000).

The manifestations of a long-term illness may confine a person to his/her home, and these attitudes may lead to social withdrawal. A person’s friends may withdraw because they may feel guilty about being healthy in the presence of someone who is ill, or they may be uncomfortable with a friend’s unpleasant symptoms. The disabling effects

of the chronic illness are magnified by the long periods of time that the individual is unable to fulfill former social and occupational roles, which may contribute to feelings of isolation. (Cacioppo, Hawkley & Bernston, 2003; Kara & Mirici, 2004; Miller, 1983).

Women with chronic illnesses who live in a rural community face additional challenges. The multitude of problems imposed by their chronic conditions is compounded by factors unique to rural residents such as long distances from healthcare resources over poor roads, climate, and geography. Many women in these situations delay medical appointments for significant periods of time, placing their health at risk. Healthcare resources in many rural areas or communities are limited, with no health promotion or health prevention services available. If these services are available, generally provider choices are limited, inadequate, or inappropriate (Leipert, 2006), which may compromise the women's ability to manage their illnesses (Sullivan & Winters, 2006). As a result, chronically-ill women who live in rural communities are considered high risk for several health-related issues, including loneliness -- a recognized social issue for women living in rural areas (Liepert, 2006). For example, physical and/or emotional isolation have been found to affect a person's ability to manage his/her condition.

It is possible that nurses and other healthcare providers might view loneliness as a purely personal issue, if it were not for the effects it can have on an individual's health. While loneliness is not a health problem in and of itself, it can increase the risk of illness (Carnevali, 1986). Thus, nurses caring for the chronically ill should know that loneliness

may be a factor to consider when a person's signs and symptoms change or when the person complains of poorer health (Carnevali, 1986). The serious impact loneliness can have on health demands that it be closely examined and that its importance not be overshadowed by other conditions. Research focused on loneliness is needed in rural areas, especially in regard to women with disabilities (Leipert, 2006).

Adaptation Framework

Many researchers in the field of chronic illness have focused on physiologic aspects of a person's diagnosis. Little attention has been directed at similarities and/or differences in people's adaptation to chronic illness, the framework used to guide the WTW study. Pollock (1986) described adaptation to a chronic illness as "a complex process involving internal and external factors that influence response and subsequent level of adaptation to the illness" (p. 90). Adaptation is based on an active process where an individual continually adjusts to his/her environment. Among the variables affecting adjustment to the environment include chronicity of an illness, adaptive behavior, hardiness, and stress (Pollock, 1986; Pollock, Christian, & Sands, 1990) such as loneliness. Rokack's (1998) final stages in the experience of loneliness are those of acceptance and coping, traits associated with adaptation.

Purpose

The purpose of this study was to contribute to the understanding of loneliness as experienced by women living with chronic illnesses in rural areas. By identifying the

factors that are associated with the presence of loneliness, nurses, as well as other healthcare professionals, will be aided in a more timely identification of loneliness. It is an important issue to consider in the planning of care for the chronically ill rural dweller, specifically, to assist them in adapting to life with a long-term illness.

Study Aims

The aims of this study were to: **(**a) to describe the levels of loneliness, depression, stress, and social support for a group of rural women with a chronic illness; (b) identify the factors associated with loneliness; and (c) explore participants' shared conversations to gain further insight into the rural chronically-ill woman's experience of loneliness.

REVIEW OF LITERATURE

Serious chronic illness impacts and alters the lives of those living with the illness; interrupts hopes and dreams for the future (Ohman, Soderberg & Lundman, 2003); and marks the beginning of a life-long process of management and adaptation (Weinert, Cudney & Winters, 2005). In navigating this path, the chronically ill person may experience loneliness in his/her day-to-day struggles.

Chronic Illness

Chronic diseases—such as cardiovascular disease (primarily heart disease and stroke), cancer, and diabetes—are among the most prevalent health problems in the United States. The prolonged course of illness and disability from chronic diseases like diabetes and rheumatoid conditions, e.g., arthritis, chronic fatigue, has resulted in extended pain, suffering, and decreased quality of life for millions (Centers for Disease Control, 2007). Chronic illness is a significant health issue, affecting a large segment of the population. In the year 2000, it was estimated that people over the age of 60 would live with at least two chronic illnesses and that those over 40 would develop one chronic illness per decade (Shaw, 2007).

The experience of health and illness is dynamic, complex and often uncertain. Individuals with a chronic health condition must constantly cope with symptoms that may be managed efficiently, but not cured. They often live with two or more illnesses, making treatment complex. The experience of living with the long-term illness varies but will almost universally be a source of frustration and challenge for individuals (Shaw, 2007).

The well-being of individuals who have a chronic health condition is affected by a number of risk factors. The effects of the illnesses are not limited to the individual who happens to have the disease; rather it touches those closest to the individual and eventually reaches the community. The resources available to people with chronic illnesses vary by location and population. People in rural locations have limited access to healthcare resources, which in turn can have long reaching effects on the person's overall health.

Rural Factors

Rural areas comprise open country and settlements with less than 2500 residents and are home to a significant number of people. In 2000, 59 million Americans or 21 percent of the population lived in rural areas, and 75 percent of the US land mass was considered rural (U.S. Census Bureau, 2000).

Leipert (2006) looked at how rural women in northern British Columbia, Canada, perceived and maintained their health and identified three problems -- physical health and safety risks, psychosocial health risks, and the risks of inadequate healthcare. The women's physical health and safety risks were related to their health status, age, and financial status. Psychosocial health risks included social and mental health issues such as loneliness and depression. Many of the women in Leipert's study were often located in the northern rural location because of their spouse's employment and did not have family and friends nearby. Single women or women without children had difficulty adapting to the rural community. Some women chose to leave, while those who stayed did so at the

risk of their psychosocial health. Unhealthy psychosocial situations included long cold winters, limited educational opportunities, and isolation. Isolation is a recognized consequence of residing in a rural area that can result in decreased communication and interaction with others (Lee, Hollis & McClain, 1998). Social isolation has been identified as a possible cause for loneliness (Foxall & Ekberg, 1989).

Loneliness

The study of loneliness has gained the interest of researchers from around the world and in many disciplines, including nursing and psychology. Peplau & Perlman (1982), pioneers in the research on loneliness, reported that loneliness was a widespread phenomenon that could have life threatening consequences. Thus, a compelling reason for studying loneliness is closely related to the influence it has on a person's physical and mental health. In addition, researchers have proposed a closer look at loneliness because of the mystery and multifaceted dimensions of the phenomenon (Nilsson, Lindstrom & Naden, 2006).

Defining Loneliness

Loneliness has been studied from many different perspectives over the past several years. The focus of the early research on loneliness was on defining and explaining the concept. This has proven difficult if not impossible; to this day, researchers have not agreed upon a definition of loneliness. The complex nature of loneliness does not lend itself to one meaning. Early research on loneliness provided a foundation to guide future research. For example, Weiss (1973) proposed a typology of

loneliness; Peplau & Perlman (1982) published data on the antecedents of loneliness; and Rokack (1998) outlined data on the six stages of loneliness, all of which have provided valuable perspectives in the development of an understanding of the broad concept.

Weiss, (1973) proposed that loneliness was based on the notion that deficiencies in different forms of social relationships would result in loneliness and loneliness-related affect (Heinrich & Gullone, 2006). Weiss's (1973) typology, defined emotional loneliness as the absence of a close, intimate attachment to another person, which results in feelings of emptiness and anxiety, whereas social loneliness is defined as the absence of a social network of friends in which the person feels a part of (Heinrich & Gullone, 2006).

Antecedents of Loneliness

Individuals are predisposed to loneliness secondary to a multitude of factors. Peplau & Perlman (1982) classified the causes of loneliness into two categories. The first were events or changes that precipitate the onset of loneliness. The second targeted factors that predispose individuals to becoming lonely or to remaining lonely over time.

Events that may trigger loneliness include death of someone close to the individual, a divorce, or a breakup (Carnevali, 1986; Murphy, 2006; Peplau & Perlman). One of the most profound factors is the death of a mate, sibling or child. It is difficult to generalize which loss will cause the most loneliness because it depends on the nature of the relationship and the need it met in the life of the individual. If the relationship is good, it often meets a significant portion of a person's need to give and receive care (Carnevali, 1986). Even when a person's relationship with their spouse or house-mate

leaves something to be desired, it still sets the pattern for the activities and demands of daily living. As a result, the loss creates a substantial gap in the survivor's daily life and a lack of human intimacy (Carnevali, 1986). Being a part of an intimate relationship may help ease the effect of a stressful life event on a person's mental health, while not having a friend with who to share feelings can increase depressive reactions to adverse life events (Murphy, 2006).

Additional factors that predispose people to loneliness include social needs, place of residence, confinement to the home, changes in living arrangements, illness and incapacity, and time (Carnevali, 1986). Loneliness is not just affected by the presence or absence of relationships; it is also influenced by the quality of social relations that provide for human intimacy (Peplau & Perlman, 1982).

Social Needs. An important antecedent of loneliness is related to a person's desired social needs. Life cycle changes in a person's desire for social relations may precipitate loneliness, especially if not accompanied by corresponding changes in actual relations (Peplau & Perlman, 1982). Relationships may be seen as deficient because they fail to meet the person's basic social needs (Peplau & Perlman, 1982).

Place of Residence. Traditionally, urban residency has been associated with an increased risk of loneliness, as opposed to rural settings (Carnevali, 1986), and Lauder, Sharkey & Mummery (2004) reported that living in a rural area was not an antecedent for loneliness. In contrast, a study on loneliness in Ireland reported that residents of urban areas were less likely to feel lonely (National Council on Aging and Older People, 2005).

However, the Irish residents were also married and in good health with access to transportation.

Confinement to the Home. Older homebound people are more apt to be lonely. In addition, any factor within a person's environment or themselves that restricts the person's ability to leave their home is a predictor of increased loneliness (Carnevali, 1986).

Changes in Living Arrangements. Disruptions in established patterns of interaction and contact may increase a person's risk of loneliness. For example, when parents or grandparents move in with their children, they could become dissatisfied because their new living arrangements are different from their familiar surroundings. As a result, the person may feel lonely in the midst of their family. On the other hand, moving into a nursing home or long-term care center presents a greater risk for loneliness. Since many of the residents have advanced mental and physical disabilities, there is little opportunity for developing meaningful relationships with others (Carnevali, 1986).

Time. Another risk factor for loneliness is the concept of time. Loneliness tends to increase at particular times of the day, week, or year. For example, loneliness may be more prevalent for people on holidays such as Christmas, or during the winter months (Carnevali, 1986).

Stages of Loneliness

Through research and working with clients, Rokack (1998) determined that loneliness is not something people go through all at once and is then recognized as loneliness. Loneliness may be situationally determined, or there may not be an obvious reason. Generally, people do not immediately recognize that they are lonely, but reach that determination through experiencing several stages (Rokack, 1998). Rokack (1998) identified six stages in the experience of loneliness: (a) pain and awareness of a problem, (b) denial, (c) alarm and realization, (d) searching for causes and self-doubt, (e) acceptance, and (f) coping.

Concepts Related to Loneliness

Conditions that are similar to loneliness are aloneness (or solitude) and lonesomeness. It is important to differentiate loneliness from these other conditions.

Aloneness. Aloneness exists when a person is without company. It can be described as mental or emotional separation, such as making a personal decision alone. Aloneness can also be physical separation from others, temporarily or long-term (Carnevali, 1986).

Lonesomeness. Lonesomeness is a status where one is not in the company of others. However, it is different from aloneness because people who are lonesome prefer to be with others. It can occur when a person is alone or in the presence of others. The discomfort associated with lonesomeness is generally mild to moderate; it is a recognizable acceptable status. Typically the person is able to resolve the situation and create more desirable conditions (Carnevali, 1986).

Differentiation from Loneliness. Loneliness is a subjective state; diagnosis is reliant on self-report or on associate indirect behaviors. Some people may be reluctant to admit that they are feeling lonely; therefore, healthcare providers must be aware of some of the signs and symptoms associated with loneliness. Loneliness may become evident in peoples' behavior as they change their approaches to activities of daily living, become very busy or apathetic. Sufferers may also become more talkative or silent, avoiding input from others (Carnevali, 1986).

Loneliness and Chronic Illness

Loneliness does not exist in isolation from other life influences. One of our primary interests is its relationship to chronic illness and other disease-related characteristics. Loneliness has a major impact on a person's mental and physical well being (Heinrich & Gullone, 2006). Researchers have observed that people suffer from loneliness associated with illness and illness-related situations (Cuevas-Renaud, Sobrevilla-Calvo & Almanza; 2000; Friedman, Florian & Zernisky-Shurka, 1989; Fuki, Koike, Ooba & Uchitomi, 2003). Fees, Martin & Poon (1999) reported a high correlation between loneliness and physical illness. Murphy (2006) reported that several researchers have studied chronic illness and its relationship to loneliness. Low self-esteem, decreased optimism, poor quality of relationships, and being hospitalized for chronic health problems are factors associated with chronic illness found to increase the vulnerability of older people to loneliness (Chen 1994; Flett, Harcourt & Alpass, 1994; Keele-Card, Foxall & Barron, 1993; Murphy, 2006).

Friedman, Florian & Zernitsky-Shurka (1989) studied the experience of loneliness in young adults with cancer. Participants completed the UCLA Loneliness Scale and also responded to open-ended questions about loneliness. No greater incidence of loneliness in those with cancer as opposed to the healthy controls was reflected in their responses. However, because the participants with cancer in this study did not suffer impairments in mobility or general physical functioning, the findings may have been due to this lack in the experimental group. Approximately half of the participants attributed loneliness to "illness-related situations," whereas no members of the control group reported such responses. Friedman and colleagues examined the relationship between the demographic variables and the levels of loneliness and found that unmarried cancer participants had higher levels of loneliness compared with the other participants in the study.

Disease Related Characteristics of Loneliness

Foxall & Ekberg (1989) conducted a study on loneliness that was designed to determine if there was a significant difference between chronically ill adults and their spouses. In addition, they looked for possible relationships between loneliness and certain characteristics. They found that that loneliness was correlated with disease-related characteristics for the chronically ill, but not for their spouses. The lonely ill spouse had a higher number of chronic illnesses, greater disability level and overall poorer health. In addition, they reported that a length of a person's illness was not a determining factor for loneliness. These researchers discovered strong correlations between loneliness and measures of disability, and theorized that it was not the illness that resulted in loneliness, but the imposed social isolation from the immobility associated with the illness. For

example, people with arthritis (which often causes a great deal of pain, stiffness, and decreased mobility) tended to be lonelier than those with less limiting conditions such as peripheral vascular disease or chronic obstructive pulmonary disease. However, Pennix, Tilburg, Kriegsman, Boeke, Deeg & Eijk et al. (1999), who also found associations between different types of illnesses and degrees of loneliness, reported that the most severe loneliness was associated with arthritis, peripheral vascular disease, and lung disease, contradicting the findings of Foxall & Ekberg (1999).

In the Pennix et al. (1999) study, feelings of loneliness in people with diseases such as cancer and diabetes did not differ from those of healthy people. An explanation for the differences in the feelings of participants' reported loneliness may be that those who were less lonely had adequate social support as opposed to the individuals with diseases associated with more severe loneliness. One possible reason for this was the episodic nature of the diseases, requiring that a person's social network be flexible. If a person's perceived degree of intimacy is not met, they may experience more feelings of loneliness.

Loneliness and Depression

Considering the many descriptions of the experience of loneliness and its distressing nature, a link to a mental health problem such as depression comes as no surprise (Ditommaso & Spinner, 1997). Numerous studies have linked loneliness and depression in adults (Heinrich & Gullone, 2006; Jackson & Cochran, 1990; Kara & Mirici, 2004; Nolen-Hoeksema & Aherns, 2002). People who experience loneliness often present with symptoms of depression. What is unclear is which precedes the other. The

two conditions may be caused by shyness, poor social skills, and maladaptive attribution style. However, despite the overlap in the features of depression and loneliness, both appear to be distinct phenomena (Heinrich & Gullone, 2006; Koenig & Abrahms, 1999). In distinguishing between the two, loneliness involves the social domain of one's life, whereas depression is more global and heterogeneous, involving multiple areas of a person's life (Boiven, Hymel, & Bukowski, 1995; Heinrich & Gullone, 2006). Depression and loneliness were found to be strong factors influencing a person's perceived low quality of life (Mullins & Dugan, 1990).

Loneliness and Stress

While long-term health conditions have been associated with depression, they have also been linked to stress and low levels of perceived social support. A study conducted by Sjostrom-Strand & Fridlund (2007) examined women's perceptions of stress before and after a myocardial infarction (MI). The participant's were interviewed during their hospitalization secondary to the MI and also at 4-10 months post-MI. Before their MI, some participants in the study associated their stress with loneliness and having various chronic illnesses. Also, some of the participants had been caring for loved ones with long-term illnesses without any support from family, friends or outside resources, which they perceived as very stressful. Their pre-MI stress was described as having feelings of low-spiritedness and loneliness. Post-MI, one participant was of the opinion that the lack of support she experienced while caring for her chronically ill husband had led to her MI; she described feeling very lonely and under a great deal of pressure.

Loneliness and Social Support

Kara & Mirici (2004) conducted a research study to identify differences in loneliness, depression, and social support between people with a chronic illness and their spouses in a sample of Turkish people with chronic obstructive pulmonary disease. They concluded that the chronically ill persons and their spouses were likely to be lonely secondary to social isolation and illness-related factors. In fact, 96.7 percent of the chronically ill participants and 93 percent of the spouses were found to have moderate to moderately high levels of loneliness. These results were consistent with others (Foxall & Ekberg, 1989; Keele-Card, Foxall & Barron 1993) in that there was no difference in the loneliness of either the chronically ill people or their spouses.

Foxall & Ekberg (1989) reported that changes in informal social roles such as church participation and friendships were the best predictor of loneliness for the ill person's spouse, but not the ill person. They did not identify a relationship between the type and number of social contacts that a person had.

Qualitative Aspects of Social Relations.

Dissatisfaction with relationships or deprivation of human intimacy can lead to loneliness (Peplau & Perlman, 1982). Verwoerdt (1976) suggested that five criteria must be present in a relationship if it is to adequately fulfill a person's need for intimacy. The first is a sense of belonging, which implies a sense of fit and harmony. The second is familiarity, because nothing that is new is considered intimate. The third is repetition of previous experiences--intimacy is not based on brief encounters. The fourth is sameness, which is based on the notion that intimacy is not cohesive with change. Sameness binds

the past, present, and future into one cohesive perspective. Finally, the last aspect is sharing. Sharing may consist of the act of sharing materials (such as possessions or money), time, or "each other." Collectively, these aspects of a relationship are important because they meet a person's intimate needs.

Summary

Loneliness has been a topic of interest among the research community over the years. As previously noted, the majority of the early literature was directed at defining the concept, and still a definition has not been agreed upon. Loneliness is complex and does not lend itself to one meaning; as a result efforts have been directed at exploring the different manifestations. However, valuable information has been uncovered regarding various antecedents of loneliness including confinement to home, changes in living arrangements and time. It is widely accepted that loneliness is associated with a person's social needs. What is most important is not the quantity of the social relationships, rather the quality. Human intimacy is important to meet a person's intimate needs (Verwoerdt, 1976). Place of residence, another antecedent of loneliness, has been examined and shown to influence a person's loneliness. Sharkey & Mummery (2004) and Carnevali (1986) have both indicated that loneliness was not associated with living in a rural community. The relationship between physical illness and loneliness has been investigated. However, findings between studies have been conflicting, possibly because the circumstances surrounding individuals varies widely. Variations in the type of chronic

illness and the social network that a person has are two factors found to influence loneliness.

Further research is needed for a fuller understanding of what makes loneliness more prevalent in some people rather than others. Support and guidance are needed to assist in the identification of loneliness among people who may not appear lonely to healthcare professionals. Depression, stress and social support are all factors known to influence a person's experience of loneliness. Further research is needed to clarify the relationship between loneliness and depression, more specifically, which precedes the other. Loneliness has been described as a stressor to people with chronic illness. Further research on potential stressors in people with a chronic condition would be helpful in the identification of loneliness risk factors.

METHODS AND RESULTS

This study was a secondary data analysis conducted to gain insight into the phenomenon of loneliness as experienced by rural women who have a chronic illness. The data on the psychosocial measures of loneliness, depression, stress, and social support, and selected demographics were obtained from the Women to Women (WTW) project. WTW was funded by a NIH/NINR grant (1 RO1 NR007908-01) and led by principal investigator Clarann Weinert SC, PhD, RN, FAAN. A brief overview of the WTW project is provided below, as an in-depth description of the project may be found in recent publications (Anderson & Weinert, 2003; Cudney, 2006; Cudney, Winters, Weinert & Anderson, 2005; Cudney & Weinert, 2000; Hill, Schillo & Weinert, 2004; Hill & Weinert, 2004; Sullivan, Weinert & Cudney, 2003; Weinert, 2000; Weinert, Cudney & Winters, 2005). In addition to the analysis of the scores on the psychosocial measures, the exchanges among the women in the online forum were analyzed for expressions of loneliness. The methods and findings for each step in the analysis are presented systematically in this chapter.

The Women to Women Project

The Women to Women project is based at Montana State University College of Nursing. This ongoing study has provided chronically ill women in rural areas with computer-based support and health-related education for the past 12 years. The overarching goal of the project is to help women successfully adapt to living with chronic illnesses in rural areas where health resources are limited. Women ages 35 to 65 with a

variety of chronic illnesses such as multiple sclerosis, rheumatoid conditions, cancer, and diabetes were actively involved. All were rural residents living in small communities or farms or ranches at least 25 miles outside of towns with populations of 12,500 or fewer (Weinert, Cudney & Winters, 2005).

WTW has evolved and been refined over time. At the point that the data for this thesis research were generated, a three group design was being used: an intense intervention group, a less intense intervention group, and a control group. The women in the intense intervention group were provided with computer hardware, if needed, and computer program training. Only this group had access at all times to an asynchronous self-help support forum called "Koffee Klatch." The women directly interacted with one another through writing or responding to postings. The postings or exchanges included sharing life experiences, voicing concerns, and offering advice and support, as they would have done if they were sitting together in person. A nurse monitor stimulated the conversation initially but then entered the conversation as little as possible while monitoring the exchanges daily (Weinert, Cudney & Winters, 2005). The less intense intervention group accessed self-study units online but did not participate in the forum. The control group did not participate in computer activity, but completed the study questionnaires. Only data from the participants in the intense intervention were used in this study.

A battery of psychosocial measures was administered to all participants at six times over a two-year period. The questionnaires were mailed at baseline, 5, 8, and 15 months to assess short-term benefits of the 22-week intervention, and also at 18 and 24

months to assess for long-term benefits (Weinert, Cudney & Winters, 2005). In addition to the scores on the key psychosocial concepts forming a basis for the analysis in this study, the computer exchanges in "Koffee Klatch" were downloaded and entered into the computer program QSR NUD*IST for analysis (Qualitative Solutions and Research Pty Ltd, 1997).

Secondary Analysis of Women to Women

The data for the secondary analysis were generated by the 57 women who participated in the WTW Phase Two intense intervention group. All necessary recoding of the data had been previously completed by the WTW research team. For the secondary analysis, missing data were handled by mean substitution using the general rule of replacement; if more than 80% of the items on the scale were completed the mean scores of the individuals' completed items were substituted for the missing score(s). This assured that no cases were lost based on a few missing responses.

Participants

The mean age of the women in the secondary data analysis was 52.2 years. Ninety-six percent of the women were Caucasian while the remaining 4 percent were American Indian. Of the participants, 44 percent had dependents younger than 18 living at home with them, 5 percent cared for an adult in their home and 30 percent were employed outside of their homes. The majority of the women were married, 3.5 percent were divorced and 5.3 percent were never married. The women had completed on

average 14.7 years of school. The mean number of years since the onset of symptoms of their chronic illness was 19.9 years. See Appendix A for demographic details.

Study Design

Selected demographic and psychosocial concepts were analyzed to explore their potential influence on loneliness. The psychosocial concepts of interest were depression, stress, and social support. The women's exchanges in the online forum, Koffee Klatch, were analyzed using content analysis.

Measures

The scores on the psychosocial variables of interest were obtained from the baseline measurement point. A basic description of each measure is provided and a copy of each instrument is located in Appendices, B, C, D and E.

Loneliness. For this study the definition of loneliness was based on Weiss's (1973) typology of loneliness (see page 9). The primary concept of interest, loneliness was measured by the UCLA Loneliness Scale (Russell, Peplau & Cutrona, 1980), which was theoretically based on Weiss' (1973) typology of loneliness. It consisted of 20 items and participants responded to the items by providing a numerical rating on a four-point Likert scale ranging from 1 to 4, with "1" being never, "2" rarely "3" sometimes, and "4" always. A total score was obtained by summing all items, resulting in a range of scores from 20 to 80 -- the higher the scores, the higher degree of self-reported loneliness.

Depression. The concept of depression was assessed using the Center for Epidemiological Depression Scale (CES-D). The CES-D is a 20-item self-report tool that measures symptoms of depression. More specifically, it assesses depressive symptoms that occurred during the preceding week. Cognitive, affective, behavioral, and somatic symptoms of depression and positive affect are all assessed for frequency and duration. For each item, participants are asked to circle a number between "0" rarely or none of the time, to "3" most or all of the time. Possible scores range from 0 to 60, the higher the score, the higher the symptomatology of depression (Radloff, 1977).

Stress. The concept of stress was measured by the Perceived Stress Scale to assess the degree that situations are stressful in a person's life (Cohen, Kamarck & Mermelstein, 1983). It is a 14-item scale, which participants in the study respond to by selecting "0" never to "4" very often. A total score is derived by adding all items. The possible range of scores is 0-56. The higher the participant's score the higher the participant's degree and duration of self-perceived stress (Cohen & Kamarck, & Mermelstein, 1983**).**

Social Support. Social support was measured by the PRQ2000 (Weinert, 2003). The PRQ2000 was developed and modeled after Weiss' (1964, 1974) relationship dimensions. Weiss' model included five key concepts: (a) intimacy and attachment, (b) social integration, or being part of a group, (c) nurturing behavior, (d) reassurance of worth, and (e) availability of assistance (Weinert, 2003). The Personal Resource Questionnaire (PRQ85) was originally developed to measure situational support and perceived support and has systematically evolved over the past 20 years. The PRQ2000 is

a 15-item, positively worded scale, with response categories ranging from “1” strongly disagree to “7” strongly agree, and with a possible range of scores from 15-105. Higher scores reflect higher levels of perceived social support (Weinert, 2003).

Demographic Characteristics

The selected demographic characteristics anticipated to be linked with loneliness were age, education, degree of rurality, employment status, and length of chronic illnesses. Except for the degree of rurality, each demographic variable was assessed by a single question. The question, “What is your birth date?” was converted into a continuous variable that reflected the difference between the stated year and the calendar year of the study. Education was a continuous variable that reflected the total number of years of school completed, including grade school through high school**,** as well as, years of college or vo-tech. A degree of rurality, for each participant, was assigned using the MSU Rurality Index (Weinert & Boik, 1995). The index is designed to rank participants’ degrees of rurality based on two variables -- the population of the county (as reported by the United States Census) and the distance (in miles) to emergency care as self-reported by the participant. The MSU Rurality Index value increases as the participant’s degree of rurality increases. Employment status was dichotomous; either the women worked outside the home or they did not. Length of chronic illness was ascertained by the following question “What year was your primary health problem diagnosed?” and was converted into a continuous variable that reflected the difference between the stated year and the calendar year of the study.

Human Subjects Consideration

Approval for this study by the Institutional Review Board for the Protection of Human Subjects (IRB) at Montana State University was granted October 9, 2007. The study was determined to be exempt. Permission to use the WTW data was granted by the principal investigator.

Data Analysis: Quantitative

The first aim of the study was to describe the levels of loneliness, depression, stress, and social support for a group of rural women with a chronic illness. This was accomplished examining the scale scores for each of the key variables.

The key concepts of interest and corresponding measures were: loneliness (UCLA), depression (CES-D) stress (PSS), and social support (PRQ2000). Reliability estimates for each measure were assessed using Chronbach's alpha. Additionally, the range of scores, means, and standard deviations were obtained. Findings were compared to those reported in the literature.

Loneliness Scores Description

A Chronbach's alpha of .94 was demonstrated for the UCLA Loneliness Scale. Numi, Toivonen, Salmela-aro & Eronen (1997) reported similar reliability, with a Chronbach's alpha of .92. High scores on the loneliness scale indicate a high degree of expressed loneliness, with possible scores of 20 to 80. The range of scores in this study

was 21 to 68. The mean score of 44.91 (sd = 9.97) was moderately higher than other studies on loneliness. Gellar, Janson, McGovern & Valdini (1999) used the UCLA loneliness scale for their study on loneliness and emergency department use. The mean loneliness score in their study was 39.06 (sd = 12.00). See Table 1 for a comparison of the mean and standard deviations of the measures in this study as compared to other studies.

Depression Score Description

The Chronbach's alpha for the CES-D in this study was .90. Conerly, Baker, Dye, Douglas & Zabora (2002) reported similar CES-D reliability with a Chronbach's alpha of .89. Higher scores on the CES-D indicated higher symptomatology of depression. Scores of 16 or higher are used as a cut point for highly depressive symptoms and for referral for further evaluation (Radloff, 1977). In this study, the scores ranged from 0-48, possible scores range from 0 to 60. The mean score was 18.56 (sd = 11.12). Fifty-seven percent of the scores were 16 or higher, indicating that more than half of the participants reported highly depressive symptoms. The CES-D was used to measure depression before and after multidisciplinary pain rehabilitation in patients who had fibromyalgia (Hooten, Townsend & Decker, 2007). The mean depression score in the study on fibromylagia was 26.40 (sd = 11.40), which was higher than the mean in this study.

Table 1. Mean and Standard Deviations of Measures

Measures	Loneliness study Mean	Loneliness Study Standard Deviation	Comparison Study Mean	Comparison Standard Deviation
UCLA Loneliness Scale	44.91	9.97	39.06	12.00
CES-D Depression	18.56	11.12	26.40	11.40
PSS Stress	25.42	7.81	25.00	8.00
PRQ2000 Social Support	79.72	13.67	79.91	14.86

Stress Score Description

A Chronbach's alpha of .88 was demonstrated for the PSS in this study. The scores on the PSS ranged from 6 to 39, possible scores range from 0 to 56. The mean score was 25.42 (sd = 7.81). Cohen, Kamarck & Mermelstein (1983) implemented a study that tested the reliability and validity of the PSS. There were three samples, one of which was with participants in a smoking cessation study; the mean score of that group was 25.00 (sd = 8.00) and the Chronbach's alpha was .86. The mean, standard deviation and Chronbach's alpha were similar to the PSS findings in this study on loneliness.

Social Support Score Description

A Chronbach's alpha of .89 was demonstrated for the PRQ2000. High scores on the PRQ2000 reflect high levels of social support. In this study, the scores ranged from 44 to 105; possible scores range from 15 to 105. The mean score was 79.72(sd = 13.67).

The PRQ2000 was utilized to measure the social support in chronically ill rural women before and after a computer intervention (Hill, Weinert & Cudney, 2006). The mean social support score in their study taken at baseline from the control group was 79.91 (sd = 14.86), which was similar to the mean score and standard deviation in this study.

Associations Among Key Variables

The second aim of this study was to identify the factors associated with loneliness. A correlation matrix was constructed for the four psychosocial measures to assess bivariate relationships. Multiple regression techniques were used to assess the impact of key variables and selected demographics on loneliness. Based on the loneliness scores, a subset of participants was selected who were considered to be the most vulnerable.

A correlation matrix was constructed to examine the bivariate relationships among loneliness, depression, stress, and social support. The correlation matrix can be used to help eliminate redundant explanatory variables. Interpreting the correlation coefficients varies, but a rule of thumb is that 0.8 to 1.0 is indicative of a very strong relationship, 0.6-0.8 is considered a strong relationship, 0.4 to 0.6 a moderate relationship, 0.2 to 0.4 a weak relationship, and .0 to 0.2 is indicative of a weak to no relationship (Salkind, 2005). The correlations overall ranged from 0.44 to 0.73. There were moderate to strong relationships among the variables. The depression and social support correlation coefficient was -.51 and the stress and social support correlation coefficient was -.44. The coefficients are representative of moderate relationships

among the variables. Loneliness was negatively correlated with social support. The correlation matrix can be seen in Table 2.

Table 2. Correlations Among Key Psychosocial Variables

		UCLATot1	CESDTot1	PRQTot1
PSSTot1 Stress	Pearson correlation Sig. (2-tailed) N	.726** .000 57	.701** .000 57	-.442** .001 57
PRQTot1 Social Support	Pearson correlation Sig. (2-tailed) N	-.712** .000 57	-.510** .000 57	
CESDTot1 Depression	Pearson correlation Sig. (2-tailed) N	.695** .000 57		

**Correlation is significant at the 0.01 level (2 tailed)

All of the key variables were highly correlated with loneliness as well as with each other. This was not a surprising finding based on previous research. These correlations provided insight into the participants' psychosocial health. Based on these findings, the women were lonely, which, could be related to the fact that they were also depressed, stressed, and had decreased social support.

Factors Related to Loneliness

Analysis of the relationship of the psychosocial and demographic variables to loneliness was conducted. To assess the relationship of the key variables and selected demographics to loneliness, multiple regression techniques were employed. Multiple regression is a statistical technique used to predict a response variable using multiple

explanatory variables (Salkind, 2005). Several different regressions were performed to explore the explanatory power of various combinations of variables on loneliness.

Loneliness was regressed on depression, age, education, degree of rurality, employment status, and length of chronic illnesses. These were the demographic characteristics identified in the literature as influencing loneliness. The explained variance for this equation was .47, and the only significant variable was depression.

Stress, in combination with the demographic variable, was explored for influence on loneliness. Loneliness was regressed on stress, age, education, degree of rurality, employment status, and length of chronic illnesses. Like depression, stress was the only variable that was significant. The explained variance of the equation was .52.

Loneliness was also regressed on social support and age, education, degree of rurality, employment status, and length of chronic illnesses. The results of this equation revealed an explained variance of .54, and three variables that were significant. The social support regression yielded the most useful information: social support was significant at .0001; length of chronic illness was significant at .036; and education was nearly significant at .060. A summary of the regression model of loneliness, social support, education and chronic illness may be found in Table 3. Women, who had lived with their illness longer, had adequate social support and tended to be less lonely. Interestingly, women with more education were lonelier than those with lesser amounts. An intriguing finding that requires more explanation was in regard to degree of rurality. Although rurality was included in the all of the regression models, it was never identified

as being significant. While it could be conjectured that rural location may be related to a sense of loneliness, it was not demonstrated in this analysis.

Table 3. Regression Outcome

Model	Unstandardized Coefficients		Standardized Coefficients		
	B	Std. Error	Beta	T	sig
(Constant)	77.603	7.679		10.106	.000
Length of Illness	-.187	.087	-.198	-2.156	.036
Education	.843	.439	.178	1.920	.060
Social Support	-.531	.067	-.727	-7.925	.000

Data Analysis: Qualitative

The third aim of this study was to explore participant's shared conversations to gain further insight into the rural chronically ill woman's experience of loneliness. This was achieved by content analysis of the unsolicited online exchanges that occurred among the women in Koffee Klatch.

Subset of Study Participants

Expression of loneliness in the day-to-day lives of chronically ill women in rural areas or communities was an area of focus in this study. Efforts to facilitate successful recognition of loneliness included identification of a subset of women who had the uppermost scores on the UCLA Loneliness Scale. This was accomplished by selecting

women whose scores were in the highest quartile, which included 12 of the 57 participants. These women were considered the most vulnerable to loneliness. They had expressed a high level of loneliness on the loneliness measure; therefore, it was of interest to explore their conversations with one another to determine whether loneliness was expressed directly, indirectly, or not at all.

Description of Data Set

Participants in the WTW project were randomly assigned to a group that participated in "Koffee Klatch" discussions. The women were free to post exchanges on any issue or topic they wished, 24 hours a day, 7 days a week. The researchers monitored the exchanges, but did not actively participate. Each of the participants' exchanges was recorded verbatim in chronological order by date and time, including any responses by other participants. The messages were de-identified and each person was assigned a number to protect the identity of all of the participants. There were a total of 591 exchanges among the 57 women.

The computer exchanges in "Koffee Klatch" were previously downloaded and entered into the computer program QSR NUD*IST (Qualitative Solutions and Research Pty Ltd, 1997) by the Women to Women research team. They used a general qualitative approach to analyze the computer exchanges. This method involved blending deductive and inductive analytic processes. There were three phases: deductive phase, inductive phase, and an integrative phase. The deductive phase consisted of converting the data into manageable categories. Multiple categories were identified, including loneliness. The

inductive phase involved looking for themes and patterns. The integrative phase entailed looking for relationships between and among themes and weaving them into a meaningful conceptual pattern. Validation of the analyses was obtained by having a research team member blinded to the first coding responding to a random sample of 10% of the coded segments (Winters, Cudney, Sullivan & Thuesen, 2006). Discrepancies were examined, code definitions were then revised. The process continued until there was 90% agreement among reviewers.

Content analysis was used to interpret the computer exchanges for the expression of loneliness. This technique is used to ferret out prominent themes and subthemes in narrative data (Polit & Beck, 2004). This investigator's analysis of the exchanges began with review of the items coded as loneliness by the WTW research team. In the vast amount of data that included all 57 participants' exchanges in the WTW study, only three exchanges had previously been coded as loneliness by the research team. A new review of the exchanges was executed using the following key words: loneliness, lonely and lonesome. Two exchanges included the term loneliness, and three contained the term lonely, zero exchanges included the term lonesome. Of the five exchanges, three were indirectly referred to in a poem. It was evident that loneliness was not directly addressed amongst the participants, indicating a need for a much more thorough search for subtle expressions. Therefore, a rigorous review of the data was performed, looking for references in the exchanges that could be representative of a woman's sense of loneliness.

Postings from the subset of the 12 women with high loneliness scores were accessed and analyzed deductively and inductively. There were three phases: deductive

phase, inductive phase and an integrative phase. The deductive phase necessitated reading each of the women's postings from start to finish, while vigilant for any sign of loneliness. Initially, all implied expressions, direct or indirect, were recorded. However, exchanges that did not seem to pertain to loneliness were ultimately withdrawn from the content analysis. The inductive phase involved reexamining all of the exchanges identified as pertaining to loneliness, this time assessing for themes or patterns. The integrative phase entailed a critical examination of the identified themes and patterns of loneliness, while attempting to capture the expression of it in a narrative form.

Searching for the terms "lonely" or "loneliness" provided very little insight into the phenomena of loneliness. For the most part, the women did not openly express feelings of loneliness or use the word "lonely." However, implied expressions of loneliness were uncovered during the review of the women's exchanges. The number of postings varied greatly among the women, as did the content. A summary of the number of postings made by each woman, the number that contained the word lonely or loneliness, and the number of exchanges identified that implied loneliness by participant may be found in Table 4.

Table 4. Loneliness Scores and Exchanges Related to Loneliness

Participant Code	Loneliness score	Total Number of Exchanges	Loneliness or Lonely in verse	Implied expressions of loneliness
1	52.00	97		3
2	52.00	112	1	3
3	54.00	4		0
4	54.00	10		2
5	57.00	40		4
6	57.00	4		1
7	59.00	15		2
8	59.00	8		0
9	61.00	16		0
10	61.00	9		0
11	64.00	218	2	5
12	68.00	58		3

Themes of Loneliness

Three prominent themes in the women's postings implied loneliness. These were longing for loved ones, "listening" in the background, and changing relationships. One other explanation of loneliness was identified, but it was experienced by just one person and appeared to be influenced by the effects of living in a rural community.

Longing for Loved Ones. There were eight postings related to yearning for family members. For one woman, it was missing a daughter who had moved. For another, it was a mother with Alzheimer's who had been moved to a nursing home. One participant wrote about her teenagers' birthdays, commenting on how fast they were growing up. Another participant's parents had passed away, she had no children, and she had a sister who lived "a mere 240 miles away." The following quotes demonstrate the loneliness two of the women were experiencing without actually stating it.

"I wish I could ride down and visit my daughter, but it wouldn't be fair to her having me along in the shape I'm in and my daughter is so busy right now that she wouldn't have time to visit much anyhow."

"My daughter [in another town] called and I told her I envied my mom's social life at the nursing home. She couldn't believe I would say something so sad. I didn't think it was sad at all. Just silly truth. I get to go see her once a week, but the drive is long for me and I hate to ask my husband anymore."

Changing Relationships. Another theme was identified that revealed trying times among the women and their spouses as well as siblings. There seemed to be detachment in some of the marital relationships or lack of support. One woman stated, "It is hard when you are married to someone who stays to themselves most of the time. I find that D. has changed a lot since we moved up here and I have to stay at home most of the time."

The women's illnesses appeared to be a factor that affected their relationships with their spouses and may have contributed to any loneliness the women experienced. For example one woman stated, "I think my disease frustrates my husband and so when I am not well he tends to stay away." When another woman tried to discuss her illness and what her future held her husband "just grumbled and walked away." One of the participants commented on how her relationship with her sister had been impacted by her illness: her sister had said to her, "You have everything wrong with you; I told her its part of my fibro."

Listening. Some women preferred to stand back in the shadows and listen. One such participant described herself as a “reader” who didn’t post much but loved listening and learning from others. Interestingly, this participant had the highest loneliness score of the subset and had one of the highest numbers of posts by the end of the project -- once she began to post, she did so frequently. In fact, at one point she stated, “Please keep writing. I mostly encourage others, but found that this is even powerful. Every time you write, a little more of you gets connected and you don’t feel so alone.” There was another woman who shared that, while she read most of the messages and enjoyed them, she really didn’t know what to say to the group and expressed her sadness by saying, “I cry pretty much about everything.” This revelation engendered a like response from another woman who said, “I also cry a lot and feel down in the dumps, so you are not alone.” The respondent encouraged her to stay in touch since she and her opinions and support were needed. However, this participant posted only four messages and was one of the two at the bottom of the group in regard to number of postings.

Rural Factors. Loneliness was influenced in at least one instance by the rural community to which the participant had moved with her husband. During the day, she was home alone except for her pets and felt like an outcast in the community because she had not been born or raised there. She stated, “What hurts me most is that when I go to the school and talk to the secretary she is very sweet, and when she is out of the school she will look the other way, and I have said hello to some of the other mothers and they turn away.”

Issues pertaining to rurality and loneliness did not appear to be a factor for the majority of the women in the subset. In a discussion that was pertinent to rurality and being homebound, one woman stated, “I guess for this group of women it is a good thing we like solitude and we do not mind our own company.”

Other Findings. While reviewing the postings for implied expressions of loneliness, it became evident that it was important to look at the big picture in regard to each participant’s postings. For instance, the woman who was having a difficult time adjusting to rural life was also having difficulty with her husband, and her child had been diagnosed with a life-threatening illness. Interestingly, she had posted two poems with references to loneliness, had the second highest UCLA loneliness score in the subset at 64.00, and had posted 218 times -- nearly double that of the next highest number of postings at 112.

The participant with the second highest number of postings at 112 had a loneliness score, of 52, which, was one of the lowest in the subset of 12 participants but was high compared with the total group. She was estranged from her mother and brother, secondary to her illness. The tenor of her postings was a possible reflection of her manner of dealing with her feelings: “People are like pressure cookers, they have to have a relief valve somewhere especially if you are a person who tends to keep things inside and left unsaid.”

Two postings contained the word “loneliness” in text that was not in a poem. In one, a woman wrote of loneliness as though it were an understood part of all of their

lives: “Hopefully with the change of the season we can all have a change in our loneliness.” Loneliness, in this instance, was written more as an afterthought than a direct expression of the feeling or experience of it. The other time the term “lonely” was actually written was in a response to another woman. It read: “I also cry a lot and feel lonely and not wanted, but that’s just me.”

Summary

The purpose of this study was to explore the phenomenon of loneliness as experienced by women with chronic illnesses living in rural areas. Analysis began with the evaluation of the participants’ scores in regard to loneliness, depression, stress and social support. A correlation matrix was used to ascertain which variables were significantly correlated with loneliness, in this study all of them highly correlated with loneliness. Multiple regression was used to help identify what the effects of the psychosocial and selected demographic variables would have on loneliness.

Analysis of loneliness as it was expressed in the online forum provided a firsthand look at how it was experienced by the women in their day-to-day lives. The correspondence among the women was rich, “family” like relationships developed over time among several participants. Discussions varied widely from light hearted subjects to intimate discussions. Loneliness was somewhat elusive, and very few times was the term actually used. The women whose postings were reviewed were selected because they were determined to be the most vulnerable to loneliness. Careful review of their

correspondence revealed the presence of loneliness. The experience and expression of loneliness was unique to each individual.

DISCUSSION

Loneliness has been described as an agonizingly painful experience. All people are affected by it at sometime in their lives, but the severity differs greatly. There is no concrete set of risk factors for loneliness; in fact it is so ambiguous that a universal definition is not available. Loneliness is easy to dismiss because of the difficulty identifying it, the shame associated with reporting it, and the difficulty resolving it. Conditions associated with loneliness, such as depression, have generally overshadowed loneliness. Depression has become more acceptable in our culture; it has been identified as an illness that is treatable with medication and or counseling. However, the identification of loneliness is elusive, and it is not amenable to medicinal treatment--although some would argue that the experience of it is just as painful as depression. There is no easy solution, but an exploration of the day-to-day lives of people experiencing loneliness has provided further insight into the mystery of the phenomenon. Some people experience loneliness even when family and friends surround them. What makes some people more susceptible to loneliness is of interest. A research study, the Women to Women Project, has positively impacted the lives of chronically ill women in rural areas. The WTW team provided women with computer support that encouraged online communication among women. The researcher of this study on loneliness worked with the principal investigator and other members of the WTW team. She was fortunate and benefited from collaborating with the team who collected the data used in her research study on loneliness.

Unraveling the mystery of loneliness began with the examination of depression, stress, and social support. Each was closely associated with loneliness. More than half of the participants were somewhat depressed, and some readily discussed this in the online forum. This is consistent with the findings of previous researchers who have identified links between loneliness and depression in adults (Heinrich & Gullone, 2006; Jackson & Cochran, 1990; Kara & Mirici, 2004; Nolen-Hoeksema & Aherns, 2002).

Loneliness involves the social domain of one's life, whereas depression is more global and heterogeneous, involving multiple areas of a person's life (Boiven, Hymel, & Bukowski, 1995; Heinrich & Gullone, 2006). Depression and loneliness are both strong factors that influence a person's perceived low quality of life (Mullins & Dugan, 1990). The overlapping nature of loneliness and depression is an important concept for nurses to remember. Clients may report that they are feeling sad or depressed, and it would be natural to attribute these feelings to the patient's illness and change in life roles. Loneliness may not be something that is on the nurse's radar; however, it is distinct from depression and needs to be identified and addressed. Treating depression in and of itself will not address the painful gap that loneliness has caused in the person's life.

Women with chronic illness are also affected by the stressful situations that their condition causes, such as managing day-to-day tasks or from financial burdens, such as paying for their medications or medical bills. The women's illnesses not only affected them physically but it also affected their relationships with others from their spouses to children to extended family and friends. The women in this study were not under particularly high levels of stress; however, their stress was related to loneliness. Stress

can be caused by many different factors, therefore, it is another risk factor for the nurse to keep in mind when assessing a person for the presence of loneliness.

Social support has been explored in the literature, and it is believed to have a direct link to loneliness. Pioneer researchers in the area of loneliness have stressed the importance of intimacy in people's lives, and that deficiencies in intimacy may result in loneliness (Carnevali, 1986; Verwoerdt, 1976; Weiss, 1973). In the Women to Women study, social support was seen as an important factor in the reduction of loneliness. Some women spoke highly of their social support contacts, such as supportive spouses, family, and friends. Conversely, other women's social support systems didn't translate into therapeutic support. Some of the women noted that, when they were not feeling well, their husbands changed. Specifically, the men seemed to distance themselves from their wives, and tended to avoid conversations related to the women's illnesses and the associated long-term implications. Peplau & Perlman (1982) reported that decreased satisfaction with relationships, or deprivation of human intimacy, could lead to loneliness. The mere presence of people in the women's lives was not sufficient to support their overall well-being -- the quality of their relationships was of utmost importance.

Additional factors thought to influence a person's experience of loneliness were examined. They included age, employment status, education, degree of rurality, and length of chronic illness. Neither age nor employment status had any significant predictive effect on whether or not the women in the study were lonely. This outcome was unexpected because it was thought that reporting to a job each day would decrease

social isolation. Consequently, no insight into the antecedents of loneliness was obtained from examining the effects of these variables.

However, the analysis of the relationships of loneliness to education, degree of rurality and length of chronic illness proved more fruitful. An unexpected finding was that women with more education had a tendency to be lonelier than women with lesser amounts of education. This was difficult to explain because it might be expected that people with higher levels of education would generally have more resources and, as a result, better coping mechanisms. Thus, the influence of education on loneliness is an area that requires further research. An intriguing study would be to further examine the relationship between education and loneliness as well as to explore the effects of education on lonely women by including them in discussions on loneliness.

The women in this study lived in rural areas; however this was not a factor that contributed to the loneliness experienced by the women. Some of the women lived in very isolated areas. Some were isolated and spent a significant amount of time alone while their spouses were working. Others were around people in small towns—but were seen as outsiders by the locals. Living in a rural location was described by one of the women as a voluntary choice. This research supported the findings of past researchers; there was no relationship between loneliness and rurality. This is an important finding to consider because factors influencing the occurrence of loneliness are not reliant on a person's physical location or environment. Nurses should not assume that a client's rural living arrangement would make them more susceptible to loneliness. It appears that a rural location has little effect on the experience of loneliness. What is not clear are what

factors are associated with loneliness for some women and not others. A comparison of rural and urban women who are lonely may aid in the identification of characteristics that impact loneliness.

The length of time a woman lived with one or more chronic illnesses was a factor that influenced the women's perception of loneliness. Women who had lived with their condition longer were not as lonely as those who had their illnesses for a shorter period of time. The longer a woman lived with her illness, the better she was able to adapt to the changes the illness imposed. This may be because the women had adjusted to the changes in their lives and roles and had accepted them. Rokack (1998) reported on the six stages of loneliness; the latter two were acceptance and coping, indicating that acceptance was a prerequisite for the last stage of coping. Once people have reached the stage of coping, they have accepted their loneliness and have found strength within themselves realizing their ability to survive despite the challenges associated with loneliness.

Time is a factor to consider with women living with life altering conditions. Nurses should be aware that loneliness often occurs because of the significant changes it imposes in a person's life, and time will be needed to allow for adaptation and acceptance of the new role. One way nurses can support clients during the initial stages of a lifelong condition is to let them know that loneliness is a feeling felt by many people in similar circumstances; however, it is known to reduce with time.

Perhaps the most important factor associated with loneliness in this research was in regard to the most vulnerable group of women to loneliness. Although each of the women was lonely their presentation of loneliness was unique. The women's unsolicited

exchanges were reviewed in detail and provided a window into their day-to-day lives. Loneliness was not a topic of conversation among the women even though their responses on the UCLA Loneliness measure indicated that they were very lonely. Some women were talkative in the online forum, and did not make obvious statements that indicated that they might be lonely. Other women who were also talkative, more readily expressed frustrations they were experiencing; however, loneliness was not directly expressed. This is consistent with data reported by Carnevali (1986) that threatening and alienating features of loneliness may evoke a denial response. People who experience loneliness acutely are unable to talk about it during or even after the episode. The greater the people's sufferings are, the more obscure and disguised their complaints become (Carnevali, 1986). Also the stigma associated with loneliness may cause people to be reluctant and embarrassed to admit that they are lonely (Peplau & Perlman, 1982).

Limitations of this research included the small sample size and time constraints. In addition, because a secondary analysis was conducted the investigator was limited to data that had been previously collected. This research study was also limited in regard to the analysis of the women's conversations, which was conducted solely by the investigator of this study on loneliness. Careful consideration was given in regard to the review of loneliness in the narrative discussions. However, it is possible that an important indicator of loneliness was omitted.

Important information was identified in this study that would be of value to nurses caring for chronically ill patients in rural and non-rural communities or locales. An important message to be captured from this research is that the women in this study were

very lonely by self-report on a questionnaire, but in their day-to-day lives it was not directly discussed or addressed with the other women in the study. Therefore, it is crucial for nurses or other allied health professionals to pay close attention to cues from their clients. Each client's presentation or expression of loneliness will differ. For example, some are talkative and cheerful; in these instances it would be beneficial to assess the client's overall risk factors for loneliness, to determine if the cheeriness is genuine. Risk factors include depression, stress levels and amount of social support. Clients with increased levels of stress, perhaps from the financial burden of their medications, are at risk for loneliness. In this scenario, the nurse could act as a client advocate in assisting them to pursue all avenues to obtain medication, thereby reducing their stress, which may in turn reduce loneliness. Nurses are in a unique position to observe loneliness cues and focus clients toward recognition of loneliness, investigating the cause of loneliness and propose implementation of interventions directed at the resolution of that loneliness.

This study did not address effective interventions for loneliness. However, an obvious intervention confirmed in this study was social support. The researcher's data analysis results revealed that people who had social support were not as lonely as those with less social support. Nurses have the ability to evaluate the person's social support network and recommend strategies to strengthen that support, especially in regard to intimate contacts.

The nurse must be a bit of a sleuth and be alert for signs of loneliness, which will be challenging for the nurse or allied health professional because the presentation of loneliness will differ from person to person. Loneliness is a very painful experience and

warrants attention from healthcare professionals. When a woman presents for healthcare and has had a chronic illness for a short period of time, be alert for other risk factors such as being highly educated, depressed, experiencing stressful circumstances, and having poor relationships. Providing holistic care for women with a chronic illness includes addressing loneliness, which usually occurs beneath the surface; however, it is necessary to assist women in adapting to the changes in their lives that the illness had imposed. The mystery of loneliness remains unsolved, however further research and awareness of it will lead to positive changes in the lives of women.

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APPENDICES

APPENDIX A

DEMOGRAPHIC CHARACTERISTICS

Appendix A: Demographic Characteristics

Characteristic		Frequency
Age in years		
37 to 39		7
41 to 49		10
50 to 59		32
60 to 65		8
Mean 52.7	Median 50	
Race		
White		55
American Indian		1
More than one race		1
Marital Status		
Married		50
Divorced		2
Separated		1
Widowed		1
Never Married		3
Years of school completed		
12		10
13		10
14		12
15		4
16		6
17		8
18		6
20		1
Mean 14.69	Median 14.00	
Income		
Less than $15,000		9
$15,000 to 24,999		8
$25,000 to 34,999		9
$35,000 to 44,999		11
$45,000 to 54,999		9
$55,000 to 64,999		4
$65,000 to 74,999		5
$75,000 to 84,999		2

APPENDIX B

UCLA LONELINESS SCALE

A

Appendix B: UCLA Loneliness Scale

For each statement, please indicate how often you feel the way described by **CIRCLING** the number that best measures how you feel.

	Never	*Rarely*	*Sometimes*	*Always*
1. How often do you feel you are "in tune" with the people around you?	1	2	3	4
8. How often do you feel your interests and ideas are not shared by those around you?	1	2	3	4
9. How often do you feel outgoing and friendly?	1	2	3	4
10. How often do you feel close to people?	1	2	3	4
11. How often do you feel left out?	1	2	3	4
12. How often do you feel your relationships with others are not meaningful?	1	2	3	4
13. How often do you feel no one really knows you well?	1	2	3	4
14. How often do you feel isolated from others?	1	2	3	4
15. How often do you feel you can find companionship when you want it?	1	2	3	4
16. How often do you feel there are people who really understand you?	1	2	3	4
17. How often do you feel shy?	1	2	3	4
18. How often do you feel people are around you but not with?	1	2	3	4
19. How often do you feel there are people you can talk to?	1	2	3	4
20. How often do you feel there are people you can turn to?	1	2	3	4

APPENDIX C

CES-D

Appendix C: CES-D

This series of questions is about your feelings and how often you experienced them in the past week. Answer each question, but do not spend a great deal of time on any one question. Please **CIRCLE** the appropriate response.

In the past week:	*Rarely or none of the time (less than 1 day)*	*Some or little of the time (1-2 days)*	*Moderate amount of the time (3-4 days)*	*Most or all of the time (5-7 days)*
1. I was bothered by things that usually don't bother me.....	1	2	3	4
2. I did not feel like eating; my appetite was poor	1	2	3	4
3. I felt that I could not shake off the blues, even with help from my family or friends	1	2	3	4
4. I felt that I was just as good as other people	1	2	3	4
5. I had trouble keeping my mind on what I was doing	1	2	3	4
6. I felt depressed	1	2	3	4
7. I felt that everything I did was an effort	1	2	3	4
8. I felt hopeful about the future	1	2	3	4
9. I thought my life had been a failure	1	2	3	4
10. I felt fearful	1	2	3	4
11. My sleep was restless	1	2	3	4
12. I was happy	1	2	3	4
13. I talked less than usual	1	2	3	4
14. I felt lonely	1	2	3	4
15. People were unfriendly	1	2	3	4
16. I enjoyed life	1	2	3	4
17. I had crying spells	1	2	3	4
18. I felt sad	1	2	3	4
19. I felt that people disliked me	1	2	3	4
20. I could not "get going"	1	2	3	4

APPENDIX D

PSS

Appendix D: PSS

This series of questions asks you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, do not try to count up the number of times you felt a particular way, but rather indicate the response alternative that seems like a reasonable estimate. **CIRCLE** the response most appropriate to you.

	Never	*Almost Never*	*Sometimes*	*Fairly Often*	*Very Often*
1. In the last month, how often have you been upset because of something that happened unexpectedly?	1	2	3	4	5
2. In the last month, how often have you felt that you were unable to control the important things in your life?.....	1	2	3	4	5
3. In the last month, how often have you felt stressed or nervous?.....					
4. In the last month, how often have you dealt successfully with irritating life hassles?.....	1	2	3	4	5
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	1	2	3	4	5
6. In the last month, how often have you felt confident about your ability to handle your personal problems?	1	2	3	4	5
7. In the last month, how often have you felt confident that things were going your way?	1	2	3	4	5
8. In the last month, how often have you found that you could not cope with all the things that you had to do?	1	2	3	4	5
10. In the last month, how often have you felt that you were on top of things?	1	2	3	4	5
11. In the last month, how often have you been angered because of things that happened that were outside of your control?	1	2	3	4	5
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?	1	2	3	4	5
13. In the last month, how often have you been able to control the way you spend your time?	1	2	3	4	5
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	1	2	3	4	5
15. Overall, you would describe your CURRENT life as:	1	2	3	4	5

16. Do you think there is anything you personally should do to improve the way you cope with stress?

__ Yes

__ No (If you answered no, please go to page 5)

17. If you answered YES to # 16, what is the most important thing you think you should do to cope with stress? (CIRCLE ONLY ONE)

1. Exercise more
2. Learn to relax, worry less
3. Get out more often, make new friends, socialize
4. Change jobs, move, leave home, change situation
5. Reduce drug/medication use
6. Reduce alcohol use
7. Spend more time with family and close friends

18. What is stopping you from doing this? (CIRCLE ALL THAT APPLY)

1. Nothing
2. Problem not serious, no urgency
3. Lack of time
4. Lack of self discipline
5. Too depressed
6. Don't know how to get started; lack knowledge
7. Peer pressure
8. Lack of support from family or friends
9. Don't want to change current habits
10. Too difficult
11. Too costly

APPENDIX E

PRQ 2000

Appendix E: PRQ2000

Below are some statements with which some people agree and others disagree. Please read each statement and **CIRCLE** the response most appropriate for you. There is no right or wrong answers.

	Strongly Disagree	*Disagree*	*Somewhat Disagree*	*Neutral*	*Somewhat Agree*	*Agree*	*Strongly Agree*
1. There is someone I feel close to who makes me feel secure....	1	2	3	4	5	6	7
2. I belong to a group in which I feel important.....	1	2	3	4	5	6	7
3. People let me know that I do well at my work (job, homemaking)	1	2	3	4	5	6	7
4. I have enough contact with the person who makes me feel special	1	2	3	4	5	6	7
5. I spend time with others who have the same interests that I do.....	1	2	3	4	5	6	7
6. Others let me know that they enjoy working with me (job, committees, projects).....	1	2	3	4	5	6	7
7. There are people who are available if I need help over an extended period of time.....	1	2	3	4	5	6	7
8. Among my group of friends we do favors for each other.....	1	2	3	4	5	6	7
9. I have the opportunity to encourage others to develop their interests and skills	1	2	3	4	5	6	7
10. I have relatives or friends that will help me out even if I can't pay them back.....	1	2	3	4	5	6	7
11. When I am upset, there is someone I can be with who lets me be myself	1	2	3	4	5	6	7
12. I know that others appreciate me as a person.....	1	2	3	4	5	6	7
13. There is someone who loves and cares about me.....	1	2	3	4	5	6	7
14. I have people to share social events and fun activities with..	1	2	3	4	5	6	7
15. I have a sense of being needed by another person.....	1	2	3	4	5	6	7