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Substance Use Disorder: Experiences of Affected Family Members Social Support

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SUBSTANCE USE DISORDER: EXPERIENCES OF AFFECTED FAMILY MEMBERS SOCIAL SUPPORT

by

Eileen Kane

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Requirements for the Degree of

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ABSTRACT

SUBSTANCE USE DISORDER: EXPERIENCES OF AFFECTED FAMILY MEMBERS SOCIAL SUPPORT

by

Eileen Kane

The University of Wisconsin- Milwaukee, 2020
Under the Supervision of Dr. Julia Snethen

Background: Social support is a factor in the health and well-being of all populations (WHO, 2018). Having a loved one with SUD negatively affects family members. Affected Family Members (AFM) providing support for the individual with ISUD, are at risk of losing their social support network. Losing social support negatively influences AFMs health and well-being. The purpose of this study was to explore the affected family member (AFM) of an individual with a substance use disorder (ISUD) perceptions and experiences of social support. A secondary purpose was to examine the association of social support and how it contributes to the health and well-being of the AFM of an ISUD.

Methods: A mixed methods cross-sectional study was conducted using a convenience sample (N=134) of AFM's. Participants completed an anonymous survey, including participant characteristics, the *Alcohol, Drugs, and Family Social Support Scale* (ADF SSS), and the *Public Health Surveillance Well-Being Scale* (PHS-WS). A subsample of n =101 completed the open-ended questions with n = 1088 responses received.

Findings: Positive social support is significantly associated with increased health and wellbeing of the AFM r (133) = .25, p = .004. Additionally, five themes emerged from the qualitative analysis. (1) *We are all alone, and we have to fend for ourselves*. (2) *No one understands what we are going through*. (3) *Healthcare providers do not know how to provide care and are* *clueless*. (4) *We have no access to effective care or treatment*. (5) *People cannot relate and recoil from us*.

Discussion: The AFMs perceptions and experiences of social support impacts the stress and burden of care for the ISUD. The positive or negative social support of the AFM influences their feelings of health and well-being.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF NOMENCLATURE

Definitions and Abbreviations

- Affected family member (AFM): Any individual, recognized as family, of an ISUD.
- Family: "Any individual that is self- reported as being part of or belonging to a family" (Kaakinen, Coehlo, Tabacclo, Steele, & Hanson, 2015, p. 239).
- Individual with substance use disorder (ISUD): An individual with the recurrent use of a substance causing clinical and functional impairment as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), (American Psychiatric Association, 2013).
- Social support: The intentional efforts to help a person are social support (Vaux, A.,1988).
- Substance use disorder (SUD): The problematic recurrent use of substances despite risks of harm to self and others.

Keywords: Addiction, Drug Abuse, Drug Use, Family Members, Health, Social Support, Substance Use Disorder, Well-Being

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I give a huge shout out to the AFM's who participated in this survey. I am so grateful for the opportunity to hear your story. I am hopeful this study and future studies will bring improved assessments, education, and programs to help lighten your stress and foster improved social support from family, friends, the community, and health care professionals. And, I hope that improved social support will lead to improving everyone's health and well-being.

Thanks to my loving and supportive family, friends, and coworkers., I have not forgotten your untiring support. Yes, we will be able to reconnect and spend time together again. I will step out of my office and participate in our lives again.

Chapter 1

The purpose of this study was to explore the affected family member (AFM) of an individual with a substance use disorder (ISUD) perceptions and experiences of social support. A secondary purpose was to examine the association of social support and how it contributes to the health and well-being of the AFM of an ISUD. Social support is known to improve the health and well-being of many populations and disease processes (Caplan, 1974; Lincoln, 2000; Uchino, 2004; Vaux, 1988). Social support is recognized to influence positive outcomes for the ISUD (Brooks et al., 2017: Orford, Templeton, Patel, Copello, & Velleman, 2007, Orford, Templeton, Velleman, & Copello, 2010, Orford, Velleman, Natera, Templeton, & Copello, 2013, Toner & Velleman, 2014). This research study sought to explore the relationships between social support and the health and well-being of the AFM.

Significance

This research study is significant in increasing nursing knowledge about the experiences and perceptions of the AFM, specifically, their social support and the associations to their health and well-being. Identifying the specific needs of the AFM is a crucial step in the development of programs designed to improve the social support and the health and well-being of the AFM.

Nurses are healthcare providers that have the unique role of being close in space, time, sociologically, and psychologically to the AFM (Caplan, 1974). This unique role allows for the identification of the AFM needing assistance. The nurse, as a healthcare professional, can utilize this unique role to recognize, support, interpret, and advocate for the AFM to other healthcare providers (Caplan, 1974).

AFMs are involved in multiple ways to provide social support to the ISUD, including providing needed food, housing, healthcare, and transportation for the ISUD. It is essential to gain a greater understanding of the circumstances of the AFM to ensure needed social support and their health and wellbeing.

Substance Use Disorder (SUD)

Substance use disorder (SUD) is the problematic use of drugs, alcohol, or other psychotropic substances (SAMHSA, 2018). Deaths due to SUD continue to be a public health concern despite many education, prevention, and drug control programs within the United States. The United States Health and Human Services have reported that 116 people die from a drug overdose per day (United States Department of Health and Human Services (USHHS), 2018). The National Survey on Drug Abuse and Health (2017) reports 20.1 million individuals, over the age of 12-years, have a SUD in the United States. The statistics indicate that approximately 7.5% of the population of the United States had a SUD in 2016 (SAMHSA, 2018). These numbers do not represent the number of AFM's. However, the numbers do support the idea that there exist many family members affected by SUD.

The ISUD actively seeks out drugs despite harmful consequences (Nutt & McLellan, 2014). The individual results of SUD include infectious diseases, homelessness, and lack of healthcare, poverty, and malnutrition. SUD causes clinical and functional impairments such as health problems, disability, and failure to meet responsibilities at work, school, or home (Substance Abuse and Mental Health Services Administration (SAMHSA) 2018). The harmful consequences of actively seeking out and using drugs by the ISUD have the potential to affect their family members (Lander, Howsare & Byrne, 2013). The family and family functioning of the ISUD may suffer similar consequences (Lander et al., 2013).

SUD is a chronic disease requiring on-going supportive care. Recovery from SUD is challenging. Recovery from SUD may include several cycles of relapse and recovery before achieving recovery maintenance. As the ISUD cycles through treatment, recovery, and relapse, the AFM also cycles through the stressful and costly cycle of relapse and recovery. SUD can cause emotional, psychological, physical, and financial strain on the family and family functioning (Casey, 2017; Kelly, Fallah-Sohy, Cristello & Bergman, 2017; Lander et al., 2013).

Affected Family Member (AFM)

The World Health Organization (WHO) has estimated that SUD has resulted in 2 million deaths and 11.2 million disability-adjusted life years (DALY's) lost (2018). Research on the impact of another's SUD on the AFM is limited (Lander et al., 2013). While there is evidence that SUD impacts morbidity and mortality rates, Degenhardt, Whiteford, and Hall (2014), found limited research related to the global burden of disease and SUD. Degenhardt et al. (2014) found that the Global Burden of Disease Study, reported in 2010, did improve the epidemiological reporting of substance use in regional and global reporting. However, the magnitude of risk for injuries, violence, mental health, and physical health due to SUD did not generate much data. More data is needed to recognize the actual burden of disease caused by the SUD on the AFM (Degenhardt et al., 2014).

The AFM is at risk for unmet development needs, economic hardship, emotional problems, and violence (Dion, 2014; Lander et al., 2013). The risks to the AFM include stigma, disrupted lives, loss of support, loss of quality of life, and chronic stress (Dion, 2014). Chronic stress places added strain on the health and well-being of the AFM (Graessel, Berth, Lichte & Grau, 2014). Chronic stress negatively impacts the psychosocial, physical, and financial well-being of the AFM (Sakiyama, Padin, Canfield, Laranjeira & Mitsuhiro 2015), leading to declining health, disability, or death (Orford, Copello, Velleman & Templeton, 2010). The increasing prevalence of SUD contributes to the increased risk to the health and well-being of the AFM (Sakiyama et al., 2015; Selbekk, Sagvaag, & Fauske, 2015).

The ISUD may rely on the affected family member (AFM) for guidance, as well as, physical, financial, and emotional support during the cycles of relapse and recovery (Casey, 2017, Sakiyama, et al., 2015). The social support supplied to the ISUD, by the AFM, has been identified as being useful in the reduction of drug use, treatment, and better family functioning (Selbekk et al., 2015). Social support and its connection to the health and well-being of the AFM's remains neglected, unrecognized, and limited (Baharudin et al., 2014; Orford et al., 2013; Selbekk et al., 2015).

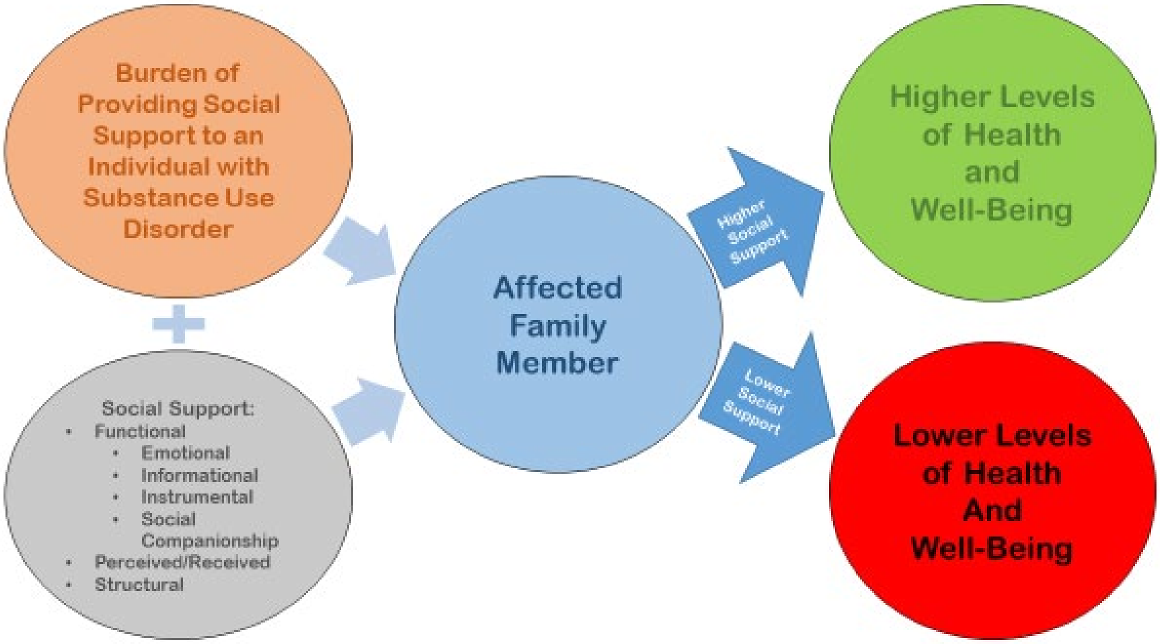
Social Support

Social support is an essential factor in the health and well-being of individuals (Caplan, 1974; Frey, 1988; Lincoln, 2000; Vaux, 1988). Reduced social support places individuals at risk of decreased health and well-being (Caplan, 1974; Vaux, 1988). Family members affected by another's drug use represent a large population at risk for reduced social support. Thus the health and well-being of the AFM's may be at risk.

The conceptual framework of social support guides this research study. Social support has a beneficial influence on well-being, regardless of the stress experienced by the individual (Armstrong, Birnie-Lefcovitch & Ungar, 2005; Caplan, 1974; Vaux, 1988). The conceptual framework of social support for this study includes the functional, perceived and received, and structural constructs. The definitions of the constructs of social support utilized for this study follow. For the conceptual model used for this study, see Figure 1.

Figure 1

Social Support and Affected Family Member



Functional Social Support

The functional dimension of social support refers to the type, quantity, and quality of aid or assistance provided. The functional aspect of social support includes emotional, informational, instrumental, and social companionship.

Emotional. Emotional support may be expressive, emotionally sustaining, appraisal, esteem, close affirmation, affect support, and autonomy (Caplan, 1974; Toner, 2009; Vaux, 1988). Emotional, social support may be conveyed verbally or nonverbally, including methods of communicating reassurance, appreciation, respect, love, and affection. Emotional support also includes allowing for the expression or ventilation of feelings of frustration or anger without reprisal. Emotional support leads to the bolstering of self-worth and self-identity.

Informational. Informational support may include advice, cognitive support, guidance, and feedback (Caplan, 1974; Toner, 2009; Vaux, 1988). The transmission of knowledge and the ability to obtain knowledge are essential aspects of informational support. The provision of information on how one goes about acquiring knowledge, advice, skills, feedback, and guidance, help with motivation and problem-solving skills (Vaux, 1988). Guides to action and strategies for coping are a function of informational support. Armstrong et al. (2005) found that pathways or guides to action were an essential aspect of social support.

Instrumental. The instrumental functional dimension of social support is the most tangible, concrete, or material form of support (Caplan, 1974; Toner, 2009; Vaux, 1988). The provision of resources, material help, goods, services, transportation, errands, chores, financial, and physical support make up instrumental support (Caplan, 1974; Vaux, 1988). The ability to help solve practical problems and increase a feeling of control are aspects of instrumental social support.

Social Companionship. Social companionship, positive social interaction, or socializing support are part of collaboration (Vaux, 1988). The shared tasks, interests, leisure activities, recreation, sharing concerns, and conversations of collaboration lead to positive health outcomes. The events become a shared experience rather than just a provision of help. The function of just enjoying each other's company with positive verbal and nonverbal cues reduces loneliness and isolation. Social companionship will strengthen social bonds, distract from worry, facilitate positive affective emotions, and produce feelings of well-being (Caplan, 1974).

Perceived and Received

Perceived and received social support is the perception of the social support of the AFM. Perceived and received social support is the appraisal of the support received and the opinion of the amount and quality of the support. Perceived social support is the cognitive perception of the availability of support and supportive actions. Received social support is the actual number of supportive activities received by the AFM. The uniqueness of each AFM may lead to differences in how social support is perceived and received (Caplan, 1974; Vaux, 1988)). Each AFM may process the assessment of social support differently and according to their unique perspective, experiences, and knowledge. Perceptions of available support may influence feelings of well-being in individuals, even if the support is not used or needed (Caplan, 1974; Vaux, 1988).

Structural

Structural social support does review the type and number of social networks. The type and number of social networks include the community, social networks, and intimate and confiding relationships. The number of available contacts in the social network is reviewed, not the quantity (Uchino, 2004; Vaux, 1988; Veiel & Baumann, 1992).

Social support can be provided to an individual on an ongoing or as-needed basis. Many social support dimensions also may co-occur, making it challenging to identify which aspect has the most significant impact on health and well-being. The types of social support are essential to know in understanding social support. The effects of social support are imperative to know when identifying how they affect health and well-being. Figure 1 (p. 6) represents the conceptual model of SUD, AFM, and Social Support as developed and utilized for this study. Figure 2 (p. 15) represents the conceptual model of SUD, AFM, and Social Support with the measurement instruments used for each construct within the study.

Purpose of the Study

The purpose of this study was to explore the affected family member (AFM) of an individual with a substance use disorder (ISUD) perceptions and experiences of social support. A secondary purpose was to examine the association of social support and how it contributes to the health and well-being of the AFM of an ISUD.

Research Questions

The research study addressed the following research questions (RQ) quantitatively and qualitatively.

RQ # 1: What are the social support perceptions of AFM's?

RQ # 2: What are the social support experiences of AFMs while providing support to an ISUD?

RQ # 3: What is the association between AFM reported social support levels and their perceptions of health?

RQ # 4: What is the association between AFM social support levels and their perceptions of well-being?

RQ # 5: What is the relationship of the subscales, functional, perceived and received, and structural levels of social support, to health and well-being reported by the AFM?

RQ # 6: Is there an interaction between social support and the perceived health and well-being of the AFM?

Research Hypotheses

The research hypotheses (HO) for this study are included below:

H0 # 1: The AFM, who perceives receiving positive social support, will report higher levels of health and well-being.

H0 # 2: The AFM, who perceives receiving inadequate positive social support, will report lower levels of health and well-being.

Study Variables

Table 1 includes the study variables.

Table 1:

Study Variables

Type	Variable	Components/Scales
Dependent	Health Status of AFM Well-being of AFM	PHS-WS
Independent	Characteristics	Age Gender Race Ethnicity Education Relationship Status Employment Status Living situation Participant Characteristic Survey
Independent	Social Support • Functional Support o Emotional o Informational o Instrumental o Social Companionship • Perceived/Received Support • Structural Support	Quantitative Data Collection ADF SSS 25 item survey Qualitative Data Collection Self-report responses to open-ended questions

Operational Definitions

Dependent Variables

The dependent or outcome variables in this study are the health status and well-being of the AFM and the recovery status of the ISUD. One item measured the recovery status of the ISUD within the Participant Characteristic Survey (see Appendix A). One self-report question measured the health status of the AFM. The one-item question measured health as poor, fair, good, very good, and excellent. The Public Health Surveillance Well-Being Scale (PHS-WS), as developed by Bann et al. (2012), was used to measure well-being (see Appendix B).

Independent Variables

Demographics

This study used the participant characteristics survey developed by the research team members. The participant characteristics data include age, gender, race/ethnicity, education, employment status, living situation, and relationship status of the AFM. The Participant Characteristic Survey is included in Appendix A.

Social Support

Social support was measured both qualitatively and quantitatively. The qualitative method of measurement used open-ended questions relating to the constructs of social support (See Appendix C). The quantitative approach utilized the 25-item Alcohol, Drugs, and Family Social Support Scale (ADF SSS – 25 Item) (See Appendix D). This study used the ADF SSS total scale scoring and the subscales to collect the quantitative data related to the experiences and perceptions of social support of the AFM. The total ADF SSS scale scoring includes aspects of functional, perceived and received, and structural types of social support. The subscale of positive functional support measures emotional, social companionship, and instrumental types of social support. The subscale of positive ADF specific support measures formal and informal informational, emotional, support for coping, and attitudes and actions towards the ISUD. Additionally, the subscale of negative ADF specific support measures support for coping and attitudes towards the ISUD (Toner & Velleman, 2012). The following paragraphs describe the social support constructs measurement instruments used in this study.

Functional Support. Functional support is the type, quantity, and quality of the support available to an individual. Functional support includes emotional, informational, instrumental, and social companionship. Functional support was operationalized with open-ended qualitative self-response questions and with eleven quantitative Likert response items included in the ADF SSS- 25 item questionnaire.

Emotional. Emotional support provides affirmation, appraisal, esteem, and affect support. Emotional support was operationalized with two open-ended questions and the ADF SSS- 25 item questionnaire.

Informational. Informational support includes offers of advice, guidance, and feedback. Two open-ended questions and the ADF SSS -25 item questionnaire operationalized informational support.

Instrumental. Instrumental support is tangible, concrete, practical, or material support. Instrumental support was operationalized with two open-ended questions and the ADF SSS -25 item questionnaire.

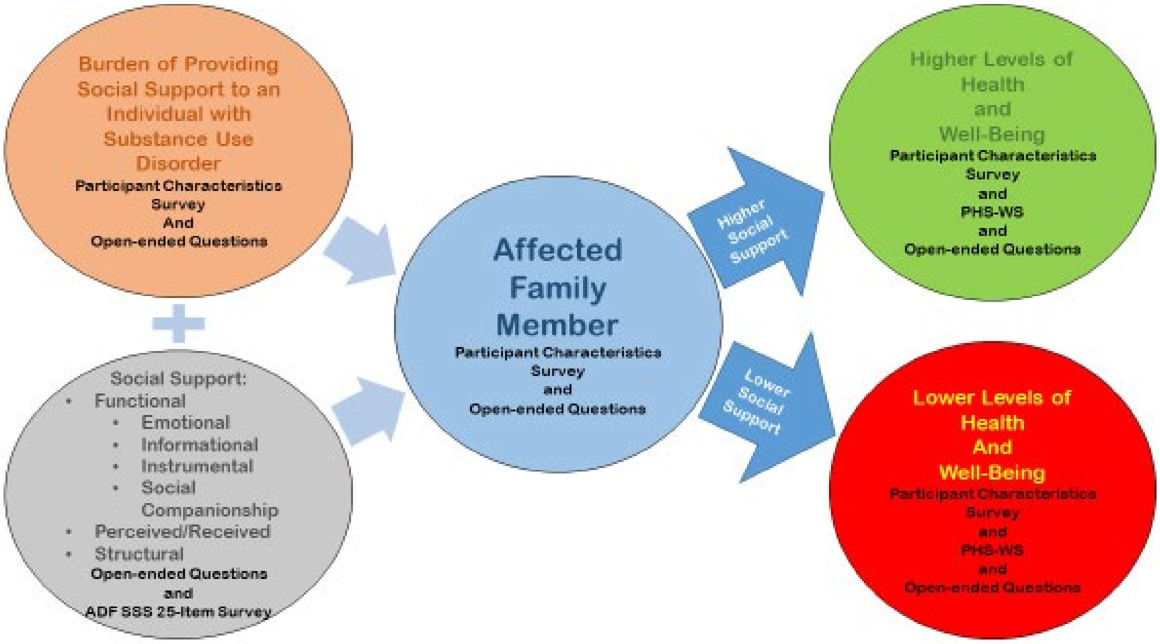
Social Companionship. Social companionship provides positive social interaction, socialization, and social activities. Social companionship was operationalized with two open-ended questions and the ADF SSS -25 item questionnaire.

Perceived and Received. Conceptually the perceived and received support refers to the general perception of support and the actual support received. Two open-ended questions operationalized perceived and received support.

Structural. The conceptual definition of structural support lends itself to a quantities approach. Structural support refers to the existence of, the size of, the quantity of, and the frequency of contacts considered social supports. The structural supports were measured and operationalized with two open-ended questions and the ADF SSS -25 Item questionnaire. See Figure 2 for the conceptual model, constructs of social support, and the corresponding measurement instruments.

Figure 2

Social Support, Affected Family Member and Measurement Instruments



Personal Statement

The topic of substance use is very personal to me. I am an AFM. I am the mother of two sons with SUD. My sons are addicted to heroin. My sons are both in recovery currently. Over the last 12 years, I have experienced the effects of SUD from four distinct viewpoints, which have all changed my life and my beliefs related to SUD. The first viewpoint is that of the ISUD. This viewpoint occurred as I watch and listen as my children struggle with SUD, overdose, and the consequences of criminal activity. The second is the viewpoint of a being a parent, helpless in the treatment and recovery of SUD. A third viewpoint comes from my profession of nursing, which includes the difficulty, frustration, and attitudes of other healthcare professionals while trying to provide care for an ISUD and the AFM. The fourth viewpoint is that of belonging to the community of people affected by another's SUD through my normal activities and participation in social support groups. My experiences and my research about SUD has led me to this research study.

Summary

Social support is known to influence health and well-being. SUD is a disease that causes decreased health and well-being for the individual and the family. The AFM may be at increased risk for health and well-being problems as they provide support for a loved one with SUD. The research was needed to improve the nursing knowledge base about the experiences and perceptions of the AFM. This added insight into the social support of family may lead to the development of interventions that may improve the health and well-being of the family.

The response from healthcare providers and the consequences of a diagnosis of SUD has led to fear and secrecy among those that are affected by drug use (Martin & Stanley, 2008; Palamar, 2012). The AFM of the ISUD may also experience fear and secrecy (Orford et al., 2013). The fear and secrecy undermines the ability to provide adequate care and is detrimental to the health and well-being of the AFM. Fear and secrecy can lead to increased social isolation, lack of disclosure of medical needs, and inadequate treatment (Martin & Stanley, 2008). The fear of discovery and legal, financial, career, and family concerns deter AFM's from treatment. The AFM of the ISUD may not report physical (Copello, Templeton, & Powell, 2010) emotional, social, or financial health concerns due to fear exposure or censure for themselves or their family member. Gaining knowledge about the AFM and their social support was essential. This knowledge provides useful information for future research and intervention programs for the AFM.

Chapter 2

Literature Review

Substance use disorder (SUD) causes devastation to the lives and health of those that encounter it (Barnard, 2007). Government and public concern, as well as health policy and research, have often focused on the ISUD. The health risks, criminal behavior, and the potential for increased morbidity and mortality of the ISUD are well-publicized (Copello et al., 2010). The devastation of SUD that finds its way to the parents, siblings, children, and close relatives is less recognized (Barnard, 2007). The consequences to the affected family member (AFM) may include danger, stress, strain, and the debilitation of their health and well-being (Barnard, 2007). The AFM may not recognize the impact the SUD is having on their lives because they are focused on the needs of the ISUD (Barnard, 2007). The AFM is often the primary source of social support for the ISUD. The social support provided by the AFM improves the health, well-being, and recovery of the ISUD (Orford et al., 2010). The AFM may provide social support to the ISUD, causing the AFM an adverse outcome to their social support, health, and well-being (Barnard, 2007; Copello et al., 2010). The AFM is at risk for decreased social support, health, and well-being. The purpose of this study was to explore the experiences and perceptions of social support and associations with the health and well-being of the affected family member (AFM) of an individual with a substance use disorder (ISUD).

The following paragraphs include a discussion of the current literature available related to AFM, Social Support, Health and Well-being, and the ISUD. Extensive research was available relating to the ISUD. The researcher completing a quick search within MEDLINE was able to locate the following articles related to the ISUD. The materials retrieved included the following topics:

- Genetic epidemiology of substance use disorders (Prom-Wormley, Dick, & Bowers, 2017)
- Social support and the link to depression for the ISUD (Leghari, Bano, Ahmad, & Akram, 2018)
- Associations among mental illness and SUD (Hartz et al., 2017)
- The complexities of group therapy for SUD treatment (Wendt, & Gone, 2018)
- The non-medical use of prescription opioids and subsequent SUD (McCabe et al., 2019)
- Childhood adaption and experiences with parental SUD (Håkansson, Söderström, & Øie, 2018; McCutcheon et al. .2018)
- Codependency (Kelly, 2017)
- Concurrent disorders (O'Grady & Skinner, 2012).

A gap in the research was evident through the difficulty in retrieving articles relating to the effects of an ISUD on the social support, health, and well-being of the AFM. The literature review used a comprehensive integrative review format due to the difficulty in obtaining reports regarding the AFM (Knafl & Whittemore, 2017).

Literature Review Methods

The purpose of this literature review was to identify articles relating to AFM, Social Support, Health and Well-being, and the ISUD to social support. An integrative literature review allowed the researcher to examine relevant articles from a variety of databases. The articles reviewed dated from 1974- 2018. The databases included in the literature search were the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Pub Med, Google Scholar, and MEDLINE. The keywords and combinations of keywords used to complete the literature search are as follows: (a) drug abuse, (b) drug use, (c) substance abuse and use,(d) substance use disorder,(e) caregiver, (f) informal caregiver, (g) family, (h) family members, (i) parents,(j) siblings, (k) extended family, (l) chronic illness, (m) chronic disease, (n) social support,(o) health, and (p) well-being). Inclusion criteria were: (a) written in English, (b) substance use disorder, (c) affected family members, (d) social support, (e) chronic disease, (f) health and well-being, (g) interventions, and (h) measurement instruments. Exclusion criteria were non-English language, not within the stated dates, and not related to the keywords. The initial search utilizing substance use disorder, family member, and social support resulted in 10,237 publications. A review of titles and abstracts resulted in 71 articles chosen for in-depth analysis. Five items were unable to be obtained. Sixty-six articles with full text available met the inclusion criteria. The researcher selected twenty-five articles for the literature review according to the inclusion criteria. The researcher read each article at a minimum of two times.

The articles were categorized into groups representing the following themes and subthemes. The first theme was social support. The first theme was categorized into the following subthemes of health and well-being, access to social support, and social support self-help groups. The second theme identified was the AFM. The second theme was categorized into the following subthemes of the impact of SUD on the AFM, social support provided by the AFM in SUD, and interventions for the AFM. Additional themes identified in the literature review include stigma and measurement instruments. The themes and subthemes are discussed in the following paragraphs.

Social Support

The literature review identified social support, particularly from family members, was linked to improved health and well-being of the family in a variety of circumstances. Social support is a factor in the health and well-being of families with family members with chronic illness and disease (Armstrong et al., 2005; Frey, 1988). Access to social support researched in studies completed by Gage-Bouchard, Panagakis, & Shelton (2015), Gage-Bouchard (2017), Selbekk, et al., (2015), Selbekk and Sagvaag (2016). Social support through self-help groups was the topic of research for studies completed by Kelly et al., (2017) Sakiyama et al., 2015, and Stenton, Best, and Roberts (2014).

Health and Well-Being

Due to difficulty, locating articles relating to health, well-being, and social support of the AFM with ISUD, required the inclusion of complementary articles. Included in the literature review are articles about chronic illness/disease, health and well-being, and the effects on the family. Research conducted by Frey (1988) and Armstrong et al. (2005) conducted studies that included health and well-being as related to chronic disease. The chronic illnesses represented are insulin dependents diabetes mellitus (IDDM) and cancer. IDDM and cancer are chronic illnesses requiring long-term care and support for the patient and the AFM. SUD is a chronic disease that requires long-term care and support for the ISUD and the AFM. Comparisons from this chronic disease research can be applied to SUD and the AFM.

Frey identified the effects of social support on the health and well-being of the family and family members in 1988. Frey (1988) studied 103 families with children with IDDM, finding that social support provided to the parents improved overall family health. Parents that perceived higher levels of support reported higher levels of family health. Frey (1988) reported this as a significant finding with ($t=4.87$, $p<0.05$). The discussion stressed the need for further study to examine the relationship between social environments and health.

Armstrong et al. explored social support as a mechanism for the health and well-being of parents of children with cancer in 2005. The impact of social support provided both main effects and buffering effects for the parents of ill children, thus improving the resilience of the child. The results of social support for the parents of ill children is comparable to the impact of social support for the AFM, thus increasing the recovery of the ISUD. Armstrong et al. 2005 recommended both qualitative and quantitative research into the effects of social support of the parents. Armstrong et al., 2005 indicated that the knowledge of social support of the parents could contribute to effective prevention, assessment, and intervention models for the family. The overall benefits of social support for the parents would then benefit the parents and the ill child. This review aimed at the parents' support for sick children; is a parallel for the family member supporting the ISUD. The need to understand the social support of the affected family member will provide an opportunity to improve the health and well-being of the AFM and the ISUD.

Access to Social Support for the AFM

Gage-Bouchard et al., (2015), studied the support parents of pediatric cancer patients had access to during their child's illness. Eighty parents were interviewed about their support. Gage-Bouchard et al. (2015) found that the parents received structural support from a broad network. The network of support included pre-existing relationships, friends, family, other cancer families, health care professionals. The parents received functional support, which included emotional, informational, instrumental, and social companionship support through family, friends, and support groups with other families with a child with cancer. Health care professionals acted as both support and brokers of support developing new networks and connections of social support for the parents (Gage-Bouchard et al., 2015).

Gage-Bouchard (2017) looked at social support as a critical factor for parents or family members to learn to navigate the healthcare system to receive needed care for their loved ones and support for themselves. This study focused on pediatric cancer care, parents, and caregivers (Gage-Bouchard, 2017). The information provided has many similarities and concerns that apply to the AFM of a loved one with SUD. Social support may shape family members' health through many different mechanisms (Gage-Bouchard, 2017).

In 2015, Selbekk et al. recognized the growing concern for the well-being and health of families due to the consequences of addiction. Including the family members in the treatment process also improved the treatment and health outcomes for ISUD. However, the stress and strain on the family members were not explicitly recognized. Selbekk et al., 2015, reviewed theoretical models that may be effective in research dedicated to the AFM of the ISUD. The researcher reviewed the stress-strain-coping-support (SSCS) model and the social-ecological (SE) model. The SSCS model focuses on the individual needs of the AFM and mobilizing social resources. The SSCS was found not to focus on the relationships of the AFM and the ISUD. The SSCS provided concrete, practical, and convenient methods for the AFM through the 5-Step intervention. The SE has an extensive focus on the entirety of addiction, including the relationship between the AFM and the ISUD (Selbekk et al., 2015). The SE provided an overarching framework. The SE did not offer a concrete intervention to be utilized by either the AFM or the ISUD (Selbekk et al., 2015).

Selbekk and Sagvaag (2016) conducted in-depth interviews with the directors and clinical staff from drug treatment centers located in Norway. The aim of the study conducted by Selbekk and Sagvaag was to determine the options available for AFMs in need of treatment due to their loved ones with SUD (2016). Selbekk and Sagvaag found that there was a recognition of the need for family intervention to improve outcomes (2016). However, healthcare professionals did not see that providing care to the AFM was also useful in the care of the ISUD. There remains a need to identify the needs of the AFM as separate from the ISUD while remaining open to the improved outcomes with family interventions.

Self-Help Groups and Social Support

The use of self-help groups increases feelings of health and well-being for the AFM (Kelly, 2017; Stenton, 2014). Kelly et al. (2017) identified that the use of opioids is a public health crisis in which assistance and intervention focus on the ISUD, not the AFMs. The AFM also suffers from the effects of the SUD. Kelly et al. (2017) completed a mixed methods study investigating the support offered to AFMs through one support group located in New England. The study included 509 participants attending the support group either in person or online. The participants, comprised of 77 % women, and 97.8% described themselves as white, with a median household income of 100,000 thousand per annum. AFMs were parents, spouses, siblings, aunts/uncles, cousins, friends, children, and grandchildren. 88.7% of the participants were parents. Substances used included heroin, other opioids, alcohol cannabis, cocaine/crack, and benzos. The results of the study presented three themes. The themes include benefits of participation, Narcan training, and the participant's responses to what they like most/least about the support group. The participants reported benefits such as a greater understanding of addiction, able to help loved ones more, less blame on themselves for the addiction, less bothered, less stress, improved coping, and improved communication with their loved one (Kelly et al., 2017). 64.6 % of the participants received Narcan training. Participants reported Narcan training as very helpful, and 44% had reported utilizing the training in overdose reversals. In response to what the participants liked about the group, imparting information, instilling hope, universality, and cohesion were most indicated (Kelly et al., 2017). In response to what the participants least liked, included meeting content, process, and logistics of attending meetings (Kelly et al., 2017). The limitations of the study include a lack of diversity and a relatively high socioeconomic status of participants. The use of support groups may be a valuable and helpful resource for AFMs of ISUD. There is a need for future research of support groups in more diverse cultural and economic populations.

Stenton, Best, & Roberts, 2014, conducted a mixed methods study located in Australia. Thirty-nine participants completed the survey. The participants were attending self-help groups due to a loved one with SUD. The study by Stenton et al. (2014) had two aims; (a) identify the relationship status of the ISUD to the AFM and (b) identify the benefits of the self-help groups on the well-being of the AFM. The effects of having a loved one with SUD were reported as unsatisfactory relationships, distrust, fear, anxiety, sadness, grief, child neglect, poor communication, and financial difficulties. Seventy-one percent of the participants reported dissatisfaction with the information and the timeliness of the information available through the self-help groups. However, over 90% of the participants reported the traditions, opportunity to share, meeting others, tips for self-care, and learning strategies for survival as positive aspects of the self-help groups (Stenton et al., 2014). More than 50 % of the participants reported improved happiness and quality of life through the attendance in the self-help group. Participants who reported greater satisfaction with the self-help group reported better quality of life ($x^2 = 13.97$, *df* =6, p<.05) (Stenton et al., 2014).

Self-help groups improve the health and well-being of the AFM. However, there is a lack of support groups, and the reluctance of the AFM to seek help. Sakiyama et al. (2015) completed a study in Brazil, exploring the experiences of AFMs who were already seeking help from support groups. Sakiyama et al. (2015) found that 67.6% of the respondents were parents of the ISUD. Another 30.4% of the participants included spouses, siblings, grandparents, aunt/uncle, and boyfriend/girlfriend of the ISUD. Only 2% of the participants were children of the ISUD. The study revealed that the substances used included cannabis, cocaine, alcohol, and crack cocaine. Key themes in the study results included support seeking and conflicts with the ISUD. Family members reported a lack of understanding of where to seek help. Forty-two percent sought help immediately. The other 58% sought help on average of over six years to seek help (Sakiyama et al., 2015). Common reasons for not seeking help was a decreased knowledge of the

SUD, and a belief the substance use was transient. The participants reported conflict with the ISUD included difficult communication, unacceptable behaviors, physical fights, and financial issues. Limitations of this study are the sample included one group of high socioeconomic AFMs seeking support in Brazil. Future research indicated would consist of barriers to seeking help, education related to the chronicity of SUD, the availability of support services, and the diversity of the AFM in need of assistance (Sakiyama et al., 2015).

Affected Family Member (AFM)

The review of the literature identified two themes related to the affected family member. The first theme was the impact of SUD and chronic disease on the AFM. Velleman et al., (1993), Nebhinani, Anil, Mattoo, & Basu, (2013), and Fotopoulou and Parkes, (2017) explored the effects of SUD on the AFM. Wittenberg, Saada, and Prosser, (2013) and Amankwaa, (2017) provide a broader view of the impact of chronic disease/illness on the family members with spillover effects and informal caregiver stress. The second theme identified was the impact of social support provided by the AFM on the recovery of the ISUD. Hornberger and Smith (2011) provided some insight into the need for family and the effects of family on recovery for SUD. The third theme identified was interventions for the ISUD that included the AFM. The following paragraphs provide a discussion of the themes and related studies.

Impact of SUD on the AFM

The impact of SUD on the AFM was explored in the following studies conducted in the United Kingdom, India, Brazil, and Greece. The research studies were completed using a variety of designs and approaches, including qualitative, quantitative, and mixed methods. The following paragraphs contain a presentation of the research studies.

Velleman et al. (1993) conducted semi-structured interviews with 52 family members from 50 families of individuals with SUD. There was a total of 33 women, and 19 men interviewed. The participants included parents, partners, siblings, and one child. The substances used by their family members with SUD included tranquilizers, opiates, and amphetamines. The results obtained showed that the family members experienced a wide range of negative behaviors from the ISUD. The negative behaviors included unpredictable behavior, stealing from the family member, being lethargic, and behaving negatively (Velleman et al. 1993). The family members also reported experiencing loneliness, fatigue, malaise, anxiety, depression, guilt, apprehension, worry, tension, worry, and suicidal ideation because of their experiences with the ISUD (Velleman et al. 1993). Some of the family members reported some support. However, most family members were dissatisfied with the support received (Velleman et al. 1993). The study identified the need for support from other family, friends, and healthcare professionals.

In a study completed in India recognized the burden that substance use places on the family and family members. Nebhinani et al. (2013) explored the type of substance use and the influence on the amount of burden experienced by the AFM. The study included eighty family members involved in the care of individuals with SUD. The burden felt by the AFM of individuals injecting substances was significantly higher than those with a relative with a non-injecting ISUD were. Seventy percent of AFMs of the individual with an injecting ISUD had a more significant severe objective burden and compared to 5% in the non-injecting group with a $P<0.01$ (Nebhinani et al., 2013).

Additionally, 80% reported severe subjective burden as compared with 50% for the non-injecting group. However, both groups reported substantial subjective and objective burden while supporting their loved one (Nebhinani et al., 2013). Small sample size limited the study.

Future research recommendations include increasing the sample size, increasing demographic parameters, and the inclusion of life events such as coping, stress, and social support (Nebhinani et al., 2013).

Fotopoulou and Parkes (2017) completed a qualitative study of family members affected by another's SUD in Greece. The stress-strain-coping-support model was employed in the analysis and interpretation of the findings. The study sought to interview parents of problem drug users. The researchers report that they were unable to recruit parents willing to participate despite the consent of problem drug users in treatment (Fotopoulou & Parkes, 2017). The study was revised to recruit participants belonging to a parent support group. The revised study included forty problem drug users and eight parents (Fotopoulou & Parkes, 2017). Fotopoulou and Parkes (2017) identified three themes after analysis of the interview data. The three themes identified were coping with the drug problem, sources of support, and stress and strained relationships.

Fotopoulou and Parkes (2017) found that family members employed a wide variety of methods of coping. The families used the techniques of coping to deal with the ISUD. The family members would assist with treatment, withhold resources, limit access to drugs, limit access to money, and threaten expulsion from their homes. The family members did report utilizing state resources if the previously listed methods were not helpful. Family members accessed sources of support for the ISUD. Family members turned to extended family and provided social support for the ISUD. Family members did not report accessing social support for their health and well-being. Family members reported seeking state services and support groups to help their loved one with SUD, not to help themselves. Family members did report increased stress and strained relationships because of the ISUD. Family members reported issues related to finances, time, effort, family integrity, social isolation, professional life disruption, worry, and embarrassment as concerns related to the ISUD (Fotopoulou & Parkes, 2017). Limitations of this study are the small family member sample, the participants were all members of the same social support group, and the interpretation of the findings through the lens of the SSCS model only. Fotopoulou and Parkes (2017) do advocate for a non-pathological view of AFM as they provide social support to the ISUD. Fotopoulou and Parkes discuss the need for greater awareness of the needs of the AFM (2017). The greater awareness of the needs of the AFM may destigmatize SUD and the AFM. The destigmatization of SUD and the AFM may decrease efforts to conceal drug use, reduce barriers to treatment, and increase the development of interventions.

Impact of Chronic Disease on the AFM

Wittenberg et al. 2013 studied the effects of chronic illness on family members. The study utilized a qualitative approach with semi-structured telephone interviews conducted with 49 participants. Chronic diseases in the study did not include SUD. The study did include chronic illnesses of Alzheimer’s disease, arthritis, cancer, cerebral palsy, and depression. The chronic diseases included do not carry the stigma of SUD but do place added strain on the family. The family members reported non-health, psychological, and somatic effects because of supporting the loved one with a chronic illness. Non-health effects included adverse effects on work, finances, social activities, church attendance, loss of activities (Wittenberg et al., 2013). Psychological adverse effects included decreased general emotional health, worry, stress, anxiety, fear, feeling helpless, sadness, depression, frustration, impatience, and resentment because of the support needed by the loved one with chronic illness (Wittenberg et al., 2013).

AFMs reported physical pain, sleep disturbance, fatigue, and loss of appetite as adverse physical health effects (Wittenberg et al., 2013).

Amankwaa (2017) reviewed the stress placed on informal caregivers providing support for an older adult. Amankwaa does not discuss the role of informal caregiver with SUD (2017). Amankwaa does raise some important issues for the informal caregiver. The matter of time off to care for a family member and social support from friends and family are two such concerns. The AFM supporting a loved one with SUD is often not eligible for paid time off from their employment. The AFM may not receive social support from friends and family. This same time off from work and support from family and friends is often available to the family whose loved one suffers from other illnesses with less stigma attached to the disease. Amankwaa does identify that the informal caregiving places the family member at a higher risk for physical illness, mental illness, and mortality (2017).

Impact of Social Support provided by the AFM in SUD

The family often is identified as part of or the entire problem in SUD. The individual has linked the substance use by the family to substance use. The significant others in the ISUD have been identified as enabling or codependent in the problem. Recent literature has recognized the value of the family and family members in the treatment and recovery of SUD.

Hornberger and Smith (2011) reviewed family involvement in adolescent treatment and recovery. Hornberger and Smith found that the family is necessary to ensure the quality of care. The recommendations include strengthening the family, building leadership, improving education and training, increase funding and policies, and measure the outcomes of family involvement (Hornberger & Smith, 2011). Adolescence and emerging adulthood present with the highest incidence of SUD (SAMHSA, 2019). The ages of 12-25 years are a concern for families and healthcare providers. SUD is a chronic disease with no cure; there is a need for family in all ages of SUD. The AFM needs to be involved in identifying their unique needs, as they support their loved-one with SUD.

Interventions for the AFM

Orford et al. (2007) conducted a qualitative study to evaluate the 5-Step family intervention. The intervention used with family members affected by another's drug or alcohol use—the 5-Step family intervention, based on the stress-strain-coping-support (SSCS) model developed by Orford in 1992. The improvement in the mental and physical health of the AFM was the intended outcome of the intervention (Orford et al., 2007). The 5-Step family intervention includes nonjudgmental listening, providing information, counseling about ways of coping, discussing increased social support, and identifying help and support options (Orford et al., 2007). The study consisted of 143 family members participating in semi-structured interviews for over 12 weeks.

Orford et al. (2007) found the following three themes represented in the study. Almost 50 percent of AFM's reported positive transformations in their lives due to the intervention. AFM has reported an increased ability to focus on their own life and needs, remain calm, and be assertive. Seventy-one percent of the participants felt that the one on one interview was more effective than receiving a written self-help manual. Other participants felt the intervention was not helpful, did not reveal new information, provided no direction, and the interviewers lacked compassion or expertise. The limitations of the study by Orford et al. (2007) are the lack of percentages for the themes produced. An improvement in the study would include the AFM identifying the positive and negative aspects of the specific interventions utilized. The further recommendations recognize the need to provide this support to AFM's; however, there is a need to educate the health care professionals (Orford et al., 2007). The health care professionals would need to be trained on how to identify at-risk family members and how to convey the support to the AFM best.

Copello et al. (2009) conducted a study on the efficacy of two levels of primary care intervention for AFMs of an ISUD. The two levels of intervention were full or brief intervention utilized by primary care professionals. The full level of the intervention included five face-to-face interventions with a professional. The brief level intervention included the provision of a self-help manual and introduction session (Copello et al., 2009). Professional training manual and training with group or individual sessions were given to the primary care professionals. Fifty-one participants received the full intervention, with ninety-two participants receiving a brief intervention and self-help manual. No significant difference existed between the groups at follow up. There was a preference from both groups for the face-to-face interaction rather than the self-help manual and brief introduction (Copello et al. 2009). There was a significant reduction in symptoms for both groups at follow-up and reportedly ($t=4.08$, $p<0.001$) (Copello et al., 2009). Limitations of the study included a lack of randomization and a small sample size, which may have affected the results. The need for further research with a larger, more generalized sample is needed. However, the ability to recruit primary care professionals and the significance of both interventions reducing symptoms in the AFM shows promising possibilities for effective interventions in the future (Copello et al., 2009).

Templeton (2009) identified an increased recognition of family member needs and conducted a study utilizing the 5-step intervention in South West England. Twelve family members were recruited to complete a pre and post questionnaire scheduled around a themed carer program. The group consisted of eight females and four males. The group included parents, one stepfather, one partner, and one sibling. The prequestionnaire identified that the family member's health was affected, they were utilizing a variety of strategies, and they were losing hope for the future of their relative.

Following the carer program, there was a significant change noted in the responses of the participants. Total physical symptoms showed a significant change from 29.68 to 17.27, with a p-value of <0.005. Overall, an improvement in the health of the family members was noted with the 5- step intervention. Templeton (2009) discusses the need for further studies utilizing family interventions. It is difficult to ascertain if the results obtained were due to the specific intervention or if another intervention would yield the same results.

The SSCS model is used in interventions and research related to the AFM supporting the ISUD (Orford et al., 2010). The SSCS does assume that having a relative with SUD causes stress and strain leading to ill health. The ill-health can manifest either physically or psychologically or both. The building blocks of the model are coping and social support. Social support is valuable to the AFM is effective coping and contributes to their health and well-being (Orford et al. 2010). SUD can be disempowering and demoralizing for family members. SUD is highly stressful, and family members need to know they did not cause it (Orford et al., 2010, p. 42) need to be cared for and receive social support."

Baharudin et al. (2014), recognizing the need for family in enhancing and maintains an ISUD recovery, also acknowledges the stress the family endures providing this support. The family may be affected emotionally and financially. The family member can suffer due to the lack of support that is offered to them to endure the difficult situation of supporting their loved one (Baharudin et al., 2014). Family intervention was recognized as one method for helping the family support the ISUD. Baharudin et al. (2014) explored the experiences of family members involved in a family intervention program in Malaysia. The family intervention was located at a drug treatment and rehabilitation agency. The family intervention included psycho-education, support groups, and retreat for the family members.

Data was collected using interviews and observations of eight participants enrolled in the study. Baharudin et al. (2014), found the following five themes after analyzing the data collected. The therapeutic alliance between the counselor and the family members was key in the family member feeling comfortable, listened to, and respected. Participants received effective practices from the program included new insights, different ways of handling problems, more knowledge, and understanding of SUD. The participants utilized effective methods during the family intervention, including prayer and connecting with other family members regarding the SUD. The participants identified helpful things they had learned as part of the family intervention. The effective practices learned included teamwork among family members, positive thoughts regarding the situation, communication, and sharing techniques. Family members were asked to relate the unhelpful aspects of the family intervention. The family members recognized that the lack of diversity in the language used for family intervention. The family intervention being presented in only English with interpreters did decrease the understanding and ability to interact with some of the non-English speaking participants. Some participants felt they would have benefitted from a more in-depth and personal counseling intervention. Baharudin et al., (2014), found through observation of the participants an overall increase in sharing, expressing emotions, communications, connecting with others, encouraging, and supporting each other. The findings do support further research into the increased involvement of family and family interventions in drug treatment programs (Baharudin et al., 2014).

Denomme and Benhanoh, (2017), evaluated the efficacy of a multi-phase treatment program designed to assist the AFM in regaining and maintaining their well-being. A secondary benefit of the multi-phase treatment program was to provide the AFM with options and resources available to them. The study conducted in Canada for over eight years, completed in three phases, with three separate data collection points. Data were collected with a questionnaire at each phase of the treatment program. One hundred and twenty-five participants completed the first two phases of the treatment program. The participants included a treatment group N=97 and a comparison group N=28. Of the treatment group, 44 participants did complete the three phases and questionnaires. Of the comparison group, 16 participants completed the three phases of questionnaires. The treatment program significantly lowered stress, increased social support, and reduced conflict with the ISUD. A strength of this study was the use of a comparison group. However, a limitation of the study was the lack of random assignment to the treatment or comparison group. The assignment to groups was by participant choice. Another significant limitation was the attrition rate of participants completing the three phases of the treatment program. Recommendations for future research include random assignment of participants and methods to improve retention within the study.

Stigma

The review of the literature revealed three different views of stigma pertinent to this research study. Stigma refers to the preconceived notion or thoughts that mark a person for social condemnation due to their position or activities within society (Leghari et al., 201). A discussion of stigma and nursing care (Monks & Newell, 2013), stigma, and the AFM (McCann & Lubman (2018), and stigma of the ISUD (Leghari et al., 2018) follows.

Stigma and Nursing Care

Monks and Newell (2013) found that stigma was associated with dissonant care from nurses engaged in the care of ISUD on medical wards in the United Kingdom (UK). The nurses identified that a lack of knowledge and preparation coupled with negative attitudes and stigma contributed to a negative nurse-patient relationship. These negative relationships extended to the family members of the ISUD. Interestingly, Monks and Newell (2013) did find that nurses with more educational preparation through experiences with friends and family members were more likely to develop person-centered nurse-patient relationships with the ISUD. The nurses with personal experience related to SUD held less stigma and negative attitudes towards the ISUD and the AFM. The need for educational programs directed to improving the care of the ISUD was identified for healthcare professionals to decrease negative attitudes and stigma (Monks & Newell, 2013). The need for educational programs about SUD for the public may also improve attitudes, reduce stigma, and improve care for the ISUD and the AFM.

Stigma Associated with Supporting an ISUD

McCann and Lubman (2018) completed a qualitative study utilizing 31 AFMs in Australia. The study aimed to explore the stigma experienced by AFM supporting an ISUD. McCann and Lubman (2018) found two themes with subthemes reflecting the experience and the response of the AFM to stigma. A third theme involved the adoption of behaviors to deflect the stigma.

The first theme identified was engaging in secrecy and minimizing contact with others. The AFMs reported frequent stigma, both public and privately. The stigma the AFMs received caused them to alter their behaviors by engaging in secrecy and reducing their contact with others. The AFMs reported shame and embarrassment, fear of judgment, isolation, and a decrease in accessing informal and formal support due to the stigma (McCann & Lubman, 2018).

The second theme was the lack of knowledge, lack of empathy, and judgmental attitudes reinforcing the isolation of the AFM (McCann & Lubman, 2018). The participants reported a lack of knowledge, lack of understanding, and judgmental attitudes received from family, friends, and clinicians (McCann & Lubman, 2018). The AFM was reluctant to seek support because of these attitudes.

Adopting measures to moderate the effects of stigma was identified as a third theme. The AFMs reported adopting behaviors to deal with the stigma they received from others. Some AFM would challenge the misconceptions or the lack of knowledge individuals held about SUD. Other AFM would choose to be selective in their choice of individuals that they would share the secret of the support they provide to an ISUD (McCann & Lubman, 2018).

A large number of female participants and current membership in a support group were limitations of this study. Future research in methods to decrease stigma and increase the use of formal and informal supports may prove useful for the AFM of an ISUD.

Social Support in Reducing Adverse Effects of Stigma

Leghari et al. (2018) found that social support provided by the AFM, to the ISUD, reduced the adverse effects of stigma, improving their health and well-being. The study included 200 males with SUD with ages ranging from 25-50 years of age. The results showed a significant relationship between stigma and depression in the participants ($r=.565$, $p< .001$) (Leghari et al., 2018). The results of this study also showed that social support was a significant moderator between stigma and depression in the participants. Recommendations from this study include the increased knowledge of the social support of the AFM to the ISUD in treatment and recovery

(Leghari et al., 2018). Limitations of this study are the only male sample from one city in Pakistan, causing a decreased ability to generalize the results to other populations (Leghari et al., 2018).

Measurement of Social Support

Toner and Velleman (2014) developed and tested a new scale to measure the functional, quality, and adequacy of social support perceived by AFM's of an ISUD. A mixed methods approach was used in the development and testing of the scale. The scale is called the Alcohol, Drugs, and the Family Social Support Scale (ADF SSS) and is comprised of 25-items (Toner & Velleman, 2014). The study was multi-leveled, beginning with a 75-item scale and then refining it to the 25-item scale after testing and revisions. The 25-items ADF SSS has good internal consistency. The Cronbach's alpha was reported at 0.812 for the overall scale. Test-retest reliability was seen with frequency scale correlations reported at 0.934, 0.894, and 0.891 for the three subscales. Kappa values were reported at 0.385-0.749 (subscale 1), 0.402-0.806 (subscale 2), and 0.390-0.727 (subscale 3). The total frequency score showed a correlation with $p<0.01$, 0.394 for general, and 0.273 for structural social support questions. Validity was ensured with qualitative data supporting the quantitative findings (Toner & Velleman, 2014). The ADF SSS 25-item measure provides a quantitative method to operationalize and measure social support (Toner & Velleman, 2014). Limitations to this measurement may be the testing completed in the United Kingdom (UK) and may not be representative of AFMs in the United States. There is a need to utilize the ADF SSS 25-item instrument with different cultural and gender groups. Further research is needed with larger, more diverse samples on a longitudinal basis that would enhance the generalizability of the results.

Summary of the Literature

The review of the literature revealed the benefits of social support on the health and well-being of families experiencing the chronic illness of a family member (Frey, 1988; Armstrong et al., 2005). Gage-Bouchard et al. (2015) and Gage-Bouchard (2017) explored the process of how social support was needed, utilized, and developed. Gage-Bouchard et al. (2015) and Gage-Bouchard (2017) reinforced the need for social support for family members of pediatric cancer patients. Social support was identified as essential to improve the family member's abilities to cope and maintain their health and well-being. The family members utilized functional and structural social support to assist in the care of their family members with chronic illness. The functional social support aided them in emotional, informational, instrumental, and social companionship needs (Gage-Bouchard et al., 2015; Gage-Bouchard, 2017). The structural social support included building the social network members for the family member. The building of social networks was started by health care professionals recommending support groups and introducing the family member to a possible social support person, both professional and non-professional (Gage-Bouchard et al., 2015).

Selbekk et al. explored the need to include family members in the treatment of the ISUD (2015). The inclusion of family members was an asset in the treatment of individuals with SUD. However, Selbekk et al., (2015), also recognized the stress and strain that family members included in the treatment would experience. The findings of this study influenced Selbekk and Sagvaag (2016) to explore the resources available to the AFM. Selbekk and Sagvaag (2016) found the resources to the AFM very limited. Providing resources for the AFM was difficult and costly for many drug treatment centers, leaving the AFM without assistance.

Kelly et al., (2017), Sakiyama et al., (2015), and Stenton et al., (2014), explored less costly self-help groups. Stenton et al., (2014), chose a mixed methods approach to identify who the members of self-help groups were and the participant's experiences with the self-help groups. Self-help group membership includes a variety of demographics. Members did report positive experiences by belonging to the self-help groups. However, members did report difficulty in accessing self-help groups, with most referrals coming from fellow AFMs rather than health care professionals. Sakiyama et al., (2015), found the members of self-help groups to report positive effects on their health and well-being. Sakiyama et al. (2015) also found that members relied on other AFMs to locate and gain access to the self-help groups. Many participants reported waiting more than two years before accessing help. Kelly et al. (2017) reported similar findings with member recruitment primarily through other AFMs and not through health care professionals. Members did report positive outcomes from belonging to the self-help group. A common theme presented by all three studies was the lack of information about SUD and the assistance available for AFMs.

The effect of chronic illness and SUD on family members is explored in the research. Velleman et al., (1993), found the AFM experienced many negative effects from the SUD of another. The negative effects ranged from financial, physical, emotional, and social. The AFM often reported feeling confused and unsure in their approach to dealing with the negative effects. A lack of information was noted for AFM to assist them in how to help their loved ones with SUD. The lack of information available to the AFM was supported by a research study completed by Nebhinani et al. (2013). Nebhinani et al. (2013) found a significant burden placed on the AFM due to the SUD of their loved one. The burden was often financial to pay for the treatment and the expenses for the ISUD. The negative effects, burden, spillover effects, and decreased health and well-being are identified with family members affected by another's SUD or chronic illness (Amankwaa, 2017; Fotopoulou & Parkes, 2017; Wittenberg et al., 2013).

Often family is the only support available to the ISUD. Hornberger and Smith (2011) found that family participation improves treatment outcomes and strengthens the recovery process for the ISUD. Orford et al. (2007) found that the provision of a self-help manual and brief discussion with a health care professional was beneficial to the AFM. Templeton (2009) reported similar results with the provision of a self-help manual and the utilization of a five-step intervention based on previous research completed by Orford and fellow researchers at the University of Bath. Copello et al. (2009) further explored the benefits of a brief intervention or a more involved 5-step intervention, both with the provision of a self-help manual.

Interestingly both interventions resulted in positive outcomes (decreased stress and increased coping) for the AFM. However, there was no difference shown between the two interventions utilized. Baharudin et al. completed a similar study in 2014. Baharudin et al. (2014) found that an intervention utilizing psych-education, support group, and family retreat resulted in positive outcomes (increased knowledge, less stress, a better relationship with the individual using drugs) for family members involved in a loved one's drug treatment. Denomme and Benhanoh (2017) found that a multi-phase intervention for AFM did result in a positive outcome for the AFM. Positive outcomes included increased knowledge, improved coping, improved communication, increased social activities, and an improvement in their social support networks and family functioning.

Family interventions do show promising results in positive outcomes for the AFM. However, one barrier in the literature is stigma. Stigma applied to the AFM was identified by nursing professionals (McCann & Lubman, 2018; Monks et al., 2012) and from the community

(Leghari et al., 2018). Improving education and knowledge regarding SUD is key in reducing stigma, and social support is key in reducing the effects of stigma for the ISUD and AFM (Leghari et al., 2018; McCann & Lubman, 2018; Monks et al., 2014).

Limitations

Limitations identified in the review of the literature included small sample sizes, lack of diversity in samples, and a higher representation of women than men in the research studies (Baharudin et al., 2014; Gage-Bouchard et al., 2015; McCann & Lubman, 2018; Stenton, Best, & Roberts, 2014; Templeton, 2009; Velleman et al., 1993; Wittenberg et al., 2013). Copello et al. (2009), Denomme and Benhanoh (2017), and Toner and Velleman (2014) found recruitment and attrition of participants a limitation in their research studies. The lack of clear conceptual or theoretical frameworks is a limitation in the studies presented. Orford et al. (2010) discuss the Stress-Strain-Coping-Support model as the basis for the 5-Step intervention. The lack of consistent measurement tools is a limitation. The literature review produced only one instrument for the measurement of social support in the AFM (Toner & Velleman, 2014).

Recommendations

Recommendations for future research include:

- A more diverse representation of the AFM
- The experiences and perceptions of the AFM
- The use of a measurement instrument tailored for the AFM
- The use of a conceptual model in the study design of the AFM

Research that reflects the experiences and perceptions of social support of the AFM is lacking in the literature. Research on social support and the health and well-being of the AFM of an ISUD is needed.

Summary

SUD is a chronic disease that adversely affects the individual and the AFM. The in ISUD benefits from social support received from the AFM (Hornberger & Smith, 2011; Leghari et al., 2018; McCann & Lubman). The social support available to the AFM may be decreased by their efforts to assist the ISUD. The reduced social support places the health and well-being of the AFM at risk (Frey, 1988).

It is imperative to gain knowledge about the experiences and perceptions of the AFM and their social support. The knowledge gained may be utilized to educate healthcare professionals and community members about the social support needs of the AFM. The knowledge gained can be used in the development of intervention and social support programs for the AFM.

Chapter 3

Methods

The purpose of this study was to explore the affected family member (AFM) of an individual with a substance use disorder (ISUD) perceptions and experiences of social support. A secondary purpose was to examine the association of social support and how it contributes to the health and well-being of the AFM of an ISUD. This study utilized a mixed methods design. The mixed methods approach was practical for the complex phenomena of the experiences and perceptions of social support and the health and well-being of the AFM. The mixed method design was appropriate to answer research questions and explore the hypotheses of this study. The quantitative data may identify a relationship among variables, and the qualitative data may provide insight into the reasons for the connection. The mixed methods design provided a complementary approach, which added to the ability for triangulation, furthering the validity of the study results (Polit & Beck, 2014).

Research Questions and Hypotheses

This study sought to answer the following research questions (RQ) and aimed to support the research hypotheses (H0) listed below.

Research Questions

- What are the social support perceptions of AFM's?
- What are the social support experiences of AFMs while providing support to an ISUD?
- What is the association between AFM reported social support levels and their perceptions of health?
- What is the association between AFM social support levels and their perceptions of well-being?

- What is the relationship of the subscales, functional, perceived and received, and structural levels of social support, to health and well-being reported by the AFM?
- Is there an interaction between social support and the perceived health and well-being of the AFM?

Research Hypotheses

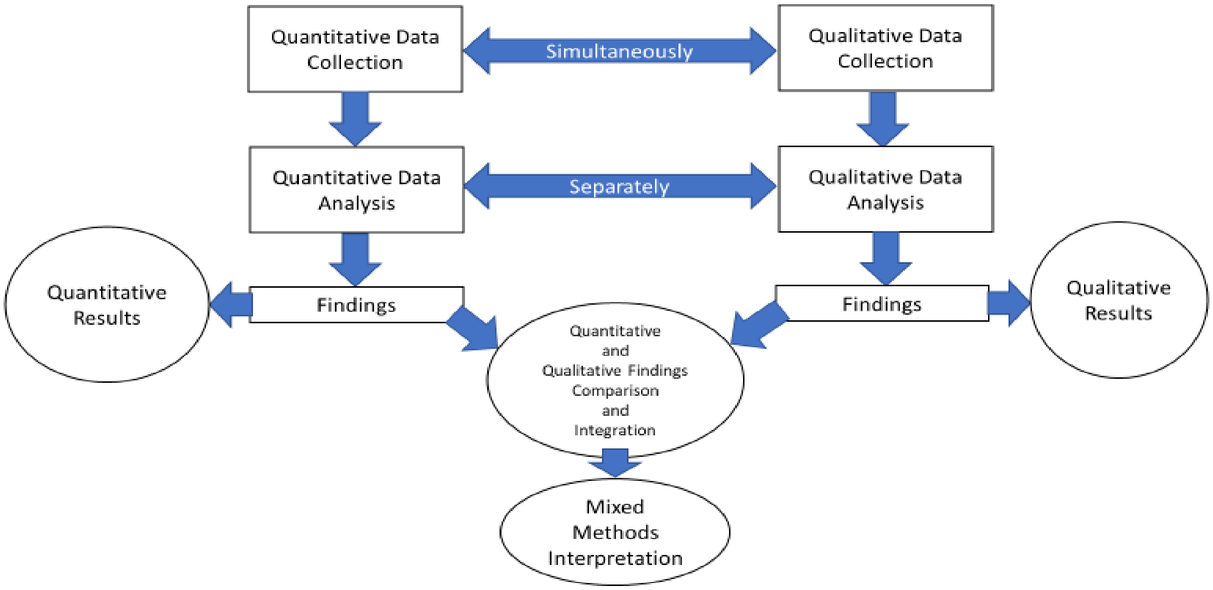
- H0 # 1: The AFM, who perceives receiving positive social support, will report higher levels of health and well-being.
- H0 # 2: The AFM, who perceives receiving inadequate positive social support, will report lower levels of health and well-being.

Design

This study used a convergent parallel mixed methods design. The convergent parallel research design allowed for the concurrent collection of qualitative and quantitative data. The study used a mixed methods QUAN + QUAL design. Data was collected using one online survey instrument for both qualitative and quantitative data. The Qualtrics®, data management system, was used in the data collection. The quantitative findings discussed in Chapter 4. The qualitative results are discussed in Chapter 5. Chapter 6 includes the discussion and integration of the qualitative and quantitative analyses and presenting the findings of the mixed method. The quantitative and qualitative data collection methods included in the study support the research questions, the hypotheses, and the mixed methods approach (see Figure 3).

Figure 3

Research Design



Participants

The participants recruited for this study are self-reported affected family members (AFM) of an individual with a substance use disorder (ISUD). The AFM is biologically or self-identified as being family of the ISUD. Inclusion criteria for participants: (a) 18 years of age or older; (b) affected family member (AFM); (c) able to give informed consent; (d) English speaking; and (e) able to complete the paper or online survey instrument. Exclusion criteria for participants: (a) children under the age of 18 years and (b) individuals that provide social support to ISUD through their employment.

Recruitment

After gaining IRB approval from the University of Wisconsin-Milwaukee, recruitment of participants proceeded as per the IRB guidelines. Recruitment of a convenience sample occurred in-person and online. Snowball sampling included referrals from friends, colleagues, career contacts, local support groups, advocacy groups, and other participants. Recruitment materials included a script (see Appendix E), a cover letter (see Appendix F), a flyer (see Appendix G), and two business cards (see Appendix H). The recruitment of participants occurred over five months, beginning at the end of August 2019 and ending in January 2020.

The student researcher conducted in-person recruitment at two health fairs, two grocery stores, three town libraries, three town halls, and four support groups. The recruitment occurred in central Massachusetts. The student researcher posted flyers in the recruitment areas. Additionally, the student researcher conducted in-person recruitment, which consisted of approaching possible participants and providing a brief description of the study as per the study script. The participant had the choice to complete the survey on the researcher’s personal computer or on paper at that time. The researchers provided a table, chair, and a privacy screen for the participant to complete the survey at that time. No participants chose to complete the survey at the time of first engagement with the researcher.

The potential participant received a flyer, a business card, or the paper survey to complete, as per the participant's choice. The student researcher handed out twenty paper surveys with prepaid, self-addressed envelopes. The student researcher received no paper surveys. The student researcher retrieved two paper surveys, including the envelopes, from the trash at one health fair.

The student researcher conducted online recruitment through the posting of the online cover letter and the survey link in twelve online support groups for family members. The researcher is a member of all support groups included in online recruitment.

Privacy and Protection of Human Rights

The researchers ensured that they took steps to protect the participants from harm. The population of the AFM may be viewed as a vulnerable population, as defined by Chesnay and

Anderson (2016). Ensuring the protection of all study participants was crucial. The researchers obtained approval through the institutional review board of the University of Wisconsin-Milwaukee before any data collection commenced. The organization of the online survey helped ensure study participant protection. The first pages of the online survey included the cover letter introducing the study, written informed consent, and instructions on how to complete the survey, and the survey questions. The IP address and email address collection options were turned off through the Qualtrics® set up for the online survey. All participants remain anonymous; no names or IP addresses were collected. All de-identified information was collected via a Qualtrics® online survey and then downloaded into the Statistical Package for the Social Science (SPSS) 26® computer database on a password-protected computer. The researchers received no paper surveys for use in the study.

Informed Consent

The student researcher made every effort to inform participants that the survey was voluntary and anonymous. The written informed consent was provided to the participant before completing the survey (see Appendix I). No signed informed consent documents were collected. The completion of the survey implied informed consent. The sensitive nature of the issue of addiction required the voluntary and anonymous status of participation. Therefore was no retention of a signed paper informed consent. All survey respondents remain anonymous, and all data is unable to be linked to any respondent. Participants could stop their participation at any time before submitting any survey. However, once the survey was submitted, as no names or identifying information were collected, there was no way to identify the participant. A participant is unable to withdraw after survey submission. As of this date, there have been no requests to rescind a survey. All recruitment materials included the contact information of the student researcher and the number to a dedicated cell phone. The dedicated cell phone was utilized only for this study. The purpose of the phone was to provide private support and information for participants. However, no participants called or texted the cell phone. The potential for an emotional response from the participant prompted the researchers to include contact information for support services in the informed consent (Al-Anon and Nar-Anon).

The conceptual framework of social support was used throughout the data collection and data analysis processes. The conceptual framework of social support, including functional, perceived and received, and structural constructs guided the process for the development the open-ended questions and for the inclusion of the ADF SSS 25-item survey instrument. Decisions for both the qualitative and quantitative data inclusion and integration process for this study included the conceptual framework of social support.

Data Collection

All data were collected through the online survey administration. The data collection instruments contain no identifying questions. The instructions for the survey include a reminder for the participant to refrain from adding identifying information to the survey. The online survey was administered by using a survey link developed with Qualtrics®.

Instrumentation

The research study utilized the participant characteristic survey, the Public Health Surveillance Well-Being Scale (PHS-WS) and the Alcohol, Drugs, and the Family Social Support Scale: 25 items (ADF SSS) survey instrument, and open-ended questions.

Participant Characteristics Survey. The participant's characteristics survey (see Appendix A) was designed by the researchers to collect demographic data. The survey includes 22 self-report responses. The responses are related to age, gender, race, ethnicity, relationship status, living situation, and employment status of the AFM. The AFM was asked to provide data about the ISUD. The responses include the relationship with the individual, the age, gender, race, ethnicity, relationship status, living situation, and health and recovery status of the ISUD. No questions included legal or criminal disclosures.

Public Health Surveillance Well-Being Scale (PHS-WS). The Public Health Surveillance Well-Being (PHS-WS) Scale is a ten-item scale with six subscales. The PHS-WS designed is meant to capture self-reported life satisfaction, days cheerful, days hopeless, family life satisfaction, health, and energy (see Appendix B). Prior psychometric testing and development of the PHS-WS completed in 2012 by Bann, demonstrated good internal consistency (alpha = 0.87) and correlated highly with scores for the entire item pool (r = 0.94). Additionally, high correlations were noted between days cheerful (r = 0.58) , life satisfaction (r = 0.74), and health (r = 0.70). The well-being scale scores differed as expected across demographic groups and associated with global and domain-specific measures of similar constructs, supporting its construct validity (Bann et al., 2012).

Alcohol, Drugs, and the Family Social Support Scale (ADF SSS). The Alcohol, Drugs, and the Family Social Support Scale (ADF SSS) is a 25-item survey instrument (see Appendix D) design to measure the perceived social support of family members of an ISUD (Toner & Velleman, 2014). Psychometric testing completed by Toner and Velleman (2014) indicated internal consistency with Cronbach's alpha for the overall scale reported at 0.81. Test-retest reliability showed an overall scale correlation coefficient of 0.970. Content validity scores correlated significantly and reported at 0.888 ($p<.01$). The construct validity had reported correlations of emotional (0.394, $p<0.05$), functional (0.503, $p<0.05$), practical (0.385, $p<0.05$), general (0.349, $p<0.01$), and structural (0.273, $p<0.01$) support questions (Toner & Velleman, 2009). The qualitative information from the family further supported the validity of the survey instrument, confirming the wording and content applied to the topic and the population of interest (Toner & Velleman, 2014). The ADF SSS 25-item scale does provide a unique measure that includes the AFM and their social support, which is congruent with the aims of this study.

Open-ended Questions. The researchers developed open-ended questions for the survey. The constructs of emotional, informational, instrumental, social companionship, perceived and received, and structural social support are represented in the open-ended questions. Two open-ended questions ask the AFM to share information they feel is important for other AFMs and health care professionals. The last question asks for an evaluation of the survey (see Appendix C).

Data Analysis Methods

The data analysis for this study utilized qualitative, quantitative, and mixed methods processes. The following sections provide a discussion of the data analysis procedures for each arm of the study. The data analysis procedures used in this study organized as to the research question, the data type, the data collection method, and the data analysis method utilized are included in Table 2 and discussed in the following paragraphs.

Table 2:

Data Analysis

Research Question	Data Type	Data Collection Method	Data Analysis Method
RQ #1 What are the social support perceptions of AFM's?	Qualitative Quantitative	Open-ended Questions ADF SSS (ordinal)	Thematic Analysis Bivariate Correlation
RQ #2 What are the social support experiences of AFMs?	Qualitative Quantitative	Open-ended Questions ADF SSS (ordinal)	Thematic Analysis Bivariate Correlation
RQ #3 What is the association between AFMs reported social support and their perceptions of health?	Quantitative	ADF SSS (ordinal) PHS-WS (ordinal)	Bivariate Correlation
RQ #4 What is the association between AFMs social support and their perceptions of well-being?	Quantitative	ADF SSS (ordinal) PHS-WS (ordinal)	Bivariate Correlation
RQ #5 What are the relationships of the subscales, positive functional support, negative ADF specific support, and ADF positive ADF specific support and the health and well-being reported by the AFM?	Quantitative	ADF SSS (ordinal) PHS-WS (ordinal)	Bivariate Correlation
RQ #6 Is there an interaction between social support and perceived health and well-being of the AFM?	Quantitative	ADF SSS (ordinal) PHS-WS (ordinal)	Bivariate Correlation Multiple Regression

Quantitative Analysis Methods

The researchers and the statistician collected the data through Qualtrics® and downloaded them into The Statistical Package for the Social Science (SPSS) 26® for analysis. Each survey was assigned an identification number in hierarchal order. One hundred and seventy-one online surveys were submitted. Thirty-seven surveys were not complete. One hundred thirty-four surveys met the completion criteria for inclusion in the quantitative analysis. All decisions regarding data, variables, and coding are in the study codebook.

Preliminary quantitative data analysis employed descriptive statistics for all study variables and sample characteristics. The frequencies and shapes of distributions were analyzed. The sample size, demographics, and characteristics are reported through measures of central tendency (mean, median, mode) and measures of variability and normality (standard deviations, minimum and maximum values, skewness, and kurtosis). Assessing for normality included a review of descriptives, extreme values, tests of normality, histograms, Q-Q plots, and boxplots for each variable. An analysis of outliers identified no errors in the data. There was less than 1% missing data in the surveys. The researchers replaced these items with the mean. Researchers excluded surveys with missing data within either measurement scale (ADF SSS or PHS-WS) from the study.

The next step in the quantitative data analysis was to determine overall scores and reliability for the scales utilized in data collection. This study used two instruments for data collection, the Public Health Surveillance Well-Being (PHS-WS) Scale and the Alcohol, Drugs, and the Family Social Support Scale (ADF SSS 25) discussed previously. It was necessary to reverse negatively worded items, develop total scores for both scales, and test reliability. The Public Health Surveillance Well-Being (PHS-WS) Scale had two negatively worded items reversed in the Statistical Package for the Social Science (SPSS) 26® data set. The Alcohol, Drugs, and the Family Social Support Scale (ADF SSS 25) had eight negatively worded items reversed. All items on the ADF SSS 25 consisted of five-point Likert scoring. The ADF SSS 25 item scale does show excellent reliability as included in this study.

The use of Pearson correlation explored the associations among the PHS-WS total score of health and wellbeing and the overall score for the ADF SSS 25 and subscales. Bivariate correlations and multiple regression identified the positive or negative associations and the strength of the associations. Multiple regression identified the direction of relationships between the dependent and independent variables of this study. Chapter 4 presents the quantitative findings of this study.

Validity

Methods to improve statistical conclusion validity included a large sample size N = 134. The sample size is large enough to produce a small effect of .23. The use of accurate measuring instruments, the PHS- WB, and the ADF SSS 25 item scales helped to maximize the precision of the study. The reliability of the instruments was assessed with Cronbach's alpha coefficients, as included in the following paragraphs.

Cronbach's alpha coefficient showed the reliability of the PHS-WS scale. The seven items using a 5-point scale achieved a Cronbach's alpha coefficient of .873. The PHS-WS seven items show positive values within the inter-item correlation matrix, and the interitem correlation mean at .497. The reliability of the three items of the PHS-WS scoring 0-10 produced a Cronbach's alpha of .789, with positive inter-item correlations. The PHS-WS scale shows good reliability.

Cronbach’s alpha on the ADF SSS 25 item scale calculated to .893. The ADF SSS subscale of positive functional support measuring eleven items Cronbach’s alpha was .925, with positive inter-item correlations. The ADF SSS subscale of negative specific support measuring eight items Cronbach’s alpha was .827 with positive inter-item correlations. The ADF SS subscale of positive specific support measuring six items Cronbach’s alpha was .681 with positive inter-item correlations.

The cross-sectional design and the recruitment of one group of participants were a threat to the internal validity of this study. The use of the participant characteristics survey and clearly describing the demographics of the group will improve internal validity. Attempts to decrease risks to internal validity included methods to ensure temporal ambiguity by clearly reviewing the results to ensure the independent variable preceded the dependent variables.

Clearly stated, operational definitions of the variables enhanced construct validity. A thorough examination of the reliability of the instruments enhanced the validity of this study. The anonymous nature of the survey and the ability of the AFM to complete the survey at their convenience further decreased threats to construct validity, such as reactivity to the study situation and researcher expectancies (Polit & Beck, 2014).

External validity is a concern with this study. Most of the sample are White/Caucasian, married women, with an average age of 52 years. The geographic region the participants reside in was not collected. The ability to generalize the results to more extensive or different populations is a threat to the external validity of the study (Polit & Beck, 2014). There is a need to replicate the research and compare findings.

Qualitative Analysis Methods

The qualitative data collection occurred with the same survey as the quantitative data collection. The survey included fifteen open-ended questions placed at the end of the survey. One hundred and one of the participants chose to complete responses to the open-ended question with 1088 responses received for analysis. The qualitative data analysis included data management, organization, and thematic analysis, as discussed in the following paragraphs.

Data Management and Organization

The data management and organization prepared the data for the thematic analysis and creation of themes by the researchers. The participants typed their responses to the online survey. No transcription of the data was needed. The researcher downloaded the responses into an Excel® spreadsheet. The responses were then checked for accuracy to ensure no errors occurred in the export of the data from the Qualtrics® system. The data copied and pasted verbatim into word documents allowed for more straightforward data analysis. Each researcher reviewed the documents to ensure readability, accuracy, and understanding of acronyms to ensure the quality of the data before analysis (Polit & Beck, 2014).

Data Analysis

The researchers used thematic analysis of the qualitative data. Through thematic analysis, the researchers were able to discover, interpret, and report patterns and clusters of meaning within the data. Qualitative data review with the systematic development of codes, categories, and themes occurred (Ritchie, Lewis, McNaughton Nicholls & Ormston, 2014). The qualitative data analysis processes are discussed in the following paragraphs.

The qualitative data analysis process entailed reviewing and organizing the responses into word documents that accurately represented the text responses received for each open-end question. The researchers individually reviewed each word document indexing and sorting the data to develop coding, categories, themes, and subthemes for each question (Ritchie et al., 2014). The researchers then reviewed and discussed the separate analyses together to ensure inter-rater reliability and to identify any biases or coding errors.

A second analysis occurred with each researcher reviewing the data and organizing it into categories that were more manageable for the data analysis. The process allowed the researchers to create conceptual categories. Data broken into segments of similar and dissimilar aspects determined the coding scheme. The coding schemes emerged as abstractions offering clear and provocative labels for the data. The next step in the process involved coding the data and placing excerpts into the conceptual file folders (Polit & Beck, 2014). The review of the qualitative data, categories, coding, and conceptual files identified five overarching themes (Ritchie et al., 2014). The researchers then examined and discussed their separate analyses together to ensure inter-rater reliability and to identify any biases or coding errors.

A third thematic analysis included a review of all qualitative data to clarify the overarching themes, subthemes, and emerging unanticipated themes. The third thematic analysis ensured accurate coding, identify errors, and decrease biases among the findings. Chapter 5 includes qualitative analyses and findings.

Trustworthiness and Integrity

The trustworthiness of this study utilized the criteria of credibility, dependability, confirmability, transferability, and authenticity (Lincoln & Guba, 1985). The believability of the findings enhances the credibility of this study. Methods that enhanced the credibility of this study were and the ability for the respondent to free text their responses in the survey, thus negating the opportunity for inaccurate transcription. A codebook was maintained throughout the study to ensure that the coding process was accurate and systematic. The study manuscript provides detailed descriptions of the planning, recruitment, data collection, data analysis, and findings, which enhance the credibility of the study (Polit & Beck, 2014).

A comparison of similar studies reinforced the dependability of the study. Confirmability is the participant's voice, not the researcher’s biases, motivations, and perspectives (Polit & Beck, 2014). The disclosure of the researcher’s experiences and perceptions of affected family members and social support enhanced the confirmability of this study. The researcher maintained a reflexive journal throughout the study to review and debrief with a fellow researcher to maintain objectivity in analyzing the data and reporting the findings. A large sample (n = 101) and a significant response number of (1088) added to the transferability of the study to other populations. The researchers report the study findings in ways that the readers can understand the lives of the participants using quotes to enhance the authenticity of the study.

Mixed Methods

The convergent parallel design of this study lent itself to the process of merging the findings (DeCuir-Gunby & Schutz, 2017). This design included the process of combining, comparing, and contrasting the quantitative and qualitative findings. The data integration process utilized a narrative approach. The mixed methods design enabled the triangulation of the findings, which added to enhance the validity and credibility of the results.

The quality criteria for the mixed methods design will include inference quality and inference transferability. The ability to integrate the qualitative and quantitative findings of this study will provide triangulation and support the reliability and credibility of the study. The researcher will work to ensure that the inductive and deductive conclusions from the study are believable and accurate to achieve inference quality (DeCuir- Gunby & Schutz, 2017; Polit &

Beck, 2014). Chapter 6 includes a discussion of the study findings, strengths, limitations, and recommendations.

Summary

This research study introduced a mixed methods design that explored the experiences and perceptions of family members affected by SUD. The research design utilized the underlying conceptual framework of social support throughout the development, data collection, analysis, and discussion of the study. The study includes qualitative and quantitative data collection. The qualitative and quantitative data were collected simultaneously using one survey instrument. The analysis of the qualitative and quantitative data occurred separately. The integration of qualitative and quantitative findings occurred after the quantitative and qualitative data analysis. The mixed methods approach will help with triangulation and a better representation of the experiences and perceptions of the AFM regarding social support and the association with health and well-being (Decuir-Gunby & Schutz, 2017).

Chapter 4

Quantitative Findings

A purposive sample of affected family members (AFM) participated in this study. The researcher conducted recruitment online and in-person. Participants completed an online survey. The online survey included participant characteristics survey (Appendix A), the PHS-WS scale (Appendix B), and the ADF SSS 25 item questionnaire (Appendix D) for the quantitative arm of this study. The conceptual model, constructs of social support, and the corresponding measurement instruments for the quantitative portion of this study (see Figure 4). The survey administration utilized Qualtrics® in the administration of the survey and the data collection. The Statistical Package for the Social Science (SPSS) 26® provided the means to complete descriptives and bivariate correlation analysis of the data. Data analysis proceeded to answer the research questions and to accept or reject the study hypotheses. The research questions asked were:

- What are the social support perceptions of AFM's?
- What are the social support experiences of AFMs while providing support to an ISUD?
- What is the association between AFM reported social support levels and their perceptions of health?
- What is the association between AFM social support levels and their perceptions of well-being?
- What is the relationship of the subscales, functional, perceived and received, and structural levels of social support, to health and well-being reported by the AFM?

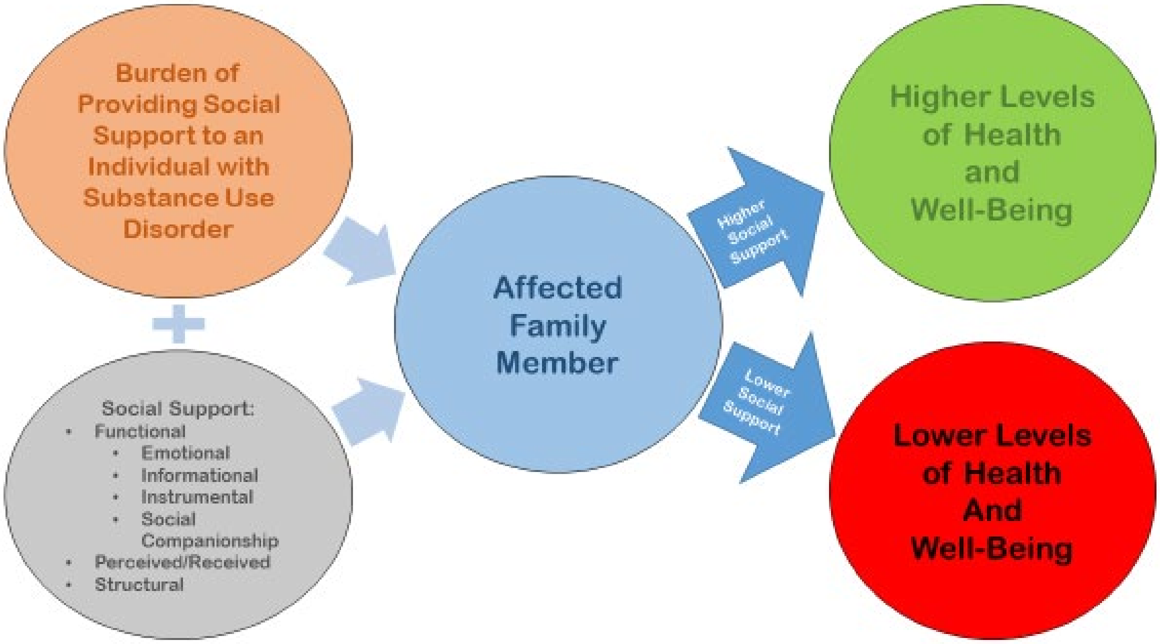
- Is there an interaction between social support and the perceived health and well-being of the AFM?

The hypotheses of the study include:

- The AFM, who perceives receiving positive social support, will report higher levels of health and well-being.
- The AFM, who perceives receiving inadequate positive social support, will report lower levels of health and well-being.

Figure 4

Social Support, Affected Family Member and Quantitative Measurement Instruments



Sample

Participants Characteristics

The Qualtrics® data management system received N = 171 surveys. The researchers carefully reviewed the surveys for any missing data. The participant completion of the ADF SSS scale and the PHS-WS was an inclusion requirement for the analysis. The number of surveys deemed acceptable for the quantitative arm of this study totaled N = 134. The sample was predominantly White/Caucasian females identifying as the mother of the individual with a SUD (ISUD). The participants making up the sample for the quantitative data consisted of primarily White/Caucasian (95.5%), females (97%), with an age range of 23-82 years. Age was not a variable used in the data analysis of this study. The participant age of 82 years at first glance appears to be high; however, the researcher is aware of recruiting over ten potential participants over the age of 80 years, who received the recruitment materials. The response by this participant is not erroneous for this reason. Age was not a variable used in this study's statistical analysis.

Most of AFM's reported being married (70.1%) and working full-time (59%). Many AFM reported being the mother (81.3%), with less identified as the father (3%) of the ISUD. A large number (62.7%) of the AFM reported providing support to the ISUD for seven or more years. Many AFM (76.9%) reported owning their own home and responsible for finances (66.4%) (see Table 3).

Table 3

Participant Characteristics AFM

Characteristics of the AFM	N = 134	(%) or mean (range)
Age in years	52.13	(23-82)
Gender		
Male	4	(3%)
Female	130	(97%)
Identify with other gender	0	-
Other	0	-
Race/Ethnicity		
White/Caucasian	128	(95.5%)
Black/African American	1	(.7%)
Native American	1	(.7%)
Hispanic/Latino	3	(2.2%)
Asian	1	(.7%)
Other	-	-
Relationship Status		
Single	7	(5.2%)
Married	94	(70.1%)
Separated	1	(.7%)
Divorced	16	(11.9%)
Living with Significant Other	12	(9%)
Other	4	(3%)
Employment Status		
Working Part-time	24	(17.9%)
Working Full-time	79	(59%)
Not Working	4	(3%)
Disabled	9	(6.7%)
Retired	16	(11.9%)
Other	2	(1.5%)
Relationship with ISUD		
Mother	109	(81.3%)
Father	4	(3%)
Sibling	6	(4.5%)
Grandmother	-	-
Grandfather	-	-
Aunt	2	(1.5%)
Uncle	1	(.7%)
Spouse	1	(.7%)
Partner	2	(1.5%)
Friend	1	(.7%)
Child	7	(5.2%)
Other	1	(.7%)

Years Providing Support		
Less than 1 year	4	(3%)
1-2 years	15	(11.2%)
3-4 years	17	(12.7%)
5-6 years	14	(10.4%)
7 or more years	84	(62.7%)
Resident Status		
Own	103	(76.9%)
Rent	25	(18.7%)
Live with a family member	2	(1.5%)
Live with a non-family member	3	(2.2%)
Other	1	(.7%)
Person responsible for finances		
Myself	89	(66.4%)
Significant Other	15	(11.2%)
Partner	1	(.7%)
Spouse	26	(19.4%)
ISUD	2	(1.5%)
Friend	-	-
Other	1	(.7%)
People living in residence		
1-2 people	55	(41%)
3-4 people	57	(42.5%)
5-6 people	16	(11.9%)
7 or more people	6	(4.5%)
Does ISUD live with you?		
Never	58	(43.3%)
Sometimes	37	(26.6%)
About half the time	7	(5.2%)
Most of the time	6	(4.5%)
Always	26	(19.4%)

Several questions posed to the AFM asked about the characteristics of the ISUD in their lives. The average reported age of the ISUD was 29.94 years with male (63.4%) female (35.8%), and other (.7%). Many of the ISUD identified as White/Caucasian (94%) and single (58.2%). There was a variety of employment status ranging from not working (42.5%) to working full-time (33.6%). Many ISUD had been using substances seven or more years (66.4%), and some remain using substances (38.8%). Some ISUD utilize outpatient recovery (11.9%), and some (5.2%) utilize inpatient recovery, which indicates over 80% of the ISUD recovery status is unknown (see Table 4).

Table 4

Characteristics of the ISUD

Characteristics of the ISUD	**N = 134**	**(%) or mean (range)**
Age in years	29.94	(14-83)
Gender		
Male	85	(63.4%)
Female	48	(35.8%)
Identify with other gender	0	-
Other	1	(.7%)
Race/Ethnicity		
White/Caucasian	126	(94%)
Black/African American	2	(1.5%)
Native American	2	(1.5%)
Hispanic/Latino	3	(2.2%)
Asian	-	-
Other	1	(.7%)
Relationship Status		
Single	78	(58.2%)
Married	11	(8.2%)
Separated	3	(2.2%)
Divorced	19	(14.2%)
Living with Significant Other	20	(14.9%)
Other	3	(2.2%)
Employment Status		
Working Part-time	19	(14.2%)
Working Full-time	45	(33.6%)
Not Working	57	(42.5%)
Disabled	4	(3%)
Retired	3	(2.2%)
Other	6	(4.5%)
Years with SUD		
Less than 1 year	2	(1.5%)
1-2 years	7	(5.2%)
3-4 years	18	(13.4%)
5-6 years	18	(13.4%)
7 or more years	89	(66.4%)

Health Status ISUD		
Poor	31	(23.1%)
Fair	46	(34.3%)
Good	43	(32.1%)
Very Good	7	(5.2%)
Excellent	7	(5.2%)
Person responsible for finances for ISUD		
Yourself	32	(23.9%)
Your Significant Other or Partner	-	-
Your Spouse	5	(3.7%)
ISUD	81	(60.4%)
Significant Other or Partner of ISUD	4	(3%)
Other	12	(9%)
People living in residence of ISUD		
1-2 people	45	(33.6%)
3-4 people	45	(33.6%)
5-6 people	17	(12.7%)
7 or more people	7	(5.2%)
Other	20	(14.9%)
Recovery Status of ISUD		
Remains using substance	52	(38.8%)
Outpatient Treatment	16	(11.9%)
Inpatient Treatment	7	(5.2%)
Not using Substance at this time	44	(32.8%)
Unknown	15	(11.2%)

Quantitative Procedures

The following paragraphs are inclusive of the quantitative procedures utilized in the analysis of the data. This study used a cross-sectional design to collect data using an online survey administered through Qualtrics®. The data from the online survey underwent downloading from Qualtrics® into the SPSS 26® data management system. The researchers made comparisons of the data sets and verified the data transferred to the SPSS 26® was accurate. The researchers screened and cleaned the data for errors or outliers. The researchers examined extreme outliers to ensure no errors existed in the data set. The presence of an extreme outlier existed in the ages of the AFM (82 years) and ISUD (83 years). The researchers consulted on this outlier and retained it.

Quantitative data collection used the participant characteristics survey, the Alcohol, Drugs, and the Family Social Support Scale (ADF SSS) and the Public Health Surveillance Well-Being Scale (PHS-WS). The participant characteristics survey collected demographic data for the study. The ADF SSS measured the social support of the AFM. The ADF SSS is a 25-item survey made up of three subscales positive functional support, positive ADF specific support, and negative ADF specific support. The scale provides a score for each of the subscales and total positive support. The PHS-WS measured the health and well-being of the AFM. The PHS-WS includes the subscales of health, energy, personal life satisfaction, days cheerful, days hopeless, and family/social life satisfaction.

Data Analysis

Data analysis consisted of descriptive, bivariate correlation with Pearson product-moment, and multiple regression, with the reliability of scales, determined. Statistical analysis was completed using SPSS 26® data management system.

Preliminary data analyses of the data collected using the participant characteristics survey included descriptive statistics to describe the sample using descriptive data, including frequencies. The study variables underwent review, including descriptive statistics, including mean, standard deviation, range of score, skewness, and kurtosis, to check for any violation of assumptions before statistical analyses addressing the research questions.

The research questions were the impetus for the analytical techniques utilized for data analysis for this study. After running descriptive statistics, a calculation of the total scale and subscale scores for the ADF SSS and the PHS-WS occurred. Checking the reliability of the scales was the next step in the analyses, as described in Chapter 3.

The Alcohol, Drugs, and the Family Social Support Scale (ADF SSS 25) total scale reflected good internal consistency with Cronbach's alpha coefficient of .893. The ADF SSS Positive Functional Support, 11 item subscale, resulted in Cronbach's alpha of .925, with positive inter-item correlations. The ADF SSS 8 item subscale of negative specific support had a Cronbach's alpha of .827 with positive inter-item correlations. The ADF SS 6 item subscale of positive specific support had a Cronbach's alpha of .681 with positive inter-item correlations.

The Public Health Surveillance Well-Being (PHS-WS) Scale analysis resulted in Cronbach's alpha coefficient .873, which indicated good internal consistency of the total scale. The PHS-WS includes the subscales of health, energy, personal life satisfaction, days cheerful, days hopeless, and family/social life satisfaction. The 3-item subscale of life satisfaction had a Cronbach's alpha at .883. The 3-item subscale of family/social life satisfaction demonstrated internal consistency with a Cronbach's alpha of .789. The researchers discuss the statistical analysis completed for each research question in the following paragraphs.

Results

Research Question # 1

What are the social support perceptions of AFM's?

The total and subscale scoring of the quantitative data collected with the ADF SSS instrument provided information about the social support perceptions of the AFM. The ADF SSS variable consisted of 25 items measured, which include three subscales. The subscales are Positive Functional Support (subscale #1), Positive ADF Specific Support (subscale #3), and Negative ADF Specific Support (subscale #2).

ADF Specific Support Measures. Positive functional support measures emotional, social companionship, and instrumental types of social support. Positive ADF specific support measures formal and informal informational, emotional, support for coping, and attitudes and actions towards the ISUD. Negative ADF specific support measures support for coping and attitudes towards the ISUD (Toner & Velleman, 2012). Each item consisted of a 5-point Likert scale transformed to represent values ranging from 0-3 for each item. The Total ADF SSS Score or the Total Positive Social Support score calculation is to add the total scores of subscale #1 to subscale # 3 and then subtracting subscale # 2. The maximum score achievable is 51, and the minimum score is -24 (Toner & Velleman). The higher the score, the greater the positive responses received per question (see Appendix J).

ADF SSS Scale Scoring. The overall score for the ADF SSS scale and the subscales determined participant perceptions of social support to be more positive than negative in this study. When scoring the ADF SSS, the highest score possible indicating positive social support is 51, and the lowest possible score indicating negative social support is -24. The mean ADF SSS score for the AFM's participating in this study was 32.4 (SD of 9.6). The mean score of 32.4 indicates the AFM's in this study reported a higher number of positive social support experiences than negative experiences. While the standard deviation (SD) does show some variability, the 5 % trimmed mean for the ADF SSS scale and subscales are very consistent with the mean scores indicating little effect from extreme scores. The researchers retained all cases for data analysis (see Table 5).

Table 5

ADF SSS Scale and Subscale Means and Standard Deviations

Scale/Subscale	Mean	5% Trimmed Mean	SD	Min/Max/Range
Total Positive Social Support	32.40	32.38	9.64	(9-54) 45
• Positive Functional Support	38.43	38.76	8.52	(11-55) 44
• Positive ADF Specific Support	15.16	15.15	3.8	(6-26) 20
• Negative ADF Specific Support	21.19	21.31	5.11	(8-34) 26

Research Question # 2

What are the social support experiences of AFMs while to an ISUD providing support?

The ADF SSS was the quantitative instrument used to collect data about the social support experiences of the AFM's. The frequency of responses to the questions included in the ADF SSS gave some indication of the experiences of the AFM's. Each item used a 5-point Likert scale for participant responses. The response choices included not applicable, never, sometimes, often, and always. When reviewing the frequencies, some questions related to AFM's experiences with health care professionals showed concerning findings.

The concerning findings were that 27.6% of the respondents replied they "never" received helpful information from the health care providers or social workers. Additionally, 33.6% of the respondents indicated that healthcare professionals and social workers "never" made themselves available to the AFM. Another 31.3% of AFMs stated that they had "never" confided in their health/social care worker about their situation. These findings indicate the AFM's participating in this study found health care professionals unwilling to provide support or needed information to the AFM. Additionally, the AFM's did not confide their situation to healthcare professionals, thereby decreasing the amount of social support possible (see Table 6).

Table 6

ADF SSS Question, Response, Frequencies, and Percentages

Question (N = 134)	**Frequency**	**%**	**Type of Support**
1-Friends/relations have understood what it is like for me to live with my relatives' drinking or drug taking.			Positive Functional Support
Not Applicable	9	6.7	
Never	20	14.9	
Sometimes	75	56	
Often	22	16.4	
Always	8	6	
2-Friends/relations have helped to cheer me up.			Positive Functional Support
Not Applicable	9	6.7	
Never	12	9	
Sometimes	77	57.5	
Often	24	17.9	
Always	12	9	
3-Health/social care workers have given me helpful information about problem drinking or drug taking.			Positive ADF Specific Support
Not Applicable	39	29.1	
Never	37	27.6	
Sometimes	43	32.1	
Often	9	6.7	
Always	6	4.5	
4-I have friends/relations whom I trust.			Positive Functional Support
Not Applicable	4	3	
Never	5	3.7	
Sometimes	29	21.6	
Often	39	29.1	
Always	57	42.5	
5-Friends/relations have listened to me when I have talked about my feelings.			Positive Functional Support
Not Applicable	3	2.2	
Never	3	2.2	
Sometimes	43	32.1	
Often	44	32.8	
Always	41	30.6	
6-Friends/relations have backed my decisions that I have taken towards			Positive Functional Support

my relative and their drinking or drug-taking			
Not Applicable	9	6.7	
Never	5	3.7	
Sometimes	45	33.6	
Often	46	34.3	
Always	29	21.6	
7-Friends/relations have put themselves out for me when I needed practical help (i.e., aid or assistance).			Positive Functional Support
Not Applicable	13	9.7	
Never	20	14.9	
Sometimes	48	35.8	
Often	29	21.6	
Always	24	17.9	
8- Friends/relations have advised me to focus on myself and my own needs.			Positive Functional Support
Not Applicable	11	8.2	
Never	7	5.2	
Sometimes	39	29.1	
Often	48	35.8	
Always	29	21.6	
9- Friends/relations have questioned my efforts to stand up to my relatives' problem drinking or drug taking.			Negative ADF Specific Support
Not Applicable	12	9	
Never	42	31.3	
Sometimes	50	37.3	
Often	23	17.2	
Always	7	5.2	
10- Friends/relations have been too critical of my relative.			Negative ADF Specific Support
Not Applicable	7	5.2	
Never	36	26.9	
Sometimes	59	44	
Often	28	20.9	
Always	4	3	
11- Friends/relations have given me space to talk about my problems.			Positive Functional Support
Not Applicable	6	4.5	
Never	13	9.7	
Sometimes	49	36.6	
Often	47	35.1	
Always	19	14.2	
12- Friends/relations have said my relative should leave home.			Negative ADF Specific Support
Not Applicable	44	32.8	
Never	15	11.2	
Sometimes	31	23.1	

Often	28	20.9	
Always	16	11.9	
13- Friends/relations have said things about my relative that I do NOT agree with.			Negative ADF Specific Support
Not Applicable	8	6	
Never	24	17.9	
Sometimes	73	54.5	
Often	26	19.4	
Always	3	2.2	
14- Friends/relations have avoided me because of my relative's drinking or drug taking.			Negative ADF Specific Support
Not Applicable	14	10.4	
Never	66	49.3	
Sometimes	36	26.9	
Often	14	10.4	
Always	4	3	
15- Health/social care workers have made themselves available to me.			Positive ADF Specific Support
Not Applicable	39	29.1	
Never	45	33.6	
Sometimes	33	24.6	
Often	12	9	
Always	5	3.7	
16- Friends/relations have blamed me for my relative's behavior			Negative ADF Specific Support
Not Applicable	9	6.7	
Never	86	64.2	
Sometimes	34	25.4	
Often	2	1.5	
Always	3	2.2	
17-Friends/relations have said that my relative does NOT deserve help.			Negative ADF Specific Support
Not Applicable	7	5.2	
Never	84	62.7	
Sometimes	33	24.6	
Often	7	5.2	
Always	3	2.2	
18- I have identified with the information within books/booklets about people living with a problem drinker or drug taker.			Positive ADF Specific Support
Not Applicable	10	7.5	
Never	6	4.5	
Sometimes	41	30.6	
Often	56	41.8	
Always	21	15.7	
19- Friends/relations have told my relative off on my behalf.			Positive ADF Specific Support
Not Applicable	11	8.2	

Never	74	55.2	
Sometimes	38	28.4	
Often	10	7.5	
Always	1	.7	
20-Friends/relations have advised me to leave my relative.			Positive ADF Specific Support
Not Applicable	34	25.4	
Never	42	31.3	
Sometimes	45	33.6	
Often	12	9	
Always	1	.7	
21- Friends/relations have been there for me.			Positive Functional Support
Not Applicable	4	3	
Never	8	6	
Sometimes	47	35.1	
Often	41	30.6	
Always	34	25.4	
22- Friends/relations have provided support for the way I cope with my relative.			Positive Functional Support
Not Applicable	8	6	
Never	11	8.2	
Sometimes	61	45.5	
Often	40	29.9	
Always	14	10.4	
23-Friends/relations have talked to me about my relative and listened to what I have to say.			Positive Functional Support
Not Applicable	7	5.2	
Never	6	4.5	
Sometimes	55	41	
Often	42	31.3	
Always	24	17.9	
24- Friends/relations have said nasty things about my relative.			Negative ADF Specific Support
Not Applicable	6	4.5	
Never	43	32.1	
Sometimes	62	46.3	
Often	20	14.9	
Always	3	2.2	
25-I have confided in my health/social care worker about my situation.			Positive ADF Specific Support
Not Applicable	34	25.4	
Never	42	31.3	
Sometimes	36	26.9	
Often	11	8.2	
Always	11	8.2	

The analysis for the following research questions required the PHS-WS total scale and subscale score analysis. The PHS-WS is inclusive of seven items with Likert type responses (1-5) and three items with range scales (1-10). The PHS-WS total scale mean score was 36.28 (SD of 9.67). The PHS-WS includes six subscales, including life satisfaction, days cheerful, days hopeless, family satisfaction, energy, and health. While the standard deviation (SD) does show some variability, the 5 % trimmed mean for the ADF SSS scale and subscales are very consistent with the mean scores indicating little effect from extreme scores. The researchers retained all cases for data analysis (see Table 7).

Table 7

PHS-WS Scale and Subscale Means and Standard Deviations

Scale/Subscale	Mean	5% Trimmed Mean	SD	Range
Total Health and Well-Being	36.28	36.49	9.67	48
• Life Satisfaction	10.54	10.71	3.42	12
• Days Cheerful	3.00	3.01	.98	4
• Days Hopeless	2.48	2.42	1.25	4
• Family Satisfaction	9.30	9.27	5.89	20
• Energy	6.92	6.93	3.35	13
• Health	3.04	3.05	1.01	4

Research Question # 3

What is the association between AFM reported social support levels and their perceptions of health?

The ADF SSS scale and the PHS-WS provided the data used in the analysis required to answer this research question. The ADF SSS scale provided the data about the AFM's social support, and the PHS-WS provided a one-item question about the health of the AFM. The AFM responses to their current health included: poor, fair, good, very good, and excellent.

The bivariate correlational analysis determined if associations between the reported social support levels and perceptions of health among the AFM's existed. The relationship between social support (as measured with the ADF SSS) and health (one item) investigated using person product-moment correlation coefficient showed a small association. Preliminary analysis ensured no violation of the assumptions of normality, linearity, and homoscedasticity. Correlations are significant at the .01 level (two-tailed). The bivariate correlations revealed a small positive correlation between social support and perceived health r (132) = .18, p =.042. The small positive correlation indicates that when the AFM's participating in this study experience, higher levels of social support, they report higher levels of health.

The additional investigation utilized bivariate correlational coefficient analysis between the subscales of the ADF SSS (positive functional, positive ADF specific, and negative ADF specific support) and health. There existed a small negative correlation between the subscale negative ADF specific support and health with r (132) = -.29, p = .001. The finding is significant and indicates that the participants of this study who reported experiencing higher levels of negative support experience lower levels of health.

Research Question # 4

What is the association between AFM social support levels and their perceptions of well-being?

The analysis included data obtained from the ADF SSS scale and the PHS-WS to answer this research question. The ADF SSS scale provided the data about the AFM's social support, and the PHS-WS provided data about the well-being of the AFM. The bivariate correlational analysis determined if there existed associations between the reported social support levels and perceptions of well-being among the AFM's participating in the study. The relationship between social support (as measured with the ADF SSS) and well-being (as measured with the PHS-WS) investigation included Pearson product-moment correlation coefficient. Preliminary analysis ensured no violation of the assumptions of normality, linearity, and homoscedasticity. Correlations are significant at the .01 level (two-tailed). A bivariate correlation analysis explored the associations between the total score of positive social support and the total scale score of wellbeing. Pearson product-moment correlation r (131) = .25, p = .004, showed a small positive association between the AFMs receiving positive social support and their perceived well-being. The findings are significant and indicate that when the AFM's included in this study experienced higher levels of positive social support, they reported higher levels of well-being.

Research Question #5

What is the relationship of the subscales, functional, perceived and received, and structural levels of social support, to health and well-being reported by the AFM?

The ADF SSS scale provided the data about the AFM's social support subscales of positive functional support (emotional, social companionship, support for coping, and instrumental support), positive ADF specific support (informational, emotional, support for coping, and attitudes and actions toward the ISUD), and negative ADF specific support (support for coping and attitudes and actions towards the ISUD). The PHS-WS provided the data for the health and well-being of the AFM (life satisfaction, days cheerful, days hopeless, family/social satisfaction, health, energy level). The bivariate correlational analysis determined if associations existed between the reported social support levels and perceptions of health and wellbeing among the AFM's participating in the study. Preliminary analysis ensured no violation of the assumptions of normality, linearity, and homoscedasticity. Correlations are significant at the .01 level (two-tailed). The total scores and the subscales of the ADF SSS the PHS-WS scale were analyzed using bivariate correlation with the following significant findings.

Positive Functional Support. The relationship between positive functional support and life satisfaction showed a small positive correlation between the two variables, r (131) = .26, p = 002. The findings in this study indicate that a higher level of positive functional support is associated with higher levels of life satisfaction. The AFM's in this study, reporting higher levels of functional social support, experienced higher levels of life satisfaction.

The relationship between positive functional support and health and well-being showed a small positive correlation between the variables, r (131) = .24, p = .005. Higher levels of positive functional support were significantly associated with health and well-being. These results indicate that the AFM's who participated in this study when they receive higher levels of positive functional support they experience higher levels of health and well-being

Negative ADF Specific Support. A medium positive correlation between the variables of negative ADF specific support and days hopeless, r (132) = .42, p = .000 existed. Higher levels of negative ADF specific support are associated with higher levels of days hopeless. The participants included in this study, when experiencing higher levels of negative ADF specific support, also experience more days hopeless.

When examining the relationship between negative ADF support and health, a small negative association existed r (132) = -.29, p = .001. Higher negative ADF specific support is associated with lower levels of health. This finding does indicate higher levels of negative ADF specific support experienced by the AFM will result in lower levels of health reported by the AFM. The participants in this study, when experiencing higher levels of negative ADF specific support, also experienced less cheerful days. There was a small negative correlation between negative ADF specific support and days cheerful, r (132) = -.28, p = .001). Higher levels of negative ADF specific support are associated with lower levels of days cheerful.

Positive ADF Specific Support. There existed no significant correlations among positive ADF specific support and the scale and subscales of the PHS-WS using a significance level .01 (two-tailed) (see Table 7). Positive ADF specific support did not show a significant correlation with life satisfaction, health, days, cheerful, days hopeless, family life satisfaction, well-being, or total health and well-being for the AFM's in this study.

Total Positive Social Support. There existed a medium, positive correlation between total positive social support and life satisfaction, r (131) = .31, p = .000. A small positive correlation between the variables of total positive social support and days cheerful, r (132) = .23 p = .008 existed. The analysis between total positive social support and total health and well-being presented with a small positive correlation, r (131) = .25, p = 004. The relationship between total positive social support and days hopeless showed a small negative correlation, r (132) = - .24, p = .005.

The findings indicate that AFMs participating in this study reporting higher levels of total positive social support are associated with experiencing higher levels of total health and well-being, days cheerful, and life satisfaction, with fewer days hopeless. Higher levels of total positive social support are associated with lower levels of days hopeless. The results of the bivariate correlations between total positive social support and the scale and subscales of the PHS-WS indicate that higher levels of positive social support benefit the AFM's health and well-being (see Table 7).

Table 8

Means, Standard Deviations, and Correlations of Public Health Surveillance Well-Being Scale and Subscales with Alcohol Drugs and the Family Social Support Scale and Subscales

	M	SD	Positive Functional Social Support	Negative ADF Specific Support	positive ADF Specific Support	Total Social Support ADF SSS
Life Satisfaction	10.54	3.42	.26**	-.17	-.03	.31**
Days Cheerful	3.0	.98	.19*	-.28**	-.21*	.23**
Days Hopeless	2.48	1.24	-.10	.42**	.20*	-.24**
Satisfaction with Family, Friends and Social Life	9.3	6.92	.08	.10	.08	.05
Energy Level	6.93	3.35	.18*	.02	-.06	.12
Health	3.04	1.01	.07	-.29**	-.11	.18*
Total Health and Wellbeing (PHS-WS)	36.28	9.67	.24**	-.10	-.05	.25**

** Correlation is significant at the 0.01 level (2- tailed)
*Correlation is significant at the 0.05 level (2-tailed)

Research Question # 6

Is there an interaction between social support and the perceived health and well-being of the AFM?

To determine if there was an interaction between social support and the health and well-being of the AFM, the researchers employed the use of standard multiple regression. The analysis included the independent variables positive functional support, positive ADF specific support, and negative ADF specific support (as measured with the ADF SSS). The dependent variable is the health and wellbeing of the AFM (as measured with the PHS-WS).

Multiple regression can identify how well the independent variables can predict the dependent variable, health, and well-being, of the AFM, providing support to an ISUD. To ensure not violating the assumption of singularity required the exclusion of the total positive social support scale due to the combination of repeated scale items within the scale and subscales (Pallant, 2016). The scatterplots generated ensured the assumptions of normality, linearity, homoscedasticity, and independence of residuals of the scores (see Appendix K). The researchers excluded outliers greater than three standard deviations.

The multiple regression using the predictor variables of positive functional support, positive ADF specific support, and negative ADF specific support showed a relationship with health and well-being. The tolerance values ranged from .710 to .983, which are not less than .10. The tolerance values suggest no violations of multicollinearity. The variance inflation factor (VIF) values ranged from 1.017 to 1.408, which are below the cutoff point of 10, supporting no violations of multicollinearity. The Mahalanobis distance value of 16.509 is slightly higher than the critical value of 16.27, so no cases were excluded (Pallant, 2016). Cook's distance maximum value of .121 reinforces there are no significant problems in the data.

The multiple regression indicates that the predictor variables could explain 7.4 % of the variance of the dependent variable. The results showed that the model was a significant predictor of health and wellbeing, F (3, 129) = 3.432, p = .020. The predictor variables of positive functional support, positive ADF specific support, and negative ADF specific support can explain 7.4 % of the variance in the dependent variable health and well-being.

The multiple regression analysis did show that negative ADF specific support did not significantly predict an impact on their health and well-being (ß = -.11, p = .28). Additionally, the study showed that positive ADF specific support did not significantly predict health and well-being (ß = -.03, p =.796.) However, the multiple regression analysis did show that positive functional support was a significant predictor of health and well-being (ß = .25, p =.004) (see Table 8). Positive functional support was a significant predictor of health and well-being in the AFM participating in this study.

Table 9

Regression Analysis Summary for ADF SSS Subscales Predicting Health and Well- Being of the AFM.

Variable	**β**	**t**	**p**
Positive Functional Support	.254	2.968	.004
Negative ADF Specific Support	-.109	-1.089	.278
Positive ADF specific Support	-.026	-.259	.796

Note. $R^2 = .271$ (N = 132, p < .01).

The multiple regression does indicate a relationship between positive functional social support, including emotional, social companionship, support for coping, and instrumental support as being a significant contributor to the health and well-being of the AFM's in this study.

Summary

The quantitative arm of this study recruited 134 participants self-reporting as the AFM of an ISUD. Sample characteristics identified most participants as married (70.1%) females (97%), identifying as the mother (81.3%) of the ISUD. Many (62.7%) reported the substance use of the ISUD as occurring over seven or more years. The participant has completed an online questionnaire, including demographics, the PHS-WS, and the ADF SSS. The PHS-WS and the ADF SSS showed scale reliability, as included above.

The quantitative data analysis of the data for this study utilized descriptive statistics, bivariate correlations, and multiple regression. The analysis of the data indicates that higher levels of positive social support are associated with higher levels of health and well-being. The study findings also suggest that higher levels of negative ADF specific support are associated with lower levels of health and well-being in this population of AFM, providing support to an ISUD.

Chapter 5

Qualitative Findings

The mixed methods design (QUAN-QUAL) of this study required the analysis of the qualitative and quantitative data separately (DeCuir-Gunby & Schutz, 2017). This chapter discusses the qualitative thematic analyses from the participant’s short answer responses and identifies the emergent themes. The wealth of information shared by the participants allowed the researchers to capture the voice of the participant's through their collective perceptions and experiences. Included in the following paragraphs are the sample characteristics and qualitative analyses with findings. The information collected from this study has significant implications for healthcare providers caring for the AFM.

Sample

The mixed methods design of this study yielded different sample populations for each arm of the study (quantitative and qualitative). The sample represented in the qualitative findings is those participants who chose to respond to the open-ended short answer survey questions. There were 134 participants included in the entire study (N = 134), with a sub-sample of (n = 101) participants responding to the open-ended short answer survey questions. The responses to the open-ended questions totaled 1088 responses, making up the qualitative data analyzed. The highest number of participants responding to the open-ended short answer survey questions is a sub-sample (n = 101) for this study. Figure 5 contains the conceptual model for the qualitative arm of this study. Figure 6 includes the qualitative response trail for this study.

Figure 5

Conceptual Model for the Qualitative Arm of the Study

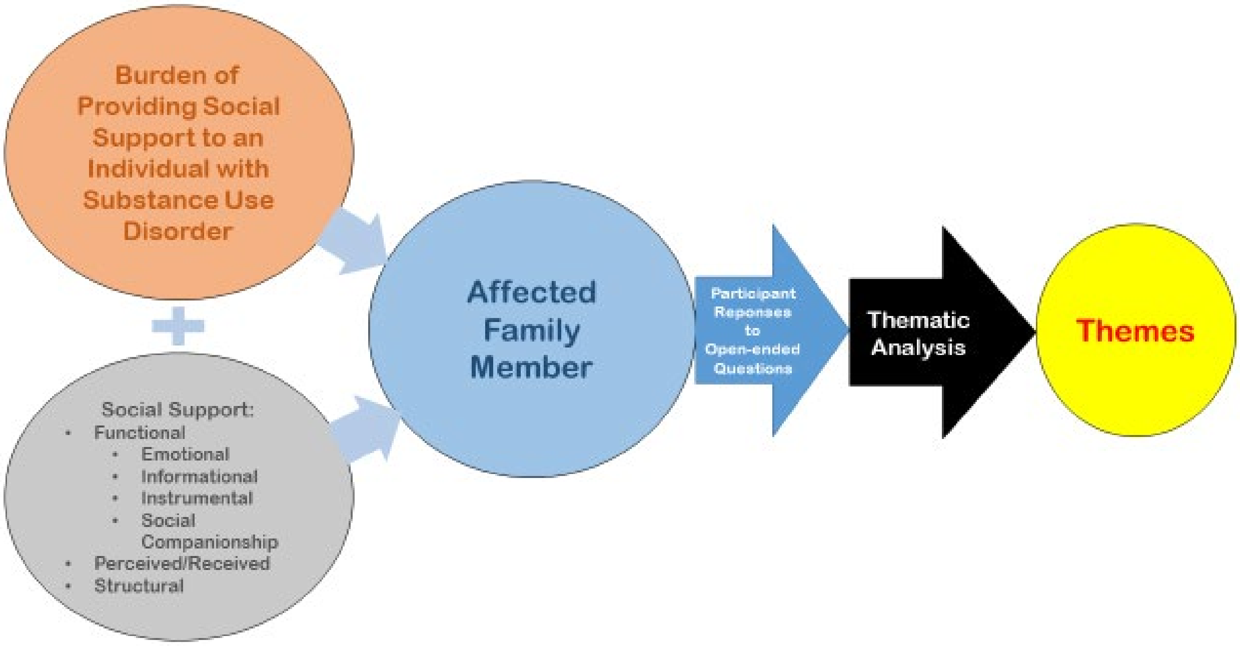
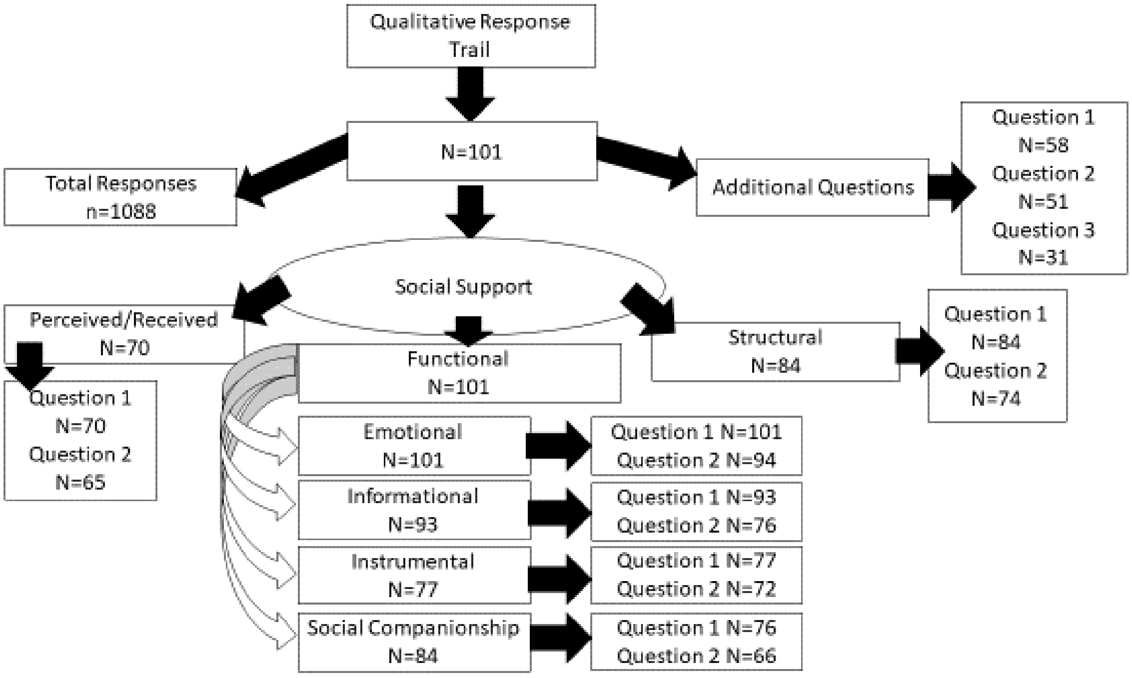


Figure 6

Qualitative Response Trail



Participant Characteristics

This paragraph provides the sample characteristics of the qualitative sub-sample included in this study. The sub-sample for the qualitative arm of the study was predominantly White/Caucasian females (n = 101), with (n = 83) identifying as the mother of the ISUD. The average age of the AFM was 52.23%, with a range of 18-82 years for the subsample. The ISUD was primarily White/Caucasian (93.1%), the average age of 30.31%, with a range of 15-83 years. The AFM's identified more males (60.4%) than females (38.6%) as ISUD (see Table 8).

Table 10

Qualitative Participant Responses (AFM)

Characteristics of the AFM	**N = 134** **n=101**	**(%) or mean (range)**
Age in years	52.23	(18-82)
Gender		
Male	2	(2%)
Female	99	(98%)
Identify with other gender	0	-
Other	0	-
Race/Ethnicity		
White/Caucasian	96	(95%)
Black/African American	1	(1%)
Native American	1	(3%)
Hispanic/Latino	1	(1%)
Asian	-	-
Other	-	-
Relationship Status		
Single	6	(5.9%)
Married	71	(70.3%)
Separated	1	(1%)
Divorced	12	(11.9%)
Living with Significant Other	8	(7.9%)
Other	3	(3%)

Employment Status		
Working Part-time	18	(17.8%)
Working Full-time	59	(58.4%)
Not Working	3	(3%)
Disabled	8	(7.9%)
Retired	11	(10.9%)
Other	2	(2%)
Relationship with ISUD		
Mother	83	(82.2%)
Father	2	(2%)
Sibling	6	(5.9%)
Grandmother	-	-
Grandfather	-	-
Aunt	2	(2%)
Uncle	1	(1%)
Spouse	-	-
Partner	-	-
Friend	1	(1%)
Child	6	(5.9%)
Other	-	-
Years Providing Support		
Less than 1 year	3	(3%)
1-2 years	10	(9.9%)
3-4 years	11	(10.9%)
5-6 years	9	(8.9%)
7 or more years	68	(67.3%)
Resident Status		
Own	73	(72.3%)
Rent	23	(22.8%)
Live with a family member	2	(2%)
Live with a non-family member	2	(2%)
Other	1	(1%)
Person responsible for finances		
Myself	67	(66.3%)
Significant Other	11	(10.9%)
Partner	1	(1%)
Spouse	19	(18.8%)
ISUD	2	(2%)
Friend	-	-
Other	1	(1%)
People living in residence		
1-2 people	39	(38.6%)
3-4 people	47	(46.5%)
5-6 people	10	(9.9%)
7 or more people	5	(5%)

Does ISUD live with you?		
Never	49	(48.5%)
Sometimes	27	(26.7%)
About half the time	4	(4%)
Most of the time	4	(4%)
Always	17	(16.8%)

The AFM provided some of the characteristics of the ISUD in their lives. The average reported age of the ISUD was 30.31 years with male (60.4%) female (38.6%), and other (1%). Many of the ISUD identified as White/Caucasian (93.1%) and single (59.4%). There was a variety of employment status ranging from not working (43.6%) to working full-time (31.7%). Many ISUD had been using substances seven or more years (70.3%), and some remain using substances (33.7%) and some not using substances (36.6%). Some ISUD utilize outpatient recovery (12.9%), and some (4%) utilize inpatient recovery (see Table 9).

Table 11

Qualitative Participants Responses Individual with a SUD (ISUD)

Characteristics of the ISUD	**N=134 n=101**	**(%) or mean (range)**
Age in years	30.31	(15-83)
Gender		
Male	61	(60.4%)
Female	39	(38.6%)
Identify with other gender	0	-
Other	1	(1%)
Race/Ethnicity		
White/Caucasian	94	(93.1%)
Black/African American	2	(2%)
Native American	2	(2%)
Hispanic/Latino	2	(2%)
Asian	-	-
Other	1	(1%)

Relationship Status		
Single	60	(59.4%)
Married	9	(8.9%)
Separated	1	(1%)
Divorced	16	(15.8%)
Living with Significant Other	14	(13.9%)
Other	1	(1%)
Employment Status		
Working Part-time	15	(14.9%)
Working Full-time	32	(31.7%)
Not Working	44	(43.6%)
Disabled	3	(3%)
Retired	2	(2%)
Other	5	(5%)
Years with SUD		
Less than 1 year	2	(2%)
1-2 years	4	(4%)
3-4 years	11	(10.9%)
5-6 years	13	(12.9%)
7 or more years	71	(70.3%)
Health Status ISUD		
Poor	21	(20.8%)
Fair	35	(34.7%)
Good	32	(31.7%)
Very Good	7	(6.9%)
Excellent	6	(5.9%)
Person responsible for finances for ISUD		
Yourself	23	(22.8%)
Your Significant Other or Partner	-	-
Your Spouse	2	(2%)
ISUD	63	(62.4%)
Significant Other or Partner of ISUD	3	(3%)
Other	10	(9.9%)
People living in residence of ISUD		
1-2 people	34	(33.7%)
3-4 people	36	(35.6%)
5-6 people	10	(9.9%)
7 or more people	4	(4%)
Other	17	(16.8%)
Recovery Status of ISUD		
Remains using substance	34	(33.7%)
Outpatient Treatment	13	(12.9%)
Inpatient Treatment	4	(4%)
Not using Substance at this time	37	(36.6%)
Unknown	13	(12.9%)

Qualitative Analysis

The methodology for this study was a mixed methods convergent concurrent design (DeCuir-Gunby & Schutz, 2017). The qualitative data collected for this mixed methods study are the participant responses to open-ended short answer survey questions. The survey design required the participant to type their short answers to the items in the survey. The conceptual framework of social support was foundational to the development of the open-ended question development (Vaux, 1988). Twelve open-ended questions represented an exploration of social support. Two additional questions asked participants to share their advice for other AFM's and healthcare professionals, with one item asking for feedback about the survey itself. The open-ended questions aimed to gain knowledge about RQ 1: What are the social support perceptions of AFM's? and RQ 2: "What are the social support experiences of the AFM?" The researchers present the findings in a narrative summary utilizing quotes and phrases from the participant responses as evidentiary support for the overarching themes. Appendix L contains the participant identification number and corresponding quote to ensure variability within the data and participants.

Overarching Themes

The analysis of the subsample of participant's short answer responses totaled 1088 comments that contributed to the emergence of five themes. The researchers identified five overarching themes emerging from the qualitative data analysis. The themes are:

1. *We are all alone, and we have to fend for ourselves*
2. *No one understands what we are going through*

3. *Healthcare providers do not know how to provide care and are clueless*
4. *We have no access to effective care or treatment*
5. *People cannot relate and recoil from us*

The five overarching themes are described in the following paragraphs.

Theme 1

We are all alone, and we have to fend for ourselves

Several factors contributed to the theme, "*We are all alone, and we have to fend for ourselves*." The participants shared feelings of loneliness, isolation, distancing, abandonment, and privacy contributing to feelings of being all alone. Loneliness occurred because of the AFM's relationship with the ISUD. One participant was able to express this feeling in the following quote: "*I am lonely and wish people would remember that I am a mother of a drug addict but am still a real person* (participant # 125)."

Other AFM's experienced isolation. The responses indicated two types of isolation, the AFM that chose to self-isolate and the AFM that was isolated by the actions of others. Self-isolation occurred as self-protection from the reactions of others. The AFM's decided not to share or talk with other family or friends, fearing a negative response. Still, other AFM's just expressed the desire to be alone and not depend on others. One AFM shared the following "*I have not discussed the addiction with anyone*" (participant # 34). However, other AFM's felt isolated as their family, friends, and coworkers distanced themselves from the participant and refused to acknowledge or speak to the ISUD. One participant shared:

> *There are a number of nieces who don't speak to me anymore. Family get togethers are always tense because everyone is worried about whether or not my daughter is coming. She rarely does attend anything. But when she does we have to worry about her drinking*

> *and getting out of control. I don't think most of the family truly understands why my daughter doesn't just "get help." Most - if not all - of her cousins drink, smoke cigarettes, smoke weed - and none of them are addicts in the sense that they can't or don't function. All have jobs, homes, families of their own. They can't understand why she is such a mess. My siblings can't relate because they have little to no experience with substance abuse* (participant # 117).

Other AFM's reported not being allowed at family gatherings or holidays because of their relationship with the ISUD. The actions of some family members caused the AFM to feel all alone and emotionally broken while caring for their loved ones. As exhibited by the statement:

> "*My mother and father never come around anymore, no Holidays Nothing! For 43 years of my life, my whole family was together for get-togethers, game night, Christmas, Thanksgiving now I have nothing left! I am emotionally broken!*" (participant # 65)

Another cause of isolation, identified in the participant responses, was the encouragement to abandon the ISUD. Many AFM's experienced people were telling them to kick out the ISUD and not help or enable them, and to leave their loved ones homeless on the street. Hearing harsh comments added to the AFMs feeling of being all alone in the struggle to care for their loved ones. As one participant shared, "*Family and friends basically told me I should just kick him out of my life"* (participant # 4).

Privacy was another concern among AFM's, for themselves and their loved ones, exacerbating their feelings of being all alone. AFM's felt they were protecting the ISUD privacy and did not want others to know about their situation. Responses from the AFM's included, "*I don't really discuss this with other people. I have always been an extremely private person and* *sometimes am better to just be able to spend time alone with my thoughts"* (participant # 69) and "*Friends offer but I keep private"* (participant # 33).

Theme 2

No one understands what we are going through

A feeling of a lack of understanding by the AFM appeared consistently throughout the participant responses. The lack of understanding of family and friends led to the limited encouragement the AFM received as they attempted to support the ISUD. AFMs felt that understanding only came from people who were living in the same circumstances, as described in the following statements, "*Most people don't understand the feeling I have towards my daughter. I love her and don't want to see her die but I know if she keeps on that is what will happen*" (participant # 89), and "*They don't understand what it is like, because they have never went through anything like this!"*(participant # 63). Other AFMs were searching for understanding and agreement for their choices from family and friends, as exhibited by one participant's thoughts:

> "*Have a husband, SIL, sister, mother, adult children who have listened when I have been upset but I feel like they don't understand and sometimes didn't agree with me so I find myself keeping to myself more and more"* (participant # 40).

The AFMs purported a lack of knowledge that contributed to the limited understanding of family and friends. The AFMs viewed education and increased awareness about the disease of addiction as strategies that would enable their family and friends to understand the disease of addiction. Frustrated AFMs, expressed their growing difficulties in obtaining understanding for their support of the ISUD in the following manner: "*Lacking an understanding of the disease of* *addiction is the most difficult situation to deal with*” (participant # 87). Similarly, another participant expressed their perspective:

> *Some family members simply do not understand how SUD effects the person/loved one. They wish to fix that person or have them just "get over it." This is a long and sometimes frustrating situation. Support and understanding are the only things that appears to have a positive effect on the loved one effected* (participant # 3).

Family and friends without any knowledge of addiction may have desired to help. Still, their ability to provide the needed support, according to one mother, was ineffective: “*Friends didn’t have much knowledge about addiction, and therefore they really weren’t much help at all”* (participant # 4). Reportedly, those who wanted to help, but had limited knowledge, could not: “*I have a family who wants to be supportive but doesn’t really know how*” (participant # 76). Other AFM’s tried to increase the understanding of their support system with varied success and shared: “*I had to attempt to educate my friends and relatives about the disease of addiction. Some came to understand, and some didn’t*” (participant # 100).

Theme 3

Healthcare providers do not know how to provide care and are clueless

Nearly a fourth of the participants (n = 23) shared a general frustration with healthcare providers’ lack of knowledge to adequately care for the ISUD. The sense was that staff were only required to have limited education to be eligible to work within the treatment facilities. AFM’s seeking help for themselves or loved ones found primary care providers (PCP), including pediatricians, did not know about treating the disease of addiction. Knowledge or education deficits in treating addiction delayed obtaining help for the ISUD. One concerned mother described the inability of the PCP to recognize addiction and provide treatment:

When my daughter first confessed she used heroin, I called her PCP who did HIV test, Aids testing, etc. and told my daughter to 'go home and take it easy, your body has been through a lot.' She didn't realize my daughter was addicted, withdrawing, and needed inpatient help" (participant # 10). Pediatricians, not educated in treating addiction, limit the ISUD from receiving timely treatment or guidance. Additionally, the inadequate education of the healthcare professional contributed to the stigmatization of the mother and adolescent, as an alarmed participant shared:

> *Most health care professionals are ill-equipped, the worst being pediatricians. They were useless and judgmental when my son was 15, and we looked to them for guidance. Addiction starts before the age of 21; pediatricians are first responders and should be trained as such* (participant # 80).

Another participant shared an experience where the healthcare professional demonstrated inadequate knowledge of SUD. The healthcare professional suggested prescribing drugs for the ISUD, which risked contributing to and exacerbating the addiction, as a disappointed mother reported:

> *In the beginning, I brought my teenage son to our Family practitioner; he was clueless and wanted to prescribe medication (more drugs) within the first 10 min. Never asked my son about any drug use or offered to speak to him alone; it was very disappointing* (participant # 19).

Situations existed where inexperienced staff at the treatment facilities alarmed the AFMs, as reflected in this mother's thoughts: "*Workers at the facility she was in were all inexperienced* *youngsters"* (participant #18). Concerns raised about treatment centers caring for ISUD included the encouragement of addictions such as cigarette smoking as shared by one parent:

> "*At this facility, many of the counselors and staff were recovered addicts. We were told oh you can't quit drinking and smoking the same time. Too hard on your system*" (participant # 9).

Another participant shared that the treatment center provided inadequate basic needs for food and rest for the ISUD. Patient's rights were not respected:

> *My son hated the way he was treated at times. He couldn't sleep one night and asked for a yogurt. He was told no, even though they had it on the ward and it was for the patients. Another time he asked if he could have a glass of juice and was told they don't have juice in the wards* (participant # 46).

Facilities were known to violate the privacy of the ISUD. Requiring the ISUD to post their name in a public area to receive voluntary counseling services, but did not mandate counseling. A mother who was appalled by their child's treatment discussed counseling:

> *I was appalled that counselling time each day was not mandatory. Rather the patient had to sign their name on a public board to access any counselling. My son wanted to be invisible. It would take more than one appt to gain his trust. Perhaps he would have found that person had counselling time been mandatory* (participant # 46).

Facilities routinely provided no treatment plan or follow-up care for ISUD. AFMs assumed that the provision of a follow-up plan of care would be automatic. However, in most cases, it was not, as a mother shared: "[My] *Son was discharged from rehab with no plan No referral to sober living despite being clean and followed all rules"* (participant # 45).

Theme 4

We have no access to effective care or treatment

Over a third, (n = 37) of respondents indicated that access to effective care for their loved ones was a problem. Barriers to accessing care included a lack of information, availability, financial, privacy laws, healthcare professional, and stigma related issues. Therefore, even when care was available, the AFM could not obtain information about the status of the ISUD so that they could provide support and resources.

AFMs expressed frustration at their inability to access information on the disease of addiction and the alternative treatments available. As one respondent discussed, "I *just wanted to know what to do, and there were no answers*" (participant #1). Another AFM stated, "*It's hard to know where to look for formal information. The resources only seem to exist if you have money to pay out of pocket"* (participant # 12).

AFM's found that the availability of treatment was a barrier to accessing care, regardless of whether they were in a crisis or non-crisis situation. The AFM's identified limited services during off-hours for emergencies, with access to counseling only available by telephone, with no in-person help. As evidenced by, "*In an emergency situation....you feel lonely and only have telephone counselling available in that instance*" (participant # 37). Participants shared that when they brought their loved one to the hospital or treatment center, they would be turned away due to no treatment beds available. One participant shared this in the alarming response: "*Took him to the hospital three times, said he was going to commit suicide. Nobody had a bed available, had to take him back home!*" (participant # 65).

Financial issues created a barrier to accessing care, especially the lack of insurance, not the right coverage, and limited finances. The AFM's reported difficulty locating rehabilitation facilities that accepted patients with no insurance. However, even with insurance coverage, some AFM's found difficulties in finding appropriate care for their loved ones:

> *He has been to rehab for heroin, and asked to leave for cigarette smoking. WE once paid $1700.00 out of pocket for 3 remaining days at a rehab that ins. refused to cover (after having ALREADY APPROVED his stay.) The cost of 30 days was $24000.00.--for THIRTY DAYS, The brain BEGINS to clear at 30 days. Again, the last 3 days they reneged and would not pay* (participant # 19).

Others shared trying to obtain care multiple times; however, "*hitting a brick wall unless you have money*." The treatment for addiction can be costly and a tremendous financial burden on the family. Families reported utilizing their savings and the savings of other family members to pay for treatment. A respondent said the grandparents of the ISUD as having used all their retirement savings to assist in getting care, as they shared: *"It's been an incredible financial burden on my family. Both myself and my parents have given thousands of dollars to pay for my sister to go to rehab. This has come out my savings and my parents retirement savings*" (participant # 107). Even with money, AFMs' found that access to care was challenging, and not necessarily helpful:

> *Her recovery center was supportive while she was a patient but that that relationship pretty much dissolves the second the "check clears" and the patient graduates. Very disheartening- our bill was in excess of $35000, and she went 3 times. And 1 day after her discharge, they didn't remember her name. I think $105K should entitle you to some aftercare* (participant # 23).

Adult privacy laws affected access to care for the ISUD. Many respondents shared the inability to access care due to HIPPA laws, Privacy, and the need for release forms from the

ISUD. The ISUD can also alienate the family and friends by not signing release forms or updating contact information, making it impossible for the family member to assist in treatment. As evidenced by an AFM:

> "*Detox facilities and law enforcement are not helpful unless you have a release form from the adult addict which most times they are not willing to provide when they are not receptive to getting help"* (participant # 96).

AFM's experienced issues when attempting to access care for their loved ones, as the healthcare professionals were not supportive of them seeking care for the ISUD. Healthcare professionals also refused to provide referrals for needed long-term care programs, or sober living housing. As reflected in the following response:

> "*I have felt very frustrated, angry and hopeless when I am trying 110% to assist my son with a treatment plan and lack assistance in doing so. So many barriers to contend with. Not the right insurance plan. Lack of continuum of care. Overcrowded, understaffed treatment facilities. etc.* (participant # 87)."

Theme 5

People cannot relate and recoil from us

AFM's shared their experiences of feelings of shame, humiliation, and negativity, causing them to withdraw from family, friends, community members, and healthcare providers. The inability to relate to another person's situation can result in stigma applied to the person or group. The failure to understand or lack of knowledge can lead to the AFM feeling ashamed, embarrassed, or rejected when they just wanted to help their child: "*People have told me to Give up on my kid. People act as if it is a choice. People have stopped talking to me bc they don't like how I have dealt with it"* (participant # 36), and "*They either don't ask or say "what don't they* *just stop? "what's wrong with them?" "Why don't you.....?*" (participant # 88). Participants were fearful of disclosing information to others because they expected a negative reaction:

"*My parents struggle and become emotional I know that they do not understand why their two granddaughters just can't stop doing drugs I don't typically confide in healthcare providers and I don't have many friends most people in The area I live in cannot relate and recoil if I do mention drug use or prostitution both of which my daughter and my niece do………* " (participant # 105).

The negative responses received by the AFM came from the personal experiences and beliefs of family and friends. One respondent shared, "*My sister thinks addicts will always be untrustworthy*" (participant # 67). Negativity and labeling expressed in both words and actions occurred. Some respondents (n = 33) indicated receiving harsh and hurtful comments from friends and family members:

> "*Sadly, it is a sister of mine with whom I have had the most negative relationship due to my son's drug use. She lacks empathy for people with these conditions and has often used terms such as "loser" and "scumbag" to describe members of her husband's family; I have had to distance myself from the negativity"* (participant # 84).

Another respondent found law enforcement official's responses to requests by the AFMs for help impacted by the officer's prior experiences with ISUD. Bias towards ISUD by law enforcement officials was evident in statements from respondents, one of whom just wanted to save their child's life:

> *"How to deal with an addict who wants to kill themselves. The police responded to our 911 call, until they heard she was an addict and then were no longer interested in finding her to prevent her from trying to kill herself*" (participant #79).

Additional Analysis

Additional analysis using tabulation and frequencies (quasi-statistics) provided percentages of positive or negative responses to the open-ended questions of social support. The open-ended questions underwent coding by the researchers as positive, negative, or not applicable/not answered. A 0-3 scale, with the higher number associated with positive responses, a bivariate correlation between total positive social support, total positive responses, and health and well-being, was conducted. There was no significant association between health and wellbeing and total positive responses. There was a small association positive correlation between total positive social support and total positive responses $r = .232$, $p < .01$. This result does suggest that as total positive social support increases, the total positive responses also increase.

Social Support

The respondents (34%) expressed receiving positive emotional support. Positive emotional support consisted of listening, talking, understanding, providing advice, conveying respect, love, and affection, supporting decisions, and sharing. The participants valued receiving emotional support without judgment or fear, which is an essential aspect of emotional support. Emotional support is essential and leads to feelings of self-worth and self-identity (Caplan, 1974; Toner, 2009; Vaux, 1988).

Slightly more respondents (35%) reported receiving little or no emotional support. Not receiving emotional support included a lack of understanding from family, friends, and healthcare professionals or negative comments or told how to handle the situation. Not receiving emotional support can have a negative effect causing loss of self-worth and self-identity (Caplan, 1974).

Informational support does play a key role in the life of the AFM. The AFM's response rate was equal at 28 % reporting positively and 28% reporting negative experiences with informational support. There was a no-responses rate of 44%. The transmission of knowledge and the ability to obtain knowledge are essential aspects of informational support and help with motivation and problem-solving skills (Vaux, 1988).

The instrumental dimension of social support is the most tangible and measurable. As it concerns the provision of resources, material help, goods, services, transportation, errands, chores, financial, and physical support make up instrumental support (Caplan, 1974; Vaux, 1988). Instrumental support helps the AFM solve practical problems, thereby increasing their feeling of control and ability to handle stressful situations. However, there was a 63% no response rate, with 9% positive and 28% negative.

Many people can identify social companionship as social support. However, the importance of activities such as just enjoying each other's company is sometimes not recognized. Social companionship will reduce loneliness, strengthen social bonds, distract from worry, facilitate positive affective emotions, and produce feelings of well-being (Caplan, 1974). Unfortunately, there was a 58% no response rate, with 23% reporting negatively and 19% reporting positive social companionship. Some respondents reported personal preferences, such as enjoying dinner, movies, walking, talking, and vacations with friends and family.

Perceived and received social support is a perception of social support held by the AFM. Perceived social support is the cognitive perception or belief of the availability of support and supportive actions. Received social support consists of the actual supportive activities received by the AFM. There was a 54% no response rate to this question. However, the responses received showed 32% positive and 13% negative responses. The perceptions of and the actual social support received can influence the feelings of well-being in individuals among the respondents in this study (Caplan, 1974; Vaux, 1988).

Structural social support is the type and number of social networks identified by the AFM (Uchino, 2004; Vaux, 1988; Veiel & Baumann, 1992). There was a 40% no response rate to this question. Of the responses received, 54% were positive responses, and only 6% were negative, indicating most respondents feel they have support systems. Sources of support included family, spouses, children, parents, siblings, grandparents, friends, coworkers, support groups. A small number of respondents identified healthcare professionals as being a source of structural support.

Summary

The thematic analysis identified many areas of distress in the life of the AFM. The opinions and beliefs of others can be hurtful, unhelpful, and destructive. Statements such as "it is a choice." "Why don't they just stop? What's wrong with them? , or Why don't you…." show a lack of knowledge or a lack of understanding. However, linked with the stress, the AFM already feels these statements are hurtful at the very least and may cause further undue stress or despair for the AFM. The AFM is already feeling alone and unsupported by family, friends, coworkers, and healthcare providers with little or no resources to help their loved one. The lack of social support often caused feelings of despair and led to isolation and or abandonment feelings for the respondent. The inability of AFMs to access care for their loved ones also affected them negatively, causing distress and concern. Therefore, the AFM is at risk for decreased health and well-being.

The overarching themes provide the graphic nature of the participant responses within the overall data that was available to the researchers. Themes are inclusive of the thoughts and feelings the participants chose to share with the researchers and not just answer to the open-ended questions. Statements were representative of what participants want us as healthcare professionals to know and to understand regarding their lived experience.

The themes that emerged from the data are very imaginable, visual, and heart-wrenching. The AFM's in this study expressed feeling alone and unsupported in this battle with substance use disorder with their loved one. The need for education among family, friends, law enforcement, and especially healthcare professionals is dire. These findings are essential for healthcare professionals to view and understand as they care for the AFM and the ISUD.

Chapter 6

Discussion

The purpose of this study was to explore the affected family member (AFM) of an individual with a substance use disorder (ISUD) perceptions and experiences of social support. A secondary purpose was to examine the association of social support and how it contributes to the health and well-being of the AFM of an ISUD. The findings of this study do support the research hypotheses. (1) The AFM, who perceives receiving positive social support, will report higher levels of health and well-being. (2) The AFM, who perceives receiving inadequate positive social support, will report lower levels of health and well-being.

This study used a mixed methods convergent concurrent design (DeCuir-Gunby & Schutz, 2017). The qualitative data and the quantitative data collection co-occurred with the use of a cross-sectional online survey. The participant was able to answer questions included in the participant characteristics survey, the PHS-WS, the ADF SSS 25, and type in short answer responses to open-ended questions in the same survey.

An advantage of the mixed methods design is complementarity; the use of two approaches can help to decrease limitations that occur with a single research approach. The mixed methods approach enhanced validity, increasing triangulation, and increasing the generalizability of the results (DeCuir-Gunby & Schutz, 2017; Polit & Beck, 2014; Ritchie et al., 2014). The mixed methods approach was able to exhibit links between the concepts and conclusions developed and allowed the researchers to describe the findings in rich, authentic detail (Ritchie et al.). Presented in this chapter are the results of the study, including the strengths, limitations, and implications for future research.

Participants

The participants of the quantitative arm of the study included N = 134 self-identified affected family members (AFM) of an ISUD. A sub-sample of n = 101 participants made up the qualitative arm of this study. The participant characteristics for the sample and the subsample of participants showed no significant characteristic differences. The participants who did not respond to the qualitative part of the study showed no significant differences to those participants who did not choose to provide the qualitative responses (see Appendix M).

The AFM's participating in the survey identified as mostly White/Caucasian (n = 128), females (n = 130), and were the mothers (n = 109) of the ISUD. Many participants (n = 94) were married, working full-time (n = 79). The AFMs reported that most of their ISUD were White/Caucasian (n = 126), single (n =78), and male (n = 85). A large portion of the ISUD (n = 52) continued to use substances and had a history of SUD (n = 89) for over seven years.

All participants completed an online survey consisting of characteristics, the Public Health Surveillance Well-Being Scale (PHS-WS), and the Alcohol, Drugs and the Family Social Support Scale (ADF SSS) for the quantitative arm of this study. The qualitative arm of the study asked participants (N = 134) to short answer open-ended questions, which were responded to by a subsample of participants (n = 101).

Quantitative Discussion

The purpose of this study was to identify association(s) between the AFMs social support experiences and perceptions and their health and wellbeing. The researchers used bivariate correlations to analyze data collected with the AFM with the ADF SSS and PHS-WS instruments. The analyses conducted did identify an association between AFM's reported social support and their health and well-being. Small to medium correlations between AFMs receiving increased positive social support correlates with their improved health and well-being. AFMs receiving higher levels of positive social support are associated with them having higher levels of health and well-being.

Further investigations using bivariate correlations identified the relationships of the subscale's positive functional support, negative ADF specific support, and positive ADF specific support and the health and well-being reported by the AFM. The subscales showed a significant association between total positive social support and positive functional support leading to AFMs increased life satisfaction. This study found that social support was associated with the health and wellbeing of the AFM of an ISUD.

There exists limited research on the effects of social support on the AFM, providing support to the ISUD. However, social support is a recognized factor in the health and well-being of the individual and the family by healthcare providers with chronic illnesses such as diabetes, kidney disease, and pediatric cancer diagnoses. Bustamante, Vilar-Compte, Lagunas, and Ochoa Lagunas (2018) conducted a study with 259 older adults of Mexican heritage. The study investigated the effects of social support on diabetes management. Bustamante et al. found that social support was a strong predictor of improved diabetes management (2018).

Additionally, Ibrahim, Teo, Che Din, Abdul Gafor, Ismail, and Remuzzi (2015) studied the effects of personality and social support with a sample of 200 participants suffering from various levels of chronic kidney disease. The investigation found that affectionate, loving, and informational social support increased health-related quality of life in the sample of people living with chronic kidney disease. These effects of social support improving the health and well-being of the AFM is comparable to the studies of other chronic disease supporting this study’s findings.

Gage et al., in 2015, investigated the supportive resources of eighty parents of children diagnosed with cancer. The investigators found that access to social networks was effective in accessing needed social support for the parents. Social support was essential to parents locating information, financial help, and coping during their child's illness and treatment. The AFM of the ISUD would benefit from social support during the relapse, recovery, and treatment of their family member, as seen in this study.

Additionally, this study showed that when AFMs received negative ADF specific support, it produced a small negative correlation with health. The AFMs in this study reporting higher negative ADF specific support was associated with their reports of lower levels of health. Negative specific ADF support was associated with AFMs reporting decreased levels of health.

These findings are consistent with a study completed by Riffin, Lockenhoff, Pillemer, Friedmand, and Costa in 2012. The researchers examined the effects of the receptiveness of individuals receiving care and the emotional health of the caregiver in a sample of 312 dyads of older adults. The dyads represented an older adult with a disability and an informal caregiver. Riffin et al. found that receptiveness of the older adult needing care to the care they received was associated with the caregiver having an increased level of emotional health. The study by Riffin et al. provides a comparable introspection on the relationship between the AFM and the ISUD. The ISUD is often not receptive to the AFM's attempts to provide methods for treatment and recovery.

Quantitatively, the AFM, who perceives receiving positive social support, will report higher levels of health and well-being, which supports the first hypothesis of the study. The AFM, who perceives receiving inadequate positive social support, will report lower levels of health and well-being, which supports the second hypothesis of the study. The findings indicate there is a relationship between social support and the AFMs perceived health and well-being.

Qualitative Discussion

Social support may have many different meanings and perceptions among people. This study utilized the constructs of social support as described by Caplan (1974) and Vaux (1988). Social support represented by functional, perceived/received, and structural types of support (see Chapter 1). The qualitative arm of this study sought to gain knowledge on the experiences and perceptions of the AFM, providing support to an ISUD. The researchers sought to provide a comprehensive mixed methods approach that was complementary and would enhance the trustworthiness of the findings (Polit & Beck, 2014).

Qualitative data collection occurred at the same time as the quantitative data collection, by the participant completing open-ended short answer questions in the online survey. The qualitative data included 1088 written responses from the sub-sample (n = 101) of the total study participants (N = 134). The responses went through a rigorous thematic analysis by the researchers. The thematic analysis resulted in five overarching themes discussed in the following paragraphs.

Theme 1: *We are all alone, and we have to fend for ourselves*

In this theme, the AFM's expressed their perceptions or feelings of inadequate or negative social support. Many AFMs expressed feelings of abandonment, isolation, and loneliness. At times, the AFM resisted the help of others due to a fear of negative responses, which led to them having inadequate emotional support. While not directly relating to AFM's and ISUD, a study conducted by Chen and Feeley in 2014 has interesting correlations with this theme. Chen and Feeley studied social support, social strain, and well-being among 7,367 older adults. The investigators found that support from partners, spouses, and family reduced loneliness. However, Chen and Feeley did find that strain from family, friends, and children increased loneliness. Loneliness was a mediator between social support and health and well-being (Chen & Feeley, 2014). This finding is consistent with the AFM's participating in this study loneliness was in part from the strain received from family and friends response and was also related to a lack of social support from family and friends.

Associated with this theme was a lack of social companionship, as the AFM perceived that family members were judging and withdrawing from them. McCann and Lubman (2018) found similar responses in a study of thirty–one AFM's, where they discussed in interviews the struggles to find support for themselves while providing care for the ISUD. The investigators found that shame and isolation due to the ISUD was a barrier to the AFMs receiving social support. However, AFM's may overcome isolation by building strong interpersonal trusting relationships and creating social networks, as McCann and Lubman (2018) reported. The researchers concluded that the AFM must overcome their perceived sense of shame and humiliation to reduce their social isolation.

Healthcare professionals may be able to assist the AFM to overcome their reported shame and humiliation. Healthcare professionals are a necessary asset in identifying the AFM in need of social support or a social network. Locating resources for the AFM also requires the involvement and support from their healthcare providers, as evidenced in a study conducted with pediatric cancer families. In the Gage-Bouchard et al. (2015) investigation, the AFMs are overwhelmed with all they needed to learn to provide support and care for their children with a potentially life-limiting cancer diagnosis. During the study, the investigators found that there were improved AFMs outcomes when the health care professionals linked the families to resources and social support networks. Healthcare professionals are an essential link that can assist the AFM in identifying and building social support networks to decrease their feelings of isolation and abandonment.

Theme 2: No one understands what we are going through

AFM's responses included limited support due to a lack of understanding. Friends and families just could not understand their situation, choices, or fears about their loved ones with a SUD. The AFM's attributed knowledge or lack of knowledge about addiction contributed to misunderstandings about their situation and reinforcing the need for informational support. The lack of understanding or empathy about their situation caused the AFM increased stress and frustration, and affected the AFM's ability to benefit from social support. Chronic stress negatively influences the health and well-being of the AFM. However, nothing was found in the literature to either support or refute these findings, suggesting that this might be new information to consider for future research.

At times, the limited understanding due to lack of knowledge came from healthcare professionals and law enforcement agencies. McCann and Lubman (2018) found that family, friends, and clinicians contributed to the AFMs decreased health and well-being due to their lack of knowledge or understanding, and judgmental attitudes. The AFM's included in this study did report inadequate or negative informational social support. Healthcare professionals need to obtain education about SUD to provide appropriate intervention and treatment for the AFM and the ISUD.

Theme 3: Healthcare providers do not know how to provide care and are clueless

AFM's shared their frustrations with healthcare professionals, including issues with individual healthcare professional's education and attitudes. Sterling, Kline-Simon, Wibblesman, Wong, and Weisner (2012) examined barriers to identifying alcohol and drug use within a group of 437 pediatricians. Sterling et al. found that the pediatricians (42%) felt unprepared to diagnose alcohol abuse, and (56%) felt unprepared to diagnose drug abuse. The investigator's result suggests that not only do the AFM’s feel that healthcare professionals have a lack of knowledge, but many healthcare professionals have similar views regarding SUD intervention and treatment.

Healthcare providers limited knowledge of SUD that further supports the findings of a study conducted by Williams et al., (2017). The investigators examined barriers to providing medication-assisted treatment to individuals with alcohol use disorder. The study included twenty-four primary care providers. The researchers found that limited knowledge and experience with alcohol use disorder was a barrier to effective treatment. Additionally, the researchers found preconceived beliefs and stigma contributed to a lack of appropriate care for the ISUD.

Frustration with healthcare was not limited to providers but extended to healthcare facilities without proper staff or treatment to care for their loved ones. Monks and Newell (2013) studied nurses from an acute care treatment hospital in the United Kingdom. The researchers found that nurses lacked knowledge and experience to properly care for ISUD and the AFM, which led to detrimental relationships and dissonant care delivery. Negative attitudes, lack of services, and lack of treatment for the ISUD, negatively affects the AFM.

Theme 4: We have no access to effective care or treatment

An inability to access effective care for the ISUD was a significant stressor for the AFM’s. The barriers to finding or accessing treatment include financial, availability, and merely an inability to navigate the system. In the study by McCann and Lubman (2018) conducting interviews with 31 AFMs, investigators found AFMs encountered difficulty locating social support in the form of groups or services. The AFMs often resorted to internet searches with minimal resources identified. The researchers found that participants reported not seeking needed assistance due to previous negative encounters as support by the AFMs. When healthcare professionals are ineffectively interacting with the ISUD, the AFMs can be resistant to taking the ISUD back to the providers. McCann and Lubman suggest that the AFM becomes frustrated and disheartened with the lack of support from healthcare professionals. The feeling of frustration is building with constant barriers the AFM encounters with their loved ones.

Alternatively, in the study reported on by Gage-Bouchard et al. (2015) with parents of pediatric cancer patients, the healthcare professionals assessed the AFMs need for support and provided resources. The investigators found that healthcare providers were an essential link to gaining information and support for the parents. The investigator's report did support this study's finding that informational and instrumental social support for AFMs were critical factors needed to navigate the healthcare system.

Theme 5: People cannot relate and recoil from us

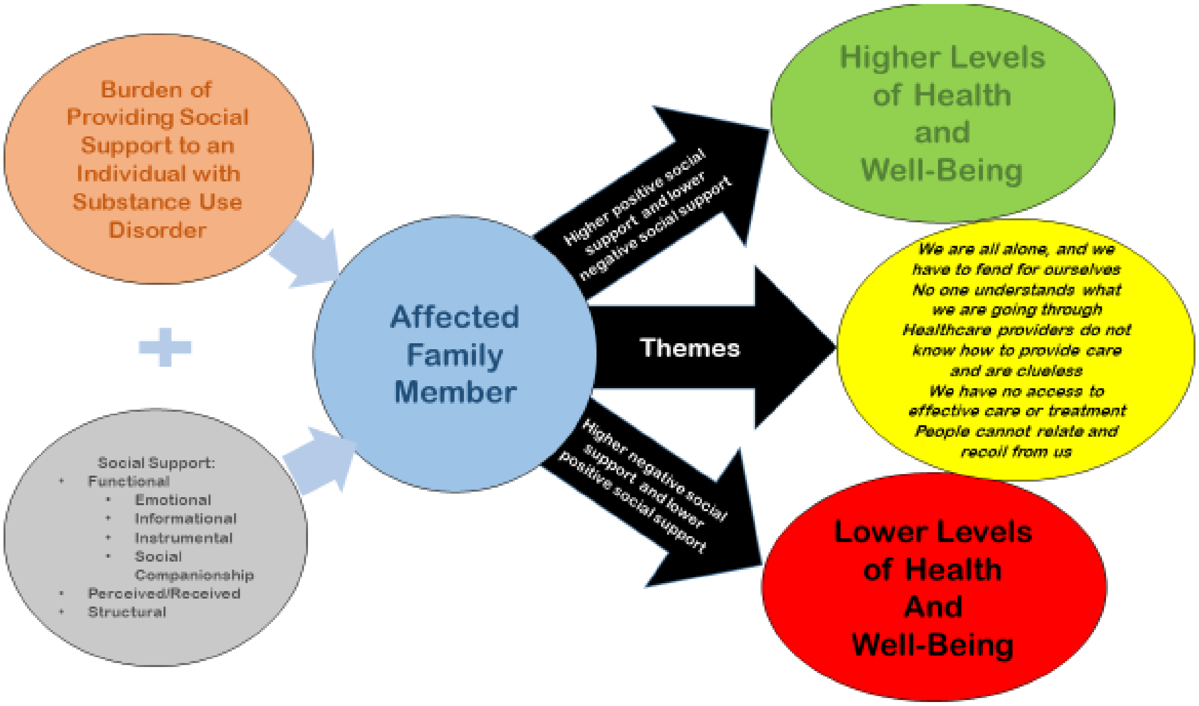
Unfortunately, AFM's in this study perceived and experienced negative attitudes and judgments form others due to providing support for their loved ones. Stigma, shame, and humiliation are feelings shared by the AFM's, which caused the AFM's to engage in secrecy and minimizing contact with others, reinforcing their social isolation. Similarly, Rafiq and Sadiq (2019) conducted a study with 200 AFM's in Pakistan. The investigators found that the stigma of having a family member with a SUD brought embarrassment and discrimination, which damaged the family's reputation. Drug users engaging in illicit sexual or criminal behavior further defamed the family reputation causing increased caregiver stress and health concerns for the family (Rafiq & Sadiq, 2019).

Stigma discussed in Corrigan, Watson, and Miller's (2006) work, where they studied stigma applied to families due to a family member's mental illness or drug dependence. Interestingly, Corrigan et al. (2006) found more stigma applied to the families of drug users compared to families whose relatives have schizophrenia. Parents or spouses of the ISUD received the most blame for the SUD. Family members reported feelings of shame and self-blame, which led to limited accessing to social support or needed treatment for the AFM and the ISUD.

Self-isolation and privacy caused stress and frustration for the AFM's in this study. AFM's attributed a lack of knowledge, understanding, and empathy from family, friends, and healthcare professionals contributed to this shame and humiliation, which pushed them towards isolation. Attributing stigma to the AFM negatively influences their ability to provide support to the ISUD adequately. The AFM is needed to ensure the ISUD care and recovery, as evidenced by a study completed by Denomme and Benhanoh (2017). In their study, the investigators found that including family in the ISUD recovery, improved the ISUD feelings of wellbeing and support. Brooks et al. (2017) reported similar support for the findings of this study. The study conducted with 33 individuals with alcohol-related SUD found that including social support networks, such as the AFM, in the recovery of the ISUD did improve continued sobriety. There is a recognized need for social support in the recovery from substance use disorder. Including the AFM in the care of the ISUD can be effective and should be encouraged. Healthcare professionals may be able to diminish stigma for the AFM and the ISUD by improving community education and programs. Figure 7 illustrates the conceptual model and the findings of this study.

Figure 7

Conceptual Model and Findings of the Study



Strengths and Limitations

A strength of this study is the mixed methods design. The mixed methods design provided greater depth of the personal perceptions and experiences of the AFM than the statistics produced from the quantitative data. AFMs voice, when they frequently reported they had no voice. The qualitative and quantitative data are complementary and combined; they provide more significant support for the study results (DeCuir-Gunby & Schutz, 2017; Polit & Beck, 2014).

This study has limitations for consideration. The data collection was cross-sectional with the inability to provide causal conclusions for social support and the health and well-being of the AFM. However, by incorporating the qualitative arm of the study, there was a greater ability to obtain the AFMs perspective of their social support and their health and well-being. Participants who responded to the invitation to be in the study were homogeneous, despite efforts made to recruit a diverse sample. Recruitment included in-person and online strategies at a multitude of locations and media platforms. Limited diversity minimizes the ability to generalize the quantitative results to a broader population. The mixed methods design with the qualitative arm of the study aimed to gain greater insight into the AFMs perspectives. The ability to generalize to a larger population was not the original intent of the study.

The reliability of self-reported data is always a concern. Yet, the fact that the surveys were on-line, so there was no contact with the investigators was one way to minimize response bias. The ability to complete the survey online privately and at the AFMs convenience may have helped to reduce social desirability bias. The reliability of the scales showed good Cronbach's alpha coefficients. The ADF SSS total scale presented with a Cronbach's alpha of .893 and the PHS-WS total scale Cronbach's alpha was .873, demonstrating reliability in the scales. Bias is always a risk due to self-report measures, which lends itself to participants choosing answers with a central tendency or a social desire to avoid extreme choices (Douven, 2018).

The interpretation of the results could include researcher bias; however, efforts to ensure rigor and decrease investigator bias occurred. The researchers conducted analyses separately and then discussed the reviews before final decisions on the results. Attempts to control for researcher bias included debriefing and reflexive journaling. Another limitation was the inability to confirm the findings with the participants due to the anonymity maintained.

Implications and Recommendations

This research study expands the existing knowledge base regarding the AFM and their unique healthcare needs as they provide support for their loved ones with SUD. This study identified significant implications for nursing and practice change. The findings of this study with their application to nursing practice, policy, and future research discussion are included below. The connections with the conceptual model of social support are included.

Implications for Practice

This study has important implications for healthcare professionals, especially nurses. Nursing is the largest healthcare profession in the United States, as reported by the American Association of Colleges of Nursing (AACN, 2020); Bureau of Labor Statistics (BLS, 2020). According to the AACN, nurses are the primary providers of hospital patient care, playing a vital role in the health and well-being of many populations. Nurses provide direct patient care to primary and preventative care in diverse roles such as registered nurses and advanced practice nurses. Additionally, nurses provide care indirectly through their education of new members of the nursing profession in the academic setting. The AFM providing support to the ISUD is an additional subset of the population who can benefit from advances across practice related to SUD.

This study utilized the conceptual model of social support, as discussed by Caplan (1974) and Vaux (1988). The benefits of social support, seen with many chronic illnesses, do indicate improved the health and well-being of people, the individual with chronic disease, and the family caring for the individual benefit from social support. The findings of both the quantitative and qualitative components of the study supported the need for positive social support of the AFM. There exists a need to reduce negative social support and improve positive social support. The implications for practice follow.

Social Support

The AFMs in this study shared that the receipt of negative support indicated they had fewer cheerful days and more days that are hopeless. Idstad, Ask, and Tambs (2010) conducted a study with 9,740 couples; one was the caregiver of an individual with a chronic mental health condition. The caregiver reported excessive burden, which was significantly associated with their experiencing higher levels of anxiety and depression and lower levels of subjective well-being. Idstad et al. did not specifically investigate the chronic condition of addiction, yet the burden the caregivers experienced was similar to the AFM caring for the ISUD.

In this study, AFMs expressed, We *are all alone, and we have to fend for ourselves.* The quantitative findings further suggested that positive social support for the AFM was a predictor of increased health and well-being. AFMs have shared their isolation, abandonment, and inability to find information as some of the social support deficits that they were experiencing, puts them at risk for decreased health and well-being. Diminished health and well-being by the AFM's in this study included high blood pressure, anxiety, and depression, with some requiring medications. For healthcare professionals to accomplish the provision of support, there is a need to assess the AFM's social support networks or the lack of positive social support to ensure a complete assessment of needs. The healthcare professionals can develop strategies to provide or assist the AFMs with support, whether through education, resources, or research, to identify a more effective treatment for ISUD.

Understanding

AFMs expressed profound feelings of being misunderstood, and do not receive support due to that lack of understanding. As represented by theme two, No *one understands what we are going through.* Nurses and healthcare professionals can utilize the information garnered from these findings as they approach the AFM and provide care. Feeling misunderstood affects the AFMs relationship with healthcare professionals and leads to the AFM feeling frustrated and receiving ineffective treatment. Person-centered care and individualized care research and application to the AFM has occurred. Ross, Tod, and Clarke (2014) conducted a study using semi-structured interviews with 14 nurses about person-centered care. The researchers identified the patients need to feel valued and recognized by the healthcare professional to create a respectful and trusting patient-provider relationship with the healthcare professional. Ross et al. found that many nurses viewed their patients as a "set of problems" (p. 1227). It was difficult for the nurses to see the person or the social network, and it was important to connect with the family to provide patient-centered care best. AFMs in this study reported a lack of trusting relationships with healthcare professionals, and there is an increased need for healthcare professionals to gain an understanding of the AFM. Person-centered care or individualized care is one strategy for care where a healthcare provider can recognize and understand the unique needs of the AFM with and ISUD, and build a trusting, respectful, and effective relationship.

Nursing

Healthcare professionals must obtain and remain current on assessments and treatments for ISUD and the effects on the AFM. As stated in theme three, *Healthcare providers do not know how to provide care and are clueless.* The AFMs identified healthcare professionals as lacking in knowledge and experience with SUD. Nurses, while not singled out in this study, are part of the multidisciplinary healthcare team. Multiple encounters with healthcare professionals who possessed limited or no education or experience with SUD produced ineffective treatment and increased frustration for the AFM. Health care professionals require the necessary knowledge of the disease of addiction. This knowledge base includes the needs of both the ISUD and the AFM.

AFM's reported bringing their loved ones to pediatricians and primary care providers looking for information and treatment for the ISUD but did not receive appropriate assessment, diagnosis, or treatment. Interviews conducted with 24 health care providers in a study by Williams et al. (2017). The investigator explored the treatment barriers and facilitators in the treatment of individuals with severe substance use disorder. Barriers to the provision of care and treatment for the alcohol users included lack of knowledge, training, or confidence in newer interventions or treatments. The healthcare providers felt training and support would improve their willingness to engage in the care and treatment of patients with a severe alcohol disorder.

Additionally, the healthcare professionals did not recognize the increased risks to the health and well-being of the AFM's seeking healthcare for themselves due to the adverse effects of the ISUD. A qualitative study, including forty adult ISUD and eight parents utilizing interviews, found that family life was adversely affected (Fotopoulou & Parkes, 2017). Investigators found that the emotional and physical health of the AFM's was profound due to the extreme stress of trying to deal with the almost unmanageable condition of the SUD of their loved one.

Nurses and other healthcare professionals are in a unique position to be accessible to the AFM and the ISUD during care for prevention, intervention, treatment, and recovery. Improved education about SUD effects on the AFM is needed for all healthcare professionals to ensure appropriate care delivery to improving the AFMs quality of life. The AFM's in this study reported the care and treatment of their loved one was an important component of their health and well-being. Healthcare professionals must recognize that the AFM feels alone, abandoned, and misunderstood, as evidenced in the findings of this study.

Stigma

The final implication for practice is very hurtful and unsettling. The AFM and the ISUD received negative and hurtful comments and a lack of treatment due to the personal beliefs of others. The implications for practice include the non-judgmental care for the AFM and the ISUD. This implication for practice resonates in the following theme: *People cannot relate and recoil from us*

The AFM's in this study shared experiences and perceptions of hurtful and demoralizing treatment from family friends and healthcare professionals, affecting the support received. A study of drug-using men and parents conducted in Greece supports the findings of the current study. Fotopoulou and Parks (2017) found that drug-affected families are viewed as pathological rather than helpful, holding traditional expectations of the child irrespective of the drug use. For many, it is difficult to imagine the family feels a sense of duty to the child unable to conceive of a course of action that does not ensure the welfare of their child (Fotopoulou & Parkes, 2017).

Additionally, in this study, AFM's responded that healthcare professionals stigmatized the AFMs and the ISUD affecting treatment. Support for this finding included a study conducted by Williams et al. (2017). The researchers conducted a study of healthcare providers, and patients with severe alcohol disorder found that stigma was a barrier to the provision of treatment (2017). The researchers found that providers stigmatized the patient with alcohol disorder as causing their problem with alcohol. The providers recommended punitive measures rather than treatment for the ISUD. Lack of knowledge and understanding contributes to inadequate social support and exacerbates the stigma directed towards the AFM and ISUD. The current study highlights the need for increased education at all levels of healthcare, including instruction extended into the community.

Future Research

The importance of social support as perceived and experienced by the AFM identified in this study indicates a need for more research. This study did not identify sources of beneficial social support for the AFM, indicating research aimed at identifying sources of social support is necessary. The identification of social support sources that are beneficial to the AFM can lead to the development of those sources to facilitate the AFMs ability to provide care. Respite care support and support groups offered to caregivers of individuals with chronic conditions is one option that might be available for the AFM of ISUD.

Characteristics of the AFM's identified in this study lacked valid descriptors, including educational level, income level, and current health conditions. The researchers did not explore participant characteristics that contribute to or detract from the AFMs perceptions and experiences with social support. Further research exploring the characteristics of the AFMs as related to their social support can increase understanding of the dynamics of social support and the effects on their health and well-being. Social inequality can affect different people and different groups in many different ways. Understanding the differences that exist is critical when planning future research and interventions (Bartlett, Brown, Shattell, Wright, and Lewallen, 2013).

Researching with an interdisciplinary healthcare team approach might be beneficial, as the diversity of healthcare professionals can provide different insights and perspectives. The differing viewpoints would facilitate the healthcare professionals in identifying how they would assess for and promote social support for the AFM's. Insights into healthcare professionals' education on SUD and the effects on the AFM are a highlight of the findings in this study. Future research directed at the complexity of treatment and education about SUD for nurses and healthcare professionals is needed. A plan for the dissemination of the information into the practices of healthcare professionals will be required. Of further value would be investigating how interventions that combine educational sessions for healthcare professionals in conjunction with opportunities for clinical experiences, to improve the development of a comprehensive approach with assessment, education, and interventions for the AFMs.

The researchers of this study are supportive of future research identifying stigma applied to the AFM and the ISUD. The hope is to improve understanding and communication among family, friends, community, and policymakers for the AFM and ISUD. A voice needs to be given to the AFM and the ISUD. The identification of methods to decrease the stigma AFMs experience when providing support to a loved one with SUD is a necessity to improve their health and well-being. As the recruitment of AFMs is challenging, decreasing the stigma attached to caring for an ISUD could increase the ability for recruitment in the future. Further research with a more diverse population is needed to identify programs and interventions for the AFM adequately, which can be generalized to a larger population.

Implications for Policy

This study has important implications for future policy, including listening to the needs of the AFM's, requiring needed SUD education for healthcare professionals, and dispelling the stigma applied to the AFM and the ISUD. The implications for policy, as identified in the current study, include the following.

Giving AFM's a Voice

The need for the AFM to have a voice appeared in the participant's responses shared in this study. The AFM's expressed feeling, alone, not having information, no resources to obtain information, and a general lack of understanding of their situation. Policymakers and leaders need to include the AFM in the decisions regarding drug treatment, intervention, and recovery programs. The AFM's have vital first-hand knowledge of the needs of the ISUD and the AFM. Fotopoulou and Parkes (2017), in a study conducted in Greece, reported that rarely are the voices of drug-affected family's voices heard. Similarly, the researchers in this study found the voices of the AFM were often unheard, by family, friends, and healthcare professionals.

Education

The lack of education and experience received from healthcare professionals and healthcare institutions shared in the responses from the AFM’s in this study are concerning. Currently, there does not exist a required SUD curriculum in many healthcare professional academic programs. A study conducted by Stein, Arnsten, Parish, and Kunins (2011), found that instruction about SUD, including diagnosis and treatment, was limited in the education of Internal Medicine residents. The investigators implemented a SUD curriculum for first-year residents, which improved patient outcomes. In another study conducted in a large Massachusetts academic hospital, internal medicine residents felt unprepared to treat substance use disorders (Wakeman, Pham-Kanter, Baggett & Campbell, 2015). The investigators implemented and enhanced the curriculum design to prepare the residents to diagnose and treat individuals with SUD. The investigators reported 98% of the internal medicine residents felt the curriculum had a positive impact on their ability to care for patients with SUD.

Farrell (2020) discussed the limited time available to cover the complexity of substance use disorder in baccalaureate nursing schools. Farrell suggests the inclusion of SUD education throughout the curriculum; however, nursing instructors may not have the needed educational background to provide the training themselves. Savage et al. (2016) discussed the need to include SUD related content in the advanced practice nurse curriculum. According to Savage et al., the current curriculum inadequately prepares healthcare professionals in the treatment of ISUD. In an additional study conducted by Stewart and Mueller (2018) with baccalaureate and masters nursing students, an enhanced curriculum on SUD improved student scores about SUD in a pretest-posttest design. While the investigators were exploring substance use disorder amongst nurses, the limited curriculum about SUD was identified in the study. The limited curricula can also be applied to the knowledge needed to care for the AFM. The culmination of the studies included above does reinforce the need for improved SUD curricula in many academic programs for healthcare professionals.

A policy change requiring all healthcare professionals to complete educational programs on the disease of addiction is needed. The SUD education needs to include assessment, treatment, and ways to reduce stigma for the individual and the family. While educating healthcare professionals is important, we must remember that educating the family, friends, coworkers, and the overall community on the needs of the AFM with a loved one with SUD is a necessity. Education is key to dispelling the myths about SUD and the AFM.

Access to care

The AFMs inabilities to locate, afford, or rely on effective treatment for their loved one with SUD was distressing to the AFMs. The implication for practice representing a need for access to care described in the following theme: *We have no access to effective care or treatment* The National Survey on Drug Use and Health (2018) estimated that 21.2 million individuals need treatment for substance use in the United States (SAMHSA, 2019). 6.1 million people received treatment, which translates to about 11 % of individuals receiving needed treatment.

Ali, Teich, and Mutter (2016) used the National Survey on Drug Use and Health (NSDUH) data to investigate factors contributing to ISUD not receiving treatment. The investigators found that reasons for not seeking or receiving treatment included financial access, stigma, and the reluctance of the ISUD to begin treatment. The findings of Ali et al., are representative of the responses received from the AFM’s participating in this study, and contribute to the distress of the AFM. The ability of the AFM and the ISUD to access care needs improvement within the practice setting.

It is imperative that the policymakers review programs that contribute to accessing care for the AFM and the ISUD. Krupski, Campbell, Joesch, Lucenko, and Roy-Byrne (2009) conducted a study assessing the impact of utilizing a recovery support service to the person receiving treatment for chemical dependence in Washington State. The recovery services included case management, transportation, housing, and medical services, along with the treatment the ISUD was already receiving. Krupski et al. (2009) found that the clients stayed in treatment an average of 42.5 days longer and were more likely to complete treatment. Additionally, the investigators found improved employment and fewer arrests among the participants than the non-participants in the study. While this study sample is the ISUD, the program and the support services model may be useful when building programs for the AFM and the ISUD.

Stigma

Programs aimed at reducing stigma for the AFM and the ISUD are vital to improving the health and well-being of the individual, the family, and the community. Bartlett et al. (2013) published a review investigating compassion and harm reduction for persons with addiction. The investigation identified the Harm Reduction Coalition as one example of reducing stigma within the community and among healthcare professionals. While the review focused on the ISUD, much of the discussion can be applied to the AFM. If the ISUD or the AFM are the recipients of hurtful comments or rejection because of their choices, they will be less likely to seek needed treatment or social support when truly needed. Replacing the negative attitudes about the ISUD and the AFM, replacing them with non-judgmental care and support can influence their health and well-being positively (Bartlett et al., 2013). The organization of the Harm reeducation Coalition may be one example to build the structure for an organization aimed at harm reduction within the AFM population.

Another organizational structure that may be helpful is “Celebrating Families (CF),” as discussed by Sparks and Tisch (2018). CF focuses on breaking the generational ties of SUD. The program is family-focused and has been effective at decreasing the perpetuation of drug use and decreasing violence, abuse, and neglect (Sparks & Tisch, 2018). Again while not directed at the AFM, the program can add some structure when developing programs for the AFM.

Conclusion

Research and funding allocated to the fight against the disease of addiction have not produced a significant decrease in substance use. The numbers of AFMs and ISUD remain constant. The continued need for effective education, treatment, and recovery programs remains.

This study does bring to light the needs of the AFMs in the struggle against substance use disorder. The need for social support provided by the AFM to the ISUD in their recovery is evident. The needs of the AFM highlighted in this study include social support, reduced isolation, information, understanding, educated healthcare professionals, and access to affordable, trustworthy, and effective treatment for their loved ones. The research aimed at gaining the needed knowledge to provide care to those affected by substance used disorder must be a priority. This study is one more step in the fight against SUD and the support for the AFM. Future research with larger samples that are more diverse is a requirement.

Additionally, educational opportunities for healthcare professionals need to review and support from the community and policymakers. Currently, healthcare professionals are not required to complete any education programs about the assessment, treatment, and recovery of the ISUD or the AFM. The lack of educational programs is a massive hurdle in the care of the AFM and the ISUD.

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Appendix A

Participant Characteristics Survey

Please do not put your name or any identifying information on this questionnaire: Choose the best response to each category or fill in the blank if a space is provided.

	About you		
1	Age (in years)	A. __________	
2	Gender	A. Male B. Female	C. Identify with other gender D. Other
3	Race/Ethnicity	A. White / Caucasian B. Black/African American C. Hispanic/Latino	D. Asian E. Other: __________
4	Relationship Status	A. Single B. Married C. Separated	D. Divorced E. Living with significant other F. Other
5	Employment Status	A. Working Part-time B. Working Full-time C. Not working	D. Disabled E. Retired F. Other
7	Relationship with ISUD (I am the _________ of the individual using substances.)	A. Mother B. Father C. Sibling D. Grandmother E. Grandfather F. Aunt	G. Uncle H. Spouse I. Partner J. Friend K. Child of ISUD L. Other
8	How many years have you been providing support (physical/emotional/psychological/financial) directly related to the substance use of the ISUD?	A. Less than 1 year B. 1-2 years C. 3-4 years	D. 5-6 years E. 7 or more years
9	Residence status (yourself)	A. Own B. Rent C. Live with a family member	D. Live with a non-family member E. Other
10	Who is responsible for the main finances in your residence?	A. Myself (person responding to survey) B. Significant other C. Partner	D. Spouse E. ISUD F. Another person
11	How many people are living in your residence?	A. 1-2 people B. 3-4 people	C. 5-6 people D. 7 or more people
12	Does the ISUD live with you?	A. Never B. Sometimes	C. About half the time D. Most of the time E. Always
About ISUD			
13	Age (in years)	A. Under 13 years of age B. 13-18 years of age	E. 40-49 years of age

		C. 19-29 years of age D. 30-39 years of age	F. 50-59 years of age G. 60 and older
14	Gender	A. Male B. Female	C. Identify with other gender D. Other
15	Race/Ethnicity	A. White / Caucasian B. Black/African American C. Hispanic/Latino	D. Asian E. Other: _________
16	Relationship status	A. Single B. Married C. Separated	D. Divorced E. Living with significant other
17	Employment status	A. Working Part-time B. Working Full-time C. Not working	D. Disabled E. Retired F. Other: __________
18	To the best of your knowledge, how many years has this individual been with SUD?	A. 1-2 years B. 3-4 years	C. 5-6 years D. 7 or more years
19	Overall health status (ISUD)	A. Poor B. Fair C. Good	D. Very good E. Excellent
20	Who is responsible for the main finances of the ISUD?	A. You B. Significant other C. Partner	D. Spouse E. ISUD F. Another person
21	Number of persons living in household where ISUD resides?	A. 1-2 persons B. 3-4 persons	C. 5-6 persons D. 7 or more persons
22	What is the recovery status of the ISUD?	A. Remains using substance B. Outpatient treatment program C. Inpatient treatment program	D. Not using substances at this time E. Unknown

*Developed by the researchers for this study.

Appendix B

Public Health Surveillance Well-Being Scale (PHS-WS)

Section A:

In this section, there are a number of statements with which you may or may not agree. For each statement listed, please indicate whether you personally agree or disagree with it using a scale where 1 means "strongly disagree," 2 means "somewhat disagree," 3 means "neither agree nor disagree," 4 means "somewhat agree," and 5 means "strongly agree." If you don't understand a statement or it is not applicable to you, please let that row blank.

Question	1	2	3	4	5
	Strongly Disagree	Somewhat Disagree	Neither Agree or Disagree	Somewhat Agree	Strongly Agree
1. I am satisfied with my life.					
2. My life has a clear sense of purpose.					
3. Most days I feel a sense of accomplishment from what I do.					

Section B:

In this section, there are a number of statements. For each statement listed, please indicate your personal feeling in the past 30 days using the following scale: 1 means "none of the time," 2 means about ¼ of the time" 3 means "about ½ of the time," 4 means "about ¾ of the time, and 5 means "all of the time." If you don't understand a statement or it is not applicable to you, please let that row blank.

Question	1	2	3	4	5
	None of the time.	About ¼ of the time. (7-8 days)	About ½ of the time. (15 days)	About ¾ of the time. (20 days)	All of the time.
1. How much of the time during the past 30 days have you felt cheerful?					
2. How much of the time during the past 30 days have you felt hopeless?					

Section C:

In this section, please tell me on a scale of 1-10 how satisfied you are with the following items. (1 means very dissatisfied, and 10 means very satisfied.)

Question	1	2	3	4	5	6	7	8	9	10
3. How satisfied are you with your family life?										

4. How satisfied are you with your friends and social life?										
5. How satisfied are you with your energy level?										

Section D:

Question	1 Excellent	2 Very Good	3 Good	4 Fair	5 Poor
1. In general, would you say your health is?					

Section E:

Question	1 None of the time.	2 About ¼ of the time. (7-8 days)	3 About ½ of the time. (15 days)	4 About ¾ of the time. (20 days)	5 All of the time.
1. During the past 30 days, for about how many days have you felt very healthy and full of energy?					

* Bann, Kobau, Lewis, Zack, Luncheon, & Thompson. (2012). Development and psychometric evaluation of the public health surveillance well-being scale. Quality of Life Research, 21(6), 1031-1043.

Appendix C

Open-Ended Questions
Please answer to the best of your ability.

A.	Emotional Support
1.	What emotional support have you received from family, friends, and healthcare professionals? This may include talking, listening, and sharing that has been helpful to you.
2.	Please share your experiences in which family, friends, and healthcare professionals have not provided emotional support. This may include acting distant, lacking understanding, and/or having a negative reaction.
B.	Informational Support
1.	What informational support have you received from family, friends, and healthcare professionals? This may include information, advice, and/or guidance.
2.	Please share your experiences when you may not have had informational support when you needed it.
C.	Instrumental Support
1.	Describe any incidences when you received instrumental support. These may include offers of assistance, transportation, money, food, and and/or supplies.
2.	Please share your experiences where you may have needed instrumental support but did not receive it.
D.	Social Companionship
1.	Please share any instances where you were offered social companionship. This may include activities such as conversation, entertainment, and/or recreational activities that provide distraction and improve your mood.
2.	What are some instances when you may have benefitted by social companionship but did not receive it?
E.	Perceived and Received Support
1.	Please share your feelings about the support available to you in the past three months?
2.	Please list the type and times you have received support in the past three months?
F.	Structural Support
1.	Who or what do you consider your social supports? (i.e., family, friends, support groups, health professionals, work, career)
2.	Please list the social supports you feel are available to you.
G.	Additional Informational Questions:
1.	Please share any additional information you feel other family members of a loved one with SUD may benefit from.
2.	Please share any additional information that you feel would help health care professionals provide care to you and your family.
3.	Do you have any comments on how to improve this survey? Please share them with the researchers. Thank you in advance.

Developed by the researchers for this research study.

Appendix D

Alcohol, Drugs, and Family Social Support Scale: ADF SSS-25 Item Questionnaire:

The questionnaire asks about what has happened to you in the last three months. The words friends/relations means *anyone you have met in that time, and relative means the person with the drinking and/or drug taking problem.* Please check one answer to each question. In this section, there are a number of statements with which you may or may not agree. For each statement listed, please indicate the answer that applies to your experiences. If the question does not apply to you please indicate not applicable.

Question	Not Applicable	Never	Sometimes	Often	Always
	1	2	3	4	5
1. Friends/relations have understood what it is like for me to live with my relatives' drinking or drug taking.					
2. Friends/relations have helped to cheer me up.					
3. Health/social care workers have given me helpful information about problem drinking or drug taking.					
4. I have friends/relations whom I trust.					
5. Friends/relations have listened to me when I have talked about my feelings.					
6. Friends/relations have backed my decisions that I have taken towards my relative and their drinking or drug-taking.					
7. Friends/relations have put themselves out for me when I needed practical help (i.e., aid or assistance).					
8. Friends/relations have advised me to focus on myself and my own needs.					
9. Friends/relations have questioned my efforts to stand up to my relatives' problem drinking or drug taking.					
10. Friends/relations have been too critical of my relative.					
11. Friends/relations have given me space to talk about my problems.					
12. Friends/relations have said my relative should leave home.					
13. Friends/relations have said things about my relative that I do NOT agree with.					

14. Friends/relations have avoided me because of my relative’s drinking or drug taking.					
15. Health/social care workers have made themselves available to me.					
16. Friends/relations have blamed me for my relative’s behavior.					
17. Friends/relations have said that my relative does NOT deserve help.					
18. I have identified with the information within books/booklets about people living with a problem drinker or drug taker.					
19. Friends/relations have told my relative off on my behalf.					
20. Friends/relations have advised me to leave my relative.					
21. Friends/relations have been there for me.					
22. Friends/relations have provided support for the way I cope with my relative.					
23. Friends/relations have talked to me about my relative and listened to what I have to say.					
24. Friends/relations have said nasty things about my relative.					
25. I have confided in my health/social care worker about my situation.					

Toner, P., & Velleman, R. (2014). Initial reliability and validity of a new measure of perceived social support for family members of problem substance users. In Addiction Research & Theory, 2014, Vol.22 (2), P.147-157, 22. (2), 147-157.

Appendix E

Script:

Hello,

My name is Eileen Kane. I am a registered nurse, and I am conducting a research study. The research study is to learn more about the experiences of family members affected by the substance use disorder of another family member or a loved one. A substance use disorder is the problematic use of drugs or alcohol. I would like to learn more about the experiences of family members to better provide care for them and their loved ones.

I am interested in finding family members that are willing to complete a survey about their experiences. The survey will take approximately 20-30 minutes of your time. The survey will ask questions about your experiences with a loved one or family member with a substance use disorder. You will also be asked to share your experiences of support for yourself. You do not have to respond to any question that you do not want to respond to and can choose not to answer any question. You may stop the survey at any time.

The survey can be completed on paper with a prepaid return envelope, via phone call to the researcher's cell phone number, or online via survey link. No information identifying you to the survey responses will be collected.

I can also provide the survey information for you to give to another family member that has been affected by the substance use disorder of another.

Appendix F

Cover Letter:

Hello,

My name is Eileen Kane. I would appreciate your help in completing a very important research project that is very personal to me and may be to you. The research project is designed to find out more information about the family members affected by a loved one's substance use disorder (SUD). These family members may become affected family members (AFM).

The problematic use of substances or SUD is very personal to me. I am an AFM. I have loved ones with SUD. Over the last 12 years, I have experienced the effects of SUD on my children, myself, my family, in my profession of nursing, and in my community. As an AFM, I have experienced many difficulties, frustration, and attitudes due to my relationship with my loved one and SUD. There is little research related to the experiences of the family members affected by SUD. The healthcare profession, the community, and other AFM's may benefit from the experiences and knowledge you have as an AFM.

I would like to know your experiences and gain greater knowledge of being an affected family member (AFM). I am hoping to bring together these experiences and knowledge to develop programs and educational materials that will help to support the health and well-being of AFM's.

If you are interested please complete the survey via the survey link or call my cellphone as provided. The survey will take about 20-30 minutes to complete. The survey is completely voluntary and anonymous. I realize this is a sensitive and personal subject and I respect your choice to participate or to not participate.

Survey Link:
https://tinyurl.com/sudafm
Thank you,
Eileen Kane
Please contact me with any questions.
Cell: 1-774-241-6458
Email: sudafm2019@gmail.com
Email: kaneem@uwm.edu

Disclosure: This research project is a requirement to receive my Ph.D. in Nursing through the University of Wisconsin- Milwaukee. I plan to continue studying affected family members and individuals with SUD after completing my Ph.D. in Nursing. I believe there are better programs and treatments for the AFM and individuals with SUD that will help decrease the devastation SUD causes.

Support Services:
Al-Anon: Provides support services for family members of an individual with alcohol addiction. www.al-anon.org
NAR-ANON: provides support services for family members of an individual with a narcotics or opioid addiction. www.nar-anon.org

Appendix G

Recruitment Flyer:

DOES YOUR LOVED ONE HAVE A PROBLEM WITH SUSBTANCE USE?

WE WOULD LIKE TO HEAR YOUR STORY!

Substance Use Disorder
And
Affected Family Members
Eileen Kane
University of Wisconsin-Milwaukee
kaneem@uwm.edu
sudafm.org

Research Study Participants Wanted
Completely anonymous and voluntary.
Your privacy will be ensured.

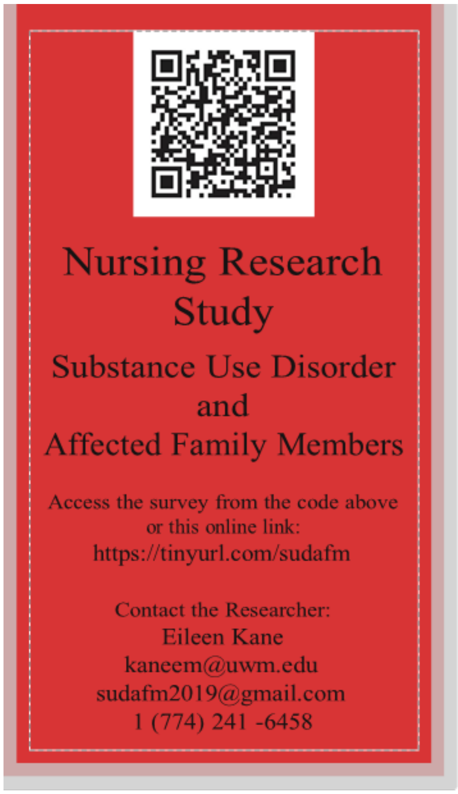
Study consists of a short survey that can be completed online.

Survey Link
sudafm.org

Appendix H

Business Cards:

Nursing Research Study
Substance Use Disorder: Affected Family Members Social Support
Eileen Kane
Cell: 1-774-241-6458
Email: sudafm2019@gmail.com
Email: kaneem@uwm.edu
Online Survey Link:
https://tinyurl.com/sudafm



Nursing Research Study

Substance Use Disorder
and
Affected Family Members

Access the survey from the code above
or this online link:
https://tinyurl.com/sudafm

Contact the Researcher:
Eileen Kane
kaneem@uwm.edu
sudafm2019@gmail.com
1 (774) 241 -6458

Appendix I
University of Wisconsin – Milwaukee
Consent to Participate in Survey Research

Study Title: Substance Use Disorder: Affected Family Members and Social Support

Person Responsible for Research: Dr. Julia Snethen, Eileen Kane

Study Description: An individual with a substance use disorder refers to an individual whose use of drugs or alcohol is problematic. Increasing numbers of families in the U. S. have family members or friends with a substance use disorder. However, we as healthcare providers are not always sure how to best provide care to the family members or friends who support a family member or friend with a substance use disorder. The purpose of this research study is to explore the experiences of the family/support person of an individual with a substance use disorder.

If you agree to participate, you was asked to complete a survey. This will take approximately 20-30 minutes of your time. The survey will ask questions about your experiences related to the support you provide for the individual in your life. You will also be asked to share your experiences of support for yourself. You do not have to respond to any question that you do not want to respond to and can choose not to answer any question. You may stop the survey at any time. Approximately 200 people will participate in this study.

Risks / Benefits: Risks that you may experience from participating are considered minimal. However, sharing your experiences may make you feel stressed or emotional. You do not have to respond to any questions that you choose not to respond to. The researchers are only interested in hearing what you think is important for us to know and are comfortable sharing. We do not want you to share anything that you do not what to share, and you can choose not to respond to any questions that you are asked. There are no costs for participating, and there are no known benefits from participation other than to assist healthcare providers in having a greater understanding of how we can provide care for the family/support persons of an individual with a substance use disorder.

Confidentiality: During the survey, no identifying information was collected. Your name will not be written down anywhere, and your name and the names of the family/friend who has a substance use disorder will not be recorded. An arbitrary ID number was put on the survey, for data management and analysis purposes only, which cannot be identified back to you. All study results was reported as grouped data. No individual information was shared. However, direct quotes without any identifying information may be used in publications or presentations. Unidentified data from this study was saved on the investigator's password protected computers in a locked room until all the data has been disseminated. Dr. Julia Snethen and Eileen Kane will analyze all data. A person experienced in statistics called a biostatistician will have access to the unidentifiable data for analysis purposes. The Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records. De-identifiable (meaning no information to connect you or your loved one to the data) and group data from this study may be used to conduct a secondary analysis in future research studies.

Voluntary Participation: Your participation in this study is voluntary, and you may choose not to take part in this study. If you decide to take part, you can change your mind later and withdraw from the study at any time, up until you have given your unidentified data to the investigator. Once your unidentified data is given to the investigator, there is no way for the investigator to know who you are, and will not be able to return the data. Your decision to participate or not participate will not change any present or future relationships with the University of Wisconsin Milwaukee or the UWM College of Nursing.

Who do I contact for questions about the study: For more information about the study or study procedures, contact Eileen Kane at kaneem@uwm.edu.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject? Contact the UWM IRB at 414-229-3173 or irbinfo@uwm.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must be 18 years of age or older. By completing the survey, you are assuring us that you are 18 years of age or older, and are giving your consent to participate in this research project voluntarily.

Appendix J

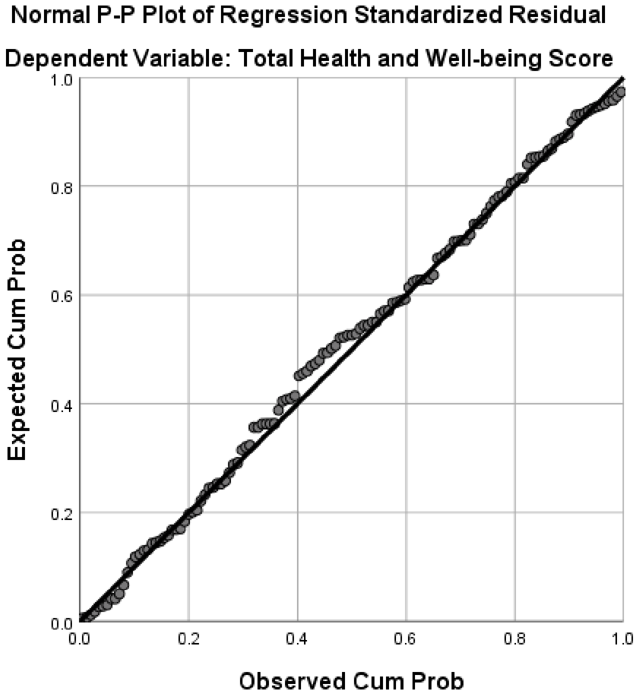
The scale structure and scoring system for the final ADF SSS:

Subscale 1 + Subscale 3 - Subscale 2 = Total ADF SSS Score.

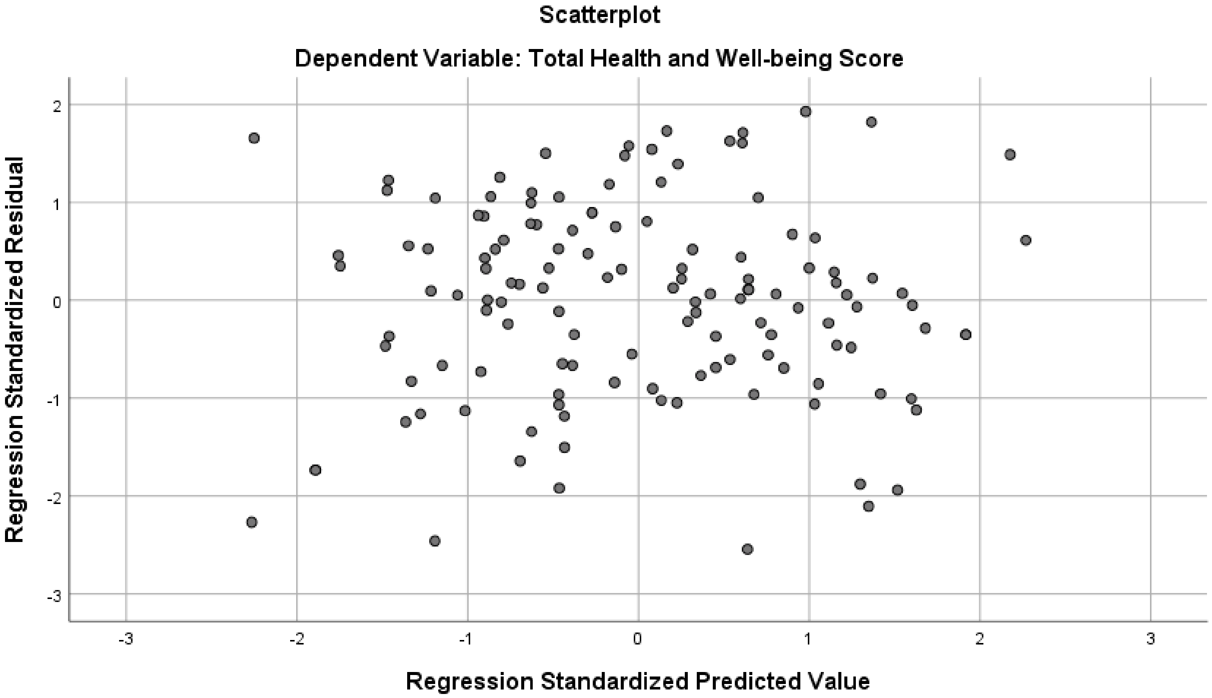
Scales		ADF SSS	
		Number of Items	Maximum Score
1	Positive Functional Support (Emotional, Companionship, Support for Coping and Instrumental Support).	11 Items: (1,2,4,5,6,7,8,11,21,22,23)	33
2	Negative ADF Specific Support (Support for Coping and Attitudes and Actions towards the using Relative).	8 Items: (9,10,12,13,14,16,17,24)	24
3	Positive ADF Specific Support (Informational (both formal and informal) and Emotional Support, Support for Coping and Attitudes, and Actions towards the using Relative).	6 Items: (3,15,18,19,20,25)	18

Total Score	ADF SSS
Maximum	51
Minimum	-24

Appendix K



Normal P-P Plot of Regression Standardized Residual
Dependent Variable: Total Health and Well-being Score
Expected Cum Prob
1.0
0.8
0.6
0.4
0.2
0.0
0.0
0.2
0.4
0.6
0.8
1.0
Observed Cum Prob



Scatterplot
Dependent Variable: Total Health and Well-being Score
Regression Standardized Residual
2
1
0
-1
-2
-3
-3
-2
-1
0
1
2
3
Regression Standardized Predicted Value

Appendix L

Raw Data

Participant Identification Number and Respective Quote:

Participant ID	Quote
1	I just wanted to know what to do and there were no answers.
1	I have not really received support. No one appears to know what to do.
3	Some family members simply do not understand how SUD effects the person/loved one. They wish to fix that person or have them just "get over it." This is a long and sometimes furstrating situation. Support and understanding are the only things that appears to have a positive effect on the loved one effected.
4	Family and friends basically told me I should just kick him out of my life. Friends didn't have much knowledge about addiction and therefore they really weren't much help at all.
9	At this facility many of the counselors and staff were recovered addicts. We were told oh you can't quit drinking and smoking the same time. Too hard on your system.
10	When my dtr first confessed she used heroin, I called her PCP who did HIV test, Aids tesing ect and told my dtr to 'go home and take it easy, your body has been through a lot'. She didn't realize my dtr was addicted, withdrawing and needed inpt help
12	It's hard to know where to look for formal information. The resources only seem to exist if you have money to pay out of pocket.
12	The most helpful thing people have done for me is being supportive of how I choose to handle my relationship with my loved one.
18	Workers at the facility she was in were all inexperienced youngsters.
19	In the beginning I brought my teenage son to our Family practitioner, he was clueless and wanted to prescribe medication (more drugs) within the first 10 min. Never asked my son about any drug use or offered to speak to him alone, it was very disappointing. He has been to rehab for heroin, and asked to leave for cigarette smoking. WE once paid $1700.00 out of pocket for 3 remaining days at a rehab that ins. refused to cover (after having ALREADY APPROVED his stay.) Te cost of 30 days was $24000.00.--for THIRTY DAYS, The brain BEGINS to clear at 30 days.Again, the last 3 days they reneged and would not pay.
20	I've tried support and coping groups and they are just not for me
23	Her recovery center was supportive while she was a patient but that that relationship pretty much dissolves the second the "check clears" and the patient graduates. Very disheartening- our bill was in excess of $35000 and she went 3 times. And 1 day after her discharge they didn't remember her name. I think $105K should entitle you to some aftercare. No one has EVER said a negative thing about our daughter.
24	Friends offer but I keep private

25	In crisis situations where it is obvious my loved one is attempting to use due to high emotions. There are very limited resources on weekends or for my loved one's age group.
27	I have done all research for myself
31	None
33	Friends offer but I keep private
34	I have not discussed the addiction with anyone except immediate family.
36	People have told me to Give up on my kid. People act as if it is a choice. People have stopped talking to me bc they don't like how I have dealt with it. People have limited access to my son. People will agree to supervise him so I can have an hour alone and then don't follow through and get mad at him for relapsing.
36	I am Deeply pained by the loss of a relative because I didn't "put him in rehab" which he won't consent to and has to I'm our state. She has acted As if I have failed him. I have been told to just discipline him more. I feel angered by this. I was made fun of for calling the police. I will not forgive that. I feel alone and exhausted.
37	In an emergency situation ..you feel lonely and only have telephone counselling available in that instance
39	I'm very grateful.
40	Have a husband, SIL , sister, mother, adult children who have listened when I have been upset but I feel like they don't understand and sometimes didn't agree with me so I find myself keeping to myself more and more.
45	Son was discharged from rehab with no plan No referral to sober living despite being clean and followed all rules
46	I was appalled that counselling time each day was not mandatory. Rather the patient had to sign their name on a public board to access any counselling. My son wanted to be invisible. It would take more than one appt to gain his trust. Perhaps he would have found that person had counselling time been mandatory. My son hated the way he was treated at times He couldn't sleep one night and asked for a yogurt. He was told no, even though they had it on the ward and it was for the patients. Another time he asked if he could have a glass of juice and was told they don't have juice in the wards.
63	They don't understand what it is like, because they have never went through anything like this!
65	My mother and father never come around anymore, no Holidays Nothing! For 43 years of my life my whole family was together for get togethers, game night, Christmas, Thanksgiving now I have nothing left! I am emotionally broken!!
65	I asked for help when he was 17 for a mental evaluation! Took him to the hospital three times, said he was going to commit suicide. Nobody had a bed available, had to take him back home!

67	My sisters think addicts will always be untrustworthy
69	I don't really discuss this with other people. I have always been an extremely private person and sometimes am better to just be able to spend time alone with my thoughts.
76	I have a family who wants to be supportive but doesn't really know how. Health care professionals.... none really
78	I was offered dinner at a friends house and declined as I was too depressed.
79	How to deal with an addict who wants to kill themselves. The police responded to our 911 call, until they heard she was an addict and then were not longer interested in finding her to prevent her from trying to kill herself.
80	Most Health care professionals are ill-equipped the worst being pediatricians. They were useless and judgemental when my son was 15 and we looked to them for guidance. Addiction starts before the age of 21, pediatricians are first responders and should be trained as such.
84	Sadly, it is a sister of mine with whom I have had the most negative relationship due to my son's drug use. She lacks empathy for people with these conditions and has often used terms such as "loser" and "scumbag" to describe members of her husband's family, I have had to distance myself from the negativity.
85	I had a wonderful experience requesting a fresh produce donation from Wegmans Grocery. My son was at Cushing House with the Gavin Foundation and the boys did not have fresh produce. Wegmans granted me approx $200 to take fresh produce to the boys weekly.
87	Lacking an understanding of the disease of addiction is the most difficult situation to deal with.
88	They either don’t ask or say “what don’t they just stop?””what’s wrong with them?” “Why don’t you.....?”
89	Most people dont understand the feeling I have towards my daughter. I love her and dont want to see her die but I know if she keeps on that is what will happen.
96	Detox facilities and law enforcement are not helpful unless you have a release form from the adult addict which most times they are not willing to provide when they are not receptive to getting help.
100	I had to attempt to educate my friends and relatives about the disease of addiction. Some came to understand, some didn’t.
105	I don’t typically confide in healthcare providers and I don’t have many friends most people in The area I live in cannot relate and recoil if I do mention drug use or prostitution both of which my daughter and my niece do
107	It's been an incredible financial burden on my family. Both myself and my parents have given thousands of dollars to pay for my sister to go to rehab. This has come out my savings and my parents retirement savings.
108	Group meetings, reading material, video, etc

117	There are a number of nieces who don't speak to me anymore. Family get togethers are always tense because everyone is worried about whether or not my daughter is coming. She rarely does attend anything. But when she does we have to worry about her drinking and getting out of control. I don't think most of the family truly understands why my daughter doesn't just "get help." Most - if not all - of her cousins drink, smoke cigarettes, smoke weed - and none of them are addicts in the sense that they can't or don't function. All have jobs, homes, families of their own. They can't understand why she is such a mess. My siblings can't relate because they have little to no experience with substance abuse.
121	There was always something going on in our group of friends but we were so depressed over our son we distanced ourselves. We were afraid to leave her home we were afraid he would OD while we were gone. So we just sit home and watched him.
121	I found a place that my son could go to. It's a great outpatient service and they provide medicine for him and therapy they also talked to me when I go there. they accept insurance so that's been a great support. He has been clean now 62 days and uses Suboxone but I don't care what he has to use as long as he is alive and healthy and a productive citizen and he is and I'm proud of him for that.
125	I am lonely and wish people would remember that I am a mother of a drug addict but am still a real person.
130	Often I felt alone

Appendix M

Sample Characteristics of Participants Not Responding to Open-ended Questions

Sample Comparison

Table 12

Sample Characteristics of Participants Not Responding to Open-ended Questions

Characteristics of the AFM	**N = 33**	**(%) or mean (range)**
Age in years	50.76	(23-65)
Gender		
Male	2	(6.1%)
Female	31	(93.9%)
Identify with other gender	0	-
Other	0	-
Race/Ethnicity		
White/Caucasian	31	(93.9%)
Black/African American	0	-
Native American	0	-
Hispanic/Latino	1	(3%)
Asian	1	(3%)
Other	-	-
Relationship Status		
Single	1	(3%)
Married	24	(72.7%)
Separated	0	-
Divorced	1	(3%)
Living with Significant Other	5	(15.2%)
Other	2	(6.1%)
Employment Status		
Working Part-time	5	(15.2%)
Working Full-time	20	(60.6%)
Not Working	3	(9.1%)
Disabled	0	-
Retired	5	(15.2%)
Other	0	-
Relationship with ISUD		
Mother	24	(72.7%)
Father	2	(6.1%)
Sibling	0	-
Grandmother	0	-
Grandfather	0	-
Aunt	0	-
Uncle	0	-
Spouse	2	(6.1%)
Partner	2	(6.1%)
Friend	0	-
Child	2	(6.1%)
Other	1	(3%)

Years Providing Support		
Less than 1 year	1	(3%)
1-2 years	5	(15.2%)
3-4 years	8	(24.2%)
5-6 years	3	(9.1%)
7 or more years	16	(48.5%)
Resident Status		
Own	28	(84.8%)
Rent	4	(12.1%)
Live with a family member	0	-
Live with a non-family member	1	(3%)
Other	0	-
Person responsible for finances		
Myself	19	(57.6%)
Significant Other	4	(12.1%)
Partner	0	-
Spouse	9	(27.3%)
ISUD	0	-
Friend	0	-
Other	1	(3%)
People living in residence		
1-2 people	14	(42.4%)
3-4 people	11	(33.3%)
5-6 people	8	(24.2%)
7 or more people	0	-
Does ISUD live with you?		
Never	8	(24.2%)
Sometimes	10	(30.3%)
About half the time	2	(6.1%)
Most of the time	2	(6.1%)
Always	11	(33.3%)

Table 13

Sample Characteristics of ISUD of AFM Not Responding to Open-ended Questions

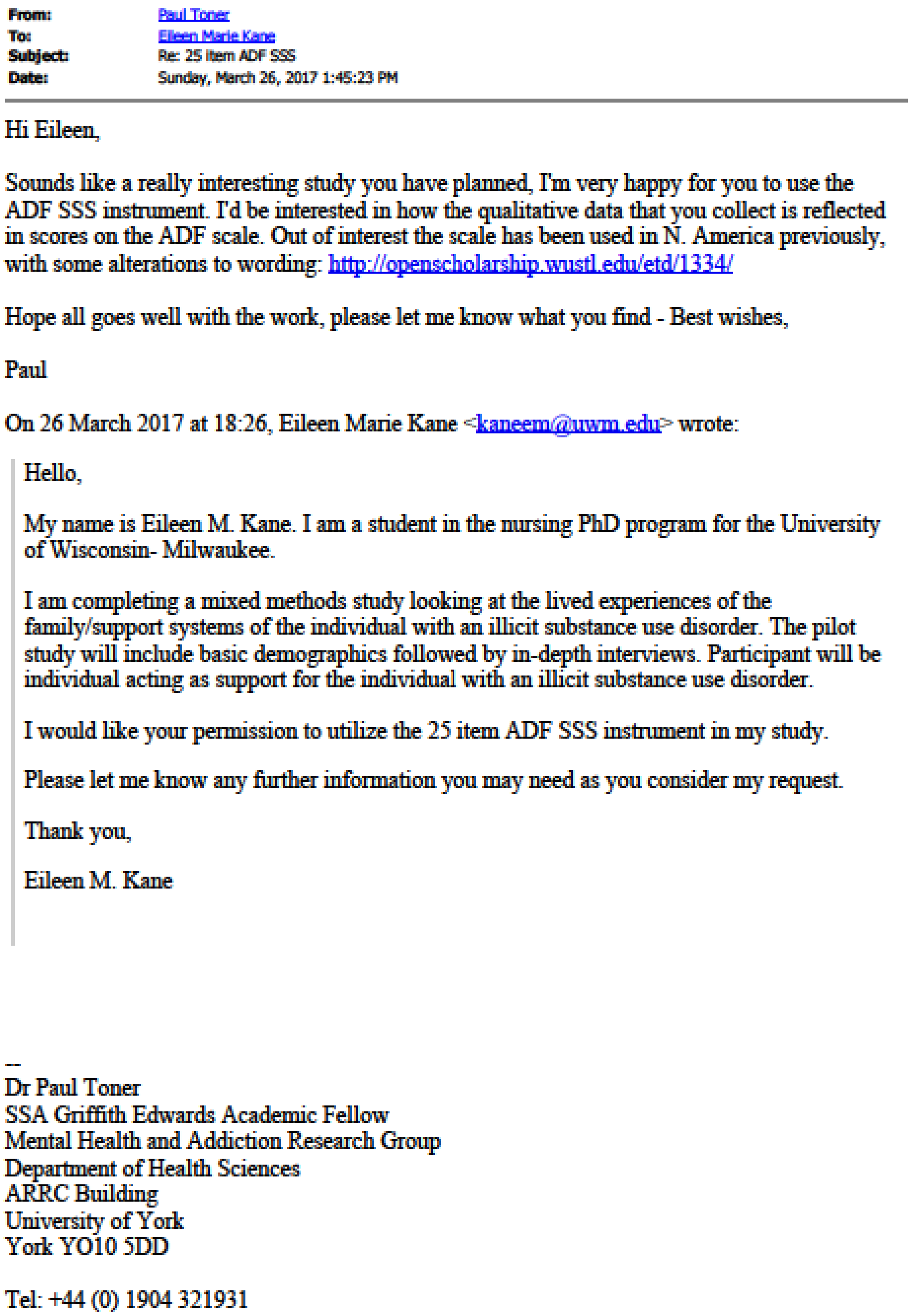
Characteristics of the ISUD	**N=33**	**(%) or mean (range)**
Age in years	29.59	(17-52)
Gender		
Male	26	(78.8%)
Female	7	(6.1%)
Identify with other gender	0	-
Other	0	-

Race/Ethnicity		
White/Caucasian	31	(93.9%)
Black/African American	0	-
Native American	0	-
Hispanic/Latino	2	(6.1%)
Asian	0	-
Other	0	-
Relationship Status		
Single	18	(54.5%)
Married	3	(9.1%)
Separated	2	(6.1%)
Divorced	2	(6.1%)
Living with Significant Other	6	(18.2%)
Other	2	(6.1%)
Employment Status		
Working Part-time	4	(12.1%)
Working Full-time	15	(45.5%)
Not Working	10	(30.3%)
Disabled	2	(6.1%)
Retired	1	(3%)
Other	1	(3%)
Years with SUD		
Less than 1 year	0	-
1-2 years	3	(9.1%)
3-4 years	6	(18.2%)
5-6 years	5	(15.2%)
7 or more years	19	(57.6%)
Health Status ISUD		
Poor	9	(27.3%)
Fair	9	(27.3%)
Good	13	(39.4%)
Very Good	1	(3%)
Excellent	1	(3%)
Person responsible for finances for ISUD		
Yourself	8	(24.2%)
Your Significant Other or Partner	0	-
Your Spouse	0	-
ISUD	25	(75.8%)
Significant Other or Partner of ISUD	0	-
Other	0	-
People living in residence of ISUD		
1-2 people	34	(33.7%)
3-4 people	36	(35.6%)
5-6 people	10	(9.9%)
7 or more people	4	(4%)
Other	17	(16.8%)

Recovery Status of ISUD		
Remains using substance	34	(33.7%)
Outpatient Treatment	13	(12.9%)
Inpatient Treatment	4	(4%)
Not using Substance at this time	37	(36.6%)
Unknown	13	(12.9%)

Appendix N

Permissions



From: Paul Toner
To: Eileen Marie Kane
Subject: Re: 25 item ADF SSS
Date: Sunday, March 26, 2017 1:45:23 PM

Hi Eileen,

Sounds like a really interesting study you have planned, I'm very happy for you to use the ADF SSS instrument. I'd be interested in how the qualitative data that you collect is reflected in scores on the ADF scale. Out of interest the scale has been used in N. America previously, with some alterations to wording: http://openscholarship.wustl.edu/etd/1334/

Hope all goes well with the work, please let me know what you find - Best wishes,

Paul

On 26 March 2017 at 18:26, Eileen Marie Kane <kaneem@uwm.edu> wrote:

> Hello,
>
> My name is Eileen M. Kane. I am a student in the nursing PhD program for the University of Wisconsin- Milwaukee.
>
> I am completing a mixed methods study looking at the lived experiences of the family/support systems of the individual with an illicit substance use disorder. The pilot study will include basic demographics followed by in-depth interviews. Participant will be individual acting as support for the individual with an illicit substance use disorder.
>
> I would like your permission to utilize the 25 item ADF SSS instrument in my study.
>
> Please let me know any further information you may need as you consider my request.
>
> Thank you,
>
> Eileen M. Kane

--
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CURRICULUM VITAE

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Major: Nursing

MSN, Western Governors University, June 2013
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PhD., University of Wisconsin- Milwaukee, May 2020

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Memberships:

- Sigma Theta Tau International Honor Society of Nursing
    - Eta Nu Chapter Member
    - Iota Phi Chapter Member