

Experiencing Co-Occurring Mental Health and Substance Misuse Disorders:

The Voices of Rural Older Adults

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Dedication

I dedicate this dissertation to Paige, Sophia, Nicolas, Chase, Grace, Zoe, Gavin, Caitlin, and Jocelyn for making me laugh and reminding me of that which really matters.

Abstract

This exploratory qualitative study investigated the perspectives of rural older adults who experience co-occurring mental health and substance misuse disorders. These disorders co-occur frequently and have serious consequences. Risk and protective factors have been identified for older adults with co-occurring disorders. A treatment model addressing the specific needs of rural older adults with co-occurring disorders has not been developed. The literature does not reflect the views of rural older adults about their experiences with these disorders, treatment, or recovery.

Critical theory was employed to examine the inattention to co-occurring disorders in rural older adults. Resilience theory facilitated understanding participants' strength in coping with these disorders. Grounded theory was used to develop theory throughout the exploration and analysis of rural older adults' perceptions of their experiences.

Data consisted of in-depth qualitative interviews collected from older adults living in rural Iowa who identified as having co-occurring disorders. Interviews with 23 older adults ages 55 to 90 living in rural Iowa explored their perceptions of experience with co-occurring disorders; the responses of family, providers, and community; treatment and recovery; and policy issues.

The analysis reveals that older adults experience multiple individual, community, and structural service risks to develop co-occurring disorders. Individual resilience, supportive relationships, and treatment lead to recovery.

The treatment model developed from the analysis focuses on principles of treatment; prevention that provides information for individuals, family, community, and

providers; and integrated treatment that includes older adult role models, responds to the needs of older adults, and is accessible to those living in rural communities.

The study concludes that in spite of risks and lack of appropriate prevention and treatment, rural older adults with co-occurring disorders exhibit resilience that can be supported through culturally relevant prevention and treatment. Barriers and risks need to be addressed at individual, community, and service structure levels. Stigma about co-occurring disorders, age, and rural communities contributes to the absence of appropriate services. Implications for social work education and practice, policy, and research are noted.

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Chapter 1: Introduction and Overview

The purpose of this chapter is to introduce the dissertation topic of co-occurring mental health and substance misuse disorders as they manifest in older adults living in rural communities. The chapter begins with a brief background of the issue followed by the problem statement, the purpose of the study, and the research questions. The chapter concludes with an overview of individual dissertation chapters in an effort to connect individual chapters into an entirety. The dissertation ends with a proposed practice model for treatment of rural older adults with co-occurring disorders that is based on their perspectives.

Background and Significance

In order to understand the basic concepts of rural older adults who experience co-occurring disorders, each aspect is first considered individually. The knowledge base for co-occurring disorders, disorders as they manifest in older adults, the role of the rural community, and the function of stigma are briefly described.

Co-occurring disorders. As many as 19% of persons over age 65 or almost eight million older adults may experience co-occurring disorders (Center for Substance Abuse Treatment [CSAT], 2007d; Substance Abuse and Mental Health Services Administration [SAMHSA], 2010). Co-occurring disorders are defined as a person having at least one mental health disorder and at least one substance abuse disorder at the same time (CSAT, 2006a). Substance misuse among people with mental health disorders has been documented since the 1800s (McKinley, 2000). While dimensions of the problem, effects, and treatment approaches have progressed, causes of co-occurring

disorders remain unknown. No theory adequately explains co-occurring disorders. The theory that currently garners the most support to explain co-occurring disorders focuses on substance misuse disorders following mental health disorders (Kessler, 2004; CSAT, 2007c).

As modern society acquired an understanding of mental health and substance misuse issues, treatment programs and approaches developed separately as did policy and administration. This left those who experienced co-occurring disorders to navigate a maze of agencies that conflicted in treatment philosophies and often refused to assist the person because of the co-occurrence of disorders (SAMHSA, 1998).

The federal government first acknowledged co-occurring disorders in 1970 legislation and by 1982, co-occurring disorders were identified as a major problem. In 1992, the federal government formed Substance Abuse and Mental Health Services Administration in response to the need to recognize the co-occurrence of mental health and substance misuse disorders and to develop research, policy, and treatment that addressed this combination of disorders (SAMHSA, (1998).

Principles of treatment for people with co-occurring disorders include integrated care where providers take responsibility for providing combined mental health and substance misuse services to the client (CSAT, 2007b). Stages of change are recognized and a stage approach to recovery is used. Assertive outreach, emphasis on engagement, and motivational interventions emphasize starting where the person is. Best treatment is individualized to meet the needs, goals, and perspectives of individuals from diverse cultures who are in various stages of change (CSAT, 2006c; Drake et al., 2001).

Collaborative work between primary care, aging, and behavioral health providers is especially important for older adults who are less likely to be seen in behavioral care facilities (SAMHSA, 2002).

Older adults. Co-occurring disorders may begin at any age and it is increasingly recognized that many disorders start in childhood (Kessler, 2004). Disorders may also begin during older adulthood and disorders that went into remission may reactivate in later years (CSAT, 1998). Older adults who have recovered from co-occurring disorders may need support services to sustain recovery (SAMHSA, 2002).

The perspectives of older adults about experiencing co-occurring disorders while living in rural communities are not found in the literature. Research and treatment have often focused on young urban adults with severe co-occurring disorders and other populations including rural older adults have received little attention. While research on older adults with individual mental health or substance misuse problems is being conducted, co-occurring disorders are a singular condition. Rural older adults with co-occurring disorders require a culturally relevant treatment approach that recognizes co-occurring disorders, age-related issues, and a rural context. However, older adults are nearly invisible in research and development of services for co-occurring disorders (U.S. Department of Health and Human Services [U.S. DHHS], 2002).

Rural communities. Resources and culture interact to make rural communities resilient in unique ways. Rural communities include members who retain a willingness to assist those in need and support systems are frequently long lasting and strong.

Individuals who experience problems are more likely to approach informal than formal resources (Krout, 2003; Porter, 1998; Summers, 1998).

Rural communities also face numerous challenges. Public transportation is frequently absent or undersupplied while poverty, age, and co-occurring disorders may interfere with individual ability to arrange transport. Rural communities are diverse requiring flexible approaches to services including those for co-occurring disorders. Supports for jobs, housing, and other material resources are often missing or inadequate, and absence of assistance for other needs may increase the risk to develop co-occurring disorders. Policy and practice guidelines are usually developed by and for urban communities that can incorporate economy of scale unavailable in rural communities. Rural values that include attitudes of individual responsibility and preference for use of informal sources may leave the need for co-occurring disorder services unseen. (Bellamy, Goins, & Ham, 2003; CSAT, 2009a; Kerschner, 2003; Krout, 2003).

Stigma. Stigma interferes with developing appropriate services for rural older adults with co-occurring disorders. Stigma about co-occurring mental health and substance misuse problems inhibits asking for help, provision of information, and development of services. Older adults also experience stigma related to age. Older adults with co-occurring disorders often find that misinformation and stigma related to both age and co-occurring disorders is particularly intense in rural communities. Policy is developed for urban areas leaving rural societies to struggle to meet requirements that do not fit their needs. Stigma related to co-occurring disorders, age, and rural

communities combine to make identification of need and provision of services challenging (Bellamy et al., 2003; Brown, 2003; Bull, 2003).

The Impact of my Experience on this Study

Rural experiences. I grew up in a rural community and as an adult have lived and worked in both rural and urban Midwestern communities. When I returned to a rural community after my first urban experience, my awareness of differences in rural and urban culture increased, and I observed how culture was specific to rural communities, as well as to broad rural and urban areas. I became aware that change needed to be gradual, a practice that was initially related to survival, continued in the form of skepticism of new ideas, practices, and people. I noticed that my level of comfort was higher with people who had grown up in rural communities regardless of where we were living at the time. Our values of connection to the natural environment, recognition of interdependence with others, respect for privacy, and expectation of personal responsibility to fulfill needs were more often similar than values of persons who grew up in urban communities.

Mental health and substance misuse experiences. I interacted with people with mental health problems from early childhood although it was not until years later that I could name these problems. When family and personal problems occurred in rural communities, no one talked about mental illness or substance misuse problems. The value of personal responsibility was too strong to consider the possibility of a disorder affecting behavior. I watched community members assist grieving families through helping with funerals, providing food, and assisting with necessary tasks. Privacy was given in the form of not openly asking questions or discussing such events.

As long as people kept their disorders out of public view, their privacy was usually respected. However, if someone engaged in inappropriate public behavior, they were teased and mocked in an effort to enforce unwritten community rules. This provided another lesson about the importance of privacy in rural communities.

I worked at a state mental institute as a psychiatric technician during college. While I learned a good deal about mental health disorders, there was no opportunity to process the experiences. My initial response was to avoid mental health work. However, during a mental health internship in graduate school, I had the opportunity to process client mental health and substance misuse problems. I started to develop an understanding of the disorders, and began to learn ways to bring about change. It was then that I understood the value of addressing mental health and substance misuse problems rather than hiding them. It was also during this internship that I began to see the interaction of mental health and substance misuse issues although no one talked about co-occurring disorders.

It was common to see mental health and substance misuse problems interact throughout my work in outpatient and inpatient mental health settings. Responses varied among agencies and personnel. Several of these agencies used approaches where practitioners who specialized in mental health or substance misuse respected each other's knowledge and abilities, shared expertise and perspectives to develop treatment plans, and were willing to work together in the best interest of the client. Other agencies and practitioners were less flexible in their approach to co-occurring disorders. I watched clients struggle with the expectation that they could set aside one disorder while receiving

treatment for the other. They frequently failed. Too often they were labeled as being unmotivated for treatment. It seemed to me that the disorders often went hand in hand and needed to be addressed at the same time.

Experiences with older adults. I have interacted with older adults all my life through family, community, and practice. My undergraduate advisor was in her 60s when I first met her. While she retained a good deal of the privacy and self-sufficiency of rural people, she also looked at and talked about aging experiences objectively. Listening to her describe her aging process helped me understand what aging may mean to an individual.

During my work in mental health facilities, I saw relatively few older adults. Some supervisors understood aging issues and helped me figure out how to work with older adults. One supervisor refused to admit older adults to services, believing that they could not handle the demands of the program. No facility in which I worked had services designed for older adults. Some of the older adults needed more services than my agencies provided. When we did not have enough resources to see all the people who needed services, there was an unspoken bias toward serving younger people.

Development of this study. I explored the development of mental health services in a Midwestern state during my doctoral history class, and I became aware of co-occurring disorders as an area of practice and policy. The idea of integrated treatment for people with co-occurring disorders was practical and seemed logical. I was fascinated to learn how program and policy development separated assistance for mental health and substance misuse and challenged rural practice settings to provide integrated treatment.

The National Comorbidity Survey of 1990-1992 did not gather data on people older than 54 based on earlier study findings that persons older than 54 were unlikely to experience substance misuse and therefore co-occurring disorders (Kessler, 1994). My practice had provided practical knowledge of older adults who used substances, often in response to mental health issues. I brought together my interest and experience in rural communities, mental health and substance misuse, and older adults to develop my dissertation. Because there was so little knowledge of rural older adults with co-occurring disorders, a qualitative study using a grounded theory approach seemed like the best way to address the issue.

I began this study with several assumptions. I made an effort to maintain awareness of these suppositions throughout my study to keep my biases from affecting the study. The assumptions I identified are as follows:

1. Age may play a role in development of co-occurring disorders as well as their prevention and treatment.
2. Risk and protective factors may be significant in the development of and recovery from co-occurring disorders.
3. The time of onset of the disorders may affect the experience of the disorder.
4. Particular disorders may have different impacts on the older adult's experience of co-occurring disorders.
5. Older adults who experience chronic disorders may have a different experience from those who experience acute disorders.

6. Gender, race and ethnicity, social class, sexual orientation, status of citizenship, and other unidentified factors may affect the experience of co-occurring disorders.
7. Rural residence may impact the experience of older adults in the development, identification, and treatment of co-occurring disorders.
8. Structural factors may affect older adults' experience of co-occurring disorders.
9. The attitudes of older adults may impact their experience of co-occurring disorders.
10. Provider attitudes may affect older adults' experience of co-occurring disorders.
11. Recognition of resilience may play an important part in developing a model for prevention and treatment of co-occurring disorders for older adults.

Problem Statement

While information about older adults' risk and protective factors for co-occurring disorders have been identified, much is left to discover about how co-occurring disorders, older adults, and rural communities interact. Little is known about how rural older adults view their experience of co-occurring disorders and what they believe is needed to assist them with these disorders. Without an understanding of rural older adults' perceptions of their disorders and requirements, services that develop may not meet their needs.

Purpose of this Study

Given the lack of knowledge of rural older adults with co-occurring disorders, the purpose of this study was to explore their experience. The absence of the perspective of older adults led to the goal of understanding how older adults view their experience of co-occurring disorders and the impact of living in a rural community. Important aspects

of the experience include how risk for the disorders develops including personal, rural community, and structural barriers. Personal and contextual resiliencies and supports that assist the person to recover from these disorders are important to identify. Knowledge of how rural older adults view their experiences of co-occurring disorders and the dynamics of the individual, the social support system, the community, and service structures can assist development of appropriate and culturally relevant practice interventions.

Research Questions

The paucity of knowledge about older adults with co-occurring disorders who live in rural communities and the absence of their own perspectives in the literature form the basis for this study. This dissertation focused on using the perceptions of rural older adults with co-occurring disorders to develop an understanding of their experiences using the following questions:

- 1) How do rural older adults view their experience of co-occurring disorders?
- 2) What do older adults living in rural communities experience relative to treatment of their co-occurring disorders?
- 3) What do older adults living in rural communities experience relative to policy that affects their treatment for co-occurring disorders?

Overview of the Dissertation

This overview provides a brief synopsis of the information that is found in each chapter. The goal of these summaries is to assist the reader to connect the chapters that together address the research questions.

Chapter two reviews the literature on older adults living in rural communities who experience co-occurring disorders. The literature review is not comprehensive in its coverage of these concepts. Rather, the review focuses on what is known about the interaction of co-occurring disorders, older adults, and rural communities.

Chapter three provides the theoretical framework for the study. Critical theory was employed to create a framework with which to analyze the inattention to co-occurring disorders in rural older adults. Resilience theory was added to the theoretical framework to understand the participants' strengths as they dealt with disorders and neglect of their needs.

Chapter Four presents the methodology used in this study and provides a rationale for the qualitative method and use of grounded theory. The chapter includes sampling process, sample strengths and limitations, ethical issues, and discussion of the instruments used in the study. Data collection, data analysis, and data validation are described. Strengths and limitations of the study are included. The goal of this chapter is to demonstrate the systematic procedures and process of conducting this qualitative study.

Chapters five through eight present the findings of the study. Chapter five describes the participants. Chapter six identifies risk factors communicated by participants while chapter seven portrays barriers to help encountered by participants. Chapter eight presents protective factors and resilience recognized by participants. Participant ideas were organized into concepts and narrative quotations illustrated their views.

Chapter nine discusses the two major themes that are identified from the findings.

The theme, there are multiple paths to co-occurring disorders is described relative to the interaction of individual, rural community, and structural risk factors. The theme, there are multiple paths to recovery, identifies paths of people are more than their troubles, personal resourcefulness, acknowledgement of co-occurring disorders, accepting help, revitalization through helping others, and it is never too late for recovery and revitalization.

Chapter ten provides a model for assisting older adults with co-occurring disorders that is based on participant ideas. These ideas include increasing prevention by expanding knowledge and understanding of co-occurring disorders throughout rural communities, decreasing stigma and discrimination, and improving assistance for co-occurring disorders and other problems that enlarge risk for co-occurring disorders. The resulting model focuses on principles to assist rural older adults with co-occurring disorders and provide appropriate prevention and treatment.

Chapter eleven presents the major conclusions of the study. Social work, policy, and research implications are included.

Chapter 2: Literature Review

This literature review examines the current understanding of co-occurrence of mental health and substance misuse disorders in older adults living in rural communities in the United States. It begins with an overview of co-occurring disorders and then considers factors specific to older adults who experience these disorders. Rural concerns that affect older adults and their treatment are reviewed. Major treatment issues are examined. The review ends with unanswered questions that lead to this study.

The review of the literature occurred before, during, and after the completion of gathering the data. This allowed for the interaction of the literature, the data collection, and my own thoughts (Charmaz, 2006; Patton, 1990; Strauss & Corbin, 1998). Prior to data collection, I reviewed literature that seemed relevant to the research question. As I collected data, I found that I was hearing about ideas that I had not fully considered prior to beginning the research interviews. After I completed the interviews, I recognized that there were additional ideas that I needed to understand more completely. This process of reviewing the literature provided the best way to understand the issue of rural older adults with co-occurring disorders and discover where my findings were relevant.

Co-Occurring Disorders in the United States

Recent studies indicate that five to 10 million adults in the United States experience co-occurring mental health and substance misuse disorders in any given year (CSAT, 2007d; SAMHSA, 2010). Co-occurring disorders are defined as having at least one mental illness disorder and at least one substance misuse disorder that coincide. These disorders can be diagnosed independently and are not a cluster of symptoms resulting from a single disorder (CSAT, 2005, 2006a). The difficulty of accurately

determining that the disorders are independent has led to the use of a service definition. This definition includes individuals who have an established diagnosis of one disorder with symptoms evolving into the other disorder, individuals who have resolved symptoms of one or the other diagnosis, and individuals with a unitary disorder and acute symptoms of a co-occurring disorder (CSAT, 2006a). The Co-Occurring Center for Excellence recommends use of this service diagnosis for program and system planning since individuals within these categories may require the same range of services as those who meet the criterion that both conditions were established independently (CSAT, 2006a).

Epidemiology. About half of the United States population will experience at least one mental health or substance misuse disorder within their lifetime and the first onset is usually in childhood or adolescence (Kessler, Berglund et al., 2005). Of the 45 million adults with a mental illness in 2009, over 19% or nearly nine million experienced a co-occurring substance misuse disorder according to the 2009 National Survey on Drug Use and Health (SAMHSA, 2010). The same study found that nearly 43% or about nine million of the almost 21 million adults with a past-year substance misuse disorder experienced a co-occurring mental illness in 2009 (SAMHSA, 2010). Regardless of whether the first diagnosis was a mental health or substance misuse disorder, having one disorder increased the risk to develop a co-occurring disorder (SAMHSA, 2010).

Rates of co-occurring disorders were higher among some populations. Nearly 26% of the five to seven million adults with a serious mental illness experienced co-occurring disorders (SAMHSA, 2012). This estimate is considered to be very

conservative as it included only those with serious mental illness and did not include persons who were incarcerated, lived in long-term care institutions, currently served in the military, or did not speak English (CSAT, 2007d). Studies conducted in mental health and substance-use disorder settings found that up to 75% of clients had lifetime co-occurring disorders (CSAT, 2007d).

Other factors may affect findings about co-occurring disorders. Some studies did not survey hospital or prison populations, which eliminated a proportion of groups that are likely to experience high rates of co-occurring disorders (Grant et al., 2004). Most of the studies supporting the findings were small, were often convenience samples, and defined co-occurring disorders differently (Kessler, Chiu et al., 2005; CSAT, 2007d). Some studies may leave out the one third of cases that are considered mild (Kessler, Chiu et al., 2005).

Etiology. The etiology of co-occurring disorders is unknown (CSAT, 2006c). One disorder may cause the other, a third condition may cause both disorders, or the co-occurrence may be coincidental (CSAT, 1994; Drake, McLaughlin, Pepper, & Minkoff, 1991). Given the limited knowledge about causes, many researchers and clinicians believe that it is best to consider both disorders as primary (CSAT, 2006a; Drake et al., 2001; Minkoff, 2001) and recognize that subgroups may experience co-occurring disorders for different reasons (Mueser, Drake, & Waller, 1998).

Current co-occurring disorder theoretical models. No theoretical model yet explains co-occurring disorders for any subgroup. Several theories may help frame the

issue and assist with the development of a model for treating co-occurring disorders in older adults.

Current theories are grouped into four ways to explain co-occurring disorders (Mueser et al., 1998). The common factor models look at whether certain characteristics contribute to co-occurring disorders. Secondary substance-use disorder models hypothesize that serious mental illness increases vulnerability to develop substance use disorders. Secondary psychiatric disorder models suggest that substance use precipitates severe mental illness. Bi-directional models theorize that either disorder can increase vulnerability to the other disorder. The common factor models and the secondary substance use disorder models have garnered the most support while the secondary psychiatric disorder model and the bidirectional models are either untested or have failed to show consistent results (Conrod & Stewart, 2006; Mueser et al., 1998).

The common factor model suggests that both co-occurring disorders are vulnerable to a specific risk factor. Studies with young adult inner-city populations found that anti-social personality disorder contributes to both co-occurring disorders while genetic risk is associated with development of mental illness but not substance misuse disorders (Kessler et al., 1997; Mueser et al., 1998; Mueser et al., 1999; Regier et al., 1990). The common factor of anti-social personality disorder and its association with both substance misuse and serious mental illness disorders may help explain the development of co-occurring disorders in some populations. Examining individual difference variables that are common to both substance misuse and mental health

disorders may help understand risk to develop co-occurring disorders (Kushner et al., 2006).

Recent studies support the theory that mental health disorders most often precede substance misuse disorders (Kessler, 2004; Kessler, Berglund et al., 2005). Most mental health disorders begin in adolescence while the co-occurring substance misuse disorders begin five to 10 years later (Kessler, 2004). Secondary substance-use disorder models have found that persons with serious mental illness are more likely to have negative outcomes from substance use than the general public, and this may result in co-occurring disorders. Several studies indicate that the common risk factor of environmental stress is likely to precipitate a psychotic episode in people with schizophrenia who use substances (Drake & Wallach, 1993; Lehman, Meyers, Dixon, & Johnson, 1994; Mueser et al., 1998; Mueser et al., 1999). These results suggest the importance of person and environment interaction in the development of co-occurring disorders.

Theoretical models for co-occurring disorders have been tested primarily with young, urban populations with severe mental illness. None of the theoretical models has been tested with a population of older adults or rural populations. The lack of research results in little understanding of the social context, health issues, treatment needs, and other factors that lead to development of co-occurring disorders in rural older adults.

Older Adults with Co-Occurring Disorders in Rural United States

Older adults suffer from the co-occurrence of mental health and substance misuse disorders, yet the 40 million persons over age 65 in the United States (Howden & Meyer, 2011) are just beginning to be included in the research on co-occurring disorders. Few

are receiving adequate treatment (SAMHSA, 2012; U.S. Department of Health and Human Services [U.S. DHHS], 2002). Theoretical and practical understanding of co-occurring disorders is limited. No theory adequately explains co-occurring disorders in older adults or the lack of services for older adults (Mueser, Drake, & Wallach, 1998). No research has asked older adults what help they want for these disorders.

More than one-half of all older adults will have experienced at least one mental health or substance misuse disorder by age 75 (Kessler, Berglund et al., 2005). As many as one third of older adults who misuse alcohol are estimated to also experience a primary mood disorder (CSAT, 1998). Based on the findings of the 2009 National Survey on Drug Use and Health, about 19% or nearly eight million older adults experience co-occurring disorders (SAMHSA, 2010). Given the lack of inclusion of people living in institutions, homeless people not living in shelter, and people who speak languages other than English or Spanish, this number may be low (CSAT, 2007d). These findings suggest that older adults experience co-occurring disorders in significant numbers.

Nearly 11% of persons age 65 and older experienced a mental illness in the past year (SAMHSA, 2012). Many mental disorders may interact with substance misuse disorders in older adults. Major categories include psychotic, mood, anxiety, post-traumatic stress, and personality disorders. Other disorders such as attention deficit, eating disorders, and pathological gambling may co-occur as well (CSAT, 2006a). Mental health disorders, including depression, have been found to precipitate or maintain late-onset alcohol disorders (CSAT, 1998, 2009a). Depression and stressful events

precipitate drinking, especially among women, (Blow & Barry, 2002; North, 1996; CSAT, 1998, 2009a). These results are relevant to older adults and support the finding that mental health disorders most often precede substance misuse disorders (Kessler, 2004). The results further suggest that women and men may have different risk factors and that some older adults may be at higher risk to develop co-occurring disorders than are others (CSAT, 2009a).

It is estimated that up to 20 percent of older adults engage in alcohol misuse (Benshoff, Harrawood, & Koch, 2003). Several categories of substances may interact with mental health disorders. Older adults experience substance misuse problems with alcohol, prescription drugs, and over-the-counter medications (Emlet, Hawks, & Callahan, 2001; Hanlon, Fillenbaum, Ruby, Gray, & Bohannon, 2001; Najm, Reinsch, Hoehler, & Tobis, 2003). Problems with complementary and alternative medicine and illicit drugs are less common. Recent studies indicate that illicit substance use is increasing in older adults (SAMHSA, 2010). While hospital admissions for addiction treatment of adults age 55 and over are stable, more older adults are being admitted with illicit drug use, prescription drug misuse, and co-occurring disorders (Duncan, Nicholson, White, Bradley, & Bonaguro, 2010; Lay, King & Rangel, 2008).

Older adults with early-onset substance misuse disorders beginning before age 40 were nearly three times more likely to be diagnosed with a mental health disorder than those with late-onset disorders (CSAT, 1998). However, most late-onset disorders beginning after age 40 are co-morbid and this increases the likelihood of severity of the disorders (Kessler, Berglund et al., 2005). Members of the baby-boom generation may

be more likely that older generations to have greater exposure to drug and alcohol use and may also drink or consume drugs at greater rates (CSAT, 2009a). Late-onset alcohol problems appear to be a significant issue for women (CSAT, 1998, 2009a). Gender, generation, age at onset, and various combinations of disorders may all be factors in how co-occurring disorders develop and may affect assessment and treatment for older adults.

Risk and Protective Factors for Older Adults

Although there are no theories for why older adults develop co-occurring disorders, some factors that increase risk and other factors that offer protection from developing them have been identified. These dynamics may help form a theoretical understanding of co-occurring disorders in older adults.

Risk factors. Older adults experience risk factors for developing co-occurring disorders that may differ in likelihood, frequency, and intensity from other age groups. These include relationship loss and bereavement, chronic illness, caregiver role, social isolation, and loss of meaningful social roles (Mrazek & Haggerty, 1994; SAMHSA, 2002; U.S. DHHS, 1999). Other risk factors include chronic physical disabilities, chronic pain, and reduced coping skills (CSAT, 1998, SAMHSA, 2002). Trauma and violence that occurred at any age may affect older adults especially if they have not received treatment (Alexander, 1996; Goodman, Rosenberg, Mueser, & Drake, 1997; CSAT, 2009a). Some risk factors may have begun early in life and continued into later life. Others may begin in later life, increasing risk to develop late-onset co-occurring disorders. Risks may differ by social class, gender, and other characteristics, (CSAT, 1998).

Protective factors. Several factors that protect older adults from developing co-occurring disorders have been identified. These attributes include informal and formal social supports, appropriate health and social services, opportunities for productive social roles, and good problem solving skills (Mrazek & Haggerty, 1994; U.S. DHHS, 1999). While other risk and protective factors may be identified, these provide a place to begin understanding risk for and protection from co-occurring disorders in older adults.

The resilience literature does not directly address older adults with co-occurring disorders. However, studies identify a number of notions that contribute to the idea of resilience in this population. Resilience may be defined as, “the ability to achieve, retain, and/or regain a level of physical and/or emotional health after devastating illness or loss” (Felten, 2000, p. 102). Thus, resilience may assist a person to regain a previous level of functioning or attain it for the first time. Several ideas expand the definition of resilience. A stable and coherent sense of self-identity is essential to resilience. Self-identity may be regained in old age or it may develop for the first time during this stage of life (Borden, 1992). Resilience may assist a person to “grow past” previous levels of functioning (Pentz, 2005; Greene, et al., 2007). Recognition that resilience is not rare (Bonanno, 2008) may make it easier to identify resilience in the everyday lives of older adults.

Many resilience studies focused on personal qualities. Others noted the importance that community plays in providing external social and material support, and the impact of supports on the choices available to older adults (Leopold and Grieve, 2009; Greene, et al., 2007). Some noted that external supports may reduce risk and support recovery. However, persons can regain normal levels of functioning both with

and without the help of external interventions (Staudinger, Marsiske, & Baltes, 1993).

Finally, multiple and unexpected pathways to resilience exist, suggesting the constraint of assuming that a few factors can explain resilience (Bonanno, 2008).

Rural Communities

The Federal Census Bureau defines rural as that which is not urban. More specifically, rural areas are those with fewer than 2,500 persons and areas with fewer than 50,000 people that are not linked to a densely settled core (U.S. Census Bureau, n.d.). Fewer than 60 million people or about 19% of the population of the United States live in rural areas. About 40 million older adults comprise 13% of the entire population. However, the 3.4 million older adults who live in rural communities make up over 17% of the rural population confirming that rural communities have a higher percentage of older adults than do urban communities. Many more live in micropolitan areas, those places with a population of at least 10,000 but less than 50,000 (Werner, 2011). Rural communities are different from urban communities in more ways than numbers. A less well-developed infrastructure, less economic diversification, and a concentrated power structure are common. Face-to-face relationships and more informal business transactions are customary (Martinez-Brawley, 1998; Messinger, 2004). Resources and culture, including perceptions and stigma, interact to make rural communities unique.

Resources. Transportation is a particularly rural barrier to accessing services, as public transportation is frequently missing or undersupplied (Bellamy et al., 2003; Kerschner, 2003; Summers, 1998). Supports for jobs, housing, and other material resources are often missing or inadequate to meet needs (Bull, 2003; Krout, 2003; Folts

& Muir, 2003). Poverty rates in rural communities are high and interfere with accessing appropriate services (Bellamy et al., 2003; CSAT, 2009a). Poverty in conjunction with transportation issues may increase isolation and limit access to treatment. It is more often a barrier for women than for men (Bull, 2003; CSAT, 2009a; Kerschner, 2003).

Rural communities often lack treatment resources. Less than 11% of rural hospitals provide substance misuse treatment while over 26% of urban hospitals provide this service (Dempsey, Bird, & Hartley, 1999). Community based long-term care options are much more limited in rural communities (Coburn & Bolda, 2003). Trained and experienced providers are scarce everywhere and scarcity is more likely in rural counties (Crowe & Reeves, 1994; Jenkins, 2003; SAMHSA, 2012). There is no economy of scale in rural communities and treatment provided in traditional ways is expensive due to higher per client costs for staff, facilities, and supplies (Bull, 2003; Coburn & Bolda, 2003; Crowe & Reeves, 1994). The many gaps in data about co-occurring disorders and rural communities make planning for services difficult (SAMHSA, 2012).

Rural culture. Support systems remain relatively strong in rural communities. Family and friends are likely to be aware of problems and offer assistance. Social welfare organizations typically operate in an interactive and cooperative fashion. While churches are still an important source of support, schools are becoming the organization most likely to interact with individuals and families (Krout, 2003; Martinez-Brawley, 1998; Pentz, 2005).

Rural culture values privacy, confidentiality, self-help, and use of informal help and support. Because rural communities have limited access to specialists, the need for

expert and professional provision of services is not always recognized (York, Denton, & Moran, 1998). Successful rural providers employ a personal and individualized approach that often translates into high time consumption, especially when distance between communities is considered (Shenk, 1998, Sullivan, 1989; Summers, 1998). Individuals who have trouble are more likely to approach informal than formal resources. Older adults prefer to receive helping services from religious leaders rather than from social workers (Zellmer & Anderson-Meger, 2012). These values interact with rural residents' willingness to seek services for co-occurring disorders and their expectations of service providers (Boyd et al., 2008; Hoyt, Conger, Valde, & Weihs, 1997; Jackson et al., 2007).

Stigma. Stigma about both age and co-occurring mental health and substance misuse disorders remains a significant barrier to older adults receiving services (World Health Organization [WHO], 2002). People living in rural communities experience heightened stigma compared to urban areas (Brown & Blancato, 2003; SAMHSA, 2002). Older adults, their families, and professionals may believe that depression is normal in older adults. Substance misuse in older adults is relatively common but is often undetected or ignored by health and social service workers. Professionals, families, and older adults themselves may believe that there is little point in treating co-occurring disorders due to advanced age (Bartels, Horn, Sharkey, & Levine, 1997; Emler et al., 2001; Sheehan, 1999; WHO, 2002).

Stigma about co-occurring disorders may occur at program and community levels when community members, providers, and leaders do not understand the importance of providing treatment, especially when resources are scarce (Boyd et al., 2008; Walsh et

al., 2007; WHO, 2002). In spite of increased recognition of co-occurring disorders in specialty settings, many providers have not received training in these disorders, may not recognize the co-occurrence, and may attach stigma to one or the other disorder or age (Curie, Minkoff, Hutching, & Cline, 2005; Minkoff & Cline, 2004, 2006; WHO, 2002). Recruitment of providers who want to practice in rural communities is challenging (Jenkins, 2003). Beliefs combined with stigma and lack of knowledge about the benefits of treatment, may lead to missed opportunities for early intervention for co-occurring disorders (Brown, 2003; CSAT, 2007a, 2009a; WHO, 2002).

Northwest Iowa

About 43% of Iowa's population is rural (*Iowa Rural & Agriculture Health*, 2009). While Iowa has the fourth highest percent of older adults of all U.S. states at 14.9% (Werner, 2011), Northwest Iowa counties range in percent of adults age 65 and over from 14% to 23.2% with 16 of 29 counties having 20% or more older adults (U.S. Census Bureau, State & County Quickfacts, n.d.). Dearth of opportunity has led young people to leave the area to seek career and other opportunities elsewhere (*Iowa Farm and Rural Life Poll*, 2011). Some counties with lower percentages of older adults had higher percentages of immigrants drawn to communities with packing plants (Grey, 1996).

Industry and economics. Agriculture is the dominant industry in Northwest Iowa and many businesses serve the needs of the agriculture community. Packing plants provided well-paying jobs for area residents with high school diplomas beginning in the 1930s. However, with the loss of unions in the 1980s, wages decreased (Grey, 1996). Sioux City, the only community larger than 25,000 in Northwest Iowa, lost population

and entered an economic slump as the packing plants left the city and it has never recovered industry or population (Dreeszen, 2010). Education, health care, and social services now employ the largest percentage of workers (U.S. Census Bureau, 2007-2011 American Factfinder: Sioux City, Iowa, n.d.). Smaller communities frequently exist as bedroom communities and residents drive 10-70 miles for jobs, groceries and gas, schools, social services, and medical care (U.S. Census Bureau, American Factfinder: Community Facts, n.d.).

Conservatism. Northwest Iowa is the most politically conservative corner of the state (Muller & Bruce, 2012). The population in most counties is racially, ethnically, and religiously homogeneous (“Iowa Religions”, n.d.; “Religion and the 2012”, 2012; U.S. Census, American Factfinder, Community Facts: Race, n.d.). Religion contributes to the conservatism and there are a number of private religious-based schools in the area (Muller & Bruce, 2012). These communities prefer to meet their own needs with little government assistance or intervention (Muller & Bruce, 2012). The power structure has remained firmly in the hands of long-time residents. Newcomers are viewed with wariness and when they are from non-dominant racial and ethnic groups, mistrust is intensified (Grey, 1996).

Services for older adults. Social services in Northwest Iowa are limited for all groups including older adults. Major federal programs for older adults include Social Security and Medicare. Iowa’s Area Agencies on Aging were reorganized into six regions in 2012 and the Northwest Iowa service area is the largest covering twenty-nine counties with one service office. These agencies provide information and assistance that

assist many older Iowans to stay in their own homes (“About Area Agencies”, n.d.). The Iowa Department of Human Services offers dependent adult reporting as well as home and community-based waiver services. County Department of Human Services offer case management and dependent adult services as well as a location to apply for Medical Assistance (“Protective Services”, n.d.). Nineteen community action programs share a common mission to assist with greater self-sufficiency. Services vary by agency (“Member Services”, n.d.).

Health services. Northwest Iowa has sixteen hospitals and two of these are located in its major city. Rural hospitals provide inpatient general medical and surgical units, outpatient services, and emergency services. Some hospitals affiliate with hospice and health departments while in other counties, these services are separate (“Services”, n.d.; “Cherokee Regional Medical Center Welcomes You”, n.d.; “Hospitals”, n.d.; “Departments”, n.d.). One hospital offers a behavioral health unit for older adults (“Services”, n.d.). Local physicians often refer patients needing specialty care to University of Iowa hospitals, a four-to-eight hour drive from this corner of the state (“Search for”, n.d.). There is no public transportation from Northwest Iowa to the University of Iowa hospitals (“Fares & Schedules”, n.d.). Public health department services vary by county (“Buena Vista County Public Health and Homecare”, n.d.; “Pocahontas County Iowa Public Health”, n.d.).

Mental health and substance misuse services. In 2012, the Iowa State Legislature passed its first legislation making the state responsible to provide mental health services. Prior to this, counties bore full responsibility for the mental health care

of citizens (“Mental Health & Disability Redesign”, n.d.). Iowa has four state psychiatric hospitals and the one located in Northwest Iowa provides inpatient services to adults and children but offers no specialized services to older adults and does not treat substance misuse (Cherokee Mental Health Institute, n.d.). Each County Board of Supervisors chooses mental health services for their county. Three community mental health centers serve most of Northwest Iowa. Two counties have chosen non-CMHC services to provide services in their counties. Larger communities may have a fulltime outpatient mental health clinic while smaller community clinics may be open one or two days a week (“Iowa Community Mental Health Centers”, 2012; “Hours & Locations”, n.d.). State funded substance abuse services are provided by 20 service agencies. One Northwest Iowa agency serves nine counties and seven have offices (“Iowa Department of Public Health Funded Substance Abuse Assessment and Treatment”, 2013). All but nine of Iowa’s 99 counties are classified as mental health professional shortage areas meaning they have ratios greater than 30,000 residents to every psychiatrist (*Iowa Rural & Agriculture*, 2009).

Housing, transportation, and nutrition. Senior housing options include living in one’s own home, low income and market-based senior apartments, independent living, assisted living, and nursing homes. Few accept Medical Assistance payment (“Health Facilities Division”, n.d.).

Area Agencies on Aging assist communities with congregate meal sites as well as home delivered meals. Meals may be made and delivered by nursing homes and restaurants. Meals are available one or more days a week in larger communities and are

not available in smaller communities or to those living outside city limits (“Buena Vista Dinner Date Locations”, n.d.).

Transportation services include limited bus service and some communities have a private taxi service. Nine Northwest Iowa counties have a private not-for-profit bus service that provides some local service Monday through Saturday with hours varying by community. Services are provided within city limits and medical trips are provided within the nine-county area (“Fares & Schedules”, n.d.; “Public Transportation”, n.d.). Many communities have a volunteer fire department that provides ambulance services.

Perception of resources. With the exception of housing options and hospitals that are often for-profit, few services advertise (“Storm Lake Times, 2013, February 2). Social and health care services are a patchwork of public and private agencies that do not coordinate within and between service areas and may or may not address the needs of the older population. Without information, those in need are often unaware that the services exist, do not know the cost for services, or criteria for receiving services. Under the stress of illness or other difficulties, searching out service may be difficult.

Treatment Considerations for Older Adults with Co-Occurring Disorders

There is no known cause or cure for co-occurring disorders and the goal for treatment focuses on recovery (CSAT, 2006c). Persons with co-occurring disorders may experience treatment challenges, poor outcomes, and may not receive integrated treatment, which is considered a best practice (CSAT, 2007a; Najt, Fusar-Poli, & Brambilla, 2011). However, with appropriate treatment and support, people with co-occurring disorders can recover (SAMHSA, 2011a). Treatment for rural older adults

with co-occurring disorders shares some characteristics with those of all people with co-occurring disorders. However, the person, the age, and factors such as race and ethnicity, language, gender, gender orientation, social class, and differential ability need to be considered when planning services (CSAT, 2006a). Principles of treatment, models of treatment, stages of treatment, recovery, barriers to treatment, lack of treatment, and costs and savings associated with treatment are all important considerations when developing services for rural older adults with co-occurring disorders.

Principles of treatment. Several principles for providing care for older adults with co-occurring disorders have been developed. Providers should expect to see older adults with co-occurring disorders in multiple settings and being prepared to assist wherever older adults enter the system. Treatment should be individualized and respect the cultural perspective of the person being treated. No one model works best for every person or community. Those providing treatment must believe that people with co-occurring disorders can recover. Policy and treatment planning need to recognize consumer contributions and the interaction with community (CSAT 2006c).

No wrong door. A no wrong door approach offers services regardless of where an older adult enters the system of care. Systems need to work with professionals in all related fields. With this approach, all service agencies are committed to responding to the needs of the individual, either through direct service or linking the person to appropriate services. Individuals are not sent from one agency to another searching for services (CSAT, 2005, 2006c; Minkoff & Cline, 2004).

Cultural competence. Demonstration of respect for the person and avoidance of an age-biased view provide a foundation to develop culturally competent services for rural older adults with co-occurring disorders. Consultation with persons who are knowledgeable about aging issues and co-occurring disorders assists with understanding how to help older adults with their disorders. When systems use culturally competent approaches, the strengths of both individuals and communities support the prevention and treatment of co-occurring disorders (U.S. DHHS, 1999; CSAT, 2006c).

Belief in capacity to recover. The need for empathy, respect, and belief in the capacity for recovery is essential to help older adults with co-occurring disorders. While it is expected that person's with co-occurring disorders will experience difficulties, providers need to maintain confidence in the person's ability to recover. Recognition and use of strengths in all stages of treatment is essential (CSAT, 2006c).

Address local needs. Different locations require diverse programs for people with co-occurring disorders. Rural communities struggle with issues of transportation, confidentiality, providing services for small numbers of people, and inadequate infrastructures of social services. At the same time, rural communities have strong and enduring informal systems of care. Addressing both the strengths and the challenges of the community is vital for planning services. Rural communities typically provide fewer services than urban communities do, but these communities may offer other resources that can be incorporated into services (Greene et al., 2007; Kellehear & Young, 2007; Schorr, 1998; SAMHSA, 1997).

Models of Treatment. Three treatment models for co-occurring disorders are recognized. The integrated treatment model provides treatment for both disorders simultaneously in the same organization. The parallel treatment model treats both disorders at the same time but in different agencies. The sequential model treats first one disorder and the other (CSAT, 1994; Carey, 1996; Drake et al., 1991). The integrated model is the easiest for clients to use and provides the best outcomes. Providers view both disorders as primary, address both disorders with a common vision, and focus on the individual rather than on the program. Individuals with co-occurring disorders do not have to coordinate services and treatment plans (CSAT, 2006b, 2006c, 2007b; Minkoff, 2001).

Most treatment facilities still use either the sequential or the parallel model (U.S. DHHS, 2002; Watkins, Burnam, Kung, & Paddock, 2001). Lack of practitioner training in both disorders contributes to the use of these less desirable models as do substance misuse and mental health services that often remain administratively separate. Federal and state funding and regulations for mental health and substance misuse further complicate provision of integrated services. These issues make delivery of integrated services challenging and the provision of sequential or parallel services easier to provide (CSAT, 1994, 2007b, 2007c; U.S. DHHS, 2002).

Stages of treatment. Treatment models focus on engagement, screening, assessment, and treatment. Clients are best served when these components are integrated and each component addresses the interaction of mental health and substance misuse problems (CSAT, 1994, 2006b).

The engagement stage involves the client in a relationship and establishes the initial recognition that a problem exists. Clients with co-occurring disorders are often more difficult to engage than clients who have a single disorder. This may result from multiple symptoms as well as from the receipt of conflicting messages from agencies that do not address both disorders. An assertive outreach approach is recommended to help with engagement (CSAT, 2005, 2007a; Drake et al., 1991; Ridgeley, 1991).

Integrated screening establishes the need for further evaluation of both disorders. Integrated assessment addresses both disorders, each within the context of the other. Diagnoses, level of functioning, readiness for change, and initial level of care are addressed (CSAT, 2006b).

Treatment planning addresses both disorders and determines the appropriate care setting and interventions. Clients are actively involved, strengths and skills are identified, the cultural context is considered, and priorities are set when developing treatment plans (CSAT, 2006b).

Motivational approaches are collaborative, person-centered, and engage the client as an active partner to bring about change. These approaches are used throughout the treatment stages to increase individual motivation to change, reduce problems and symptoms, and increase stabilization and level of functioning (CSAT, 1999).

Recovery. Since there is no cure for co-occurring disorders, treatment focuses on recovery, stabilization of symptoms, and improved quality of life. Recovery from co-occurring disorders is defined as “a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full

potential” (del Vecchio, 2012, para 5). Abstinence from substances causing impairment is indicated and the ability to function despite symptoms of mental illness are both important parts of recovery (CSAT, 2006a; del Vecchio, 2012).

Four dimensions that support recovery and enhance its definition are health, home, purpose, and community. Persons with co-occurring disorders need to manage disorder symptoms by making informed healthy choices. Each person needs a stable and safe place to live. Everyone needs meaningful daily activities. Every person with co-occurring disorders needs relationships and social networks that provide support, friendship, love, and hope (del Vecchio, 2012). Adequate housing, food and clothing, physical health, transportation, vocational plans, psychosocial relationships, legal assistance, and avoiding the criminal justice system are all part of good quality of life and assist with stabilization of symptoms (CSAT, 2006c; del Vecchio, 2012).

Barriers to treatment. Barriers sometimes interfere with rural older adults receiving the help that they need to recover from co-occurring disorders. Barriers may lie within the individual, support system, and provider system. Older adults may not identify or seek services for co-occurring disorders due to stigma (U.S. DHHS, 1999, 2002). Some older adults, families, and providers believe that older adults do not suffer from the co-occurrence of mental health and substance misuse disorders (Kessler et al., 1996; U.S. DHHS, 1999). Rural communities are challenged to find providers who want to work with older adults with co-occurring disorders, and who want to work in rural communities (Boyd et al., 2008; Brown, 2003; CSAT, 1998, 2007a; Gatz & Pearson, 1988; Jenkins, 2003; Walsh et al., 2007).

Other barriers are structural. Obstacles such as finances, administrative regulations, location of services, and transportation interfere with older adults receiving services. Lack of specialized programs and personnel, inadequate insurance benefits, and turf guarding negatively impact the delivery of mental health services to older adults (CSAT, 2009a; Robb, Chen, & Haley, 2002; U.S. DHHS, 1999).

Lack of treatment. Although appropriate treatment approaches are known, more than two-thirds of people with co-occurring disorders do not receive any treatment. Of those who do receive treatment, less than 10% receive help for both disorders. About 20% receive mental health care while less than 10% receive substance misuse treatment. Substance misuse treatment was increased by the presence and severity of a mental health problem. Overall, mental health care is more common than substance misuse treatment. Co-occurrence of disorders did not increase treatment over those with one disorder (CSAT, 2007a; Harris & Edlund, 2005; SAMHSA, 2010; Watkins et al., 2001).

The presentation of disorders in older adults differs from that of younger adults on whom treatment practices have been standardized and engagement, assessment, and treatment of older adults may need to be different. Both primary care and specialty providers frequently lack training to recognize mental health and substance misuse co-occurring disorders in older adults (U.S. DHHS, 1999, 2002).

Costs and savings. People with serious mental illness have a life expectancy of, on average, 25 years fewer than the general population (SAMHSA, 2011b). Co-occurring disorders and their consequences may include inability to maintain family and other social relationships, inability to work, homelessness, exposure to trauma and

violence, and involvement in the criminal justice system (SAMHSA, 2011a).

Co-occurring disorders create social and economic costs for the person experiencing them as well as to their family, friends, and society (SAMHSA, 2011a).

Mental health disorder outlays amounted to over \$57 billion in 2006. The estimated societal cost for misuse of substances in the United States is \$510 billion per year (Miller & Hendrie, 2008; SAMHSA, 2011a). About one quarter of adult hospital stays are related to mental health or substance misuse disorders. About 5% of the population account for nearly 50% of the total costs, due in part, to multiple co-occurring disorders (SAMHSA, 2011b).

However, people with co-occurring disorders can recover. Prevention and treatment can reduce both personal and monetary costs. Treatment of older adults with late-life depression reduces symptoms and may result in complete recovery (SAMHSA, 2011b; Unutzer et al., 2002). Early prevention and treatment of co-occurring disorders brings savings of two to 10 dollars for every dollar spent on these programs. Savings derive from reduction of costs for health care, criminal justice, education, and lost productivity (SAMHSA, 2011b, 2012).

Unanswered Questions

There are significant gaps in the literature regarding older adults with co-occurring disorders. Although older adults experience co-occurring disorders, they are just beginning to be included in research and program design. Rural communities are typically not included in system development and planning. The voices of older adults

telling of their own experiences of co-occurring disorders, treatment, and recovery were not found in the literature.

Although current research suggests that adults with severe mental illness are those most likely to experience co-occurring disorders, these studies have excluded older adults, which limits this finding. People with short-term and less severe disorders have been almost completely omitted from the research so even less is known about their issues than those with more severe and chronic disorders. The interaction of risk and protective factors with age has been explored minimally. Understanding of how age and rural location interact with risk and protective factors for co-occurring disorders is almost completely absent from the literature.

Although attitudinal and structural barriers have been identified that help explain the lack of identification and treatment of older adults, older adults with co-occurring disorders themselves have not been asked what obstacles and supports they have encountered. Finally, little is known about how strengths and resilience may be useful in developing an understanding of the prevention and treatment of co-occurring disorders in older adults living in rural communities.

Based on the gaps in knowledge, an exploratory study was designed and conducted to investigate the experiences of older adults with co-occurring disorders who live in rural Iowa. The following questions were the foundation for the study:

- 1) How do rural older adults view their experience of co-occurring disorders?
- 2) What do older adults living in rural communities experience relative to treatment of their co-occurring disorders?

- 3) What do older adults living in rural communities experience relative to policy that affects their treatment for co-occurring disorders?

Chapter 3: Theoretical Framework

Several theories have been created to understand the development of co-occurring disorders (Mueser, Drake, & Wallach, 1998). Many theories attempt to explain how people age and the roles that older adults perform in society as they age (Bengtson & Schaie, 1999). No theory has emerged that explains or predicts the development, persistence, or recovery from co-occurring disorders in older adults. Critical theory and resilience theory assist in better understanding these processes. The contributions of critical theory and resilience theory together provide a framework to begin to understand the complex development, persistence, and recovery from co-occurring disorders in older adults living in rural communities.

Critical Theory

Critical theory suggests that experiencing a phenomenon is quite different from describing it (Lynott & Lynott, 1996). Habermas examined the epistemological relationship between the practical use of facts and their objects of concern, asked the purpose of knowledge, and offered three answers (1971). The first purpose of knowledge has to do with interest in control. Relative to aging, knowledge allows for interventions that bring about changes or control (Habermas, 1971). The second purpose of knowledge has to do with understanding. Understanding may refer to the researcher's understanding or the participants' understanding, and this type of understanding may be referred to as a "double hermeneutic" or an interpretation of interpretation (Giddens, 1976; Habermas, 1971). A third purpose of knowledge has to do with emancipation (Habermas, 1971). While all action produces objects, the source of objects gets lost. The purpose of

research is to analyze the transformation of genuine knowledge to knowledge that has been separated from its source. The challenge is to identify the understanding of experience as separate from those who experience it (Lynott & Lynott, 1996).

Moody based his description of a critical gerontology method on Habermas' (1971) work, and he identified four goals for this approach: theorizing subjective and interpretive dimensions of aging, focusing on active involvement in practical change, linking academics and practitioners, and producing emancipatory knowledge (1988). Dannefer & Uhlenberg (1999) suggest that critical gerontology should create positive models of aging that emphasize strengths and diversity. Critical theory endorses understanding co-occurring disorders from the experience of older adults themselves with emphasis on their strengths. Older adults in rural communities represent diversity within the older population whose strengths need to be identified and whose diversity needs to be understood from their own expression of their experience.

Given the paucity of theory to explain and predict co-occurring disorders in older adults living in rural communities, critical theory provides a framework to consider this problem. Critical theory validates the importance of hearing the descriptions of older adults with co-occurring disorders who live in rural communities. Understanding the experience of older adults with co-occurring disorders requires listening to their own subjective and interpretive description of these experiences. Although hearing is not the same as the actual experience, listening brings the listener a step closer to understanding and adds to the dimensions of understanding as the listener comes closer to the experience itself.

A critical gerontological approach requires active involvement in practical change and linking academics and practitioners. Bringing the voices of older adults who live in rural communities and experience co-occurring disorders together with developing a model for prevention, identification, treatment, and recovery services is practical. It connects academic research with the practitioners that will provide the services. Most importantly, it involves the older adults who have the knowledge. Sharing the knowledge and understanding of older adults with co-occurring disorders who live in rural communities can free these adults from the stigma of co-occurring disorders while liberating both academics and practitioners from misinformation.

Resilience Theory

The concept of resilience builds on general systems theory and is best seen as a framework or model to understand complex socio-ecological systems (Anderies, Walker, & Kinzig, 2006; Masten, 2001). Discussion of resilience in social science began with the exploration of resilience in children of mothers with schizophrenia, and this study led to investigation of both risk and protective factors that relate to resilience (Luthar, Cicchetti, & Becker, 2000). Recognizing that resilience can occur at any age broadens understanding of the times in life when resilience can occur (Greene & Cohen, 2005).

According to Reynolds, social work practice “is always shaped by the needs of the times, the problems they present, the fears they generate, the solutions that appeal, and the knowledge and skill available” (Reynolds, as cited in Greene & Cohen, 2005, p. 367). Resilience theory is a product of and response to the current times with its problems and fears. Most definitions of resilience refer to positive adaptation despite

adversity and define resilience by its success in recovering from or avoiding negative outcomes (Garmezy, 1991; Luthar et al., 2000; Masten, 2001; Rutter, 1987). Additional research suggests that resilience is not rare and there may be many and surprising ways to achieve resilience (Bonanno, 2008).

Resilience may be more than regaining a previous level of functioning, and people may experience a reserve capacity that allows them to “grow past” their earlier performance of life tasks (Pentz, 2005). While some studies have focused on individual capacities, others have added the need for a fit between the individual and the environment to enhance resilience (Leipold & Greve, 2009). Thus, resilience can be viewed as a phenomenon of a normal developmental course under potentially endangering circumstances expressed as a constellation of individual resources, social conditions, and developmental challenges or problems (Leipold & Greve, 2009).

Resilience theory adds an important way to understand older adults who experience co-occurring disorders. Studies focusing on older adults have considered the ideas of adversity, adaptation, (Luthar, Cicchetti, & Becker, 2000) and the ability to regain normal levels of functioning after developmental setbacks, both with and without the help of external interventions (Staudinger, Marsiske, & Baltes, 1993).

A number of potential risk factors for development of co-occurring disorders have been identified. These factors help understand the development and persistence of co-occurring disorders. Protective factors that assist in keeping disorders from developing and help people recover have also been recognized. Resilience that develops within different populations may not include the same components (Pentz, 2005). Differential

protective factors may be relevant to older adults living in rural communities where culture and resources differ from urban communities. Resilience may also be different for older adults than for younger ones. The idea that health can be achieved, retained, or regained after a devastating illness provides a resilience framework for co-occurring disorders as it allows for development, persistence, and recovery (Pentz, 2005). Health that is regained after a devastating illness also provides an excellent framework for developing practice and policy interventions for older adults with co-occurring disorders (Pentz, 2005).

Fit between Theory and this Study

Resilience theory provides a way to understand the complex social systems of older adults living in rural communities and experiencing co-occurring disorders while focusing on their strengths and diversity. Both critical theory and resilience theory take into account subjective and interpretive dimensions of aging. Resilience theory is practical, allows for linkage between academics and practitioners, and creates a positive model with which to view older adults with co-occurring disorders. Critical theory maintains a focus on keeping as close as possible to the original experience of the older adults themselves. Thus, critical theory and resilience theory together provide a foundation for model and theory building for older adults living in rural communities who have co-occurring disorders.

Chapter 4: Methodology

The goal of this exploratory study was to understand the experience of older adults with co-occurring disorders and the impact that living in a rural community had on this experience. People with co-occurring disorders who are in prison and people with chronic and severe disorders who live in institutional settings have received some attention from researchers. The goal of this study was to understand older adults who live independently in rural communities and whose co-occurring disorders range in severity. This population has been left out of the existing research and little is known about whether their treatment needs are met.

A qualitative approach using grounded theory was used. Original data was gathered through in-depth interviews with persons residing in rural Northwest Iowa. This qualitative process provided the best fit with the goals of critical and resilience theory.

This study relied on the strengths of grounded theory, an exploratory research methodology, to study the experiences of older adults with the co-occurring disorders of mental illness and substance misuse. The study design, sample, ethical issues, instruments, data collection plan, data analysis plan, and study strengths and limitations are described in the following sections.

Exploratory Design

Use of an exploratory design enabled examination of a topic that had little previous observation. Qualitative methodology refers to a process of research and analysis carried out to discover concepts and the relationships among these concepts. These ideas are organized into a theoretical explanation (Strauss & Corbin, 1998). Older

adult participants described their experiences of co-occurring disorders during in-depth exploratory interviews. The study came as close as possible to Moody's goal of understanding co-occurring disorders from the experience of older adults themselves. Careful listening allowed perception of multiple layers of the experience (Moody, 1988). These concepts and the relationships among them were organized into an explanation of the experiences.

Grounded Theory

This exploratory study used a grounded theory design. Rather than beginning with a preconceived theory, grounded theory develops from the data and the analysis of that data. Analysis components emerge from patterns found within the study without assuming the outcome. This inductive method relies on interaction between the researcher and the data. Understanding of the data arises from the researcher's experience with the participants and their information, and theories are grounded in this direct experience (Patton, 1990; Strauss & Corbin, 1998).

Glaser and Strauss developed grounded theory methodology in response to their conviction that the best way to understand complex and variable phenomena comes from gathering data in the field. Essential aspects of grounded theory for Glaser and Strauss include simultaneous involvement in data collection and analysis, construction of analytic codes and categories from data rather than from hypotheses, use of a constant comparative method during every stage of analysis, and developing theory during every stage of data collection and analysis. The goal of sampling is to assist with theory construction. Memos assist with the analysis by documenting the progress and direction

of the research and the researcher and provide a way to reconstruct the research. From the perspective of Glaser and Strauss, grounded theory defines meaning through interaction, sensitivity to the process of events, and by comparing data that identify, develop, and relate concepts (Charmaz, 2006; Strauss and Corbin, 1998).

I used the grounded theory method developed by Strauss and Corbin. The data was systematically gathered and analyzed throughout the research process while systematic techniques and guidelines were used to carry out the process. Strauss and Corbin favor the technical procedure of coding to build theory, provide tools to handle raw data, and consider alternative meanings of phenomena. Data collection, analysis, and theory are in close relationship to one another. Key concepts are description, conceptual ordering of data, and theory building (Charmaz, 2006; Strauss & Corbin, 1998).

The advantage of grounded theory for this study was the ability to obtain in-depth and detailed information from the point of view of older adults that had not been limited by predetermined categories set by the researcher. These extensive participant interviews along with field notes resulted in thick description (Charmaz, 2006; Patton, 1990). Participant perspectives, emotions, and actions within the context of their lives were revealed through this rich data. The findings are “grounded” in the experiences of the participants. Grounded theory provided a way of thinking about and viewing the world and offered methods that came as close to the real world of the participants as possible. These methods allowed flexibility to follow ideas, while still providing techniques and procedures to organize those ideas (Charmaz, 2006; Patton, 1990; Strauss & Corbin, 1998).

Grounded theory helped when interpreting the data in addition to being useful when conducting this study. It enabled discovery and understanding of meaning found in the interviews. Furthermore, it provided a mechanism by which to explore the environmental and societal context from the point of view of the participants. Grounded theory served as a way to learn about the world being studied, and a method for developing theories to understand them (Patton, 1990; Strauss & Corbin, 1998).

Grounded Theory Sample Process

The goal of sampling in a qualitative study is to find information rich cases that clarify the questions being studied. Grounded theory focuses on finding cases that represent the major concepts and assist in understanding how those ideas vary. The sampling process develops as concepts emerge from the ongoing analysis and appear to be relevant to the evolving theory. The goal is to make the most of opportunities, to compare experiences, and to see how a category varies in terms of its properties and dimensions (Charmaz, 2006; Patton, 1990; Strauss & Corbin, 1998).

The sample becomes more specific as the theory evolves. The researcher initially gathers information in a wide range of pertinent areas to generate as many categories as possible. After the categories are developed, sampling focuses on developing these categories. Comparisons must be made systematically so that the categories can be fully developed. However, flexibility is also needed in order that unexpected events can be used. The goal for the size of the sample is to reach saturation, that is, to reach the point where no new information or ways of viewing the information are found in the interviews. Relationships among categories have been established and validated by

knowing where the comparisons within and between categories have led the researcher, and how these relationships clarify theoretical categories (Charmaz, 2006; Strauss & Corbin, 1998).

Sampling Procedures

The study sample was selected using non-probability purposive sampling. The sample could not be fully determined relative to either size or characteristics before beginning to gather data. Initial criteria for cases were older adults living in rural communities who were able to describe their experiences with co-occurring disorders. Analysis of early interviews guided the choice of later interviews that could develop and saturate the categories (Strauss & Corbin, 1998).

Participants were selected based upon their age, residence in rural Iowa, history of experiencing co-occurring disorders, and willingness to participate in the study. Efforts were made to select a sample that included both men and women living independently, those with short-term and long-term disorders, and persons who reflected the racial and ethnic diversity of northwest Iowa. As the study progressed, these variables continued to be important criteria for selecting participants. In addition, efforts were made to find participants who experienced both mild and severe disorders as well as participants who had gone through various types of treatment.

Sample

The sample for this study consisted of 23 adults, ages 55 to 90, living in rural Iowa, whose screening interview indicated that they had co-occurring mental health and substance use difficulties and who themselves believed that they had these disorders and

described relevant issues. No one had been diagnosed with co-occurring disorders by a mental health professional. Participants were cognitively and physically able to participate in a one to two hour interview. Most were married or lived with a partner while nine were widowed or separated. Education varied from less than high school to completion of advanced college degrees. See Table 1.

Table 1

Sex, Age, Marital Status, and Education of Participants

Sex	Women: 13		Men: 10		
Age	55-59: 2	60-69: 6	70-79: 9	80-89: 5	90-99: 1
Marital Status	Married/Partner 12	Widowed 7	Divorced 2	Always single 2	
Education	Less than High School 2	High School/GED 12	Some College 2	B.A. 4	M.A. 4

For the purposes of this study, the initial plan was to use the service definition of co-occurring disorders developed by the Center for Substance Use Treatment and recommended for use by the Co-occurring Center for Excellence was used (CSAT, 2006a). This definition includes individuals who have an established diagnosis of one disorder with symptoms evolving into the other disorder; individuals who have resolved symptoms of one or the other diagnosis; and individuals with a unitary disorder and acute symptoms of a co-occurring disorder (CSAT, 2006a, p. 3). The DSM-IV-TR definitions of mental illness and substance misuse disorders were used (American Psychiatric Association, 2000). All participants reported that they experienced co-occurring disorders. All participants reported that they experienced depression and 22 of the 23

participants experienced alcohol misuse. See Table 2. However, no participant had received a diagnosis of co-occurring disorders from a mental health professional.

Therefore, the criteria for participation was revised to meeting the screening assessment for co-occurring disorders along with self-report of co-occurring disorders.

Table 2

Participant Mental Health, Substance Misuse, and Co-Occurring Difficulties

Co-Occurrence	Depression & alcohol	Depression & prescription medication	Anxiety & Alcohol	Depression & Over-the-Counter Medications Depression & poly- drugs Depression, anxiety & marijuana Anxiety & Prescription Medication		
	22	8	7	1 of each		
Mental Health Problem	Depression	Suicidal Thoughts	Anxiety	Post-Traumatic Stress Disorder	Anger	Personality Disorder Sexual Dysfunction Gambling
	23	7	8	4	4	1 of each
Substance Misuse	Alcohol	Prescription Drug	Marijuana	Poly-drug	Over-the-Counter Medications	
	22	8	1	1	1	

Participation was limited to those who lived in communities of 20,000 or fewer within the state of Iowa in order to maintain consistency of rural experience. In fact, all participants lived in Northwest Iowa in communities of 10,000 or fewer residents.

Participant statements that they were current residents of Iowa were used to determine residency. The sample was chosen in this purposeful manner with the assent of the participants.

Table 3**Participants by Size of Community**

Size of Community	Community of 10,000	Community between 1-2,000	Community between 500-1,000	Community below 500	Farm or Acreage
Number of Participants	15	1	1	2	4

Sample Strengths and Limitations

The strengths of this qualitative study include developing deep and rich understanding of rural older adults' experiences with co-occurring difficulties. This is particularly important given that little is known about the phenomenon of older adults with co-occurring disorders who live in rural communities. The details of understanding older adults' feelings and thoughts may assist with understanding individual variations among older adults. The rural sample provided knowledge of the issues for a population that is rarely studied.

This sample allowed the identification of participants who could describe relevant events related to the experience of co-occurring mental health and substance misuse difficulties. A limitation of the study is that participants had not received a diagnosis of co-occurring disorders from a mental health professional. Generalizability of the sample, as the term is used in quantitative research, is limited. Sampling error and bias are unavoidable given that there is no sampling frame. However, the sampling approach used was appropriate for this grounded theory study as it provided the means to explore

both initial categories and categories that developed as the study proceeded (Patton, 1990; Strauss & Corbin, 1998; Yegidis & Weinbach, 2012).

The purpose of applied research is to contribute knowledge and potential solutions that help people understand a problem and be able to address it effectively. Because the nature of research is generally limited to a specific time, place, and condition, the goal is to seek limited rather than universal generalizations. Context is essential in qualitative research. The variability of social phenomena and the importance of context do not permit everlasting generalizations since conditions change over time and place. When context and timeframe are considered, generalizations are always hypotheses, not conclusions (Charmaz, 2006; Cronbach, 1975; Patton, 1990; Sherman & Reid, 1994).

Generalization may be contrasted with particularization where understanding the particular issues within all context is a form of naturalistic generalization (Stake, 1978). Lincoln and Guba emphasize the impact of the context on any human behavior and criticize generalization as context-free (1985). In response to concerns about generalization, I included detail in how and why the sample was chosen. Those who read the report will decide the integrity of the data and the persuasion of the argument.

Ethical Issues

The participants in this study were considered vulnerable because of both age and co-occurring disorders. Several steps were taken to ensure that the study procedures protected the participants. These included the Institutional Review Board approval, informed consent, and confidentiality. In addition, the voluntary nature of the study,

possible risks and benefits, compensation, and storage of data were reviewed with the participants.

Institutional review board. The Human Subjects Institutional Review Board at the University of Minnesota reviewed and approved this study. Although the participants were considered vulnerable because of both age and co-occurring disorders, the study qualified for Exempt Review.

Informed consent. Participants were fully informed about the purpose of the study and were offered the opportunity to receive the results of the study. The written consent form was reviewed with each participant. The form was signed only after answering any questions that the participant had about the study (See Appendix A: Informed Consent Form).

Confidentiality. Confidentiality of the participants was maintained throughout the study. No identifying information was included in any part of the report. Pseudonyms were used in all parts of the study. Other identifying information such as third party names, locations, and dates that could compromise confidentiality was deleted. Replacement words, such as “wife” for the name of a spouse, were bracketed to indicate that the information had been changed.

Voluntary nature of the study. Participants were informed that their participation in the study was voluntary and that the decision to participate or not would have no effect on their relationship with the University of Minnesota or with me. The participants could choose not to answer any question that they did not want to answer (See Appendix A: Informed Consent Form). They could withdraw from the study at any

time with no penalty, including after the interview was completed. Although several participants asked questions, all were willing to complete the interviews. One person did not want to have the interview recorded. No recording was made of that interview and only written notes were taken during that interview.

Risks and benefits. Human subject concerns were of particular concern given the mental illness and substance use co-occurring disorders of the participants. Although interviews could have been stressful for participants, direct information from those who experience the disorders was essential to obtain the best understanding of co-occurring disorders in older adults. All participants were given a list of counseling resources and treatment groups that were available in Northwest Iowa. This list provided options for help if a participant found that the interview was stressful. No one reported any stress from the interviews. One participant noted that the interview gave him the opportunity to talk about experiences that are important to him, yet rarely discussed with others.

Compensation. The interviews took a good deal of time, as they consisted of both a screening interview and a full research interview. The screening interviews took about one-half hour and the research interviews lasted from one to three hours. As a thank you for their time, participants were given a \$5 gift card to a local grocery store when they completed the screening interview. They were given a \$15 gift card to a local grocery store when they completed the research interview. In this way, if participants completed the screening interview but did not take part in the research interview, they received some compensation.

Data storage. Confidentiality was addressed through careful handling of data at all times. All paper data related to this study were kept in a locked file cabinet in a room that was secured or occupied by me at all times. Computer files relating to the study were placed on a password protected computer and only I have the password. The computer is part of the Buena Vista University system, and this system regularly reviews and upgrades security, anti-virus technology, firewalls, and other protections including encryption software. The University of Minnesota Data Privacy Standards were reviewed by Buena Vista University Information Services staff who provided assurance that the computer complies with University of Minnesota data privacy standards. The data including audiotapes will be kept until the study is completed. The data will then be destroyed.

Instruments

Since no research had been conducted to understand the experience of older adults with co-occurring disorders, there was no existing instrument with which to gather data. A screening interview form, a mental health screening form, and a substance misuse form were used during the screening interview. A research interview form was used during the research interview.

I developed a screening interview form and a research interview form based on information from the literature review. I adapted existing mental health disorder and substance misuse screening forms to gather information about the co-occurring disorders.

Screening interview forms. The Screening Interview Form (Appendix B) asked the participant's age and sexual orientation. Gender and race or ethnicity were observed

and recorded. Participants were asked what mental health and substance misuse difficulties or disorders they experienced, either in the present or in the past. Participants were asked what led them to believe that they experienced co-occurring disorders. If participants met the initial criteria for the study, they completed the Mental Health Screening Form-III-Adapted (See Appendix C) and the Simple Screening Instrument for Substance Abuse-Adapted (See Appendix D) to identify the disorders they experienced.

The Mental Health Screening Form-III screened for mental illness. This 17-item questionnaire provided a way to assess symptoms of major categories of mental illness, whether the participant had received any kind of treatment, whether the participant or others felt that the participant needed help with an emotional problem, and whether the participant had ever been suicidal. The Mental Health Screening Form-III has face validity and supportive psychometric findings (CSAT, 2005). It was adapted to gather information about mental health problems throughout the participant's entire life by starting each question with "Have you ever". While this form was designed for use in a clinical setting, it addressed the need to ensure that clients had or currently experienced a mental illness.

An adapted version of the Simple Screening Instrument for Substance Abuse was used to screen for substance misuse. The original instrument screened for alcohol and illicit drug use (CSAT, 2005). The form was reworded to screen for prescription drug use, over-the-counter drug use, and complementary and alternative medicine use as well as alcohol and illicit drugs. The instrument was adapted to gather information about substance misuse problems throughout the participant's entire life by starting each

question with “Have you ever”. While this may have invalidated the statistical validity and reliability of the instrument, it was essential to include both history of and current substance use for this study. The 15-item questionnaire asked about use, symptoms, concerns about use by the participant and others, and whether the participant had ever sought help for substance use problems.

Research interview form. The Research Interview Form (See Appendix E) addressed the relevance of age and rural residence as they related to the participants’ experience of co-occurring disorders. Risk and resilience factors, experience with treatment, the recovery process, attitudinal issues, and structural barriers were explored. The Research Interview Form was used throughout the study. The outline underwent changes as new variables were discovered and the order in which information was gathered changed to follow the flow of the interview.

Data Collection

After receiving IRB approval to proceed, data was gathered from participants in rural Northwest Iowa. Interviewing continued until no new information was forthcoming. This approach was in keeping with the qualitative research method of collecting data to the point of redundancy and focusing on information-rich cases rather than sample size (Lincoln & Guba, 1985; Patton, 1990; Strauss and Corbin, 1998). I conducted all interviews between October 2007 and June 2009. Data collection began in Buena Vista County, Iowa, a rural county with a high number and percentage of older adults. Buena Vista County is also racially and ethnically diverse. Interviews were

conducted in other rural communities in Northwest Iowa when appropriate participants contacted me.

Participant recruitment. Advertisements for participation in the study were placed in housing for older adults, Senior Centers, and in local newspapers asking persons interested in taking part in the study to contact me. Presentations were made at several Senior Centers where the research was discussed and information was provided about how to contact me if attendees or someone they knew wanted to participate in the research. Several Alcoholics Anonymous (AA) contact persons were informed of the research by phone and in writing. These leaders were asked to share information with AA participants age 55 and over who had co-occurring disorders and who might be interested in participating in the research.

Participant procedures. Once potential participants contacted me, the purpose of the research and ethical issues were discussed. If the person was a resident of rural Iowa, was over age 55, believed that she or he met the criteria for co-occurring disorders, and expressed a desire to be part of the study, she or he was invited to take part in a screening interview.

Potential participants completed the eight-item Screening Interview Form to ensure that they met the rest of the criteria for the study. During the screening interview, the purpose of the project was explained, and any questions that the potential participant had about the research were answered. If they chose to continue, potential participants completed the Mental Health Screening Form-III-Adapted and the Simple Screening Instrument for Substance Abuse-Adapted to assure that they met the criteria for

co-occurring mental illness and substance use according to the definition used in this study (CSAT, 2005). Individuals who did not have co-occurring disorders, were less than age 55, did not live in rural communities, or were physically or cognitively unable to participate in interviews were excluded from the sample.

Appropriate respondents who agreed to participate were sent a confirmation letter with the date and time of the research interview and a follow-up reminder call was made near the time of the interview. Participants completed individual open-ended interviews lasting one to three hours. Although participants were informed that interviews could be divided into two shorter interviews, all participants completed the research interviews in one session.

Each research interview began by reviewing the purpose of the project and answering any questions that arose. Interviews focused on the experience of co-occurring disorders from the participants' perspective. The interview protocol began with a predetermined list of questions about the co-occurring disorders and their impact on the participant's life. Additional issues that arose within the interview were probed. Prompts were used to assist participants to consider additional possible issues. I cued verbal exchanges throughout the interview to keep it focused on relevant issues. As interviews continued, the order of material changed to make more sense to the participants. The protocol was reviewed after each interview, and it was revised to reflect categories that emerged in the interview.

Twenty-three interviews were completed for this study. The collection of data ended when the categories of information about co-occurring disorders experienced by older adults living in rural communities were sufficiently explored.

Problems in collecting data. The major problem in this study was finding participants who were willing and able to participate. Every effort was made to recruit and include participants who varied in gender, race and ethnicity, age, and experience of co-occurring disorders. Variation in gender, age, and experience of co-occurring disorders was achieved. However, all participants were white and all were life-long residents of the United States.

Data Analysis

This section describes the data analysis method and the steps taken to analyze and validate the data. The purpose of the analysis is to listen carefully to the participants' narratives and discover, from the data, rather than from preconceived ideas, the full meaning of the data and the categories developed from the data. The data is first described and then analyzed. Those reading the description must be able to develop their own understanding of its meaning. The description must contain enough detail so that the reader can "enter into" the relevant circumstances and ideas of the participants. Enough aspects of the participant's physical and relationship context, emotions, and relevant life history are included to allow the reader to have an in-depth understanding of the meaning of the experience for the participants. The description provides a basis for interpretation, while the interpretation provides understanding of the description (Patton, 1990; Strauss and Corbin, 1998).

Grounded theory originates in the data; therefore grounding theory in the concepts is crucial. Several steps are necessary to build theory in this way. Data is first described, with the understanding that it will form the foundation of the theory. The next process is conceptual ordering, or organizing data into distinct categories based on important components and using description to clarify the elements. Coding procedures assist with organizing the data that is used to systematically explain an issue and build theory (Strauss & Corbin, 1998).

Since the goal of grounded theory analysis is to develop theory from the data, I looked for concepts, first within individual interviews and then across interviews to begin to understand the experience of older adults with co-occurring disorders. Participant quotations and description of their issues were used to depict the concepts. Concepts were named and their meanings were discovered by “breaking apart” the data to understand the extent of its possible meaning. Field notes assisted with the process of questioning the data. After reviewing the concepts, I began to group them into categories more abstract than the concepts. The process of grouping into categories assisted with understanding what the experience of older adults with co-occurring disorders might be. As the categories became clearer, I attempted to understand the features and variations within the categories. Finally, theoretical coding integrated the categories and led toward theory and a beginning understanding of the experiences of older adults with co-occurring disorders (Charmaz, 2006; Strauss & Corbin, 1998).

Transcription. I audiotaped interviews, which provided the actual and complete words of the participant, and allowed me to hear the emotion that accompanied the

statements. The audiotapes assisted me to avoid ignoring or interpreting participant ideas during the interview. I took notes during the interviews and these notes helped me return to issues when the participant had gone in another direction. I could document non-verbal behavior. Finally, I could make quick notes of my own reactions to what was said which provided prompts for more complete notes following the interview. I transcribed each audiotape verbatim including pauses, false starts, laughs, and other remarks. Interviews provided the participants' subjective narratives of their lives as they related to co-occurring disorders. This included their perspective of the experience of the disorders as well as environmental factors including family, significant relationships, support systems, important life events, work, treatment, interaction with the criminal justice system, self-perception, and identity issues.

Transcription was completed as soon as possible after the interview. While transcription took a good deal of time, it was a way to get to know the data well. Listening and re-listening to the audiotapes while transcribing helped identify possible concepts as well as the context surrounding the participant.

Field notes. I made notes during and after each interview. The notes included basic information about the interview. I included my responses to the person and the interview process. I recorded beginning thoughts about what I heard in the interview and possible meanings of these ideas. I noted concepts and ideas that seemed especially important for understanding the experience of the participant. Sometimes I recorded a specific quotation that identified or illustrated an important idea. As I proceeded through the interviews, I began to make comparisons of experiences with concepts that developed

and considered possible explanations for what I was hearing. These notes assisted in identifying my assumptions, opinions, and perspectives and sensitized me to work toward maintaining understanding the data rather than judging it (Patton, 1990).

My practice with people with individual and co-occurring mental health and substance misuse difficulties was both helpful and an obstacle during the research process. Practice experience assisted with interviewing and helped me understand the general issues of co-occurring disorders. The challenge was to remember to listen to the participant and not to discount new information did not fit my past knowledge. I needed to remember my biases that developed from practice and research and instead, focus on the here and now with the participant. My notes sensitized me to my experience and helped me remain open to new ideas (Patton, 1990; Strauss and Corbin, 1998).

Data analysis process. Critical reflection of the data was a continuous process. Analysis was inductive as findings emerged from the data. This study began with several assumptions that derived from the literature and from my practice, and when these assumptions were found valid, they were continuously refined. However, when my assumptions did not fit, I used the analysis process to question what was different and consider alternative explanations of the data. While assumptions were used as a place to begin gathering information, I remained open to new ideas and understood that beginning assumptions might not fit with the experience of the participants (Patton, 1990; Strauss & Corbin, 1998).

The process of data collection and analysis was ongoing. Each transcribed interview was reviewed several times for beginning concepts, patterns that began to

develop, and awareness of possible meaning of the data. Observations and thoughts were noted and as the interviews progressed, beginning connections across interviews were made forming concepts and beginning categories. Data from each interview was used to revise the interview protocol and guide future interviews. (Strauss & Corbin, 1998).

Coding stages. Three stages of coding occurred. The first stage consisted of breaking information into small units and naming these units or concepts. A comparative process was used to identify units that shared common qualities, and these concepts were placed within the same code. These beginning codes were impermanent, while providing a placeholder for ideas. I began by reading the entire interview and questioning what was meaningful and important to understand older adults with co-occurring disorders. After reading the interview to get an understanding of the big picture, I read the data several more times to find meaningful pieces of information. I went beyond my own assumptions and documented the data as it was presented. Strauss and Corbin's open coding procedures allowed me to move beyond description and personal assumptions. I found complex levels of abstraction as I labeled phrases, stories, and interactions, and began to identify concepts (1998). This phase of the work also helped me to note areas that needed further exploration. These beginning concepts were placed on a Data Reduction Form (See Appendix F) to keep track of them. As data and concepts were added, the Data Reduction Form changed (Charmaz, 2006; Strauss & Corbin, 1998).

The second stage of coding focused on systematically developing categories and subcategories. Interviews were repeatedly read and compared. The goal of this work

was to find common concepts and turn them into categories. These categories were more abstract than the concepts and began to provide explanations of the data.

As categories emerged from the data, they were labeled with names developed from the data and the literature. Both general and specific features of the categories were identified and variations were examined to assist with understanding patterns inside the category (Strauss & Corbin, 1998). The Data Reduction Form continued to change as more complete and abstract categories developed.

The next stage of data analysis involved relating categories and subcategories. While the category identifies the problem, the subcategories clarify the issue by answering questions about it and providing more explanation for the phenomena. This stage began during open coding when concepts were developed into categories and subcategories. These categories and subcategories were examined to identify their relationships and look for explanations. The coding provided context for the phenomena of co-occurring disorders in older adults by answering questions about the development of co-occurring disorders, the circumstances in which these disorders occurred, how older adults were affected by the co-occurring disorders, and how they began the recovery process (Strauss & Corbin, 1998).

Theoretical coding signifies the process of integrating and refining categories that form theory. While the development of the co-occurring disorders in older adults was important, participants' resilience in finding ways to recover was the central theme or category that integrated the categories and formed the theory. Once the resilience category was identified, it was refined by reviewing the other ideas for consistency, gaps

in logic, revising poorly developed categories, and validating the findings. I reviewed the data to assure that resilience was the central category and that the categories fit with resilience. Categories were reviewed to ensure that they were well developed but that they did not include unnecessary data (See Appendix G, Data Reduction Matrix).

The process of coding was not sequential. During each stage of coding, ideas for other stages became apparent. Notes were used to keep track of these ideas, and these notes were reviewed continuously. The process developed theory that was grounded in the data. While not every case was a perfect fit for each part of the data, each participant demonstrated resilience in dealing with co-occurring disorders. In addition, rural communities provided a particular context in which the process occurred (Strauss & Corbin, 1998).

Data Validation

The research was validated in three ways. The research process, member checking, and checking with practitioners were used to enhance the validity of the findings. Member checking and checking with practitioners refers to reviewing findings and themes with participants and practitioners (Lincoln & Guba, 1985).

Validation of the research process. The performance of the research process has much to do with validity when conducting a qualitative study. The credibility of this study is supported by its use of qualitative research methods to plan the project, gather good quality data, and carefully analyze the data. The credibility of the researcher is an important part of the process as well. Experts in qualitative research guided me in developing and conducting this study. Belief in the process of qualitative research is also

important. In the process of exploring this issue, it became clear that only a qualitative methodology and analysis would provide the depth of understanding that I wanted (Lincoln & Guba, 1985; Patton, 1990).

Participant validation. In addition to the processes described above, member checks provide evidence of credibility of the findings. Member checks can occur at different times in the process. They can be conducted directly after gathering information from the person to test for accuracy of understanding the interview. Member checks can be carried out near the end of the project as a way to confirm that the interpretation of the findings is or it not a fit for the participants from whom the data was gathered. Member checking strengthens the credibility of a study (Doyle, 2007; Lincoln & Guba, 1985).

I used member checks to see whether I had interpreted the data in keeping with the participants' perspectives. Eight participants reviewed the analysis of the study findings. Participants reviewed categories and themes derived from the interviews and commented on the model that was developed based on these categories and themes. Participants participated in this review based on several criteria. Participants had agreed to take part in this follow-up process. Participants included men and women ranging in age from 62 to 89. The severity of co-occurring disorders had ranged from mild to severe. All were in some stage of recovery. The participants confirmed the findings of the study. In addition, participants provided clarifying comments and their ideas expanded and emphasized certain ideas. These additional ideas were integrated into the final report.

Practitioner validation. Lincoln and Guba recommend use of a panel of stakeholders to review the findings as a way to test the credibility and enhance the trustworthiness of the report (1985). Two practitioners who work in the mental health and substance misuse field reviewed the study findings. The practitioners both have extensive experience with co-occurring disorders and have worked with people whose disorders range from mild to severe. One practitioner has worked with older adults and currently works in a rural setting. Their expertise provided validation from a practice perspective.

The practitioners independently reviewed the categories and themes found in the study, participant ideas for developing an approach to assisting older adults with co-occurring disorders, and the model that was developed based on the findings. These practitioners validated the model as appropriate for practice. They made suggestions for updating some practices and emphasizing ideas within the model that are important to good practice with older adults with co-occurring disorders. These ideas have been incorporated into the model and report.

Study Strengths and Limitations

Grounded theory provided a flexible yet systematic method of developing the study and analyzing the data. This approach allowed the data to inform the theory, a necessary process given the paucity of knowledge about older adults with co-occurring disorders. Grounded theory provided explicit procedures that assisted with focus and objectivity (Charmaz, 2006; Patton, 1990; Strauss & Corbin, 1998). In addition, grounded theory empowered older adults to tell their own stories and provided the

potential to inform research, practice, and policy (Rapp, Kishardt, Gowdy, & Hanson, 1994).

Use of a small, non-probability sample limited the generalizability of the study. While a random sample might have allowed for quantitative validity and reliability, that was not the main purpose of this study. This qualitative research focused on finding trustworthy data that provided deep and rich understanding of older adults who live in rural communities and experience co-occurring disorders. Describing the sample and procedures were more important than sample size in order that the reader could make decisions about trustworthiness of the analysis and to what populations the data is relevant (Patton, 1990; Strauss & Corbin, 1998).

Use of a voluntary sample meant that diverse experiences with co-occurring disorders were not as broad as desired. There may be significant differences between those who volunteered to take part in such a study and those who did not. At the same time, the participants provided understanding of the issues for white, English-speaking older adults with co-occurring disorders living in rural communities. This beginning theoretical understanding can be used to explore other populations with co-occurring disorders.

Summary

This chapter described the methodology used to develop this study of older adults who live in rural communities and have co-occurring mental health and substance use disorders. The qualitative grounded theory design was explained. The sample, ethical issues, instruments, data collection, data analysis, and validation of the research process

were described. Strengths and limitations of the methodology were discussed. This grounded theory approach provided the best way to answer the research questions.

Chapters five through eight describe participant thoughts about and responses to these questions. Chapter five provides a description of the participants. Chapter six describes the risks that participants believed led them toward co-occurring disorders. Chapter seven identifies barriers that participants felt made dealing with co-occurring disorders more difficult. Chapter eight reports the protective and resilience factors that participants found helped them cope with and sometimes recover from co-occurring disorders.

Chapter 5: Participant Description

Chapters five through eight present results of the participant interviews and meaning that the older adult participants living in rural Iowa gave to the experience of co-occurring disorders of mental health and substance misuse. Although individual participants experienced disorders uniquely, use of grounded theory to understand participants' narratives of co-occurring disorders permitted discovery of several categories of meaning. Chapter five describes participants and their co-occurring disorders. Chapter six presents description of risk factors that participants associated with their co-occurring disorders. Chapter seven identifies participants' perceptions of barriers to receiving help for co-occurring disorders. Chapter eight focuses on the protective and resilience factors that participants identified as assisting in recovery from co-occurring disorders.

Study Participants

Twenty-three participants who experienced co-occurring mental health and substance use disorders took part in this study. Thirteen women and ten men ranging in age from 55 to 90 completed study interviews. All participants were white and were citizens of the United States who lived in rural communities in Northwest Iowa. See Table 1.

Participants' pseudonym, sex, and age were provided. Mental health and substance misuse disorders that co-occurred were identified. Participants who experienced multiple co-occurring disorders and participants who experienced more than one onset of co-occurring disorders were noted. Time of onset of co-occurring disorders, severity of disorders, order in which disorders occurred, treatment, and recovery status were discussed. See Table 4.

Table 4

Co-Occurring Disorders and Recovery Status by Participant

Participant	Age & Sex	Onset of Co-Occurring Disorders	Order of Disorder Occurrence	Severity of Co-Occurring Disorders	Mental Health Disorders	Substance Misuse Disorders	Recovery Status
#1 Neil	Male 61	Adult	1 st . MH 2 nd . SM	Moderate	Depression with anxiety	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: mild
		Older adult	1 st . MH 2 nd . SM	Mild	<ul style="list-style-type: none"> ▪ PTSD ▪ Personality Disorder 	Prescription medication	
#2 Michael	Male 55	Adolescence	1 st . MH 2 nd . SM	Mild	Depression with anxiety	Alcohol Marijuana	In recovery
		Older adult	1 st . MH 2 nd . SM	Moderate	Depression with anxiety	Marijuana	
#3 Dove	Female 75	Adult	1 st . MH 2 nd . SM	Moderate	Depression with anxiety	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: mild
		Older adult	1 st . MH 2 nd . SM	Mild	Depression with anxiety	Prescription medication	
#4 Robert	Male 76	Adolescence	1 st . MH 2 nd . SM	Moderate	<ul style="list-style-type: none"> ▪ Depression with anxiety ▪ Anger disorder 	Alcohol	In recovery
#5 Connie	Female 62	Adult	1 st . MH 2 nd . SM	Severe	<ul style="list-style-type: none"> ▪ Depression with suicidal thoughts ▪ PTSD ▪ Gambling 	Alcohol	In recovery
#6 Joan	Female 73	Adult	1 st . MH 2 nd . SM	Moderate	Depression with anxiety	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: in recovery
#7 Mina	Female 73	Adult	1 st . MH 2 nd . SM	Moderate	Depression	Alcohol	<ul style="list-style-type: none"> ▪ MHD: moderate ▪ SMD: moderate

#8 Nancy	Female 66	Adolescent	1 st : MH 2 nd : SM	Severe	<ul style="list-style-type: none"> ▪ Depression with suicidal thoughts ▪ Anger disorder 	Alcohol, Prescription, OTC, CAM	<ul style="list-style-type: none"> ▪ MHD: moderate ▪ SMD: moderate
#9 Marva	Female 70	Adult	1 st : MH 2 nd : SM	Mild	Depression with anger	<ul style="list-style-type: none"> ▪ Alcohol ▪ Prescription medication 	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: moderate
#10 Laura	Female 64	Adult	1 st : MH 2 nd : SM	Severe	Depression complicated by grief	<ul style="list-style-type: none"> ▪ Alcohol ▪ Prescription medication 	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: in recovery
#11 Chuck	Male 71	Adult	1 st : MH 2 nd : SM	Moderate	<ul style="list-style-type: none"> ▪ Depression with anxiety ▪ OCD 	Alcohol	In recovery
		Older adult	1 st : MH 2 nd : SM	Moderate	<ul style="list-style-type: none"> ▪ Depression with anxiety ▪ OCD 	Alcohol	
#12 Celia	Female 66	Adolescence	1 st : MH 2 nd : SM	Severe	<ul style="list-style-type: none"> ▪ Depression with anxiety ▪ Sexual disorder 	<ul style="list-style-type: none"> ▪ Alcohol ▪ OTC 	<ul style="list-style-type: none"> ▪ MHD: moderate ▪ SMD: moderate
#13 Amy	Female 85	Adult	1 st : MH 2 nd : SM	Severe	Depression with anxiety	<ul style="list-style-type: none"> ▪ Alcohol ▪ Prescription medication 	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: in recovery
#14 Don	Male 85	Childhood	1 st : MH 2 nd : SM	Severe	<ul style="list-style-type: none"> ▪ Depression ▪ PTSD 	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: in recovery
#15 Rich	Male 60	Adolescence	1 st : MH 2 nd : SM	Severe	Depression with suicidal thoughts & plan	Alcohol	In recovery
#16 Mitch	Male 59	Adult	1 st : MH 2 nd : SM	Severe	Depression with suicidal thoughts	<ul style="list-style-type: none"> ▪ Alcohol ▪ Poly-drug use 	<ul style="list-style-type: none"> ▪ MHD: moderate ▪ SMD: in recovery
#17 Vince	Male 81	Older adult	1 st : SM 2 nd : MH	Severe	Depression with suicidal thoughts	Alcohol	In recovery

#18 Debra	Female 76	Adult	1 st . MH 2 nd . SM	Moderate	<ul style="list-style-type: none"> ▪ Depression ▪ OCD 	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SM: in recovery
#19 Leon	Male 86	Adolescence	1 st . MH 2 nd . SM	Severe	<ul style="list-style-type: none"> ▪ Depression with suicidal thoughts ▪ PTSD 	Alcohol	In recovery
#20 Mere	Female 90	Adult	1 st . MH 2 nd . SM	Moderate	Depression	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: in recovery
#21 Ed	Male 85	Older adult	1 st . SM 2 nd . MH	Moderate	Depression	Alcohol	<ul style="list-style-type: none"> ▪ MHD: mild ▪ SMD: moderate
#22 Lois	Female 70	Older adult	1 st . MH 2 nd . SM	Mild	Depression with anxiety	Prescription medication	In recovery
#23 Jean	Female 77	Older adult	1 st . MH 2 nd . SM	Severe	<ul style="list-style-type: none"> ▪ Depression with suicidal thoughts ▪ Anger Disorder 	Prescription medication	<ul style="list-style-type: none"> ▪ MHD: moderate ▪ SMD: in recovery

Sex: M = Male; F = Female

MHD = Mental Health Disorder; SMD = Substance Misuse Disorder

Mental Health Disorders: PTSD = Post-traumatic stress disorder; OCD = Obsessive-compulsive disorder

Substance misuse disorders: OTC = Over the counter medications; CAM = Complementary and alternative medications

Mental health disorders. Mental health disorders were identified by using the Mental Health Screening Form III-Adapted. See Appendix C. Based on the screening instrument, all 23 participants exhibited symptoms of depression, eight experienced anxiety, and seven had suicidal thinking at some point in their lives. Other disorders, including anger, post-traumatic stress, obsessive-compulsive, personality, sexual dysfunction, and gambling problems occurred much less frequently. Ten participants showed evidence of more than one mental health disorder. Table 2 displays the number of participants who experienced each disorder and Table 4 presents the disorders experienced by each participant.

Substance misuse disorders. Substance misuse was identified by using the Simple Screening Form for Substance Abuse-Adapted. See Appendix D. Based on the screening instrument findings, 21 of the 23 participants had some level of alcohol misuse. Six participants with alcohol difficulties also went through prescription drug misuse at some point while two experienced prescription drug misuse only. Two participants misused over-the-counter medication. One person each experienced marijuana, complementary and alternative medication, and poly-drug misuse. Each of these three also had alcohol difficulties at some point. The number of participants who experienced each disorder are displayed in Table 2 while Table 4 presents the disorders experienced by individual participants.

Co-occurrence of disorders. The co-occurrence of disorders was complex. Each participant experienced at least one mental health difficulty and one substance misuse difficulty. Others experienced multiple disorders of one or both types.

Participants experienced as many as three mental health disorders and two substance use disorders. Participants developed co-occurring disorder symptoms as early as childhood and continued to experience them into older adulthood. One participant developed co-occurring disorders as a child and six more participants developed co-occurring disorders during adolescence. Twelve participants developed co-occurring disorders as adults. Four participants first developed co-occurring disorder symptoms as an older adult. Four participants developed co-occurring disorders early in life, resolved them, and developed different co-occurring disorders as older adults. See Table 4.

Onset, severity, and order of disorders. Participants described three factors related to the development of co-occurring disorders. Age at onset, severity of disorders, and order in which disorders occurred provide a partial picture of the development of the co-occurring disorders. Onset refers to the time that the participant first experienced symptoms of a mental health or substance misuse disorder. For the purpose of this study, childhood onset refers to ages 0-12, adolescence onset refers to ages 13-19, adult onset refers to ages 20-54, and late adult onset refers to age 55 and older. Order refers to whether participants first experienced mental health or substance use difficulties.

The assessment forms did not provide a way to measure degree of difficulties. This study used the DSM-IV-TR severity specifiers of mild, moderate, and severe. Mild refers to disorders where the symptoms result in minor impairment of social or occupational functioning. Severe refers to disorders where the symptoms result in marked impairment in social or occupational functioning. Moderate refers to disorders where impairment falls between mild and severe (American Psychological Association,

2000). I assessed degree of difficulty based on the participant's description of the disorders. See Tables 4 and 5.

Table 5

Onset and Severity of Mental Health and Substance Misuse Difficulties

Onset of First Mental Health Difficulty	Highest Ever Severity			Total Disorders by Age at Onset
	Mild	Moderate	Severe	
Childhood	1	4	6	11
Adolescence		3	1	4
Adult	2	3		5
Older adult	1	1	1	3
Total Mental Health Disorders by Severity	4	11	8	23
Onset of First Substance Misuse				
Childhood		2	1	3
Adolescence	2	1	3	6
Adult	2	6	4	12
Older adult	2			2
Total Substance Misuse by Severity	6	9	8	23
Onset of First Co-occurrence of Disorders				
Childhood			1	1
Adolescence	1	1	4	6
Adult	1	7	4	12
Older Adult	1	1	2	4
Total Co-occurring Disorders by Severity	3	9	11	23

Onset. Fifteen participants in this study reported childhood or adolescent onset of first mental health disorders while eight participants reported first onset as adults or older adults. Nine participants reported first onset of substance misuse in childhood or adolescence and 14 reported first onset as adults and older adults. Participants sometimes experienced a second onset with different disorders. See Table 5.

Participant co-occurring disorders most often began during adulthood. Seven participants experienced onset of both disorders during childhood or adolescents. Sixteen developed first onset of co-occurring disorders as adults or older adults. While four participants developed co-occurring disorders for the first time as older adults, two others had resolved co-occurring disorders earlier and developed a different set of disorders in later life.

Severity. The terms mild, moderate, and severe were used to describe participant co-occurring disorders. No participants experienced extended institutionalization. All participants lived in the community except during inpatient treatment of less than two months. While some participants experienced disabling effects, no one had applied for formal disability diagnosis or benefits. Four participants had been fired when their co-occurring disorders interfered with work. Seven participants had experienced suicidal symptoms.

Of the 23 participants, eleven developed severe co-occurring disorders, nine developed moderate co-occurring disorders, and three developed mild co-occurring disorders. When onset and severity of co-occurrence were examined together, the participant whose disorders began in childhood developed severe co-occurring disorders. Four of the six participants who developed co-occurring disorders as adolescents experienced severe disorders. When co-occurring disorders began in adulthood, four of 12 had severe disorders, seven experienced moderate disorders, and one developed a mild co-occurrence. Of the four whose disorders began in older adulthood, two experienced

severe disorders while one experienced moderate disorders and one experienced mild disorders. See Table 5.

Order. When the participants of this study described their co-occurring disorder symptoms, all but two reported that mental health disorders preceded substance use disorders. The two who reported substance use preceding mental health difficulties started drinking alcohol in childhood.

Treatment. Eleven participants obtained treatment for one or both disorders. Nine participants attended inpatient treatment, outpatient treatment, or self-help groups. Two of the nine participants repeated inpatient treatment. Five of the nine participants received more than one kind of treatment. One additional participant was evaluated for substance misuse and one additional participant received medication for depression from her physician. Two other participants received treatment for issues not related to co-occurring disorders. Ten participants received no treatment of any kind. See Table 6.

Eight participants received some form of treatment for substance misuse disorders while three participants received some type of treatment for mental health disorders. One participant received consecutive treatment for both disorders. No one received integrated treatment for co-occurring disorders.

Of the eleven participants who received treatment for one of their co-occurring disorders, seven had severe disorders. Of the 10 participants who received no treatment, seven had moderate disorders and two had severe disorders.

Treatment relationship to onset and severity. For the purposes of this study, disorders that occurred during childhood and adolescence were referred to as early-onset

while disorders that occurred between ages 20-54 were identified as adult onset. When disorders began at age 55 or later, they were labeled as late-onset. See Table 5.

Table 6

Severity of Difficulties, Treatment, and Recovery Status by Participant

Participant	Severity of Co-Occurring Disorders	Inpatient Treatment	Out-Patient Treatment	Self-Help Group	Other	No Treatment	In Recovery
1	Moderate			MH			No
2	Moderate				SM Evaluation		Yes
3	Moderate					0	No
4	Moderate					0	Yes
5	Severe	MH	MH				Yes
6	Moderate					0	No
7	Moderate					0	No
8	Severe				Grief Group		No
9	Mild					0	No
10	Severe			SM			No
11	Moderate					0	Yes
12	Severe					0	No
13	Severe			SM			No
14	Severe	SM	SM	SM			No
15	Severe	SM	SM	SM			Yes
16	Severe	SM; MH	SM; MH	SM			No
17	Severe	SM		SM			Yes
18	Moderate			SM			No
19	Severe					0	Yes
20	Moderate					0	No
21	Moderate					0	No
22	Mild				Medication		Yes
23	Severe				Marital counsel		No
Total		MH—2 SM--4	MH—2 SM—3	MH-1 SM-7	4	10	Y = 8 N = 15

MH = mental health; SM = substance misuse

Treatment was associated with early-onset and severe disorders. Eleven participants had at least one severe disorder, and ten of those disorders began in childhood or adolescence. Of the 11 participants with severe disorders, nine received

some kind of treatment for at least one of the disorders. Two participants with severe disorders received treatment that was not related to co-occurring disorders. See Table 6.

Four participants with at least one early-onset severe disorder received inpatient treatment for substance misuse and two of those participants were also treated on an outpatient basis. Two participants received inpatient mental health treatment and the same two received outpatient mental health counseling. One participant received substance misuse and mental health inpatient treatment consecutively. Six participants, including one whose co-occurring disorders began as an adult, attended support groups for substance misuse. Of the remaining participants with severe disorders, one had attended a grief group and one had attended marital counseling. Neither the grief group nor the marital counseling addressed co-occurring disorders. Two participants with severe disorders received no treatment of any kind. See Table 6.

Those with mild or moderate co-occurring disorders were unlikely to receive treatment. Two of 10 participants with moderate co-occurring disorders attended a support group while one received a substance misuse evaluation. One of two participants with mild co-occurring disorders received medication. Seven participants with moderate co-occurring disorders and one participant with mild co-occurring disorders obtained no treatment of any kind. See Table 6.

Recovery. At the time of interviews, eight participants described themselves as being in recovery from their co-occurring disorders. Eight participants described themselves as being in recovery from one disorder and working toward recovery from the other. Seven participants were still experiencing symptoms of both disorders. See Table 4.

Summary. Participants experienced co-occurring difficulties beginning at all times of life. Mental health difficulties most often preceded substance use difficulties for the participants in this study. When one or both disorders began early in life, the co-occurring disorders were more likely to be severe than those co-occurrences that began later in life. No participant received integrated treatment for co-occurring disorders and only one participant received treatment for both disorders. About one-third of the participants were in recovery from both disorders, about one-third were in recovery from one disorder, and about one-third had two active disorders.

The description of the co-occurring disorders, treatment, and recovery status portray the participants in limited ways. Participants described complex lives that included risk factors for developing co-occurring disorders and barriers that they experienced as they attempted to resolve their problems. Participants wanted those who read this report to understand that not only their co-occurring disorders and difficult times but also their resilience and rewarding experiences were significant.

Chapter 6: Risk Factors

Chapter six reports risk factors for co-occurring disorders identified by participants. Childhood difficulties, which included deprivation, parental mental health and substance misuse problems and childhood mental health and substance misuse problems, comprised the first sub-category of risks. The second sub-category of risks described by participants had to do with gender. Women participants discussed lack of partner support, gender roles, loss of children, and other gender issues. Participants described several kinds of loss that placed them at risk to develop co-occurring disorders as the third sub-category of risk factors. Participants described losses that included hopes and dreams, early loss of parents, and sibling deaths. Caregiving that occurred during childhood and adolescence as well as during adulthood and older adulthood comprised the fourth sub-category of risk identified by participants. See Appendix G, Data Reduction Matrix, for details of individual participants' risk factors.

Childhood Difficulties

Many of the participants in this study described childhoods that left them with a sense of insufficient support and care from families. Participants experienced deprivation through poverty, neglect and abuse, and institutional actions that increased the deprivation. Some had parents who experienced mental health and substance misuse problems and were not physically or emotionally available to their children. Several participants experienced their own mental health or substance misuse difficulties during childhood. See Appendix G: Data Reduction Matrix and Table 7.

Deprivation. Inadequate care occurred in several ways. Some participants grew up in families where poverty was critical enough to deny them basic needs. Several experienced severe neglect and abuse within their families. A few participants noted that societal institutions played a role in separating them from family. These factors sometimes interacted, leaving the participants to face multiple challenges during childhood.

Table 7

Childhood Risk Factors

Deprivation	Parental Mental Health or Substance Use Problem	Childhood & Adolescent Mental Health or Substance Misuse Problem
<ul style="list-style-type: none"> ▪ Poverty: 6 ▪ Neglect/Abuse: 5 ▪ Societal Institutions: 3 		<ul style="list-style-type: none"> ▪ Childhood mental health problem: 11 ▪ Childhood substance misuse problem: 3 ▪ Adolescent mental health problem: 4 ▪ Adolescent substance use problem: 6
10 Individuals	11 Individuals	17 Individuals

Poverty. Several participants described childhoods defined by poverty. Not simply the inadequacy of material resources, but also feeling insufficient support from parents created a feeling of deprivation. Leon described the poverty and abuse that he experienced as a child. He was emphatic that his father's imprisonment, the community attitude toward his family, and the school's attitude toward him were significant parts of feeling isolated and alone.

Dad was in prison when I started school. . . . I was teased about Dad being in prison and got in fights about it. Mom claimed he was working. The second time he was

in prison I could read and saw it in the paper. I never saw him again. He was never a father. . . . We didn't have enough as kids. We ate at the soup house. We'd pick up soup from the hospital. It was the leftovers from what they cooked for the patients. . . . My mother was abusive. . . . I was the third of the family and Mother's whipping post. Mom whipped me with a lilac stick until I bled. . . . The whole town [had the attitude] that if you're a [family name], you're bad. I decided to leave school in 1939 [at age 15]. . . . Education is wonderful but I was abused there. . . . When I left home, it was like being out of the storm and going into the sunshine. . . . When I was in the army and during childhood, I was depressed and suicidal. These two experiences were two of a kind.

For Leon, childhood was comparable to the combat he was in during World War II.

Neglect and abuse. Some participants described neglectful and abusive parental behaviors. Whether or not these behaviors accompanied poverty, the participants felt deprived of safety and care.

Connie talked about abuse from parents, her father's gambling and alcoholism, and poverty that affected her health care.

When I was in 3rd grade, I had polio. . . . We didn't have any health insurance so I couldn't be in the hospital. . . . I spent three months in bed quarantined. I had no support. Mom would say, "I wish you had never been born. You're too much work." . . . I was sexually abused [by my father]. . . . My childhood was hard. There was no love. . . . Dad gambled. . . . My dad was alcoholic. Mom was an enabler and verbally abusive.

Although Connie had two life-threatening illnesses between ages five and eight, she felt that the neglect and abuse of her parents was the most difficult part of her childhood.

Societal institutions. Some participants identified welfare departments and parental imprisonment as contributing to their sense of loss by separating them from their parents and families or demeaning them for parental behavior. This contributed to their sense of deprivation in childhood and long after.

Jean's father died when she was one year old. Jean noted the resulting poverty that was enforced by the "welfare department."

I was one year old when Dad died so I have no memories of him. He died of a heart attack at age 37. . . . Dad was a county engineer and built us a new house. We lost it when he died. Welfare took Mom's new refrigerator and told her people who are on welfare don't need new refrigerators. Mom tried to trade food for my sister's dance lessons but welfare heard about this and wouldn't let her do this either saying people on welfare don't need dance lessons. . . . I remember taking the wagon to get welfare supplies. We wore hand-me-downs from everyone in town. A doctor and his wife adopted us and gave us fresh raspberries and things.

When Jean's mother went to work, Jean stayed with her grandmother rather than her mother and siblings.

I spent summers with mom's Mom in [another town]. . . . This happened because Mom worked. My sisters stayed with friends and Mom's roommate took care of the boys so Mom could work. . . . I was very lonely there [at Grandmother's

home]. My uncle was different, not mentally retarded exactly but something like that, and no one would let their kids come to play.

In Jean's view, her mother knew how to cope with lack of money. "Welfare" was the reason that the family was poor and she was separated from family.

Poverty, neglect and abuse, and negative societal involvement in family life left participants feeling isolated and alone. In addition to feeling helpless to change these conditions, participants did not identify adults, whether family members or others, who were helpful to them. Several felt that the adults who represented institutions added to their misery.

Parental mental health and substance misuse problems. Eleven participants described parents who experienced mental health and substance use difficulties. Five of the 11 reported that these parents were also neglectful or abusive. Their mental health and substance misuse difficulties sometimes contributed to family poverty.

Mitch described a father with physical health and substance misuse problems. Mitch's mother was absent from his narrative. Mitch had thought a good deal about his father's expectations of him as well as his expectations of his father.

Dad was probably alcoholic. When I was growing up his drinking was an embarrassment. My friend's dads didn't drink. Dad had a brain tumor. . . . Dad wanted an All American boy. He couldn't relate to me as a son. It was a laissez faire relationship. We. . . let each pursue our own lives. . . . At times, I blamed Dad. He should have been like other dad's. Now I know he wasn't the problem.

When I was a kid, I felt I needed to pick up the farm. I was overly responsible so people wouldn't know how much Dad drank.

As a child, Mitch had no adult who provided a sense of security or to whom he could turn. Rather, Mitch felt a duty to care for his father in whatever ways he could.

Laura watched her father fall into alcoholism and talked about how it affected her childhood.

My dad was an alcoholic. I was the oldest of six children. I had the best of my dad. I had six good years with him. . . . Dad's parents did not drink. His paternal grandfather was a drinker. His brother had no problem drinking. Dad was the only sibling who drank. His oldest sister married a drunk. . . . I remember when I was about six years old. Dad had a sister and her husband who drank. Dad came out of their house and fell down. I ran to him. I thought he had died. He had passed out from drinking. It felt terrible. After that, I don't have much memory until age 11. Then we moved to town and he had access to the bar. . . . Dad's drinking—I didn't like it. I couldn't bring friends home. He drank at the bar. I didn't know what he would do afterward. I was ashamed. He would jerk us out of bed for a lecture.

Laura's childhood was affected by her father's drinking. After being very close to him as a small child, she watched him develop alcoholism that took away the sense of security she had previously known.

Rich did not understand how he developed his alcoholism since he knew of no history of alcohol problem in previous generations of his family.

There were no known alcoholics in Mom's family. . . . I don't know about Dad's family—they were all in Sweden. . . . Mom always took care of someone. . . . Mom was an enabler. . . . I guess she was my role model. . . . I have no family history of alcoholism. My parents drank minimally. . . . Dad was on all kinds of medication. In his eighties, he became suicidal. He called me and said, "I'm not right in the head". He was on valium and was addicted. He went through detox. Mom was always on pills. I guess she was addicted to medications.

Although Rich knew of his parents' addiction to prescription medication, he did not associate it with alcohol addiction.

Reaction to parents with mental health or substance use difficulties varied. While some were fearful of these parents, others felt the need to care for and protect their parents. The common thread for these participants was a belief that they had no parent or other adult to whom they could turn for help.

Childhood mental health and substance misuse problems. No participant stated that any family, school, or other agency identified her or him as having mental health or substance misuse issues in childhood. Nevertheless, several recognized that they had developed disorders prior to adulthood. See Table 8.

Participants who recognized that they had mental health and substance use problems during childhood or teenage years related these issues to a variety of factors that included parental co-occurring disorders, abuse, neglect, and the absence of their parents. Some participants talked about growing up not just in a family, but also in a society where children were expected and encouraged to drink alcohol. People who lived

in their communities and had mental health problems seldom received identification or treatment services.

Nancy talked about the complex issues of a childhood that included poverty, a parent who drank too much, abuse from several family members, and a learning disorder. She stated,

My childhood was hard. There was no love. My dad was alcoholic. Mom was an enabler and verbally abusive. . . . My oldest brother is not a nice person. . . . We had little food and it was cheap food. . . . When I was a child I had a speech problem/impediment and was perceived as dumb. . . . I was bullied which impaired my memory and I can't remember names of objects. . . . My self-esteem was low as a child. . . . When I was depressed, it was like being in a big black hole. . . . I'm not like Mom [abusive] and . . . I learned from my psychology classes . . . I'm not bad.

Nancy still struggles with the depression that began in childhood. It was very important to Nancy to clarify that she is different from her abusive mother. Nancy's psychology classes provided her with information about abuse, though not about co-occurring disorders.

Table 8

Participant Co-occurring, Mental Health, and Substance Misuse Disorders by Age of Onset and Severity

Participant		Co-occurring Disorders				Mental Health Disorders				Substance Misuse Disorders			
Name	Age	Age at Onset	Mild	Moderate	Severe	Age at Onset	Mild	Moderate	Severe	Age at Onset	Mild	Moderate	Severe
1: Neil	61	Adult		X		Adult		X		Adult		X	
		Older Adult	X			Older adult		X		Older adult		X	
2: Michael	55	Adolescent	X			Child	X			Adolescent	X		
		Older Adult		X		Older adult				Older adult		X	
3: Dove	75	Adult		X		Adolescent		X		Adult		X	
4: Robert	76	Adolescent		X		Adolescent		X		Adolescent		X	
5: Connie	62	Adult			X	Child			X	Adult			X
6: Joan	74	Adult		X		Adult		X		Adult		X	
7: Mina	73	Adult		X		Adult		X		Adult		X	
8: Nancy	66	Adolescent			X	Child			X	Adolescent			X
9: Marva	70	Adult	X			Adult	X			Adult	X		
10: Laura	64	Adult			X	Adult			X	Adult			X
11: Chuck	71	Adult		X		Child		X		Adult		X	
		Older Adult		X		Older adult		X		Older adult		X	
12: Celia	66	Adolescent			X	Adolescent		X		Adolescent			X
13: Amy	85	Adult			X	Child			X	Adult			X
14: Don	84	Child			X	Child		X		Child		X	
15: Rich	60	Adolescent			X	Adolescent			X	Adolescent			X
16: Mitch	59	Adult			X	Child			X	Adult			X
17: Vince	81	Older adult			X	Older adult			X	Child			X
18: Debra	76	Adult		X		Child		X		Adult		X	
19: Leon	86	Adolescent			X	Child			X	Adolescent	X		
20: Mere	90	Adult		X		Child		X		Adult	X		
21: Ed	85	Older Adult		X		Older adult		X		Child		X	
22: Lois	70	Older adult	X			Older adult	X			Older adult	X		
23: Jean	77	Older adult			X	Child			X	Older adult	X		
Totals			3	9	11		3	11	9		6	9	8

Note: Childhood & adolescent onset disorders highlighted

Don described an early accident in which he lost vision of one eye. Don talked about the resulting trauma.

When I was two years old, I was playing with other kids. Another boy had a stick and took out my eye. It affected me, as I was always small. I learned not to ruffle older boys. I always came out second best. I still ruffle some others.

Don struggled with depression throughout childhood and adulthood. Although Don reports that his depression improved when he quit drinking, he became depressed again with his partner's illness and death.

Vince talked about growing up in a farming community where drinking was the norm and children were allowed to drink.

I drank all the time. When I was growing up, we had the thrashing machine. Seven people worked together. Each made homemade brew beer. When I was a kid, they would give me a drink and I would fall asleep.

Teens in Vince's community drank regularly. Vince said, "The boys started drinking at dances and after school and I drank with them."

Vince entered the military after high school. Once again, Vince found a community where his drinking was accepted.

In the service, there were more chances to drink. At [military base], there was always beer and schnapps with the kitchen crew. Nobody minded as long as you didn't make an ass of yourself.

Family, friends, and the military service supported Vince's drinking that began in childhood. No one expressed concern to Vince about his drinking.

Rich, on the other hand, grew up in a household where his parents drank little alcohol. However, drinking was common in the community. Rich first drank when a neighbor for whom he worked gave him beer. “After we finished work, he bought some beer and that was the first time I drank. I liked the feeling I had when I was drinking.” Rich started drinking as a junior in high school. “I worked. I didn’t participate in sports. My parents had no money.” The neighbor, a man about 10 years older than Rich, continued to buy and drink alcohol with Rich and the other adolescents who worked for him. The community provided an entrance to drinking for Rich.

Summary. Participants frequently experienced multiple childhood difficulties that formed a context within which the participants’ co-occurring disorders developed. Three factors that stand out are the lack of sense of support and care from families, the impact of parents who experienced mental health and substance misuse, and the early-onset of mental health and substance misuse difficulties in participants. Participants talked about the life-long effect of these experiences.

Gender Related Risks

Female participants brought up risks associated with support systems, gender roles, loss of children, and other gender issues, and related them to their co-occurring disorders. These issues were important parts of women’s stories of developing co-occurring disorders, while the same factors rarely figured in the narratives of male participants. See Appendix G.

Gender and support systems. While men frequently relied on their partners for support, women more often did not perceive their partners as emotionally available to

assist them during difficult times. Even women who had positive relationships with their partners did not necessarily view them as a primary support. This sometimes left them feeling alone and without adequate assistance during difficult times.

Some participants felt a lack of support regarding family issues. Marva described her husband as a man who was committed to his work and traveled a good deal. Marva felt that all the family responsibility was on her shoulders and she described one of these times.

My mother had dementia and died at age 89. She went to assisted living, then broke a hip, and then moved to a care center. My sister moved [out of state]. She had always lived by Mom. Since she moved, I had to be there as much as possible. [My daughter's] baby was born one day and Mom died the next. [My daughter] had to have surgery. We had the [mother's] wake and postponed the funeral. It just had to be. [My husband] was not helpful.

Marva felt continuously frustrated and angry that her husband would not help more with family matters.

Debra wanted to go to a support group when her husband's drinking was out of control. "I felt about to lose my mind. My sister-in-law invited me [to an Al Anon meeting] and I wanted to go. [My husband] tore the phone out of my hand and wouldn't let me go." The actions of Debra's partner kept her from finding support not only from him but also from others.

Mina did not express resentment at the lack of support from her husband when their daughter died, but simply said, “We were not as close as some [couples] are. We handled things differently.”

It was common for women participants to feel that they could not reach out to anyone for support, including partners, even when the issues were life and death. The participants’ perception was that partners and others did not offer support when they were struggling with difficult issues.

Male participants, on the other hand, often felt that their partners were their most important supports. Rich was grateful that his wife stuck by him as he struggled to get his co-occurring disorders under control.

When [my wife] left, at first it was a relief. Then it was devastating. She came back. I was lucky. [My wife] went to Al Anon. She stayed involved while I drank. She told me “I want back the man I married. This isn’t you.” It hit me. I wanted to stop and couldn’t.

Rich believed that his partner’s willingness to confront him and set limits on his drinking, yet still stay with him, was key to his recovery.

Don had been happy with his marriage, especially after he quit drinking. Don felt lost when his partner died several years ago. Don reported that he did not start drinking again after his wife died. However, he experienced grief and depression still in evidence several years later. “When I retired, we remodeled the house. My wife became sick with cancer. . . . My world came to an abrupt halt. The remodeling came to an end. I haven’t even reconnected the doorbell.”

Female and male participants had very different experiences relative to support from partners. Gender appeared to be a significant factor in how participants obtained support. Women participants perceived a relationship between inadequate support and mental health and substance use symptoms when they felt that they could not ask partners and others for the support that they needed.

Gender roles. Several women participants felt disapproval when they took on roles and actions that were unexpected or deemed to be inappropriate for women. Women participants reported gender-based stereotypes, discrimination, and abuse.

Most women participants struggled with alcohol problems at some point in their lives. Laura, who developed depression and alcohol disorders in her twenties and started attending Alcoholics Anonymous in her thirties, talked about the stereotype that women do not become alcoholic. Laura found it difficult to attend Alcoholics Anonymous meetings in her hometown due to her husband's jealousy and lack of women role models in the group.

I was 38 when I got sober. It was unheard of for middle-aged women to be alcoholics. My husband was a drawback. He didn't believe me—didn't believe in me—that I could quit. Alcoholics Anonymous was mostly men at that time and my husband was jealous. The [different community] meeting had more women and that is where I got my first sponsor.

Laura drove to an out-of-town meeting in order to get her treatment needs met and cope with her husband's jealousy.

Nancy talked about the gender discrimination she felt in work situations and how it affected her self-esteem.

Women—people don't take you seriously, especially if you are pretty, and I was. It was hard to be taken seriously. . . . I sold cars for my husband. They [customers] would ask for a man. I sold them anyway. . . . I overcame a lot. . . . I taught my daughters to be self-sufficient and to stand up for themselves.

Nancy, who had struggled with self-esteem and depression since childhood, noted that gender issues made it difficult to maintain her self-worth.

Joan was an excellent student and eventually earned a master's degree. She felt that instructors did not value her talents and did not want her to speak up in class. Joan said of her experiences in grade school, high school, and college, "The teachers liked boys better." Her perception was that teachers considered it inappropriate for girls to take the lead in class and that gender was more important to the teachers than ability.

Connie's early life experiences of abuse and neglect led her to view being female as not just undesirable, but as dangerous. "Being a woman is usually a negative. I was sexually abused. I've never married." The abuse that Connie suffered led her to believe that women were at risk to be used by men.

Women participants noted that family, customers, and professionals expected women to act in ways that fit their stereotypes. These stereotyped expectations of women interfered with family relationships, education, and careers, as well as getting help for co-occurring disorders.

Loss of children. While the men in the study cared about their children, none associated the loss of a child with their co-occurring disorders. Women, however, felt that they received little support from family or community after these losses and they associated the death of a child with an exacerbation of their co-occurring disorders.

Mina received no assistance when her daughter died at age seven. Mina was tearful as she talked of her daughter's illness and death that had occurred nearly 30 years earlier.

My daughter died of a brain tumor. She was always tired, which seemed odd. She was in third grade at [school]. She had a stomachache so went to her grandparents. It was blamed on her emotions but the teacher knew it was more than that. . . . At Thanksgiving, the family person who was an M.D. was asked to look at her. He said to take her to [doctor], a pediatrician, the next week. [Doctor] called [hospital in another community] and she saw a neuro-pediatrician who diagnosed her and did surgery. . . . She had the best care and doctors. They couldn't get all the tumor and she lost her sight. We were in [hospital, five-hour drive from home] for six weeks over Christmas. We arranged to bring her home. She died [date]. . . . I don't talk about her much anymore. . . . My biggest regret is that I didn't handle it well with the other children. I didn't talk about it with them. . . . I bottled it up. . . . I'm not touchy-feely.

Mina did not express resentment regarding the lack of support from family or professionals. Instead, she developed a style of coping with feelings where she did not reach out to others for support. Mina recognized that her children might have benefited

from emotional support when they lost their sister. She did not express the same sentiment for herself. Only the tears told her feelings.

Laura, who lost her only daughter to Sudden Infant Death Syndrome, discussed the interaction of this loss and her co-occurring disorders.

We had one little girl born in the early 1970s who died of SIDS. . . . By age 26-27, I was more into it [alcohol]. We didn't have much money. I was feeling stressed. We didn't go anywhere. The drinking took off after my daughter died. I was in total shock and turned from drinking into alcoholism. . . . When my daughter died, it was painful. She was two months old. Someone held her always. I drank to ease the pain.

Laura could not separate her depression, grief, and drinking. For her, each disorder made the other worse.

Regardless of societal recognition of the loss of a child and involvement of partners and medical and spiritual providers, women participants perceived that they were alone with this loss. Several stated that depression and substance misuse were ways that they coped with the loss and grief that they felt. No one sought treatment and no one offered help for these losses.

Other gender issues. Participants experienced negative consequences both when conception occurred and was unwanted and when they were unable to become pregnant. Post-partum depression and empty nest syndrome also impacted one participant.

Adolescent pregnancy. Adolescent pregnancy brought family and societal disapproval, stigma, and shame to women from the generations included in this study.

Family and society more often held women but not men responsible for pregnancy that occurred prior to marriage. Costs associated with early pregnancy and the lack of control over unwanted pregnancies included loss of the developmental stage of adolescence, the end of formal education, and loss of career opportunities. Celia described the primary stressor in her life as getting pregnant at 15.

I got pregnant in my sophomore year of high school and earned a GED in my sixties. . . . I was 15 and [my husband] was 20. . . . He worked at the packing plant. . . . It was difficult to make ends meet. I was 16 when our first child was born and 21 when the third was born. It was stressful. . . . I had three kids, I was young, we had little money, no insurance, and a little house. . . . It was stressful to deal with Mom's family. . . . They were very disapproving of me because of the early pregnancy. Mom's sister wanted me to give up my child.

Celia's adolescent pregnancy interfered with completion of her education and career goals. The impact of the early pregnancy has lasted into older adulthood.

I worked at [store] for a while. I managed the apartments. I've had several jobs—a florist. I still have a silk flower shop. . . . I'm not working now and I don't want to. But I want more than to be a "housewife".

Inability to conceive. The inability to get pregnant also created loss for women. Not unlike an early pregnancy outside of marriage, the inability to conceive carried both grief and shame. Dove described the period before she and her husband adopted as a time of major stress and depression.

It was very stressful before we adopted the boys. I wanted to have children so much. . . . With [my husband] and me waiting for children—I cried every month. Then waiting to see if we would be able to adopt was stressful as well. . . . We adopted when we were 33 and 35. We waited 12 years. It [depression] got worse as time went by.

Dove did not feel that she could confide in anyone. “I keep my sadness to myself.” In spite of long-time sadness about being unable to bear children, Dove related that she neither sought help nor was any offered by family, friends, medical, or spiritual providers. She perceived her loss as individual, a grief that had to be borne alone.

Both Celia and Dove related their co-occurring disorders to the stress of these experiences. Unable to let go of the loss and shame, these female participants reported that depression settled in and substance use provided relief that became a coping mechanism.

Post-partum depression and empty nest. One participant brought up postpartum depression and two participants mentioned empty nest as issues related to co-occurring disorders. Amy noted, “I had after-baby depression at least once.”

While no participants reported that co-occurring disorders started when their children left home, Amy reported an exacerbation of symptoms. “I’d get depressed when we would take them to college and I would drink.” Children provided some motivation for her to control co-occurring disorders. When the children left home, she felt that she lost this motivation.

Although empty nest may be more often associated with women and gender issues, Don described challenges he experienced as his children left home. When the children left, Don felt that an important life role was gone and there was nothing to replace it. He became increasingly depressed and his drinking increased.

My alcohol use went from social to a problem when I was 45-50. I was getting older. The family [children] was getting married and leaving. The household was disrupted and changed. . . . When the kids left home, there was a lot of change. My wife had her clubs. The kids had their lives and children and lived in the city. The grandchildren were city children and didn't have interests similar to mine. When the kids were gone, all I had was work and maintain the house. I felt left out from the kids—shut off and sad. I didn't have any feelings about it. I was numb.

While a limited number of participants noted conception, post-partum depression, and empty nest syndrome, these issues were serious concerns for those who reported them.

Summary. Gender, generation, and context all appear to be a part of the role expectations for women participants in this study. Women in the participants' generations were seen as the center of the home and family. Responsibilities, personal experiences, and societal expectations were quite different for women and men and this may have been more pronounced in rural than in urban communities. In addition to societal expectations, rural communities frequently lack formal services to address the issues that women participants raised. Perhaps this is why the female but seldom the

male participants identified issues related to pregnancy and children as risk factors for co-occurring disorders. Although many of these difficulties occurred during adolescence and young adulthood, the effects lasted well into later adulthood and played a role in their co-occurring disorders. When placed within a framework of risk, lack of support systems, gender role issues, death of a child, and other gender issues appeared to present significant risks for women to develop or exacerbate co-occurring disorders.

Loss and Grief

Most participants had suffered events that they interpreted as losses. Losses that were particularly painful included life dreams and deaths of family members.

Unrecognized grief and the perception of little formal or informal support from family, friends, community, and service providers appeared to increase difficulty in coping with losses. Most participants felt alone with their loss. Many participants experienced lowered self-confidence in relation to these events. Some participants experienced significant financial and other resource struggles relative to their losses.

Hopes and dreams. Most participants talked about their hopes and dreams for careers, family, and life meaning. Several talked about the increase in co-occurring disorder symptoms when dreams and hopes were dashed.

One kind of loss associated with hopes and dreams had to do with education. Chuck experienced undiagnosed learning difficulties as a child and grew up believing that he was not intelligent. Chuck reported that he performed poorly in school. He believed that teachers allowed him to graduate because he was not troublesome. He described his frustration with learning.

When I was growing up, I had severe dyslexia that was undiagnosed. . . . I was so frustrated with school. . . . I'd think 'I want to learn.' I kept thinking, 'I should be able to do this'. There was no one to help me. I thought I was dumb.

The effects of the early misperception of low intelligence lasted into older adulthood.

These consequences affected Chuck initially in terms of low self-esteem and depression and later as pressure to compensate for the early lack of success in education.

A particularly rural loss occurs when people lose farms. They lose not only their business but also their homes. Rural families often experience loss of status and shame as the entire community is aware of the loss. Don talked about losing the family farm.

The farm was a quarter section with the house in the middle. My wife and I had been married five or six years and our oldest daughter was four or five. We moved the house closer to the road to make it easier to get to town and school. It took most of our money to do so. The county put in a new ditch and it cost me \$11,000. I had to sell the land I was buying from my dad. I tried to shut it out of my mind [by drinking].

Don was already depressed and perhaps at risk for co-occurring disorders. Don connected the loss of the farm with his increased drinking.

Some dreams were related to generation and gender. Amy taught for a brief time but gave it up to marry, as was expected of women at that time. "I earned a teaching degree. I taught at [community]—the second grade. I loved it but I got married."

Hopes and dreams bring possibilities while the loss of these dreams may create suffering and grief. Participants indicated that the impact of the loss seemed to increase when early experiences left them feeling alone with their loss and helpless to change it.

Early parental loss. Three participants lost their fathers from death when they were small children. Two other participants had no relationship with fathers who went to prison while they were young. Four of these participants experienced severe poverty.

Mere was eight and her family was split up when her father went to prison. The welfare department found her mother a live-in job where she was unable to keep her children.

I was in and out of orphanages since age eight. . . . We were all separated as children. Dad was a bootlegger. He got turned in and the authorities took the kids. . . . The authorities got Mom a job [keeping house] with two farmer bachelors. Some kids went with aunts and uncles. My middle sister and I went to the orphanage. [tears] . . . My father came to the orphanage to see me. I had never seen him. They let me look through the door but I didn't get to speak to him. . . . At age 11, I went to a foster family and worked ever since. I didn't know where I belonged.

After her father was sent to prison, Mere did not see or speak to him again until she was 22 years old.

My daughter is 70 now. When she was two, my mother-in-law said, "Your dad wants to see you." I got to see and talk to him with the police present.

Mere, at age 90, was still tearful as she talked about the separation from her father that also brought about the breakup of the rest of the family.

Debra was married to a man who drank heavily. She took care of the farm as well as worked at her own job. Debra stated, “When [my husband] drank, friends would ask, ‘why do you stay?’ My answer was that I loved family. I didn’t have one [as a child].” Debra lived with her mother and 11 siblings. Yet the loss of her father at age two left her feeling that she did not have a family.

Participants had few memories of fathers who were out of their lives very early. In addition to the loss of the father, participants reported poverty and separation from other family members.

Sibling loss. Five participants lost a brother or sister through death while another lost contact with siblings after being placed in an orphanage. These sibling relationships had provided support in families where there was often little other emotional care.

Laura, who saw her father become alcoholic, had lost three siblings. She was especially close to her sister who died after both Laura and her sister had stopped drinking.

My sister and I drank together. We would go out together. When my sister died, I was sober. . . . When my sister had been sober six weeks, she traveled for work. On her way home, she was in a car accident and was killed. She pulled out in front of a semi. God really wanted her. She died 21 years ago. I had been sober four years then. It was horrific for me. We were close throughout our lives especially when we were both sober. My sister had said, “I want to die first.

You're my only friend." I was pissed off that she died. I got through the funeral but was really hurting. I couldn't look at my sister's picture until two years ago. Before that if I saw a picture of her, I cried. A few years ago, it was wonderful to remember my sister without sadness. I finally released her. It took time. I dreamed about my sister. It helped me get through the first year.

Without the support of their siblings, participants frequently reported that they had no one else who understood their struggles with poverty, abuse, parental mental health and substance misuse issues, and their own problems. This increased participants' sense of being uncared for and alone. All who reported sibling losses were women. It may be that only women participants experienced sibling losses. There may be other explanations for this gendered finding.

Summary. Many participants experienced loss. Some participants maintained their hopes and dreams despite losses and found ways to achieve them. However, losses often led to increased co-occurring disorder symptoms, which affected participant lives for some time. While the experiences themselves were not different from the losses suffered by other people, participants perceived lack of support related to the loss and relationship of the lack of support to co-occurring disorders. Some participants related the loss to the development or exacerbation of their co-occurring disorders, not in a blaming way, but as a way to understand their mental health and substance misuse problems.

Caregiving

Participants came into the caregiving role in different ways and at different times in their lives. Most participants described feeling alone with the responsibilities of caregiving. All participants found their roles as caregivers to be highly stressful although some also found it to be rewarding.

Two participants provided care for parents during childhood and adolescence. Six participants took on this role during adulthood. Eleven participants first became caregivers as older adults and two continued the role from adulthood into older adulthood. Some participants found themselves in the role of caregiver more than once. Several participants struggled to cope with co-occurring disorders while they provided care for partners and others during final illnesses. A number of participants found their co-occurring disorder symptoms increasing when they took on the care of partners or other loved ones.

Caregiving during childhood. Two participants took on the role of caregiving during childhood and adolescence. Even at an early age, these participants were aware of the need to assist parents. They perceived a notable lack of assistance from family or community.

Rich was the youngest child of older parents and he began taking care of them as an adolescent.

My parents had no money. They lived on social security and IPERS [retirement pension]. . . . The folks came to me to keep them at home. I paid bills and fixed the house. . . . Dad came from Sweden when he was 17. I bought tickets for my

parents to go back for a visit. . . . I got them the extras. . . . I didn't know how to say no and I didn't know how to take care of myself. . . . I was single and lived at home with my parents until I was 28.

Rich reported that he did not take part in most high school activities and instead worked to provide for his parents. It was during this time that Rich began drinking alcohol.

While participants took on the role of caregiving voluntarily, this role replaced the role of child, of being cared for, and being helped to learn the skills to grow into adulthood. Participants felt alone in their caregiving tasks.

Caregiving in adulthood and later life. About half the participants provided caregiving as older adults. Although most wanted to fill this need for partners and other family members, several felt overwhelmed by the responsibility. Few participants were aware of community resources to assist with caregiving. Some of the people to whom they gave care did not want outsiders assisting. Other participants found that family members and friends did not help.

Chuck, age 71, had prided himself on coping mechanisms that helped him recover from his co-occurring disorders as an adult. However, Chuck talked about feeling very alone as he cared for his wife while she went through a terminal illness. Chuck was not aware of community resources to assist him with her care. In addition, Chuck's partner did not want formal services brought into the home.

My second wife had cancer. This was the most frustrating experience. It was horrible to see her suffer and not be able to help her. I did what I could but there

was no cure. . . . With my wife, basically it was just me to do everything. The [friends] helped some. But it was all on my shoulders and it was overwhelming.

Chuck talked about how the lack of available resources, both to assist while his wife was dying and afterwards to help him with his loss and grief exacerbated his co-occurring disorders.

It was the most stressful year of my life. The fear and anxiety lasted for about a year after her death. I had a sense of responsibility and fright. It was not over for me. When my wife died, I had dreams and early [morning] awakening.

The stress of caregiving did not end for Chuck with the death of his partner. He continued to experience not only loss and grief but difficulties that were a part of his co-occurring disorders.

Ed, age 85, had used alcohol since he was a child. As Ed's wife slipped into dementia and he tried to figure out how to care for her, Ed misused alcohol and he became aware of depressive symptoms for the first time.

My wife had Alzheimer's disease for eight to ten years. . . . My wife started showing signs of Alzheimer's. We were. . . . having coffee with my wife's good friend. I noticed that [my wife] couldn't answer easy questions. I covered for her. She stayed home until [year]. At that point, the children said, "It's too much for you. She needs to go to a nursing home." She was there seven and a half years . . . when she died.

The biggest stress of my life was my wife becoming ill. It was a natural occurrence so you have to accept it. . . . I was depressed when [my wife] was ill. .

. . I was not aware of any help. I was always self-sufficient. I fought having her go to the nursing home. . . . We didn't have any home help. She went to the Day Care Center for a few months. . . at the hospital for respite. That way I could have some time to do things. When it was time to go get her I'd think, "How am I going to do it [take her home and take care of her]?" when it was time to pick her up again. . . . She didn't want to go to respite care. She'd become agitated.

Chuck and Ed wanted to care for their partners but needed assistance. Both participants reported that their co-occurring disorders worsened when they did not receive help. Whether resources were lacking or whether they did not know about existing resources, the participants experienced exacerbation of their co-occurring disorders as their stress increased.

Jean's relationship with her partner had been negative for a long time. Jean's caregiving began in adulthood and continued into later life.

I took care of my husband who was very ill and retired at age 48. . . . I was his caregiver. He was sick 22 years—ages 48-68 when he died. He died 4 years ago. . . [My husband] drank and had two affairs and then was sick. He couldn't drink any more or run around. He had a stroke and a heart attack and had open-heart surgery. He had a defibrillator. It was awful. It kept going off. It would go off in the night and he'd get all upset . . .He'd wake up screaming. . . . There was lots of fear. He'd be near death. There were not a lot of resources to help—no home care. . . . I always thought things would get better. After he was sick, I couldn't leave.

While Jean felt responsible to care for her partner, she also resented not receiving any support from him in return.

I had a mastectomy in [year]. I had cancer. He had his mind; never put his arm around me and said it would be OK. No support. He was very self-centered. . . . I didn't get a whole lot out of marriage. . . . Two months ago, I started wondering when I had the last decent conversation with him.

Jean did not expect or receive much assistance from family, friends, or formal organizations. She simply slipped deeper into depression and substance misuse.

[My husband] was sick—no one came and asked, “What help do you need?”. . . . Even a visiting nurse or help with discharge planning [would have helped]. . . . Someone to say, “It will be OK.”. . . Toward the end, my son and his wife got a hospital bed for [my husband]. No one said he needed it. His [son's] wife works in the medical field and thought he needed it. They were trying to help. There was no assessment of needs. [My husband] didn't like it. “Why can't I sleep in my own bed?” I let him. . . . Home health agencies don't advertise.

Jean worked at a local hospital in administrative services but was unaware of home health care organizations, whether or not they were available. Jean described increasing despair and anger the longer she fulfilled the caregiver role without adequate support.

Summary. All of the participants who served as caregivers experienced a great deal of stress related to the role. Participants experienced a conflict between wanting to care for family members yet feeling that the task was too much without support and resources. Participants felt alone with the responsibility and work of caregiving. Many

participants connected the lack of support with exacerbation of their co-occurring disorders. Several participants talked about the lack of knowledge of formal resources that could have reduced the stress of providing care.

Conclusion to Risk Factors

Participants suffered many kinds of risks for developing co-occurring disorders. While their risk experiences were no different from those that many people have, participants reported a sense of aloneness and helplessness that increased the stress related to the events. Multiple risk factors often complicated their situations and perhaps their ability to seek support in difficult times. The combination of stressors made it more difficult to grow through these experiences. Participants were at risk to follow many paths to develop co-occurring disorders.

Chapter 7: Barriers to Help

Chapter seven presents barriers described by participants that made it difficult to receive help for co-occurring disorders. These obstacles to recovery were organized into sub-categories of participant barriers, family and friend barriers, rural community barriers, and rural structural service barriers. Participant barriers included lack of information, lack of role models, and fear of treatment. Family and friends often lacked understanding of co-occurring disorders. Family and friends sometimes actively interfered with participants getting help for co-occurring disorders. At other times, family and friends simply did not know how to help. Rural community provider barriers included medical providers, spiritual leaders, and employers who did not understand co-occurring disorders and did not assist participants in gaining services for co-occurring disorders. Rural structural barriers included difficulty accessing treatment and lack of help for other problems that exacerbated participants' co-occurring disorders. Viewing co-occurring disorders as normal was an obstacle for participants to receive help.

Participant Barriers

Several kinds of barriers interfered with participants getting help with co-occurring disorders. Lack of information about co-occurring disorders, absence of role models to demonstrate how to deal with co-occurring disorders, fear of treatment, and views of co-occurring disorders and associated behaviors as normal all interfered with seeking help through treatment.

Lack of information. While the experience of older adults with co-occurring disorders varied widely, no participant had received information about these disorders as

part of their education. No one had seen public service announcements about co-occurring disorders. With few exceptions, medical and social service providers did not share information about co-occurring disorders with older adults. Even treatment facilities did not help treat or educate participants about co-occurring disorders. Thus, as participants experienced their difficulties, they had limited understanding of what was happening to them, knowledge of alternative ways to cope with the precipitants, or the relationship between co-occurring disorders.

Most participants took the lack of information for granted. They had not expected to receive this information. Celia did not get treatment for her co-occurring disorders. Celia stated, “There is a lack of information in the environment. I had insurance and a doctor but got no information.” Having insurance and seeing a physician did not assist Celia to get information about and treatment for her depression and alcohol and medication misuse.

Rich talked about the lack of education in rural communities coupled with the culture of heavy drinking. While he did not think that the lack of information caused his co-occurring disorders, he did feel that it made drinking easier for everyone.

Alcohol was always a part of my life. There was no education about the dangers of alcohol. The town and county I grew up in and still live in has a history of heavy alcohol use. It becomes part of the culture—rural use.

Rich received education about alcohol disorders in treatment but received no information about depression or other mental health issues.

Several participants grew up with mental health problems and substance misuse as part of their daily lives. Some parents provided alcohol to participants when they were children while others learned to drink with peers. Don said, “We always had whiskey in the house. It was the Bohemian way.” Several participants became depressed as children and no one noticed. Some participants recognized their early depression as they reviewed their lives. Amy noted, “I worried a lot as a child.”

Lack of role models. Once co-occurring disorders became troubling, participants often felt alone and confused about how to cope with them. Participants found few role models to provide examples about how to deal with co-occurring disorders. Community leaders and providers in the community did not talk openly about co-occurring disorders. Treatment facilities and community support groups engaged in little outreach, instead waiting for people to request assistance. Participants asserted that the media provided little information about co-occurring disorders. Even when the media acknowledged co-occurring disorders, there was no inclusion of, let alone focus on, older adults.

Celia’s son had trouble with drugs and alcohol during high school, which she described as one of the most stressful times in her life. She was proud of advocating for him to receive treatment.

My son—it was stressful when he was in school. . . . I don’t know if drugs were involved. I think beanies. . . . He went off the deep end and went to inpatient treatment in [two locations]. At times, he was OK. Then he would get back into difficulty. Drinking was involved. . . . He was 17 when he went to treatment at [city]. . . . I was about to lose it. Mom and I agreed that we must do something before he

turned 18. The doctor didn't do anything. He was after the insurance money. My son was better when he was on some meds. . . . I stood up to the doctor for my son. I was really angry with the doctor. My son was worth saving. They did an MMPI. I requested the results. . . . It was an accomplishment that I didn't let the system do him in, and an example of what I can do if I put my mind to it.

Celia described the worsening of her own depression as another highly stressful time in her life. Although Celia had consulted with physicians about her son, she did not do so for herself and her physician did not explore her depression, drinking, and medication misuse.

Two years ago, I didn't care about anything. . . . I felt like I wasn't needed. I had no purpose. . . . I don't know what caused it or why it went away. I was down on myself and everything. It lasted about a year. I was unhappy and caustic. . . . I didn't get any official help with it. I thought about going for help. I didn't know who to go to. I felt like I had to do it myself.

When it came to getting help for herself, Celia did not know what to do. The experience with finding services for her son did not assist Celia to help herself and no one showed her that there were options to depression and misusing alcohol and medications.

Fear of treatment. Even when participants were aware of resources, they did not always have accurate information about help they might receive. Several participants had heard frightening stories about treatment, especially inpatient care, although outpatient treatment was also associated with fears and myths. Participants feared losing control of their lives to family or treatment facilities. For other participants, needing assistance to

address the co-occurring disorders damaged their pride in being able to take care of problems by themselves. Some participants feared the stigma associated with letting others know they had a problem that they could not handle alone. These fears interfered with participants' acceptance of co-occurring disorders and seeking help.

Laura was fearful of treatment, having heard stories about the nearest state mental health institute where people were taken for mental health and substance use treatment as well as her brother's bad experience. In addition, her husband, a police officer who knew the commitment procedure, threatened her with commitment.

I was scared to go to treatment. It was at [state mental health institute]. I knew it as a nuthouse and was fearful of being locked up. . . . My brother went to treatment and had a bad experience. He couldn't crack the way they wanted him to. . . . My husband was on the verge of committing me.

The absence of accurate information about treatment and fear of losing control over her life interfered with Laura getting the help that she needed for her co-occurring disorders.

Rich had seen himself as being capable of managing his life with no help. Although he educated himself about substance use, his pride interfered with believing that he needed assistance to stop drinking.

There was a psychiatrist in charge of treatment the first time. I told him, "I don't need you to tell me what's wrong. I can quit." . . . I didn't drink for two years. I also didn't change my thinking or attitude. I stayed on the dry drunk for two years and then went back to drinking alcohol. . . . My first treatment involved very little AA. I figured, "I can do this myself." . . . I was a self-made man and it

made it hard to accept that I had a problem I couldn't fix by myself. I didn't know how to ask for help. I could see the problem in others but not in myself. Rich went through treatment three times before he accepted the need for assistance. While he found inpatient and outpatient treatment helpful, he found the assistance from members of Alcoholics Anonymous contributed to his recovery by demonstrating how they had maintained sobriety.

In [larger community] AA is available all the time. I used to go a lot. There were some 'successful' people at the meetings, which helped. I went to 140 meetings in 80 days. I saw the same people there and saw that it worked. I read about AA. . . . I found out, "It's not just me."

Alcoholics Anonymous provided role models that helped Rich address his pride issues, figure out how to manage his co-occurring disorders, and move into recovery.

Amy's husband, friends, and physician thought she should go to treatment for alcoholism. Amy did not want to go to treatment and put off their suggestions.

My family and friends suggested treatment. I'd say, "I'll handle it. Give me another chance." . . . My doctor would suggest treatment and say, "Don't let this go on." He knew I was drinking. How do you cover an alcohol problem? [My husband] had suggested treatment but he didn't know about AA. . . . My image of treatment? I didn't want to be gone for four weeks. My life was too busy. I didn't know anyone who had done treatment.

Amy reported that her negative reaction to the suggestion of treatment came from stigma related to treatment, not knowing anyone who had been through treatment, and fear of losing control of her life.

Summary. The combination of lack of information and misinformation interfered with participants' seeking and finding help for co-occurring disorders. Without accurate information or role models who had recovered from co-occurring disorders, many participants spent most of their lives viewing the symptoms and behaviors of co-occurring disorders as normal. Mental health symptoms were something with which participants had to live. Substance misuse was viewed as normal behavior. With little accurate information, treatment was something to be feared and avoided. The co-occurring disorder symptoms and behaviors became a way of life.

Family and Friends

All participants were involved in family and friend social systems that were important to them. Sometimes family and friends supported co-occurring disorder behaviors and did not encourage the participant to get treatment. Participants reported that they were encouraged to drink alcohol by family, friends, and community groups, sometimes beginning in childhood or adolescence. Mental health problems were often ignored. When participants developed co-occurring disorder symptoms that interfered with family, work, or legal status, family and friends often overlooked the problem or stigmatized the individual.

Participants described family members and friends who often did not know what to do to help participants recover from co-occurring disorders. Some partners had grown

up with parents who had co-occurring disorders. These partners had no expectation that participants would change their actions, even if the partners found the behaviors distressing. Children who had grown up with parents with co-occurring disorders did not know their parents any other way. Sons and daughters often accepted that the behaviors were just the way their parents acted, whether or not they were upset by the behavior. Family and friends sometimes thought of behaviors related to co-occurring disorders as the result of lack of will power rather than being associated with mental health and substance misuse disorders that needed treatment. Not only participants but also family, friends, and the larger community frequently viewed co-occurring disorders, if not normal, at least to be expected.

Don's wife had grown up with a father who drank too much. She disliked Don's drinking but had no idea that it could change. Don said,

My wife was losing her mind about my drinking. She shielded me from the kids. "He'll drink anyway so let him drink." It was resignation on her part. . . . When I went to treatment, she had given up hope. Her dad was an alcoholic when she was in high school and grade school. . . . He never went to treatment.

The experience of Don's wife led her to believe that there was nothing to be done when Don drank too much. She had no role model to suggest otherwise.

Some family and friends pretended not to notice behaviors associated with co-occurring disorders or attributed actions to physical illness. Amy stated,

My friends knew I had a problem toward the last. I'd get "sick" when I drank too much. . . . People I worked with in organizations tried to think that I was sick, not

drunk. So I tried faking that I was sick. . . . One friend came for coffee and cried and said, “I’m worried about you.”

Others family and friends were disgusted with the behaviors and engaged in criticism, insults, and threats. These behaviors triggered participants’ fear of loss of control over their lives and increased risk for the disorders to continue.

Even after getting help for her alcohol use and becoming sober, Laura recalls that her husband taunted her about drinking.

[My husband] drinks beer. He used to tease me with a beer when we went camping. It went on and on. I didn’t tell anyone. Finally, I got pissed and took a beer that he pressed on me. It scared him and he never did it again.

Laura did not know how else to stop her husband from hounding her about her past drinking. The memory was still painful 25 years later.

Vince grew up in a family and community where alcohol was part of everyday life. Vince went into treatment for alcohol in his late fifties and has been in recovery for 22 years. He talked about his parents’ lack of understanding of alcohol use as a disorder.

My parents never could understand. They offered me beer even after treatment.

They blamed [my wife] for putting me in treatment. . . . My parents thought alcoholism was a matter of will and those that drank too much lacked will power.

Lack of comprehension by family and friends interacted negatively with participants’ own lack of information and understanding. Family and friends lacked role models for different ways to respond to the participants’ behavior. Participants continued to feel alone with their difficulties.

Rural Community Provider Barriers

Participants reported that community providers lacked knowledge and held attitudes similar to those of participants, family, and friends. The rural communities where participants lived lacked providers that were knowledgeable, accessible, and specialized to meet the needs of older adults with co-occurring disorders. Community providers and members sometimes tried to provide assistance but seldom understood the problems of older adults with co-occurring disorders. Other times community providers and members were openly rejecting. Most people in the participants' rural communities believed that co-occurring disorders were a personal problem, not a community concern.

Medical providers. Participants frequently perceived that providers did not address their concerns about co-occurring disorders. Since medical providers were often the person to whom participants turned to for support, their lack of assistance often served barred participants from receiving help.

Laura told of the depression that took her to the brink of suicide and drinking that gave her some relief from the depression but also created new problems.

I experience depression. I have a deep self-pity of the last drinking years. I feel shame and guilt. The depression was never assessed or treated separately. . . .
I've been suicidal at times. I wanted to die. I didn't make any attempts.

Laura described the interaction of her depression and drinking that became worse after her daughter died.

My worst drinking was after my daughter until two years after my third boy was born [about 10-12 years]. I got pregnant with my third son while I was drinking. . . I slowed down but couldn't quit.

In spite of depression that took her near suicide and drinking during pregnancy, Laura said, "Doctors never asked about drinking."

Both Dove and her husband experienced serious medical issues. Dove suffered depression about her inability to conceive children. As a younger woman, Dove drank alcohol excessively and as an older adult, she misused prescribed medications. Dove reported, "The doctor did well with [my husband]; less well with me." Dove felt that the physician listened more carefully to her husband's complaints and responded more thoroughly to him than to Dove. Physicians did not ask Dove about mental health or substance misuse problems.

When Lois felt depressed and anxious in her late sixties, she asked her physician for a referral for counseling. "I talked to my doctor about it once—the sadness. He told me not to see a therapist. I wanted to. He put me on a medicine [antidepressant]." Lois did not feel that the medication was helpful and stopped taking it. She did not know how to seek counseling without a referral.

Participants reported that medical providers did not ask about individual or co-occurring disorders when they were younger, and this lack of evaluation carried into older adulthood. Both women and men reported that physicians failed to consider the possibility of individual or co-occurring mental health or substance misuse disorders. Medical providers were frequently the person that participants turned to for help in their

rural communities. When medical personnel did not assess co-occurring disorders, participants felt a lack of support in communities with limited options to obtain either knowledge or treatment.

Spiritual leaders. Spirituality and religion were important to many participants. Several participants felt rejected when their struggles with co-occurring disorders were not understood. Some participants tried talking to religious leaders, but found that without an appreciation of co-occurring disorders, these advisors were unable to help. While some participants noted that spiritual providers were barriers to receiving help for co-occurring disorders, others simply noted that they did not receive assistance with co-occurring disorders from spiritual leaders and communities.

Rich had attended religious services all his life. When Rich tried to talk to a pastor about his co-occurring problems, he felt that the pastor sympathized but did not understand. Rich stated, “To go for help to those with no alcohol [comprehension] doesn’t work well”. For Rich, awareness of his struggles with co-occurring disorders was essential to understand him. When the pastor did not, it left Rich feeling even more alone with his trouble.

Not only religious leaders but also religious organizations affected the participants in their struggle with co-occurring disorders. Laura had attended religious services as a child. When Laura tried to quit drinking, she turned to her religious organization for support. Laura did not find the acceptance she had hoped to find.

I quit [drinking] for one month. I was in a Christian group and couldn't tell the ladies [that I had quit.] They were too judgmental. They made fun of me for not being able to pronounce words in the Bible. I got out and drank worse than before. Laura felt that the co-occurring disorders were a part of her. When Laura's expectation that this religious group would accept her was not met, she felt alone and rebuffed.

Neil is divorced, estranged from his daughter and granddaughter, and has no close family or friends in his current community. Neil described himself as religious but he does not attend services. He stated, "They only care if I come to church. They don't care about my troubles." The religious organizations he had tried did not help him reduce his isolation or his co-occurring disorders.

Participants were disappointed when religious leaders and groups did not understand co-occurring disorders. Participants described a sense of rejection when their expectation that they would receive acceptance from persons associated with religion were not met. These feelings of rejection and disappointment sometimes included a feeling that religion had let them down.

Employers. Four participants had been fired from jobs for reasons related to their co-occurring disorders. Employers saw the symptoms of co-occurring disorders but did not recognize disability and offered no assistance.

Rich, a long-time employee, was let go from his job for drinking that affected his work. Rich stated,

I worked at the [organization] for 34 years. I ended up managing three [sites]. They told me to retire eight months before I was eligible to retire. They paid me off. Work didn't suggest that I go to treatment. They just bought me out. It felt terrible.

Rich's employer made no attempt to get Rich to stop drinking or to seek treatment even though he was a long time manager in the company.

Connie was fired after she received inpatient treatment and asked for time off work to go to outpatient treatment.

Getting this help cost me my job. . . . I went to [hospital] for a two-week stay [for psychiatric care]. They [employer and supervisor] turned things around. They [employer and supervisor] said, "We can't trust you with the children." I tried to fight it with a lawyer. It didn't work. It was personal to those two people. It was not policy it was politics. They threatened me—said they would tell people. . . . That was difficult. I didn't want to say why I needed the time off. Bad things happen when you tell.

Although she knew that the firing was wrong, Connie believed that those making the decisions were very powerful and could harm her in ways worse than being fired if she tried to fight the discharge.

Two participants felt that their firings were justified. Michael, who worked in a professional capacity, was well liked by his employers. Michael had found his employment was increasingly stressful and began using marijuana to unwind. Michael was arrested for possession of marijuana and he was fired from his job. Michael stated,

The job loss was just the [organization's] policy. . . . The policy served itself and me. I knew the consequences ahead of time. I am not addicted. Addiction is different. A person needs to ask for help before they are found out.

Michael believed that the organization's policy to fire him was acceptable. Michael believed that he should have recognized his problem and taken charge of it himself.

In contrast to employees with problems, Debra needed time off from work when her partner was treated for alcoholism. She stated, "My boss was wonderful. He told me to take off as much time as I needed and that it was OK to take time off." The attitude of Debra's employer toward her as a family member was quite different from the employers of those with co-occurring disorders. Whether participants tried to hide their co-occurring disorders or sought help for them, employers were not willing to assist these participants but were willing to help family members.

Summary. While a few providers understood the issues of co-occurring disorders, medical providers, religious leaders and groups, and employers frequently shared the view of participants, family, and friends that co-occurring disorders were normal and to be tolerated until behaviors became a problem for the provider or the organization. Once problems could not be ignored, some providers tried to help while others saw co-occurring disorders as a personal problem and were rejecting. Other providers simply did nothing. Participants received little assistance from their communities and the providers that they had expected would help them.

Rural Structural Service Barriers

While structural barriers to treatment exist in all communities, older adults with co-occurring disorders who live in rural communities face particular obstacles. Formal services for nearly all social and economic needs were scarce and not specialized to address the needs of participants with co-occurring disorders and the needs of older adults. When assistance existed at all, information was difficult to find. Services were expensive to access, often existing only at long distances. Participants spoke of the need for after-care services in order for older adults to stay in recovery from co-occurring disorders. In addition to treatment and recovery services, participants noted that problems other than co-occurring disorders sometimes interfered with obtaining or maintaining recovery.

Accessing services. Participants initiated little discussion of service barriers. Like most people in rural communities, participants viewed co-occurring disorder problems as personal and had low expectations that their communities would provide services. However, when asked, participants had found it difficult to access services.

No participant found treatment services that were planned for persons with co-occurring disorders. No participant who went to treatment as an older adult received age-appropriate services. Participants reported that treatment was hard to find and expensive.

Treatment was scarce. No participant received treatment for co-occurring disorders. No participants received inpatient or outpatient treatment in their home communities. Rich went through substance misuse treatment three times. Rich first went through outpatient treatment 50 miles from home. Rich's second treatment was inpatient and took place 150

miles from home. Rich's third treatment was inpatient, followed by outpatient treatment and two months in a recovery house, all in a community 50 miles from home.

Connie went out of state to find mental health inpatient care. Connie then went to outpatient treatment and stated, "Treatment was 40 miles away. I needed time off from work in order to go. That was difficult."

Self-help groups were sometimes available in home communities. No participants found self-help groups for co-occurring disorders or that specialized in helping older adults. Even self-help groups were not always available when and where they were needed. Rich was retired when he began attending Alcoholics Anonymous. Rich noted, "When you quit at retirement age, it could be pretty lonely. . . . You need people your own age to hang out with. It relates to the rural setting, that meetings are spread out."

Rural groups often serve people with many kinds of substance misuse or mental health problems. Rich said of the Alcoholics Anonymous groups in his rural area, "Cross addiction—in this area, addiction is addiction. Meetings will accept a person with any addiction." Neil was the only participant who had attended a self-help group for mental health issues.

Participants found limited mental health or substance misuse treatment options. No treatment for co-occurring disorders for persons of any age existed. Participants either accepted less than ideal treatment or received none at all.

Appropriate treatment was unavailable. Participants lived in rural communities served primarily by generalist providers who had little experience with either

co-occurring disorders or older adults. Even when they traveled to cities for treatment, no participant received services for co-occurring disorders or treatment planned for older adults.

Don's experience with inpatient treatment for substance misuse was challenging, in part because he was the only older adult in the program.

I was the oldest one there [inpatient treatment]—64. I had a tough time dealing with it. Everyone else was younger. The men's section was full so I was on the women's section. . . . I did have trouble. . . . Older adults are left out because younger and middle aged people don't know what older adults are talking about. They think they can do better than old people and don't want the wisdom that comes with age.

Don felt the lack of age appropriate treatment made it more difficult for him to be a part of the treatment process. He received no assistance with the co-occurring depression that had been with him since he was a child.

Rich found that age complicated his substance misuse treatment experience. He received no assistance with mental health issues. "Being in my fifties was hard. I felt old. It was expensive. It was difficult to accept help. I felt like I should know what to do. Treatment was made harder by age." Rich did not complain about paying for three separate treatment episodes out of pocket. He took responsibility for his difficulty accepting help. He found the lack of age-related support difficult, especially as he entered treatment.

None of the participants received treatment for co-occurring disorders.

Participants who entered treatment as older adults did not receive treatment that addressed age issues. Participants had to figure out co-occurring disorder and age issues for themselves.

Treatment was hard to find. Participants reported that media coverage of co-occurring disorders and services for older adults is virtually non-existent in rural communities. Local newspapers listed support groups but carried no information about older adults experiencing mental health, substance use, or co-occurring difficulties. Treatment facilities rarely advertised and did not mention older adults. Participants seldom knew how to access services for their disorders.

Vince had started drinking as a child. By the time he was in his fifties, he would get up early in the morning to drink and drank all day long. As both his depression and his drinking worsened, Vince realized that he had a problem and began looking for help.

During the last few years, I knew I had a problem. I called [nearby city] looking for help. I didn't want people locally to know that I had a problem. I went to my doctor and asked for Antabuse.

Vince did not find help. The drinking and depression that had been part of his life since he was a child grew increasingly worse.

One day [my wife] came home from work and I was on the floor. I said, "I'm going to shoot myself". [My wife] said, "Go ahead." She [my wife] went to town to a friend who was active in AA. She told him that I said I would shoot myself. The friend took me to treatment at [community].

It was not until Vince became suicidal that family and friends helped him get to treatment.

Treatment was costly. Participants found that treatment was costly. Four of the five participants who went to inpatient treatment had insurance that covered part of the expense. Rich stated, “I had no insurance so I paid out of pocket for [all three] treatments.” Rich is still making payments four years after his last treatment.

Other participant expenditures involved driving to outpatient treatment and self-help groups. When asked what made getting treatment easier, Don stated, “Finances. Our insurance picked up part of the cost of treatment.” There was no assistance for driving to weekly outpatient treatment or support groups after Don completed inpatient treatment.

Self-help groups generally do not charge fees. Some groups place ads in Yellow Pages so that those in need can find them. Local groups pay for these ads out of pocket. Rich, who took leadership roles in his self-help organization, stated,

It is expensive to maintain that listing--\$59 per month. The rural meetings are getting smaller. There are no dues. So far, we've found ways to keep paying for the listing. It's essential that people be able to find us when the need us.

Small rural communities mean fewer people to support each service organization and pay related costs.

Recovery supports. Participants reported that they wanted and needed support to preserve their recovery. Other participants had found the support they needed for one disorder but still struggled with their other disorder. Some participants still had active disorders and needed assistance for both disorders.

Don talked about groups closing as older adults can no longer drive to them and younger adults are less likely to join.

I went to AA right after treatment—immediately. I knew members and we clicked. They knew how to handle an older person coming out of treatment. . . .

All of a sudden, the [community] group folded. Now there is just the [community] AA group with 2-3 men. [Community] has an AA group—catch as catch can.

Even though Don has been in recovery from alcohol use for 20 years, he feels strongly that the support group is necessary for him to maintain recovery. Don noted, “People say, ‘You still go?’ I say, ‘I am. I need it’”.

Don has had less success dealing with the depression that returned after his partner’s death. There is no support group available in his community to help Don address grief and loss or ongoing depression.

Summary. Access to treatment was complicated by several factors. Participants found that treatment for co-occurring disorders was not available in their small rural communities. Even when they traveled to cities, no participant found treatment that was designed for persons with co-occurring disorders or who were older adults. Information about treatment is difficult to locate and services are costly. Participants noted the importance of services to maintain recovery.

Lack of help for other problems. In addition to difficulty accessing treatment for co-occurring disorders, participants described problems locating resources for other needs. Participants who cared for partners or other family members seldom knew how to

find support services. Other participants were concerned with obtaining services to maintain independence as they aged. Some participants reported that the stress related to lack of services exacerbated their co-occurring disorders.

Ed talked about not knowing how to find assistance when providing care for his wife as she developed dementia. Ed had always been able to take care of his needs and had not required help. When caring for his partner became too much for Ed to handle, he had no idea how to find assistance for his partner or for himself. “I needed help with caregiver issues.” Without that help, Ed experienced co-occurrence of depression and alcohol misuse for the first time.

Lois at age 70 is in good health, active, and still works. However, she is concerned about finding supports to help her maintain independence and reduce stress for herself and other older adults.

There are times when it is difficult to live alone. [Older adults need] small things—bench at a store [to rest]; someone to bring breakfast when a person is sick. . . . There should be a place to organize transportation, small chores, help when people are temporarily ill. Churches help but are not available for everything and everyone.

Lois had experienced co-occurring disorders a few years ago. Lois was aware that stress relating to unmet needs could reactivate her disorders, and she wanted to prevent a reoccurrence.

Jean addressed the limited support services for older adults and lack of information about existing services. In addition to needing information to assist with caregiving, Jean noted that she and other older people need assistance with chores.

Another difficulty is small home repairs. The kids help two times a year. It isn't enough. I don't want to impose on them and have them think that's the only reason I want them to visit. . . Home help—a handy man—so people can stay in their own home.

Jean has had medical problems as an older adult. She talked about her frustration with not getting the information that she needs to cope with her medical issues.

My eye problem is thyroid related. I had one roto-rootered in 2005. The surgery was not successful. Glasses help. [Clinic] is not good for eyes and don't have good discharge system. If it weren't for Dr. [local optometrist], . . . I couldn't see after the last surgery. I called back in nine days and the person I talked to said, "This happens sometimes." I go back this summer. They'll run a lot of tests. They won't tell me the results. I wish I could read. . . . No one has ever told me what I could do to help me with my eyes.

Jean found travel challenging due to difficulty walking and poor vision. She drives in spite of her poor vision.

I'd like to travel. My eyesight problems make it difficult. They tell you there will be a wheelchair. You get there and it isn't there. . . . I don't drive far. Only roads I know. I drive to the kid's houses—50 or 60 miles. Not to Chicago or in heavy

traffic. . . . It is challenging and frightening to be an older adult. What if my knee gives out?

Jean, who had experienced depression earlier in life, developed co-occurring disorders as an older adult when she began to misuse prescription medications. Although Jean continued to suffer from depression, she was determined to be active and involved. Jean recognized that she needed several kinds of help to do so.

Most participants were aware of problems and needs that interacted with co-occurring disorders. Some participants needed assistance with active disorders while others focused on maintaining their recovery. Lack of information and services for treatment, recovery, and other problems increased stress and created risk for reactivating participants' co-occurring disorders.

Summary

The needs of older adults with co-occurring disorders often went unnoticed, perhaps a product of rural community attitudes about co-occurring disorders, ageism, and asking for help. Beliefs and values of service providers, community groups, friends, family, and the participants themselves appeared to contribute to the lack of resources. Older adults with co-occurring disorders were essentially invisible to the community. Stigma interfered with some participants seeking and finding services.

Lack of information and misinformation about treatment sometimes stopped participants from seeking help. Participants found few role models to assist them to figure out their road to recovery. Family and friends also lacked information about

co-occurring disorders that limited their ability to assist participants in dealing with co-occurring disorders. Family and friends found a dearth of role models for themselves.

Medical providers, spiritual leaders, and employers seldom understood the effects of co-occurring disorders and did not know how to help participants. While some tried to assist, others ignored the participants' problems.

Participants described communities where their needs went unmet. Many participants received no treatment of any kind. Treatment options did not address co-occurring disorders and they were not designed for older adults. Services for substance misuse and mental health disorders were limited, difficult to find, distant, and costly. Participants who received treatment had no assistance with how to manage the interaction of the two disorders.

As participants aged, self-help groups dwindled as driving became less feasible. Loss of self-help groups reduced needed support for recovery. Help for needs that indirectly affected co-occurring disorders was often missing and this increased stress, which challenged participants' maintenance of recovery.

Each of the barriers to receiving help with co-occurring disorders isolated participants and increased risk for continued problems with co-occurring disorders. When the informal and formal support systems lacked knowledge and understanding of co-occurring disorders and older adults, participants found themselves alone and without resources to help them sort out the issues.

Chapter 8: Protection and Resilience

While risks for co-occurring disorders in older adults are important to understand, personal characteristics and outside supports that protect people from developing co-occurring disorders or assist in recovery are just as essential to appreciate. These personal and treatment protective factors do not adequately explain the participants' ability to renew their lives after experiencing co-occurring disorders since the suggested supports are mostly missing from rural community and treatment is often unavailable. Participants demonstrated resilience after living with co-occurring disorders for varying lengths of time and while experiencing mild to severe disorders.

Participants did not escape the negative consequences of co-occurring disorders, nor did they always adapt well in a negative context. Many did find recovery from co-occurring disorders through a combination of personal factors and environmental supports. This resilience suggests qualities and supports that are worth exploring and understanding. See Appendix G, Data Reduction Matrix for protective and resilience factors noted by participants.

Chapter eight includes protective and resilience factors that participants believed helped them revitalize their lives. Sub-categories of protection and resilience included participant factors, acknowledgement of co-occurring disorders, acceptance of help, and rural resources. Personal resourcefulness consisted of persistence, social embeddedness, and religion or spirituality. The theme of helping others was present in all of these sub-categories. When participants acknowledged co-occurring disorders, many decided to address problems associated with co-occurring disorders. Accepting help involved

treatment, unexpected forms of help, and rural resources. Neither the severity nor the length of time that participants experienced co-occurring disorders appeared related to the resilience that helped participants reclaim their lives from their disorders.

Participant Resourcefulness

Personal assets were important to revitalizing participants' lives after they experienced multiple difficulties related to co-occurring disorders. Resourcefulness helped participants survive and reclaim their lives while growing past whatever brought about the co-occurring disorders. Several sub-categories comprise this category of protection and resilience. Persistence, social embeddedness, and religion and spirituality all assisted participants regain meaning in their lives. These factors helped them overcome symptoms of their co-occurring disorders.

Persistence. Participants in this study did not recover from simple difficulties. The combination of mental illness and substance misuse disorders presented numerous challenges to participants. Several had been suicidal at some point. Participants all experienced developmental life challenges and at the same time, coped with co-occurring disorders whether disorders were active or in remission. Developmental difficulties included the same problems that most older adults face including loss of important people, jobs, and dreams, caregiving responsibilities, and dealing with age-related stereotypes and negative expectations. Regardless of the combination of challenges, participants persisted. Some participants developed habits and coping skills that keep the symptoms of co-occurring disorders in remission while others persisted in spite of those symptoms.

Participants carried out their life work and responsibilities to the best of their ability. Most participants accomplished this with no treatment for their co-occurring disorders. Some inner strength assisted participants to get through difficult times and focus on living.

All participants persisted. However, they did so in different ways. Leon focused on work and family.

I raised 6 sons and 5 foster children and 3 grandchildren. . . . All my boys grew to adult hood. Their deaths were not my fault. Three were killed in accidents. . . . One son and daughter-in-law died in a motorcycle accident. We raised his son. . . . The older boy was electrocuted. . . . The other boy died in a car accident. . . . After I quit farming, I bought old houses to fix and sell. I still own three. . . . In 1990, we moved to [community] so my wife could spend time with her mother. I fixed up a house for her to live in.

Leon had been severely depressed and suicidal as a young man. Initially he coped by drinking. However, he stopped drinking and by concentrating on taking care of his family and working, he resolved his depression.

After barely graduating from high school, Chuck found work that used his analytic skills rather than requiring reading skills. He eventually found out about learning disorders and came to realize that he was intelligent.

In my mid-twenties, I heard about dyslexia and realized that I was not dumb. . . . Since then I've tried to fill the gaps. I have taught myself how to learn around it.

I taught myself to read German. . . . Once I understood my problem, I challenged myself to learn. I like challenges.

Chuck had a recurrence of his co-occurring disorders as he cared for his partner during her terminal illness. After struggling for some time after her death, Chuck began to apply his ability to think logically to figure out personal as well as work problems.

I used the same coping mechanisms. I'd ask myself 'What is the problem?' and 'What needs to be solved?' I was helped by 30 years of work that required problem solving.

Chuck used coping skills that he learned to recover from co-occurring disorders as an adult to help him achieve recovery a second time in later life.

Don talked about the importance of family, friends, and community in maintaining recovery from his co-occurring disorders. Don viewed his family's visits and phone calls while he was in treatment as supportive.

We are a well-knit family. My son who lives in the area came every visiting day. My daughter who lives in [another state] came every weekend. My daughter who lives in [community where he was in treatment] was in and out. My son who lives in [community 150 miles away] visited when he could. My son who lives in [home community] stopped in a couple of times. My son in [state] didn't visit but he called a couple of times.

Several participants used self-help or mutual support groups to refocus their energy. They found that people with similar issues helped them learn how to manage

their co-occurring disorders. Don continued to need support after treatment and found friends who were willing to help.

When I got out of treatment, I was fortunate to be in [home community]. There were two older men my age and younger but not young. They were free to go to [Alcoholics Anonymous] meetings and they invited me to go with them. We were the Three Musketeers.

Don also spends time with friends who are not in Alcoholics Anonymous. “I go to congregational meals. . . . I go out with women. It is good to be with old friends.” Don found that a combination of relationships provided the support that he needed to stay in recovery from his substance misuse disorder and keep his depression at a manageable level.

Self-help groups were useful to participants by providing acceptance and role models. Laura described her experience with Alcoholics Anonymous:

AA “took”. I wasn’t the worst person in the world there. People were open and honest and it attracted me. I felt at home. The first meeting was a miracle. It gave me tools, a sponsor, and the Big Book. I still wanted to drink but I didn’t have to. . . . I was amazed that men felt similar feelings. They spoke from their heart and feelings. The men I knew didn’t talk about feelings. . . . There was a woman in AA who lost a friend about the same time [I lost my sister] so I could talk with her.

After trying to participate in church groups and feeling that she did not belong, Laura found a group that understood her disorders and accepted her. She persisted in finding

her way out of co-occurring disorders and into recovery from both depression and substance misuse.

As an older adult, Neil took on the caregiving role for a granddaughter injured in an accident and had a recurrence of his disorders when this role ended. Neil then searched for other ways to find meaning in his life. When asked what had helped him cope with his co-occurring disorders, Neil said, “My spiritual beliefs, friends, and the mental health group have all been helpful”. Neil had seen a notice for the mental health support group on a bulletin board and noted, “The support group is great. Knowledge helps”.

The self-help groups offered participants different ways to take part. This allowed participants to choose the kind of participation that met their needs.

Other participants found that helping themselves meant helping others. Participants found various kinds of involvement.

Dove noted that she started her career as a bookkeeper in a for-profit organization. She switched to working for a non-profit nursing home where she found the work meaningful because it helped the residents. “When I worked for [non-profit nursing home] it was working for people and doing more. I didn’t care for a few people. But I liked the work a great deal more. I felt like I was helping people.” Dove quit work due to health problems of her own and her husband. However, she still volunteers with several organizations. “I help at [nursing home] on Wednesday mornings. I distribute communion. I also serve on an advocacy board.” Dove found meaning in helping people, whether it was paid or volunteer work. She persists in helping others even when

her co-occurring disorders and other health problems make it impossible for her to work in paid positions.

Mere, at age 90 experiences some depression although she no longer drinks alcohol. Mere is aware of the depression and tries to overcome it by helping others.

I get depressed about working and my money doesn't stretch. . . . I like to golf and bowl and cook and do volunteer work. I drive people to their appointments. I figure someday I'll need someone to drive me. . . . I can do for others and others do for me.

Mere takes a practical approach to dealing with depression. Helping others is an important part of maintaining supportive relationships and finding a valuable role.

Participants often found meaning for their own lives and persisted by helping others. Participants took pleasure and pride in assisting others to have a better life. Many participants found that they benefitted as they contributed to the well-being of others.

Social embeddedness. Relationships with family, friends, and community helped revitalize participant' lives by providing meaningful roles and tasks. For some participants, it meant family and friends who stuck by them even when they were angry and frustrated with the participants' behavior.

Some family members viewed Vince's drinking negatively. Family relationships have improved since Vince quit drinking.

My aunt couldn't tolerate the drinking. When she saw me drinking, she stared at me [in a mean way] about it. But she sent me a card when I was in treatment

saying she was glad I went to treatment. . . . The grandchildren never saw me drunk. I'm grateful for that.

Vince has been able to retain some friends from the past even though he no longer drinks alcohol. "I've been able to keep some friends. Some drink. They offer me pop and are respectful [of my decision not to drink even though they do]." Vince survived the drinking and depression that brought him close to suicide. Vince values the relationships that outlasted his co-occurring disorders and support him in his recovery.

Chuck had a learning disability, that along with his depression, interfered with the confidence to develop relationships and that he associated with developing co-occurring disorders. He talked about the importance of having people in his life as he grew past the learning disability and co-occurring disorders and developed awareness of his abilities.

Connection [to people] is more important to me as I become aware of being older. The rewards now outweigh the negatives. . . . Church helped the most that first year—the fellowship. People were interested in the same things as me. It provided an incentive to get on with my life. It helped to see them—that there were things to do and I didn't have to be a hermit.

The connection with people has continued to help Chuck develop new interests, gain self-confidence, and maintain his recovery.

Some participants found new groups that provided a place where they could be themselves. Amy discovered that Alcoholics Anonymous provided role models, understanding, and long-lasting relationships, and all help her maintain control of her disorders.

Lots of women at AA talk about worry and fear. They understand me. . . . When I started going to AA I went to the meeting at [community]. Two men and I started the [home community] group. They're both gone now. They have a good meeting—18 people attend. There's lots of love. We've known each other for years.

Although Amy does not follow all the Alcoholics Anonymous guidelines, the group accepts her.

In regard to the Amends step of the 12 Steps—there are too many people to make amends to. I do jobs over and do them better than when I was drinking. . . . I volunteer to make up for drinking.

Amy participates in Alcoholics Anonymous to maintain control of her disorders.

I go to regular meetings. I make the coffee so I have to go. . . . I was the treasurer until I got sick.

Amy found a support group that welcomed her, assisted her with her co-occurring disorders, and accepted her ways of coping.

There were participants whose previous ways of coping disintegrated when family, employers, or community learned of their co-occurring disorders. Some participants developed new careers and relationships that provided them with meaning and worth.

Rich lost a job that provided value and status for his life. Rich has become involved with the Alcoholics Anonymous state organization. He enjoys the administrative duties as well as helping individuals.

I go to the . . . AA meetings on weekends and a Thursday AA meeting. My sponsor and I go to [location] prison once a month. . . . I'm the General Service Representative for my home group. I go to the meetings as part of that. . . . I'm careful not to let AA take over my life. But it feels so good to help others.

Rich found that the administrative roles provide him with status while helping individuals brings another kind of meaning to his life.

Mina, who lost a young daughter, struggles with depression and mixes alcohol use with prescription medication. As an older adult, Mina found a set of friends who help her cope.

I belong to a faith-sharing group. We are very close and it is helpful. I've been in it a long time. I feel free to express my opinions there. We discuss people who are difficult. I have time to understand them now.

Lois continues to work at age 70. In addition, she has supportive relationships with her daughters and brothers.

My two daughters and I form a triangle to help each other. For example, reminding each other to get colonoscopies. We take care of each other; watch out for each other. There are lots of telephone calls. . . . I had 8 brothers. . . . The siblings are close-knit. I am the only girl and the youngest. . . . We get together two times a year for a long weekend—talk and reminisce. . . . Two brothers live in [my community] and I see them weekly or daily.

Social involvement with family, friends, and organizations provided participants with activities and relationships to revitalize their lives. Each participant found roles that

supported empowerment and in this way, reclaimed the positive aspects of their lives. Participants renewed, and sometimes for the first time, developed positive relationships that supported their efforts to overcome their co-occurring disorders. Work and community activities provided positive tasks and status. Family, friends, and community embedded participants in systems that provided the support they needed to work toward recovery.

Religion and spirituality. All but one participant grew up attending religious services. Fifteen of the participants currently attend religious services regularly while eight do not. Participants who found religion important focused on personal practices such as prayer or volunteer work through their religious organization. Regardless of religious attendance, seventeen participants identified spirituality as an important part of life.

Marva grew up attending church services regularly. However, she finds the important aspects have changed as she has gotten older. “Religion—when I was young, it was integral. . . . As I got older, the life you had, not the rules, became important.”

Spirituality had various meanings for participants. Six participants regularly attended Alcoholics Anonymous or Al Anon. These participants found the spiritual aspect of these groups helped their recovery. Two participants attended mental health support groups that do not have the spiritual foundation of Alcoholics Anonymous. The participants, however, found spirituality an important part of the group.

Laura grew up attending church. “I no longer go to church. Alcoholics Anonymous is my spirituality.” She talked about the difference for her between the

spirituality of religion and the spirituality of Alcoholics Anonymous. “My deep faith never left me. The difference is the gratitude I feel with Alcoholics Anonymous. I didn’t feel that as a child. The church has a lot to do with it. I always had a religious background.”

Rich also talked about the difference between religion and Alcoholics Anonymous. “The religious belief was always there but I didn’t let my higher power help. From the point where I admitted that ‘I don’t have to do this myself’ I had total acceptance.” For both Laura and Rich, the spirituality of Alcoholics Anonymous provided a supportive way to help manage their co-occurring disorders through a belief that a “higher power” was assisting them.

Connie had been active in religious organizations all her life. However, it was not until she was in her late thirties and sought treatment for depression that she found the importance of spirituality. “I didn’t see my gifts before, only shame. I thought I had nothing to give. Now I realize that I have spirituality, gifts, and a healing process.” Connie found that both religion and spirituality helped in the revitalization of her life.

Several participants saw religious organizations as helpful social supports whether or not they, themselves, participated. Chuck became involved in a religion after his divorce. “I got involved in the [denomination] church that year [that I got divorced]. Lots of people from the University . . . attended. I liked being around them. It is a positive religion.” He especially liked the intellectual aspect of the religion, stating that a good result was that “I learned something today”. Mitch, who has not attended religious

services as an adult stated, “Organizations can provide resources. One to one is what matters. Church can be good—the social aspect.”

Although not everyone in the study experienced full recovery from the symptoms of co-occurring disorders, many participants felt that spiritual practices had been helpful in reducing symptoms. While participants did not use the word resilience, their ability to reclaim their lives from co-occurring disorders appeared related to their search for meaning beyond their own lives and to the support they experienced as they became involved in religious and spiritual activities.

Summary. The theme of helping others often emerged as participants talked about their personal resources. Participant descriptions of persistence, social embeddedness, and spirituality often focused on helping relationships. Participants valued not only the help that they received, but also appreciated being able to help others. Assisting people appeared to help in reducing symptoms of co-occurring disorders as well as result from a reduction of problems. Reclaiming their lives from the ravages of co-occurring disorders was no small task for the participants. Self-confidence and self-respect gained from assisting others provided meaning to life regardless of whether the co-occurring symptoms continued. Whether they were in full or partial recovery, participants persisted in working toward making their lives better.

Acknowledgement of Co-occurring Disorders

Identifying and acknowledging co-occurring disorders was an important step for each participant. With awareness came recognition of the importance of changing so that they could gain control over the co-occurring disorders and their lives.

Acceptance of co-occurring disorders occurred in several ways. Some participants identified their disorders early and reduced their symptoms quickly, while others struggled with their symptoms for years, even after they recognized their difficulties. Several participants long held the belief that they did not have a problem while others recognized their disorders quickly. Regardless of when and how recognition occurred, acknowledging co-occurring disorders was an important step that participants took to reclaim their lives.

Recognition sometimes came when an outside force brought the issue to the participant's attention in a way that they could no longer avoid it. Family members of several participants offered assistance in finding help.

Laura described her early drinking. "I liked the feelings—light-headed and giddy." Laura married and began having children. Laura then described drinking that relieved stress and depression related to lack of money and the death of her daughter. "I was scared for a time after we married. We struggled and didn't have enough money. I felt responsible. Drinking let the fear go away and relieved the pressure." Eventually the drinking did not take away the stress or depression.

I was miserable the last two to three years that I drank. I wanted to quit but I couldn't. . . . I didn't take care of him [new baby]. The boys [older sons] babysat him. It was a combination of guilt and drinking. . . . I hated myself.

Laura's brother had become sober through treatment and Alcoholics Anonymous. He encouraged her to quit drinking.

My brother made me so mad. He'd visit for six months. He'd bring AA stuff and go over it and talk to me. I loved what he had to say until he said 'I have the choice to drink. I choose not to.' I wondered: why don't I have a choice? If he can do it, I can. He drank worse than I do. That [hating myself] plus the baby plus my brother who went through treatment one and one-half years [before me] is what got me to quit. My brother was a big help in life. He told me about AA. He drove 100 miles to take me to my first meeting.

Attending the first self-help group meeting with her brother provided Laura with the support she needed to make the changes necessary to manage her substance misuse.

Laura did not get treatment for depression. Laura talked about how she used Alcoholics Anonymous to assist her to cope with depression.

The depression was never assessed or treated separately. I use my gratitude list [an Alcoholics Anonymous technique] to dissolve self-pity.

For other participants, acceptance of disorders came during private moments.

Mitch had been to treatment for alcohol but returned to drinking.

When I got straight, I was in my loft in my shop and thought 'what are you doing?' I might as well cut off my hands as drink. It finally dawned on me that I don't have to do this. . . . I didn't start drinking again.

Later when Mitch became suicidal, he recognized that he needed help and went to the hospital voluntarily for assistance.

Participants were sometimes able to acknowledge co-occurring disorders without formal help. Robert talked about how meeting and marrying his wife helped him recognize and overcome both his anger problem and his drinking.

As a young man, I drank quite a bit. When I was in the service, I drank quite a lot. When I met my wife and we started dating, that helped me a lot. She didn't like having me drink. I had quite a temper. Over time, I learned to control that [drinking and temper].

Robert was relatively young and his co-occurring disorders were of moderate severity. He felt that his partner helped him recognize his disorders and provided him with the motivation and support to address them.

Still others recognized co-occurring disorders but did not find help. Celia reported that she knows she is depressed and misuses alcohol. Celia tolerated the consequences of the depression and waited out the worst of her symptoms. Celia continues to drink alcohol. “[My partner] and I drink once a week. [My partner] has two beers a week and never gets drunk. I get drunk on beer. Or hard drinks—I sip until I'm drunk.” In spite of recognizing her disorders, Celia has not changed her behaviors.

Participants' acceptance of co-occurring disorders was an important step toward regaining control of their lives. Once this first step occurred, many but not all participants were able to proceed with other actions necessary to manage symptoms and find new meaning in life.

Acceptance of Help

Acceptance of help assisted some participants achieve or regain a level of recovery after experiencing co-occurring disorders. Eleven participants received evaluation or some kind of treatment for co-occurring disorders while two other participants received treatment that did not address co-occurring disorders. Some participants received unexpected kinds of help with their co-occurring disorders.

Experiences with treatment varied. Participants found treatment helpful whether they went voluntarily or whether they were forced to go. Some participants needed more than one episode of treatment to reach recovery. Ease of access to appropriate treatment varied. Participants reported that when providers had knowledge of co-occurring disorders in older adults, they found the treatment to be more helpful.

It appeared that treatment help reduce disorder symptoms and assist participants to reach recovery. Eight participants were in full recovery from all disorders at the time of the interview and eight more were in recovery from one but not both disorders. Disorders that were still active were either less severe or the same as earlier in life. Participants used the help that was available to find ways to get their symptoms under control. Many participants were active with family and community, using their recovery to enhance not only their own lives but also the lives of others. See Tables 4, 6, & 9.

Treatment was beneficial. Seven participants found treatment while five went to treatment when family members insisted that they do so. One received assistance from a medical provider. Law enforcement forced three people to go to either or both evaluation or treatment. Some participants went to treatment more than once, sometimes referred by

self or family, and other times referred by the court system. Participants who went to inpatient treatment were sometimes referred to outpatient treatment or self-help groups.

See Table 10.

Table 9

Number of Participants Receiving Treatment for Substance Misuse & Mental Health Disorders

	Self-Help	Out-Patient	In-patient	Other Treatment	No Treatment
Substance Misuse	7	3	4	Court evaluation: 1	15
Mental Health	1	2	2	Grief group: 1 Marital counseling: 1 Medication: 1	17
Total	8	4	5	4	10

Note: Total refers to the number of different participants who received a kind of treatment. One participant received substance misuse and mental health outpatient and inpatient treatment.

Table 10

How Participants Found Treatment

Type of Treatment	Self-Help	Out-Patient	In-Patient	Other
Found by participant	2		2	3
Found by family	2		3	
Referred by physician	1			
Referred by criminal justice system	2		2	1
Referred by another type of treatment	4	4		

Most participants who received treatment for one of their disorders, found it to be beneficial whether treatment was voluntary or forced. Participants who went on their own were appreciative of the help available to deal with their disorders. Participants whose families insisted that they go to treatment were eventually grateful for the help. Even participants coerced into treatment by law enforcement accepted the need for treatment.

Don's children insisted that he go to treatment. They made all the arrangements and arrived at his doorstep to take him. Don described his experience.

One April on a Sunday we came home from church and four of the kids were here. They said, "Dad, we're taking a trip" and they took me to treatment. I said, "I can't go. I have too much to do." They said, "We have it lined up in the [community] Treatment Center." So I went.

Don protested but did not refuse to go to treatment. He described his reaction to his children's actions.

I knew I needed help. I knew I was drinking too much, not eating properly, not sleeping properly, not acting properly. My wife had said, "Why don't you quit or slow down?" I said I would but I didn't.

Don's inpatient treatment program referred him to both outpatient treatment and a self-help group. Don attended both but soon quit the outpatient program. He preferred the self-help group where he felt he received the most help with recovery. "People who have known me 40 or 50 years say, 'You sure have changed since you started that program [AA].' It would have been good if I had started sooner."

Rich went through inpatient treatment three times before he gained control of his symptoms. Rich felt that he benefited every time since each treatment helped move him toward accepting his co-occurring disorders and the need for help. Rich knew that he needed help but could not bring himself to go to treatment voluntarily.

[My wife] moved out. I didn't know it for four days. The rest of the family went on an annual family outing. I called the sheriff for help. The sheriff asked me if I was going to AA. I told the sheriff to pick me up if he saw me. I went out driving, and he picked me up. My in-laws signed papers to commit me because I refused to go to treatment voluntarily. I went into treatment in handcuffs. This finally woke me up, and I got it. . . . I was befuddled. When I called the sheriff, I wanted help. I had to give up in order getting help.

Rich could not bring himself to ask for help directly. Rich finally acted in such a way that treatment was forced.

One participant did not believe that treatment was beneficial. Jean and her husband saw a psychiatrist for marriage counseling in response to Jean's concerns about her husband's affairs and drinking. "We went to marriage counseling. . . . We didn't get a lot out of it. He'd talk to [my husband] about cars and refrigerators. He'd listen to me and make no response." Jean felt that she did not receive any help for her marriage nor did the marriage counselor offer assistance or refer her for help with her own co-occurring disorders.

Regardless of how participants arrived at treatment or the type of treatment received, all but one participant found it helpful even though only one participant received treatment for both disorders.

People may need more than one treatment. Two participants repeated inpatient treatment. Both participants indicated that they remained sober for some time after initial substance use treatment but then returned to drinking.

Two participants repeated treatment and attended a support group for substance use after the last treatment. Rich found that Alcoholics Anonymous helped him stay sober and he continued to attend. “I went to 140 meetings in 80 days. I saw the same people there and saw that it worked.” Rich also addressed his mental health concerns with the help of this support group.

Mitch found treatment helpful each time but continued to relapse. Mitch described how he recovered from alcohol use.

The treatment was worthwhile but I was not cured. I had numerous relapses. . . . In 1994, I got sober in earnest. I think it ran its course. I decided I didn’t have to do it anymore. It was burdensome to stay inebriated enough to take care of the pain. I got an OWI in 1994—my second one. My first was in the 1980s right after my divorce. I finally said, “Enough. I don’t have to do this.” I didn’t start drinking again. I was required to go to AA weekly and had two years’ probation. I put up with AA. I just quit. If I thought about drinking, I procrastinated.

Mitch did not find Alcoholics Anonymous helpful and stopped attending as soon as court-ordered treatment was over. Mitch eventually received inpatient and outpatient

mental health treatment, which helped him manage his depression. Both participants felt that some aspects of treatment helped them recover from their disorders and manage remaining symptoms. However, they found different facets of treatment to be helpful.

Ease of access to treatment. While those who went to treatment found it helpful, ease of obtaining treatment varied. One participant found inpatient treatment by herself. Two participants who went to inpatient treatment had families that found treatment facilities. One partner asked a family friend who had been through treatment for help to find treatment. Participants who attended a support group following treatment received referrals from the treatment facility. Three other participants found support groups through efforts of family members and medical providers.

One participant experienced “one-stop shopping”. Each time Mitch needed treatment he simply showed up at the Veterans Hospital and told them what he was going through. Hospital personnel assessed Mitch’s needs and offered him treatment.

All I have to do is call the VA—one number—and they get me the help I need. I have nothing but praise for the VA. There is mutual respect. The VA goes out of its way to help. They figure it out.

Some of the 10 participants who did not receive any treatment had more difficulty finding help. One participant requested a referral for counseling from her general medical provider who refused, telling Lois that she did not need counseling. Several others knew that they had a problem but did not know where to turn for help. These participants continued to experience symptoms of their disorders.

Provider knowledge of co-occurring disorders and old age. A few participants received help from providers who understood that older adults could experience co-occurring disorders. Amy's husband found a physician who knew about Alcoholics Anonymous and encouraged her to attend.

Connie found a spiritual director who helps her use spirituality to cope with her depression and addiction issues. "I have a spiritual director. . . . The connection between the psychologist and the pastor was really important—the spiritual connection." Connie especially appreciated that her mental health and spiritual providers worked together.

Some participants went to self-help groups where older adult members helped them feel accepted and comfortable. Vince, Don, and Rich all attended Alcoholics Anonymous groups with members who were older and who understood their needs as older adults with alcohol problems. Vince said, "There are lots of old timers in AA. They keep things going. We started attending AA in [community]. There were lots of old timers there and they told you what they thought."

Summary. Of those who went to treatment, all but one person found that it helped with their co-occurring disorders even though treatment addressed only one disorder and may not have been at the ideal level of treatment. Each participant reduced symptoms and some moved into recovery. Seven of 10 participants who did not receive treatment, even those with mild and moderate symptoms, continued to have difficulties with co-occurring disorders that affected their lives, their families, and their work.

Unexpected Forms of Help

Help does not always come in expected forms. Four participants lost jobs due to their co-occurring disorder symptoms. For each, this became an opportunity. After taking time off to regroup, Michael started a business. “I’m 55 and starting on a new job and career. We’re in the second year [of having a business]. I hope not to lose money.” Rich, who referred to himself as a “self-made man”, had worked his way up through a corporation, and achieved a high position. Rich was fired due to drinking during work hours. Rich had poured all of his energy into a job that ultimately did not value him. Rich struggled with his disorders for several years even with treatment. After his third inpatient treatment, Rich became active in Alcoholics Anonymous and spoke of the many benefits to himself that came from helping others through this organization. “I am very involved with AA. I will help anyone. I found out it’s not just me.”

After being fired from jobs that were stressful, finding vocations and avocations that were meaningful and reduced stress assisted with recovery from co-occurring disorders for several participants. Connie, who lost her job after going to treatment, has found meaningful work. She also writes and speaks publicly about her experiences and recovery. “I speak on abuse issues, not locally, but in [city]. Far enough away that local people don’t know about it.”

Mitch found work that uses his creative skills. Mitch attributes his ability to stay in recovery to this occupational change.

Once I got straight, I realized that the marriage couldn't work. I had sold out to become a working class hero. I'm not a company man. I'm an artist. If I don't do something with that part of me, I must drink.

These participants differed from those whose losses resulted in increased co-occurring disorder symptoms. For some participants, the loss of a job or career provided new opportunities

Rural Resources

While rural communities offer limited resources to older adults with co-occurring disorders, these communities have some positive aspects. Don worked with a local church that provided space for self-help meetings.

Five years ago we met in the . . . church basement and paid rent. The state AA said, "Watch it about paying rent. If you do that you have to have liability insurance." The priest then let us donate instead of paying rent.

Don used his persistence and his social embeddedness in his communities to work out the meeting space problem for the group.

Summary of Protective and Resilience Factors

Protective and resilience factors helped all participants reduce their symptoms and some moved into recovery. Many factors helped participants achieve better functioning. The participants used personal resourcefulness, recognition, and acceptance of their disorders, and formal and informal help to find new ways, not just to cope with their co-occurring disorders, but also to move through disorders and achieve improved levels of functioning. While each factor is important, it is perhaps even more important to

recognize the multiple pathways to attaining and regaining recovery and the interaction of these paths/resources.

Conclusion to Findings

The participants' narratives presented the meaning of the experience of co-occurring disorders for older adults living in rural communities. Participants described their co-occurring disorders and the personal and environmental aspects that they believed placed them at risk to develop co-occurring disorders. Participants identified childhood difficulties, gender issues, loss and grief, and caregiving as key factors in developing co-occurring disorders.

While participants focused on these personal risks, they also identified barriers to receiving help to either prevent or recover from co-occurring disorders. Participants consistently noted the lack of information about co-occurring disorders and especially that older adults can experience co-occurring disorders. Participants had few role models to help them understand the disorders and how to cope with and recover from them. In addition to lack of information, participants sometimes had misinformation about treatment that led them to fear getting help. While family and friends were sometimes essential supports, they also often lacked information about co-occurring disorders and sometimes served as obstacles to participants getting help.

Participants noted that few people in rural communities understand co-occurring disorders. When participants looked for help, they most often turned to medical providers and spiritual leaders. Neither of these groups provided much assistance. Employers demonstrated little understanding of participants' difficulties.

Rural communities offered little in the way of identifying or treating co-occurring disorders. Recommended treatment models for co-occurring disorders are not in use in participants' rural communities. No participant received integrated treatment for co-occurring disorders. About half the participants received treatment for one disorder. Even then, treatment was scarce, costly, and hard to find. No participant received treatment developed for older adults. In addition to difficulty obtaining treatment for co-occurring disorders, some participants struggled to find help for other problems that interacted with co-occurring disorders such as caregiver issues and services to assist with maintaining independence.

At the same time that participants struggled with co-occurring disorders and barriers to finding help, participants also demonstrated resilience. Participants were personally resourceful in figuring out how to manage co-occurring disorders. They were persistent in their efforts to find ways to cope with disorders. They used their place in their families and communities as well as religious and spiritual beliefs and organizations to search for meaning in life. Very often participants helped others as a way of helping themselves.

While the lack of information about co-occurring disorders was a hindrance, participants eventually acknowledged their disorders. Participants who found treatment found it useful in dealing with co-occurring disorders. Even when they only received treatment for one disorder, participants often used that knowledge to work on their other disorders. While many participants have not found full recovery, most have reduced the severity of their disorder symptoms. Some participants found help in unexpected ways. Participants who lost jobs

sometimes found the freedom to try new careers and interests that they found fulfilling. Rural resources were scarce, but participants made the most of what existed. Protective factors and resilience helped participants overcome feeling alone and helpless.

The findings help develop an understanding of factors that introduce risks for older adults living in rural communities to develop co-occurring disorders. Rural communities lacked both preventive and treatment resources. Feeling alone and helpless was pronounced as participants described these issues. Protective and resilience factors that assist older adults to grow through these disorders were identified. Both individual and environmental factors played a part in achieving or regaining recovery after experiencing co-occurring disorders. All participants identified helping others as a way of revitalizing their lives. The changes came at all times of life, making it clear that it is never too late to address co-occurring disorders. Finally, participants found multiple paths to both development of and recovery from co-occurring disorders that involve both personal and environmental factors.

Several themes emerged from the categories described by participants. Theme one has to do with the sense of aloneness and helplessness brought about by early life experiences. A second theme reveals that participants grow through their disorders and find meaning in their lives, often by helping others. Multiple paths led to co-occurring disorders in older adults and multiple paths lead to protection, resilience, and revitalization for older adults who experience co-occurring disorders is theme four. Finally, the idea that it is never too late is an essential theme. Age does not take away the ability to change, to learn new ways to cope with co-occurring disorder symptoms, and find new meaning in life. It is never too late to benefit from information and assistance. Chapter nine will discuss these themes.

Chapter 9: Discussion

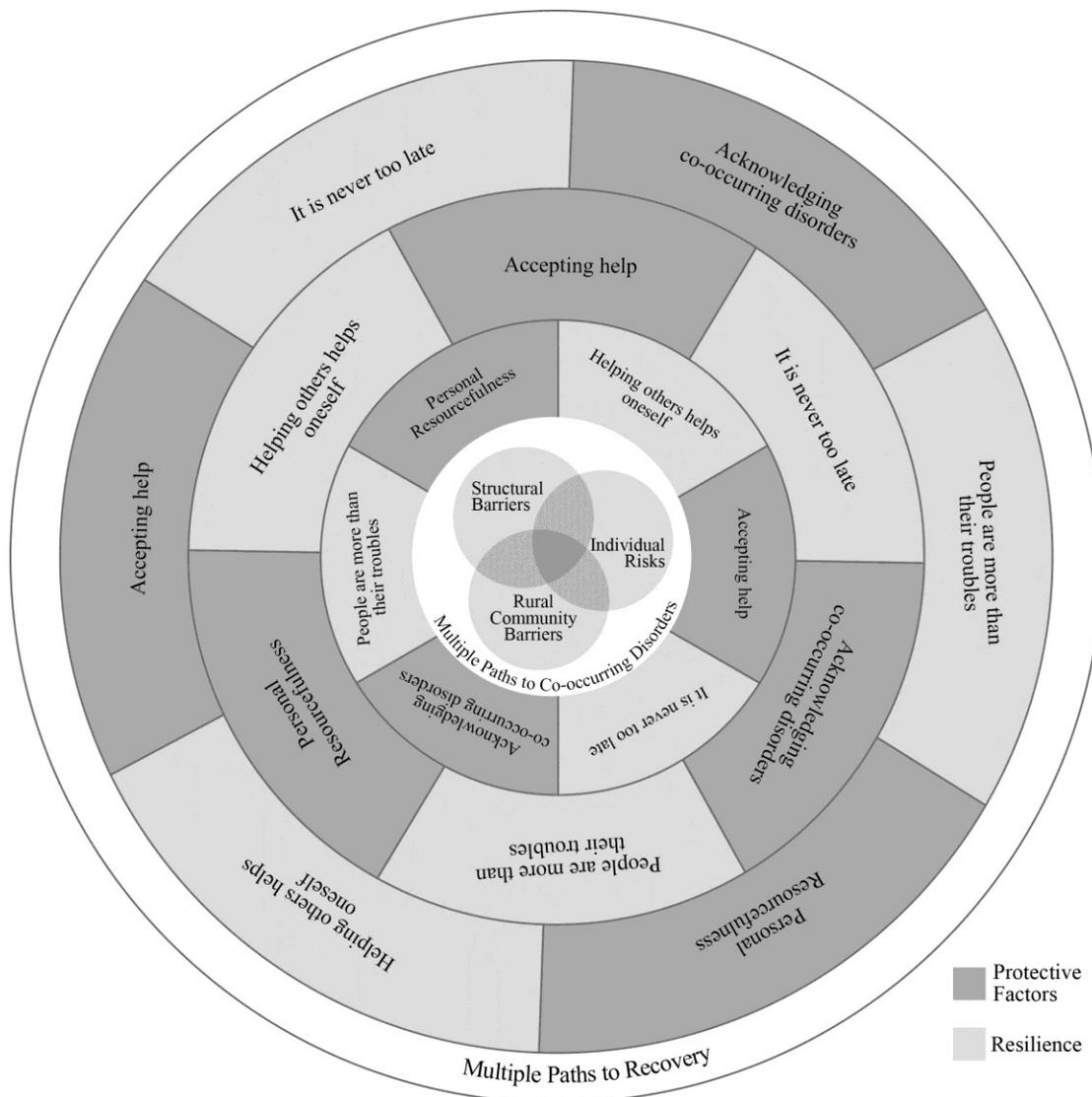
The findings of this study focused on the experiences and perspectives of older adults living in rural communities who had co-occurring mental health and substance misuse disorders. Some participants still had active co-occurring disorders, presenting the disorders as they manifested in older adults. Other participants were in full or partial recovery from co-occurring disorders, and their perspectives provided insights into their recovery process and the need for services to achieve and maintain recovery. Although participants' narratives reflected some ideas from previous research, their age and rural residence provided perceptions about co-occurring disorders and services not found in the literature.

The purpose of this chapter is to discuss key ideas and identify themes that originated in the findings about rural older adults with co-occurring disorders. Each theme and data that describes the theme is discussed. Theme one, there are many paths leading to co-occurring disorders, is illustrated by individual risks, rural community barriers, and structural barriers encountered by participants. This theme derived from participants' narratives of how co-occurring disorders developed and affected them. The perception of being alone and helpless, stigma about co-occurring disorders and age, and rural values were in evidence throughout discussion of the theme. Theme two, there are multiple paths to recovery from co-occurring disorders, is illuminated through the concepts of people are more than their troubles, personal resourcefulness, acknowledgment of co-occurring disorders, acceptance of help, helping others can help oneself, and it is never too late for recovery. These two themes assist with recognition of

how co-occurring disorders develop and the protective factors and resilience that helped participants work toward recovery. See Figure 1.

Figure 1

Multiple Paths to Co-Occurring Disorders and Multiple Paths to Recovery



Participants did not avoid the negative consequences of co-occurring disorders nor did they always adapt well in rural environments that lacked supports. Participants

also demonstrated resilience that implied strength that assisted with recovery from co-occurring disorders. The participants described both risks and resiliency, and their examples illustrate the themes of multiple paths. In addition to understanding personal risk and resourcefulness of older adults experiencing co-occurring disorders, this discussion identifies the features of rural communities and the structure of services that figure in developing, preventing, and recovering from co-occurring disorders. Individual risk and resilience factors, rural communities, and service structures are examined through the lens of age and rural residence.

Multiple Paths to Co-Occurring Disorders

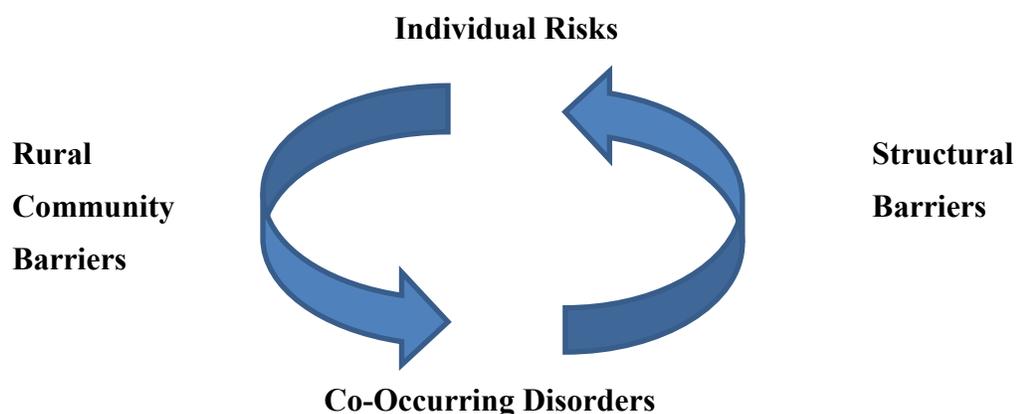
Participants described multiple paths to co-occurring disorders that included individual risks, rural barriers, and structural barriers. Individual risks often set participants on the path toward co-occurring disorders. The rural community contributed barriers to the absence of treatment for co-occurring disorders through lack of recognition of co-occurring disorders. Participants did not label stigma as a rural community barrier but described ways in which stigma contributed to difficulty in obtaining assistance for co-occurring disorders. Structural barriers had to do with the dearth of services for older adults with co-occurring disorders. Participants experienced multiple risks and barriers that intersected and interacted consecutively, concurrently, and in any order as participants developed co-occurring disorders. See Figure 2.

Individual risk factors. The risks that participants believed were related to the development of their co-occurring disorders included childhood deprivation, gender issues, loss and grief, and caregiving coupled with the perception that they received little

help or guidance in how to cope with these difficulties. Participants believed that the combination of risks led to the development of their co-occurring disorders. Perceptions of feeling alone and helpless with these life difficulties were an important part of the risk that increased the likelihood of developing disorders. Participants described misuse of alcohol and prescribed and over-the-counter medications to relieve mental health problems followed by development of a co-occurring substance misuse disorder. Some participants thought that genetic factors or health issues were related to their co-occurring disorders. These risk factors are not exhaustive but are the risks identified by participants as relevant to themselves.

Figure 2

Multiple Paths to Co-Occurring Disorders



Childhood deprivation. All but four participants described childhood difficulties of deprivation of basic needs, parental mental health and substance misuse problems, and the development of their own mental health and substance misuse problems. Combination of the experience coupled with feeling alone with the problem created the path toward co-occurring disorders. This implies that both childhood experiences and the

person's perception of those incidents are significant in the development of co-occurring disorders. This finding suggests that while negative experiences cannot always be avoided, assistance to deal with the feelings and perceptions about the experience may aid in preventing co-occurring disorders.

Gender related risks. Gender issues concerned all but one female participant. The support issues and stereotypes described by participants indicated that women might have unique risks for co-occurring disorders and that these risks may vary by generation. Gender role issues, such as stopping work outside the home after marriage, might have been more likely for women in past generations since today women expect to engage in paid work and careers. Other risks such as lack of support in primary relationships and loss of children may be common to women of all generations. In addition to the risks described in this section of the Findings, only women participants reported loss of siblings as major stresses, and women were much more likely to report lack of assistance from medical providers than were male participants.

While women who do not experience co-occurring disorders share many of these gender-related risks, a common factor for female participants was the feeling of being alone as they experienced limited support from partners, stereotyping, loss of children, and other gender-related issues. Both generation and rural location may play a part in the aloneness. Female participants grew up in generations that are particularly private about personal issues. Rural communities support this privacy and lack the kinds of supportive services that might encourage women to reach out for help.

Gendered concerns may have been unrecognized by some participants, their families and medical and spiritual providers. Given the perception of some participants that others did not consider their issues important, they may not have acknowledged these difficulties. The findings suggest that gender, generation, and rural location appear to be significant in understanding risk for the development of co-occurring disorders. Overgeneralization of risk factors may lead to ineffectual grasp of the risks for co-occurring disorders.

Loss and grief. About two thirds of the participants described various kinds of loss and grief. The perception of being alone with loss and feeling helpless to change the consequences may have been as important in the development of co-occurring disorders as the loss itself. The lack of formal support services in rural communities coupled with the rural value of maintaining privacy that is especially appreciated by older adults may have placed these participants at greater risk for developing co-occurring disorders. If participants had no positive ways to express loss and grief, these emotions may have developed into depression. With very limited mental health services as well as stigma attached to using such services, misuse of alcohol and other drugs may have provided a method of coping for participants. Thus, loss, perception of loss, absence of supportive services, and individuals or community valuing privacy over receiving help may combine in various ways to foster development of co-occurring disorders. Information and supportive services may assist in reducing the effects of losses.

Caregiving. Caregiving had been provided by about two thirds of the participants, and over one half filled the role as older adults. Several participants had

given ongoing care for more than one person. Caregiving interacted with all of the participants' other issues. While most participants wanted to provide care services, they did not know how to access assistance, whether or not services were available for caregiving and for themselves as caregivers. The overwhelming demands of caregiving stressed many participants. Some participants had their own health concerns including co-occurring disorders that made caring for others more demanding of their physical, mental, and emotional reserves. Aging, coupled with limited resources in rural communities, increased the participants' sense of aloneness and difficulty caring for both self and the person for whom they provided care. Information and formal and informal support for emotional and concrete needs could make caregiving more effective while reducing stress for the caregiver.

Perception as risk. All of the participants perceived being alone with their troubles at one time or another and felt unable alter the difficulties. Whether the feelings developed from childhood events, gender issues, losses, or caregiving, perceptions of being alone without help led to a sense of despair. When aloneness occurred during childhood, helplessness was particularly prominent since participants had little control over their lives as children. However, participants experienced aloneness and helplessness relative to gender, losses, and caregiving at all ages. Regardless of when it happened, the perception that there was no one to help with an overwhelming situation left the participant feeling alone and helpless. These feelings interacted with other risks in the development and maintenance of co-occurring disorders. Assistance with reactions

to negative experiences appears to be a way to reduce perception as a risk for development of co-occurring disorders.

Age as risk. The relationship between age and co-occurring disorders was complex. One path to severe co-occurring disorders occurred when participants who experienced disorders in childhood or adolescence felt alone and helpless. Some participants first developed co-occurring disorders as adults or older adults or had recurrences after having been in recovery from disorders developed when they were younger. Regardless of when co-occurring disorders started, they did not disappear with age. Symptoms continued to affect participants, and stressful events sometimes precipitated new disorders. Even when symptoms were in remission, participants needed to manage their disorders so that symptoms did not reoccur.

Participants like Dove, who kept her sadness to herself, sometimes identified with the beliefs that they were not valuable and did not deserve assistance. These beliefs, coupled with the lack of privacy when seeking assistance in rural communities may have contributed to participant reluctance to discuss disorders and ask for help. The invisibility of older adults and lack of knowledge of their needs placed participants at risk to receive little assistance from both formal and informal resources. While everyone needs information and support, attention to the requirements of distinct populations such as older adults in rural communities could reduce risk for co-occurring disorders.

Rural community barriers. Rural community characteristics interacted with personal risks of older adults to make paths toward co-occurring disorders. Participants, family and friends, and providers lacked information about co-occurring disorders and

this dearth of knowledge sometimes led to fear of treatment. Few role models were available to assist participants in accepting and learning about their difficulties. Stigma related to both co-occurring disorders and age increased the barriers to assistance for older adults. Absence of resources, appropriate assistance, help for other problems that intersected with co-occurring disorders, and rural values made rural communities unaccommodating for older adults with co-occurring disorders. These barriers both preceded and followed others risks. Not only individual risks but also rural community barriers need to be addressed to reduce co-occurring disorders in older adults.

Provider lack of information. In addition to participants and their families and friends, rural providers were uninformed about co-occurring disorders and even the separate disorders of mental health and substance misuse. The physicians who referred participants to assistance with their disorders served metropolitan areas, not rural communities. Lack of training in both co-occurring disorders and older adults may lead to uninformed providers. Stereotypes of older adults as uninteresting and of little value to the community may precede beliefs that there is no point in using scarce resources to assist them with co-occurring disorders. The absence of information coupled with stereotypes increases isolation. Informed rural providers are an essential part of a system to assist older adults with co-occurring disorders.

Absence of role models. Participants found few role models to help them understand co-occurring disorders as most people in rural communities were guarded about sharing this information. For example, Connie spoke to groups but only at a distance so that her local community would not find out about her difficulties. On the

other hand, Rich wondered how anyone was to learn about available help if everyone maintained anonymity. Rich spoke to community groups about substance misuse in an effort to be a role model and to provide accurate information about treatment and recovery services. Rich provided a model of how older adults could address their disorders. The lack of role models interacts with individual factors and community barriers to increase risk for older adults to develop and continue co-occurring disorders. Role models like Rich help break down isolation and inaccurate information about co-occurring disorders.

Stigma. The stigma attached to asking for help with co-occurring disorders was powerful at both individual and community level. Cultural values prevented help that might have assisted participants. Participant narratives reflected the belief that responsibility lay with the individual, not the community. Older adults may be even more steeped in the rural values of self-reliance and avoidance of services than are younger persons. While self-reliance can be a strength, it also may isolate persons from needed assistance. Education about co-occurring disorders can provide a foundation for accurate understanding and assist with acceptance of services for older adults in rural communities.

Scarce resources. Barriers to services, not only for co-occurring disorders, but also for many kinds of health and social services, education, and employment, were so much a part of rural communities that they were nearly unnoticed by participants. Thus, when participants encountered a lack of appropriate services for co-occurring disorders, it was expected and accepted. Vince attended treatment neither developed for, nor

provided by counselors with training in either co-occurring disorders or older adults.

Vince and other participants accepted the expectation that they adapt their needs to the available services and silence any protest, even though they paid for treatment that did not fit their needs.

No participant in this study had been formally diagnosed with co-occurring disorders, and only a few had received assessment and treatment for any disorder. The rural communities in this study did not provide treatment for co-occurring disorders and participants were not referred elsewhere for such services.

The effects of co-occurring disorders continued into old age and participants needed support services whether or not they had active symptoms. Amy, who began attending a self-help group in her fifties, continued to do so thirty years later. Amy still struggled with depression, and she still thought about drinking. The only treatment available in rural communities consisted of support groups for one or the other disorder. Symptoms of co-occurring disorders may go into remission but disorders are not cured and older adults need maintenance services in order to stay in recovery. The scarcity of treatment and recovery resources interacts with other risks and barriers to increase risk of relapse.

As long as participants functioned at least minimally, community leaders and providers ignored their co-occurring disorders. However, when co-occurring disorders interfered with functioning, the community shunned participants and their employers sometimes fired them. Lack of treatment led to the loss of income, benefits, and standing in the community that harmed family members as well as the participant.

The absence of appropriate treatment designed for co-occurring disorders and older adults draws attention to the invisibility and perceived expendability of this population. Stigma about co-occurring disorders and age, rural values, and scarce resources intersect with lack of information and role models to create barriers to assistance for older adults with co-occurring disorders.

Other problems. Lack of help for other problems was a less obvious but significant barrier for participants to recover from co-occurring disorders. Several participants had a recurrence of symptoms after having moved into recovery from co-occurring disorders. These recurrences happened when participants experienced stresses related to caregiving, work, and health issues. Resources for assistance were either missing or not advertised. The lack of services to assist and the lack of information about available services may contribute to co-occurring disorders, especially for those in rural communities where resources are scarce and accurate information is unavailable.

Summary. Rural community barriers both preceded and followed co-occurring disorders. Barriers to receiving assistance with initial risks preceded development of co-occurring disorders. Once co-occurring disorders developed lack of information about and role models for treatment and recovery brought about the same feelings of aloneness and helplessness that preceded co-occurring disorders. Family, friends, community, and providers also lacked information about co-occurring disorders. Without assistance and guidance, the barriers were overwhelming. Stigma about co-occurring disorders and age and scarcity of appropriate resources contributed to development and lack of recovery from co-occurring disorders.

Structural barriers. Structural barriers were a significant part in the development and continuance of participants' co-occurring disorders. The level of formal supports available to the participants was quite low. The protective strategy of providing educational information about co-occurring disorders in older adults was absent in participants' rural communities. Neither educational nor treatment outreach was offered to any participant. No formal services attempted to engage older adults with co-occurring disorders. Assessment of any disorder by medical and social service providers was the exception. Evaluation of single disorders seldom took place until participants were court ordered or taken to a treatment facility, and no participant was assessed for co-occurring disorders. Even when treatment occurred, no one received services for co-occurring disorders or services developed for older adults. The absence of prevention, treatment, and recovery services interfered with participants' efforts to manage their symptoms and improve their quality of life.

The organization of services in Iowa has created barriers for co-occurring disorder services. Mental Health Services in Iowa are administered by the Department of Human Services (Division of Mental Health & Disability Services, n.d.) while Substance Use Services are directed by the Department of Public Health (Bureau of Substance Abuse, n.d.). This structure of services for mental health and substance misuse has impeded the development of integrated services for persons experiencing co-occurring disorders. Billing issues also hamper the integration of services, as agencies cannot bill for providing treatment for both co-occurring disorders (M. Sharon, Clinical Director, New Opportunities, Inc., personal communication, October 5, 2012).

Iowa's state facilities provide limited care for persons with co-occurring disorders. Iowa has only one state facility that provides a dual diagnosis program for adults in all 99 counties (Mount Pleasant Mental Health Institute, n.d.). Only mental health providers can refer clients with co-occurring disorders to this facility. The institution does not allow providers of substance misuse services to refer to this institution (M. Sharon, personal communication, October 5, 2012). A different state facility offers gerontology services in all of Iowa's 99 counties (Clarinda Mental Health Institute, n.d.). Older adults and their providers must choose the health need to address since services are not integrated and co-occurring disorders and other gerontological needs cannot be addressed in one facility.

This service structure disregards not only the economic and human cost for older adults with co-occurring disorders but also for the communities in which they live. Rural communities depend on volunteers to provide most of their services. Older adults perform paid employment and a great deal of unpaid service. When participants were debilitated by their disorders, they could not carry out this work. The cost of co-occurring disorders is measured in dollars. The human cost is articulated in participant narratives.

Summary. Individual risk factors, rural community barriers, and structural barriers interact and intersect to develop paths to co-occurring disorders. Each participant's path was complex and involved risks and barriers, underscoring the challenges faced by rural older adults with co-occurring disorders. Perceptions were part

of the risk for co-occurring disorders to develop. Barriers associated with age and stigma further complicated these paths.

The risks and barriers connected to the concept of aloneness and helplessness dominated the lives of the participants, often for years. Family, friends, and rural communities in which participants lived added to the sense of aloneness, sometimes in a misguided effort to be respectful, other times enforcing community norms, and each time, resulting in isolation for the participant.

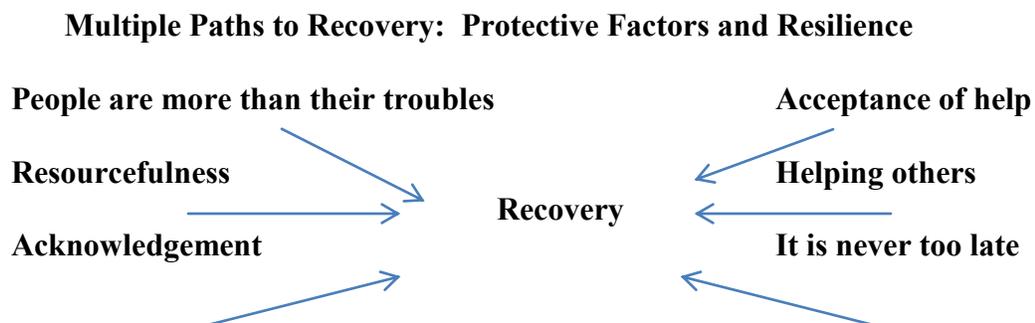
Service barriers that were structural added to aloneness and helplessness. Without information and role models, participants, families, friends, and communities assumed that there was little help for co-occurring disorders. When providers and programs did not deliver appropriate services to older adults with co-occurring disorders, participant and family assumptions were not far off the mark. Not only participants, but also family, friends, and even communities felt alone and helpless to bring about change. The structural barriers to help interacted and intersected with individual risk factors and rural community barriers to develop or intensify the paths to co-occurring disorders.

Multiple Paths to Recovery

Just as there are multiple paths to co-occurring disorders, protective factors and resilience provide multiple paths to recovery. Protective factors including personal resourcefulness, acknowledgment of co-occurring disorders, and acceptance of help support remission of co-occurring disorders and revitalize lives. Unexpected forms of help and rural resources also assist with recovery. Resilience-based beliefs contribute to recovery. Recognition that people are more than their troubles, helping others helps

oneself, and appreciating that it is never too late to work toward recovery are convictions that support recovery. Recovery is a complex and individualized journey. Protective factors and resiliencies vary even among rural older adults. See Figure 3.

Figure 3



People are more than their troubles. Participants understood that they were not their disorders and that their co-occurring mental health and substance misuse disorders were only one part of their lives. Participants frequently talked about their joys. Sometimes pleasure related to recovery. Other times, happiness involved family, friends, career, and avocation achievements.

While participants had difficulties, they also contributed to family and community life. Participants worked, volunteered, and looked for balance between taking part in recovery-oriented activities and saving time for other pursuits. Recognition of both troubles and contributions is an important step in acceptance of self. Wanting others to recognize both difficulties and talents speaks to connection with social systems that may provide support in dealing with co-occurring disorders and finding recovery.

Personal resourcefulness. Participants demonstrated remarkable personal resourcefulness in the face of difficult co-occurring disorders. The interaction of

persistence, social embeddedness, and spiritual and religious resources of participants as they struggled with co-occurring disorders helped explain this resilience.

Persistence. Participants exhibited resilience even when other important protective factors were missing. Participants displayed persistence when family, friends, and religious and health care organizations failed to understand their problems and needs, and when employers devalued them. Determination helped participants search for ways to cope with co-occurring disorders and the stresses that magnified their difficulties to the point of becoming suicidal.

Recovery was not a given for participants. About one-third of the participants were in full recovery from both co-occurring disorders, about one-third were in recovery from one disorder and still experienced symptoms of the other. About one third of the participants experienced symptoms of both disorders. Participants were tenacious in their efforts to find meaning in their lives, and this helped them overcome at least some of the symptoms of their disorders even when they were not in full recovery. The ability to persist when feeling alone and helpless seemed to be an essential aspect of resilience.

Some participants were in recovery from the symptoms of their co-occurring disorders, but Nancy still struggled with depression and prescription drug misuse. In spite of this, Nancy achieved her goal of obtaining a master's degree and taught for several years. Nancy's statement, "I just keep going. I never give up." epitomizes the attitude of the participants. The effects of Nancy's childhood learning disorder, extreme poverty, and neglect and abuse from her parents have not disappeared. Nancy simply seeks ways to renew the meaning of her life. Participants searched for ways out of their

aloneness and worked hard to overcome the helplessness they felt. Nancy's personal resourcefulness and persistence helped her to keep trying to prevail over her co-occurring disorders.

Persistence is important regardless of other protective factors that are present or absent. The search for life meaning provides a goal and focus. Once goals are set, persistence helps achieve them. When stabilization of symptoms and improved quality of life are goals, persistence assists with focusing on them and trying again when failure occurs.

Social embeddedness. Even when there was conflict, participants were embedded in systems of people. Laura's husband threatened to force her into treatment, taunted her when she quit drinking, and was jealous of her relationships with men in her self-help group. In spite of this, Laura appreciated that her husband stayed with her while she was drinking, and they worked out a meaningful relationship. Laura was close to her sons and she was helping raise a grandson. Laura's self-help group provided supportive relationships that gave meaning to her life. As participants figured out their lives, their support systems surrounded and helped maintain them even when carried out in insensitive ways.

Social embeddedness provides a foundation of safety from which to work on co-occurring disorders. Knowing that a family, group, or system will accept the person, if not the person's behaviors, gives a sense of belonging that allows space to try new behaviors and change what does not work.

Spirituality and religion. Participants identified both spirituality and religion as sources of renewal, revitalization, and focus that grounded their lives. Some participants found that personal prayer and participation in religious activities provided this help. Other participants who did not find acceptance or comfort in institutionalized religion attained it in an individualized search for meaning. Mitch focused on his artistic abilities and found significant renewal of self in those activities. Participants who appreciated the spiritual focus of a self-help group found that it helped them manage their disorders. Even when they grappled with co-occurring disorder symptoms, spirituality and religion helped participants find importance outside themselves and ways to persevere in their efforts to manage their lives.

Summary. Many people struggle with co-occurring disorders and environments that contain few formal resources. Persistence provided the drive to keep going when life was difficult and efforts to achieve goals failed. Informal and long-time relationships may applaud successful efforts at change and offer a foundation of stability and safety to return to when difficulties return. Religious and spiritual convictions provide abstract and concrete guidance to work through co-occurring disorders and toward recovery. Family, friends, religion, and self-help systems assist with joys and sorrows and support revitalization efforts. The qualities of life meaning, self-acceptance, stability, and safety balance life troubles.

Acknowledgment of co-occurring disorders. When participants acknowledged their co-occurring disorders, it was a step toward revitalizing their lives. Twenty of the participants experienced long-term disorders and most had experienced aloneness and

helplessness for decades. Participants had arranged their lives to cope with the symptoms of their disorders and had arrived at a kind of equilibrium. To acknowledge that they experienced co-occurring disorders and that they needed help meant that participants had to tolerate disequilibrium for a time. Acknowledgement conflicts with the rural value of self-sufficiency and it may bring fear of being viewed as weak and unable to take care of oneself. Others who do not respond with shame and stigma provide a mirror for self-acceptance. Acknowledgement may help with self-acceptance and move toward stability and safety.

Acknowledgement assists with improvement of co-occurring disorders through personal efforts and by seeking outside help. The ability to endure the changes that acknowledgement of disorders brings resiliency. Acknowledgement meant recognition that a person is more than their troubles and has worth.

Accepting help. Help comes in several forms. Treatment assists some people in efforts to recover from co-occurring disorders. Help sometimes arises from unexpected sources. Although rural communities have limited formal resources and values sometimes conflict with accepting help, communities also provide informal support that aid people with co-occurring disorders in their journey toward recovery. Acceptance of help may be challenging, as it requires changes in behavior and thinking.

Treatment. Eleven participants obtained some kind of treatment for their disorders. Although many participants initially denied that they needed treatment, several agreed to go when confronted and assisted by family, physician, or the courts. For others, acceptance was more difficult. Rich was committed to treatment after he

invited the sheriff to pick him up for drinking and driving. Although Rich was unable to initiate treatment, he assisted the sheriff to intervene for him. Accepting treatment may be frightening when it challenges independence and being in control.

Since no participant received integrated treatment for both disorders, even those who went through treatment needed to develop an understanding of the interaction and management of co-occurring disorders. The ability to accept treatment and find ways to make meaning of help that addresses only one disorder speaks to resourcefulness, resiliency, and the rural value of helping oneself. Accepting help also means challenging the value that one should always be able to take care of one's own needs and facing the fear of being unable to do so.

Unexpected forms of help. Help for participants did not always come in expected forms. Loss of a job or career was frightening and it carried stigma. Although participants initially felt a sense of loss when fired from jobs, each found freedom to try new vocations and avocations that enhanced their lives. The possibility of opportunity mingled with stress, as participants explored options. Participants regained self-worth and confidence when hope helped turn dreams into reality. Participants left behind despair that developed from aloneness and helplessness. New pursuits brought encouragement and support from others, achievements reenergized the participant, and renewed quality of life provided motivation to find different ways to manage disorders. Formal and informal supports, along with individual persistence, assisted participants to find and use unexpected help.

After being fired, Michael acknowledged problems and accepted help. His arrest and evaluation challenged his perception of substance misuse. Although Michael's depression initially worsened, support from his partner provided stability and safety in which to explore his options. Spiritual beliefs provided understanding that life was bigger than Michael's immediate problems. These supports assisted Michael to try new career goals. He resolved his co-occurring disorders and moved forward through a combination of expected and unexpected help.

Use of unexpected sources of assistance requires challenging old ways of thinking. Difficulties may be opportunities to change behaviors and assumptions. Renewing goals from the past or developing new goals may bring stability and safety. Spirituality may assist understanding that life is bigger than immediate problems.

Rural resources. While rural communities create barriers to help, they also provide a cultural value of maintaining close family and friend relationships. Laborsaving devices eliminate the need to work together to ensure survival, but the sense of community endures. Families of many participants remained emotionally close and often lived nearby. Lives intertwined, offering physical and emotional support, even when families were in conflict. The closeness often helped family and friends see participants as whole people rather than focus only on symptoms.

The rural community provided participants with opportunities to stay embedded in the community through service. Vince at age 81 still actively farmed and welcomed newcomers to his self-help group. The limited formal services of the rural community sometimes assisted participants to feel needed by family and volunteer organizations.

This feeling helped participants believe that they could change and that it was not too late. Families and communities sometimes support resilience and recovery. While resources may be sparse in rural communities, resilient persons use the available resources.

Accepting help may mean overcoming long held beliefs and changing behavior. Treatment is one kind of help that may facilitate recovery. Unexpected forms of help and rural communities offer resources that may not be readily apparent. Resilience assists people to recognize the resources and make use of them.

Revitalization through helping others. Helping others, a strong rural value, reverberated throughout the narratives of the participants. Participants consistently brought up helping others as they described working their way out of difficulties associated with co-occurring disorders. Participants found that as they helped others, they helped themselves. Helping others reduced participant aloneness and helplessness. Participants helped in multiple ways and age was not a factor in helping. Helping was part of most participants' rural value system. Some participants provided help for philosophical reasons while others offered practical motives for helping. Helping others supported a sense of self-worth and motivation to recover.

Helping others reduced aloneness and helplessness. Participants were aware that as they helped others, they reduced their sense of aloneness. Assisting others provided opportunities to feel helpful, rather than helpless. Don, who at age 84 remained active in Alcoholics Anonymous, stated, "On the third Thursday we have coffee after the meeting with lunch. Anyone getting medallions or chips gets this at the lunch as we have

a party. I'll get my 20 year chip on [date]." By organizing the meetings, the lunch, and the recognition of others' sobriety, Don benefitted from the socialization and recognition of his own sobriety.

Some participants were aware of not only the challenges brought about by childhood privation, gender issues, losses, and caregiving but also the impact of ongoing despair on their lives. Connie spoke to groups about her childhood abuse. Connie felt alone with these experiences long after the abuse ended. Through public speaking, Connie found a way of helping other escape feeling alone and helpless while empowering herself. Participants who found assistance for mental health and substance misuse problems in self-help groups offered support that lessened the aloneness for self and others. As Rich noted about his self-help group, "It feels so good to help." Reducing difficulties for others may lessen barriers of aloneness and helplessness that increase a sense of self-respect and support recovery.

Many ways to help. Participants varied in the ways they helped others. Some focused on informal, individual helping. Leon raised several grandchildren and provided a home for his mother-in-law. Mitch took care of his partner as she was dying. Other participants focused outside the immediate family. Chuck felt obligated by his moral code to help others and volunteered at the hospital and his church in order to feel useful to society. Still other participants focused on helping through careers. Mina valued the help she gave in her profession as a nurse. Dove, Joan, and Celia were active in religious service organizations and other participants helped through schools and senior citizens organizations. Several participants assisted the self-help groups that they attended to

manage their co-occurring disorders. Vince sponsored new members and served on state committees while Amy made coffee and kept the books. Both Vince and Amy helped keep their groups functioning. Regardless of how helping others is done, it may assist with feeling valuable, a part of the community, and lead to self-acceptance.

Never too old to help. Not one participant talked about being too old to help. Amy, age 85, thought that she could not make amends to all those she had harmed while she was depressed and drinking. However, Amy believed that she could make up for this harm through helping with meetings, teaching religious classes, and hosting social events. Neil had co-occurring disorders in adulthood, resolved them, and then developed new disorders as an older adult. Although Neil still struggled with symptoms, he took part in a mental health support group and provided rides to people in his senior housing. Age and health did not stop any of the participants from helping others. The need for the skills of all community members to keep rural organizations and communities functioning may assist with feeling essential. This feeling of being valued may assist persons with co-occurring disorders attain and maintain recovery.

Helping as a rural value. Helping others was essential in rural communities that lack adequate formal services. Participants thought first of informal help rather than looking for formal services when they or someone else needed assistance. Mere believed that if she helped others, someone would help her when she needed it. Mitch served on the city council to assist his community. Rich supported the anonymity of Alcoholics Anonymous but recognized the barrier that it presented and stated, “How do people find me with anonymity?” Rich gave up anonymity when he placed his name and phone

number in the Alcoholics Anonymous' Yellow Pages advertisement. Rich, who was active in a number of community activities, was open about his reasons for not drinking. Rich believed that he served as a role model for people who struggled with alcohol problems and found that this service assisted him to stay sober and positive.

Revitalization through helping others occurs in many ways. Rural culture that requires people to help each other may reduce aloneness and helplessness. The recognition that a person is never too old to help provides self-worth, and rural communities offer many ways to help others. The act of helping may assist people with co-occurring disorders as they search for ways to give meaning to life.

It is never too late for recovery and revitalization. Participants began their journey toward revitalization at many ages and employed many kinds of resilience. Participants reversed and resolved problems at all ages and found multiple paths to recovery and revitalization of their lives. Those who resolved aloneness and helplessness early in life frequently found meaningful relationships sooner rather than later. Robert married in his early twenties and found a partner who brought a new set of expectations to his life. He changed his attitudes, his behaviors, and his social group, all of which assisted him in resolving depression, anger, and drinking problems. Although Leon came close to suicide early in life, escaping the oppression of family of origin and community offered him opportunities to build a life he wanted. Leon's relationships with his wife and children and the value he found in work gave him reasons to live and helped him resolve his depression and cope in ways other than drinking.

Other participants experienced problems longer. Connie was in mid-life when her co-occurring disorders became so overwhelming that she sought inpatient treatment for depression that led her close to suicide. Connie first overcame the depression and later stopped drinking and gambling as she learned different means to transcend the oppressive aspects of life with which she could not previously cope. Treatment started Connie on a journey of seeking assistance through a combination of traditional mental health treatment and spiritual guidance. Both treatment and spirituality helped Connie find self-acceptance and appreciation. As Connie helped others with similar problems through writing and speaking, she resolved her own aloneness and helplessness, despair, and co-occurring disorders.

Several participants found their way out of co-occurring disorders as older adults. Don, Vince, and Rich entered substance misuse treatment as older adults and started journeys toward recovery and revitalizing their lives. While each participant regained connection with family, they also found new and meaningful relationships in self-help groups where they assisted others as well as met their own needs. Participants used self-help groups to learn new coping methods and received the support they needed to recover. Participants gave this same help to others, fulfilling the circle of helping and being helped.

Age does not diminish the ability to revitalize lives. Assisting others may aid in maintaining resolution of the symptoms of co-occurring disorders. Rural values support helping and rural communities provide many avenues to help. Recovery occurs at all ages. Helping others at any time of life may provide revitalization for self and assist

recovery by breaking through aloneness and helplessness. It is never too late to help others and self.

Summary. Participants did not follow one path to recovery from co-occurring disorders any more than they all followed the same path to develop their disorders. Participants used many protective factors and types of resilience to move toward recovery. Personal resourcefulness, acknowledging co-occurring disorders, and accepting help for co-occurring disorders were protective factors that helped participants recover. Participants recognized that they were more than their troubles, that helping others helped themselves, and that it was never too late to revitalize their lives. There is no one course of protective and resilience factors that must be followed. Many paths may lead to recovery.

Results Inform Theory

Critical theory was used to frame this study to help understand the paucity of research about rural older adults with co-occurring disorders. Critical theory proposes that knowledge not only develops understanding but also allows for interventions that bring about change or control (Habermas, 1971). Stigma and rural values appeared to be factors in the lack of knowledge about co-occurring disorders, older adults, and rural communities as well as in the dearth of services. This understanding assisted both the participants and the researcher of this study to develop greater understanding of stigma, co-occurring disorders, rural issues, and older adults. Participants as well as the researcher may be able to act upon this knowledge in ways that will benefit rural older

adults with co-occurring disorders, transforming knowledge into action (Habermas, 1971).

Use of a critical theory approach to a problem can assist in theorizing a dimension of aging and then focus on active involvement in practical change, a purpose of knowledge (Moody, 1988). The recognition of stigma and development of knowledge of how disorders co-occur in rural older adults can bring about change by developing appropriate prevention and treatment for this population as well as contribute to a theoretical understanding (Habermas, 1971). Recognition of rural values may help rural residents, practitioners, and policy makers acknowledge the importance of services to assist older adults with co-occurring disorders to maintain their ability to care for themselves. Thus, this study has the potential to bring about practical change as well as theoretical knowledge.

Study findings support the two current theoretical models that best explain co-occurring disorders. Participants most often developed a mental health problem prior to developing a substance misuse difficulty, thus supporting the secondary substance use disorder model. The risks described by participants identified common factors involved in the development of co-occurring disorders as well (Mueser et al., 1998). Perceptions of feeling alone and helpless with these problems may be a common factor that can be addressed, both at a prevention level and at a treatment level. The existing co-occurring disorder theories were relevant to a rural older adult population, thus extending the populations in which they have been studied. This research achieves the critical theory goal of connecting academic research with practice (Moody, 1988).

The resilience framework provided a way to look at rural older adults with co-occurring disorders from a strengths perspective and pinpoint that despite individual, community, and structural barriers, many participants were able to adapt positively (Luthar, et al., 2000; Masten, 2001). Resilience provided a way to understand the impact of rural social systems on the participants while focusing on their strengths (Leipold & Greve, 2009). The concept of being able to “grow past” co-occurring disorders was demonstrated as participants were resilient when the environment provided even minimal resources (Pentz, 2005). Culturally relevant prevention and treatment services could provide a better fit between the individual and the environment and further enhance resilience (Pentz, 2005; Leipold & Greve, 2009).

Both critical theory and resilience theory take into account subjective and interpretive dimensions of aging. Resilience theory is practical, allows for linkage between academics and practitioners, and creates a positive model with which to view older adults with co-occurring disorders. Critical theory maintains a focus on keeping as close as possible to the original experience of the older adults themselves. Thus, critical theory and resilience theory together provided a foundation for model and theory building for older adults living in rural communities who have co-occurring disorders.

Conclusion to Discussion

Risks and perceptions of risks lead to feeling alone and helpless with troubles. Rural community and structural barriers add risks and interfere with prevention of and recovery from co-occurring disorders. Stigma related to co-occurring disorders, age, and gender may increase risks while rural values and living in rural communities limit the

resources available to assist people with co-occurring disorders. Multiple paths result in co-occurring disorders.

Paths to recovery and revitalization through protective factors and resilience are also available. In spite of the risks and barriers faced while developing co-occurring disorders, persistence helps in looking for ways to recover and rejuvenate lives. Learning and knowing that a person is more than their disorders and finding joy and self-worth is essential. Personal and community resources may help find ways to reduce symptoms of co-occurring disorders. Acknowledgment of co-occurring disorders and acceptance of help may lead toward recovery. Helping others may bring hopes and dreams back to life and help overcome barriers. Revitalization may occur at many ages and junctures, sometimes more than once. Family, friends, and communities as well as people with co-occurring disorders benefit from renewed quality of life. It is never too late to recover.

Chapter 10: Practice Model to Serve Rural Older Adults

With Co-Occurring Disorders

This chapter presents a practice model designed to meet the needs of older adults with co-occurring disorders who live in rural communities. The model is based on ideas drawn from participant interviews. Participant ideas that relate to practice with rural older adults with co-occurring disorders are identified in Table 10, Participant Concepts for Practice with Rural Older Adults with Co-Occurring Disorders. The ideas from Table 10 were developed into the practice model presented in Table 11, Practice Model for Rural Older Adults with Co-Occurring Disorders.

Prevention that makes use of information, protective factors, and resilience is the focus of the model. Both treatment and recovery services are a part of prevention as they may reduce the effects of co-occurring disorders. Each part of the proposal is supported by practice and research. Recommendations for policy and research are grounded in the current study.

Multiple Paths to Co-Occurring Disorders and to Recovery

The participants identified multiple risks and barriers that contributed to developing co-occurring disorders. Participants also identified multiple protective factors and resilience that assisted participants to recover from co-occurring disorders. Participants described complex interaction among the risks and barriers as well as among protection factors and resilience. The model is based on the idea that multiple paths to co-occurring disorders interact and intersect in unique ways for each person, as do multiple paths to recovery from co-occurring disorders.

Ideas Are Specific to Older Adults, Co-Occurring Disorders, and Rural Communities

Participants' perspectives were those of older adults who lived with co-occurring disorders and the challenges of recovery. Participants identified risks and resiliencies that are specific to older adults living in rural communities. Participants could look back and recognize risks that came from earlier periods in their lives as well as those that developed when they were older. Participants classified personal protective factors, resiliency, and informal and formal supports that contributed to recovery at various stages of life. Participants believed that supports are necessary to maintain recovery as older adults. The interaction of multiple factors as co-occurring disorders develop and resolve is a constant consideration for assisting rural older adults.

Participants recognized the particular difficulties and advantages that living in rural communities offered older adults who cope with co-occurring disorders. Participants came from a perspective of rural values and culture that stressed independence, privacy, and reliance on informal rather than formal resources. Participants wanted services that addressed the challenges of their rural community and were in accordance with the advantages and values of their rural setting. See Table 11.

Participant Focus on Prevention

Participants identified a number of ideas to assist rural older adults with co-occurring disorders that focused on prevention. These preventative ideas emphasized reducing aloneness and helplessness, increasing knowledge about co-occurring disorders, reducing stigma, providing assistance for other problems that interact with co-occurring

disorders, increasing assistance from informal and formal resources, and using the resilience of older adults with co-occurring disorders. Participants wanted treatment for co-occurring disorders that meets the needs of rural older adults.

Table 11

Participant Concepts for Practice With Rural Older Adults With Co-Occurring Disorders

<p>Decrease aloneness & helplessness by increasing preventive and supportive services for risks</p> <ul style="list-style-type: none"> ▪ Childhood difficulties ▪ Gender issues ▪ Loss and Grief ▪ Caregiving
<p>Increase knowledge and understanding of co-occurring disorders for</p> <ul style="list-style-type: none"> ▪ Older adults ▪ Family and friends ▪ Providers ▪ Community members
<p>Decrease stigma and discrimination related to</p> <ul style="list-style-type: none"> ▪ Co-occurring disorders ▪ Age ▪ Gender
<p>Increase assistance for other problems</p> <ul style="list-style-type: none"> ▪ Support services ▪ Information about available services
<p>Help from others</p> <ul style="list-style-type: none"> ▪ Family and friends ▪ Religious leaders and organizations ▪ Medical providers ▪ Employers
<p>Help oneself</p> <ul style="list-style-type: none"> ▪ Recognize, value, and use personal resources ▪ Acknowledge co-occurring disorders ▪ Accept help ▪ Help others
<p>Increase assistance for co-occurring disorders</p> <ul style="list-style-type: none"> ▪ Treatment <ul style="list-style-type: none"> ▪ Mutual Self-Help Groups ▪ Outpatient ▪ Inpatient

Prevention of aloneness and helplessness. No participant suggested that life difficulties could be prevented. However, participants emphasized that feeling alone and helpless with troubles intensified the experience and may have led to the development or exacerbation of co-occurring disorders. Participants wanted more support during difficult periods, whether the challenges came from childhood difficulties, gender-related issues, loss and grief, or caregiving. Participants wanted both informal and formal helpers and identified family and friends, religious leaders, and medical providers as the persons they wanted to be able to turn to in times of need.

Prevention through increased knowledge of co-occurring disorders.

Participants consistently identified a need for increased knowledge of co-occurring disorders for themselves, family and friends, community providers, especially religious leaders, medical personnel, employers, and community members. Participants wanted information that depicts co-occurring disorders, older adults, and treatment accurately and corrected the myths surrounding each of these areas. Participants emphasized that knowledge of and education about co-occurring disorders and the available help are needed by people of all ages as co-occurring disorders can happen at any time of life. Since many participants first received treatment as older adults, they highlighted the need to include older adults in learning about co-occurring disorders. In addition, participants stressed the need to understand the specific ways that older adults experience co-occurring disorders, recurrence, and recovery.

Prevention by reducing stigma. One participant used the word, stigma, in her interview. Many more participants described stigma and discrimination that impacted their experiences with co-occurring disorders, aging, and gender issues.

Co-occurring disorders. Families and communities that did not understand mental health and substance misuse problems sometimes believed that co-occurring disorders were a sign of personal weakness and lack of will power. The absence of information and services led families and communities to focus on individual deficits rather than consider the need for services. Participants wanted accurate information about co-occurring disorders to help reduce the stigma about these disorders.

Age. Participants experienced ageism both generally and specific to co-occurring disorders. Participants remarked that as older adults, they were seldom consulted about their wants and needs. The participants who went to treatment noted that services were not developed with older adults in mind. Some participants commented that older adults and their mental health and substance misuse problems were frequently invisible in society. Participants wanted their difficulties recognized and they wanted to be part of decisions about how those needs were met.

Gender. Female participants noted stigma and discrimination relative to gender and co-occurring disorders. Women participants believed that gender issues interacted with their co-occurring disorders, yet treatment was designed for men. Women participants wanted freedom to be themselves, to be accepted as individuals and women, and to have their needs relative to co-occurring disorders taken seriously by family,

friends, and providers. Women participants wanted treatment that addressed gender-related issues.

Prevention by providing assistance for other problems. Participants who had received help for issues other than co-occurring disorders appreciated the support and others were aware of the needs of peers. Participants who had provided caregiving were especially sensitive to the stress of unmet needs and believed that stress from other problems had increased or reactivated co-occurring disorder symptoms. Participants wanted support services and information about services. Participants felt that addressing problems in other areas of life would help older adults better manage co-occurring disorders while improving quality of life and independence.

Prevention by increasing help from informal and formal sources. Participants identified both informal and formal persons and systems as essential sources of assistance for co-occurring disorders. While participants identified family members as important supports, they also wanted help from others, especially religious leaders and medical providers. Participants identified employers as potential supports.

Family and friends. Participants identified the need for support from family and friends before, during, and after recovery. Participants wanted family and friends to understand that their behaviors related to disorders and to have a sense of their experience with co-occurring disorders. Don identified his wife as being essential to his recovery. “If [wife] had been drinking, I couldn’t have stayed off it.” While Don attended inpatient treatment, outpatient treatment, and Alcoholics Anonymous, his wife attended Al Anon, which provided knowledge and understanding of substance misuse problems for family

and friends. Extended family members and friends were also important supports for participants. Don stated, “My sister was helpful. She was happy I got sober.”

Religious leaders and organizations. Participants wanted both religious leaders and organization members to recognize and appreciate their struggles with and recovery from co-occurring disorders. Participants believed that non-judgmental leaders and members would assist participants to feel comfortable taking part in religious activities. Participants voiced a desire for leaders or members who were open about experiencing co-occurring disorders themselves.

Medical providers. Participants wanted medical providers who were knowledgeable about co-occurring disorders and provided concrete assistance. While understanding and support from family, friends, and religious leaders were important, participants expected medical providers to understand that older adults needed help with co-occurring disorders, talk with them about the problems, and provide referrals.

Employers. Participants who had been fired from jobs thought that employers needed knowledge and education about co-occurring disorders. These participants believed that employers could assist employees to get help for the disorders and that this help could benefit the company as well as the employee.

Summary. Participants believed that they needed both informal and formal support to cope with co-occurring disorders. Participants identified family and friends, religious leaders and organizations, medical providers, and employers as those from whom they wanted support.

Prevention by employing the resilience of older adults. Participants were firmly embedded in the rural tradition of taking responsibility for their co-occurring disorders. Participants who brought up stigma and discrimination about co-occurring disorders, age, and gender and those who had been fired from jobs still held themselves responsible for dealing with their co-occurring disorders. Participants believed that personal resources of persistence, relationships, positive thinking, learning new coping skills, and spirituality facilitated management of co-occurring disorders. Participants also believed that acknowledging disorders, accept help, and helping others assist with recovery and revitalization. Participants maintained the idea that they were responsible for themselves even as they wanted help for problems that were too big to handle alone. Until participants went to treatment, they were seldom introduced to the idea that responsibility did not mean doing it all themselves.

Assistance for co-occurring disorders. Participants who had received some kind of help perceived treatment as a means of gaining control over co-occurring disorders. Participants who were in recovery believed that treatment had prevented the disorders from becoming worse, improved relationships with family and friends, and sometimes saved their lives.

Many participants found mutual self-help groups to be an essential part of treatment. Participants found these groups to be a place where they developed understanding of issues and symptoms related to co-occurring disorders, felt that they belonged, and could be themselves. Participants differentiated support group members from family and friends as people who understood co-occurring disorders because they

had experienced the disorders themselves. Participants believed that family and friends were important but not sufficient to help them with co-occurring disorders. Mutual self-help groups provided role models who had found ways to recover by stabilizing their symptoms and gaining or regaining a meaningful life. Whether participants attended mutual self-help groups only or as part of outpatient and inpatient treatment, they found that the support of peers assisted their recovery.

Participants wanted outpatient and inpatient treatment that is accessible, affordable, and adapted to individual co-occurring disorders and age-related needs. Participants wanted older adults who had experienced co-occurring disorders involved in providing treatment so that providers have both theoretical and practical understanding of what older adults experience.

Participants believed that life could be better for themselves and others who struggle with co-occurring disorders. Participants suggested that reducing aloneness and helplessness, increasing information, eliminating stigma, helping with other problems, increasing support, accessing personal resilience, and appropriate treatment were all ways that could prevent co-occurring disorders or help with recovery. Participant ideas for assisting rural older adults with co-occurring disorders were not linear but interacted and intersected in many ways.

Practice Model for Rural Older Adults with Co-occurring Disorders

The purpose of the practice model is to offer principles and services for co-occurring disorders so that assistance for rural older adults is relevant to problem,

person, and place. The ideas in Table 10 provided a foundation for the practice model to serve this specific population. Each of the practice concepts is based on the experiences of older adult participants, the help that they wanted, and practice and research evidence. Recommendations for policy are founded on structural barriers identified in the study. Research recommendations originate in gaps in the knowledge base. The model identifies multiple paths to recovery by offering preventive services with the expectation that help will be adapted to the person rather than expecting the individual to adapt to treatment. See Table 12.

Principles of Providing Assistance

Participants identified several principles that apply to providing assistance for older adults with co-occurring disorders who live in rural communities. These principles include assistance that is informed by rural older adults with co-occurring disorders, having role models assist with providing information and treatment, a no wrong door approach to services, assertive outreach to provide information for co-occurring disorders and other needs, assistance that is offered without stigma, and use of an integrated model for co-occurring disorders. Practice and research corroborate each of these principles.

Assistance informed by rural older adults. Participants wanted assistance for co-occurring disorders developed with input by rural older adults. Some had experienced services in facilities that did not expect older adults to take part in their programs and made no adaptations to neither meet their needs nor consult them as to what they wanted or needed. Having recovered from aloneness and helplessness, they wanted to be involved in the services they used.

Table 12

Practice Model for Rural Older Adults with Co-Occurring Disorders

Principles for Assisting Rural Older Adults With Co-Occurring Disorders Assistance Informed by Rural Older Adults with Co-Occurring Disorders Role Models No Wrong Door Assertive Outreach Stigma Free Integrated Model for Co-Occurring Disorders	
Population Served	
<ul style="list-style-type: none"> ▪ Older Adults ▪ Family ▪ Providers ▪ Community Members 	Information, Screening, and Referral Provided by: <ul style="list-style-type: none"> ▪ Role Models ▪ Professionals
Older Adults With Additional Needs	Information and Referral for Other Needs and Services Provided by: <ul style="list-style-type: none"> ▪ Role Models ▪ Professionals
Older Adults With Co-Occurring Disorders <ul style="list-style-type: none"> ▪ Mild ▪ Moderate ▪ Severe with treatment 	Mutual Self-help Groups Referred by: <ul style="list-style-type: none"> ▪ Role Models ▪ Treatment Programs Led by: <ul style="list-style-type: none"> ▪ Role Models ▪ Others as appropriate
Older Adults With Co-Occurring Disorders <ul style="list-style-type: none"> ▪ Moderate to Severe 	Outpatient Treatment > Mutual Self-Help Groups Options: <ul style="list-style-type: none"> ▪ Local treatment through outreach clinics ▪ Distant specialized setting ▪ Integrate mutual self-help groups into outpatient treatment Role models: <ul style="list-style-type: none"> ▪ Lead mutual self-help groups ▪ Assist in other aspects of treatment
Older adults With Co-Occurring Disorders <ul style="list-style-type: none"> ▪ Severe 	Inpatient treatment > Out-patient treatment > Mutual Self-Help Groups Options: <ul style="list-style-type: none"> ▪ Treatment in local hospitals ▪ Distant specialized setting ▪ Integrate mutual self-help groups into inpatient treatment Role models: <ul style="list-style-type: none"> ▪ Lead mutual self-help groups ▪ Assist in other aspects of treatment

Participants identified the importance of having services developed locally. Participants were keenly aware of community differences and wanted services that were relevant to rural older adults. Participants were wary of control by governmental organizations and providers who did not listen to their ideas.

Supporting ideas from practice and research. Virtually every social service agency gathers input from their clients about service satisfaction. Many social service organizations use advisory boards made up of consumers. Both National Alliance on Mental Illness (NAMI, n.d.) and Alcoholics Anonymous (Alcoholics Anonymous, 2007) have advisory boards made up of consumers. Organizations find that integrating input from several stakeholders expands knowledge of program strengths and needs by forming a dialogue of many perspectives (Simon-Rusinowitz et al., 2002). Organizations find that two-way communication, perception that consumers provide valuable knowledge, and providing training for consumers involved in advising programs all enhance programs and services (Fleisher, 1978; Foss, 1985).

Role models. Rural participants who had received treatment found that it was helpful to have people in recovery as part of the treatment team. Role models who provided services helped older adults recognize and acknowledge co-occurring disorders, accept help, and move toward recovery.

Participants believed that older adult role models could assist older adults, their families, providers, and community members to understand co-occurring disorder issues and ways to recover. Role models could lessen the stigma associated with older adults and co-occurring disorders by acknowledging the disorders and demonstrating recovery.

Role models could carry out prevention services by providing information, screening, and referral as well as assisting with treatment. Role models could provide help within social and medical organizations and meet with individuals not yet involved in services. Role models could use an assertive outreach approach to discuss co-occurring disorders, provide information, and offer initial screening for those who hesitate to ask openly for information.

Supporting ideas from practice and research. Both mental health and substance misuse models have demonstrated the use of indigenous community members in the provision of service. Mile Square Health Center provides health and mental health care in a low-income Chicago community and uses indigenous workers to engage community members and assist with access to clinic services (Sanchez, Chapa, Ybarra, & Martinez, 2012). Alcoholics Anonymous members help others achieve sobriety as a way to help themselves (Alcoholics Anonymous, 2012).

Butler and Eckhart described a rural program in which older adults provide companionship and assistance to frail elderly in the community (2007). Mileage reimbursement and a small stipend made it possible for low-income people to serve in this program (Butler & Eckhart, 2007). This program approach could be adapted to meet the needs of older adults with co-occurring disorders. The use of role models to bridge informal and formal services is consistent with rural values (Shenk, 1998). The combination of having dealt with co-occurring disorders and age while living in rural communities provides credibility for role models (Drake et al., 2001).

No wrong door. One participant experienced a no wrong door approach to accessing services. Each time Mitch contacted his medical organization for help with substance misuse and mental health problems, the contact person assessed his issues and referred him to appropriate services. Mitch found the process easy to navigate and without stigma. At the time Mitch needed assistance, he was not functioning well. Mitch believed that he would have had difficulty navigating complex service systems on his own and that he would have had difficulty following through had assistance been stigmatized. Mitch was surprised that the no wrong door approach was an unusual experience for participants and enthusiastically advocated for its use.

Although only one participant commented directly on the no wrong door approach to services, the number of participants who had difficulty getting help suggests that had they been able to use a no wrong door approach, they would have applauded it. Participant concern about stigma that kept those with co-occurring disorders from requesting information might have been reduced by a no wrong door approach.

Supporting ideas from practice and research. When the no wrong door approach is used, caring and accepting service provision or referral for appropriate services is made by any service agency approached by the consumer (CSAT, 2006c). Over one-half of people with co-occurring disorders are not seen in mental health or substance misuse clinics. Since many of these same persons are seen in health care clinics, social services, or religious organizations, a no wrong door approach could assist with providing information, initial screening, and appropriate referrals (CSAT, 2007a).

Rural agencies may feel overburdened by their existing duties and inadequate resources and role models could assist them (CSAT, 2007a). Older adults in recovery from co-occurring disorders could be trained to provide outreach, engagement, initial screening, and referrals. Technology could allow this to be done by telephone or internet conference calls when older adults do not want to use in-person services (Redford & Goins, 2003).

Assertive outreach. Co-occurring disorders were not always the first problem with which participants wanted help. While participants did not use the phrase, assertive outreach, they described it by saying that information about co-occurring disorders should be available where other information is located, reflect the issues of older adults, be provided by people they trust, and be available everywhere. Participants believed that older adults and their support systems need accurate information about co-occurring disorders and services to assist with recovery, manage symptoms, and increase quality of life. Participants identified existing rural systems that provide other information to many older adults and information about co-occurring disorders could be available in these organizations.

Supporting ideas from practice and research. Assertive outreach is defined as establishing a trusted relationship over time and providing services desired by the client before the client takes part in treatment (Drake et al., 2001). Outreach is especially important for people who are marginalized, isolated, alone, or homeless. Assertive outreach adds another path to delivering information to older adults with co-occurring disorders. If assistance starts with services that the person values, it may be possible to

develop a relationship to address co-occurring disorders. The helping relationship that is central to assertive outreach requires the provider to be trustworthy and helpful in eyes of the consumer (CSAT, 2007a).

Stigma-free help. In order to change the stigma that has been associated with co-occurring disorders in older adults who live in rural communities, participants wanted accurate information provided to as many people as possible. Participants brought up religious and medical providers and employers as key persons to involve in reducing stigma.

Participants thought that stigma about age interfered with receiving services. Participants believed that they were not listened to at inpatient and outpatient treatment and preferred mutual self-help groups where older adults were present. Treatment facilities did not expect older adults to take part in their programs and made no adaptations to meet their needs. Stigma or age discrimination may have been present in other agencies as well. A participant who served on the board of a local senior center commented that center participants were not consulted when the center was moved.

Women participants were concerned that treatment, support, careers, and medical care, were negatively influenced by gender. Women wanted treatment provided in surroundings where gender-related issues that interacted with co-occurring disorders were understood. Women wanted to receive appropriate support in treatment, just as they wanted understanding and support in other areas of their lives.

Participants wanted services provided without the stigma that many had experienced relative to co-occurring disorders, age, and gender. Too many had been

silenced by the stigma. Participants wanted to voice their issues and to be heard without feeling shame. Participants wanted this silence to end.

Supporting ideas from practice and research. Stigma contributes to lack of identification and treatment for older adults with co-occurring disorders. Stigma is based on shame and inaccurate stereotypes accepted by older adults, their families, and providers (Brown & Blancato, 2003; U.S. DHHS, 1999, 2002; WHO, 2002). When stereotypes and myths about older adults are brought into practice, programs are less likely to be developed that address the needs of older adults (Hall, Amodeo, Shaffer, & Vander Bilt, 2000; Schneier, 2000; Walsh et al., 2007; WHO, 2002). When services are limited as they are in rural communities, the motivation to stigmatize anyone with less power, which includes people with co-occurring disorders, older adults, and women, is stronger (Boyd et al., 2007; WHO, 2002).

Women experience stigma related to gender expectations across cultures. Social stigma is the major reason that women do not seek treatment for substance misuse. Older women attach greater stigma to substance misuse problems and tend to hide their use. The violence and trauma experienced by older women across their lifespans is seldom acknowledged in treatment (Hightower, Smith, & Hightower, 2006; Walsh et al., 2007). Gender-specific issues need to be considered within each treatment stage and a trauma-informed approach enhances care within co-occurring disorder programs (CSAT, 2009a).

People with co-occurring disorders have complicated conditions. Adverse selection, where it is economically advantageous not to serve such individuals results from the effects of stigma and discrimination (CSAT, 2007c).

Integrated model of treatment. Participants all had co-occurring disorders but received help for only one in treatment programs. The only participant to receive help for both disorders went through separate episodes of treatment. Some participants received help for substance misuse from organizations that presented the use of medication for mental health disorders as conflicting with substance misuse recovery. These approaches left participants to sort out how to recover from disorders not addressed in their treatment and to deal with conflicting information. Although the self-help groups that participants attended were open to people with a wide range of disorders, this did not always work well. The groups developed around a specific disorder that did not include issues related to other disorders. The participants wanted role models who had experienced co-occurring disorders and wanted help that integrated treatment for the difficulties rather than expecting the individual to solve the issues.

Supporting ideas from practice and research. Current research and practice support the use of integrated treatment so that persons receive assistance for both mental health and substance misuse disorders at the same time in the same place (CSAT, 2006b). Recommended treatment approaches for mental health and substance misuse programs include stages of change, stages of treatment, and motivational interviewing (CSAT, 2006b).

States are slowly moving toward providing integrated services (CSAT, 2007b). Providers are beginning to receive education about co-occurring disorders. Iowa is promoting dual diagnosis capability, the ability to provide appropriate services to people with co-occurring disorders, within its mental health and substance misuse agencies

(Minkoff & Cline, 2006). Several agencies in Iowa are providing integrated services (“Magellan Behavioral Care,” 2008). Some of Iowa’s rural providers educate clients about co-occurring disorders and may refer to and work closely with concurrent services. However, most rural providers cannot yet provide integrated services due to a lack of resources and the absence of coordination at the state systems level (M. Sharon, personal communication, October 5, 2012).

Peer recovery support services designed and delivered by people in recovery are recognized as helpful particularly in the engagement stage (CSAT, 2009b). Dual recovery mutual self-help groups for people with co-occurring disorders are gaining acceptance. These programs stress personal responsibility, peer support, and frequently identify a process for planned change in coping with co-occurring disorders. Dual recovery mutual self-help groups recognize that both disorders are primary, an advantage over single disorder self-help groups. Dual recovery mutual self-help groups provide members with acceptance, support from peers, and empowerment to change. Taking part in a dual recovery mutual self-help group assists with better drug and alcohol abstinence, better adherence to psychiatric medication use, and lower symptom severity and hospitalization (CSAT, 2005).

Prevention Services

Participants wanted information about co-occurring disorders for all members of the community including older adults, family and friends, providers, and community members. Participants believed that information for other services would assist older adults avoid exacerbation of co-occurring disorders.

Information, screening, and referral. Participants wanted information to be widely available to older adults with co-occurring disorders and to all members of the rural community. Participants thought that persons who are knowledgeable about the co-occurrence of mental health and substance misuse disorders and older adult issues should provide the information. Participants wanted this information given by people they trusted. Role models, older adults in recovery from co-occurring disorders, could fulfill these criteria.

Participants were familiar with many ways that information about co-occurring disorders in older adults could be shared in rural communities. Health fairs, senior centers, libraries, and public bulletin boards are places where information about co-occurring disorders and older adults could be accessed. Participants suggested that health care centers provide brochures about co-occurring disorders. Local service groups might invite speakers to provide information about co-occurring disorders, older adults, and services for both. Self-help groups could share information about co-occurring disorders with members. Participants thought that the internet would be a good way to reach some older adults.

Participants wanted help from religious leaders, medical providers, and employers. Participants noted that some religious leaders and organizations were not helpful and sometimes stigmatized mental health and substance misuse problems, but others assisted by providing space for self-help groups to meet. Participants wanted religious leaders and organizations informed to break down myths about co-occurring

disorders and learn how to assist older adults through information, screening, and referrals.

A number of participants observed that medical providers asked about substance use but rarely mentioned mental health or co-occurring disorders. Even when asked about substance misuse, discussion of the problem, recommendations, and referrals were limited. Participants wanted help from medical providers and were disappointed when it was not forthcoming.

A limited number of participants brought up the power that employers have to assist people with co-occurring disorders. Information that helps break down myths and provides information for services about co-occurring disorders could be helpful to employers and retain employees.

Supporting ideas from practice and research. Older adults in recovery who understand older adults with co-occurring disorders could serve as role models who provide information giving, initial screening, and treatment referral with training in basic helping approaches (CSAT, 2006b). Role models could use an assertive outreach approach, providing assistance for a variety of needs desired by older adults prior to discussing co-occurring disorders (CSAT, 2007a).

Older adults with co-occurring disorders are found in workplace, religious, welfare, and education settings. Many, if not most, older adults with co-occurring disorders will be seen in settings other than mental health and substance misuse specialty agencies. These other settings provide opportunities for identification, initial engagement, and early intervention (CSAT, 2007a; Wagner & Niles, 2003).

Information about co-occurring disorders could be part of religious leaders and medical providers initial and continuing education. Federal and state agencies could develop informational materials about older adults with co-occurring disorders. Materials could include information about the importance of outreach, engagement, and referral to appropriate services. Role models could provide administrative bodies, human resource departments, employee assistance programs, and employer associations with educational materials, information to provide appropriate screening and referrals, and local resources for co-occurring disorders (CSAT, 2006b).

Rural communities must provide positive supports that work alongside negative social influences in order that older adults receive the resources needed to recover from co-occurring disorders. Persons without information about older adults with co-occurring disorders tend to normalize early signs of deteriorating functioning. Lack of familiarity with warning signs combined with stigma about co-occurring disorders lead to missed opportunities for early intervention (CSAT, 2007a; Kellehear & Young, 2007).

Co-occurring disorder information and education for religious, medical, and employer organizations would assist rural older adults with their co-occurring disorders. Information needs to include older adults and the positive aspects of addressing co-occurring disorders. Providers who are educated about co-occurring disorders and who make appropriate referrals for services assist not only individuals but also entire communities to develop resilience. All settings need to serve as gatekeepers (CSAT, 2006b; CSAT, 2006c; CSAT, 2007a). Just as multiple paths to recovery need to be

developed for individuals, multiple paths to understanding co-occurring disorders need to be developed for communities.

Information about other services. Participants needed help for problems other than co-occurring disorders. Many participants provided caregiving. Gender and loss issues were also prominent in participant narratives. Some participants had health problems while others needed additional supports to maintain independence and quality of life. Participants reported that these stresses interacted with co-occurring disorders and they wanted assistance with these concerns. Participants wanted their communities to provide information about existing services as well as develop services for unmet needs. Participants suggested that a local central location with information about resources and support groups offered with non-judgmental approaches would be helpful to older adults when they are looking for services.

Supporting ideas from practice and research. An assertive outreach approach could assist older adults with information about other services as well as co-occurring disorders. Role models could help maintain current information about these services. Existing rural systems could be used to deliver information. Providers of other services could be educated about co-occurring disorders in older adults and use an assertive outreach approach to engage older adults (Wagner & Niles, 2003). Virtually every community in Iowa has a website. Services for older adults could be posted there as well as in newspapers, public bulletin boards, senior centers, and libraries. With a small amount of support from government or local colleges, lists of resources could be developed and made available at these sites, health fairs and other public places. Role

models could provide individualized information and referral services when appropriate (CSAT, 2007a).

Treatment Services

Participants identified mutual self-help groups, outpatient treatment, and inpatient treatment as important for recovery from co-occurring disorders. Use of role models and individualized treatment plans and services are necessary to provide culturally competent assistance to older adults with co-occurring disorders living in rural communities.

Options to offer treatment locally and use of technology may be helpful.

Mutual self-help groups. Older adults with co-occurring disorders may need more than information. Several participants attended self-help support groups and found them useful for single disorders. Some participants belonged to groups where they were able to get support for both disorders, even though the groups were developed for one disorder. While some participants had attended self-help groups only, others with more severe disorders first completed inpatient or outpatient treatment and then went to self-help groups.

Participants found it helpful that people in recovery led and participated in self-help groups. These peer leaders engaged older adults in the process of recovery by understanding both age and recovery concerns and educating about principles of revitalization. Women participants preferred groups with female role models and openness to gender-related issues. Most groups were free and available in or near participants' communities. Participants found that support groups were helpful,

cost-effective, and accessible. Participants believed that the mutual self-help model could assist older adults with co-occurring disorders.

Supporting ideas from practice and research. Older adult role models who are knowledgeable about co-occurring disorders and age could help develop co-occurring disorder mutual self-help groups. Outpatient providers could consult with role models who take on new responsibilities. Mutual self-help groups provide continuity of care when older adults with co-occurring disorders leave inpatient or outpatient treatment. Some older adults may prefer groups that focus on older adults with co-occurring disorders. Gender-specific groups may be helpful to participants when gender issues are relevant to their co-occurring disorders (CSAT, 2005).

Outpatient and inpatient treatment. Some participants with moderate to severe disorders needed treatment that went beyond the support and education of a mutual self-help group. The outpatient treatment available to participants did not address issues specific to older adults or co-occurring disorders. Outpatient treatment was not available locally and participants had to travel outside their communities to receive assistance due to large rural catchment areas. Driving to or staying near the treatment facility was expensive. Participants who worked had conflicts between employment and program hours. Participants who had lost driving privileges had difficulty getting to outpatient treatment as rural communities offer little public transportation.

Participants preferred outpatient care that supplemented treatment with mutual self-help groups led by role models. Starting the group while in treatment made the

transition back to participants' home community easier as they had a familiar support system available.

Several participants with severe disorders went to inpatient treatment. As with outpatient programs, inpatient help was not available locally and involved travel, sometimes out of state. Although most participants were open about having co-occurring disorders when they went to treatment, none received assistance for both disorders. No one received services developed for older adults. Some but not all were able to attend self-help groups led by role models during inpatient treatment. Based on their experiences, participants wanted treatment options available closer to home. Participants wanted help that addressed co-occurring disorders and age and they wanted role models involved in the treatment.

Supporting ideas from practice and research. Outpatient and inpatient programs could utilize older adult role models to address issues relevant to older adults. Role models could assist with some aspects of treatment including engagement. Participants are likely to feel the least connected during early stages of treatment. Role models could assist participants to understand how treatment works, what to expect, and how participants may initially feel about treatment. Sharing their own stories may assist new participants to engage more fully in the treatment process. Older role models could be especially helpful to those who may see few other older adults in treatment (Butler & Eckhart, 2007). Role models or local self-help groups could provide mutual self-help groups for those in outpatient and inpatient treatment in exchange for the facility providing a regular place for the group to meet (CSAT, 2005).

The option of small treatment units housed in local outpatient clinics and hospitals could make both outpatient and inpatient treatment more accessible to older adults while reducing the cost of travel. Local providers trained in co-occurring disorders, issues of older adults, and gender concerns could deliver services in cooperation with local clinics and hospitals. Specialized providers could travel to these clinics. Telemedicine and internet conferencing could be used to supplement services. Local treatment would bring providers to those in need and an integrated approach would be available so that older adults receive help for all co-occurring disorders. Those who wished could still travel to more distant specialized settings. These options would meet more needs of older adults through individualized treatment (CSAT, 2006c; Sanchez et al., 2012).

Individualized treatment plans and services to accommodate specific needs, goals, and cultural perspectives of individuals in different stages of change are needed to provide best services to older adults living in rural communities. Telecommunication and internet services may support treatment when in-person services are not available. Some older adults will want to use telecommunication and internet conferencing and others will not. Some older adults do not have their own computers and use of public computers compromises privacy. Participants may feel less connected to and be less open with providers using these methods as conveying genuineness is more difficult when services are not offered in person. Offering services in these ways requires sensitivity to the individual (CSAT, 2006c; M. Sharon, personal communication, October 5, 2012).

The Practice Model for Rural Older Adults with Co-Occurring Disorders focuses on principles of practice, prevention, and treatment. While there are many aspects

involved in offering competent services to rural older adults with co-occurring disorders, these ideas were the most important to participants.

Practice Actions

Prevention and treatment are needed to serve more of the rural older adults who have co-occurring disorders. Specific ways to apply the principles of the model and bring about greater and more appropriate prevention and treatment services for older adults in rural communities are as follows:

1. Services for rural older adults with co-occurring disorders can begin by identifying practitioners in local agencies who are willing and able to develop these services. Not every practitioner has to participate in order to create these services. These practitioners could come together with the express purpose of learning about older adults with co-occurring disorders.
 - a. The state of Iowa provides training in co-occurring disorders, but has not included agencies in Northwest Iowa (Magellan Behavioral Care of Iowa, 2008). Rural community providers can lobby to be included in this training. Some training can be provided through distance technology to reduce the cost in time and travel for rural practitioners.
 - b. Substance Abuse and Mental Health Services Administration provides training materials for practitioners (Integrated Treatment for Co-occurring Disorders, 2010).

- c. Training for practitioners in the issues of rural older adults can be obtained from the Area Agencies on Aging Speakers Bureau, (“Speakers Bureau”, n.d.)
 - d. Continuing education credits can be offered to validate the education and encourage participation.
 - e. Training and development of a supportive work group for interested providers means that a small group of workers can expand rural resources.
2. Key providers in mental health and substance misuse agencies who have received training in co-occurring disorders can work together to first coordinate concurrent treatment within their agencies for people with co-occurring disorders. As coordination develops, these providers can work with their agencies to develop integrated treatment at the local level.
 - a. Following development of outpatient services, these key providers in mental health and substance misuse agencies can approach local hospitals to expand options for inpatient treatment.
 - b. Local hospitals that offer behavioral health for older adults will only need to take one more step to offer treatment for co-occurring disorders.
3. Once practitioners have training in addressing co-occurring disorders, they can identify older adults who are in recovery from co-occurring disorders to fill a number of roles.
 - a. Role models can receive training to provide initial engagement, screening, and referral.

- b. Role models can deliver materials to community organizations.
 - c. Role models can serve on an advisory board for professional providers to assure that the voices of older adults with co-occurring disorders are heard.
 - d. Role models can be trained to assist in and lead mutual self-help recovery groups.
 - e. Role models who are comfortable with public speaking can provide information to community groups. This would begin to break up stereotypes of older adults with co-occurring disorders.
4. With technology as simple as cell phones, role models can be called by social service and medical agencies when they encounter an older adult who may have co-occurring disorders. Role models can work with these agencies to provide information, conduct initial screening, and provide referral to appropriate services, thus putting the no wrong door concept into practice.
5. Alcoholics Anonymous provides a model that mutual self-help co-occurring disorder groups can use to begin to offer services in rural communities.
- a. While no rural community in Northwest Iowa currently offers daily Alcoholics Anonymous groups, typically a group meets every day within a 40-mile radius.
 - b. Alcoholics Anonymous has worked its way into the rural culture. Although substance misuse still carries stigma and some people want to maintain their anonymity, others are willing to speak up.

- c. Many community organizations provide meeting space to Alcoholics Anonymous free of charge.
6. Mutual self-help co-occurring disorder groups can use the AA model to offer services.
 - a. Persons in recovery from co-occurring disorders can receive training in engagement and group work skills from local practitioners in order to serve as leaders in dual disorder recovery groups.
 - b. Practitioners can offer consultation for the group leaders.
 - c. Local organizations can be approached to provide meeting space.
7. Dual Diagnosis Recovery Network and the Dual Recovery Empowerment Foundation both provide training and information through the resource and information clearinghouse (DRA Group Start-UP Packet, 2004; Articles & Publications, n.d.).
8. Substance Abuse and Mental Health Services Administration has informational material about co-occurring disorders. This material can be obtained free and placed in community clinics, religious organizations, libraries, senior centers (Co-Occurring Disorders, SAMHSA, n.d.). Materials can be adapted to provide information about local and distant resources including on-line resources.
9. The state of Iowa Department of Public Health has a goal to develop recovery-oriented services for co-occurring disorders. This state-level office can be lobbied to provide funding for informational material (Co-Occurring Disorders, Iowa Department of Public Health, n.d.).

10. Many social service and medical agencies as well as businesses have bulletin boards where local groups post information. Having information easily available where people can see it as they go about their daily lives can help reduce the stigma of seeking information about co-occurring disorders.
11. Agencies and practitioners can work with role models and rural university social work programs to educate the public.
 - a. Educational materials not available elsewhere can be developed and distributed throughout communities.
 - b. Speakers bureaus can be developed and provide needed information to community groups.
12. Rural agencies can use preexisting consortiums to lobby state and federal policy-makers to address the organizational barriers that interfere with provision of integrated treatment. Role models who are willing to speak about the need for services would be especially effective.
13. Funding for role models may be available through U.S. Department of Labor's Green Thumb program to provide some compensation for role models (Employment & Training Administration, n.d.).
14. Similar approaches can be used to develop services for other needs identified by rural older adults. Agencies, role models, and universities can identify and develop information about additional services, place this information throughout rural communities, and develop speaker bureaus to inform community groups.

This provision of information may open doors to then discuss co-occurring disorders.

Conclusion to Proposal

This chapter presented a model for meeting the needs of rural older adults with co-occurring disorders. Individual, community, and structural issues were addressed. The model was based on ideas drawn from participant interviews and focused on co-occurring disorders as distinct from individual disorders, older adults in all stages of the disorder, and provision of services in rural communities. Approaches to carry out the proposal were provided and ideas were supported by practice and research.

Chapter 11: Conclusion

The goal of this exploratory study was to understand, from their own perspective, the experience of older adults who live in rural communities and have co-occurring disorders. The findings provided the views of rural older adults about the risks to develop co-occurring disorders, the barriers they encountered, and the protective factors and resilience that led toward recovery. The discussion focused on the themes of multiple paths to develop co-occurring disorders and multiple paths to recovery from co-occurring disorders. The proposal developed these ideas and themes into a practice model for rural older adults with co-occurring disorders. Major conclusions of the study are briefly summarized in this chapter. Implications of the study for social work, policy, and research to support practice with rural older adults with co-occurring disorders are offered.

Rural Older Adults With Co-Occurring Disorders Have Specific Needs

Culture-specific interventions are recommended for addressing co-occurring disorders (CSAT, 2006c, Sanchez et al., 2012). This study suggests the value of listening to specific populations such as rural older adults with co-occurring disorders. Older adults have their own set of risks for developing co-occurring disorders and resilience that assists with recovery. Age plays a part in how co-occurring disorders need to be addressed. Gender brought out a subset of issues and needs within the population of rural older adults with co-occurring disorders. Generations are likely to perceive issues differently.

Rural communities provide a good deal of informal support for older adults. The lack of formal resources has led to an absence of preventive information and treatment. In order for rural older adults with co-occurring disorders to receive the help that they want and need, practice and policy must address disorders, age, and locale in culturally relevant ways. This study suggests that specific populations would be well served by practitioners and policy makers listening to the concerns of those for whom they develop services.

Risks and Barriers that Contribute to Developing Co-Occurring Disorders

A number of risks appear to relate to the development of co-occurring disorders. The common theme among the risks is the perception of being alone with problems and feeling helpless to bring about change. A major barrier that appears to influence the development of co-occurring disorders has to do with lack of information about these disorders and treatment options. Neither informal information provided by role models nor formal information provided through agencies is readily available in rural communities. Family, friends, and community providers as well as older adults lack information about co-occurring disorders and available help.

Rural communities lack access to treatment. Even when treatment exists, it does not address co-occurring disorders or age-related issues. Assistance for problems that exacerbate co-occurring disorders is often missing as well. Stigma about co-occurring disorders and age discourage asking for help. Service structures that do not see the needs of rural communities add another barrier. These risks and barriers interact in multiple ways to develop paths to co-occurring disorders. In order to assist rural older adults,

providers and policy makers need to recognize co-occurring disorders and their complexity.

The Role of Stigma

Stigma and discrimination related to co-occurring disorders, age, and rural communities play a role in the absence of appropriate prevention and treatment. Stigma about co-occurring disorders encourages older adults to hide these disorders, thus interfering with the receipt of appropriate help. Structural barriers that ignore the needs of people with co-occurring disorders, older adults, and rural communities send a message that these people and communities are not important.

Protective Factors that Assist with Recovery and Revitalization

Resilience theory provides a framework within which to view rural older adults with co-occurring disorders. A resilience model provides opportunities to identify positive dynamics that assist in prevention and recovery from co-occurring disorders.

Much of the assistance available for recovery in rural communities comes from informal relationships. Individual persistence enhanced by enduring family and friend relationships and spiritual connections appear to assist older adults to recover from co-occurring disorders. Acknowledgement of co-occurring disorders and accepting help promote recovery. Treatment resources that provide information and role models to demonstrate steps to recovery and offer support during the process contribute to revitalization.

Openness to change resulting from opportunities that may come in unexpected ways is another kind of resilience. Recognition that a person is more than disorders

appears to be an aspect of self-worth that promotes revitalization. Helping others may be part of spiritual recovery and rural communities offer endless opportunities to help. Age is not a barrier to recovery. Many protective factors and types of resilience contribute to recovery regardless of risks. Helping older adults find meaning in their lives may activate resilience. Individual resilience, informal and formal community resources, and appropriate structural services all interact to bring about recovery and revitalization.

The Role of Prevention

This study identified information as a primary prevention factor for the rural older persons and communities involved. Information presented by older adults in recovery from co-occurring disorders provides role models for recovery. In addition to helping with understanding, information provided by role models may assist in reducing feelings of aloneness and helplessness. Treatment offers secondary and tertiary prevention. Treatment that occurs early may prevent co-occurring disorders from becoming serious and avert associated consequences. Persons with serious and persistent disorders who receive treatment are able to recover from co-occurring disorders sooner and can contribute to family and society as well as benefit from recovery themselves (SAMHSA, 2011b). Assistance with problems other than co-occurring disorders may assist to prevent occurrence or recurrence of disorders.

Interaction of Factors

Addressing the needs of rural older adults with co-occurring disorders requires attention to the interaction of factors, not just to the discrete components. Stages of change may provide a metaphor for appropriately addressing these needs. It is essential

to assess the whole person within the specific social context in order that the needs of rural older adults with co-occurring disorders are successfully met.

Practice Model for Treatment

The practice model for assisting older adults with co-occurring disorders who live in rural communities incorporates principles of treatment identified throughout the findings and discussion chapters. Culturally relevant help can be achieved with services informed by rural older adults and provided by older adults in recovery. Assertive outreach, a no-wrong-door approach, and informed community members and providers assist with services that are stigma free. Services that integrate both mental health and substance misuse issues provide relevant help.

Implications for Social Work Education and Practice

Social workers encounter older adults in all fields of practice and must be aware of the potential for older adults to experience co-occurring disorders. Social workers need to understand co-occurring disorders, manifestation in older adults, and appropriate services. Social workers may not provide primary treatment to older adults with co-occurring disorders. Social workers may be in an ideal position to engage, screen, provide initial information, and refer older adults to needed services.

Social workers provide most social services in rural communities. Rural social workers have the potential to educate individuals, families, and the community about co-occurring disorders in older adults. This education may occur informally and formally through conversations, development of educational materials, and speaking to the community. Social work education about co-occurring disorders and older adults is vital.

Instruction needs to begin in formal educational programs. Continuing education is needed to inform and provide updates about new developments in the field of co-occurring disorders and older adults to those already working in the field.

Implications for Policy

While the focus of this proposal is a practice model, several policies could support practice recommendations for services for older adults with co-occurring disorders residing in rural communities. These policies include coordinating formal and informal services, increasing access to care, merging administrative units, providing resources to increase competent services for rural older adults, and providing resources to enhance distance services. These policies affect practice, and recognition of practice needs is necessary to serve rural older adults with co-occurring disorders well.

Coordination of informal and formal services. Formal services need to work in cooperation with informal supports to reinforce independence and protect the privacy valued by rural older adults. The Practice Model for Rural Older Adults with Co-occurring Disorders addresses this need for coordination by proposing that role models provide some services for rural older adults. Governmental agencies could provide training for role models, pay for informational materials, and find resources to pay older adults to serve as role models. Formal services could engage older adults and rural communities as partners in an effort to provide more services for rural older adults with co-occurring disorders. Advisory boards made up of rural older adults with co-occurring disorders could inform services (Krout, 2003; Shenk, 1998).

In addition to coordination of informal and formal resources, public and private services need to coordinate to provide integrated services. Integration is needed at all levels of care throughout the systems where older adults with co-occurring disorders are seen. In order to best serve this population, real integration provided with a desire to help, is required.

Access to care. Access to health care, especially specialty mental health and substance misuse services, is limited in rural communities. Reduced advocacy for rural older adults has left these communities with fewer aging services. Transportation options are limited, poverty levels are high, and the lack of economies of scale all contribute to reduced access (Bull, 2003).

Integration of services for people with co-occurring disorders into existing primary care provides a way to offer services to this population (Collins et al., 2010). Integrating mental health services into the primary care setting may assist with access closer to home. Providing integrated services in the same location as other health needs minimizes stigma and discrimination often associated with co-occurring disorders. Most people with co-occurring disorders treated in primary care have good outcomes if the clinic connects to local specialty care services (Funk & Ivbijaro, 2008).

The Patient-Centered Medical Home concept in the Affordable Health Care Act of 2010 may assist with the goal of access to care for older adults with co-occurring disorders by encouraging integrated health care systems (Collins et al, 2010; Sanchez et al., 2012; SAMHSA, n.d.). The World Health Organization recommends integrating

mental health services into primary care as the most viable way of closing the gap in prevention and treatment of mental illness (2011).

These recommendations support the participants' desire for better access to services with less stigma. However, simply integrating mental health and health care is not enough. Integrating services for co-occurring disorders into primary care requires that providers be educated about co-occurring disorders and older adults. Primary care providers must work with specialty care to meet the needs of older adults with co-occurring disorders. At present, few rural providers have either the knowledge or the support systems to provide adequate service for older adults with co-occurring disorders. Existing rural mental health and substance misuse services may be unable to take on additional work (Bull, 2003). Although older adults are entitled to use these specialty services, they are underserved through a combination of their own reluctance to ask for services and avoidance of this population by agencies. More information and rural resources are needed (Bull, 2003; Collins et al., 2010; Jenkins, 2003; Sanchez et al., 2012).

Competent services for rural older adults. Policy needs to be developed with consideration of co-occurring disorders, older adults, and rural communities. Knowledge and understanding of co-occurring disorders as a distinct practice is limited in rural communities. Providers who are adequately trained to assist older adults with co-occurring disorders are critically needed in both specialty and primary clinics. Providers educated in co-occurring disorders and age would assist with service integration. Training in co-occurring disorders for case managers and social workers

who work with older adults could assist with treatment coordination. Integrated services need funds for and incentives to cross-train staff in all services that work with older adults (Curie et al., 2005; Minkoff & Cline, 2004).

Distance services. Telecommunication and internet services can increase availability of services. Interactive televideo (ITV), internet webinars, and teleconferencing provide opportunities to educate providers and older adults about co-occurring disorders. These technologies offer providers connections to specialists for consultation. Specialty providers can interact with clients without either traveling long distances. On-line or telephone assessments can assist with monitoring clients. Policy can assist rural older adults to receive appropriate services by recognizing the role that distance plays in providing services and funding appropriate infrastructure development (Redford & Goins, 2003; SAMHSA, 2011a).

While telecommunication and internet can increase services, their use requires sensitivity to the individual. The emphasis needs to remain on providing individualized options that meet the needs identified by those being served.

Cost containment. Co-occurring disorders are often more severe than single disorders. Early prevention and treatment for these disorders is cost effective with cost-benefit ratios varying from 1:2 to 1:10. Savings come from reduced health costs, criminal justice system costs, education costs, and lost productivity (Miller & Hendrie, 2008; SAMHSA, 2011b). Some agencies find ways not to serve people with co-occurring disorders due to the higher expense of treating complex disorders. Policies

are needed to eliminate cost containment that impedes treatment for more severe disorders and support co-occurring disorder treatment (CSAT, 2007c).

Coordinating administrative units. Many gaps in integrated services challenge rural older adults with co-occurring disorders to find their way through the system and obtain services. Policy and funding for substance misuse and mental health that formed separately at federal and state levels has made the development of integrated services for people with co-occurring disorders difficult.

Coordination of administrative units would help bring about system changes that would enhance integrated services for people with co-occurring disorders. Guidelines that allow mental health and substance misuse funds to be combined or specific guidelines on how to provide integrated services within the context of existing funding mechanisms are needed (Minkoff & Cline, 2004). Coordination needs to occur at local, state, and federal levels, across related systems, and involve both public and private institutions so that programs can effectively assist older adults with co-occurring disorders (Coburn & Bolda, 2003). Substance Use and Mental Health Services Administration has funded initiatives to begin to integrate services (2011b). More integration is needed at the systems level.

Summary. Much remains to be done to assist older adults with co-occurring disorders who live in rural communities. Policies that address rural values through coordination of formal and informal services, access to care, adequate and competent services, distance services, cost containment, and coordination of administrative units could assist to bring about needed practice change. These modifications would cost very

little compared to both the human cost and the dollar cost of untreated co-occurring disorders and would greatly enhance co-occurring disorder services for rural older adults.

Implications for Research

While research about older adults with mental health or substance misuse problems is increasing, there is still limited research for older adults who experience co-occurring disorders. Research on single disorders does not adequately address co-occurring disorders, which require their own treatment modality. There has been some research in rural communities but much remains to be done. The issues of older adults change with generations. Continuous research is needed to maintain awareness of these changes and identify best practice approaches. Co-occurring disorders, older adults, and rural communities are seldom addressed together. More research is needed in each area and research about this unique combination is especially important.

Older adults. Both qualitative and quantitative studies are needed to explore the issues for older adults with co-occurring disorders. While it is important to understand risks for co-occurring disorders, it is essential to move away from a deficit model to a resilience model. Research has developed a reasonable understanding of the risks related to co-occurring disorders and older adults. The current research demonstrates that older adults are highly resilient and are capable of recovery. More research into how to assist recovery through support of assets and resilience is indicated.

Much of the previous research on co-occurring disorders has focused on young adults with serious mental illness. The current study suggests that older adults with mild, moderate, and severe co-occurring disorders also benefit from treatment. While there

remains controversy as to whether those with mild disorders need treatment (Kessler, Chiu et al., 2005; U.S. DHHS, 1999), participants in this study reported that assistance with mild and moderate disorders would have assisted them to recover. More research needs to be conducted so that this population can benefit from both prevention and treatment for co-occurring disorders and receive appropriate services to maintain recovery.

Relationship among onset, order, and severity of disorders. The results of the current study suggest that there may be relationships among time of onset, the order in which disorders occur, and severity of co-occurring disorders in older adults. The findings further indicate that older adults may experience onset of difficulties at any time in their lives. Time of onset appeared related to severity of disorders in the current study. Greater understanding of these variables may aid in prevention and treatment of co-occurring disorders in older adults.

Specific populations. The current study was qualitative and engaged participants who were willing to take part. All participants were rural, older, white, born in the United States, and heterosexual. Even within this group, gender brought different issues. These findings suggest that further research should be conducted in relationship to older women, and studies need to recognize differences among generations of women. Future studies need to look at other specific populations of older adults. It is essential to understand the needs of older adults with co-occurring disorders who are part of communities of color, immigrants, and of all sexual orientations to avoid overgeneralization.

Rural. Rural populations have been under-investigated. The current study suggests that rural community values and limited resources reduce the likelihood that older adults with co-occurring disorders will get help. Many rural communities have a large number of older adults (Bellamy et al., 2003; Werner, 2011). In any given community, some older adults will experience co-occurring disorders. It is essential to explore the best ways to provide integrated prevention and treatment for older adults in rural communities. Finding best practices to serve relatively small populations is an especially important part of service delivery in rural communities.

Childhood experiences. The current study suggests that early childhood experiences were significant in the development of co-occurring disorders and concurs with a recent study that found that mental illness begins very early in life (Kessler, Berglund et al., 2005). These findings suggest that research into prevention and early treatment of co-occurring disorders should include children, and that this research would indirectly benefit older adults.

Theory development. Much more research is needed to develop theories to address co-occurring disorders, older adults, and rural communities. It may be most helpful to develop theory around specific populations such as rural older adults with co-occurring disorders.

Summary

Much about helping rural older adults with co-occurring disorders to recover remains unanswered. Both qualitative and quantitative data will be useful in constructing practice standards and evaluation of prevention and treatment for rural older adults with

co-occurring disorders. Research is also needed to inform the development of policy for older adults living in rural communities who have co-occurring disorders. Listening to older adults themselves brings us closer to real understanding of their experiences and their views of the best ways to address their needs. Enhanced understanding of older adults, rural communities, and specific populations can help us better serve rural older adults with co-occurring disorders.

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Appendix A

Informed Consent Form

Co-occurring Disorders of Mental Illness and Substance Use: The Missing Voices of Older Adults

You are invited to be in a research study about older adults who have emotional or mental health issues and who also over-use alcohol, prescribed medications, over-the-counter medications, or health supplements. You were selected as a possible participant because you have these difficulties and you volunteered to talk about your own experience with these issues. I ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Kathryn McKinley, Department of Social Work, University of Minnesota.

Background Information

The purpose of this study is to understand what it is like for older adults who have mental health issues like depression; and how this interacts with over-using prescribed or over-the-counter medications, health supplements, and alcohol. If the issues for older adults can be identified and understood, this information may be used to develop better prevention and treatment for all older adults. This means that there may be an indirect benefit for you.

Procedures:

If you agree to be in this study, I would ask you to do the following things: You will be asked to complete a screening interview that will take about 30 minutes. If you are chosen to complete the second part of the study, you will be asked to complete an interview that will be audio-taped. This interview will take one to three hours. We can break the interview into two parts if it becomes too long for you to complete at one time. Here are a couple of examples of questions that you will be asked in the Research Interview:

“ What relationship, if any, do you think there is between your [mental health and substance use] difficulties or disorders?

What stands out in your mind as significant or important experiences about treatment of both kinds of difficulties/disorders, whether you received treatment or not?”

When the study is over, you will be asked to take part in a third interview where I will ask you whether what I wrote fits with what you think.

Risks and Benefits of being in the Study

The study has minor risks: First, you might feel upset when you are asked some questions. Second, you might wish after you answered a question that you had not answered it.

Your participation is completely voluntary. You are under no obligation to answer any question if you do not want to. You may stop the interview at any time that you wish. The researcher may stop the interview if it appears to be too distressing for the participant.

If you complete the interview and then wish that you had not, you may withdraw from the study and your information will not be used in the research. There are no direct benefits to you to take part in this study.

Compensation:

You will receive a \$5 gift card for the screening interview and a \$15 gift card for the initial (research) interview to a grocery store or Walmart.

Confidentiality:

The records of this study will be kept private. Results of this study may be published in a professional journal. However, no individual participant will be identifiable. In any sort of report I might publish, I will not include any information that will make it possible to identify a participant. Research records will be stored securely in a locked file cabinet and I am the only person who will have access to the records. I will be the only person who will listen to the audio tapes of our interview. Once I transcribe your interview, the tape will be destroyed.

Voluntary Nature of the Study:

Taking part in this study is voluntary. Your decision to participate or not will have no effect on your current or future relations with the University of Minnesota or with me. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The researcher conducting this study is: Kathryn McKinley. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact me at Buena Vista University, 712-749-2139, mckinley@bvu.edu. If you wish, you may also contact my advisor, Jeffrey Edleson. His phone number is 612-624-8795 and his e-mail address is jedleson@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the Research Subjects' Advocate Line at D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455, or telephone (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers and I understand what I am agreeing to do. I consent to participate in the study.

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____

Appendix B

Screening Interview Form

Identifying # _____

Date _____

Identifying Information

1. What is your age?
2. What is your gender? (observed)
3. What is your race/ethnicity(observed)?
4. What is your sexual orientation?

Residency

5. How long have you lived in rural Iowa?

Information about disorders

6. What emotional or mental difficulties or disorder(s) do or did you experience?
 - Categories
 - ◆ Depression or Mood disorders
 - ◆ Anxiety
 - ◆ Psychotic disorders
 - ◆ Dementia
 - ◆ Paranoid disorders
 - ◆ Other

7. What substance use difficulties or disorder(s) do or did you experience?
 - Categories
 - ◆ Alcohol
 - ◆ Prescription medications
 - ◆ Over-the-counter medications
 - ◆ Complementary and alternative medications like health food supplements
 - ◆ Other

8. What is the basis for your belief that you have co-occurring disorders?
 - ◆ Diagnosed by a professional?
 - ◆ Other?

Have participant complete screening instruments

Appendix C

Mental Health Screening Form-III-Adapted

Guidelines for using the Mental Health Screening Form III

Each MHSF-III question is answered either “yes” or “no”. The original Form has been adapted so that all questions reflect the respondent’s entire life history; therefore all questions begin with the phrase “Have you ever. . .”

The mode of administration is for the principal investigator (PI) to read each item to the respondent and get their “yes” and “no” responses. Then, after completing all 18 questions (question 6 has two parts), the PI will inquire about any “yes” response by asking “When did this problem first develop?”; “How long did it last?”; “Did the problem develop before, during, or after you started using substances?”; and, “What was happening in your life at that time?” This information will be written below each item in the space provided. There is additional space for PI comments at the bottom of the form.

The MHSF-III features a “Total Score” line to reflect the total number of “yes” responses. The maximum score on the MHSF-III is 18 (question 6 has two parts).

The first four questions on the MHSF-III are not unique to any particular diagnosis. Questions 5 through 17 reflect symptoms associated with the following diagnoses/diagnostic categories: Q5, Schizophrenia; Q6, Depressive Disorders; Q7, Post-Traumatic Stress Disorder; Q8, Phobias; Q9, Intermittent Explosive Disorder; Q10, Delusional Disorder; Q11, Sexual and Gender Identity Disorders; Q12, Eating disorders (Anorexia, Bulimia); Q13, Manic Episode; Q14, Panic Disorder; Q15, Obsessive-Compulsive Disorder; Q16, Pathological Gambling; Q17, Learning Disorder and Mental Retardation.

The relationship between the diagnoses/diagnostic categories and the above cited questions was investigated by having four mental health specialists independently “select the one MHSF-III question that best matched a list of diagnoses/diagnostic categories”. All of the mental health specialists matched the questions and diagnoses/diagnostic categories in the same manner, that is, as noted in the preceding paragraph.

A “yes” response to any of questions 5 through 17 does not, by itself, insure that a mental health problem exists at this time. A “yes” response raises only the possibility of a current problem.

Mental Health Screening Form III—Adapted

Identifying # _____

Instructions: These questions are designed to help me understand emotional issues that you may have had in the past or that you have now. Please remember that any information that you provide to me will be kept in strict confidence. It will not be released to any outside person or agency. If you do not know how to answer any question, ask me for guidance. Please note, each item refers to your entire life history, not just your current situation. This is why each question begins “Have you ever . . .”

- | | | |
|---|-----|----|
| 1. Have you <u>ever</u> talked to a psychiatrist, psychologist, therapist, social worker, counselor, or your physician about an emotional problem? | YES | NO |
| 2. Have you <u>ever</u> felt you needed help with your emotional problems, or have you had people tell you that you should get help for your emotional problems? | YES | NO |
| 3. Have you <u>ever</u> been advised to take medication for anxiety, depression, hearing voices, or for any other emotional problem? | YES | NO |
| 4. Have you <u>ever</u> been seen in a psychiatric emergency room or been hospitalized for psychiatric reasons? | YES | NO |
| 5. Have you <u>ever</u> heard voices no one else could hear or seen objects or things which others could not see? | YES | NO |
| 6. a. Have you <u>ever</u> been depressed for weeks at a time, lost interest or pleasure in most activities, had trouble concentrating and making decisions, or thought about killing yourself? | YES | NO |
| b. Did you ever attempt to kill yourself? | YES | NO |
| 7. Have you <u>ever</u> had nightmares or flashbacks as a result of being involved in some traumatic/terrible event? For example, warfare, gang fights, fire, domestic violence, rape, incest, car accident, being shot or stabbed? | YES | NO |
| 8. Have you <u>ever</u> experienced any strong fears? For example, of heights, insects, animals, dirt, attending social events, being in a crowd, being alone, being in places where it may be hard to escape or get help? | YES | NO |
| 9. Have you <u>ever</u> given in to an aggressive urge or impulse, on more than one occasion that resulted in serious harm to others or led to the destruction of property? | YES | NO |

- 10. Have you ever felt that people had something against you, without them necessarily saying so, or that someone or some group may be trying to influence your thoughts or behavior?
 YES NO
- 11. Have you ever experienced any emotional problems associated with your sexual interests, your sexual activities, or your choice of sexual partner?
 YES NO
- 12. Was there ever a period in your life when you spent a lot of time thinking and worrying about gaining weight, becoming fat, or controlling your eating? For example, by repeatedly dieting or fasting, engaging in much exercise to compensate for binge eating, taking enemas, or forcing yourself to throw up?
 YES NO
- 13. Have you ever had a period of time when you were full of energy and your ideas came very rapidly, when you talked nearly non-stop, when you moved quickly from one activity to another, when you needed little sleep, and believed you could do almost anything?
 YES NO
- 14. Have you ever had spells or attacks when you suddenly felt anxious, frightened, or uneasy to the extent that you began sweating, your heart began to beat rapidly, you were shaking or trembling, your stomach was upset, you felt dizzy or unsteady, as if you would faint?
 YES NO
- 15. Have you ever had a persistent, lasting thought or impulse to do something over and over that caused you considerable distress and interfered with normal routines, work, or your social relations? Examples would include repeatedly counting things, checking and rechecking on things you had done, washing and rewashing your hands, praying, or maintaining a very rigid schedule of daily activities from which you could not deviate.
 YES NO
- 16. Have you ever lost considerable sums of money through gambling or had problems at work, in school, with your family and friends as a result of your gambling?
 YES NO
- 17. Have you ever been told by teachers, guidance counselors, or others that you have a special learning problem?
 YES NO

Thank you for answering these questions. Do you have any questions for me right now?

Total Score: _____ (each yes = 1 point)

Reviewer's Comments: _____

Appendix D

Simple Screening Instrument for Substance Abuse-Adapted

Identifying # _____

Instructions: These questions are designed to help me understand issues that you may have had in the past or that you have now with substances including alcohol, prescription drugs, over-the-counter medications, and health food supplements over your entire life. Please remember that any information that you provide to me will be kept in strict confidence. It will not be released to any outside person or agency. If you do not know how to answer any question, ask me for guidance. Please note that each item refers to your entire life history, not just your current situation. This is why each question begins “Have you ever. . .”

- | | | |
|--|-----|----|
| 1. Have you ever used alcohol or other drugs? | YES | NO |
| 2. Have you ever felt that you used too much alcohol or other drugs? | YES | NO |
| 3. Have other people ever felt that you used too much alcohol or other drugs? | YES | NO |
| 4. Have you ever tried to cut down or quit drinking or using drugs? | YES | NO |
| 4. Have you ever gone to anyone for help with your drinking or drug use? This might mean talking to your physician, a psychiatrist, psychologist, therapist, social worker, or counselor about your use. It might also mean going to Alcoholics Anonymous, Narcotics Anonymous, Cocaine Anonymous, or any treatment program. | YES | NO |
| 5. Have you ever experienced any of the following: | | |
| a. Blackouts or other periods of memory loss | YES | NO |
| b. Injury to your head after drinking or using drugs | YES | NO |
| c. Convulsions or delirium tremens (DT's) | YES | NO |
| d. Hepatitis or other liver problems | YES | NO |
| e. Feeling sick, shaky, or depressed when you stopped drinking or using drugs | YES | NO |
| f. Feeling a crawling feeling (coke bugs” under the skin, after you stopped using drugs | YES | NO |
| g. Injury after drinking or using drugs | YES | NO |
| h. Using needles to shoot drugs | YES | NO |
| 6. Has drinking or other drug use ever caused you problems at school or at work? | YES | NO |

- 7. Has drinking or other drug use ever caused problems between you and your family or friends?
YES NO
- 8. Have you ever been arrested or had other legal problems such as bouncing checks, driving while intoxicated, theft, or drug possession?
YES NO
- 9. Have you ever lost your temper or gotten into arguments or fights while drinking or using drugs?
YES NO
- 10. Have you ever need to drink or use drugs more and more to get the effect that you wanted?
YES NO
- 11. Have you ever spent a lot of time thinking about or trying to get alcohol or other drugs?
YES NO
- 12. When drinking or using drugs, were you ever more likely to do something that you would not normally do, such as break rules, break the law, sell things that are important to you, or have unprotected sex with someone?
YES NO
- 13. Have you ever felt bad or guilty about your drinking or drug use?
YES NO
- 14. Have you ever had a drinking or drug use problem?
YES NO
- 15. Have any or your family members ever had a drinking or drug problem?
YES NO

Thank you for answering these questions. Do you have any questions for me?

Total Points: _____ (Each yes = 1 point)

Reviewer's Comments

Appendix E

Research Interview Form

Research Interview for Experiencing Co-Occurring Mental Health and Substance Misuse

Disorders: The Voices of Rural Older Adults

Identifying # _____

Date _____

Please answer the questions to the best of your ability. There are no right or wrong answers. If you do not want to answer a particular question, you do not have to.

The purpose of this study is to understand what it is like for older adults who live in rural communities and experience co-occurring mental health and substance misuse co-occurring disorders. If the ways that they handle the challenges of these co-occurring disorders can be identified and understood, this information may be used to develop better help and policies for all older adults. This means that there may be an indirect benefit for you.

Tell me about yourself

1. I'd like you to start by telling me a little bit about yourself.
2. I'd like to hear about several times in your life that have been rewarding.
3. At what ages did these times or events occur?
4. How did these rewarding experiences impact you and your life?

Prompts:

- ◆ Did they seem to bring more positive experiences?
 - ◆ Did they seem to bring or be followed by stressful events?
 - ◆ How did these experiences relate to your co-occurring disorders?
 - ◆ Specifically, how did these experience impact how you handled your co-occurring disorders?
 - ◆ Childhood experiences
 - ◆ Experiences relative to gender
 - ◆ Experiences related to losses
 - ◆ Experiences of caregiving
5. I'd like to hear about several times in your life that have been stressful.
 6. At what ages did these times or events occur?

7. How did these stressful experiences impact you and your life?

Prompts:

- ◆ Did they seem to bring more stresses and difficulties?
- ◆ Did they seem to bring or be followed by more positive or rewarding events?
- ◆ How did these experiences relate to your co-occurring disorders?
- ◆ Specifically, how did these experiences impact how you handled your co-occurring disorders?
- ◆ Childhood experiences
- ◆ Experiences relative to gender
- ◆ Experiences related to losses
- ◆ Experiences of caregiving

8. What do you think there is about yourself that has helped you develop the ways that you cope with or handle co-occurring disorders?

Prompts

- ◆ Personality
- ◆ Attitudes
- ◆ Skills
- ◆ Values
- ◆ Spirituality
- ◆ Ways you spend your time
- ◆ Health
- ◆ Work
- ◆ Other

9. What do you think there has been in your environment that has helped you develop the ways that you cope with or handle co-occurring disorders?

Prompts

- ◆ Family
- ◆ Friends
- ◆ Work
- ◆ Religious organization
- ◆ Social Agencies or organizations
- ◆ Medical providers
- ◆ Other

10. Are other factors that sometimes affect people and how they handle co-occurring disorders. Have any of these been a factor in how you cope with them? If so, how?

Status issuesPrompts

- ◆ Race
- ◆ Class
- ◆ Gender
- ◆ Gender orientation

(Question 10 continued)

Adequate resources

Prompts

- ◆ Food
- ◆ Clothing
- ◆ Shelter
- ◆ Health care
- ◆ Support system
- ◆ Transportation
- ◆ Finances
- ◆ Adequate health insurance

Age

11. How do you think age has interacted with how you have handled co-occurring disorders?
For example, do you handle them differently now than you did 20 years ago? 40 years ago?
What impact has age had on how you handle your disorders?

Rural

12. How do you think that living in a rural community impacts how you handle co-occurring disorders.

Prompts

- ◆ How you came to realize that you have co-occurring disorders
- ◆ How the community responds to you and other people who have co-occurring disorders
- ◆ Availability of information about co-occurring disorders
- ◆ Awareness of others who have co-occurring disorders
- ◆ Availability of help for co-occurring disorders
- ◆ Understanding of treatment for co-occurring disorders

Risk

12. What put you at risk for having both mental health and substance misuse difficulties/disorders?

Prompts

- ◆ Did you experience any of the following and did they put you at risk for your disorders?
(Go back to stresses mentioned in Question 5)
- ◆ Childhood difficulties
- ◆ Gender issues
- ◆ Relationship loss/bereavement
- ◆ Being in the caregiver role
- ◆ Being socially isolated
- ◆ Loss of meaningful social roles
- ◆ Chronic illness
- ◆ Chronic physical disabilities
- ◆ Chronic pain
- ◆ Reduced coping skills
- ◆ Trauma
- ◆ Violence

(Question 12 continued)

- ◆ Interpersonal/cognitive skills
- ◆ School, work, or other failure
- ◆ Poverty
- ◆ Roles in life and role responsibility
- ◆ Lack of regularly structured activities
- ◆ The habits of people you spent time with
- ◆ Living in community with high rates of drug availability
- ◆ Other

13. How do you think you came to have these particular difficulties or disorders?

Prompts

- ◆ Genetic
- ◆ Life events
- ◆ Stressors
- ◆ Other

Development of Co-occurring disorders

14. About how old were you when you first experienced emotional difficulties or mental illness and substance misuse or disorders?

(early/late onset)

15. What role has age played in your experience of these difficulties?

16. What changes in disorders have you experienced over time?

17. What relationship, if any, do you think there is between your difficulties or disorders?

Prompts

- ◆ Do you think that one caused the other?
- ◆ Do you think that they are completely separate?
- ◆ Do you think that anything in the environment—the people or place or experiences that you had—made a difference in you having both difficulties/ disorders?
- ◆ Do you think that any personal characteristics that you have influenced your difficulties/disorders?
- ◆ Do you think that there is anything about the way that you think that influenced your difficulties/disorders?
- ◆ Do you think that there is anything about your relationships with people that influenced your difficulties/disorders?
- ◆ Do you think that there is anything about your biological or genetic make up that influenced your difficulties/disorders?
- ◆ Do you think that anything else influenced your difficulties/disorders?

Identifying Co-occurring disorders

18. What stands out in your mind as significant or important experiences that helped you identify having these difficulties/disorders?

Treatment

19. If you received any kind of treatment, what stands out in your mind as significant or important experiences about treatment of these difficulties/disorders?

Use Questions 20 and 21 if participant received treatment. If not go on to question 22.

20. Did your treatment include any of the following kinds of help?

- ◆ Treatment for both disorders at the same time in the same place (integrated)
- ◆ Treatment for both disorders in different locations (parallel)
- ◆ Treatment for both disorders at different times (sequential)
- ◆ Treatment for mental health problems only
- ◆ Treatment for substance misuse problems only
- ◆ Did anyone approach you and offer help? (Assertive outreach)
- ◆ Were you offered assistance in managing your co-occurring disorders (case management)
- ◆ Treatment that tried to help motivate you to recover from your disorders (motivational interventions)
- ◆ Manage illnesses/pursue functional goals
- ◆ Treatment that did or did not take into consideration your culture whether that relates to race/ethnicity, age, rural community, or other cultural aspects (Cultural competence)
- ◆ Use of treatment that took place over a period of time and that was different at different times depending on what you needed for motivation (longitudinal, stage-wise motivational approaches to treatment).

21. What was the impact of the treatment on your mental illness/substance use difficulties?

Recovery

22. If you are in recovery, what stands out to you as significant experiences relating to your recovery from co-occurring disorders?

Prompts

- ◆ What has been helpful to maintaining recovery?
- ◆ What has made maintaining recovery difficult?

23. What difficulties have you experienced during the time that you have had co-occurring difficulties/disorders?

Prompts

- ◆ Difficulty with family
- ◆ Difficulties with friends
- ◆ Difficulty with others in your community
 - Religious leaders/groups
 - Medical personnel
 - Employers
- ◆ Work
- ◆ Religion

(Question 23 continued)

- ◆ Health problems
- ◆ HIV/AIDS
- ◆ Economic difficulties
- ◆ Homelessness
- ◆ Trauma
- ◆ Suicide
- ◆ Violence
- ◆ Criminal justice system
- ◆ Other

Attitudinal Issues

24. Some people have struggled with their own attitudes about having mental health and/or substance use difficulties/disorders. Please tell me your current attitude about having these disorders.

25. Has your attitude always been the same or has it changed over time? If it has changed, how has it changed?

26. Some people have struggled with other people's attitudes about having mental health and/or substance use difficulties/disorders. What has been your experience with other people's attitudes about you having these disorders?

Prompts

- ◆ Family
- ◆ Friends
- ◆ Work
- ◆ Religious leader/groups
- ◆ Medical professionals
- ◆ Social service providers
- ◆ Employers
- ◆ Community organization members
- ◆ Society
- ◆ Others

27. Some people have encountered stigma or negative or shaming attitudes and behaviors from people or organizations relating to having mental health and/or substance use difficulties/disorders. What experiences with stigma have you had relative to these disorders?

Prompts

- ◆ Family
- ◆ Friends
- ◆ Work
- ◆ Religious leaders/groups
- ◆ Medical professional
- ◆ Social service providers
- ◆ Community organizations
- ◆ Society and others

Structural Issues

Sometimes the way that services are organized makes getting help easier or more difficult.

28. What made it easier for you to identify/receive treatment/maintain recovery from having mental health and substance use difficulties/disorders?

Prompts

- ◆ Structural supports
 - ◆ Information about treatment
 - ◆ Help from others who have co-occurring disorders
 - ◆ Accurate information about treatment and recovery
 - ◆ Personal finances
 - ◆ Administrative regulations that reduced barriers
 - ◆ Location of services
 - ◆ Transportation
 - ◆ Availability of services
 - ◆ Adequate insurance reimbursement
 - ◆ Medicare
 - ◆ Formal or informal outreach
 - ◆ Agency financial resources
 - ◆ Personnel knowledgeable about co-occurring disorders
 - ◆ Other
- ◆ Status issues
 - Race
 - Class
 - Gender
 - Gender orientation
- ◆ Adequate resources
 - Food
 - Clothing
 - Shelter
 - Health care
 - Support system
- ◆ Other

29. What made it more difficult for you to identify/receive treatment/maintain recovery from having mental health and substance use difficulties/disorders?

Prompts

- ◆ Structural barriers
 - Personal finances
 - Administrative regulations
 - Location of services
 - Transportation
 - Lack of services
 - Low/no insurance reimbursement
 - Medicare
 - No outreach

(Question 29 continued)

- Agency financial barriers
- Personnel lack of knowledge of co-occurring disorders
- Regulatory barriers
- Turf guarding
- ◆ Other barriers
- ◆ Status issues
 - Age
 - Race
 - Class
 - Gender
 - Gender orientation
- ◆ Inadequate resources
 - Food
 - Clothing
 - Shelter
 - Health care
 - Support system
- ◆ Other

30. How do you think that age has interacted with your treatment experience?

31. How do you think that living in a rural community interacted with your treatment experience?

32. How do you think that other factors (from list above) have interacted with your treatment experience?

Assistance for problems other than co-occurring disorders

33. What other kinds of assistance would be helpful for older adults who live in rural communities and have co-occurring disorders?

34. From whom would you prefer to receive help?

Prompts

- ◆ Family
- ◆ Friends
- ◆ Religious organizations
- ◆ Medical providers
- ◆ Social service organizations
- ◆ Other

What do you want others to know?

35. You have knowledge about the experience of having mental health and/or substance use difficulties/disorders. What do you want others to know about what it is like to be an older adult who lives in rural communities and has these disorders?

Prompts

- ◆ Family/friends
- ◆ Practitioners
- ◆ Policy makers
- ◆ Researchers
- ◆ Community

36. What have we not talked about that is important for me to know about your experiences with having mental health and/or substance use difficulties/disorders?

I'd like to ask some other information that may help me understand you and your experience.

37. I'd like to ask some questions about your living situation.

With whom do you live?

- ◆ Alone
- ◆ Partner
- ◆ Children
- ◆ Non-related people

38. Please describe your general physical health.

- ◆ Excellent
- ◆ Good
- ◆ Fair
- ◆ Poor

39. How do you spend your time?

Prompts

- ◆ Working? If so, how many hours per week?
- ◆ Retired?
- ◆ If retired, in what activities do you regularly engage? How many hours/week?

40. In what religious activities, if any do you participate? How often per week?

41. How adequately do your income and assets meet your needs?

Thank you for participating in this interview. Do you have any questions for me now? If so, let's talk about them.

If no, please do not hesitate to contact me if you have questions later.

Is it OK if I contact you for a follow-up interview after I have completed my research? The reason for the follow-up interview is to see if my findings fit with your experience.

YES **NO**

Once again, thank you.

Appendix F

Data Reduction Form

Categories	Sub-Categories	Concepts
Risks for Co-Occurring Disorders	Childhood Difficulties	<ul style="list-style-type: none"> ▪ Deprivation <ul style="list-style-type: none"> ○ Poverty ○ Neglect & Abuse ○ Societal Institutions ▪ Parental mental health & substance use problems ▪ Childhood mental health & substance use problems
	Gender-Related Risks	<ul style="list-style-type: none"> ▪ Gender & Support Systems ▪ Gender Roles ▪ Loss of children ▪ Other gender issues
	Loss and Grief	<ul style="list-style-type: none"> ▪ Hopes and dreams ▪ Early parental loss ▪ Sibling loss
	Caregiving	<ul style="list-style-type: none"> ▪ During childhood ▪ During adulthood & later life
Barriers to Help	Participant Barriers	<ul style="list-style-type: none"> ▪ Lack of information ▪ Lack of role models ▪ Fear of treatment
	Family & Friend Barriers	
	Rural community Barriers	<ul style="list-style-type: none"> ▪ Medical providers ▪ Spiritual leaders ▪ Employers
	Structural Service Barriers	<ul style="list-style-type: none"> ▪ Accessing services <ul style="list-style-type: none"> ○ Treatment is scarce ○ Appropriate treatment was unavailable ○ Treatment was hard to find ○ Treatment is costly ○ Recovery supports ▪ Lack of help for other problems

Protection & Resilience Factors	Participant Resources	<ul style="list-style-type: none"> ▪ Persistence ▪ Social embeddedness ▪ Religion and spirituality
	Acknowledgment of Co-Occurring Disorders	
	Acceptance of Help	<ul style="list-style-type: none"> ▪ Treatment <ul style="list-style-type: none"> ○ Treatment was beneficial ○ People may need more than one Treatment ○ Ease of access to treatment ○ Provider knowledge of co-occurring disorders and older adults
		<ul style="list-style-type: none"> ▪ Unexpected forms of help ▪ Rural resources

Appendix G

Data Reduction Matrix

Category	Sub-Category	Concept	Participants by Number																								
			1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	#	
Risk Factors	Childhood Difficulties	Deprivation			X		X			X		X			X			X		X	X	X			X	10	
		Parental MH/ SM	X				X			X		X		X		X	X	X		X	X	X					12
		Childhood MH/SM		X	X	X	X			X			X	X	X	X	X	X	X	X	X	X	X			X	17
	Gender Related Risks	Support systems			X				X	X	X	X		X						X		X			X	X	10
		Gender roles			X			X		X	X	X		X	X										X		8
		Loss of children							X			X										X					3
		Other gender issues			X		X							X	X	X											4
	Loss & Grief	Hopes & dreams	X		X		X			X			X	X	X	X											8
		Early parental loss		X																	X	X	X			X	5
		Sibling loss					X			X		X			X								X				5
	Caregiving	Childhood															X	X									2
		Adult							X	X	X		X	X						X		X			X	X	5
		Older adult	X		X				X				X			X					X	X	X	X	X	X	13

		Participants by Number																									
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23			
Barriers to help	Participant Barriers	Lack of information	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	23		
		Lack of role models	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	23	
		Fear of treatment	X									X		X	X	X	X		X							7	
	Family/Friend Barriers						X				X			X	X	X		X	X						X	8	
	Rural Community Provider Barriers	Medical providers			X							X		X	X	X	X		X						X	X	9
		Spiritual leaders	X					X				X		X			X										5
		Employers		X			X	X									X	X									5
	Rural Structural Service Barriers	Accessing services					X	X		X		X		X	X	X	X		X	X					X	X	12
		Treatment scarcity								X				X	X	X	X		X	X						X	8
		Appropriate treatment unavailable	X		X		X	X		X		X	X	X	X	X	X		X		X	X	X	X	X	X	17
		Difficulty finding treatment						X		X				X	X	X	X		X	X					X	X	10
		Treatment cost					X			X				X		X	X		X							X	7
		Recovery supports			X			X					X	X	X	X				X		X	X	X	X	X	11
		No help for other issues	X		X					X			X	X			X				X	X	X	X	X	X	11

		Participants by Number																									
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23			
Protection & Resilience Factors	Personally Resourceful	Persistence	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	23	
		Socially embedded	X	X	X	X	X	X	X	X	X				X	X	X	X	X	X	X	X	X	X	X	X	20
		Spirituality/religion		X	X	X	X	X	X			X	X	X	X	X	X		X	X	X	X	X	X	X		18
	Acknowledge Co-occurring Disorders		X				X	X		X		X	X		X	X	X	X	X	X					X	X	14
	Accept Help	Treatment	X				X					X			X	X	X	X	X	X						X	10
		Unexpected forms of help		X			X						X				X	X									5
		Rural resources	X	X								X			X	X	X		X	X							8