

Summer 8-13-2021

Evaluating Self-Management of Adults with Multiple Chronic Conditions Residing in Rural Communities: A Descriptive Cross-Sectional Study

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**Evaluating Self-Management of Adults with Multiple Chronic Conditions Residing in Rural
Communities: A Descriptive Cross-Sectional Study**

By

Jessica J Miller

A DISSERTATION

Presented to the Faculty of the Graduate College in the

University of Nebraska Medical Center

In Partial Fulfillment of Requirements for the

Degree of Doctoral Philosophy

Nursing Graduate Program

Under the Supervision of Professor Bunny Pozehl, PhD

University of Nebraska Medical Center

Omaha, NE

August 2021

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DEDICATION

This work is dedicated to my beloved husband Nicholas Miller, without whom I would not have made it through this process. You are my rock and have supported me through all the celebrations and struggles that I encountered along the way. Without your continued support and work as a dedicated husband and father I would not be where I am today. This work is as much yours as it is mine.

Thank you!

ACKNOWLEDGEMENTS

Thank you to my PhD committee chair, advisor, and mentor Dr. Bunny Pozehl for your unwavering support and guidance throughout this process. Your unconditional support, and wisdom was critical to my success and I could not have completed this program without you.

I would also like to thank my supervisory committee members: Dr. Christine Eisenhauer, Dr. Myra Schmaderer, Dr. Fabio Almeida, and Dr. Kevin Kupzyk for your continued support, guidance, and expertise.

I would like to acknowledge those that provided financial support to fund this dissertation and my education:

Jonas Nursing and Veterans Health Care Philanthropies

Nellie House Craven Scholarship

Wilbur & Valerie Moon Scholarship

Evaluating Self-Management of Adults with Multiple Chronic Conditions Residing in Rural Communities: A Descriptive Cross-Sectional Study

Jessica J. Miller, Ph.D.

University of Nebraska Medical Center, 2021

Supervisor: Bunny Pozehl, Ph.D.

ABSTRACT

Background

Chronic diseases are the leading cause of death and disability in the United States and are on the rise. Multiple chronic conditions are increasing in frequency with 1 in 4 adults affected.

Behaviors of adults from rural communities are at an increased risk of developing MCC because of limited access to health care resources and behaviors. Supporting the development of self-management skills can help adults be more active in their own health and promote healthy lifestyle behaviors. The Individual and Family Self-management was the guiding framework for this cross-sectional study.

Purpose

The purpose of this study was to determine the self-management perceptions and behaviors of adults from rural communities diagnosed with multiple chronic conditions. The specific aims were to:

Aim 1: Determine the feasibility of recruitment, enrollment, and data collection in rural adults with MCC

Aim 2: Explore perceptions of SM needs of rural dwelling adults with MCC

Aim 3: Describe the SM variables of self-efficacy, self-regulation, social support, and patient activation and the SM behaviors of rural adults with MCC.

Methods

A descriptive cross-sectional design was used. Data collection methods includes surveys, medical records extractions, and two focus groups. Collection occurred between January and June 2021. A

sample of 40 adults from isolated rural (RUCA 10) communities were enrolled in this study from primary care clinics in the Midwestern United States. Because of COVID-19 on health and safety protocols, participants were recruited by clinic staff, nurses, and providers. All contact with research personnel occurred through distance technology, either telephone or zoom web conferencing. Participants were enrolled and screened for inclusion, consented, and data collection virtually.

Data Analysis

Descriptive analyses, t-tests to compare sample means to the comparative means identified for each instrument, and spearman's correlation to identify relationships between self-management processes and self-management behaviors of physical activity and sleep were conducted.

Descriptive content analysis occurred for the focus groups. Two researchers worked collaboratively to refine coding into a matrix.

Results

A convenience sample of 40 adults were recruited from five rural primary care clinics. The mean age was 62.13 (range 37-90) years. Analysis revealed that adult from rural communities self-reported higher levels of social support (instrumental ($p < .001$), informational ($p < .001$), and companionship ($p < .001$)), self-efficacy ($p < .001$) and, patient activation ($p < .001$), and lower self-regulation ($p < .001$) compared to normative means. There was a statistically significant correlation between self-efficacy and the self-management behaviors of sleep ($\rho = -.508$, $p = .001$) and physical activity ($\rho = .451$, $p = .003$). Focus groups revealed significant differences in the experiences between individuals self-identifying as having high versus low self-management capabilities.

Conclusion

This study adds to the body of literature that is available on the perspectives, behaviors, and processes of self-management for rural adults with multiple chronic conditions. Next steps need

to focus on the application of these results to the development of a tailored self-management intervention specifically for rural adults with multimorbidity.

Keywords: Rural, Self-management, Self-care, chronic condition, multimorbidity

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Figure 2: Revised Individual and Family Self-Management Theoretical Framework

Figure 2 Patient Activation Stages

LIST OF ABBREVIATIONS

CDC	Center for Disease Control and Prevention
MCC	Multiple Chronic Conditions
PAM	Patient Activation Measure
PROMIS	Patient-Reported Outcomes Measurement Information System
SM	Self-Management
RUCA Codes	Rural Urban Commuting Area Codes

CHAPTER I: INTRODUCTION

Background & Significance

Chronic conditions currently affect 60% of the population in the United States and this rate is increasing rapidly (National Center for Chronic Disease Prevention and Health Promotion, 2021). Chronic conditions are the leading cause of death and disability with 88% of all deaths in the United States being attributed to these conditions (National Center for Chronic Disease Prevention and Health Promotion, 2016). The noted rise in chronic conditions is leading to a corresponding rise in the number of individuals diagnosed with multiple chronic conditions (MCC) that require daily management by the patient. Multiple morbidity or multimorbidity is a term frequently used to refer to individuals with MCC (Schmaderer, Zimmerman, Hertzog, Pozehl, & Paulman, 2016; Ward & Schiller, 2013; Ward, Schiller, & Goodman, 2014). Individuals with multimorbidity are at an increased risk for exacerbation of illnesses (Schmaderer et al., 2016), and increased health care costs (Hibbard, Greene, & Overton, 2013). The ratio of adults diagnosed with MCC is currently 1 in 4 with this number swiftly approaching 1 in 3 (Gerteis et al., 2014). Adults diagnosed with MCC experience increased risk of exacerbation of their chronic disease leading to higher rates of hospitalization, health care costs, and death (Schmaderer et al., 2016). The major risk factors for the development of chronic conditions include poor nutrition, lack of exercise, smoking and excessive alcohol intake (National Center for Chronic Disease Prevention and Health Promotion, 2021). Developing strong self-management (SM) skills in this population can support patient involvement in their own health and promote healthy lifestyle behaviors and activities. A paucity of literature has been conducted on how to best develop SM skills in individuals with MCC. Literature to date focuses on describing the barriers, treatments, and perspectives of individual diseases rather than considering the MCC in adults with multimorbidity (Noël et al., 2007).

Chronic disease SM programs have been shown to be effective at reducing health care utilization and improving quality of life (Grey, Knafl, & McCorkle, 2006; Miller, Ashing,

Modeste, Herring, & Sealy, 2015; Richard & Shea, 2011). Chronic disease management often requires adoption of new healthy lifestyle behaviors both in general and unique to the conditions in which the individual is diagnosed with. For many individuals, the implementation of new routines can be difficult and unwanted burdens that affect their daily lives; however, adaptation of healthy behaviors can result in reduction of disease risk and reduced health care costs across multiple diseases or conditions (Agha et al., 2014). Multiple studies have illustrated the influence of SM skills in individuals with chronic conditions (Lorig, Holman, & Sobel, 2012; McCorkle et al., 2011; Smith et al., 2017). Limited sustainability of these interventions is suggested to be due to lack of tailoring the intervention based on individual need (Miller, Lasiter, Bartlett Ellis, & Buelow, 2015). There is a growing need for research regarding interventions to develop sustained SM skills. A review of literature revealed that there is little consistency in how SM interventions are tailored for adults with MCC (Miller, Pozehl, Alonso, Schmaderer, & Eisenhauer, 2020). While all SM programs include a component of education the delivery and type of educational material delivered varied greatly across programs. Furthermore, when management of chronic disease is compounded by the effects of MCC, tailoring is especially important to meet individual needs.

Individuals diagnosed with MCC face increased burden associated with increased health care costs and reduced quality of life (Hajat & Stein, 2018). While this effect is seen across all MCC populations, rural adults are at an increased risk for complications of MCC due to a variety of factors (McGilton et al., 2018). Residents of rural communities are a health disparate underserved population because of limited access to health care resources (Bardach, Tarasenko, & Schoenberg, 2011). Residents of rural communities experience increased burden in accessing health care due to increased travel requirements, and lack of available care and resources in isolated communities (Bardach et al., 2011). Individuals residing in rural communities are at an increased risk of being diagnosed with MCC compared to urban adults (Ma, He, & Xu, 2020; Rural Health Information, 2018; Rural Health Information Hub, 2019). Rural adults also

experience increased health care costs, poor health outcomes and higher rates of morbidity and mortality (Rural Health Information, 2018; Rural Health Information Hub, 2019). Interventions aimed at improving SM behaviors for rural adults are needed because of cultural and behavioral differences compared to urban populations. It is imperative to identify the SM needs, behaviors, and perspectives of rural adults with MCC to develop and tailor interventions to the needs of the population. Rural adults have been shown to have less active roles in their health care and fail to actively pursue healthy behaviors such as healthy eating, physical activity, and adherence to provider recommended therapies (Bardach et al., 2011; National Center for Chronic Disease Prevention and Health Promotion, 2016).

In the United States, rurality is classified based on Rural Urban Commuting codes (RUCA). These codes are based upon population census data collected from each individual zip code (Rural Health Research Center, 2021). Zip codes can be classified into one of ten different RUCA codes (Table 1). Rural areas are classified as RUCA codes four through 10. For the purposes of this study inclusion was limited to RUCA codes of 7-10 to obtain a sample of adults from small and isolated rural areas with populations less than 2,500. It is especially important to understand the perceptions of SM and behaviors of these individuals who are of the most isolated rural areas. Individuals from isolated rural areas have unique experiences and perceptions that often go unexplored in clinical research.

Table 2

Rural-Urban Commuting Area Code Description

RUCA Code	Classification	Cluster
1	Metropolitan area core	Primary flow within an urbanized area
2	Metropolitan area high commuting	Primary flow 30% or more to an urbanized area
3	Metropolitan area low commuting	Primary flow 10% through 29% to an urbanized area
4	Large rural area core	Primary flow within an urban cluster of 10,000 through 49,999
5	Large rural high commuting	Primary flow 30% or more to large urban cluster

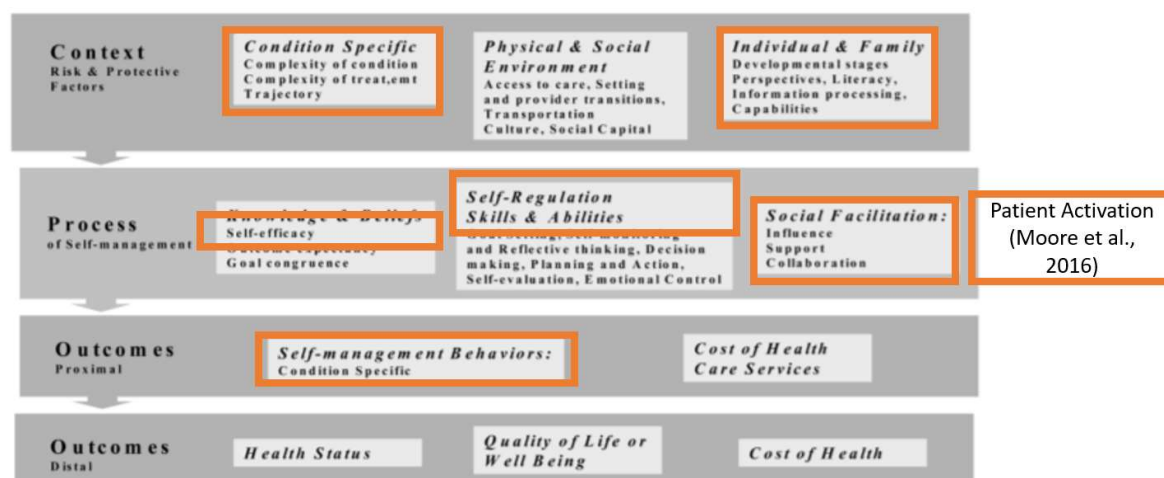
6	Large rural low commuting	Primary flow 10% through 29% to large urban cluster
7	Small rural town core	Primary flow within a small urban cluster of 2,500 through 9,999
8	Small rural town high commuting	Primary flow 30% or more to a small urban cluster
9	Small rural town low commuting	Primary flow 10% through 29% to a small urban cluster
10	Isolated small rural area	Primary flow to a tract outside of an Urbanized Area or Urban cluster

This study aims to determine the feasibility of recruitment, enrollment, and data collection in rural adults with MCC and to explore the perceptions and SM variables and behaviors of rural dwelling adults (RUCA 7-10) with MCC.

Theoretical Framework and Key Concepts

The theoretical framework and concepts guiding this dissertation are described below.

Theoretical Framework. The Individual and Family Self-Management Theory developed by Ryan (2009) was used as the guiding framework for the development of this cross-sectional descriptive study. The revised framework (Figure 1) incorporated parts of the original theory with the addition of patient activation as a process of self-management. This theoretical framework is made up of three parts that compose this SM theory including contextual factors, processes of SM, and outcomes (proximal and distal outcome). The context includes risk and protective factors. Those described in this study included the condition specific factors (MCC) and individual information processing. Processes of SM described include self-efficacy, self-regulation, social support, and patient activation. As described by Moore (2016) in addition to self-efficacy, self-regulation and social support, patient activation was included as a common data element for evaluating SM and thus was included in revised theoretical framework.

Figure 3*Revised Individual and Family Self-Management Theoretical Framework*

Rural. Rural is classified based on the Rural Urban Commuting Area codes established by the Health Resources and Service Administrations including: Office of Rural Health Policy, Department of Agriculture's Economic Research Service, and the Washington, Wyoming, Alaska, Montana, Idaho Rural Health Research Center. This classification system is based on population census of zip codes in the United States. For inclusion into this study participants had to be a resident of a RUCA classified zip code between 7-10, representing rural/isolated rural areas (Rural Health Research Center, 2021).

MCC. Multiple chronic conditions (MCC) or multimorbidity is the diagnosis of two or more chronic conditions. A chronic condition is defined by the CDC as a condition lasting longer than one year requiring lifelong management (National Center for Chronic Disease Prevention and Health Promotion, 2021). Furthermore, the definition of MCC has varied across the literature (Miller et al., 2020). This study classifies MCC as any combination of two or more diagnosed chronic conditions. Both mental health and physical conditions were included in this classification of MCC. No standard measure, such as the Charlson Comorbidity Index was used to classify MCC because of the limited scope of the conditions included in the measure.

SM. Self-Management is defined as the action a person take to promote healthy behaviors to manage and monitor their chronic condition/s (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Do, Young, Barnason, & Tran, 2015; Miller et al., 2015; Moore et al., 2016). Patient activation, self-efficacy and self-regulation have been identified as common data elements of SM (Moore et al., 2016). Social support was also evaluated in this dissertation as a process of SM, guided by the theoretical framework (Ryan & Sawin, 2009).

Self-Efficacy. The concept of self-efficacy was first identified by Bandura (1977) and is a measure of an individual's confidence in one's ability to participate in health behaviors in normal and stressful situations. Self-efficacy is a process of SM and was self-reported using Lorig (2001) self-efficacy for managing chronic disease 6-item scale.

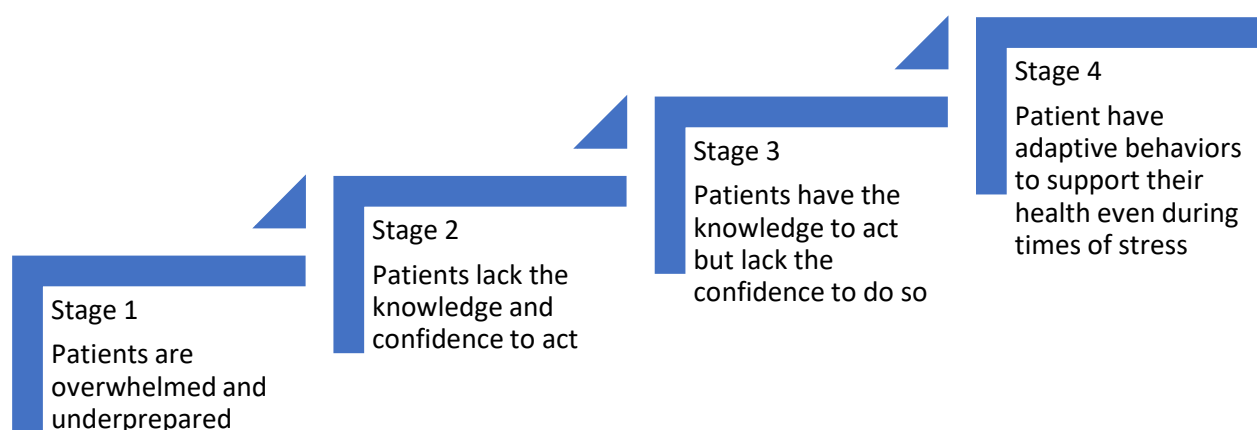
Self-Regulation. Self-regulation is the process that individuals participate in to achieve behavior change through self-evaluation (Fleury, 1998; Ryan & Sawin, 2009). Self-regulation encompasses multiple skills and abilities including goal setting, self-monitoring and reflective thinking, decision making, action planning, self-evaluation, and response management (Ryan & Sawin, 2009). This study used the Index of Self-regulation, a self-reported 9 item questionnaire, to measure self-regulation as recommended by (Moore et al., 2016) as a measure for the common data element.

Social Support. Social support is defined as consisting of emotional, instrumental, or informational support to an individual or family with a goal of promoting engagement in health behaviors (Ryan & Sawin, 2009). This study used three of the social/relationship support measures developed by Patient-Reported Outcome Measurement Information System (PROMIS). These included: PROMIS Short form Informational Support, PROMIS Short form Instrumental Support, and PROMIS Short Form Companionship. Each measure consisted of four items.

Patient Activation. Patient activation was first conceptually defined by Hibbard (2004). Activated patients are those that play a significant role in managing their care, collaboration with providers to maintain their health. Individuals with high patient activation know how to manage

their conditions, maintain function, and prevent health declines. This is achieved through the application of skills and behaviors needed to manage their condition, work with providers, maintenance of functioning, and use appropriate high-quality healthcare. Patient activation is operationally defined as a patients self-reported knowledge, skill, and confidence to self-manage one's chronic conditions (Hibbard, Mahoney, Stockard, & Tusler, 2005). The Patient Activation Measure (PAM) assists in the quantification of a patient into one of four stages of activation (Figure 2). In this study the PAM-13 self-reported measure was used to determine participant level of activation.

Figure 2 Patient Activation Stages



Purpose and Specific Aims

The purpose of this cross-sectional descriptive study is to describe SM behaviors and explore perceptions of SM needs among rural dwelling adults diagnosed with MCC.

This study aims to:

- 1) Determine the feasibility of recruitment, enrollment, and data collection in rural adults with MCC
- 2) Explore perceptions of SM needs of rural dwelling adults with MCC
- 3) Describe the SM variables of self-efficacy, self-regulation, social support, and patient activation and the SM behaviors of rural adults with MCC.

Overview of Manuscripts

The dissertation presented was conducted in the manuscript format with Chapters I and V outlining the introduction and discussion sections, and Chapters II, III, and IV prepared in manuscript format for submission to peer-reviewed journals. **Manuscript #1 (Chapter II)** is an integrative literature review describing SM intervention studies that have been implemented in individuals with MCC and has been published in the Western Journal of Nursing Research.

Manuscript #2 (Chapter III) presents the feasibility results (aim 1) discussing recruitment, enrollment, and data collection of adults from rural communities diagnosed with MCC.

Manuscript #3 (Chapter IV) discusses the results of the cross-sectional descriptive study aims 2 and 3 and consists of survey results and focus group findings.

CHAPTER II: MANUSCRIPT #1

Intervention Components Targeting Self-Management in Individuals with Multiple Chronic

Conditions: An Integrative Review

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(Published in Western Journal of Nursing Research. Copyrights belong to Sage Publishing)

The final publication is available at DOI: 10.1177/0193945920902146

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Abstract

Multiple chronic conditions (MCC) are becoming increasingly common and self-management (SM) interventions to address MCC are emerging. Prior reviews have broadly examined SM interventions in MCC; however, interventional components were not thoroughly described.

Components of SM interventions that have been delivered to individuals with MCC were identified. A review of CINAHL, Cochrane, PubMed, Psych Info, Scopus and Embase was completed. This search yielded 13,994 potential studies; 31 studies met inclusion for analysis.

The literature is multidisciplinary and describes a wide variety of interventional strategies implementing various combinations of components. A descriptive analysis of the studies' components, application of the components, delivery methods, and primary outcomes demonstrated clear variations between programs. The most common components noted in the 31 studies were education, action planning/goal setting, self-monitoring, and social/peer support.

The variation in SM programs limits conclusive evidence for which components are recommended to improve self-management in individuals with MCC.

Keywords Identified:

MeSH: Self-Management, Integrative Review, Comorbidity, Multimorbidity, Chronic Disease

Components of Interventions Targeting Self-Management in Individuals with Multiple Chronic Conditions: An Integrative Review

Chronic disease, defined as a condition lasting longer than three months and requiring lifelong management, impacts the lives of over 115 million Americans (National Center for Chronic Disease Prevention and Health Promotion, 2016). As the prevalence of chronic disease is increasing, the number of individuals with multiple chronic conditions (MCC) grows. One in four adults has MCC resulting in higher health care costs, and needs for higher level and quality of care (Panagioti et al., 2018). Successful self-management (SM) of MCC is necessary to achieve positive health outcomes in this vulnerable population and to prevent further burden on current and future individuals facing these challenges.

Identifying Components, Delivery, and Outcomes of SM Interventions in MCC

Engagement in SM has been shown to significantly improve health status, reduce health care use, and increase quality of life (Miller, Lasiter, Bartlett Ellis, & Buelow, 2015; Richard & Shea, 2011). SM has multiple definitions in the research literature. For the purposes of this review, SM is defined as the actions taken by an individual to promote healthy behaviors and to manage and monitor their MCC (Moore et al., 2016).

Many SM interventions have been trialed to promote healthy lifestyles and increase SM behaviors. Existing SM interventions have been successful at improving outcomes; however, these interventions commonly target a single chronic condition, leaving little evidence to support the SM of individuals with MCC. In addition, the most effective delivery methods, and SM intervention components for individuals with MCC remains unclear. This integrative review will further the science of SM in community-dwelling adults with MCC by evaluating intervention components, delivery methods, and subsequent outcomes used to measure success of the intervention. Interventional components were defined as underlying mechanisms incorporated to affect, address, or improve SM (Ruppar, Cooper, Johnson, & Riegel, 2019). Findings from this

review will inform the development of future research questions to explore best practices in the SM of MCC.

Purpose

The purpose of this integrative review is to identify interventional components, delivery methods, and primary outcomes used to measure success of SM interventions delivered to adults with MCC. Findings will be examined to determine which interventional components may be most useful to drive SM outcomes and to direct the development of future SM interventions in individuals with MCC. The following questions were addressed in the review: (1) What interventional components have been used to promote SM in adults with MCC?; (2) Are SM interventions targeting MCC, a single disease in the presence of MCC, or general health behaviors?; (3) What methods have been used to deliver SM interventions in adults with MCC?; and (4) What primary outcomes have been used to measure success of SM interventions?

Methods

Whittemore & Knafl's (2005) five-step integrative review method was used to guide this integrative review and address the research questions. With the assistance of a medical librarian, terminology was identified to comprehensively identify relevant articles published to date.

Inclusion/Exclusion Criteria

Peer-reviewed, published research studies were abstracted for eligibility based on the following inclusion/exclusion criteria. Inclusion criteria were: (1) community-dwelling adults aged 18 years of age and over with no upper limit; (2) interventional or quasi-experimental designs; (3) impact or reflect SM research; and (4) conducted in a population diagnosed with MCC. MCC was defined as having two or more chronic conditions. The conditions participants were diagnosed with could either be specified for inclusion (e.g. heart failure, diabetes, hypertension, depression) or unspecified. Records were excluded if: (1) pediatric, or caregiver population, (2) individuals had cognitive impairment; or (3) printed in a language other than English. Studies of individuals with cognitive impairment were excluded from this analysis

because management of their chronic conditions requires assistance from other parties and the MCC is not independently or self-managed by the individual.

Search for Eligible Studies

A thorough search was conducted of Cochrane, Embase, Pubmed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Psych info and Scopus databases. Search terms included: self-care, self care, self-management, self management, comorbid*, multimorbid,* multiple morbidity, multiple chronic condition* and intervent*. Asterisks were used at the guidance of the medical librarian to allow the database to pull all forms of the terms that may be used in published works. Medical Subject Headings (MESH) and CINAHL headings including self-care and comorbidity were used in the PubMed, CINAHL and PsycINFO databases. The search was limited to manuscripts published in English. The search was not limited by time parameters. Articles were considered starting from the databases' inception until the day of the search. The search was conducted in July, 2018 and updated in May, 2019.

Data Management and Synthesis

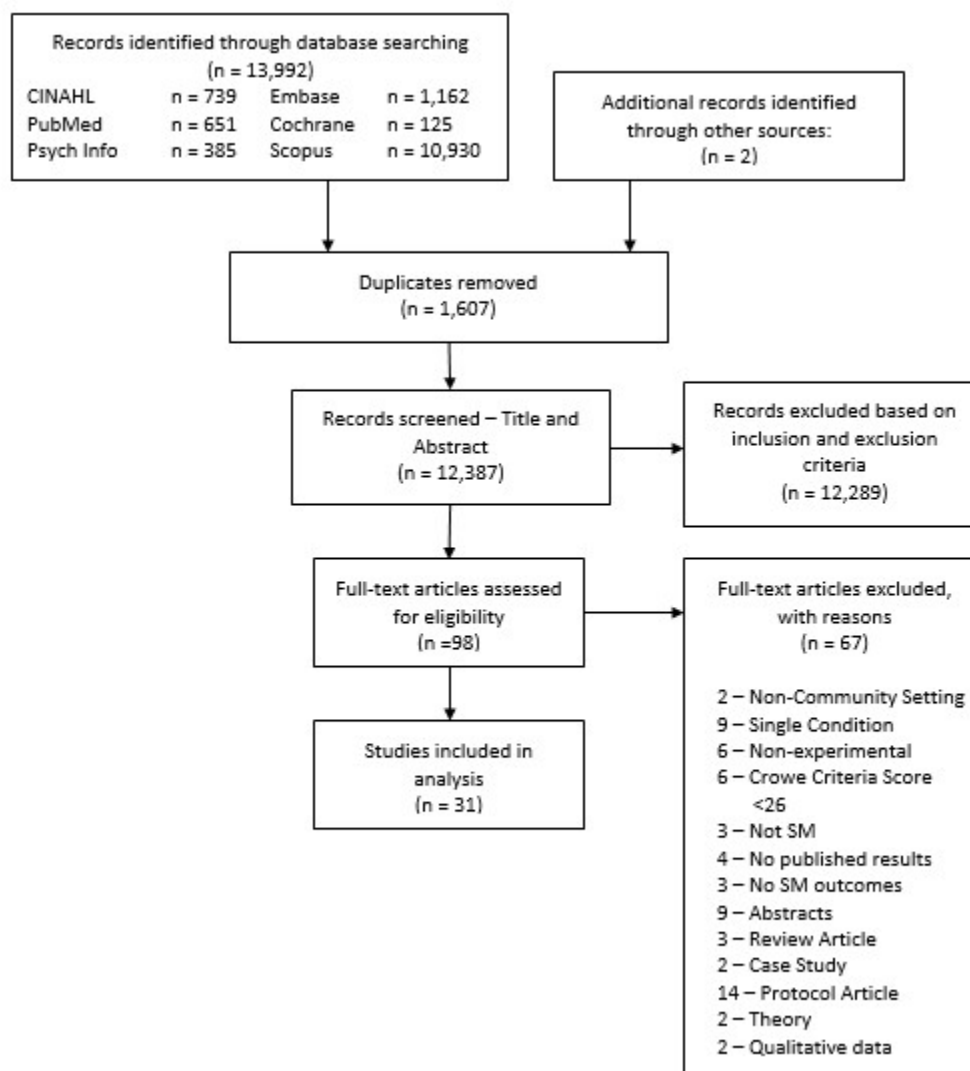
All inclusion and exclusion criteria were identified prior to the search to prevent potential bias or error in the screening of the articles. The collection of articles was screened in a step wise manner by the primary author and two additional authors using PRISMA guidelines illustrated in Figure 1. Of the 13,994 records collected, 12,387 articles were screened for inclusion.

Methodologies were limited to quantitative and mixed methods literature as this review focused on studies that delivered interventions and measured quantitative outcomes. Articles were further reviewed by three authors for quality using a critical appraisal tool developed by Crowe and Sheppard (2011). The Crowe criteria were used to appraise quality of articles prior to inclusion for analysis. The following criterion were scored for each article: purpose statement, sample size, design of the study, data collection methods and analysis, integration and interpretation of results/findings (Crowe & Sheppard, 2011). Three authors independently reviewed each article for inclusion using the Crowe criterion score of 26 or more for inclusion, and then met to discuss

any concerns or discrepancies in quality ratings for the articles. Articles scoring less than a 26 were discussed by the three authors and consensus was obtained prior to removal from the analysis in this integrative review.

Figure 1

Flow Diagram



Results

An in-depth review of all records resulted in the selection of 31 studies that met criteria for inclusion (Figure 1). The studies were reviewed to determine interventional components, targets for the outcomes (MCC, single disease or general health), delivery methods, and primary study

outcomes. Components of SM interventions varied widely across studies. Components were defined as underlying mechanisms incorporated into the intervention to affect change in behaviors (Ruppar et al., 2019).

Primary Study Descriptive Information

Sample sizes ranged from 30 to 1,306 and included diverse study populations including but not limited to Latino, African American and veterans. Countries of origin varied, with the majority originating in the United States (18). Other countries included Australia (3), Canada (4), Germany (1), Ireland (1), Netherlands (1), Sweden (1) and the United Kingdom (2). A full description of all countries represented can be found in Table 1. Findings reported from randomized controlled trials consisted of 26 of the 31 articles (84.1%). Of the remaining five studies, four pilot feasibility studies and one “trial within cohort” study were included. Twenty-six (84.1%) studies recruited subjects from urban/metropolitan areas. Only one study included a rural site as part of their recruitment (5 urban, 1 rural); however, “rural” was undefined. The remaining three articles failed to report recruitment locations.

Chronic Conditions

The studies in this review examined a wide variety of MCC including physical and psychological conditions. Diabetes and depression were the most commonly reported conditions, respectively. Psychological conditions were described in seven studies as serious mental illnesses: schizophrenia, bipolar disorder, and major depression (Table 1).

The SM interventions targeted a varying number of chronic conditions or general wellness in the presence of MCC. Many (n=13, 41.9%) targeted the SM behaviors of one chronic condition in a sample of subjects with MCC. For example, Redeker et al. (2015) examined the impact of a SM intervention on insomnia outcomes in individuals with heart failure. Insomnia was described as the primary condition of focus, and heart failure as a second condition (Redeker et al., 2015). Some studies (n=7, 22.5%) explored SM interventions that were designed to impact behavior change in two specific conditions. For example, Lynch (2014) examined the impact of a SM

Table 1. Table of Evidence.

Citation Location	Design Sample Characteristics	Conditions	Duration (follow up)	Components	Delivery Method	Delivery Format	Interventionist	Primary Outcome
Battersby et al. (2013) Adelaide, Australia Urban	RCT N = 77 Age: 57–63 years	Alcohol addiction Chronic condition (unspecified)	9 Mo (18 Mo)	Education Social support Action planning/Goal setting Behavioral coaching Motivation Self-monitoring	Telephone In-person	Individual Individual/Group	Registered nurse	Condition-specific measure ($p = .039$)
Buhrman et al. (2015) Stockholm, Sweden Urban	RCT N = 52 Age: 22–78 years	Pain Depression	8 Wks. (12 Mo)	Education Action planning/Goal setting Behavioral coaching Motivation Problem solving	Web-based	Individual	Psychology graduate students	Depression ($p = .004$) Pain ($p = .031$) Anxiety ($p = .032$)
Coventry et al. (2015) Manchester, United Kingdom Urban	RCT N = 350 Age: 46–70	Depression Heart disease or Diabetes	3 Mo (4–6 Mo)	Education Action planning/Goal setting Mental health counseling	In-person Telephone	Individual	Case manager	Depression ($p = .01$)
Daniuth et al. (2016) Minnesota, USA Urban	RCT N = 500 Age: 43–67	Musculoskeletal pain Depression	10 Mo (12 Mo)	Education Action planning/Goal setting Behavioral coaching Self-monitoring	In-person	Individual	Nurse case manager	Depression ($p = .49$) Pain ($p < .05$)
Druss et al. (2018) Georgia, USA Urban	RCT N = 400 Age: 40–58	General medical illness Serious mental illness	12 Wks. (6 Mo)	Education Action planning/Goal setting Self-monitoring Peer support	In-person	Individual Group	Mental health peer specialists	QOL – Physical ($p = .046$) – Mental ($p = .039$)
Druss et al. (2010) Georgia, USA Urban	Pre/Post N = 80 Age: 37–58	General medical illness Serious mental illness	12 Wks. (6 Mo)	Education Action planning/Goal setting Self-monitoring Peer support	In-person	Group	Mental health peer specialists	Patient activation ($p = .03$) Disease self-management – Primary care visits ($p = .046$) – Physical activity ($p = .046$) – Medication adherence ($p = .22$) QOL – Physical ($p = .41$) – Mental ($p = .96$)
Dunbar et al. (2014) Georgia, USA Urban	Pilot N = 65 Age: 49–69	Diabetes Heart failure	4 Wks. (6 Mo)	Education Self-monitoring Mental health counseling	In-person Telephone	Individual	Registered nurse	Knowledge ($p = .05$) Self-efficacy ($p < .001$) Disease self-management ($p = .05$) QOL ($p = .05$)

(continued)

Table 1. (continued)

Citation Location	Design Sample Characteristics	Conditions	Duration (follow up)	Components	Delivery Method	Delivery Format	Interventionist	Primary Outcome
Dunbar et al. (2015) Georgia, USA Urban	RCT N = 134 Age: 29–81	Diabetes Heart failure	4 Mo (6 Mo)	Education Social support Action planning/Goal setting Motivation Self-monitoring Mental health counseling	In-person Telephone	Individual	RN	QOL ($p < .001$) Disease self-management – Physical activity ($p = .002$)
Edkin et al. (2007) Colorado, USA Urban	RCT N = 200 Age: 36–53	MCC (unspecified)	6 Mo	Education Social support Action planning/Goal setting Cultural tailoring	In-person Telephone	Individual	Bilingual health educator	Depression ($p = .348$) SM behaviors – Physical activity ($p = .89$) – Dietary behavior ($p = .715$)
Ebert et al. (2017) Erlangen, Germany Urban	RCT N = 260 Age: 39–61	Depression Type 1 or 2 Diabetes	6 Wks. (6 Mo)	Education Action planning/Goal setting Problem solving	Web-based	Individual	Psychologist	Depression severity ($p < .001$)
El et al. (2017) California, USA Urban	RCT N = 348 Age: 48–64	Depression Diabetes Heart failure Coronary heart disease	6 Wks. (6 & 12 Mo)	Education Action planning/Goal setting Empowerment Mental health counseling Engagement	In-person	Individual	ProMocora	Depression ($p = .11$)
Freedland, Carney, Rich, Steinmeyer, and Rubin (2015) Missouri, USA Urban	RCT N = 158 Age: 44–66	Depression Heart failure	6 Mo (12 Mo)	Education Action planning/Goal setting Mental health counseling	In-person Telephone	Individual	Masters/ Doctoral therapists	Depression ($p = .008$)
Garvey, Connolly, Boland, and Smith (2015) Ireland Urban	RCT N = 50 Age: 50–83	MCC (unspecified)	6 wk	Education Action planning/Goal setting Peer support Engagement	In-person	Group	Occupational therapists	Social activity participation ($p < .001$)
Goldberg et al. (2013) Maryland, USA Urban	RCT N = 63 Age: 40–58	MCC (specified)	13 Wks.	Education Social support Action planning/Goal setting Self-monitoring Peer support Problem solving	In-person Telephone	Group Individual	Mental health peer leaders	QOL ($p < .05$)

(continued)

Table 1. (continued)

Citation	Location	Design Sample Characteristics	Conditions	Duration (follow up)	Components	Delivery Method	Delivery Format	Interventionist	Primary Outcome
Kroenke et al. (2009)	Indiana, USA	RCT N = 250 Age: 43–67	Depression Musculoskeletal pain	12 Mo	Education Social support Action planning/Goal setting Problem solving	In-person Telephone	Individual	Nurse case manager	Depression ($p < .001$) Pain ($p < .001$)
Ludman et al. (2013)	Washington, USA	RCT N = 214 Age: 45–67	Depression Diabetes or Heart disease	12 Mo	Education Action planning/Goal setting Motivation Self-monitoring Mental health counseling Problem solving	Telephone In-person	Individual	Nurse	Self-efficacy ($p = .056$) Depression ($p = .007$)
Lynch (2014)	Illinois, USA	RCT N = 61 Age = 44–64	Type 2 Diabetes Hypertension	6 Mo	Education Social support Action planning/Goal setting Behavioral coaching Motivation Self-monitoring Peer support Cultural tailoring	In-person Telephone	Group Individual	Dietician peer support	Condition-specific measures – Weight ($p = .81$) – Hgb A _{1c} ($p = .03$)
Markle-Reid et al. (2018)	Ontario, Canada	RCT N = 159 Age = 65+ Pre/Post	Type 2 Diabetes MCC (unspecified)	6 Mo	Education peer support Problem solving Education Action planning/Goal setting Behavioral coaching Self-monitoring	In-person	Individual Group	Nurse Registered dietician	QOL – Physical ($p = .97$) – Mental ($p = .03$) Depression ($p < .0001$)
McCusker et al. (2012)	Montreal, Canada	RCT N = 98 Age = 61 (median)	Depression Chronic physical illness (specified)	6 Mo	Education Action planning/Goal setting Behavioral coaching Self-monitoring	Telephone	Individual	Lay coach	Depression ($p < .0001$)
McCusker et al. (2016)	Montreal, Canada	RCT N = 223 Age = 44–66	Depression Chronic disease (unspecified)	6 Mo	Education Action Planning/Goal setting Behavioral coaching Self-monitoring	Telephone	Individual	Lay coach	Depression ($p = .09$)

(continued)

Table 1. (continued)

Citation Location	Design Sample Characteristics	Conditions	Duration (follow up)	Components	Delivery Method	Delivery Format	Interventionist	Primary Outcome
Rural/Urban								
Muralidharan et al. (2019) Mid-Atlantic Region, USA Urban ^a Rural	RCT N = 242 Age = 51–64	Serious mental illness (specified) Chronic disease (specified)	3 Mo (6 Mo)	Education Action planning/Goal setting Motivation Peer support Problem solving	In-person Telephone	Group Individual	Peer and nonpeer leaders	QOL – General ($p = .142$) – Physical ($p = .342$) – Mental ($p = .563$)
Newby et al. (2017) Australia Unknown	RCT N = 106 Age = 20–71	Depression Diabetes	10 Wks. (3 Mo)	Education Self-monitoring Problem solving	Web-based	Individual	Clinician	Depression ($p < .001$) Condition-specific measures – Diabetes distress ($p = .01$) – Hgb A1C ($p = .75$) Patient activation ($p = .133$) QOL ($p = .099$)
Panagioti et al. (2018) United Kingdom Unknown	Trial within Cohort N = 1,306 Age = 65–98	MCC (specified)	6 Mo	Education Behavioral coaching Empowerment	Telephone	Individual	Health advisor	Program feasibility ^a
Pratt et al. (2013) New Hampshire, USA Urban	Pre/Post N = 70 Age = 42–62	Serious mental illness (specified) Chronic disease (specified)	6 Mo	Education Self-monitoring	Automated telehealth	Individual	Nurse	
Redeker et al. (2015) Connecticut, USA Urban	RCT N = 52 Age = 45–73	Insomnia Heart failure	2 Mo (6 Mo)	Education Behavioral coaching Self-monitoring	In-person Telephone	Group Individual	Psychologist	Disease self-management – Insomnia severity ($p = .03$) – Sleep efficiency ($p = .03$) – Daytime symptoms ($p = .04$) Perception of health ($p = .023$)
Reed et al. (2018) Australia Urban	RCT N = 254 Age = 60+	MCC (specified)	6 Mo	Education Action planning/Goal setting Behavioral coaching Problem solving	In-person Telephone	Individual	Clinician	
Sajatovic, Gurtler et al. (2017) Ohio, USA Urban	RCT N = 200 Age = 43–61	Serious mental illness (specified) Diabetes	3 Mo (6 Mo)	Education Action planning/Goal setting Behavioral coaching Peer Support	In-person Telephone	Group Individual	Registered nurse peer	Condition-specific measure ($p < .001$) Depression ($p = .016$) QOL ^b Disease self-management General functioning ($p = .003$)

(continued)

Table 1. (continued)

Citation Location Rural/Urban	Design Sample Characteristics	Conditions	Duration (follow up)	Components	Delivery Method	Delivery Format	Interventionist	Primary Outcome
Sajatovic, Ridgel et al. (2017) Ohio, USA Urban	RCT N = 30 Age = 53–83	Parkinson's Depression	6 Mo	Education Action planning/Goal setting Behavioral coaching Peer support	In-person Telephone	Group Individual	Registered nurse peer	Depression ($p < .001$)
Sajatovic et al. (2016) Ohio, USA Urban	RCT N = 44 Age = 37–59	Epilepsy Serious mental illness (specified)	3 Mo	Education Action planning/Goal setting Peer support	In-person	Group	Registered nurse peer	Depression ($p = .036$)
Van Bastelaar, Pouwer, Cuijpers, Riper, and Snoek (2011) Netherlands Urban	RCT N = 255 Age = 38–62	Depression Diabetes	3 Mo	Education Action planning/Goal setting Behavioral coaching	Web-based	Individual	Coaches	Depression ($p < .001$)
Zachariades (2013) Canada Urban	RCT N = 49 Age = 37–54	Insomnia Pain	7 Wks. (5 Mo)	Education Action planning/Goal setting Behavioral coaching Self-monitoring	Telephone	Individual	Research student	Disease self-management – Time to fall asleep ($p < .05$) – Insomnia severity index ($p < .01$)

Note:

Underlined text indicates the primary condition of focus.

MCC: Multiple chronic condition.

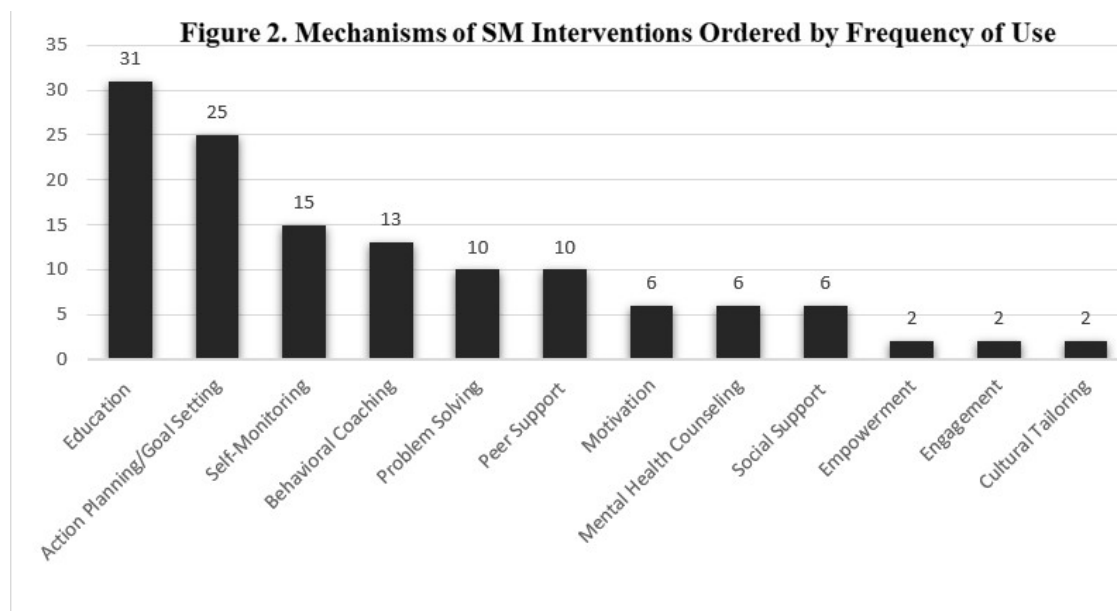
Mo: Months.

Wks.: Weeks.

RCT: Randomized Control Trial.

QOL: Quality of life.

Program efficacy was the primary outcome of measure and does not reflect the outcomes being measured for purposes of this integrative review.
No p-value was provided for QOL for this study. Therefore, none is listed.



It is notable that each study had different inclusion criteria regarding chronic conditions. All studies required potential subjects to be diagnosed with more than one chronic condition. Some (n=16) required that the participants have two specific conditions to participate (e.g. hypertension and insomnia, or diabetes and depression). Five studies required the presence of a mental health and a physical condition from a preidentified specified list of chronic conditions. Three studies required subjects to have a diagnosis of one specific condition in the presence of additional unspecified conditions, while two studies specified one chronic condition in the presence of additional conditions from a specific list. Three studies required the participant to have MCC from a list of specific conditions (e.g. hypertension, diabetes, arthritis). Finally, two studies had no requirements other than being diagnosed with 2 or more chronic conditions (Table 1).

Components

All thirty-one studies included education as an interventional component that was delivered through multiple mediums. Education was provided through written material, verbal instruction, presentations, workbooks, audio/visual material, and interactive activities. Examples of written

material were: informational packets/brochures regarding the MCCs (general health or disease specific information), nutritional information, recipes, and community resources.

Other components frequently reported include: action planning/goal setting (25/31), self-monitoring (15/31), behavioral coaching (13/31), peer support (10/31), problem solving (10/31), and mental health counseling (6/31) (Figure 2). Interventions using evaluation and feedback of participant progress or identification of barriers were classified under action planning/goal setting because of the similarities between the two methods. Behavioral coaching, referred to as assisting participants with developing and sustaining a behavioral change, was most frequently used in cognitive behavioral therapy programs (Buhrman et al., 2015; Freedland, Carney, Rich, Steinmeyer, & Rubin, 2015; Newby et al., 2017; Van Bastelaar, Pouwer, Cuijpers, Riper, & Snoek, 2011). In contrast, mental health counseling, which refers to interventionists or support personnel providing emotional support and direction to the participants, was most commonly reported in studies that identified a mental illness as one of the MCCs (Coventry et al., 2015; Dunbar et al., 2015; Ell et al., 2017). Self-monitoring included instruction to participants to track/log information such as dietary habits, blood glucose levels, symptoms, and sleeping habits (Druss et al., 2010; Goldberg et al., 2013; McCusker et al., 2012; McCusker et al., 2016; Redeker et al., 2015; Zachariades, 2013). Peer support was included in eight of the studies reviewed (Druss et al., 2018; Druss et al., 2010; Goldberg et al., 2013; Lynch, 2014; Muralidharan et al., 2019; Sajatovic, Gunzler, et al., 2017; Sajatovic, Ridgel, et al., 2017; Sajatovic et al., 2016). Peers were often used in combination with professional providers (e.g., dietitian or other health care provider) to deliver the intervention and other times the peer support occurred separately in addition to the professional provider. Five of the studies reviewed incorporated social support defined as the use of external individuals and resources such as family and friends, health care provider support, and community groups/members (Dunbar et al., 2014; Dunbar et al., 2015; Eakin et al., 2007; Kroenke et al., 2009; Lynch, 2014).

Intervention Delivery

Delivery method. Delivery methods varied across the SM interventions described. Three methods were used to deliver the designed study interventions: individual one-on-one (one interventionist to one participant) (19/31), group-based (3/31), and a combination of individual and group-based intervention methods (9/31). SM interventions were delivered in-person (7/31), over the telephone (4/31), using both in-person and telephone delivery (15/31), or using web-based technology platforms exclusively with no in-person or telephone contact (4/31). Technology was used as an adjunct to telephone communication in one study, using an automated telehealth device with four buttons for participant response (Pratt et al., 2013). Of the seven interventions delivered in person only, two were conducted in a one on one format where three were conducted in a group, and two were conducted in person using both a group and individual meeting format with the interventionist.

Duration of intervention. Fifteen of the 31 studies delivered the intervention in a time frame between 6 and 12 weeks. The remaining studies had durations of intervention delivery that varied from 4 months (1/31), 6 months (9/31), 9 months (1/31), 10 months (1/31), 12 months (2/31). Little consistency was noted in frequency, and timeframe for the SM intervention delivery across the studies reviewed. Of all 31 studies, 16 included a follow-up period at 3 months (1/16), 4-6 months (1/16), 5 months (1/16), 6 months (8/16), 12 months (4/16) and 18 months (1/16).

Intervention topics. Interventional content for chronic conditions consisted of either disease specific information (27/31), or general health (4/31). Of the 27 studies delivering disease specific information, 13 (41.9%) focused on one condition, eight (25.8%) on two conditions, three concentrated on a specified list of medical conditions, two on a specific list of four mental conditions, and one on a specific list of physical conditions. Specific information regarding the conditions in each study is included in Table 1.

Of the four studies focusing on general health, the content related to the following areas: defining self-management, incorporating physical activity, pain and fatigue management, nutrition, medication management, and effective communication. Garvey, Connolly, Boland, and

Smith (2015) used additional elements to facilitate the development of self-management behaviors by providing individual goals and providing peer support to the participants. Only two of the four studies allowed the participants to individualize their program by setting a goal for either physical activity or nutrition, general health topics individualized to participant goals (Eakin et al., 2007; Goldberg et al., 2013).

Outcomes

The primary outcomes measured across studies varied with some studies focused on disease-specific outcomes while others focused on general wellness, self-management behaviors or general outcome measures such as quality of life, self-efficacy, or knowledge. Only primary outcomes were analyzed in this review. Secondary outcomes were not summarized or reported. Twelve studies included disease-specific outcomes such as alcohol consumption (Battersby et al., 2013), glycosylated hemoglobin levels (Lynch, 2014; Newby et al., 2017; Sajatovic, Gunzler, et al., 2017), and body weight (Lynch, 2014). Disease-specific outcomes were consistently used in all studies identifying one or two priority conditions. Ten studies included general health outcomes, and 9 studies examined both disease-specific and general health outcomes. The most frequently explored outcomes across all studies were quality of life and depression. A list of all primary outcomes measured is shown in Table 2 and are categorized based on statistically significant or nonsignificant results.

Quality of life (QOL) was measured using a variety of validated quality of life instruments (ex. Health Related Quality of Life, Quality of Life Index, Europe Quality of Life, Heart Failure Quality of Life). Some authors evaluated general QOL across multiple conditions (SF-12) and one author used disease specific measures of QOL (diabetes and heart failure) in two studies (Dunbar et al., 2014; Dunbar et al., 2015). Three authors looked more specifically at mental and physical subscales of the SF-36 or SF-12 QOL scale (Druss et al., 2018; Druss et al., 2010; Markle-Reid et al., 2018; Muralidharan et al., 2019). Findings reveal that the mental QOL scale had an even split with two significant and two non-significant findings. Alternatively on the

physical QOL subscale only one study had statistically significant findings (Druss et al., 2018), compared to three studies with non-statistically significant results.

Depression was also measured using a variety of instruments including the Montgomery – Asberg Depression Rating Scale (MADRS), Patient Health Questionnaire (PHQ-9) and the Symptom Checklist-core depression scale (SCL-20). Of the 16 studies measuring depression as the primary outcome concept of interest, only 4 resulted in non-statistically significant outcomes (Damush et al., 2016; Eakin et al., 2007; Ell et al., 2017; McCusker et al., 2016).

Discussion

Despite the extensive amount of SM literature published, little has been published regarding the interventional components that have been used to improve SM in individuals with MCC. The purpose of this integrated review is to describe the components, delivery, and primary outcome measures of interventions to promote SM behaviors in individuals with MCC. The recent meta-analysis of intervention components for self-management in heart failure illustrates the importance of examining components of interventions to determine those with efficacy across studies (Ruppar et al., 2019). The state of the science for self-management interventions for individuals with MCC is in its infancy; however, it is important to continue to build the science through homogeneous studies to permit future meta-analysis.

The findings of this review indicate poor MCC definitional consistency and heterogeneity of self-management intervention components as well as the true focus of the intervention (i.e. disease-specific versus generic). While all articles incorporated participants diagnosed with at least two chronic conditions each targeted different conditions for self-management. Seven study interventions addressed multiple morbidities more generally, by not limiting the chronic conditions in which people were diagnosed for inclusion (Druss et al., 2018; Druss et al., 2010; Eakin et al., 2007; Garvey et al., 2015; Markle-Reid et al., 2018; McCusker et al., 2016; Reed et al., 2018). This is critical as the previous literature has captured single conditions yet have failed to holistically address MCC that are experienced in a variety of combinations by the population.

Table 2. Primary Outcomes of Concepts Measured.

Concept Being Measured	Statistically Significant Outcome	Nonstatistically Significant Outcome	Measures Used
Anxiety	Buhrman (2015) ($p = .032$)		Beck Anxiety Inventory
Condition Specific Measures	Battersby (2013) ($p = .039$)	Lynch (2014) ($p = .81$)	Alcohol Use Disorders Identification Test Weight
	Lynch (2014) ($p = .03$)		Hemoglobin A1C
	Newby (2017) ($p = .01$)	Newby et al. (2017) ($p = .75$)	Problem Areas in Diabetes Scale (PAID)
	Sajatovic, Gunzler et al. (2017) ($p < .001$)	Sajatovic, Gunzler et al. (2017) ($p = .091$)	Hemoglobin A1C
			Clinical Global Impression
			Hemoglobin A1C
Depression	Buhrman (2015) ($p = .004$)		Montgomery-Asberg Depression Rating Scale (MARDS)
	Coventry (2015) ($p = .01$)		Symptom Core Checklist – Major Depression (SCL-D13)
		Damush et al. (2016) ($p = .49$)	Symptom Core Checklist – Core Depression (SCL-20)
		Eakin et al. (2007) ($p = .348$)	Cumulative Illness Rating Scale (CIRS-Spanish)
	Ebert (2017) – Severity ($p < .001$)		Center for Epidemiologic Studies – Depression Scale (CES-D)
		Ell et al. (2017) ($p = .11$)	SCL-20
	Freedland (2015) ($p = .008$)		Hamilton Depression Scale
	Kroenke (2009) ($p < .001$)		Hopkins Symptom Checklist Depression (HSCL-20)
			SCL-20
	Ludman (2013) ($p = .007$)		Patient Health Questionnaire (PHQ-9)
	McCusker (2012) ($p < .001$)		PHQ-9
		McCusker et al. (2016) ($p = .09$)	PHQ-9
	Newby (2017) ($p < .001$)		MADRS
	Sajatovic, Gunzler et al. (2017) ($p = .016$)		MADRS
	Sajatovic, Ridgel et al. (2017) ($p < .001$)		MADRS
	Sajatovic (2016) ($p = .036$)		MADRS
	van Bastelaar et al. (2011) ($p < .001$)		CES-D
Disease SM	Druss et al. (2010)	Druss et al. (2010) Medication adherence ($p = .22$)	Self-Report
	- PCP visit ($p = .046$)		
	- Physical activity ($p = .046$)		Behavioral Risk Factor Surveillance System (BRFSS)
	Dunbar et al. (2014)		Summary of Diabetes Self-Care Activities (SDSCA)
	- General questionnaire ($p = .05$)		6-minute walk test
	Dunbar et al. (2015)		
	- Physical activity ($p = .002$)		
		Eakin et al. (2007)	
		- Dietary behavior ($p = .715$)	CIRS-Spanish
		- Physical activity ($p = .89$)	
	Redeker et al. (2015)		Researcher Survey
	- Insomnia ($p = .03$)		Actigraph Data
	- Sleep efficiency ($p = .03$)		Researcher Survey
	- Daytime symptoms ($p = .04$)		Sheehan Disability Scale (SDS)
	Sajatovic, Gunzler (2017)	Sajatovic (2017)	Global Assessment of Functioning (GAF)
	- General functioning ($p = .035$)	- Disability Scale ($p = .086$)	
	Zachariades (2013)		
	- Time to sleep ($p < .01$)		Sleep Diary
	- Insomnia severity ($p < .01$)		Insomnia Severity Index
Knowledge	Dunbar et al. (2014) ($p = .05$)		Minnesota Living with Heart Failure Questionnaire (MLHFQ)
Pain	Buhrman et al. (2015) ($p = .031$)		Pain Disability Index
	Damush et al. (2016) ($p < .05$)		Brief Pain Inventory
	Kroenke et al. (2009) ($p < .001$)		Brief Pain Inventory
Patient Activation	Druss et al. (2010) ($p = .03$)		Patient Activation Measure (PAM-13)
		Panagioti et al. (2018) ($p = .133$)	PAM-13
Perceived Health Status	Dunbar et al. (2015) ($p = .04$)		EuroQol (EQ-5D)
	Reed et al. (2018) ($p = .023$)		Self-rated Health Stanford Scale

(continued)

Table 2. (continued)

Concept Being Measured	Statistically Significant Outcome	Nonstatistically Significant Outcome	Measures Used
QOL – General	Dunbar (2014) ($p = .05$)	Dunbar et al. (2015) ($p = \text{unknown}$)	MLHFQ
	Dunbar (2015) ($p < .001$)		MLHFQ
	Goldberg (2013) ($p < .05$)		Audit of Diabetes Dependent Quality of Life (ADDQOL – Diabetes)
			12-Item Short Form Survey (SF-12)
			Medical Outcomes Study SF-12
QOL – Mental	Druss et al. (2018) ($p = .039$) Markle-Reid et al. (2018) ($p = .03$)	Muralidharan et al. (2019) ($p = .142$)	World Health Organization QOL
		Panagioti et al. (2018) ($p = .99$)	36-Item Short Form Survey (SF-36)
		Sajatovic et al. (2017) ($p = \text{unknown}$)	Medical Outcomes Study
		Druss et al. (2010) ($p = .96$)	SF-36
		Muralidharan et al. (2019) ($p = .563$)	SF-12
QOL – Physical	Druss et al. (2018) ($p = .046$)	Druss et al. (2010) ($p = .41$)	SF-36
		Markle-Reid et al. (2018) ($p = .97$)	SF-12
		Muralidharan et al. (2019) ($p = .342$)	SF-12
Self-Efficacy	Dunbar et al. (2014) ($p < .001$)	Ludman et al. (2013) ($p = .056$)	Self-Care Heart Failure Index (SCHFI) & Perceived Diabetes Self-Management Scale (PDSMS)
Social Participation	Garvey et al. (2015) Activity participation ($p < .001$)		Patient Activation Measure (4 items) Frenchay Activities Index

Much of the research to date has looked at single chronic conditions (heart failure, diabetes, hypertension, arthritis, COPD, etc.). There is a critical need for studies to begin to evaluate the SM needs of individuals with MCC, but in a systematic manner so pooling of data can occur in future meta-analyses.

Many of the articles incorporated mental health and physical health diagnoses indicating that MCC is not isolated to one area of health. This illustrates recognition of the need to look at individuals holistically and not as a “mental” or “physical” condition but as a person living with MCCs. The interventions in this review that did address MCC were noted to focus on behaviors that transcend individual diseases such as diet, exercise, sleep, medication adherence, symptom management, stress management, and communication with providers. It remains a challenge of researchers to target necessary condition-specific components in the presence of MCC.

Additionally, the topics that were delivered ranged from basic condition specific information, to specific SM behavior change. This too illuminates the need for increased consistency across interventions to evaluate the efficacy of such educational topics delivered to individuals with

MCC. Curiously only one study measured patient knowledge as a primary outcome. This is a key finding, because education was used in all the interventions delivered it is expected that the knowledge of the participant would be measured to determine efficacy of the education delivery. However only one study measured knowledge as a primary outcome measure (Dunbar et al., 2014).

A variety of components were identified across the reviewed literature with the most frequently used component being education to improve patient understanding of chronic disease and self-management. This was also the most frequently reported component in the meta-analysis of SM interventions in heart failure (Ruppar et al., 2019). Other components included social support, goal setting and action planning, behavioral coaching, mental health counseling, motivational interviewing, and activation (Table 1, Figure 2). The variety of combinations of components used and populations studied makes it difficult to draw conclusions on what components impact SM behavior change in individuals with MCC. Educational instruction was shown to be most effective when combined with other components such as social support.

Delivery methods employed across the studies varied widely (e.g. individual versus group, use of technology versus telephone or in person). Strong conclusions regarding which methods are more or less impactful are not apparent given the wide variability across studies. It is interesting to note that in past literature of SM in individuals with single conditions a combination of these delivery methods has been popular for affecting SM behaviors. In the recent years however, more literature is being published evaluating the use of technologies for delivery of such interventions that were once delivered in person. This method of delivery allows for improved access and feasibility in a technology driven world (Ebert et al., 2017). While findings from this review revealed only one study using technology as a mode of delivery it shows the gap in knowledge that remains to be addressed and a direction for future research. Technology such as text messaging, smartphone and web-based applications has been shown to impact SM of single diseases (Conway, Webster, Smith, & Wake, 2017; El-Gayar, Timsina, Nawar, & Eid,

2013). At this time there is not sufficient literature to draw conclusions as to whether these delivery methods would be successful in individuals with MCC (Grok et al., 2017).

The most common timeframe for delivery or length of the intervention was 12 weeks or 3 months. This finding of 3 months for delivery of the intervention may relate to the influence of the prominent Chronic Disease Self-Management Program (CDSMP) that has been referenced significantly throughout the self-management literature. While the CDSMP was not specifically identified in this review it has been referenced highly across other self-management literature. The CDSMP program consists of 6 in-person group meetings conducted every other week for a total of 12 weeks. Because the CDSMP is such an influential program that has been used consistently in the literature for improving self-management in individuals with one condition it is not surprising to see similarities with the development of programs targeting MCC. Furthermore, when implementing a program, it is critical to evaluate the length of time that it takes for the program to be effective. According to Gardner, Lally, and Wardle (2012) it is critical to have realistic expectations when working towards habit formation and that it can take around 10 weeks to develop daily habits.

Primary outcomes measured across the studies included anxiety, knowledge, pain, patient activation, perceived health, self-efficacy, depression, and social participation. Curiously, self-efficacy was only measured in two studies. This concept was measured using separate instruments including the patient activation measure (Ludman et al., 2013) and two disease specific self-efficacy scales: Self-Care Heart Failure Index and Perceived Diabetes Self-Management Scale (Dunbar et al., 2014). Depression was the most common outcome measured across the studies and was measured as both a disease specific outcome and a general outcome. There was a great deal of variability in the instruments used to measure depression with the most frequent being the PHQ-9 and the MADRS. Furthermore, only one study specifically identified the use of Spanish instruments for measurement of depression (Eakin et al., 2007).

The variability in primary outcomes and the concepts that were measured is not surprising given the wide variability in chronic conditions that were included in the reviewed MCC studies. This variability makes it difficult to draw conclusions as to which outcomes responded to the SM intervention and which should be recommended to evaluate efficacy of these interventions. In order to evaluate and compare effectiveness of interventions for SM in MCC it would be helpful to identify a common metric that would apply across the studies of SM in MCC.

Limitations must be acknowledged. To reduce screening bias, a stepwise method of screening the literature (Figure 1) was used. This review does not incorporate qualitative literature because of the broad nature of interpretation and a more focused view on patient interpretations of the intervention versus measurable outcomes regarding specific self-management behaviors targeted in the intervention. A meta-synthesis of published qualitative studies may be necessary to further inform the science of SM in MCC. Lastly, this review synthesized literature reporting only self-management interventions. Other interventions that did not incorporate self-management of MCC may have included additional components that were not discussed.

This review identified gaps in existing literature that suggest how sustainability of self-management can be achieved and what combination of interventional components and delivery methods should be incorporated together for best practice. Furthermore, this review identified a paucity of evidence to suggest how to self-manage MCC simultaneously. Lastly, technology continues to emerge as a method of SM intervention delivery but has not been explored in MCC. Additional research is necessary to identify how delivery may impact SM behaviors and potential delivery methods.

In conclusion, most interventions targeting self-management were conducted in a population diagnosed with specifically two conditions. The impact of such interventions has led to the development of multiple delivery methods, combinations of components incorporated, and outcome measures used to determine significance of the intervention. The most effective method of intervention delivery is yet to be determined in adults diagnosed with MCC; however, research

is beginning to emerge illustrating the complexities of managing MCC. These findings can guide development and delivery of self-management interventions for individuals with MCC. Currently, the incorporation of education to enhance knowledge of the patients is the most favored component throughout the literature. This supports the work frequently conducted in the clinical setting as well as provides multiple other components including social support, counseling, and coaching that could be added to enhance patient outcomes and SM behaviors.

The great variability noted across components, delivery methods, conditions, and outcomes limit the strength of the conclusions that can be drawn at this time. Further research and analysis are critical to evaluate interventions that address SM behaviors across multiple chronic conditions, rather than SM of distinct conditions. Although there remains a paucity of literature available on SM interventions for persons with MCC, progress has been made toward describing the components and primary outcomes measured when evaluating success of SM interventions for persons with MCC.

CHAPTER III: MANUSCRIPT #2

Recruitment of Rural Adults for Participation in a Research Study Through Collaboration with

Primary Care Clinics

(To be submitted to the Journal of Rural and Remote Health)

Introduction

The United States is made up of 97% geographically classified rural areas with 19.3% or about 60 million people of the country's population residing within this area (United States Census Bureau, 2016). Adults residing in rural and isolated rural areas face unique challenges such as limited access to health care resources and increased geographic barriers requiring lengthy traveling requirements to access health care, groceries, and social support systems (Bardach et al., 2011). In these isolated rural areas access to primary health care clinics are limited to larger towns with these clinics servicing large geographic areas. These challenges experienced by rural adults lead to increased health care costs, reduced quality of life, and higher rates of mortality (Bardach et al., 2011).

Chronic conditions, defined as a condition lasting longer than 3 months requiring lifelong management (National Center for Chronic Disease Prevention and Health Promotion, 2016), disproportionately affect rural adults (McGilton et al., 2018). Of those experiencing chronic conditions, 1 in 3 adults residing in rural communities are diagnosed with MCC compared to 1 in 4 of urban adults (McGilton et al., 2018). This health disparity is driven by a variety of factors including an aging population, health related behaviors such as high rates of smoking, reduced physical activity and higher rates of obesity, environmental and occupational factors, health care access barriers, reduced screening rates, and a lack of trust of outsiders (individuals outside of the rural community) (Rural Health Information Hub, 2018). Each of these factors negatively influences health behaviors leading to reduced quality of life, increased health care costs, and mortality rates (Park et al., 2019). It is essential that this population is actively represented in health care research by providing their perspectives regarding health care to positively affect quality of life and health care outcomes. To do so, the first step is to ensure the recruitment efforts targeting rural adults are effective. The purpose of this manuscript is to describe the feasibility of recruitment, enrollment and data collection of adults diagnosed with multiple chronic conditions from rural communities.

The specific aims of this manuscript were to determine the feasibility of:

1. Recruitment of adults with multiple chronic conditions through number of inquiries received, percentage of responses to contact from the PI, percentage eligible compared to total interested in participation.
2. Enrollment of participants, consenting methods (smart phone, computer, or tablet), modes of contact (telephone or web-conferencing), percentage of eligible to ineligible participants.
3. Data collection from both participants and medical records extractions by identifying trends in missing data, completeness of the data collected, and difficulties related to procedures for data collection.

Methods

Design

The parent study was a cross sectional descriptive study.

Ethics approval

This project was approved by the University of Nebraska Medical Center Institutional Review Board #690-20-EP.

Setting and population

This study targeted rural dwelling adults within a 75-mile radius of a University campus located in a rural setting of the midwestern United States. The sample was recruited from rural primary care clinics located in isolated rural areas designated as Rural Urban Commuting Area Codes 7-10.

Rural Urban Commuting Area Codes (RUCA codes) were developed by the Health resources service Administrations including the Office of Rural Health Policy, Department of Agriculture's Economic Research Service and the WWAMI Rural Health Research Center to classify areas in the United States based on current census. Zip codes of designated geographic

areas were categorized based on population census into a 1-10 system. Each RUCA classification indicated differing levels of population density. RUCA classifications of 1-3 indicate Metropolitan areas, RUCA 4-6 were classified as larger rural areas, and 7-10 classifications were indicative of small rural to isolate rural areas (Rural Health Research Center, 2021) (Table 1).

Sample and Recruitment.

A sample of 40 rural dwelling adults with multiple chronic conditions was deemed appropriate given that this study was both quantitative and qualitative design. Recruitment was targeted from RUCA codes 7 through 10 to obtain a sample representative of rural and isolated rural communities.

Establishing Clinical Partnerships

Targeted recruitment strategies included collaboration with local primary health care clinics that serve the population. A list of 15 potential clinical agencies with primary care clinics within a 75-mile radius of the University campus were identified as servicing the targeted RUCA population. The PI reached out through telephone calls and/or email to establish contact with potential collaborators at each health care system. At seven of the 15 health care systems the PI reached out to personal contacts within the system to assist in establishing collaborations. The other eight health care systems were contacted through “cold” calls and emails to office and administrative staff (providers, nurse leads, clinic managers). To begin establishing relations with each of the health care agencies the PI would begin by initiating contact through telephone call to the primary care clinic. Often the first individual spoke with would be the office assistant or front desk staff. The PI would begin by introducing herself as a rural nursing researcher attending school through the state medical center and then discuss the goal of establishing a collaborative relationship with the clinic and ask to speak to the administrator of the clinic. It was the goal that this initial contact would help to establish commonalities between the PI and the clinic as being both individuals serving rural adults in the targeted communities. Following the phone call if no contact was made with the administration the PI reached out through email to specific

administrators, guided by the discussion with the front desk staff, to share who the PI was as well as the goals and purpose of reaching out, the goal of collaborating with the clinic, and the purpose of the study.

Two of the 15 health care agencies contacted agreed to collaborate with the research team for recruitment of participants. One of two health care systems agreeing to collaborate consisted of 1 clinic on the health care agencies primary location and 4 satellite clinics located in multiple towns within a 25 mile radius of the primary health care agency location (one primary clinic site and four satellite clinics). This clinic serves approximately 10,000 patients and serving a region approximately 75 miles in diameter. A total of 6 primary care clinics (five associated with one agency and 1 clinic associated with the other) would be the locations to recruit potential participants into this study. To encourage positive relations with each health care system the PI traveled to both primary clinical agency sites. During this initial site visits the PI: 1) toured clinics, 2) met staff, nurses and providers and administration, 3) identified locations for subject recruitment, enrollment, consenting and data collection, 4) established mutual goals with the primary contact from each site, and 5) discussed strategies for recruitment of patients seen in the clinic. During the tour of the clinic the PI interacted with various staff including nurses, front desk workers, providers, and administrators to establish multiple relations throughout the clinic at various levels. During interactions with staff the PI would share her background in rural nursing and reasoning for wanting to study the experiences of rural adults. Educational goals were also shared with the staff that included why the PI wanted to obtain a Ph.D. in Nursing and how this study aides in achieving that goal.

COVID-19 Pandemic

Just after successful recruitment of clinical agency collaborators, the COVID-19 pandemic occurred. Due to the impact of the COVID-19 pandemic, procedures needed to be reevaluated and revised to protect the health and safety of patients, clinic staff, and research personnel. When the COVID pandemic hit this region, one of the two clinical agencies that had agreed collaborate

with the research team decided they would no longer have the time to be involved with the study. This resulted in the loss of once primary care clinic site. Because of the safety requirements that were implemented due to COVID-19 recruitment, enrollment, and data collection methods were revised to protect participants, health care staff, and research personnel.

Procedures

Prior to the COVID-19 pandemic recruitment was to occur in person at each clinic. The PI would travel to each clinic on different days and would have a designated area at each clinic that provided privacy for participant enrollment, consenting, and data collection. All data were to be collected in person on computer/tablets at each office. The process of consent would also be conducted on the computer/tablets in the clinic setting. This in-person data collection was planned to allow for face-to-face contact, show collaboration between the clinic and the research personnel, and develop a trusting relationship between patients and research staff by interacting one on one in person at the clinic. Because of COVID-19 protocol revisions the PI was unable to be on site for recruitment and relied on the clinic staff to recruit patients into the study.

To establish strong relations with the remaining health care agency the PI met with the Vice President of Clinic Services and the clinical agency's Board of Directors. The PI received approval to recruit participants under revised recruitment methods. Due to social distancing requirements initiated with COVID-19 pandemic, all recruitment was conducted by clinic staff, providers, and nurses located at each of the five clinic locations.

To support the development of a strong collaborative relationship with the clinic the PI met with the Vice President of Clinic Services at different stages of the study (prior to study implementation, during study recruitment, following conclusion of data collection and data analysis). The PI met with the Vice President of Clinic Services in-person at three different times as well as met over Zoom web conferencing, telephone call, and email. This allowed for both the PI and the Vice President of Clinic Services the opportunity to discuss goal, progression towards achieving goals, and challenges there were occurring. Meeting frequently allowed for early

detection of potential problems resulting in early mitigation of concerns expressed by both parties.

During each time the PI traveled to the clinical agency the PI interacted with staff and inquired about how they felt things were going in regard to COVID-19, clinic processes, and research procedures (primarily recruitment). Staff were very open to speaking with the PI and often would share positive experiences related to the research and recruitment. To thank clinic personnel for their hard work with recruitment the PI provided each staff, administrator, nurse, and provider with a small thank you gift with a personalized message.

Recruitment: Procedures following COVID-19 were established to be entirely remote for research personnel. Clinic staff, providers, and nurses were the individuals conducting recruitment at each of the clinic sites. The only method of recruitment used was brochure distribution by clinic providers, nurses, staff, and placement of brochures in the waiting and procedure rooms. One thousand brochures were delivered to the primary clinic site and were distributed by the VP of Clinic Services to all locations. Recruitment occurred from 5 primary care clinics (1 primary site, 4 remote locations) with remote sites located within a 25-mile radius of the primary site.

Adults interested in learning more about the study, were asked to fill out their contact information on the recruitment flier approved by the IRB and return it to clinic staff. This served as permission from the person to be contacted by a member of the research team. This flyer was then scanned and emailed to the PI through a secure email by the clinic staff within 24 hours. This rapid turnaround allowed the research team to contact the patient regarding participation in a timely manner. The PI maintained contact with the Vice President of Clinic Services throughout this entire process to ensure open communication and accuracy of recruitment procedures implemented throughout the course of recruitment. Communication occurred approximately every week by phone and email during the recruitment period. This communication was established to monitor current recruitment and enrollment of participants, share progression

towards achieving the targeted sample size, and discuss additional strategies that could be implemented to continue to boost recruitment of adults into the study.

Within 24 hours of receipt of the emailed recruitment fliers, the PI reached out by phone and email to potential participants. Participants were first contacted by phone, if no answer was received a voice message was left and an email was sent to establish contact. If no response was received within 7 days a second contact was initiated. After a total of three contacts with no response the person inquiring to participate was considered unable to be reached and no further contacts occurred.

When in contact with the participant, a brief overview of the study was given, and a time to conduct enrollment and data collection was established. During initial contact, participants were given the option to conduct enrollment by phone or Zoom web-conferencing at the scheduled time. They were also informed that to complete the enrollment process they would need access to a device with internet capabilities, either a smart phone, computer, or tablet. This was needed to conduct the informed consent process. A text message reminder or phone call was sent the day prior to the scheduled interview date, and on the day of the enrollment interview. If the participant opted to complete the enrollment screening over Zoom an email with a link to the web-conference was sent the day of the interview.

Enrollment: Enrollment and data collection were conducted entirely through distance communication either by phone or over Zoom web conferencing during one scheduled interview. If the participant was deemed eligible to participate, after informed consent was obtained, data collection occurred. The interview with potential participants occurred in three stages consisting of enrollment (screening for eligibility), consenting, and data collection. To determine eligibility, the participant was asked a series of screening questions. To be eligible, participants had to meet the following criteria: 1) age 19 years or older (age of adulthood in the geographic area); 2) diagnosis of two or more chronic conditions (verified through medical records obtained from each clinic following data collection); 3) reside in an area with a RUCA code between 7 and 10;

4) live independently and have the ability to perform activities of daily living and oversee personal care at home; and 5) able to read, write and speak English. Participants were excluded if they: 1) were cognitively impaired; 2) had a terminal illness with a life expectancy of less than one year; or 3) were admitted to an inpatient mental health facility within the past 1 year.

If eligible, the process of informed consent was conducted. Consent was obtained virtually over the telephone/Zoom conference. The consent was provided to the participants virtually using the Research Electronic Data Capture (REDCap) online data collection tool. A secure link was sent to participants through the Zoom web conferencing chat function, direct email, or text message dependent on participant preference. This link allowed the participants to see the informed consent document. To access the consent document an access code was required. This code was provided by the PI verbally over the phone/zoom conference. To ensure active viewing of the consent, the PI asked the participant to identify the third word in the first paragraph of the consent. Following verification of viewing of the consent, the PI reviewed the document with the participant paragraph by paragraph. Time was allotted for participants to ask questions.

After completing review of the consent, the participant was required to answer four questions by typing in responses and verbally responding to the PI to ensure understanding of the consent. These questions included the following: 1) do you fully understand the purpose of the study?; 2) do you fully understand the risk associated with participating in the study?; 3) do you fully understand the benefits of participating in the study?; and 4) have all of your questions been answered in their entirety?. The PI reviewed verbal and written responses to ensure a response of “yes” was obtained prior to continuing. Next, participants were asked to input their full first and last name, which member of the research team they were speaking with, the current date and time, and provide a “wet” signature. A wet signature was obtained by signing their name with their finger (if on a tablet or smartphone) or by drawing their signature using the computer mouse. Multiple opportunities were provided throughout the consent for the participant to

download a copy of the consent document to their device. To ensure the participant received a copy of the signed consent a paper copy was mailed to the participant.

Data Collection: The third stage of the phone call/zoom conference is when data collection of survey responses was obtained. This occurred immediately after the consent was obtained and during the same phone call/zoom conference as the enrollment procedures. All survey questions were asked verbally by the PI. Participants provided responses verbally which were marked by the PI on each digital survey on REDCap.

Data collection also occurred from the participants medical records. After each interview with the participants, an email with a secure link and code unique to each participant, participant name, and birthdate was sent to the Vice President of Clinic Services for extraction of data from the medical records. The Vice President of Clinic Services was on the IRB and completed all research training related to HIPPA privacy regulations. The link allowed for medical record information to be collected and entered in the REDCap system. Medical record data collected included most recent vital signs (blood pressure, temperature, pulse, respirations, height, and weight), BMI, ICD10 diagnoses, and medication records for the previous year.

Data Analysis

Descriptive statistics were obtained for all variables (means, standard deviations, frequency distributions and percentages).

Aim 1

Recruitment was measured across the entire recruitment period. The number of inquiries was analyzed by number of recruitment fliers received per week. Number of attempted contacts per participant was analyzed by percentage of participants of the total sample for each contact attempt. Eligible persons per total interested (recruitment fliers received) was reported as a percentage.

Aim 2

Enrollment of participants was described as number of participants enrolled per week. Consenting was analyzed by describing frequency of consenting methods, and modes of contact. Eligible participants compared to ineligible participants were reported as percentages.

Aim 3

Data collection was reported as frequency of missing data and completeness of data. Difficulties related to procedures for data collection were reported from PI reflexive notes.

Results

A sample of 40 adults were enrolled in this descriptive cross-sectional study. Participants were predominantly female (n=32), Caucasian (n=40), and non-Hispanic/Latino (n=38). Age of participants ranged from 37 – 90 years (mean 62.13, SD 14.97). A full description of participant demographics can be found in Table 2. Of those that participated, all were from isolated rural communities (RUCA 10) in the midwestern United States.

Aim 1

All participants were recruited over 16 weeks during the height of the COVID pandemic. A total of 49 adults expressed interest in participating in this study and provided consent to be contacted by research personnel. During the first seven weeks 40 adult provided information to be contacted to participate (Table 3). When contacted by the research team, 40 individuals were able to be reached to schedule enrollment interviews. Adults inquiring to participate were contacted a maximum of three times to establish enrollment interviews. After 3 unsuccessful contact attempts by phone and email participants were removed from the contact list and classified as unreachable. Out of the 49 adults inquiring to participate, 79.6% (n=39) were reached after one contact from the PI, two contacts were needed to reach 12.2% (n=6) adults, and 8.1% (n=4) adults needed to be contacted three times. Only 3 potential participants were unable to be reached after three separate contacts. Of those contacted 40 scheduled enrollment interviews, and six declined to proceed. Reasons included no longer being interested (n=4), and the time commitment was too high to participate (n=2). A total of 40 individuals were screened for inclusion, and 100% (40/40) were

deemed eligible to participate and were consented. Compared to the number of individuals agreeing to be contacted for participation 81.6% agreed to participate and were deemed eligible of the original 49 adults.

Aim 2

A total sample of 40 adults were enrolled and consented over 18 weeks (two weeks longer than recruitment as some interviews were scheduled after recruitment was completed) (Table 3). Participants were consented virtually by phone or Zoom web-conferencing. Twenty-seven (67.5%) opted to complete the consenting process over the telephone, and 13 (32.5%) used Zoom web-conferencing to communicate with the PI. For the consent to be viewed by the participant, a device with internet capabilities was needed (computer, smartphone, or tablet). Participants could choose to complete the online consent using any of these three modes: computer (n=19, 47.5%), smartphone (n=16, 40%), tablet (n=5, 12.5%). One participant did not have access to the technology to complete the consent but was able to use the local public library computer in a private area to complete the consent.

Aim 3

All data collection occurred on the REDCap data base. Two types of data collection occurred, survey questionnaires and data extracted from the patient's medical records. All data collected during the participant interviews was complete with 100% of surveys completed. No data were missing from any of the surveys collected directly from the participants. Medical records extraction occurred for each patient and included data being manually inputted by the Vice President of Clinic Services. Of the data collected only 4 incidences of missing data occurred for one question. This accounts for a 90% completion rate for the one question out of 10 questions for 40 participants. The total overall completion rate when looking at the amount of missing data for all data collected across all time points (participant interview and medical records extraction) is 99.9% completion rate.

Challenges experienced with data collection, based upon reflexive notes of the PI, included difficulty of participants understanding survey responses, manual input of responses by the PI following verbal response by the participant, and data entered for the medical records extraction was not done by the PI. When participants expressed difficulty understanding what the response options were the PI would repeat the responses as many times as necessary for each question. To mitigate errors in responses from participants, the PI repeated participant responses after entering the response to allow for a second verification that the correct response was entered. All data entered from the medical records were done independently from the PI. While all data entry points were designated as “required” and would not allow the respondent to continue without entering a response, the data that required a document to be uploaded were missing due to the data entry personnel uploading the same document for two different responses. When contacted by the PI to obtain the correct document, it was stated that the information was missing from the medical records and was unable to be uploaded into the REDCap survey.

Discussion

Recruiting individuals from rural/isolated communities often presents challenges for researchers targeting this population (Prinz, Kaiser, Kaiser & Von Essen, 2009; Dibartolo & McCrone, 2003; Pribulick, Williams, & Fahs, 2013). COVID-19 made this more challenging because of social distancing and safety protocols to prevent the spread of the virus. Because of these challenges, alternative recruitment, enrollment, and data collection methods were implemented. The use of virtual interaction with rural adults proved successful in the enrollment and collection of data from rural adults. No challenges were experienced related to access to technology or internet. This was a positive finding because no adults were excluded because of lack of access to the technological resources. Access to technology and internet has been limited in rural populations Drake, Zhang, Chaiyachati & Polsky, 2019; Greenberg, Haney, Blake, Moser & Hesse, 2018). The results of this study are unique in that the only recruitment method used was

brochure distribution by primary care clinic staff, providers and nurses which yielded high rates of adults interested in the study and participation in a short time frame of 16 weeks.

Results of this study suggest that collaboration in the development of trusting relationships between researcher and clinic partners are critical in the recruitment of rural participants into the study. It was the active recruitment by nurses, providers, and staff at the clinic that made recruitment possible. Evidence from this study suggest that building strong relationships with not only one individual, but with the clinic personnel can boost recruitment of rural adults into clinical research studies. The researchers were limited in their access to potential participants due to COVID – 19 pandemic restrictions. In person contact with patients was not possible so the research team was entirely reliant on support from clinic personnel to discuss participation in this research study with potential participants. Engagement with clinical partners and establishing relationships with key personnel within the clinics requires the nurturing of trusting relationships between research and clinic personnel. It was imperative to identify a contact at the facility that had the knowledge and power to implement recruitment methods, but who also advocates for the research by supporting research protocols and sharing recruitment material. For this study the individual that was critical to the success of recruitment was the Vice President of Clinic Services. In this position, the Vice President of Clinic Services had the authority within the clinic structure to make decisions regarding research support at the clinic level and working with the clinic staff directly to implement recruitment methods. Without this strong clinical partner being a strong advocate for this research study, the recruitment would not have been successful. Throughout the entire process of recruitment, priorities for both research and clinics were taken into consideration. The PI made it a priority to communicate with the Vice President of Clinic Services which occurred at least weekly either through telephone or email communication.

While recruitment occurred rapidly in the first month it declined drastically when the weather entered below freezing temperatures that required the closure of clinics because of temperatures

near -30 degrees F. This illustrates the influence of factors beyond the control of the clinic staff. Recruitment never reentered rapid enrollments. Other factors that could be attributed to the slowed recruitment included the local sports teams that were competing at state tournaments. Interestingly though individuals that expressed interest in participating were often easy to contact and were willing to participate to completion of the study as evidenced by 40 participants of the total of 49 interested adults completing the study. This shows dedication often seen in a rural community to assist when an opportunity to help others is presented (Eaves, Williamson, Sanderson, Elwell, Trotter & Baldwin, 2020). Anecdotally participants would express that the individual at the clinic who recruited them to participate shared that the PI was a person that could be trusted. This indicates the value that rural individuals place on trusting those they are interacting with (Greider, Krannich & Berry, 1991). In addition, clinic staff commented that patients would often inquire about the goals of the research study and expressed their interest in the success of this study with the PI during enrollment interviews.

While the process of enrollment, consenting, and data collection were conducted virtually, due to necessity during COVID, this resulted in a highly successful method for both the researcher and the participants. This allowed participants to contribute to the research without being burdened by travel requirements, exposure risks related to COVID – 19, and participation from the comfort of their own home. The virtual processes also resulted in increased efficiency for the researcher. None of the interested participants were excluded from the research or unable to participate because of the technological and internet access requirements. This was an interesting finding as research shows that access to stable internet can be limited in rural and isolated rural areas (Perrin, 2019). This could be attributed to an increased knowledge of technology and internet services provided to rural communities because of the COVID-19 pandemic. Only one participant did not have access to the required technologies in the home environment and needed to use community resources at the library to participate. This shows that

even though individuals may not have access to resources at home, community resources are still available to allow participants to participate in clinical research.

Limitations

This work is limited in that all participants were recruited from one health care system located in one isolated rural area of the Midwestern United States. Within this one health care system, convenience sampling was used. Both setting and sample may not be representative of the general rural population across the isolated rural United States. Furthermore, the participants were only recruited from on health care agencies primary care clinics. As such this sample may not be representative of those individuals that do not seek out primary care, those who do not use the health care system, or migrant workers who do not trust or have access to health care in the area.

Conclusion

Recruiting participants from rural and isolated rural communities is critical to research to adequately represent this disparate population. Rural adults have been identified as a disparate population that federal funders have placed a priority on for increasing representation in clinical research. Limitations such as access to health care, familiarity with research and geographic barriers are just a few reasons recruitment of rural participants is challenging and time consuming; however, were not a barrier to the current study. This study found that the development of strong relationships with rural clinic partners including providers, nurses, and staff cannot be underestimated. It was through a strong partnership with the rural primary care clinics that recruitment occurred rapidly and that no other recruitment methods needed to be employed. It can also be said that recruitment through trusted community partners could be a contributing factor in the high response rate of those who inquired to participant in addition to the 100% completion rate of those that participated. Further research is needed to explore additional methods of recruitment to obtain a more robust sample of participants that more accurately

represents the demographic distribution of the area. Future work should focus on strategies to recruit minority populations, migrant workers, and adult males to be more representative of similar rural communities in the US.

Table 1
Rural Urban Commuting Code Classifications

RUCA Code	Classification	Cluster
1	Metropolitan area core	Primary flow within an urbanized area
2	Metropolitan area high commuting	Primary flow 30% or more to an urbanized area
3	Metropolitan area low commuting	Primary flow 10% through 29% to an urbanized area
4	Large rural area core	Primary flow within an urban cluster of 10,000 through 49,999
5	Large rural high commuting	Primary flow 30% or more to large urban cluster
6	Large rural low commuting	Primary flow 10% through 29% to large urban cluster
7	Small rural town core	Primary flow within a small urban cluster of 2,500 through 9,999
8	Small rural town high commuting	Primary flow 30% or more to a small urban cluster
9	Small rural town low commuting	Primary flow 10% through 29% to a small urban cluster
10	Isolated small rural area	Primary flow to a track outside of an Urbanized Area or Urban cluster

Table 2
Sample Demographics

Individual Level Variables	N	Percent
Gender		
Male/Female	8/32	20%/80%
Race		
Caucasian	40	100%
Ethnicity		
Hispanic/Latino	2	5%
Non-Hispanic/Latino	38	95%
Marital Status		
Married	31	77.5%
Single	3	7.5%
Widowed	3	7.5%
Divorced	3	7.5%
Highest Level Education		
High School Graduate/GED	8	20%
Some College (non-Degree)	13	32.5%
Associate degree	11	27.5%
Bachelor's Degree	6	15%
Master's Degree	2	5%
Income Level Before Taxes		
Under \$20,000	6	15%
\$20,000-\$39,000	8	20%
\$40,000-\$59,000	7	17.5%
\$60,000-\$79,000	7	17.5%
\$80,000-\$99,000	6	15%
\$100,000 or more	6	15%
Employment		
Full Time	14	35%
Part Time	5	12.5%
Unemployed	3	7.5%
Retired	18	45%

Table 3
Weekly Recruitment and Enrollment

Week	Number of Adults Expressing Interest % = (n/49)	Adults Enrolled % = (n/40)
1	8.1% (4)	0% (0)
2	24.5% (12)	17.5% (7)
3	6.1% (3)	12.5% (5)
4	6.1% (3)	7.5% (3)
5	28.6% (14)	12.5% (5)
6	6.1% (3)	15% (6)
7	2% (1)	12.5% (5)
8	0% (0)	2.5% (1)
9	0% (0)	0% (0)
10	0% (0)	0% (0)
11	2% (1)	0% (0)
12	0% (0)	2.5% (1)
13	10.2% (5)	0% (0)
14	2% (1)	5% (2)
15	2% (1)	5% (2)
16	2% (1)	0% (0)
17	Recruitment	0% (0)
18	Closed	7.5% (3)

CHAPTER IV: MANUSCRIPT #3

Self-Management Behaviors and Perceptions of Isolated Rural Adults with Multiple Chronic
Conditions

(To be submitted to the Western Journal of Nursing Research)

Introduction

Chronic diseases are the leading cause of death and disability in the United States, and are rapidly rising (National Center for Chronic Disease Prevention and Health Promotion, 2016). Individuals diagnosed with multiple chronic conditions are following the same trends with 1 in four adults affected. Individuals diagnosed with MCC require daily management of the conditions to prevent exacerbations of illness. Major risk factors for the development of MCC include poor nutrition, lack of exercise, smoking, and excessive alcohol intake. Supporting the development of self-management skills can help adults be more active in their own health and promote healthy lifestyle behaviors. This is especially important for adults in rural communities because of limited access to health care resources and behaviors that put this disparate population at an increased risk for developing MCC (Bardach et al., 2011).

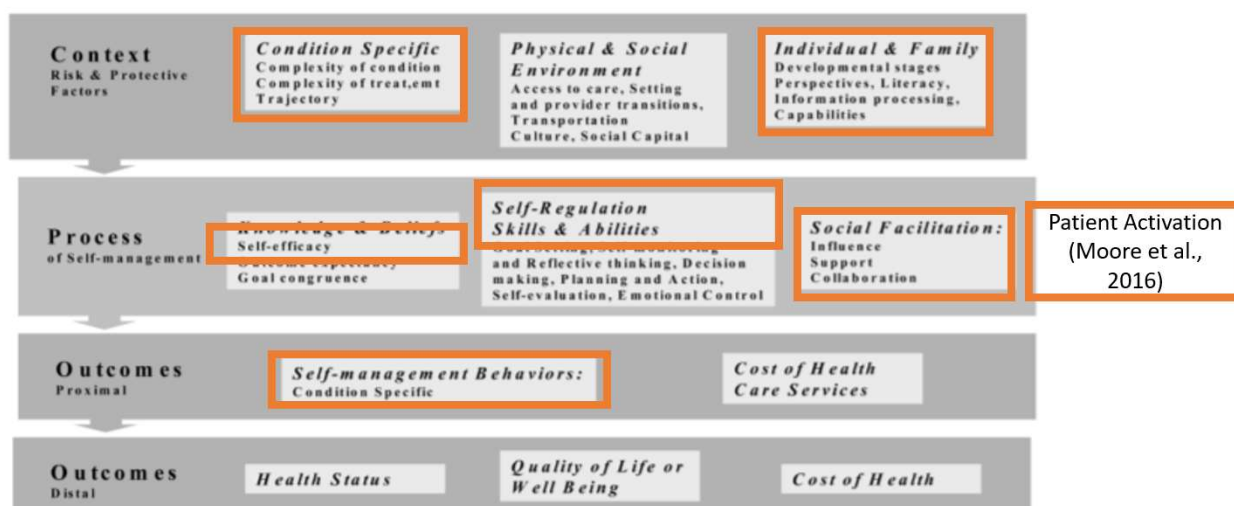
Research has shown that adults from rural communities are less active in their health care and struggle pursuing healthy behaviors like healthy eating, participating in physical activity, and adhering to provider recommended therapies required for managing chronic conditions (Bardach et al., 2011). While chronic disease SM programs have shown success at managing chronic conditions, a paucity of literature is available describing programs for rural adults with MCC. Describing the SM perceptions and behaviors of rural adults diagnosed with MCC is imperative to inform the development of an intervention that addresses SM needs of the given population.

The Individual and Family Self-management theory (Ryan & Sawin, 2009) was the guiding framework for this cross-sectional descriptive study. The revised framework (Figure 1) included pieces of the original framework and includes the addition of patient activation as a process of SM (Moore et al., 2016). The Individual and Family Self-management theory consists of three parts: contextual factors, processes of SM, and outcomes, both proximal and distal. Contextual factors refer to items that can impact the processes of SM. Those included in the revised framework include complexity of the condition, treatment, trajectory, and individual and family factors. Processes of SM are self-efficacy, self-regulation, social facilitation, and patient

activation. Proximal and distal outcomes are identified in the framework, but only proximal outcomes of SM behaviors (physical activity and sleep) were included in this study. The revised framework in Figure 1 depicts the revised Individual and Family Self-Management Theory used to guide this study. Boxes that are highlighted by a colored border are the specific variables measured in the current study.

Figure 1.

Revised Individual and Family Self-Management Framework



Purpose

The purpose of this study is to describe the SM behaviors and explore perceptions of SM needs among rural dwelling adults with multiple chronic conditions. This study aims to:

- Aim 1: Determine the feasibility of recruitment, enrollment, and data collection in rural adults with MCC
- Aim 2: Explore perceptions of SM needs of rural dwelling adults with MCC
- Aim 3: Describe the SM variables of self-efficacy, self-regulation, social support, and patient activation and the SM behaviors of rural adults with MCC.

The results of aim 1 are reported in Manuscript 2, Chapter 3.

Methods

Design

A descriptive cross-sectional design was used. Data collection methods included self-reported surveys, medical record extractions, and interview data collected from two focus groups. Data collection occurred between January and June 2021.

Ethics Approval

The University of Nebraska Medical Center Institutional Review Board approved this study prior to recruitment or data collection occurring (IRB# 690-20-EP). Participant consent was obtained from each eligible participant virtually using the online Research Electronic Data Capture (REDCap) tool before data collection occurred. Study data were collected and managed using REDCap electronic data capture tools hosted at UNMC. REDCap is a secure, web-based application designed to support data collection for research studies. REDCap at UNMC is supported by Research IT Office funded by Vice Chancellor for Research (VCR). This publication's contents are the sole responsibility of the authors and do not necessarily represent the official views of the VCR and National Institute of Health.

Sample

A convenience sample (N=40) of rural adults recruited from rural primary care clinics located in the midwestern United States was used for survey data collection and medical records extraction.

Two focus groups were conducted, stratified based on self-reported perception of SM abilities (high and low). A convenience sample was obtained for each focus group from the larger data collection sample with n=6 participating in the low self-management group and n=4 in the high self-management group.

Inclusion/Exclusion Criteria

To be eligible to participate adults needed to meet the following inclusion/exclusion criteria. Inclusion criteria were: 1) age 19 years or older; 2) diagnosis of two or more chronic conditions (verified through medical records obtained from the previous year); 3) reside in a rural area with a RUCA code between 7 and 10; 4) live independently and have the ability to perform activities of

daily living and oversee personal care at home; and 5) able to read, write and speak English.

Exclusion criteria were: 1) cognitive impairment indicated by a diagnosis in the medical records; 2) terminal illness with a life expectancy of less than one year; or 3) admission to an inpatient mental health facility within the past 1 year.

Recruitment

Participants were recruited from five primary care clinic sites associated with one clinical agency. Study brochures were distributed by clinic staff, nurses, and providers and if patients expressed interest in participating their contact information was gathered on the brochure and emailed to the research team. This served as permission from the patient to be contacted by research personnel. Due to safety requirements established with the COVID-19 pandemic, all contact from the research team to participants occurred via distance technology (telephone or web-conferencing).

Focus group participants were recruited from the larger sample of participants. During data collection all participants were asked if interested in participating in a focus group. If an indication of 'yes' was received during initial data collection participants were contacted after all survey data were collected. An email was sent to those indicating interest in the focus groups prior to holding the focus groups inquiring if participants were still interested in participating in the focus groups, and asked to answer four questions to self-identify self-management level rated on a scale of 1 to 10. The four questions were: On a scale of 1 – 10: 1) How do you feel you are doing in managing your medical conditions?; 2) How do you feel you are doing in managing your physical activity?; 3) How do you feel you are doing in managing your sleep?; and 4) How do you feel you are doing in managing your taking your medication?. Individuals indicating a six or above were stratified into the high self-management group (HSM, N=4), those indicating a 1-4 were stratified into the low self-management focus group (LSM, N=6).

Enrollment, Consenting, and Data Collection

The enrollment, consenting, and data collection were all conducted virtually via distance technology and occurred during one scheduled time point. It was based upon patient preference whether the interview was conducted over Zoom conferencing system or through telephone. A series of screening questions were asked to determine eligibility after which participants were consented. If eligible to participate and they were ready to provide informed consent. Consenting occurred virtually where the PI spoke with the participant over telephone/Zoom web conferencing while the participant viewed the informed consent document via a secured link. A digital wet signature was obtained after confirmation that the participants understood the purpose, risks, and benefits of the study were discussed and all questions were answered. After obtaining a verified signed consent, the participant entered the data collection stage of the interview where the PI asked the participants all survey questions and directly entered responses into the REDCap project surveys. All participants were consented for participation in the focus groups as part of the consent to participate in the research study.

Measures

Demographics and Chronic Condition Characteristics. (Appendix A) A revision of the University of Nebraska Medical Center CENTRIC Demographics tool was used to collect participant data. Questions included age, sex, marital status, educational attainment, number of individuals in their household, and employment status. In addition, questions were asked focusing on the number of chronic conditions the participant was diagnosed with and a listing of those specific conditions.

Multimorbidity Illness Perceptions Scale (MULTIPLeS). (Appendix B) A self-reported measure of perceptions of illness was collated using the MULTIPLeS measure (Gibbons et al., 2013). The MULTIPLeS measures perceptions of illness in the multimorbid population. This scale consists of 22 items that are scored on a Likert based scale with four responses. This measure can be broken down into five sub-scales measuring treatment burden, prioritization,

causal relationships, activity restriction, and emotional representations. Total score ranges from 0-100 with higher scores representing the presence of illness perceptions and the effects of multimorbidity. Psychometric properties of the MULTIPLEs included a Cronbach's α .81 and a correlation coefficient of $< .5$ (Gibbons et al., 2013). The Cronbach α from this study was .925.

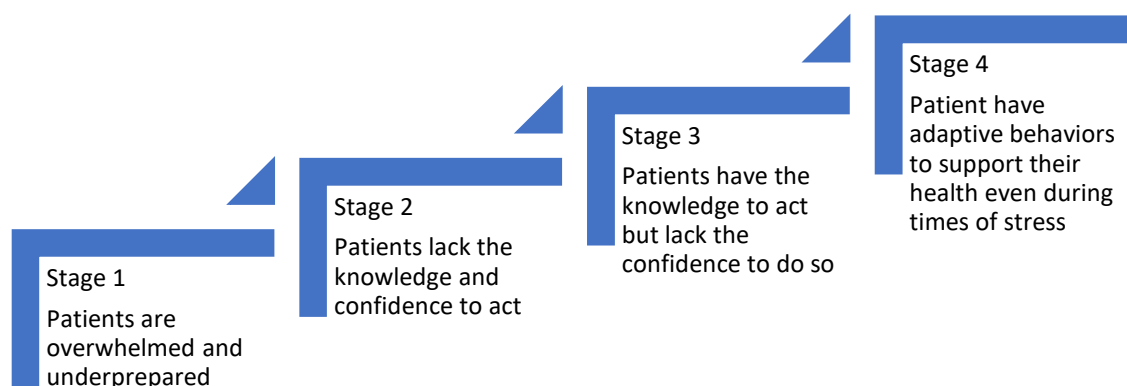
Self-Efficacy for Managing Chronic Disease. (Appendix C) Patient self-efficacy was measured using the Self-Efficacy for Managing Chronic Disease and consists of 6 items. Developed by Lorig (2001) this measure is used to indicate levels of confidence when caring for the respondent's chronic disease. The items are each scored based on a scale of 1 to 10 representing different levels of confidence (1 – not at all confident, 10- totally confident). Total score ranges from 1-10 with higher scores representing higher levels of confidence. A normative mean identified from a sample of 605 subjects was 5.17 (Lorig et al., 2001). The normative sample did not indicate rurality of the sample and was obtained from a sample of primarily female adults with an average age of 62.2 years and 2.3 conditions diagnosed per participant (Lorig et al., 2001). A Cronbach's α of .89 and correlation coefficient of .83 were reported by Lorig (2001). The Cronbach α from this study was .915.

Index of Self-Regulation. (Appendix D) A person's ability to self-regulate health behaviors was measured using the Index of Self-Regulation (Fleury, 1998; Yeom & Heidrich, 2009). This survey consists of 9 items scored on a 6-point Likert scale. Scores can range 1 to 6 with higher scores indicating the ability of the individual to use specific self-regulatory strategies (Fleury, 1998). A normative mean identified from a sample of 183 subjects was 4.64 (Yeom & Heidrich, 2009). The demographics of the normative sample for self-regulation consisted of a sample of primarily adult males with a mean age of 63.2 years and with cardiac patients who recently underwent cardiac catheterization or surgery. This measure has a Cronbach's α of .87 and a correlation coefficient of .69-.95 (Fleury, 1998). The Cronbach α from this study was .876.

Social Support. Three different types of support were evaluated: instrumental support, informational support, and companionship. All were measured using the PROMIS 4 item

measures: Instrumental Support – Short Form (Appendix E), Informational Support – Short Form (Appendix F), and the Companionship – Short Form (Appendix G). Each of these measures is scored based on 5-point Likert scale with responses being never, rarely, sometimes, usually, or always. Raw scores range from 4-20 for all three measures and can be analyzed based on a T-score ranging from 29.3 – 63.3. Scores higher than 60 represent high perceptions of social support, and scores of 40 or less are indicative of less social support. A normative mean (sample size) identified for each instrument was instrumental support 52.3 (758), informational support 53.5 (750), and companionship 52.6 (760) (Hahn, 2014). While rurality was not identified in the normative sample comparison means for social support, this normative sample included individuals from the general population consisting primarily of female adults with one or more chronic conditions (45%) between the ages of 45 and 74 (72%). A comparative fit analysis of .99 was obtained for all three with a construct validity of $p < .001$ (Hahn et al., 2014). The Cronbach α from this study for each social support measure was Instrumental Support .867, Informational Support .878, and Companionship Support .777.

Patient Activation Measure (PAM-13). (Appendix H) Activation level for each participant was measured using the 13-item patient activation measure (Hibbard et al., 2005; Hibbard et al., 2004). This survey is scored on a 4-point Likert scale with scores ranging from 0-100. Scores are categorized into four stages of activation. Stage 1 is representative of lower levels of activation (not interested in participating in care of health) and Stage 4 is indicative of high levels of activation (actively participates in health care needs even when under stress) (Figure 2). From a sample of 855 adults with multiple morbidities with rurality not indicated a normative mean score of 56.6 (Skolasky et al., 2011). A person separation index of .79-.83 in individuals with chronic conditions was obtained with a construct validity of $p < .001$. The Cronbach α from this study was .78.

Figure 2*Patient Activation Stages*

Duke Activity Status Index. (Appendix I) Activity level was assessed using the Duke Activity Status Index. The Duke Activity Status Index consists of 12 items, responses are yes/no (Fan, Lee, Frazier, Lennie, & Moser, 2014; Hlatky et al., 1989). Scores can range from 0-58.2 and are converted to METs that determine what level of activity the respondent can participate in. Higher scores (yes responses) are reflective of a high level of activity. A Cronbach's α .86 with statistically significant criterion related validity was reported. The Cronbach α from this study was .879.

Pittsburgh Sleep Quality Index. (Appendix J) The Pittsburgh Sleep Quality Index (PSQI) was used to measure sleep behaviors and quality of sleep. The PSQI consists of 11 items with both short answer and 4-point Likert responses, with scores ranging from 0-21 (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Scores higher than 5 are reflective of poor sleep quality. The reliability and validity of this measure was high with a Cronbach's α of .83 and demonstrating internal consistency and construct validity (Buysse et al., 1989). The Cronbach α from this study was .873.

Focus Group

Two 90-minute focus groups were conducted to determine variations in experiences between adults who self-identify as having high and low self-management abilities. Focus groups explored the life experiences of adults with multiple chronic conditions. Focusing specifically on perceptions of self-management, and the impact on individual lives. Both focus groups were held virtually using Zoom web-conferencing. Purposeful sampling occurred from the larger study sample with the two focus groups stratified into high and low perceived self-management abilities self-reported by participants. This form of sampling is deliberately biased to seek out perspectives from two unique groups of adults (Teddlie & Yu, 2007; Marshall, 1996). A recommended sample size for each focus group is 6-8 individuals was targeted to allow for data coding saturation to occur (Hennink, Kaiser & Weber, 2019). Qualitative data collection through focus group focuses on sample size based on individual study aims and number of focus groups and participants needed to achieve data saturation. These focus groups were analyzed using descriptive analysis in which coding saturation was achieved. Based upon responses from participants who agreed to participate and availability of participants a sample of 4 and 6 was achieved for the focus groups. A sample size of four was deemed adequate based on the collaborative discussion of the research team members and how the data obtained from the focus group was rich and provided interactive discussion between the focus group participants.

To guide the interview a semi-structured interview guide was guided by the self-management literature with approximately eight broad questions with multiple probes for each question (Appendix K). Focus groups were video and audio recorded to be transcribed for analyses, with all participants notified of when the recording started and stopped. Audio recordings were transcribed verbatim by a professional transcription service familiar with rural cultural nuances in speak patterns and verbiage.

Data Analysis

SPSS (Version 27) was used to perform descriptive analyses, t-tests to compare sample means to the comparative means identified for each instrument, and spearman's correlation to

identify relationships between self-management processes and self-management behaviors of physical activity and sleep. A significance level of $p < 0.05$ was used. A sample size of 40 was determined based on the recommendations from Hertzog (2008) based upon the study being a cross-sectional descriptive study and feasibility of recruitment, retention and survey completion/noncompletion. There was no missing data noted with 100% completion rate for all variables.

Aim 2. Patient perceptions of self-management needs were analyzed using focus groups and the MULTIPLEs instrument. Qualitative descriptive content analysis occurred to determine the findings from the focus groups (Hsieh, Shannon, 2005). Observational notes were taken by the PI. Transcripts were reviewed by two research team members. Apriori codes guided by the theoretical framework and emergent codes were identified (Nowell & Albrecht, 2019). Codes and content categories were identified based upon reflexive notes, observational notes, and transcriptions of each focus group. To ensure understanding of the content shared, member checking of content occurred at the end of each focus group (Rodgers & Cowles, 1993). The focus group interviews were coded using NVIVO by the PI and the discussed with an experienced qualitative researcher until a consensus on the coding was achieved. The coding matrix was revised and refined multiple times to allow for clarity of the content and data reduction. Coding scheme was organized into a matrix to foster data reduction and interpretation of the findings. The matrix was revised through rounds of analytic discussion with a qualitative researcher until patterns and differences were discerned that fit the data. The coding matrix was then challenged to determine clarity of the data presented. The data matrix was reviewed to identify patterns and areas of inconsistency and then evaluated for within and between group differences to determine enhances interpretation of the data collected (Vaismoradi, Turunen & Bondas, 2013). The MULTIPLEs instrument results were evaluated using descriptive statistics. Sub scales of treatment burden, prioritization, causal relationships, activity restriction, and emotional representations were analyzed to determine what the primary focus of perception.

Aim 3. Describe the SM variables of self-efficacy, self-regulation, social support, and patient activation and the SM behaviors of rural adults with MCC. Descriptive statistics conducted to analyze the self-management behaviors of activity and sleep, and the self-management processes of self-efficacy, self-regulation, social support, and patient activation. Comparative t-tests were conducted between sample means and comparative means previously identified for each instrument. Spearman correlation statistics were used to describe relationships between the theoretical model self-management processes and self-management behaviors.

Results

Demographic Analysis

A sample of 40 adults from isolated rural communities participated in the study. The sample demographics was primarily female (80%), Caucasian (100%), non-Hispanic/Latino (95%), and married (77.5%). The mean age of the sample was 62.13 years (SD 14.97). The average BMI was 32.74 kg/m² (SD 6.89). Number of diagnosed chronic conditions was self-reported and also collected from the medical record. Using a paired t-test with a confidence interval of 95%, mean chronic conditions that were self-reported were compared to the number of ICD 10 diagnoses from the medical record. There were statistically significant differences between the number of chronic conditions ($p < 0.001$) with the participants underreporting the number of conditions they were diagnosed with. A complete description of the sample demographics can be found in Tables 1 and 2. The most common chronic conditions diagnosed were high cholesterol (19/40), hypertension (16/40), hypothyroidism (12/40), osteoarthritis (12/40), anxiety (11/40), and type 2 diabetes mellitus (11/40). The mean number of chronic conditions per participant was 4.42 (SD 1.986) and a range of 2 – 11. The two focus groups consisted entirely of female, Caucasian participants with a mean age 60 (SD = 12.54, Range 43-78). The mean age for the high SM group was 63.5 (SD = 9.81), and the low SM group was 57.67 (SD = 13.57).

Aim 1

The study was deemed feasible in terms of recruitment, enrollment, and data collection. Specific results of this aim of the study have been reported in a separate manuscript (Chapter 3 of the dissertation to be submitted for publication).

Aim 2

To objectively measure patient perceptions of multimorbidity the MULTIPleS was analyzed. The mean (M) score was 31.55 with a range of 1-67 (SD = 12.27). Subscale analysis of the MULTIPleS revealed that perceptions of multimorbidity were primarily focused on the emotional effects with a mean score of 10.93 ± 6.06 . Other subscale means included treatment burden $M=5.7$ (SD = 3.26), prioritization of conditions $M=7.4$ (SD= 2.5), causal relationships $M=4.28$ (SD = 1.89), and activity restriction $M=3.25$ (SD= 2.17).

During the original data collection 29 participants indicated that they would be interested in participating in the focus groups. Of those contacted when focus group recruitment was occurring 15 agreed to participate, six declined to participate, and eight were unable to be reached. The 15 were stratified into the high (n=9) and low (n=6) self-management groups. All 6 LSM group adults participated in the focus groups. Two adults were excluded from the HSM group because they were a married couple, and three were unable to attend the focus group.

The focus groups analyses determined a common thread across both groups was the various challenges perceived in managing MCC. The results of the analyses were categorized into topical descriptions with three main areas: similarities and differences between groups, and mixed perspective between and within groups (Figure 1). Findings of the qualitative matrix were triangulated with the literature and the guiding theoretical framework. Findings were organized in a matrix into three categories: between group similarities, between group differences, and mixed perspectives between and within groups. To ensure rigor of the findings member checking occurred with each focus group at the end of each focus group to ensure the data that was understood by the moderator was an accurate representation of what was stated during the focus group (Nowell & Albrecht, 2019).

Between Group Similarities

Both the high and low self-management groups expressed having a difficult time asking others to assist them when caring for and managing their conditions “I don’t really like to ask for help. I try not to anyways. I mean if I asked my husband, he would helped me if I asked, but I have a hard time asking.” Both groups made comments minimizing the impact of their conditions such as “at least it wasn’t cancer” and “I’m not comfortable with [my conditions], but I’m okay.” In addition, the impact of social support was determined to be critical for both groups. Interestingly, when asked who they seek out for different types of support answers were fairly consistent. When asked about getting assistance for physical needs it was expressed that spouses and adult children provided the support as compared to social support which was often obtained from spouses and close friends. Mental support however was often obtained from sisters and adult daughters as they were less judgmental than spouses or friends.

Between Group Differences

Perspectives that varied greatly between the two focus groups included feeling of isolation, condition control and maintenance, burden, and loss of independence. Participants in the low self-management group (LSM) expressed experiencing feelings of social isolation “I don’t even feel comfortable going to my office to work because my cough is so out of control that I feel like I am heckled and harassed there um more so than I get when I’m at home or trying to go out in public”, and using health care system directed actions to control and maintain their conditions. The LSM also described having more barriers to attending health care visits, such as, the need to travel to visits (i.e. “My doctor told me that I had to go to [urban clinic] because he couldn’t do anything for me anymore, that I needed their special care and I didn’t wanna go to [urban clinic]”), reschedule appointments and work schedules, and a lack of motivation to attend visits (i.e. “I don’t like running to all of the appointments and stuff and it just seems overwhelming sometimes with the amount of appointments a person has to go to”). In comparison the HSM expressed being able to successfully self-direct actions at home to manage their conditions, but

discussed expenses related to prescribed medication regimens as a burden of having MCC (i.e. “So otherwise the cost at first was scary. And then when I was gonna retire, that was very scary too because I didn’t know how I was gonna pay for my medicine.”). While both groups describe experiencing a loss of independence after being diagnosed with MCC, when reacting to this loss the HSM look at this a motivating factor to improve their health status and improve quality of life where as the LSM described having feelings of depression and feeling like a failure (i.e. “I just feel weak, I feel broken, you know like part of me is broken and I’m not as good of a person as I was back then.”).

Mixed Perspectives Within and Between Groups

Areas discussed that varied across and within both groups included which daily activities they participated in at home with some participating in physical activity, and inconsistencies in the perceptions of sleep. Medication management was discussed by both groups; however, medication compliance (i.e. “I don’t have a feeling about it. It’s just something I have to do.”, “They all just sit in my cupboard and I just collect medicine”), and perspectives of taking multiple medications varied greatly. Finally, when asked how individuals felt after being diagnosed with MCC multiple response were obtained but all fell somewhere on the grief cycle. Feelings of grief, anger, denial, and acceptance were all discussed (i.e. “I didn’t want to believe it. I denied it for quite some time”, “I felt like a failure. I think I was just frustrated with myself and I probably still feel that way”, “I was angry at first at myself”). The only stage on the grief cycle that was not identified was bargaining.

Aim 3

Self-management processes. Self-management processes of self-efficacy, self-regulation, social support, and patient activation were measured (Table 3). The mean score for self-efficacy was 7.09 (SD =2.04), and self-regulation was 3.83 (SD= 0.68). Social support was measured by three different scales, instrumental, informational, and companionship support. The means of each of the social support scales were all above the normative sample mean: instrumental 59.24

(SD =6.77), informational 60.25 (SD =6.45), and companionship 57.82 (SD = 6.44). The PAM-13 sample mean was 66.0 (SD=11.76), and patients categorized into one of four levels of activation: Level 1 (n=1); Level 2 (n=6); Level 3 (n=26); and Level 4 (n=7).

One-Sample t-tests were done to compare self-management process sample averages in this study against the normative means for the instruments. There was a statistically significant difference between normative scores previously stated in the instrument measures section and the rural sample obtained in this study for all processes of self-management. Self-efficacy ($p < .001$), self-regulation ($p < .001$), social support: instrumental support ($p < .001$), informational support ($p < .001$), and companionship support ($p < .001$), and patient activation ($p < .001$). Scores for self-regulation were significantly lower than the norm. Comparatively, self-efficacy, social support, patient activation indicated statistically significant differences that were higher than average. See Table 4.

Self-management behaviors. The SM behaviors of activity level and sleep habits were assessed by self-report. The mean activity level of the sample measured in metabolic equivalent tasks (METs) was 8.18 (SD 2.02). This score is reflective of a vigorous intensity of activity. Average sleep quality scores obtained from the PSQI were 7.48 (SD 4.57) indicating poor sleep quality.

Theoretical Model Relationships. Relationships between concepts described in the theoretical framework were tested. Using Spearman's rho, two statistically significant correlation coefficients were identified. A negative relationship between sleep quality and self-efficacy ($\rho = -.508$, $p = .001$) was found indicating high self-efficacy is associated with better quality of sleep (low PSQI) and a positive correlation between activity level and self-efficacy ($\rho = .451$, $p = .003$) indicating higher physical activity is associated with higher self-efficacy. All other relationships were non-significant. Small correlations were noted between physical activity and self-regulation and social support (companionship), and between sleep and informational support. See Table 5.

Discussion

This study described the perceptions, behaviors, and processes of self-management in isolated rural adults diagnosed with multiple chronic conditions. In addition, relationships in the Individual and Family Self-Management Theory framework were tested between self-management processes and self-management behaviors of sleep and activity level. Data from this study were collected virtually from a sample of 40 adults from isolated rural communities in the Midwestern United States. Methods included survey data, medical records extraction, and two focus groups.

Self-management Processes and Behaviors

When comparing sample means to the normative means (reported for each instrument in the *Measures* section) identified under instruments this isolated rural sample (i.e. all RUCA 10) had statistically significant differences between the normative means identified across all self-management processes. The concept of self-regulation was below normative averages whereas self-efficacy, social support and patient activation levels are statistically higher than normative means. It is interesting to note that the sample mean of self-regulation was lower than the comparative average. Adults from rural areas have been shown to have higher rates of smoking, alcohol intake and obesity, and are less likely to think of healthy lifestyle behaviors such as healthy eating, participating in physical activity, and interacting with healthcare providers (National Center for Chronic Disease Prevention and Health Promotion, 2021).

When comparing normative means and this study's means, it is important to note any demographic differences between the two samples. This normative sample is quite different in terms of gender, so it is interesting that self-regulation was higher in the normative sample with more males than in our predominately female study sample. This could be due to the nature of female adults underestimating their behaviors and are more conservative in the evaluation of participation in their regulatory abilities (Kurman, 2001). The rurality of self-regulation normative samples was not described and therefore this aspect can't be compared to the current study sample.

Focus group data revealed that participants self-reporting high levels of self-management based upon self-report, also verbalized high levels of confidence when it came to managing their chronic conditions and interacting with healthcare providers. In contrast, participants identifying as having low SM abilities shared frustrations in the ability to access care, increased treatment burden related to medication and symptom management. This cross-case comparison identifies different experiences regarding confidence levels and ability to self-regulate their multiple chronic conditions.

The self-management processes of self-efficacy, social support and patient activation were noted to be higher in this study sample as compared to the normative means. The normative sample compares to the current study sample very closely in terms of gender and age. Looking at the differences between sample characteristics it is noted that the geographic location of the samples was different with the normative samples being mostly urban. The current study found adults from isolated rural communities have higher perceived social support and higher activation levels than the norm. The findings from the three different instruments that measured social support are congruent with patient experiences from both the high and low self-management focus groups. It is expressed in both focus groups that each kind of social support was provided by different individuals. For example, participants identified they reached out to spouses and friends for social support, spouses, and family members (primarily adult children) for physical support, and female friends and adult daughters for mental support. It is important to note that both focus groups consisted entirely of female participants so male counterparts might have different perceptions. These findings are congruent with previous research that indicates that rural environments are conducive to having strong social ties to community members, and family members (Letvak, 2002). High levels of social support are associated with reduced incidence of depression (Ibrahim et al., 2013) which may be why there were fewer adults with a diagnosis of depression as a chronic condition in the study. Adults diagnosed with multiple chronic conditions living in rural communities have expressed different situational needs that require different types

of support. Bardach (2011) noted that rural adults diagnosed with multiple chronic conditions expressed a focus on training support from specialists or medical, social, and auxiliary services to prevent undue pressure on family and friends. This was a noted difference in the current study as focus group participants expressed turning to family and friends for support, both social and physical support, instead of turning to healthcare providers and specialists. This again could potentially be the result of less access and availability of supportive health care providers and medical specialists especially in isolated rural areas (i.e., RUCA 10 the setting for this study). Participants seek support from family and friends in the absence of available medical providers. An interesting perception from the low self-management focus group was the need for more social support to manage the daily changes experienced in relation to multimorbidity. Obviously, there are unmet needs for support experienced by some rural dwelling individuals with multimorbidity. This is an important point because the focus group with low self-management indicated a need for more social support from individuals as they reported experiencing daily changes related to multimorbidity and would be a high priority need for any future program.

The majority of the sample scored in the level 3 classification for patient activation level (65%). This indicates that patients are ready and willing to be active in their care but may not be able to stay the course when presented with stressors and changes in health status (Insignia Health, 2021). The sample mean was higher than the comparative mean indicating higher levels of activation. This is notable as previous research has indicated that adults from rural communities diagnosed with MCC described lower levels of activation (Yadav et al., 2020). This of interest as both populations were from rural communities however the study sample consisted entirely of isolated rural areas (RUCA 10) and may be attributed to different experiences for different rural communities. Future studies should evaluate the differences between isolated rural (RUCA 10) community experiences compared to rural communities (RUCA 4-7 and 7-9).

Self-Management Behaviors

Physical Activity. Actively participating in physical activity is a critical part of chronic disease self-management. Physical activity levels for rural adults, however, tend to be lower than their urban and suburban counterparts (Martin et al., 2005). Adults from the Midwestern United States who are from rural and isolated rural communities have been shown to have a higher percent of the population not meeting recommendations for moderate physical activity levels (54.7% (Martin et al., 2005)). This has been so problematic that many researchers have proposed walking trails to address physical inactivity observed in rural communities (Brownson et al., 2000). Metabolic equivalents (MET) are used to measure levels of physical activity by identifying individuals resting metabolic rate (Jetté, Sidney, & Blümchen, 1990). Recommended MET levels for physical activity, in the general population are targeted at moderate levels (i.e., Met levels of 4.0 to 5.9 for men and 2.8 to 4.3 for women) (Jetté et al., 1990). Many chronic conditions advocate for the same recommended levels of physical activity as those in the general population. To compare our study findings with recommended levels we collected self-reported activity levels. It is striking to note this sample reported vigorous levels of daily physical activity (MET averages of 8.18) which is interpreted as unexpectedly vigorous levels of physical activity (i.e., Met level greater than 7.6 for women and 8 to 9.9 for men). One possible explanation for these findings is that physical activity levels are being self-reported. The study measured physical activity using the Duke Activity Status Index which allows participants to self-report physical activity levels based upon yes or no responses to questions. The high level of physical activity measured may be due in part to social desirability bias by the participants or because of an overestimation of physical activity levels based on the way the questions were asked. Schulz (2014) found that rural dwelling caregivers and patients spend most of their time participating in sedentary activity. The Schulz (2014) study measured activity using accelerometer data which would provide an objective measure of activity. This noted difference in measurement methods lends support to the potential explanation that individuals in this study may have over-estimated self-reported physical activity. Future studies aimed at describing the

physical activity of rural participants should incorporate both objective measures of physical activity as well as self-reported levels to identify true physical activity levels compared to patient perceptions of physical activity levels. One difference in this sample that was not found in the literature to date was that this sample consisted entirely of isolated rural participants (RUCA 10) so it is unknown if this finding is unique based on a subset of rural adults who participate in vigorous activity or if it relates to overestimation in the self-reported levels of physical activity.

Sleep. This study found that the overall sleep quality of isolated rural adults is poor when scored using the PSQI measure. The sample population self-reported spending an average of 8.34 hours in bed each night however external factors such as getting up to the restroom, disturbances by bed sharing with spouses, and restless legs frequently disrupted the quality of their sleep. A previous study of rural Midwestern adults obtained a lower average of recorded sleep with 7 to 8 hours per night (Stamatakis & Brownson, 2008). While hours spent in bed was higher in our sample the quality of the sleep was reported as being poor. Poor sleep is associated with an increased risk of weight gain and obesity which is a critical aspect of self-managing chronic diseases. Like other self-management behaviors obtained in the study, sleep was collected through self-report and may not be an accurate representation of the total sleep that isolated rural adults obtained at night. Future research should include an objective measure of sleep, with the inclusion of the sleep diary to determine overall quality and duration sleeping habits.

Testing of Relationship in the Theoretical Framework

The individual and family self-management theory was used as the foundational framework for the development of this study. Correlations were tested to determine strength of relationships between the processes of self-management and the self-management behaviors of physical activity and sleep. This study identified statistically significant relationships between self-efficacy and self-management behaviors of physical activity and sleep. Self-regulation, social support and patient activation were not significantly related to self-management behaviors of physical activity or sleep. This may be due to the small sample size or to the unique nature of the

sample with all individuals residing in isolated rural communities. Studies have identified predictive relationships between high self-regulatory abilities and physical activity (Umstattd, Saunders, Wilcox, Valois, & Dowda, 2006) that were not noted in this sample. Additional research with a larger more diverse sample to determine strength of these theoretical relationships between self-management processes of self-regulation, social support, patient activation and the self-management behaviors of physical activity and sleep. While inclusion criteria specified RUCA codes 7-10, these participants were all from the RUCA 10, isolated rural areas. This may not truly represent all rural areas. This study only considered self-management behaviors of physical activity and sleep. Additional self-management behaviors (e.g. diet and medication adherence) should be included in future studies to identify strength of relationships between specific behaviors, conditions and the self-management processes of self-efficacy, self-regulation, social support, and patient activation.

Limitations

Results of this study are limited by its cross-sectional descriptive design, in that all data were collected at one time point that occurred in the middle of the COVID-19 pandemic. Furthermore, the sample was recruited from one health care agency and consisted of 100% Caucasian adults with a predominance of females and results need to be verified with a larger, rural sample recruited from multiple geographic areas representative of RUCA 7-10. Recruitment occurred only from one primary care setting limiting the sample to only adults who access health care resources within that setting and therefore further limits generalizability to populations who lack access to health care centers, choose not to use primary care, or migrant populations that do not establish care with primary care clinics in the region. All data are self-reported with the exception of the number of chronic conditions pulled from the medical record and may be biased by social desirability of responses. The statistically significant differences between normative means and study findings may be due in part to biased responses to provide desirable response during survey data collection. Future research should incorporate methods to prevent social desirability bias

such as objective measure of physical activity and sleep (Grimm, 2010). The results of the focus group are limited due to participant perspectives from one rural midwestern region in the US. Furthermore, only two focus groups were conducted based upon the sample size and there for is limited in determining high level of informational redundancy

Conclusion

This cross-sectional descriptive study was designed to describe the perceptions, behaviors, and processes of self-management of rural adults diagnosed with multimorbidity. This research emphasizes the importance of describing the perceptions of rural adults living with multiple chronic conditions. This study is one of the first to describe the self-management perceptions, behaviors, and processes of multimorbid adults from isolated rural communities. This study identified that social support when measured using a scale was high for the population, however, when discussed in the focus groups there was a clear desire by individuals identifying as having low self-management abilities to have access to support that includes others living with multiple morbidities. This is a critical finding in that the development of a tailored self-management program for this population needs to include an aspect of group social support. Additionally, self-regulation of the predominately female sample was low compared to the normative sample in which the predominately male sample had higher self-regulation scores. Potential gender differences in self-regulatory behaviors should be evaluated in future studies. Future research should consider the self-management behaviors related to diet and medications. Finally, research is needed to describe objectively the self-management behaviors of activity and sleep in rural adults with multiple chronic conditions. This study lays the foundation for future development of self-management interventions tailored specifically for multimorbid adults dwelling in isolated rural communities.

Table 1.
Description of Categorical Demographics (N=40)

Characteristic	Frequency (%)
Sex	
Male	8 (20)
Female	32 (80)
Marital Status	
Married	31 (77.5)
Single	3 (7.5)
Widowed	3 (7.5)
Divorced	3 (7.5)
Race	
Caucasian	40 (100)
Ethnicity	
Hispanic/Latino	2 (5)
Non-Hispanic/Latino	38 (95)
Income Level Before Taxes	
Under \$20,000	6 (15)
\$20,000-\$39,000	8 (20)
\$40,000-\$59,000	7 (17.5)
\$60,000-\$79,000	7 (17.5)
\$80,000-\$99,000	6 (15)
\$100,000 or more	6 (15)
Number of People in Household	
1	6 (15)
2	19 (47.5)
3	5 (12.5)
4	7 (17.5)
5+	3 (7.5)
Employment	
Full Time	14 (35)
Part Time	5 (12.5)
Unemployed	3 (7.5)
Retired	18 (45)
Education	
High school Graduate/GED	8 (20)
Some College (Non-Degree)	13 (32.5)
Associate's Degree	11 (27.5)
Bachelor's Degree	6 (15)
Master's Degree	2 (5)
Self-Reported Number of Comorbidities	
2	19 (47.5)
3	9 (22.5)
4	6 (15)
5+	3 (7.5)
RUCA	
10 – Isolated Rural	40 (100)
BMI Classification	
Normal Weight	6 (15)

Overweight	8 (20)
Class 1 Obesity	12 (30)
Class 2 Obesity	8 (20)
Class 3 Obesity	6 (15)

Table 2.*Description of Demographics (N=40)*

Variable	Mean	Minimum	Maximum	Std. Deviation
Age	62.13	37	90	14.974
Blood pressure				
Systolic	122.1	102	168	16.11
Diastolic	67.23	50	90	8.24
Pulse	79.07	52	100	11.57
BMI	32.74	19.65	53.40	6.89
Number of Chronic conditions from medical record	4.42	2	11	1.986
Self-Reported Number of chronic conditions	3.075	2	7	1.35

Table 3*Description of Self-Management Processes and Self-Management Behaviors*

Variable	Mean	Minimum	Maximum	Std. Deviation
MULTIPLEs	31.55	1	67	12.27
Treatment Burden	5.7	0	15	3.26
Prioritization	7.4	1	12	2.5
Causal Relationship	4.28	0	9	1.89
Activity Restriction	3.25	0	9	2.17
Emotional Representations	10.93	0	24	6.06
Self-Efficacy	7.09	1.33	10	2.04
Self-Regulation	3.83	1.11	5	0.68
Social Support				
Instrumental	59.24	39.1	63.3	6.77
Informational	60.25	43.9	65.6	6.45
Companionship	57.82	42.5	63.1	6.45
PAM	66.00	45.3	100	11.77
DUKE (METS)	8.18	3.94	9.89	2.02
PSQI	7.48	0	19	4.57

Table 4

Normative Mean Comparisons to Study Means

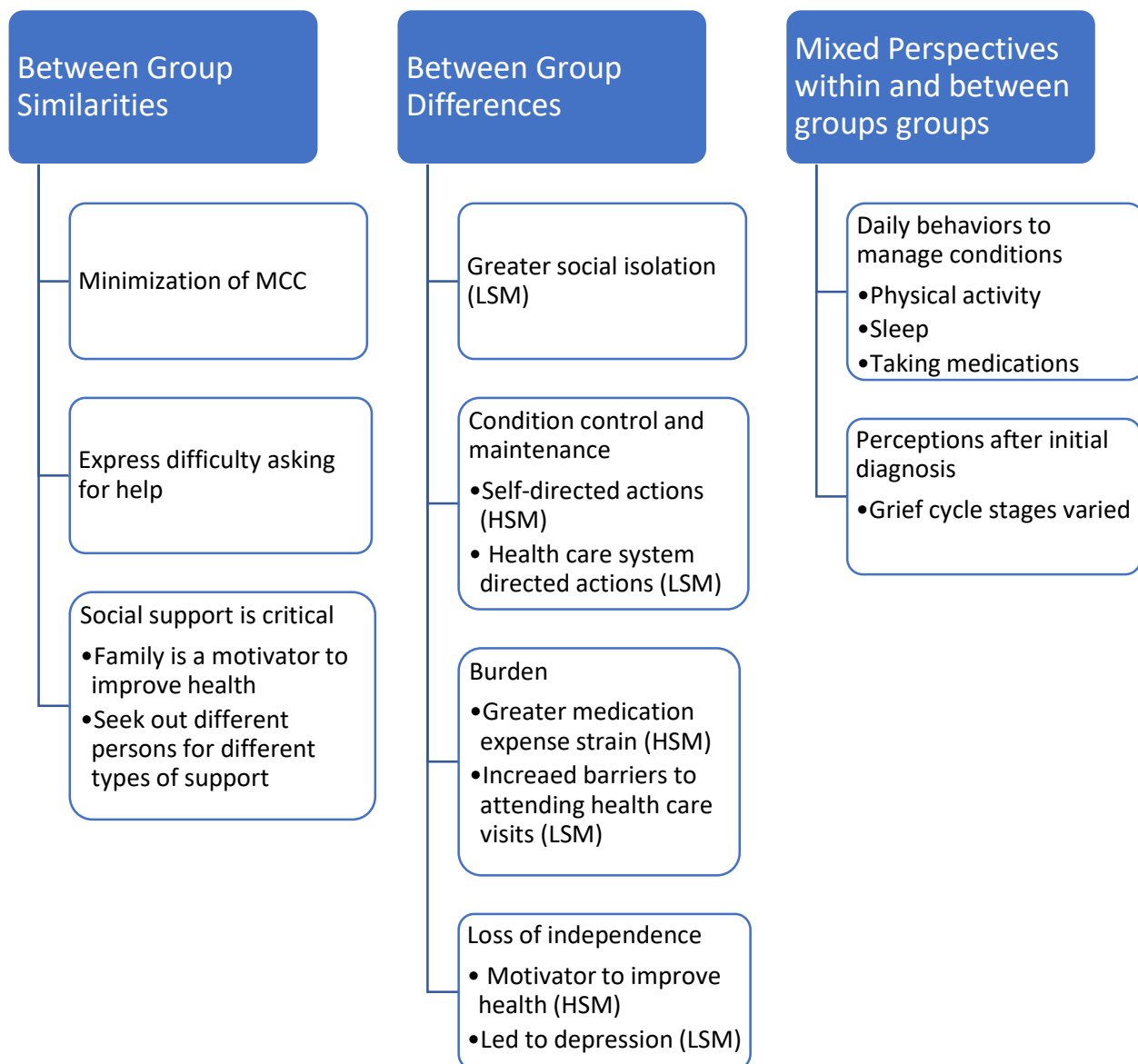
	Normative Mean	Sample Mean	Mean Difference	95% Confidence Interval of the Difference		t Value	P-Value (2-tailed)
				Lower	Upper		
Self-Efficacy	5.17	7.09	1.92	1.27	2.57	5.95	<.001
Self-Regulation	4.64	3.83	-0.82	-1.03	-0.60	-7.57	<.001
Social Support							
Instrumental	52.3	59.24	6.94	4.77	9.10	6.48	<.001
Informational	53.5	60.25	6.75	4.68	8.80	6.62	<.001
Companionship	52.6	57.82	5.22	3.16	7.28	5.12	<.001
PAM	56.6	66.00	9.40	5.64	13.17	5.05	<.001

Table 5

Spearman Correlations of the Study Variables

	Self-Efficacy	Self-Regulation	Social Support			PAM
			Instrumental	Informational	Companionship	
Physical Activity	.451*	.112	.042	.031	.233	.069
Sleep	-.508**	-.09	-.082	-.143	.014	.015

*p<.05
**p<.001

Figure 1*Qualitative Data Analysis Matrix*

CHAPTER V: DISCUSSION AND CONCLUSION

The purpose of this study was to describe SM behaviors and explore perceptions of SM needs among rural dwelling adults diagnosed with MCC. The specific aims of this study were to: 1) determine the feasibility of recruitment, enrollment, and data collection in rural adults with MCC; 2) Explore perceptions of SM needs of rural dwelling adults with MCC; and 3) Describe the SM variables of self-efficacy, self-regulation, social support, and patient activation and the SM behaviors of rural adults with MCC.

This cross-sectional descriptive study was developed under the guiding framework of the Individual and Family Self-Management theory developed by Ryan and colleagues (Ryan & Sawin, 2009). Participants were recruited in the Midwestern United States from 5 primary care sites associated with one health care agency. Participants were recruited between January and April 2021. The sample consisted of adults diagnosed with multiple chronic conditions residing in isolated rural communities (RUCA 10). All contact with participants occurred remotely either by telephone or zoom conferencing and consisted of surveys, medical records information, and two focus groups.

Results of this study help to inform future research and the development of a self-management intervention to be tailored for adults diagnosed with multimorbidity from isolated rural areas. The majority of the sample was female (80%), Caucasian (100%), married (77.5%), and from isolated rural areas (RUCA 10, 100%). The average age of the sample was 62.13 years (SD 14.97) with a range of 37-90 years. The mean number of diagnosed chronic conditions per adult was 4.42 (SD 1.986) with a range of 2 – 11 diagnosed chronic conditions.

Aim 1 of this study was to describe the feasibility of recruitment, enrollment, and data collection from the targeted population. Recruiting adults from rural communities is challenging because of geographic barriers and the distrust of research and persons outside the rural communities. Development of a strong relationship with the health care clinics where recruitment occurred was paramount to the success experienced in this study. It was through a collaborative

relationship with the Vice President of Clinic Services that 40 multimorbid adults were recruited over the course of 4 months during the height of the COVID-19 pandemic. Because of safety measures in place because of COVID-19, recruitment was conducted entirely through brochure distribution by clinic staff, nurses, and providers at each of the 5 clinic sites. This proved to be a successful method of recruitment with a total of 49 adults inquiring to participate, 40 in the first 7 weeks of recruitment. Of the participants interested in participating, 40 completed the enrollment screening with all meeting eligibility criteria and participating in the study through completion.

Enrollment, consenting, and data collection occurred virtually for all participants. Research staff never met with participant in person, and it was at the discretion of the participant whether the interview occurred over the telephone or zoom web conferencing. No participants were excluded based upon this method of data collection. Only one individual did not have access to the technologies in the home to complete the interview; however, they were able to use the city library computer to participate in the study. Consenting of all participants occurred using the REDCap data collection system. The PI spoke with the participant (over telephone or zoom) while the participant viewed the consent using a secure link and passcode to access the document. Using this method rural adults were able to participate in the study from the comfort of their own home while also maintaining research standard for providing informed consent, ensuring participant understanding of the purpose, risks, and benefits of participating in this research study. A “wet signature” was obtained for all participants using the REDCap e-consenting protocol and a copy of the sign consent was printed and mailed to all participants to ensure receipts of a copy for participant records. This method of consenting proved to be a successful method for consenting isolated rural adults into a clinical research study without placing undue travel burden on the participants or extended time in the clinic. No participants were excluded from participating because of an inability to complete consenting procedures. Participants expressed satisfaction with this method of participation because of the ease of access and the ability to participate without undue interruptions to their day.

Data collection was also collected in this manner with the research PI asking participant questions and responding verbally. The participant response was entered to REDCap directly during the interview by the PI. To mitigate potential error in data entry the PI repeated all answers back to the participant after clicking the response in REDCap. On more than one occurrence this prevented data entry errors and the correct response was able to be marked. This was a feasible method of data collection with 100% completion of all participants collected survey responses.

Medical records extraction occurred by an IRB trained nurse at the clinic following each participant enrollment. The PI, following completion of the participant interview, sent a secure email to the nurse that included a link to a REDCap data entry survey and the associated access code. Because all responses were indicated as “required” by the REDCap system all variables were filled in; however, due to missing data in the clinic system 4 documents that were to be uploaded into the system were missing and a duplicate of the ICD 10 documentation was uploaded. When verified with the clinic nurse, the PI was informed that this was because the data were missing in the clinic system and therefore could not be uploaded. Using the REDCap system, the “required” function allowed for no missing data to occur during data collection. To account for participants who preferred not to answer a question a response was added to each question that indicated “refusal to answer” however this option was never read to the participants during data collection.

Aim 2 focused on exploring the perceptions of SM needs of rural adults with MCC. This was done through survey (MULTIpleS) and focus groups. The MULTIpleS instrument mean score revealed low perceptions of multimorbidity. Meaning adults in this sample did not perceive their multimorbidity as having an impact on their lives. Subscales of the MULTIpleS identified that the primary focus when considering multimorbidity for adults was on the emotional effects with prioritizing conditions being the second most perceived factor when considering multiple morbidity. Other factors influencing perceptions measured with the MULTIpleS scale included treatment burden, causal relationships, and activity restriction. Results indicate that when caring

for this population specific care should be placed on addressing emotional concerns, and prioritization of condition management.

The two focus groups revealed similarities, differences, and between and within group differences between the high and low SM groups. Both groups expressed comments indicating a minimization of their condition and difficulty asking for help. Previous studies conducted in the rural adult population found similar findings (Greider, Krannich & Berry, 1991). In addition findings from the focus groups revealed a strong desire for social support from adults with similar experiences as it relates to MCC. Both groups indicated wanting more social support which was contradictory to the social support measures that were obtained that revealed high perceived social support for the sample. This indicates a deviation from what is known and what is desired by this rural adult population. Looking at the between group differences, individuals in the low SM group expressed feelings of isolation and looked to the health care system to direct health management behaviors and actions. While the burden of disease was experienced by both groups the high SM group expressed burden related to medication expense strain compared to the low SM who indicated barriers to attending health care appointments. Finally, a loss of independence was experienced by both groups when asked about feelings regarding their MCC but the reactions differed between groups. The high SM group looked at a loss of independence as a motivator to regain independence and better manage conditions whereas the low SM group when faced with a loss of independence experienced feelings of depression further impairing their ability to manage their MCC effectively. Management of daily behaviors and activities used to monitor and manage their MCC differed between and within groups with no consistency in the actions that were taken. Furthermore, when asked about how individuals feel regarding their MCC there was little consistency in the responses and all responses fell somewhere on the grief cycle with some adults expressing acceptance, while others experienced anger and denial.

Aim 3 of this study sought to describe the self-management process and self-management behavior of the rural adult sample. This study found statistically significant differences between

normative means and sample means for all the self-management processes (self-efficacy, self-regulation, social support and patient activation). Results of this study indicated that multimorbid adults from isolated rural communities have lower levels of self-regulatory abilities as compared to the normative means. When comparing the normative sample to the study sample for measure of self-regulation, the study sample consisted primarily of females and the normative sample of males. In addition, the study sample had self-regulation scores that were below the comparative mean. This could be due to gender differences in self-regulation abilities and needs to be addressed in future studies. This could be because females have been shown to underestimate their actions and behaviors and are more conservative in the evaluation of the self-management abilities (Kurman, 2001). Rurality of normative samples of self-efficacy and self-regulation was not described and limits comparison of rural versus urban scores.

The study population scored above the comparative norm for self-efficacy, social support, and patient activation levels. Three different types of social support were measured including informational, instructional, and companionship. These findings were in line with what participants in the focus group discussed. Social support was identified by participants in the focus group as having a large impact on their abilities to self-manage their chronic conditions, often relying on different individuals for different types of support. For example, participants identified they reached out to spouses and friends for social support, spouses, and family members (primarily adult children) for physical support, and female friends and adult daughters for mental support. The focus group samples were entirely female so the persons that male multimorbid adults turn to for support may be different but is unknown from our findings. While the MULTIPLEs measure indicated high levels of perceived social support by the study sample, it was expressed in the focus group that any program to be implemented to improve self-management of chronic conditions should include an aspect of social support consisting of adults with similar multimorbidity experiences. These findings align with previous research that has been conducted in that rural adults have strong community ties and relationship with family

members (Letvak, 2002). Future research should include the testing of applications of social support within this multimorbid population. It would also be important to obtain perceptions of social support from male adults who may have different preferences and experiences than the female counterparts.

The majority of the sample scored in the level 3 classification for patient activation level (65%). This indicates that patients are ready and willing to be active in their care but may not be able to stay the course when presented with stressors and changes in health status (Insignia Health, 2021). The sample mean was higher than the comparative mean indicating higher levels of activation. This is notable as previous research has indicated that adults from rural communities diagnosed with MCC described lower levels of activation (Yadav et al., 2020). This of interest as both populations were from rural communities however the study sample consisted entirely of isolated rural areas (RUCA 10) and may be attributed to different experiences for different rural communities. Future studies should evaluate the differences between isolated rural (RUCA 10) community experiences compared to rural communities (RUCA 4-7 and 7-9).

The self-management behaviors evaluated in the study were physical activity and sleep. The results of the study indicated that the population sample self-reported vigorously high levels of physical activity as measured by the Duke Activity and Status Index. This finding is in contrast to what is seen in the literature as adults from rural Midwestern United States have been shown to have higher percentages of individuals not meeting physical activity recommendations (Martin et al., 2005). Recommended MET levels for physical activity in the general population are aimed at achieving a physical activity level of moderate intensity (i. e., Met levels of 4 to 5.9 for men and 2.8 to 4.3 for women) (Jetté et al., 1990). It is striking to note that the study sample self-reported such high levels of physical activity and may be due to inaccurate descriptions of true activity levels. Social desirability bias by the participants may in part account for the high physical activity levels reported in this study and therefore should be interpreted with caution. In studies with rural dwelling adults where physical activity is measured objectively with accelerometers,

findings show a majority of time is spent in sedentary activity (Schulz, Zimmerman, Johansson, Hertzog, & Barnason, 2014). Future studies should incorporate aspects of both self-reported activity levels and objective measures of activity using accelerometers to describe the differences in patient perceptions compared to objectively measured activity levels.

When looking at the quality of sleep for the sample population using the PSQI measure the study found that isolated rural adults reported poor sleep quality. While spending on average 8.34 hours in bed each night, external factors such as getting up to the restroom, restless legs, and bed sharing with spouses was reported as frequently disturbing sleep and affecting sleep quality. This is of importance to note as poor sleep is associated with increased weight gain and higher levels of obesity. It is interesting to note the study sample had a mean BMI of 32.74 kg/m², obtained from patient medical records, which is indicative of an obesity classification. Future studies should include objective measures of sleep and asleep diary to determine overall sleep quality and habit of isolated rural adults diagnosed with multiple chronic conditions.

Finally, the relationships between self-management processes concepts and self-management behaviors were tested as part of the Individual and Family Self-Management Theoretical Framework. Analyses showed that the only statistically significant relationships were between self-efficacy and self-management behaviors of physical activity and sleep. Self-regulation, social support and patient activation were not significantly related to self-management behaviors of physical activity or sleep. It is interesting to note previous studies have identified a positive relationship between self-regulation and physical activity that were not found in this study. Future studies should look at additional self-management behaviors, both condition specific and general health behaviors (i.e., diet and medications), to determine relationships between the theoretical concepts and specific self-management behaviors.

Limitations

Results of this study are limited by its cross-sectional descriptive design, in that all data were collected at one time point that occurred in the middle of the COVID-19 pandemic.

Furthermore, the sample was recruited from one health care agency and consisted of 100% Caucasian adults with a predominance of females and results need to be verified with a larger, rural sample recruited from multiple geographic areas representative of RUCA 7-10.

Recruitment occurred only from one primary care setting limiting the sample to only adults who access health care resources within that setting and therefore further limits generalizability to populations who lack access to health care centers, choose not to use primary care, or migrant populations that do not establish care with primary care clinics in the region. All data are self-reported with the exception of the number of chronic conditions pulled from the medical record and may be biased by social desirability of responses. The statistically significant differences between normative means and study findings may be due in part to biased responses to provide desirable response during survey data collection. Future research should incorporate methods to prevent social desirability bias such as objective measure of physical activity and sleep (Grim, 2010). Finally, a larger sample with equal representation of both males and females is needed.

Conclusion

This cross-sectional descriptive study described the perceptions behaviors and processes of self-management experienced by adults living in isolated rural communities diagnosed with MCC. The results of the study can be used to help guide the development of a tailored self-management intervention to be implemented in isolated rural communities. The recruitment methods implemented were highly reliant on a positive collaborative relationship with clinic staff. This is a critical finding and the development of strong relationships with trusted rural providers cannot be undervalued. The consenting and data collection methods were feasible for this population and provide a guide for future studies to build upon. The study identified that while social support was high as indicated by the measured scale, focus group results indicated that a desire for additional social support from individuals having similar experiences related to having MCC. The study also identified discrepancies between normative means and sample characteristics for self-regulation. Our sample consisted primarily of female participants who had

lower average scores of self-regulation compared to the normative mean. The normative sample had mostly male participants who scored high on the self-regulation index. Future studies should look at potential gender differences and self-regulatory abilities. It is also important to note that this study measured the self-management behaviors of physical activity and sleep and used self-reported surveys. Future studies should incorporate the use of objective measures to determine differences between self-report and objective measurement of levels of physical activity and sleep quality. Overall, this dissertation provides important information to consider in the development of a self-management intervention tailored specifically for multimorbid adults residing in isolated rural communities.

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APPENDIX

Appendix A: Demographics Survey

1)	Participant Name:	
2)	Cell phone number:	
3)	Does your cell phone have text messaging capabilities?	<input type="radio"/> Yes <input type="radio"/> No
4)	Email Address:	
5)	Birthdate:	
6)	Age:	
7)	What is your current address?	
8)	Town/City:	
9)	Zip Code:	
10)	Mailing address:	
11)	Ethnicity:	<input type="radio"/> Hispanic/Latino <input type="radio"/> Not Hispanic/Latino <input type="radio"/> Unknown <input type="radio"/> Prefer not to answer
12)	Race:	<input type="radio"/> Caucasian/White <input type="radio"/> Black/African American <input type="radio"/> Hispanic <input type="radio"/> American Indian/Alaskan Native <input type="radio"/> Native Hawaiian or Other Pacific Islander <input type="radio"/> Asian <input type="radio"/> More than one race <input type="radio"/> Unknown <input type="radio"/> Prefer not to answer
13)	What is your sex?	<input type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Prefer not to answer

-
- 14) Marital Status
- ☐ Married
 - ☐ Single
 - ☐ Widowed
 - ☐ Divorced
 - ☐ Separated
 - ☐ Cohabitation
 - ☐ Prefer not to answer
-
- 15) What is the highest level of education or school that you have completed?
- ☐ Elementary School
 - ☐ Middle School
 - ☐ High School Graduate/GED
 - ☐ Some college not leading to a degree
 - ☐ Associates degree
 - ☐ Bachelor's Degree
 - ☐ Master's Degree
 - ☐ Doctoral Degree
 - ☐ Prefer not to answer
-
- 16) What type of health insurance do you have at this time? Select all that apply.
- ☐ None
 - ☐ Medicaid
 - ☐ Medicare
 - ☐ PPO
 - ☐ Disability
 - ☐ VA or Military (Covered)
 - ☐ VA or Military (not covered)
 - ☐ Private Insurance Company (Blue Cross, Aetna, Etc.)
 - ☐ Health Maintenance Organization (HMO)
 - ☐ Marketplace (ACA)
 - ☐ Don't Know/ Not Sure
 - ☐ Prefer not to answer
-
- 17) Which Income group comes closest to your total household income in the last year from ALL SOURCES BEFORE TAXES?
- ☐ Under \$20,000
 - ☐ \$20,000 - \$39,000
 - ☐ \$40,000 - \$59,000
 - ☐ \$60,000 - \$79,000
 - ☐ \$80,000 - \$99,000
 - ☐ \$100,000 or more
 - ☐ Prefer not to answer
-
- 18) How many people, including yourself, live in your household?
- ☐ 1
 - ☐ 2
 - ☐ 3
 - ☐ 4
 - ☐ 5
 - ☐ More than 5
 - ☐ Prefer not to answer
-
- 19) Employed
- ☐ Full time
 - ☐ Part Time
 - ☐ Unemployed
 - ☐ Retired
 - ☐ Prefer not to answer
-
- 20) What is your primary occupation/job?
- _____
-
- 21) What is your secondary occupation/job?
- _____

22) How many chronic conditions are you diagnosed with?

- ☐ 0
- ☐ 1
- ☐ 2-3
- ☐ 4-6
- ☐ More than 6

23) What chronic conditions are you diagnosed with or being treated for?

Appendix B: MULTIPLEs Measure

Page 1 of 2

MULTIPLEs

	0 Strongly Disagree	1 Disagree	2 Agree	3 Strongly Agree
1) One of my conditions is more serious than the others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Time spent managing my conditions has made it more difficult to carry out my usual activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) I feel so overwhelmed by the treatment for one condition it is hard to manage any others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) The causes of my conditions are linked.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5) It is difficult to take all my medications the way I am supposed to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6) Time spent managing my condition has limited my activities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7) One of my conditions is more worrying than the others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8) Taking different medications for each of my conditions has caused me problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9) I don't like mixing medications for different conditions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10) Having more than one condition makes my treatments less effective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11) One of my conditions has caused another.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12) One of my conditions dominates the others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13) My conditions interact with each other.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14) Having more than one condition makes it difficult to get the best available treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15) Time spent managing my conditions has reduced my social life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16) One of my conditions has more of an impact on my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Strongly Disagree			Strongly Agree
17)				

Appendix C: Self-efficacy for Managing Chronic Disease Scale

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

- 1) How confident do you feel that you can keep the fatigue caused by your disease from interfering with the things you want to do?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

- 2) How confident do you feel that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

- 3) How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

- 4) How confident do you feel that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

- 5) How confident do you feel that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

- 6) How confident do you feel that you can do things other than just taking medication to reduce how much your illness affects your everyday life?
☐ not at all confident - 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 - totally confident

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Appendix D: Index of Self-Regulation

Instructions here		Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1)	I think of the benefits of changing the ways that I take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2)	I remind myself of the good that I am doing by changing the ways that I take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3)	I remind myself of the importance of changing the ways that I take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4)	I keep track of how I am doing in changing the ways that I take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5)	I watch of signs of progress as I change the ways that I take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6)	I monitor myself to see if I am meeting my goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7)	I have learned new habits that help me take care of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8)	I have learned to approach old situations in new ways	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9)	I have learned to make changes that I can live with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix E: Promis Companionship Measure**PROMIS SF v2.0 - Companionship 4a**

Page 1 of 1

-
- | | | |
|----|--|---|
| 1) | Do you have someone with whom to have fun? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|--|---|
-
- | | | |
|----|---|---|
| 2) | Do you have someone with whom to relax? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|---|---|
-
- | | | |
|----|---|---|
| 3) | Do you have someone with whom you can do something enjoyable? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|---|---|
-
- | | | |
|----|--|---|
| 4) | Can you find companionship when you want it? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|--|---|
-

Acknowledgment: PROMIS Health Organization and Assessment CenterSM [View full acknowledgment](#)

Appendix F: PROMIS Informational Support Measure

PROMIS SF v2.0 - Informational Support 4a

Page 1 of 1

- | | |
|---|---|
| 1) I have someone to give me good advice about a crisis if I need it | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
| 2) I have someone to turn to for suggestions about how to deal with a problem | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
| 3) I have someone to give me information if I need it | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
| 4) I get useful advice about important things in life | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |

Acknowledgment: PROMIS Health Organization and Assessment CenterSM [View full acknowledgment](#)

Appendix G: PROMIS Instrumental Support Measure**PROMIS SF v2.0 - Instrumental Support 4a**

Page 1 of 1

-
- | | | |
|----|---|---|
| 1) | Do you have someone to help you if you are confined to bed? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|---|---|
-
- | | | |
|----|---|---|
| 2) | Do you have someone to take you to the doctor if you need it? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|---|---|
-
- | | | |
|----|---|---|
| 3) | Do you have someone to help with your daily chores if you are sick? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|---|---|
-
- | | | |
|----|--|---|
| 4) | Do you have someone to run errands if you need it? | <input type="radio"/> Never
<input type="radio"/> Rarely
<input type="radio"/> Sometimes
<input type="radio"/> Usually
<input type="radio"/> Always |
|----|--|---|
-

Acknowledgment: PROMIS Health Organization and Assessment CenterSM [View full acknowledgment](#)

Appendix H: Patient Activation Measure (13-item)

1)	When all is said and done, I am the person who is responsible for managing my health.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
2)	Taking an active role in my own health care is the most important factor in determining my health and ability to function.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
3)	I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
4)	I know what each of my prescribed medications does.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
5)	I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
6)	I am confident I can tell a doctor concerns I have even when he or she does not ask.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
7)	I am confident that I can follow through on medical treatments I need to do at home.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
8)	I understand the nature and causes of my health problems.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A
9)	I know the different medical treatment options available for my health condition.	<input type="radio"/> Disagree Strongly <input type="radio"/> Disagree <input type="radio"/> Agree <input type="radio"/> Agree Strongly <input type="radio"/> N/A

-
- | | |
|--|---|
| 10) I have been able to maintain the lifestyle changes for my health that I have made. | <input type="radio"/> Disagree Strongly
<input type="radio"/> Disagree
<input type="radio"/> Agree
<input type="radio"/> Agree Strongly
<input type="radio"/> N/A |
|--|---|
-
- | | |
|--|---|
| 11) I know how to prevent further problems with my health. | <input type="radio"/> Disagree Strongly
<input type="radio"/> Disagree
<input type="radio"/> Agree
<input type="radio"/> Agree Strongly
<input type="radio"/> N/A |
|--|---|
-
- | | |
|---|---|
| 12) I am confident I can figure out solutions when new situations or problems arise with my health. | <input type="radio"/> Disagree Strongly
<input type="radio"/> Disagree
<input type="radio"/> Agree
<input type="radio"/> Agree Strongly
<input type="radio"/> N/A |
|---|---|
-
- | | |
|---|---|
| 13) I am confident I can maintain lifestyle changes, like diet and exercise, even during times of stress. | <input type="radio"/> Disagree Strongly
<input type="radio"/> Disagree
<input type="radio"/> Agree
<input type="radio"/> Agree Strongly
<input type="radio"/> N/A |
|---|---|

Appendix I: DUKE Activity Status Index

Duke Activity Status Index

Page 1 of 1

1)	Are you able to take care of yourself? Ex. eating, dressing, bathing, using the toilet.	<input type="radio"/> Yes <input type="radio"/> No
2)	Are you able to walk indoors?	<input type="radio"/> Yes <input type="radio"/> No
3)	Are you able to walk 1-2 blocks on level ground?	<input type="radio"/> Yes <input type="radio"/> No
4)	Are you able to climb a flight of stairs or walk up a hill?	<input type="radio"/> Yes <input type="radio"/> No
5)	Are you able to run a short distance?	<input type="radio"/> Yes <input type="radio"/> No
6)	Are you able to do light work around the house? Ex. dusting, washing dishes	<input type="radio"/> Yes <input type="radio"/> No
7)	Are you able to do moderate work around the house? Ex. vacuuming, sweeping floors, carrying in groceries	<input type="radio"/> Yes <input type="radio"/> No
8)	Are you able to do heavy work around the house? Ex. scrubbing floors, lifting or moving heavy furniture	<input type="radio"/> Yes <input type="radio"/> No
9)	Are you able to do yard work? Ex. raking leaves, weeding, pushing a power mower.	<input type="radio"/> Yes <input type="radio"/> No
10)	Are you able to have sexual relations?	<input type="radio"/> Yes <input type="radio"/> No
11)	Are you able to participate in moderate recreational activities? Ex. golf, bowling, dancing, double tennis, throwing a baseball or football.	<input type="radio"/> Yes <input type="radio"/> No
12)	Are you able to participate in strenuous recreational activities? Ex. swimming, singles tennis, football, basketball, skiing	<input type="radio"/> Yes <input type="radio"/> No

Appendix J: Pittsburgh Sleep Quality Index

Page 1 of 3

Pittsburgh Sleep Quality Index (PSQI)

Date

Time

AM or PM

PITTSBURGH SLEEP QUALITY INDEX**INSTRUCTIONS:**

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, what time have you usually gone to bed at night?

(BED TIME)

2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

(NUMBER OF MINUTES)

3. During the past month, what time have you usually gotten up in the morning?

(GETTING UP TIME)

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.)

(HOURS OF SLEEP PER NIGHT)

For each of the remaining questions, check the one best response. Please answer all questions.

5. During the past month, how often have you had trouble sleeping because you . . .

5a) Cannot get to sleep within 30 minutes

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

5b) Wake up in the middle of the night or early morning

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

5c) Have to get up to use the bathroom	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5d) Cannot breathe comfortably	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5e) Cough or snore loudly	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5f) Feel too cold	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5g) Feel too hot	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5h) Had bad dreams	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5i) Have pain	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
5j) Other reason(s), please describe	_____
How often during the past month have you had trouble sleeping because of this?	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
6. During the past month, how would you rate your sleep quality overall?	<input type="radio"/> Very good <input type="radio"/> Fairly good <input type="radio"/> Fairly bad <input type="radio"/> Very bad
7. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week
8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?	<input type="radio"/> Not during the past month <input type="radio"/> Less than once a week <input type="radio"/> Once or twice a week <input type="radio"/> Three or more times a week

9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

- ☐ No problem at all
☐ Only a very slight problem
☐ Somewhat of a problem
☐ A very big problem

10. Do you have a bed partner or room mate?

- ☐ No bed partner or room mate
☐ Partner/room mate in other room
☐ Partner in same room, but not same bed
☐ Partner in same bed

If you have a room mate or bed partner, ask him/her how often in the past month you have had...

10a) Loud snoring

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

10b) Long pauses between breaths while asleep

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

10c) Legs twitching or jerking while you sleep

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

10d) Episodes of disorientation or confusion during sleep

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

10e) Other restlessness while you sleep; please describe

- ☐ Not during the past month
☐ Less than once a week
☐ Once or twice a week
☐ Three or more times a week

The Pittsburgh Sleep Quality Index: A New Instrument for Psychiatric Practice and Research (Authors Daniel J. Buysse, Charles F. Reynolds III, Timothy H. Monk, Susan R. Berman, and David J. Kupfer, © University of Pittsburgh 1989)

Appendix K: Focus Group Interview Guide

1

Interview Questions for Focus Group (Dissertation)

Interview Date:

Group:

Number of individuals:

Time:

Moderator:

Location: Zoom Conferencing

AIM: to explore the perceptions of SM needs of rural dwelling adults with MCC.

Hello Everyone, I first want to thank you for taking the time to meet with me today to share your experiences regarding having multiple medical conditions. My name is Jessica Miller and I would like to give you a little background about why I am here with you today. I am a PhD research student at the University of Nebraska Medical Center working toward my degree in nursing research. The focus of my research is to look at the experiences of adults like yourselves in living with multiple medical conditions while living in rural areas.

I am very interested in your thoughts and experiences with having multiple medical conditions and how this impacts your life, specifically your daily routines, sleep, physical activity and medications. I ask that you please share your point of view and are open and honest about your thoughts whether positive or negative. I am recording this session because I do not want to miss any of your comments. One aspect to note regarding this group discussion is that all the information you share will be kept strictly confidential. All names and identifying information will be removed from the transcript to protect your identity. I ask that each of you respect the privacy of one another by not sharing anything that is said during this time outside of this group discussion.

My role will be to ask you questions and listen to your responses. I will be asking about 10 questions and I will be moving the discussion from one question to the next.

Let's begin. (start stopwatch)

Could you each please introduce yourself only identifying yourself by your first name.

Time	Q#1: I would like to start with asking about what your daily routine looks like for you when taking care of yourself and your medical conditions?

	<p>Probe: Tell me about your experiences with sleeping? physical activity?</p> <p>Probe: how you think these activities are impacted by your medical illnesses?</p> <p>5 second rule</p>
Time	<p>Q#4: I want to go a little bit deeper into your feelings about being diagnosed with multiple illnesses. Describe for me what it felt like when you were first diagnosed with your medical illness?</p>
	<p>Probe: How did things change?</p> <p>Probe: tell me more about your feelings when you found out about your other conditions (2nd, 3rd)</p> <p>Probe: When thinking about your medical conditions how do you feel? Scared? Confident? Unsure?</p> <p>5 second rule</p>

Time	Q#5: Next I want to talk about your social interactions. Tell me a little bit about how having your medical conditions has influenced your social life or social interactions.
	<p>Probe: Who do you turn to for social support? What about physical support? Mental support?</p> <p>Probe: What type of support have you found to be the best? (physical? Mental) Why?</p> <p>5 second rule</p>
Time	Q#6: What were your feelings when you first received information about your medical conditions?
	<p>Probe: Did you feel prepared to manage your medical illnesses? Why or Why not?</p> <p>Probe: How did the providers prepare you for managing multiple illnesses/conditions versus just one?</p> <p>Probe: At what point with your medical conditions did you experience a change in your day to day</p>

	activities?
	5 second rule
Time	Q#7: What can be done by health care to better help you in caring for your medical illnesses?
	<p>Probe: What resources do you wish were available?</p> <p>Probe: Tell me about the resources you have found most helpful and why.</p> <p>Probe: When thinking about a program to help people in your community who have multiple medical illnesses what pieces do you think would be helpful to have?</p> <p>Probe: Group support?</p> <p>Probe: Online resources?</p> <p>Probe: Online or app-based programs accessible on smart phones?</p>

	5 second rule
Time	Q#8: I want to make sure you have had time to share your thoughts regarding living with multiple medical illnesses. I would invite you at this time to share any experiences, feelings that you may have not had the opportunity to share previously, now.
	5 second rule

To make sure that I understood every part of our discussion today correctly, I would like to briefly describe what was said. (summarize key concepts in approximately 3 minutes).

Thank you for sharing your thoughts regarding your role and experiences. I also want to thank you for taking the time in your busy schedules to meet with me.

Thank you for your time.

Stop Recording

