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Caregiver Role in Alcohol Abuse Treatment for Individuals with Intellectual Disabilities

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2020

Abstract

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MA, Kean University, 2005

BS, William Paterson University, 1996

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

With deinstitutionalization in the 1970s, individuals with intellectual disabilities were mainstreamed back into their communities, along with an increase in the prevalence of alcohol abuse and a necessity for family members to be the main source of care, support, and advocacy. The purpose of this hermeneutical phenomenological study was to explore the lived experiences of caregivers of family members with intellectual disabilities abusing alcohol and the obtainment of substance abuse treatment services. The conceptual framework included a combination of family stress and caring theories which provided an ontological direction as to how caregivers perceived the phenomenon of obtaining substance abuse treatment services for their family member. Data were collected through face-to-face structured interviews with 8 caregivers who were selected using purposive sampling. A modified version of van Kaam’s method of analysis assisted in the aggregation of themes and to explore caregivers’ lived experiences of seeking substance abuse treatment services. Results included the cyclic categories of (a) stress, (b) worry, (c) hopelessness and helplessness, (d) anger, and (e) self-blame, as experienced by the caregivers. Implications for policy and social change include information for stakeholders, policymakers, and human service facilitators regarding caregivers’ perceptions of seeking substance abuse treatment services for family members with intellectual disabilities who are abusing alcohol and for subsequent support programming development and management.

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Chapter 1: Introduction to the Study

Alcohol use and abuse affect individuals regardless of age, social status, economics, gender, religion, and occupation, or demographic; and most people know of or have a close family member who imbibes (National Institutes of Health [NIH], 2015). For many using alcohol, if problems arise, individuals might seek substance abuse treatment services to assist in detoxification and abstain from further use (Mulia, Tam, & Schmidt, 2014; Picci et al., 2014; Quintero, 2011). Because alcoholism is a disease that affects the mental, physical, and emotional health of users, abstinence may be vital to maintaining balanced health and lifestyle (Kurtz, 2002). Many individuals choose substance abuse treatment services that are cognitively and behaviorally designed to assist in achieving a positive outcome (Mulia et al., 2014; Picci et al., 2014; Roman, Ducharme, & Knudsen, 2006). However, because cognition is an important factor in the treatment process, individuals diagnosed with intellectual disabilities may not experience a positive outcome from treatment (Carroll Chapman & Wu, 2012; Quintero, 2011; Schmidt, 2016; Slayter, 2010; Slayter & Steenrod, 2009). Many individuals with intellectual disabilities might need advocacy in areas of everyday functioning, which may include seeking substance abuse treatment services (McMorris, Weiss, Cappelletti, & Lunsky, 2013). Advocates are usually family members who are often also the main caregivers (Kirby, White, &, Baranek, 2015). In the United States, 71% of individuals classified with intellectual and developmental disabilities lived with caregivers in 2011 (Williamson & Perkins, 2014). Without supervision, many individuals with intellectual disabilities might present with social and economic problems and risky behaviors due to a decreased ability to access services (Slayter & Steenrod, 2009; Williamson & Perkins, 2014). Caregivers might then have the additional responsibility of seeking substance abuse treatment services if needed, which could affect the quality of caregivers' lives (Bhatia, Srivastava, Gautam, Saha, & Kaur, 2015; Yoong & Koritsas, 2012). Therefore, caregiver roles might change during the lifespan of individuals with intellectual disabilities living with family or as part of the community while seeking peer acceptance, striving for individualism, independence, and normalcy (Martins & Couto, 2014; McGillicuddy, 2006; McMorris et al., 2013).

Researchers in prior studies have focused on caregivers raising children with intellectual disabilities (Larson, 2010; Ouellette-Kuntz et al., 2014). However, little research includes caregivers' experiences when trying to access community or health services for (McMorris et al., 2013; Slayter, 2010, 2016). There appears to be a lack of empirical and informational data about individuals with intellectual disabilities or intellectually disabled individuals abusing alcohol (McGillicuddy, 2006; Quintero, 2011; Slayter & Steenrod, 2009; van Duijvenbode, Didden, VanDerNagel, Korzilius, & Engels, 2018). In addition, there is a gap in the literature about caregivers' perceived understanding of how to process intellectual disabilities coupled with alcohol abuse in families, including how to seek treatment (Werner & Schulman, 2015; Williamson & Perkins, 2014). Caregiver perception might also play a role in the conceptual ideations of treatment for the intellectually disabled alcohol abuser (Wilkinson & McAndrew, 2008).

Background

Approximately 7% of people over the age of 18 self-reported as having an alcohol use disorder (NIH, 2015). According to the Substance Abuse and Mental Health Services Administration (SAMSHA, 2014) data, approximately 17.3 million individuals displayed co-morbidity of mental health and some form of substance abuse. Seven to 27% percent of people with intellectual disabilities are among the statistics of alcohol abusers (Carroll Chapman & Wu, 2012; Copersino et al., 2012; Disabled World, 2013; Kerr, Lawrence, Darbyshire, Middleton, & Fitzsimmons, 2013; Kouimtsidis et al., 2015). Through seeking individualism, autonomy, and self-identification, as well as emulating peer modeling and pressure to fit in, alcohol abuse has become a behavioral risk for intellectually disabled individuals (McGillicuddy, 2006; Pezzoni & Kouimtsidis, 2015; Swerts et al., 2017; Ting To, Neirynck, Vanderplasschen, Vanheule, & Vandevelde, 2014).

Non-intellectually disabled individuals abusing alcohol might have the ability to approach treatment from diverse sources of services, including outpatient, inpatient, therapeutic, holistic, and self-help groups such as Alcohols Anonymous (AA; Picci et al., 2014; Quintero, 2011). However, with limited cognitive understanding, individuals with intellectual disabilities abusing alcohol might not have the capability to find and decide which services will best address their addiction (Slayter, 2010, 2016; Slayter & Steenrod, 2009). Therefore, caregiver activism for substance abuse treatment services might play a significant role in assisting loved ones with intellectual disabilities and alcohol abuse in finding treatment programs supporting abstinence from alcohol use (McMorris et al., 2013; Ouellette-Kuntz et al., 2014; Stein, 2009; Williamson & Perkins, 2014).

Approximately 75% of individuals with intellectual disabilities live with family caregivers, such as parents and siblings, and in many cases, the primary responsibility of care passes to siblings when parents are no longer capable (Rossetti & Hall, 2015; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014; Williamson & Perkins, 2014). Understanding how to properly care for individuals with intellectual disabilities might prove difficult for caregivers as intellectually disabled individuals age into adulthood (McMorris et al., 2013; Rossetti & Hall, 2015; Ryan et al., 2014; Slayter, 2016; Stein, 2009).

Parents might expect risky behaviors such as alcohol and drug use from non-intellectually disabled individuals as they move through the developing years (Lieberman, Cioletti, Massey, Collantes, & Moore, 2014; McGillicudy, 2006). Caregivers of the intellectually disabled, on the other hand, might believe that family members with intellectual disabilities would not engage in such risky behaviors (Disabled World, 2013; Quintero, 2011). However, there is an increase of alcohol abuse within the intellectually disabled population (Chaplin, Gilvarry, & Tsakanikos, 2011; Simpson, 2012; VanDerNagel, Kiewik, Buitelaar, & DeJong, 2011; van Duijvenbodea, Didden, Bloemsaat, & Engels, 2012; Weiss, 2017). With the increase in alcohol use among the intellectually disabled, seeking substance abuse treatment services might become the responsibility of family members (Martins & Couto, 2014; Sullivan, 2015).

Problem Statement

Historically, the care of individuals with intellectual disabilities has been either family or institutional. However, between 1972 and 2019 and the ending of institutionalism, societal members looked to family members to care for individuals with intellectual disabilities (McMorris et al., 2013; Williamson & Perkins, 2014; Wynaden, 2007; Yoong & Koritsas, 2012). With the movement towards independence for intellectually disabled people, alcohol use has become increasingly prevalent (McGillicuddy, 2006; Slayter, 2010, 2016). As with non-intellectually disabled alcohol-abusing cohorts, substance abuse treatment might prove beneficial to abstinence and the overall well-being of users with intellectual disabilities (Gawryszewski & Monteiro, 2014; Ray, Hart, Chelminski, Young, & Zimmerman, 2011; VanDerNagel et al., 2011). However, with limited cognitive comprehension and lower self-reliance, negative consequences might occur (Parish, Rose, Dababnah, Yoo, & Cassiman, 2012; Ward & Stewart, 2008). With the ending of institutionalization, individuals with disabilities seeking individualism, educational mainstreaming, and consequential exposure to peer pressure, risky behaviors might occur (Martins & Couto, 2014; McMorris et al., 2013; Taggart, McLaughlin, Quinn, & Milligan, 2006; Williamson & Perkins, 2014). Because of the increase of alcohol use and abuse in the intellectually disabled population, caregivers' assistance in seeking substance abuse treatment services for loved ones with limited cognition levels might become necessary (Martins & Couto, 2014; Ouellette-Kuntz et al., 2014).

Purpose of the Study

For this hermeneutical phenomenological study, I explored how caregivers experience the process of finding substance abuse treatment services for intellectually disabled family members abusing alcohol. Caregivers of intellectually disabled alcohol abusers were the population of study because they were the primary carers of family members with intellectual disabilities; and therefore, are the foremost advocates for services (Gibbs, Brown, & Muir, 2008; Werner & Shulman, 2015). I interviewed eight caregivers to the point of theoretical saturation from one organization providing services to individuals with intellectual disabilities and family members in the Northeastern United States. I used a hermeneutical phenomenological design to explore the phenomenon of caregivers' ontological experiences associated with seeking substance abuse treatment services for loved ones with intellectual disabilities abusing alcohol (McMorris et al., 2013; Ouellette-Kuntz et al., 2014).

Research Questions

RQ1: How do caregivers experience seeking substance abuse treatment services for family members with intellectual disabilities abusing alcohol?

RQ: How do caregivers interpret experiences related to seeking substance abuse treatment services?

Conceptual Framework

I used a combination of conceptual interpretive frameworks of family stress and caring theories to examine core elements of the hermeneutical phenomenological scope of the research project. Nalzaro (2012) posited that frameworks, whether conceptual or theoretical, hold relational concepts to and among other concepts. With the phenomenological hermeneutical methodological research design, I used an interpretive lens throughout the study to explore descriptive texts for thematic patterns (Cara, 2003; Moustakas, 1994; von Krogh & Naden, 2011; Wagner, 2010).

For this hermeneutical phenomenological study, the integration of family stress and caring theories allowed me to investigate caregivers' lived experiences through the perceptions of carers who advocated for family members who displayed cognitive limitations and abused alcohol. Family stress theorists seek to understand how some families develop resilience to normative and non normative transitions and stressors while others become vulnerable to being maladaptive (McDonald, 2001; Patterson, 2002; Sullivan, 2015). Theorists of caring examine how caregivers experience the provision of attending others. While the use of core theoretical concepts explores the cultivation of sensitivity, trust in the relationship, and a supportive environment might benefit individuals while continuing the conceptual aspects of theory such as caregiver honor, dignity, and respect (Cara, 2003; Ozan, Okumus, & Lash, 2015; Wagner, 2010). The collective use of family stress and caring theories in this study allowed for the development of a strong understanding of caregivers' descriptive interpretations while providing detailed results. Through the formulation of research questions and the gathered data, I expected a comprehensive analysis of caregiver perceptions related to substance abuse treatment services (Lindseth & Norberg, 2004; Sullivan, 2015).

Nature of the Study

The method of inquiry for this study was a hermeneutical phenomenological design to examine the descriptive interpretations of the lived experiences of caregivers seeking substance abuse treatment services for loved ones with intellectual disabilities and alcohol abuse (Lindseth & Norberg, 2004; von Krogh & Naden, 2011). Heidegger (1972) explained that the phenomenological method is information brought *to the light* and defined caring as an ontological phenomenon (1996) or as the contemplation of compassion for another or the state of being (Moustakas, 1994; Ranheim, Karner, & Bertero, 2011). Ricoeur (1976) described interpretive interviews as a “natural and suitable” mode of expression of the unique meaning related to caregivers’ experiences to the phenomena of study (Frivold, Dale, & Slettebo, 2015; Lindseth & Norberg, 2004).

I conducted individual interviews and analyzed the descriptive text for thematic congruence to determine authenticity and provide clarity to develop an understanding of the lived experiences of participants (McManus Holroyd, 2007; Ranheim et al., 2011). Due to personal experience on the topic of study, I monitored my preconceived thoughts while adhering to the hermeneutical philosophical ideation throughout the research process (Lindseth & Norberg, 2004). Participant sampling was criterion-based with predetermined characteristics (Suri, 2011) of purposive specificity to draw a comparable connection to the research questions (Cleary, Horsfall, & Hayter, 2014). In choosing participants, a prerequisite was experience in caring for family members or loved ones with intellectual disabilities abusing alcohol and seeking substance abuse treatment services (Cleary et al., 2014).

Definitions

This section includes a definition of key terms used in this study.

Alcohol abuse: A cluster of physical and behavioral symptoms including cravings, tolerance, and withdrawals with the knowledge that continued use might adversely affect the physical, social, and psychological aspects of the life of the user (American Psychiatric Association [APA], 2013; NIH, 2015).

Family caregiver: An adult family caring for individuals with neurological or organic brain dysfunction in an informal setting such as home and in the community ("Caregiver law and legal definition," 2016).

Intellectual disability: A disorder with onset in the developmental stages of intellect, deficits in intellect (reasoning, judgment, problem-solving, abstract thinking, academic learning, and socialization), and adaptive functioning as failing to meet developmental and sociocultural standards of independence and, social responsibility (APA, 2013).

Assumptions

This study included conditions related to family dynamics and phenomenological research methods. Assumptions included that participants (a) had the ability to understand the questions and respond truthfully; (b) had experience advocating for treatment services for family members with intellectual disabilities, substance abuse treatment; and (c) were the main caregivers for family members, which Watson (2007) characterized as innate and timeless qualities.

Scope and Delimitations

This study was conducted in a Northeastern urban setting. Participants were eight caregiver advocates for intellectually disabled alcohol abusers and were interviewed to the point of theoretical saturation. The scope of the study encompassed family care, intellectual functioning, alcohol abuse, and substance treatment services to narrow the scale of caregiver roles to advocating for substance abuse treatment.

Limitations

The hermeneutical phenomenological design does not allow for generalizability of results to the larger population (Heinonen, 2015; Moustakas, 1994). Results were dependent upon participant recall, interpretation of questions, and unknown biases in responses (Bekkema, de Veer, Hertogh, & Francke, 2014; Solvoll, Hall, & Brinchmann, 2014). Culture was considered as a possible barrier, which included the influence of language, comprehension, ideations, and stigma attached to alcohol abuse and treatment (Werner & Shulman, 2015; Yu, Clark, Chandra, Dias, & Lai, 2009).

Significance

Study results may provide new perspectives to supportive services, stakeholders, and organization staffers who assist the intellectually disabled and caregiver's needs. The importance of this study was to develop an understanding of how caregivers of family members with intellectual disabilities abusing alcohol experience the phenomenon of seeking substance abuse treatment services. Prior researchers focused on caregivers providing care to family members with intellectual and other cognitive disabilities (Kirby et al., 2015; Larson, 2010; Martins & Couto, 2014). However, there was a gap in regard to caregivers who seek services for loved ones with intellectual disabilities coupled with alcohol abuse. Results of this study include information about caregivers’ understanding and choices in seeking substance abuse treatment services for people with intellectual disabilities abusing alcohol (McMorris et al., 2013; Slayter, 2016). An understanding of the perceptions of caregivers of intellectually disabled alcohol abusers might help stakeholder providers to better assist the caregivers and to assess existing substance abuse treatment services to determine if they are beneficial to the cognitively impaired (Kirby et al., 2015; Larson, 2010; Ouellette-Kuntz et al., 2014; Quintero, 2011; Slayter, 2010, 2016).

Summary

For this hermeneutical phenomenological study, I gathered data by interviewing caregivers who were seeking substance abuse treatment services for family members with intellectual disabilities and abusing alcohol (Cleary et al., 2014; Ouellette-Kuntz et al., 2014; Thorkildsen, Eriksson, & Raholm, 2015). Alcohol abuse can significantly affect the lives of individuals abusing alcohol and can be especially challenging for individuals with cognitive limitations who might have difficulty finding services (Wilkinson & McAndrew, 2008; Wynaden, 2007). Advocates of intellectually disabled individuals are often family members who then become responsible for the loved one’s actions and behaviors, including those related to alcohol use (Kvamme, Asplund, & Bjerke, 2015). Chapter 1 included an overview of the hermeneutical phenomenological study of caregivers’ experiences in seeking substance abuse treatment services for intellectually disabled family members abusing alcohol. I discussed the background, problem, purpose, significance, research questions, and conceptual framework grounding the topic of study. Chapter 2 includes a review of the literature about caregiver advocates and intellectually disabled family members abusing alcohol.

Chapter 2: Literature Review

The purpose of this hermeneutical phenomenological study was to gain a comprehensive understanding of how caregivers experience seeking substance abuse treatment for family members with intellectual disabilities abusing alcohol (Larson, 2010; McMorris et al., 2013). The review includes essential information relating to the empirical data about the intellectually disabled, the caregivers of intellectually disabled, the intellectually disabled person abusing alcohol, and caregivers of intellectually disabled abusing alcohol (Thorkildsen et al., 2015). The literature about caregivers in conjunction with intellectual disability and alcohol abuse is most relevant to my research (McGillicuddy, 2006; Quintero, 2011; Slayter, 2010, 2016; Slayter & Steenrod, 2009).

The literature reviewed in this chapter includes historical and societal ideations of the intellectually disabled and examples of how individuals with intellectual disabilities were accepted and treated within their families, environments, and communities (Noll & Trent, 2004; Rossetti & Hall, 2015). A review of the literature includes a brief understanding of basic changes in societal views about caregiver roles and advocating for caring for individuals with intellectual disabilities, and the intellectually disabled alcohol abuser (Bhatia et al., 2015; Findlay, Williams, Baum, & Scior, 2015). A study on caregivers might provide insight into the lived experiences of caring and advocating for intellectually disabled loved ones (Chou & Kroger, 2014). This literature review chapter includes the following: (a) the literature search strategy, (b) a brief history of the intellectually disabled, (c) a brief history of alcohol use and abuse, (d) a review of the literature about intellectually disabled individuals abusing alcohol, and (e) a review of the literature about caregivers of the intellectually disabled abusing alcohol.

Literature Search Strategy

I obtained information in this review from the following databases: CINAHL, ERIC, Google Scholar, Human Services and Social Services Anthology, Medline, ProQuest, PsycARTICLES, PsycINFO, PsycTESTS, SAGE Premier, SocINDEX, and SocINDEX with Full Text. I used the following search terms and phrases for this review: *intellectual disability, intellectually disabled, developmentally disabled, mental retardation, caregivers of intellectually disabled family members, carers, siblings of intellectually disabled, disability, alcohol abuse,* and *substance abuse treatment services.* Other search terms included *hermeneutical phenomenological, phenomenology, phenomena, phenomenon,* and *qualitative study.*

I accessed peer-reviewed literature and books on the topics of mental retardation, the intellectually disabled, and caregivers. I also used state and government sources such as the National Institute of Health and the Social Security Administration as sources of information. I read about 250 journals, articles, and books associated with the search terms and phrases.

Conceptual Framework

I used a combination of conceptual interpretive frameworks of family stress and caring theories to examine core elements of the hermeneutical phenomenological scope of the research project. Nalzaro (2012) posited that frameworks, whether conceptual or theoretical, hold relational concepts to and among other concepts. With the phenomenological hermeneutical methodological research design, I used an interpretive lens throughout the study to explore descriptive texts for thematic patterns (Cara, 2003; Moustakas, 1994; von Krogh & Naden, 2011; Wagner, 2010).

For this hermeneutical phenomenological study, the integration of family stress and caring theories allowed me to investigate caregivers' lived experiences through the perceptions of carers who advocated for family members who displayed cognitive limitations and abused alcohol. Family stress theorists seek to understand how some families develop resilience to normative and non-normative transitions and stressors while others become vulnerable to being maladaptive (McDonald, 2001; Patterson, 2002; Sullivan, 2015). Theorists of caring examine how caregivers experience the provision of attending others. While the use of core theoretical concepts explores the cultivation of sensitivity, trust in the relationship, and a supportive environment might benefit individuals while continuing the conceptual aspects of theory such as caregiver honor, dignity, and respect (Cara, 2003; Ozan et al., 2015; Wagner, 2010). The collective use of family stress and caring theories in this study allowed for the development of a strong understanding of caregivers' descriptive interpretations while providing detailed results. Through the formulation of research questions and the gathered data, I expected a comprehensive analysis of caregiver perceptions related to substance abuse treatment services (Lindseth & Norberg, 2004; Sullivan, 2015).

Literature Review

In this section, I review the literature related to this study. I discuss a history of the intellectually disabled population from 1500 B.C. to the present, a history of alcohol and alcohol abuse, abuse of alcohol by individuals who have an intellectual disability, and caregivers of individuals who have an intellectual disability and abuse alcohol.

A Brief History of the Intellectually Disabled Population

Individuals with cognitive limitations have co-existed in families and communities through the centuries (Harbour & Maulik, 2010; Wa Munyl, 2012). When discussing intellectual disabilities, one must consider aspects of life, such as cognitive and physical development, social and interactive skills, and comprehension levels relative to age and stages of development (Erikson, 1950; Noll & Trent, 2004). The following sections include a discussion of the nature and development of people with intellectual limitations, communal perspectives and perceptions in societies, and family views associated with the care and raising of individuals with intellectual disabilities (Brockley, 2004; Noll & Trent, 2004).

1500 B.C. to the Middle Ages

Intellectual disabilities date as far back as 1552 B.C. in Egypt and to the Middle Ages (Ainsworth & Baker, 2004; Dosen & Day, 2001; Harbour & Maulik, 2010). Negative perceptions existed among communal members who viewed intellectual disabilities as a punishment from the gods. Therefore, children with disabilities were killed at birth or left to starve (Covey, 2005; Dosen & Day, 2001; Harbour & Maulik, 2010). With the emergence of Christianity, the belief became that all individuals were equal and creations of God. However, Christian views on the intellectually disabled varied (Ainsworth & Baker, 2004; Covey, 2005; Wu Munyl, 2012). While some believed people with disabilities embodied a sin that had to be eradicated, isolated, and punished, others perceived the disabled as opportunities to test their faith providing humane treatment (Ainsworth & Baker, 2004; Covey, 2005; Wu Munyl, 2012). However, by the Middle Ages, societal views grew less tolerant of people with mental deficiency or illness, lending to ideations of witchery (Covey, 2005; Thornberry & Olson, 2005; Wa Munyl, 2012).

The 16th-18th Centuries

By the 16th century, there was an increased assumption that people were participating in witchcraft, which led to an upsurge in the inhumane treatment of the intellectually disabled. Little tolerance was given to those who displayed oddity (Covey, 2005; Thornberry & Olson, 2005). Church members, in trying to cure people with intellectual disabilities from what was perceived as evil spirits, sometimes used painful measures to exorcise demonic possession (Covey, 2005; Wa Munyl, 2012). As societal thoughts changed by the end of the century, attitudes of ambiguity remained in attempts to understand what caused intellectual disabilities and how to assist those with disabilities (Ainsworth & Baker, 2004; Thornberry & Olsen, 2005).

Records in the United States include information about intellectual disabilities in 17th century Massachusetts, where people with limited cognitive developmental issues were labeled as idiots and believed to be possessed by evil spirits (Wickham, 2002; Wu Munyl, 2012). In addition, as negative attitudes and beliefs towards the occult emerged, communities shunned and ostracized families with intellectually disabled children (Noll & Trent, 2004; Wa Munyl, 2012; Wickham, 2002). With superstitious beliefs mounting, the disabled were believed to carry the sins of the family and became the focal point of punishment in many communities (Covey, 2005; Thornberry & Olson, 2005). Labels of description such as idiot, imbecile, moron, defective, deficient, feeble-minded, and retard developed over time, and in North America, the use of idiot appeared acceptable across settings, including the medical field and rehabilitative philology (Ferguson, 1994; Noll & Trent, 2004; Wickham, 2002).

The 19th Century

Parents caring for intellectually disabled children during this time found the task burdensome and felt guilt and shamed by public stigmatization (Noll & Trent, 2004; Werner & Shulman, 2015). During the 19th century, people born with intellectual disabilities received no formal education because members in society believed that individuals with cognitive disabilities, no matter the age, would need intensive supervision due to possible behavioral problems (Howe, 2004; Stefánsdóttir & Traustadóttir, 2015). The intellectually disabled were perceived as having a lack of social and behavioral skills, being a menace to society, and presenting with unruly conduct, thus leading to negative societal attitudes and cruel treatment, which reinforced negative behaviors (Howe, 2004; Thornberry & Olson, 2005; Wolfensberger & Tullman, 1982). During this period, many intellectually disabled individuals experienced involuntarily sterilization to halt reproduction (Antonak, Fielder, & Mulick, 1993; Aunos & Feldman, 2002; Sowa & Rosenstein, 2015). By the end of the 19th century, educational housing instituted and operated by doctors surged in attempts to educate the cognitively impaired. However, many of these facilities would become future institutions for the intellectually disabled and mentally ill (Burrell & Trip, 2011; Noll & Trent, 2004; Thornberry & Olson, 2005)

With a poor understanding of cognitive impairment, institutionalization became the answer to housing, treatment, and assistance to individuals with intellectual disabilities, previously perceived as devalued or not meeting the norms of society (Noll, & Trent, 2004; Wickham, 2002; Wolfensberger & Tullman, 1982). Devalued individuals would (a) be harmed or treated cruelly, (b) assume the negative attitudes afforded by societal perceptions and isolate while avoiding integration, and (c) reflect the positive or negative perceptions of society through behavior (Noll & Trent, 2004; Wickham, 2002; Wolfensberger &Tullman, 1982).

The Early 20th Century

Existing ideations and beliefs in society would eventually move away from devaluation and shift focus towards equality and justice while teaching individuals with intellectual disabilities self-determination, integration, and normalization (Stefánsdóttir & Traustadóttir, 2015; Tropea, 2005; Wehmeyer, 2004, 2013; Wehmeyer & Patton, 2000). According to Wolfensberger and Tullman (1982), normalization is minimizing, preventing, or changing societal perceptions on how devaluation affects persons with intellectual disabilities. Through education and mainstreaming people with intellectual disabilities into social environments, the augmentation of social images and proficiency might reduce stigmatization and improve societal member perceptions (Siperstein, Albert, Jacobs, Osborne, & Stokes, 2018; Wehmeyer, 2004, 2013; Wolfensberger & Tullman, 1982).

The 1940s to 1950s

By the mid-20th century, families and caregivers began to move towards understanding intellectual disabilities. In 1947, a group of women with children diagnosed as cognitively impaired started a support group, the New Jersey Parents Group for Retarded Children (Jones, 2004). The support group continued to develop and grow, becoming the National Association for Retarded Children (NARC), then the National Association for Retarded Citizens (NARC), and eventually the Association of Retarded Citizens (ARC) with chapters in all 50 states (ARC, 2017; Jones, 2004; Wehmeyer & Patton, 2000). In 1971, the ARC in Pennsylvania (PARC) made a significant contribution in education, advocating for mainstreaming intellectually disabled children with non-intellectually disabled peers, citing that exclusion violated principles of Brown vs. Board of Education (1954) and reinforced inequality for children with cognitive disabilities (Chen, 2017; Smith & Kozleski, 2005).

The 1960s

In the 1960s, many society members perceived intellectual disability as an unsolvable problem because there appeared no comprehensive plan on what to do with a population of people who were not functioning according to societal standards (Llewellyn, 2013; Pollack & Bagenstos, 2015). In the late 1960s, people with cognitive limitations were less often institutionalized and received behavior modification treatments and structured education (Bodfish, 1992; Burrell, & Trip, 2011; Goodey, 2015; Pollack & Bagenstos, 2015; Stefánsdóttir & Traustadóttir, 2015). The ARC and related programs have become support systems for individuals with intellectual disabilities and their families, and new laws and policies set in place in the 1970s invoked changes in the treatment and perceptions of the intellectually disabled (ARC, 2017; Wehmeyer & Patton, 2000).

The 1970s-1990s

During the 1970s, new laws such as the Declaration on the Rights of the Mentally Retarded Persons (DRMRP; 1971) and the Americans with Disabilities Act of 1990 (ADA; 1990, 2008) were enacted as means to protect the rights of disabled citizens (ADA, 2016; Friedman, 1977). DRMRP through the General Assembly resolution 2856 (XXVI) declared that persons with intellectual disabilities are to have equal access and the same rights as the non-disabled, have the right to medical care, physical therapy, educational training, rehabilitation, and guidance to reach their full potential (Friedman, 1977; Gostin & Gable, 2010). Additionally, persons with intellectual disabilities had the right to seek employment and make decent wages (ADA, 2016; United Nations Enable, 2016). Also listed in the declaration is that individuals with intellectual disabilities live with family members, guardians, or foster parents when able and that families of the disabled receive assistance from community services (Llewellyn, 2013; United Nation Enable, 2016). In 1993, the Office of the United Nations High Commissioner for Human Rights (OHCHR) encompassed human rights on a global scale for all people including the DRMRP (OHCHR, 2018).

Changes in the school system occurred under the Education for the Handicapped Act (EHA; Public Law 94-142) of 1975, which moved to protect rights, meet individual needs, and assist in the goal of reaching positive results for the disabled and families

(U.S. Department of Education, 2007). The EHA amended in 1997 was renamed the Individuals with Disabilities Education Act (IDEA), expanded to the inclusion of infants to 5-year-olds with disabilities (Ladd, 2017; U.S. Department of Education, 2007). IDEA, building upon the concepts of improving education for children and youth with disabilities, legislators developed the following: (a) appropriate services; (b) Individual Family Service Plans (IFSP); (c) quality assessment and teaching; and (d) nationwide professionals monitoring for improvement and intervention in early childhood education, through local, state, and federal collaboration (Ladd, 2017; U.S. Department of Education, 2007). In addition, in 1997, the United Nations Economic and Social Council (ECOSOC) put forth a resolution for equal opportunities for persons with disabilities.

The 2000s to Present

Between the years 2000 and 2018, ECOSOC expanded the 1997 resolution with an addendum to uphold equal opportunity and human rights for individuals with intellectual disabilities and to include all types of disabilities (ECOSOC, 2010, 2016; Elfert, 2015). ECOSOC employs government involvement in setting forth standardized rules for equal opportunity to include women, children, and persons with developmental and psychiatric disabilities, and monitors for disability inclusion (ECOSOC, 2016; Llewellyn, 2013; United Nations Enable, 2016). The United Nations Educational, Scientific and Cultural Organization (UNESCO), an organization under ECOSOC, encourages peace by partnering with governmental and nongovernmental organizations, and the private sector to collaborate in fostering equality through education, science, and culture of inclusion to build knowledge as a united process to benefit all people (UNESCO, 2017).

Brief History of Alcohol Use and Abuse

The history of alcohol use dates back to prehistoric times as archaeologists find artifacts recorded to the second millennium B. C. (Guerra-Doce, 2015; Dunlap, n.d.). Wine and other fermented drinks often mentioned in the Bible date from possibly the years 6000 B. C., to the passages and books in the New Testament A. D. (Dunlap, n.d; Keller, 1979). From the years 3000-3500 B.C., some form of intoxicating alcoholic beverage was imbibed in the Middle East, Egypt, Rome and surrounding areas for ceremonial, medicinal, diplomacy, socialization, and in religious rituals throughout history (History of the Ancient World, March 30, 2015; Keller; 1979). Although alcoholic beverages acceptable as a substitute for water in supplying essential liquids to the diet, intoxication in any form was unacceptable to societal norms (Dunlap, n.d.; History of the Ancient World, March 30, 2015).

The 17th-18th Century

Alcohol introduced to the Americans was a necessity in many 17th century Euro-American households, especially beer, whereas just as in ancient times water was sometimes polluted, contaminated, and disease-infested and undrinkable (Beauvais, 1998; Crews, 2007; Frank, Moore, & Ames, 2000; Hermen-Stahl, Spencer, & Duncan, 2003). Breweries, taverns, and home-made liquor were the early refineries in the alcohol industry and accepted as the drink was embedded in colonial households and lifestyles (Crews, 2007; Harbster, 2014). Alehouses or taverns became important for socialization, but also used for mail distribution, for court proceedings, and as a place to discuss social, political, and business (Crews, 2007; Jewett, n.d.). Through trade, modeling, and accessibility, the Americans native to the land, through bartering, started to drink to excess, leading to behavioral changes within indigenous cultures (Beauvais, 1998; Fischer-Tine, 2012; Frank et al., 2000; Hermen-Stahl et al., 2003). Alcohol use was acceptable in the military as the beverage filled the need in the medical arena (for pain or anesthesia) and used as part of the overall military plan (Jones & Fear, 2011; Martin, 2011). By the end of the 18th century, alcohol use increased and was spilling over into family and societal life, causing problems in communities (Jones & Fear, 2011; Martin, 2011).

The 19th-20th Century

With the expansion of the widening scope of territorial advancement and migratory movement towards the west and west coast, alcohol was also a part of provisions for the journey and taverns would emerge as settlers built towns for socialization (Keller, 1979). With alcohol use increasingly seen as out of control, the Women’s Christian Temperance Movement (WCTU) began, viewing alcohol use as immoral and corrupting imbibing members of society (Berridge, 2006; Masson, 1997; Williams, 2017). The movement initiated policy changes of alcohol use in the United States, which continue into 21st-century political fields of restrictions (Berridge, 2006; Masson, 1997; Williams, 2017). ICAP, the International Center for Alcohol Policies, is one of the organizations that provide guidelines for the drinking of alcoholic beverages (ICAP, 2014). ICAP also presents relevant information about the harm caused by alcohol use and abuse while offering suggestions and recommendations to assist individuals seeking help (ICAP, 2014).

In early 20th-century, alcohol use created problems for individuals imbibing, and families suffered from behaviors induced by alcohol consumption, causing societal issues such as (a) disorderly conduct, (b) drunk driving, (c) illegal activity (Frank et al., 2000; Jewett, n.d.; Kurtz, 2002; Peck, 2014). In 1917, the legislature passed the 18th Amendment prohibiting alcohol use in the United States. The Volstead Act, or The National Prohibition Act, enacted as a means of enforcing the manufacturing, distribution, and sales of alcohol as a way to control use (U.S. Constitution, Amendment XIIX, 2016). The ban on liquor limited accessibility but did not stop individual consumption; as demand increased, many people started to make different forms of alcohol to sell for profit, which led to organized crime (Peck, 2014; Slayton, 2016). Major cities like New York City appeared as hubs for illegal alcohol distribution, where supply met demand (Keller, 1979; Slayton, 2016). Leaders of the prohibition movement blamed the continuance of alcohol use on people classified as foreign or non-American, such as Irish, Jews, and others, which led to protests from different religious, ethnic and gender groups including Irish, African Americans, Germans, and women (Keller, 1979; Slayton, 2016).

Many prominent people, including John D. Rockefeller, Jr., wanted to repeal the 18th Amendment of prohibition with the 21st Amendment (Peck, 2014; Slayton, 2016). The 21st Amendment also known as Repeal Amendment, or the Alcohol Beverage Control Act, (revised 2015) or A, B, and C, a multi-tiered system to investigate administrative and criminal violations of the ABC Act (N.J.S.A. 33:1-1 et seq.) gives individual states the power to control and regulate alcohol (Peck, 2014; Slayton, 2016). For example, in New Jersey, regulations set the age of drinker and purchasing, distribution, licensure to sell, limitations on where and amount of alcohol served, including over 100 other diverse regulations and violations (Alcohol Beverage Control Handbook, 2015). The 21st Amendment repealed the 18th Amendment in 1933, resulting in increased access to alcohol (Peck, 2014; Slayton, 2016). With the re-legalization of alcohol, many users found difficulty in abstaining, and study findings included information that indicated that even after long-term abstinence, alcohol continues to have profound effects on psychological, medical, employment, and legal issues, leaving many to seek treatment services such as Alcoholics Anonymous established in 1934 (Kurtz, 2002; Verdejo-Garcia, Rivas-Perez, Vilar-Lopez, & Perez-Garcia, 2007). With the end of prohibition on December 5, 1933, and some 80 years later and due to the Rockefeller's three-tiered legal framework system, state representatives continue to find loopholes in the regulation system on how to manufacture, control, and distribute alcohol to consumers (Cooper, & Wright, 2012; Peck, 2014).

Intellectually Disabled Abusing Alcohol

Since implementing deinstitutionalization in the 1970s, intellectually disabled individuals moved with families or into community housing, and with exposure to environmental stressors including alcohol use risky behaviors have risen in numbers (Burrell & Trip, 2011; Pezzoni & Kouimtsidis, 2015; Stein, 2009; Taggart et al., 2006). Institutionalization appeared as a means of protecting intellectually disabled individuals from the environs while assisting parents by providing a place to live with supervision on a continuum (Bodfish, 1992; Burrell & Trip, 2011; Slayter, 2010; Taggart, McLaughlin, Quinn, & McFarlane, 2007). In-community living presents with societal norms that link intellectually disabled individuals with the same behavioral risks as non-intellectually disabled peers, yet open to an augmented susceptibility of negative life experiences and stressors (Pacoricona Alfaro et al., 2016; Slayter, 2010, 2016; Ting To et al., 2014).

Already being a vulnerable population due to limited cognitive comprehension, intellectually disabled individuals abusing alcohol might also experience an increase of challenges in community living (Carroll Chapman & Wu, 2012; Kerr et al., 2013). Challenges might include increased levels of social isolation, victimization, stigmatization, homelessness, and educational and occupational disadvantages than non-intellectually disabled cohorts (Cantwell, Muldoon, & Gallagher, 2015; Carroll Chapman & Wu, 2012; Kerr et al., 2013). Living in community-based housing and through peer modeling and exposure, intellectually disabled individuals might also experience an increased risk for alcohol misuse while seeking normalization and self-determination (Chaplin et al., 2011; Cocco & Harper, 2002; McGillicuddy, 2006; Slayter, 2016; Slayter & Steenrod, 2009; Ting To et al., 2014). Alcohol appears to be the primary substance of use and misuse within the intellectually disabled population, estimating from 2.6% to 26% (Cocco & Harper, 2002; Didden, 2017; Kouimtsidis et al., 2015, 2017; Weiss, 2017).

While seeking normalization and self-efficacy within families, with peers, and in communities, individuals with intellectual disabilities might emulate behaviors of people considered role models (Kerr et al., 2013; Slayter, 2016; Ting To et al., 2014). As individuals attempt through self-determination to gain independence and become self-sufficient, with the ability to provide self-care while maintaining independence, people diagnosed with intellectual disabilities might look to peers for normalcy (McGillicuddy, 2006; Parcona Alfaro et al., 2016; Slayer, 2009, 2016). Mimicking behaviors of individuals perceived to be peers and possibly succumbing to peer pressure, intellectually disabled individuals abusing alcohol might not have ample insight as to whether the behaviors are positive, negative, or a danger to well-being (Copersino et al., 2012; Kouimtsidis et al., 2015; Lindsay et al., 2013; Parcona Alfaro et al., 2016).

In attempting to fit in with societal norms, perceived peer acceptance might include pressuring the intellectually disabled through bullying or coercion by cohorts to participate in alcohol use (Kouimtsidis et al., 2015; Parcona Alfaro et al., 2016; Schijven, Engels, Kleinjan, & Poelen, 2015; van Duijvenbode, Didden, Korzilius, & Engels, 2016). Without a comprehensive understanding of the effects of alcohol consumption and abuse in individuals diagnosed with intellectual disability and living in community environs there might be a further need for assistance than for people without intellectual disabilities abusing alcohol (Lunsky & Elserafi, 2011; Pezzoni & Kouimtsidis, 2015). Because of limited cognitive perception, a supportive system of family members, in community case management, or group homes to help with stabilization in life skills of independent living, including obtaining treatment services might be necessary (Parcona Alfaro et al., 2016; van Duijvenbode, Didden, Voogd, Korzilius, & Engels, 2012).

Caregivers of the Intellectually Disabled Alcohol Abuser

Deinstitutionalization has placed the lifelong care of individuals with intellectual disabilities on family members as they mature into adulthood whether residing in the home or community-based housing (Chadwick et al., 2013; Jones & Gallus, 2016; Yoong & Koritsas, 2012; Williamson & Perkins, 2014). With the assumption that family caregivers have experienced knowledge of intellectually disabled family members, society expects that family care will remain on a continuum throughout the person's lifespan to include obtaining in-community services, and substance abuse treatment services (Caton et al., 2012; Findlay et al., 2015; Irazabal, Pastor, & Molina, 2016; Rossetti & Hall, 2015; Weiss, 2017). Parents tend to be the primary carers during the childhood and the adult years, and when parents are no longer able to care and advocate for intellectually disabled children, siblings most often become the caregivers (Chou & Kroger, 2014; Greenberg, Seltzer, Orsmond, & Krauss, 1999; Rossetti & Hall, 2015). While parents raise children to become productive adults in society, those with intellectually disabled children might seek some form of normalcy throughout their child's life (Brockley, 2004; Chadwick et al., 2013).

Caregivers who find that as children with intellectual disabilities move into adolescent and the adult years, behaviors might change especially through educational mainstreaming where children and teens with cognitive limitations might face similar challenges as their non-intellectually disabled cohorts through interaction and while seeking independence (McGillicuddy, 2006; Migerode, Maes, Buysse, & Brondeel, 2012; Townsend, Biegel, Ishler, Wieder, & Rini, 2006). Parents might expect some adolescent behavioral changes and risk-taking as teens start to pull away from the traditional family roles and values by cigarette smoking, use of alcohol and other substances, engaging in sexual activity, delinquency, and other perceived negative behaviors, while parents of intellectually disabled might expect the reverse (Chou & Kroger, 2014; Jones & Gallus, 2016; Yoong & Koritsas, 2012). When faced with the same issues of age norms of peers, parents of intellectually disabled individuals might seek supportive services outside of the home (Manthorpe, Moriarty, & Cornes, 2015; Townsend et al., 2006; Yoong & Koritsas, 2012). Alcohol use has led to an increase in risky behaviors within the intellectually disabled population (Carroll Chapman & Wu, 2012; Parcona Alfaro et al., 2016; Slayter, 2016). As caregivers of intellectually disabled family members abusing alcohol, challenges might arise leading to seeking substance abuse treatment services to assist with abstinence and recovery (Robinson, Weiss, Lunsky, & Ouellette-Kuntz, 2016; Spassiani, Chacra, & Lunsky, 2017; Werner & Shulman, 2015; Williamson & Perkins, 2014).

With the advancement in medical technology, people, in general, are living increasingly healthy lifestyles promoting longevity of life and as individuals are living longer, so is the lifespan of people with intellectual disabilities (Caton et al., 2012; Findlay et al., 2015; Rossetti & Hall, 2015). Due to longevity, families caring for intellectually disabled loved ones continue to redirect their life paths while caregivers try to meet the needs of the family unit at all stages of life (Burke, Fish, & Lawton, 2015; Parish et al., 2012; Ryan et al., 2014; Taggart et al., 2014; Wilkinson & McAndrew, 2008). Caregivers of the intellectually disabled might experience a multitude of stressors that affect family dynamics on a continuum throughout the lifespan until the death of caregivers or intellectually disabled family members (Kirby et al., 2015; Manthorpe et al., 2015). In families, caregiver roles can include grandparents and siblings, as well as parents or any family member able to assist (Burke et al., 2015; Chadwick et al., 2013; Greenberg et al., 1999; Rossetti & Hall, 2015). Carers can also suffer from medical and emotional issues and stressors, related to caring for family with intellectual disabilities abusing alcohol, and might be seen as enablers or part of the problem within the family unit (Desia, Shinde, & Mobite, 2014; Didden, 2017; Irazabal et al., 2016; Kirby et al., 2015; Manthorpe et al., 2015; McDonald, 2013; Robinson et al., 2016). As caregivers become the primary support systems and advocators for family members with intellectual disabilities and alcohol abuse issues, supportive services might be necessary for the well-being of the family as a whole (Irazabal et al., 2016; Manthorpe et al., 2015; McMorris et al., 2013; Williamson & Perkins, 2014).

Summary and Conclusions

Chapter two includes a synopsis of (a) literature reviewed journal articles and other materials important to this study, (b) a literature search strategy consisting of researching diverse educational and scholarly internet sites to gather information, and (c) the use of off-campus websites to research historical facts on intellectually disabled, alcohol abuse, and caregivers of intellectually disabled abusing alcohol. A review of peer journals and other empirical literature associated with this dissertation topic, has shed clarity for building and developing a strategic plan for this study while giving a sense of direction to the hermeneutical phenomenological research project (Frivold, Slettbo, &

Dale, 2015; Newman, Cashin, & Waters, 2010; Simpson, 2012; Slayter, 2010, 2016; Slayter & Steenrod, 2009; Wilkinson & McAndrew, 2008). Using a hermeneutical phenomenological study, journal materials mostly qualitative assist with comprehension on designs in relation to sub-sections pertaining to caregivers lived experiences and perceptions on obtaining substance abuse treatment services for family members with intellectual disabilities and abusing alcohol (Manthorpe et al., 2015; Pezzoni & Kouimtsidis, 2015; Williamson & Perkins, 2014; Yoong & Koritsas, 2012; Zakrajsek, Hammel, & Scazzero, 2014). In chapter three, I present how strategies in the methods of hermeneutical phenomenological will assist in implementing this research plan. Also to include, (a) purpose of study, (b) methodology of theory, (c) conceptual framework, (d) research design, (e) methods, (f) mode of inquiry, (g) data collection and analysis, (h) trustworthiness, (i) ethical procedures, and (j) summary.

Chapter 3: Research Method

I conducted a hermeneutical phenomenological study to understand the experiences of caregivers of intellectually disabled family members abusing alcohol and the phenomenon of obtaining services. A hermeneutical phenomenological method of research using structured interviews was an appropriate choice for this study as a way of gathering meaningful and in-depth, descriptive interpretations of the lived experiences of caregivers (Moustakas, 1994). With the use of a hermeneutical phenomenological method, I expanded on prior studies on people with intellectual disabilities abusing alcohol (McGillicuddy, 2006; Moustakas, 1994; Newman et al., 2010; Slayter & Steenrod, 2009). With the exploration of caregivers' role as carers for intellectually disabled family members, the use of hermeneutical phenomenological research opened a dialogue that assisted in gathering data about caregivers lived experiences, including an understanding of the phenomenon of seeking substance abuse treatment services (Frivold et al., 2015; Moustakas, 1994). Philosopher and theorist Heidegger, one of the pioneers of hermeneutics, defined the meanings and understandings of phenomena about human experiences in the world through interpretations (Bloom, 2009; Heinonen, 2015; Moustakas, 1994; Newman et al., 2010). Husserl (1931) focused on phenomenology through descriptive scripts, using a hermeneutical phenomenological approach to develop an in-depth understanding on the topic being studied (Applebaum, 2014; Bloom, 2009; Heinonen, 2015; Iyer, 2013; Moustakas, 1994; Newman et al., 2010).

Caregivers of intellectually disabled alcohol abusers were selected as the population because they are the primary carers of family members with intellectual disabilities (Gibbs et al., 2008; Werner & Shulman, 2015). I located eight caregiver interviewees from one organization providing services to individuals with intellectual disabilities and family members in the Northeastern United States. I interviewed the eight participants to the point of theoretical saturation. The use of a hermeneutical phenomenological study facilitated the exploration of caregivers' ontological experiences associated with caring for family members with intellectual disabilities who were abusing alcohol, including the phenomenon of searching for substance abuse treatment services for intellectually disabled alcohol abusers (McMorris et al., 2013; Ouellette-Kuntz et al., 2014). Study results included addressing caregiver experiences and perceptions in seeking and obtaining services, which may provide information to supportive services, stakeholders, and organization staffers who assist the intellectually disabled and caregiver needs. This chapter includes a review of the research design and rationale, research questions, methodology of theory, conceptual framework, research design, methods, mode of inquiry, data collection and analysis, trustworthiness, ethical procedures, and a summary of the chapter.

Research Design and Rationale

I conducted face-to-face interviews using open-ended questions and audio-recorded the sessions for accuracy of informant data (Miller, 2017; Wolgemuth et al., 2015). I used pre-developed questions as a way of encouraging informants to provide meaningful, informative data through the process of interactive communication (Houghton, Casey, Shaw, & Murphy, 2013; Laverty, 2003; Miller, 2017; Moustakas, 1994). The questioning format was informal and interactive as a means of building trust in the researcher-participant relationship and to assist participants with providing in-depth, comprehensive dialogue while encouraging truthful answers to questions (Miller, 2017; Moustakas, 1994; Price, 2002).

Research Questions

The structured research questions central to this study were as follows:

RQ1: How do caregivers experience seeking substance abuse treatment services for family members with intellectual disabilities abusing alcohol?

RQ2: How do caregivers interpret experiences related to seeking substance abuse treatment services?

Follow-up questions are included in Appendix B. The two research questions provided informants with an outlet of expression and assisted with asking follow-up questions while gathering deeply imbedded, knowledge-rich data (Miller, 2017; Mustakas, 1994). Questions allowed for catharsis as informants released experiences and ideations of caring for intellectually disabled family members, which proved beneficial to any concerns of interpretation of information within the study (Salamone-Violi, Chur-Hansen, & Winefield, 2017). Observations during interviews included checking the informants' comfort with questions, as I was aware that emotional risks could occur, and to ensure I was not causing harm (Miller, 2017; Sim, 2010). I audio-recorded the interviews to assist with the accuracy of the contextual language of informants, and I reviewed the transcripts of the recorded conversations upon completion of the study to ensure accuracy (Moustakas, 1994). Three of the eight informants expressed feeling uncomfortable with tape recording but chose to participate. Instead of audio-recording the interviews of these three participants, I handwrote their answers and reviewed them for accuracy at the end of each answer.

Methodology of Theory

Theorists Heidegger, Husserl, and Ricoeur asserted that hermeneutical phenomenological study depends on the logic that emerges from participants' experiences while extending knowledge from those experiences or concepts (Bendassolli, 2013; Iyer, 2013; Moustakas, 1994; Thackeray & Eatough, 2015; Tomkins & Eatough, 2013). Through methodology, the approach of inquiry, questions of study, development of an appropriate framework, the gathering, analyzing, and storing data, patterns, categories, and themes evolved (Bendassolli, 2013; Ghasemi, Taghinejad, Kabiri, & Imani, 2011; Moustakas, 1994). The methods section of this chapter includes details about how I conducted the research. When conducting a research study, one must have a conceptual idea of the steps needed to implement the research project in an understandable and orderly manner and present clear results (Moustakas, 1994; Petrova, Dewing, & Camilleri, 2016). Using a structured strategy assisted me in achieving a natural flow to the study (Moustakas, 1994).

Using a hermeneutical phenomenological approach allowed for interpreting the lived experiences of caregivers obtaining services for intellectually disabled family members abusing alcohol (Corby, Taggart, & Cousins, 2015; Ghasemi et al., 2011; Moustakas, 1994; Newman et al., 2010; Nielson & Angel, 2016). Through hermeneutical phenomenological research and the use of Heidegger's interpretative structured interview, caregivers' views of caring for an intellectually disabled family member while seeking services were revealed (De Baets et al., 2017; Heinonen, 2015; Moustakas, 1994). This hermeneutical phenomenological research method allowed for intimacy during data collection. The face-to-face format of the interviews enabled me to observe the participants for emotions as a catharsis of suppressive attachment as memories emerged (Moustakas, 1994; Newman et al., 2010). I used a modified van Kaam's method for data analysis of the contextual data, or the interpretative language of a caregiver's lived experiences (Ghasemi et al., 2011; Moustakas, 1994). The conceptual framework used in this study included two theories—family stress and caring.

Conceptual Framework

I used a combination of family stress and caring theories as the conceptual interpretive hermeneutical phenomenological framework to investigate the lived experiences of caregivers seeking substance abuse treatment services for family members with intellectual disabilities abusing alcohol. Using a hermeneutical phenomenological approach opened the perspective lens leading to the discovery of characteristics, patterns, and themes through descriptive texts (Cara, 2003; Moustakas, 1994; Sloan & Bowe, 2014; von Krogh & Naden, 2011; Wagner, 2010). The integration of the two theories was useful in gathering descriptive interpretations and gaining an understanding of the family dynamics of caregivers, the caring process, and obtaining services (Cara, 2003; Henry, Morris, & Harrist, 2015; Martins & Cuoto, 2014).

Family stress theory. Hill's (1949) family stress theory is based on family crises, resilience, coping, and adjustment, which includes the premise that sudden stressors can push families into crises (Patterson, 2002; Rosino, 2016; Salovitas, Italinna, & Leinonen, 2003; Sullivan, 2015). Hill (1945) initiated this theory while studying families during WWII and the Great Depression. The goal was to understand the effects on family members when fathers went to and returned from the war, and why some families strived to move forward while others succumbed to the stress of loss and separation (Hill, 1945, 1947). Hill was also interested in understanding how people coped with the stressors of loss of employment and poverty during the Depression of 1929 (Hill, 1945; Rosino, 2016). Hill (1945) focused on family units, stressors, resources, and varying abilities to cope with sudden changes (Aldous & Hill, 1969; Hill, 1945, 1947, 1981). Stressors can also lead to an increase in emotional, physical, relational, marital, financial, and occupational pressures during critical states, affecting family members (Hill, 1945, 1947, 1981; Martins & Cuoto, 2014; McDonald, 2001; Patterson, 2002, Sullivan, 2015). Hill, credited for developing the ABCX Model of Family Stress Theory (see Appendix A), held four assumptions which he believed led to crisis: (a) unexpected events perceived as stressful, (b) family stress within unit, (c) the perception of stressor and family's ability to cope, and (d) outcome or family crisis (Hill, 1945; McDonald, 2001). McCubbin and Patterson (1983) expanded on Hill's ABCX model with a resilience model of stress, adjustment, and adaptation with four additional propositions: (a) added or overload of burdens, (b) family strength and cohesiveness, (c) family resources, and (d) the family's outlook on the situation (Henry et al., 2015; Saloviita et al., 2003; Sullivan, 2015). Family stress theorists seek to examine why some families are more resilient to crisis and can adapt while other families less able to cope, sink inward (Henry et al., 2015; Hill, 1945, 1947; Sullivan, 2015).

Family stress might become thematic in the lives of caregivers when attempting to care for and or seek services for intellectually disabled family member's needs (Arnold, Heller, & Kramer, 2012; Henry et al., 2015; Sullivan, 2015). As each member of the family unit has an assigned role, one or all might be recruited to take on responsibilities, not by choice, such as siblings, grandparents, or other relatives (Burke et al., 2015; Chadwick et al., 2013). Siblings within the family circle often become secondary carers inside and outside of the home and experience some of the same or similar stressors as parents (Arnold et al., 2012; Greenberg et al., 1999; Rossetti & Hall, 2015). Families raising cognitively impaired children might also feel the negative stressors of stigmatization in attitudes of stereotyping, discrimination, inequality, and biases through social settings (e.g., school, church, social events) outside the home (Didden, 2017; Mak & Cheung, 2008; Werner & Shulman, 2015). In addition, families of intellectually disabled alcohol abusers might experience stigmatization of being neglectful, as the family is purported to be the primary protector (McDonald, 2013; Quintero, 2011; Thorkildsen et al., 2015; Werner & Shulman, 2015). There is also stigma attached to the intellectually disabled and alcohol abuse because each lies outside of societal norms (Thorkildsen et al., 2015; Werner & Shulman, 2015). Furthermore, stigma can be an obstacle as to whether caregivers seek service appropriate to the needs of intellectually disabled family members abusing alcohol (Cantwell et al., 2015; Slayter, 2016; Spassiani et al., 2017; Werner & Shulman, 2015). As a licensed social worker in the field of substance abuse and mental health, I have found no specialized programs for the intellectually disabled in the Northeastern region of the United States. Not aligning with the general population for substance abuse treatment, behavioral health staff often merge the intellectually disabled into programs developed for mentally ill substance abusers and treated as such, including medication (Slayter, 2016; Spassiani et al., 2017; Stein, 2009). Mental illness and intellectual disability are distinct disorders and meet different criteria as presented in the DSM-5 (APA, 2013). Individuals with intellectual disabilities do not respond to medication intended for people with mental illness because of cognitive limitations and or impairment unless there is co-morbidity (APA, 2013).

Caregivers can also experience a lack of cohesiveness within the family unit, which can create additional problems in relational areas of the caregivers' lives (Hill, 1981; McCubbin, McCubbin, Zhang, Kehl, & Strom, 2013; Mitchell, Szczerepas, & Hauser-Cram, 2016). With daily attempts to maintain equilibrium within the family unit, carers can be exposed to an increase in stress and stressors (Hill, 1945, 1947, 1981; Rogers, 2015). In trying to keep the family intact while seeking treatment for intellectually disabled family members, caregivers might also experience mental and emotional stressors such as depression and anxiety (Cantwell et al., 2015; Manthorpe et al., 2015; Werner & Shulman, 2015).

Caring theory. The concept of Watson's caring theory, originating in the 1970s and published in 1988, is a set of standards developed to assist nurses in providing care to patients (Brewer & Watson, 2015; Watson, 2006). Watson and a group of nurses and students developed guidelines to assist nurses on how to provide humane services of care while developing sustainable and trusting relationships with recipients (Lachman, 2012; Larson, 2010; Ranheim et al., 2011; Turkel, Watson, & Giovannoni, 2018; Watson, 2006). Watson believed that due to a shortage of nurses, burnout, and economics, there was less focus on caring and the ability to continue to perform duties with kindness and compassion for the overall well-being of patients (Brewer & Watson, 2015; Clarke, Watson, & Brewer, 2009; Turkel et al., 2018; Watson, 2006). Watson denoted the importance for nurses to develop an interpersonal relationship of care with patients and developed a theory of caring (Brewer & Watson, 2015; Watson, 2006). The theory of caring includes:

- Humanistic – altruistic values – the practice of loving-kindness and equanimity with self/other;
- Being authentically present – enabling faith – hope;
- Being sensitive to self/others by cultivating on spiritual practices – beyond ego – to transpersonal presence;
- Developing and sustaining loving, trusting – caring relationships;
- Allowing for expression of positive and negative feelings – authentically listening to another person’s story;
- Creatively problem – solving – solution – seeking’ through the caring process; for use of self – use of all ways of knowing;
- Engaging in transpersonal teaching-learning within the context of a caring relationship; staying within others frame of reference – shift towards coaching;
- Creating a healing environment at all levels; subtle environment for energetic authentic caring presence;

- Reverentially assisting with basic needs as sacred acts – touching mind body spirit of other; sustaining human dignity;
- Opening to spiritual, mystery, unknown – allowing for miracles (Brewer & Watson, 2015).

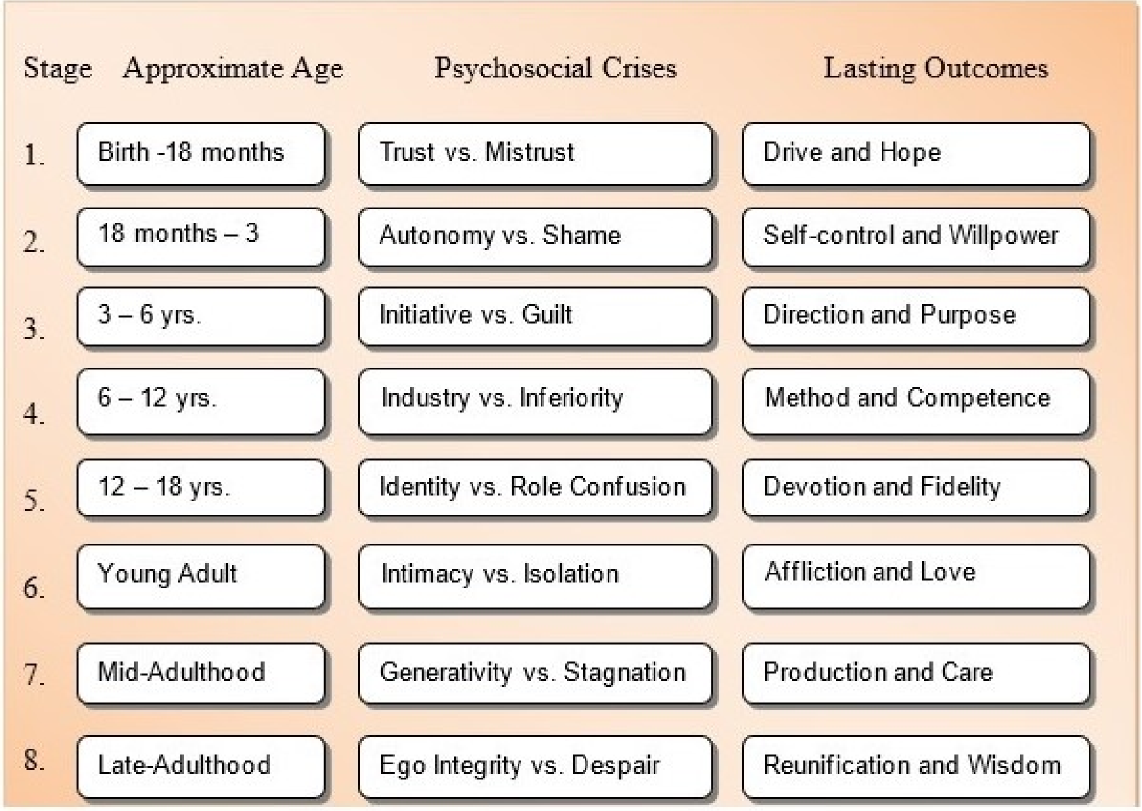
Larson (2010) conceptualized that the nature of the care provided can also affect how caregivers perceive their roles and responsibilities to loved ones. While caregivers attempt to develop a clear understanding of the life skills and limitations of intellectually disabled family members, learning coping skills might help carers to remain loving and compassionate (Robinson et al., 2016; Rossetti & Hall, 2015; Watson. 2006). Siblings and other extended family members might also assume responsibility for the well-being of the family (Coyle, Kramer, & Mutchler, 2014; Robinson et al., 2016; Rossetti & Hall, 2015). Role reversal can increase for siblings of intellectually disabled family members as parents age and are no longer able to provide care (Coyle et al., 2014; Rossetti & Hall, 2015). Siblings make up at least 75% of carers (Rossetti & Hall, 2015) who assume the role of caretaker for the ongoing needs of intellectually disabled loved ones when parents are no longer able to provide care (Coyle et al., 2014; Robinson et al., 2016). Caregivers also make sacrifices while caring for addicted family members, including self-care, employment, understanding addiction, and marital problems, which might have psychological, emotional, or social effects on carers and the family unit as a whole (Brewer & Watson, 2015; Hill, 1945; McCubbin et al., 2013; Mitchell et al., 2016; Thorkildsen et al., 2015). Therefore, an amalgamation of family stress and care theories have provided an in-depth understanding of caregivers' perceptions on the caring process through an examination of collected data gathered through strategically formulated research questions (Brewer & Watson, 2015; Henry et al., 2015; Hill, 1945, 1947, 1981; Moustakas, 1994; Turkel et al., 2018; von Krogh & Naden, 2011; Watson, 2006).

Integration of theories. Since many caregivers provide the same services to family members within the home, as nurses in hospital settings, Watson's caring theory was suitable for this study. The theory of caring is that caregivers need to adapt to the relative ideation of how to provide care with love and compassion within the interpersonal relationship (Brewer & Watson, 2015; Cara, 2003; Larson, 2010; Ozan et al., 2015; Thorkildsen et al., 2015; Wynaden, 2007). Hill's family stress theory assisted in understanding how the well-being of the family unit as a whole is essential to dynamics of caregivers as each member of the family might experience the caring of intellectually disabled family members at some point in their life (Hill, 1945; McCubbin et al., 2013; Mitchell et al., 2016). Using family stress and caring theories provided an understanding of how perceptions differed considerably as some family carers especially under age 30 viewed the situation as positive, while those over age 30 perceived the same as negative (Burke et al., 2015; Hill, 1945, 1981; McCubbin et al., 2013; Mitchell et al., 2015; Watson & Foster, 2003). The use of family stress and caring theories as the conceptual framework for this study provided an in-depth understanding of how family systems seek homeostasis (Hill, 1945; Watson, 2006).

Ontological conceptual viewpoint. Using a hermeneutical phenomenological method of study tied in closely with the constructs of how I understand and perceive lived experiences internally and externally in the environs and the world. I tend to resonate with a combination of the constructivism of Vygotsky and Erikson’s psychosocial development, both of which have guided in areas of social work with clients/patients and in personal life with family and others (Erikson, 1993; Ertmer & Newby, 2013; Vygotsky, 1978). I am an observer. I want to know how people socialize, how people understand each other, their environment, and the world. I have always had a natural curiosity about others’ perceptions of lived experiences as I tend to see the world differently than family, friends, coworkers, and associates. I am eclectic in thinking and believe that is why I perceive the world through multiple lenses. The combination of descriptive experience has allowed for an in-depth understanding of other's perspectives on perceptive ideations attuned to phenomena of lived experiences. In reviewing the materials on Erikson and Vygotsky, similarities were that individuals at birth possess the necessities for intellectual growth and that they develop an improved conceptual knowledge through curiosity and social innovation (Erikson, 1963; Kretchmar, 2017; Louis, 2009; Vygotsky, 1978). Erikson and Vygotsky also posited that children develop knowledge through daily interactions in groups of commonality and diversity, within their environments, stressing the importance of communication within primary groups (Alves, 2014; Erikson, 1950, 1963, 1993; Vygotsky, 1978, 2017).

Erikson and Vygotsky differed on some theoretical views. Erikson used the psychosocial theory to enhance his understanding of childhood development and the connection to their social environment and would eventually develop a theory based on the lifespan of humans from birth to death (Erikson, 1963). Erikson, like other scholars of his day, closely watched how the world was changing, and through those changes, he observed how people, especially children were affected by those changes (Erikson, 1950, 1963, 1993). In attempting to have an improved understanding of human development, Erikson devised the theory that consisted of eight stages, and that humans, starting at birth had to visit and complete all eight stages of development in order to fully mature into adulthood (Erikson, 1963). Erikson's belief was that if person(s) became stagnant or failed to complete a stage, then he/she would have to revisit and master the incomplete stage to attain full maturity, whereas Vygotsky (1935) put the importance of learning in the cultural aspect, social factors, and language in the cognitive development of children (Erikson, 1993; Kretchmar, 2017; McLeod, 2007; Vygotsky, 1978).

Erikson also believed that personality developed through psychosocial crises (see Figure 1.) during the different stages and that relationship with others influences growth to the next stage using relationships of significance as the catalyst (Erikson, 1950, 1991). The theory elements of Erikson (1993) are as follows:



Stage	Approximate Age	Psychosocial Crises	Lasting Outcomes
1.	Birth -18 months	Trust vs. Mistrust	Drive and Hope
2.	18 months – 3	Autonomy vs. Shame	Self-control and Willpower
3.	3 – 6 yrs.	Initiative vs. Guilt	Direction and Purpose
4.	6 – 12 yrs.	Industry vs. Inferiority	Method and Competence
5.	12 – 18 yrs.	Identity vs. Role Confusion	Devotion and Fidelity
6.	Young Adult	Intimacy vs. Isolation	Affliction and Love
7.	Mid-Adulthood	Generativity vs. Stagnation	Production and Care
8.	Late-Adulthood	Ego Integrity vs. Despair	Reunification and Wisdom

Figure 1. Erik Erikson’s Theoretical Elements of Eight Ages of Man Erik Erikson’s (1993). *Childhood and society*. New York, NY: Norton. “Reprinted from *Childhood and Society* by Erik H. Erikson. Copyright © 1950, 1963 by W.W. Norton & Company, Inc. Used with permission of the publisher, W. W. Norton & Company, Inc. All rights reserved.”

Vygotsky, however, argued that infants held the information for cognitive development. His belief was that through relationships, and the assistance of someone or something with higher intelligence was crucial to development (Alves, 2014; Vygotsky, 1978). Vygotsky held two ideations, (a) More Knowledgeable Other (MKO) and (b) the Zone of Proximal Development (ZPD), believing that individuals seek to learn from those with higher levels of knowledge, whether human or technological (Louis, 2009; Lourenco, 2012; McLeod, 2007; van Geert, 1998, 2000; Vygotsky, 1978, 2017).

The line between Erikson and Vygotsky is thin in relation to how I interpret lived experiences in the world. I believe children learn what they live and try to make sense of situations beyond their comprehensive knowledge. I also find that Erikson’s stages of development make sense to a degree because as children move from the home into society, their scope of experiences increases, and that is when choices, considerations, and consequences of the phenomena begin to modulate the development process (Erikson, 1950). These combined theories comprise my ontology and, as sole researcher-and-analyst for this study, this framing was the filter of how I made sense of resulting data from this study.

For this hermeneutical phenomenological study, the use of family stress and caring theories appeared closely attuned with the constructivist ideations of how experience and perception might influence perspectives in the lives of caregivers caring for and seeking services for intellectually disabled family members abusing alcohol. The significant subordinates of the methods section to follow are (a) research design, (b) methods, (c) mode of inquiry, (d) data collection and analysis, (e) trustworthiness, (f) ethical procedures and (g) summary.

Research Design

In this hermeneutical phenomenological study, the focus was on data acquired through interviews of informants about their perceptions of the empirical world of obtaining substance abuse treatment for intellectually disabled family members abusing alcohol (Grinnell, 1997; Taylor, Bogdan, & DeVault, 2015). The purpose of this hermeneutical phenomenological method was to gain an understanding of caregivers’ perceptive knowledge from their perspective ontology of lived experiences and meanings attached to the phenomenon of the process of seeking treatment services (Alase, 2017; Moustakas, 1994; Taylor et al., 2015). The strategy of inquiry was interviewing (Jones et al., 2015; Martinsson, Fagerberg, Lindholm, & Wiklund-Gustin, 2012; Moustakas, 1994; Taylor et al., 2015). The steps I used in the methods section were (a) design, (b) research questions, and (c) researcher role.

A hermeneutical phenomenological method design was the approach to explore the caregivers' lived experiences of obtaining substance abuse treatment services for the intellectually disabled family member(s) abusing alcohol (Chou & Kroger, 2014; Williamson & Perkins, 2014). I used a criterion and purposive sampling approach as a means of finding the participatory experiences necessary for this study (Moustakas, 1994). I interviewed eight caregivers to the threshold of theoretical saturation using open-ended questions as a means of obtaining in-depth descriptive information (Gentles, Charles, Ploeg, & McKibbon, 2015; Moustakas, 1994; Sloan & Bowe, 2014). I used van Kaam's method of analysis to analyze data for exploration and extraction of characteristics, patterns, and grouping of themes (Moustakas, 1994). Once intensive manual coding was completed, I entered contextual informational data into the NVivo software program as a tool to further organize, categorize, analyze, and process data, and for storage (Azeem & Salfi, 2012; Freitas et al., 2017; Ryan, 2006; Yakut Cayir & Saritas, 2017).

Role of the Researcher

For this hermeneutical phenomenological method of research study, I was the instrument of inquiry (Chenail, 2012; Moustakas, 1994). As a researcher in this hermeneutical phenomenological study, I depended on logic emerging from informants' lived experiences while extending knowledge from those experiences or concepts (Bendassolli, 2013; Peredaryenko & Krauss, 2013). As the instrument of research in this study, I was the primary tool used to gather, interpret, and analyze data obtained through interviews and held the role of interpreter of the descriptive information obtained through open-ended questions (Chenail, 2012; Moustakas, 1994). Because hermeneutical phenomenological methods require researchers to act as the research conduit, I attempted to set aside personal opinions and manage biases while focusing on emerging truths and ideations that surfaced through the perspective lens of informants (Chan, Fung, & Chien, 2013; Mustakas, 1994). Husserl described Epoche as making an effort to abstain from preconceived ideations, personal experiences, and prejudices while presenting a clean slate (Butler, 2016; Lindseth & Norberg, 2004; McManus Holroyd, 2007; Moustakas, 1994). As a researcher with prior knowledge and experience related to the topic of study, the challenge was to refrain from allowing personal awareness to color my perspectives and to manage any biases during the study (Lachman, 2012; Sloan & Bowe, 2014). With this knowledge in mind, I remained focused on the interview process while allowing the unknown to emerge (Moustakas, 1994; Peredaryenko & Krauss, 2013). In attempts to further address this issue, I yielded to the fact that with prior experience, self-monitoring of personal thoughts and opinions was necessary to maintain the integrity of the study during interviews and data analysis. I did, however, challenge the efforts to discover the nuclei related to each informant's selective comprehensive understanding of phenomenon through the prospective scopes of his/her perceptive ontologies related to obtaining treatment services for intellectually disabled alcohol-abusing family members (Bendassolli, 2013; Muto, 2011; Peredaryenko & Krauss, 2013).

Having had the experience of being the caregiver of six intellectually disabled siblings and living in a family of alcohol users and abusers including me, I related personal experiences to the study, which motivated passion towards this topic (Peredaryenko & Krauss, 2013). To be an effective therapist in the field of substance abuse, I have had to learn to as Charles Dickens wrote in The Haunted Man and the Ghost’s Bargain, (1848, version) from his series of novellas and as suggested in AA, to keep my memory green, and to continue with self-care. I also learned to remove myself from the therapeutic process and focus on client needs. With many years of sobriety, separating experience from the process has become easier. As a licensed social worker, I have tried to maintain impartiality while still assisting many with whom I shared background experiences. The shared experiences have not hindered but provided clarity and helped in developing a deep understanding of others, including family members’ lived experiences to phenomena while being subjective and objective (Peredaryenko & Krauss, 2013). Passion has turned to action as I seek to understand how other caregivers experience the phenomenon of obtaining treatment services for intellectually disabled family members abusing alcohol.

With knowledge and experience about this topic, I believed that using a hermeneutical phenomenological method of interviews would extract meaningful insights into informants' ontological reasoning (Moustakas, 1994). In addition, using a combined conceptual framework of family stress and caring theories would provide an in-depth and comprehensive understanding of how other caregivers perceive the process of obtaining treatment services for intellectually disabled family members abusing alcohol (Hill, 1945; Muto, 2011; Peredaryenko & Krauss, 2013; Watson, 2006). The goal was to provide informants the opportunity to freely express their thoughts and feelings while giving voice to their experiences to the phenomenon of the study. In doing so, I used the informant-centered instrument process with the full knowledge that personal experiences might be similar, but with the understanding that shared experiences might align or diverge at some point within the study (Moustakas, 1994). With expectations to be open to and to expect the unexpected approach while using the informant centered instrument, and based on informants' lived experiences new information surfaced, giving profound meaning to the phenomenon of study (Moustakas, 1994; Peredaryenko & Krauss, 2013).

Methodology

For this hermeneutical phenomenological study, the methods section provides in detail the rationale for sampling choice, size of samples, and recruitment. Given the nature of this study and the scope of empirical data related to the integration of caregivers, intellectually disabled, alcohol abuse, and substance treatment a careful selection of informants could benefit caregivers, intellectually disabled abusing alcohol, and stakeholders. With a comprehensive understanding of the specific needs of intellectually disabled who abuse alcohol and the caregivers who seek treatment services in the community, a dialogue could provide a positive step to align programs and services to the cognitively impaired. This section includes (a) participant sample, (b) sampling size, and (c) process of recruitment.

Participant Selection

Sampling was predetermined using purposive and criterion to meet homogeneous specificity with similar characteristics or traits based on the nature of this study and research questions (Etikan, Musa, & Alassim, 2016; Gentles et al., 2015; Kvamme et al., 2015; Moustakas, 1994; Suri, 2011). Purposive and criterion sampling selections were relevant to this study because the research was knowledge-driven due to the experiences of informants (Etikan et al., 2016; Kvamme, et al., 2015; Laverty, 2003). Identifying and selection of individuals who had knowledge and experience of the phenomenon of obtaining treatment services provided information-rich, in-depth data, and maximized efficiency and validity (Cleary et al., 2014; Gentles et al., 2015; Kvamme et al., 2015).

The population of study consisted of (a) eight caregivers to point of saturation, (b) male and female with the exclusion of pregnant women as a precaution for unexpected health reasons, and, (c) respondents were over age 18 and under age 70 who provide care while seeking to obtain treatment services for intellectually disabled family members abusing alcohol. Sampling decisions were central to the synthesis of this research study, and informants were chosen to address what and how of the purpose of inquiry (Cleary et al., 2014; Gentles et al., 2015; Moustakas, 1994; Suri, 2011). The criterion for selection in this study was that informant samples had experience in the phenomenon of caring for and seeking substance abuse treatment services for intellectually disabled family members abusing alcohol (Lindseth & Norberg, 2004; Nielsen &Angel, 2016).

Sample size. The numbers of informant participants were eight caregivers to the point of theoretical saturation (Etikan et al., 2016; Moustakas, 1994). Sampling size within the study was critical to the mission of research as the smaller sampling afforded an increase of concentration on the informant's contextual dialogue for interpretative analysis (Cleary et al., 2014; Gentles et al., 2015; Laverty, 2003; McManus Holroyd, 2007). For this hermeneutical phenomenological study, a smaller sampling size promoted validity and credibility as the selection appeared appropriate and necessary to the rationale of this study (Cleary et al., 2014; Gentles et al., 2015; Palinkas et al., 2015).

Process of recruitment. Recruitment of sampling informants was from one of two chosen organizations located in an urban setting in the Northeastern United States that provides services to individuals with intellectual disabilities and their families. The first step was approval from the International Review Board (IRB) at Walden University to proceed with the study (see Appendix F). The next step was phone contact with email follow-up (see Appendix C) to the board of directors/director of Organization A and Organization B. I omitted Organization B from the study due to the difficulty of direction in seeking cooperation. I then provided (a) a summary of the research study, (b) reasons for the study, (c) request of engagement and, (d) the cooperation of organizational staff to post invite with contact information for potential informants that met criteria (Moustakas, 1994). A copy of the Request Letter from Site to Conduct Study (see Appendix D), was emailed for review with a follow-up call to confirm receipt of letter and to discuss moving forward with the study with the added permission to recruit potential participants who responded through the aid of Organization A’s posting of study to website.

I provided potential informants a two-week timeframe for response, with follow-up phone calls as a means of building rapport while keeping the study moving in a positive direction. With responses from potential informants who met criteria of inclusion (see Appendix E) of (a) must be over age 18, (b) assumed the role as caregiver, (c) family member diagnosed with intellectual disabilities, and, (d) having some experience in seeking substance abuse treatment services for a family member in community? With criteria met, date and time were set. I then moved into the next phase of the study of addressing mode of inquiry.

Instrumentation

For this hermeneutical phenomenological study, interviews were the method of obtaining data from informants, and I was the instrument of obtaining information with the use of an audio-recorder for accuracy purposes. Interviews were informal and allowed for interactive dialogue during the interview process, which assisted in building trust with informants in a relaxed atmosphere of their choosing (Moustakas, 1994). Included in this section is a descriptive explanation of the researcher’s instrumental role within the study (Moustakas, 1994). This section contains the interview and informed consent.

The method of inquiry for this hermeneutical phenomenological study was a structured interview of eight informants with the intention to gather data about caregivers’ experiences in obtaining substance abuse treatment services for intellectually disabled family members abusing alcohol. I used questions beneficial to the informal atmosphere of study as a means of engaging informants while building trust to encourage participation in providing truthful answers (DuBose, 2015; Miller, 2017; Moustakas, 1994). Interview questions for this research study were central to reaching the core understanding of caregivers' perceptions of caring for family members with intellectual disabilities abusing alcohol, and the phenomenon of obtaining substance abuse treatment services (Irazabal et al., 2016; Manthorpe et al., 2015; Salamone-Violi et al., 2017).

With approval from the organization of choice to continue, I presented the informed consent at the time of interview to potential informants to (a) give brief description, (b) answer questions, (c) and to acknowledge willingness to participate. When obtaining informed consent, the importance was that individuals taking part in the study had a comprehensive knowledge of the procedure, their role, and participation in the study (Corby et al., 2015; Fisher, Cea, Davidson & Fried, 2006; Moustakas, 1994). I explained the purpose of the study, the possible harm, and benefits, and that opting out at any time during the study was permissible and without consequence (Oye, Sorensen, & Glasdam, 2016; Sim, 2010). After reviewing and signing of consent forms, I started interviews.

Data Collection and Analysis

For this hermeneutical phenomenological study, the importance was that informants of choice had firsthand knowledge and experience of the phenomenon of obtaining substance abuse treatment for intellectually disabled family members. Using this hermeneutical phenomenological research, I focused on the ontological ideations of caregivers' perceptive ideology to their lived experience in obtaining treatment services for intellectually disabled family members abusing alcohol. For the purpose of this study, I used interviews as the method of inquiry to gather detailed-rich data. Interviews appeared an appropriate mode for data collection, which unearthed and presented in-depth data of informants' connections to lived experiences while opening avenues for having their voices heard (Chadwick et al., 2013; Moustakas, 1994). I used an audio tape recorder as a means of promoting the accuracy of informants' authentic responses (Chadwick et al., 2013; Moustakas, 1994). This section includes data collection and data analysis.

Data Collection

The first step was to set a timeframe for data collection. I presented an estimation of two to four weeks of interviews of potential informants. However, because of the nature of the study and posting to the organization's website, responses lasted over an eight-week period. As each potential informant contacted me via telephone, I (a) initiated a brief screening for criteria, (b) set a calendar date for interview, (c) informed that interview session would be approximately one hour, and, (d) informed of the option to opt-out of study at any time without question or consequence (Moustakas, 1994; Oye et al., 2016). Interview sessions took place in settings of informant's choice in consideration of comfort and privacy during the interview.

Data Analysis

The first strategy in analyzing the data began with the preparation and organization of raw data with a manual word-by-word, line by line examination using descriptive, coding, categorical aggregation, and direct interpretation of information gathered during interviews where categories, patterns, and themes started to emerge (Moustakas, 1994; Yakut Cayir & Saritas, 2017). For this hermeneutical phenomenological study, Moustakas' (1994) modified version of van Kaam's method of analysis seemed appropriate to explore the data. With the use of van Kaam's method, I began the process of breakdown with hand-coding for thematic patterns (Moustakas, 1994; Ryan, 2006; Yakut Cayir & Saritas, 2017). The elements of van Kaam's method of analysis (Moustakas, 1994) are as follows:

1. Listing and preliminary grouping – The raw data provided by the informant as deemed important for analysis.
2. Reduction and elimination – Informant data were extracted, labeled, and tested for experiences that met the phenomenal experience of study while keeping in compliance with the information provided by an informant?
3. Clustering and thematizing invariant constituents – Clustering the unchanged elements into themes and labels, which was the themed nucleus of the experience.
4. Then a final identification and validation of the invariant constituents through the application, checking the consistency of invariant elements, themes, and compatibility to the informant's described experience?
5. Once the analysis was complete, a Textural-Structural Description of the essence of the study to include themes, meanings, and experiences will be shared with informants for accuracy.

6. I constructed an Individual Structural Description of experience based on each informant’s textural description and imaginative variation.
7. I developed constructs for each research informant as Textural-Structured Description of the meanings and essences of experience incorporating the invariant constituents and themes.

I then transferred coded information to the Nvivo software program for (a) re-organization of codes, (b) further processing of analysis, (c) categorization, and, (d) storage of contextual descriptive data (Freitas et al., 2017; Ryan, 2006; Yakut Cayir & Saritas, 2017).

Issues of Trustworthiness

The quality of confidence lies in the methods used, gathered data, interpretations, and rigor of study to assist in the development and movement of trustworthiness within the research procedure (Connelly, 2016; Hoffman, 2010; Moustakas, 1994). Before beginning this hermeneutical phenomenological study, I set in place procedures and protocols to promote trustworthiness as imposed by the nature and methodology used in the study (Connelly, 2016; Moustakas, 1994; Solomon & Amankwaa, 2016). Trustworthiness within this research process consisted of protocol axioms of four areas to include (a) credibility, (b) dependability, (c) transferability, and (d) confirmability (Houghton et al., 2013; Moustakas, 1994; Solomon & Amankwaa, 2016).

Credibility, analogous to internal validity, displayed the confidence, authenticity, and believability of findings in the studied data and through the interpretative assessment of information gathered and presented as informant's authentic voice (Connelly, 2016;

Houghton et al., 2013; Morse, 2015; Schwandt, Lincoln, & Guba, 2007; Solomon & Amankwaa, 2016). Since credibility was present, the findings reflected the views, interpretations, and truths of informant’s data by me the researcher (Cope, 2014; Hoffman, 2010; Solomon & Amankwaa, 2016). Dependability, comparable to reliability, referred to the stability of the data on a continuum within and throughout the study, and I expect should replicate under similar conditions and with similar participants (Connelly, 2016; Cope, 2014; Houghton et al., 2013). Transferability, akin to external validity, lent credence that findings could apply to other groups or settings where others could identify results to their own experiences (Connelly, 2016; Cope, 2014; Solomon & Amankwaa, 2016). If readers and non-participants find meaning and identify with the results of this study, then criterion has been achieved and capable of transferability (Connelly, 2016; Cope, 2014). Confirmability likened to objectivity was based on my ability to remain neutral of preconceived ideations, opinions, and biases while focusing solely on data representative of informant's responses (Connelly, 2016; Cope, 2014; Houghton et al., 2013; Morrow, 2005; Moustakas, 1994; Solomon & Amankwaa, 2016). In addition, the inference of confirmability was that the perspective truth lies within the integrity of my ability as a researcher to adequately detail the establishment of interpretations, analysis, and conclusions within the methodological research process (Connelly, 2016; Cope, 2014; Solomon & Amankwaa, 2016).

To promote increased internal validity and trustworthiness in this study, I asked interviewees to check the accuracy of transcripts (Connelly, 2016; Cope, 2014; Morse, 2015; Moustakas, 1994; Schwandt et al., 2004). The use of interviewee transcript audits before data analyses were to provide a summary of themes derived from the interviews (Connelly, 2016; Moustakas, 1994; Morse, 2015; Schwandt et al., 2007; Solomon & Amankwaa, 2016). Because of the ardor I feel for this topic and years of personal and professional experiences with the intellectually disabled, caregiving, and alcohol abuse, I came to the study with personal biases and engaged in the epoche process throughout the study (Butler, 2016; Lindseth & Norberg, 2004; McManus Holroyd, 2007; Moustakas, 1994). I monitored my personal thoughts related to the perception of shared life experiences and attempted to remain neutral so as not to influence interviews, data analysis, and/or outcome of the study (Cope, 2014; Moustakas, 1994).

Ethical Procedures

When using human subjects in research studies, principles of ethics guide researchers within the study while providing clarity of the agreement between researchers and informants on confidentiality, informed consent, and procedure (Moustakas, 1994). As a researcher, licensed social worker, and doctoral student, I looked to address do no harm as I am ethically bound to follow the National Association of Social Workers (NASW, 2008) Code of Ethics. The ethical protocol I adhere to includes confidentiality, anonymity, and informed consent as a part of the overall personal, scholarly, and professional status (NASW, 2008). Social workers held to stringent and specific ethical suggestions of protocol seek to protect and serve individuals from possible harm before, during, and after providing services, while focusing on the societal systems that have a direct effect on individuals and families (NASW, 2008; Wehrmann, 2010). As a doctoral student, I am bound by Walden's IRB Code of Ethics to follow protocol and to ensure the well-being of participant informants to the best of my ability.

Understanding that through the sharing of personal information, the nature of this study, and the hermeneutical phenomenological method chosen, the ethical question of informed consent was on a continuum as memories and emotionality surfaced during the interview process (Moustakas, 1994; Walker, 2007). Emotions were manageable and not in need of further action, and informants were provided with a 24-hour mental health hotline number to address any incurring issues if necessary. To further address such issues, I adhered to IRB and university protocol in the confidentiality process of anonymity used to protect informants within the study (Moustakas, 1994; Petrova et al., 2016; Walker, 2007). To promote such anonymity, I (a) used coded identifiers of informants and organizational names, (b) used privacy envelopes to secure informed consents detailing possible benefits and possible harm, and the right to opt-out without consequences, and (c) transferred informant data and tape-recorded transcripts onto removable disc(s) (Moustakas, 1994; Petrova et al., 2016; Walker, 2007). For added assurance of confidentiality and anonymity, I secured privacy envelops, tape recordings, removable disc(s), and paper materials in a combination locked receptacle, which is stored in a locked cabinet in my home of which only I have access (Moustakas, 1994; Petrova et al., 2016; Walker, 2007). I also reminded informants that all original data would be destroyed by me after a period of five years, but that coded data might be subject to publication through this study without intrusion on confidentiality and or anonymity (Moustakas, 1994; Petrova et al., 2016; Walker, 2007).

Summary

The methods section of this hermeneutical phenomenological study was to inform readers of protocol and to outline the steps I took to conduct this hermeneutical phenomenological research study on the caregiver's lived experiences and perceptive understanding of the phenomenon of obtaining substance abuse treatment services for intellectually disabled family members abusing alcohol. In this section, I explained in detail the process of the hermeneutical phenomenological method and rationale for, (a) design used in the study, (b) reason for study, (c) choice of informant selection, and, (d) recruitment (Moustakas, 1994; Petrova et al., 2016; Walker, 2007). This section also included information about the (a) process used to increase trustworthiness, (b) ethical procedure as an added measure to increase protection of informants, (c) participating organization(s) confidentiality and anonymity, and, (d) included the rationale for using a tape recorder during interviews (Moustakas, 1994; Petrova et al., 2016). Chapter 4 consists of (a) background, (b) research purpose, (c) methodology, (d) research questions, (e) results, and, (f) summary.

Chapter 4: Results

This chapter contains a discussion of the setting, demographics, data collection and analysis, evidence of trustworthiness, results, and a summary of the chapter. With the use of a hermeneutical phenomenological method of study, I explored caregivers' lived experiences, perspectives, and authentic voices to understand the phenomenon of obtaining substance abuse treatment services for intellectually disabled family members abusing alcohol. With the use of hermeneutical phenomenological methods, van Kaam's modified version of analysis was the tool of choice as described by Moustakas (1994). The study consisted of eight caregivers in the Northeastern United States. A hermeneutical phenomenological method of study was used to explore the unique lived experiences of caregivers of intellectually disabled family members abusing alcohol and seeking treatment services.

With the assumption that informants were truthful in responses, the data gathered might increase awareness of stakeholders, human service workers, substance abuse counseling services, and agencies providing services of the specific needs of individuals with intellectual disabilities and their caregivers in local, state, and possibly on a national scale. The method of hermeneutical phenomenology was a directive during the study and in the analysis of the phenomenon. The hermeneutical phenomenological design provided a means to understand the perceptions of lived experiences that caregivers of intellectually disabled family members acquired while seeking substance abuse treatment. Hermeneutical phenomenological method of design also assisted in revealing the similarities in carers' experiences, yet varied resilience of thoughts and behaviors (Henry et al., 2015; Hill, 1945, 1947; Sullivan, 2015). The method also provided insight into an ideology to include co-carers, relationship to individuals receiving care, caregivers' unique, yet not so unique experiences, and many avenues not explored. Using a combined framework of family stress and caring theories opened the perceptive lens that led to the discovery of characteristics, patterns, and themes through informants' descriptive texts (Moustakas, 1994; Sloan & Bowe, 2014). Culture and age may have influenced how caregivers perceived seeking services outside of the family unit.

The research questions in this study were as follows:

RQ1. How do caregivers experience seeking substance abuse treatment services for family members with intellectual disabilities abusing alcohol?

RQ2. How do caregivers interpret experiences related to seeking substance abuse treatment services?

Setting

The settings for interviews were informal and in locations chosen by informants. Two of the interviews were in a diner setting; the environment was loud and with music in the background, which did not appear to be an obstacle as informants were comfortable and the audio recording was clear and precise. A third interview was in a quiet dining area with quiet white noise, which added to the calming setting. I conducted the remaining five interviews in the quiet settings in informant community libraries for comfort, privacy, and confidentiality purposes.

Demographics

The sample was eight voluntary participants living in the Northeastern sector in the United States. Informant ages ranged from 20 to 65. Informants shared their gender, ethnicity/culture, and caregiver relationship to the recipient of care (see Table 1). Socio-economic status was also a factor for all of the participants, as ongoing employment was necessary for the homeostasis of the family unit while acting as a caregiver to family loved ones.

Table 1

*Informant Diversity**

Informant ID	Ethnicity/culture	Relationship	Age
C1	Bi-racial	Cousin (female)	47
C2	African American	Aunt	24
C3	Latino	Father	61
C4	Caucasian	Sister	65
C5	Caucasian	Father	50
C6	Italian	Sister	34
C7	Caucasian	Mother	45
C8	African American	Nephew	25

*Noted by informants.

Data Collection

For this hermeneutical phenomenological study, I collected data from eight caregiver volunteers who met the criteria presented in the Request Letter from Site to Conduct Study (see Appendix D). I posted the letter on the approved organizations' websites where informants read the post and chose to contact me by phone. In phone contact, I provided each participant with a brief summary of the study and set the date and time of interviews. Informants set the choice of locations.

To gather data for this study, I conducted face-to-face interviews with caregivers. Interviews lasted from 45 minutes to an hour. I interviewed informants over a six-week period. I audio-recorded interviews for accuracy, with the recorder visible to informants.

Three of the eight informants wanted to participate but did not want to be recorded. To resolve this sensitive issue, I handwrote responses and made time for review. On completion of interviews, I transcribed data gathered from audio recordings to a Word document and saved transcribed data to a removable disk. The removable disk, informed consents, transcripts, and other materials from the interview process are stored in a locked cabinet, to which only I have access, in my home.

Data Analysis

The first step to analyzing data in this hermeneutical phenomenological study was to prepare raw data for transcription to assist with the exploration of categories, patterns, and the development of themes (Moustakas, 1994). The process of transferring data from recording to a Word document ensued with careful listening to tapes for transcription. After transcription of recorded data into Word, the process of analysis began with the organization of collected data using the modified version of van Kaam's method of analysis for extracting core thematic information (Moustakas, 1994; Sumskis & Moxham, 2017). The design chosen for this study was to encapsulate and explore the essence of the caregivers' lived experiences in their authentic voices as related to the phenomenon of study. I began a preliminary listing of the informant's authentic voice of relevant expression as caregivers of intellectually disabled family members abusing alcohol while seeking treatment services. Reduction and elimination of immaterial data were in the immediate process. I made determinations of the importance of *moment of the experience* and relevance to the underlying understanding, and whether data could be *abstracted* or *labeled*, or needed to be expelled. The steps of analysis were as follows:

1. Listing and grouping ensued with careful and methodic listening to recordings, reading, and review of transcripts, using a line by line, and word by word examination of each informant's data as recorded. In this initial phase of analysis, I treated raw data with equal importance or horizontalization as presented by Moustakas (1994). Hand coding with colored markers was the initial step of documentation in the exploration and extraction of categories, patterns, and eventually themes. I color-coded significant data for thematic integration among the different informants, of similarities, cross-patterns, and correlated thematic expression shared (Moustakas, 1994). Clustering followed with the labeling of themes derived from the linked language of each informant.
2. I accomplished reduction and elimination by extracting thematic data from the research study. Through careful examination of listings and groupings, I looked for confirmation if each met the following criteria: (a) importance to the lived experience to the phenomenon, and (b) if reduction could take place to its latent meaning. The process of elimination of data that did not meet criteria ensued, thus, assisting in the dissembling of invariant constituents for redundancy. For example, *difficulty finding treatment*, *can't help because of intellectual disability*, *I can't help, cannot find services*, and *unable to protect* were a few segments constantly repeated in recordings. After careful evaluation, extraction ensued and overlapping information deemed as not necessary was set aside for further review and examination, while others were eliminated with immediacy. Core information

was then categorized and examined for patterns, and themes as a means of integration of informants’ similarities and differences (Moustakas, 1994).

3. Clustering and thematizing of invariant constituents of the core or essential themes derived from the reduction process and labeled for further examination. Once the theme of shared lived experiences of caregivers was determined, I developed titles for themes of similarities to present the shared authenticity of expression among the informant grouping (see Table 2).
4. The final identification of invariant constituents and themes as described by Moustakas (1994) was the checking of complete recordings of each informant for the following: (a) was the transcription authentic to each informant’s responses?, (b) was there compatibility with an expression of responses?, and, (c) were incompatible data deemed irrelevant deleted? I provided transcripts to informants for examination to verify that I properly captured the informant’s responses in the interview process (Moustakas, 1994). All eight informants provided confirmation that their experiences were accurately presented in the transcripts.

Table 2

Common Core Themes

Core themes	Cluster
Finding substance abuse treatment services	8
Adversity	8
Family history of alcohol use and abuse	6
Extended carers (other than parents)	5
Holistic health of caregivers	8
Guilt, shame	8
Caregiver’s support system	5
Motivation	8
Endurance	8
Resilience, determination	8

Core Theme 1: Finding Substance Abuse Treatment Services

For individuals seeking substance abuse treatment in the general population, choices might be based on many factors including medical, emotional, social, occupational, family, or just wanting sobriety. However, for individuals diagnosed with cognitive limitations and comprehension issues, others might have to intervene. Caregivers in this study are the advocates and seekers of services and for some of the same reasons as individuals’ non-ID; however, as non-ID have the ability to comprehend that health, finances, relationships decline with further use, and individuals diagnosed with intellectual disabilities may not have the capacity to connect issues related to alcohol use. Informants understanding the limitations of intellectual disabled family members abusing alcohol have assumed the responsibility in advocating for substance abuse treatment services. As caregivers expressed difficulty finding services, the supportive language was: C1 “I’ve called many agencies… they can't help because of her intellectual disability…I also reached out to programs treating substance, abuse and refused because of intellectual disability.” C2 “we tried to find basic stuff...we asked questions of the doctor…the doctor prescribed a referral…” C3 “I have received no help… frustrating, frustrating...when you cannot find the right services…very hard to get him services.” C4, “I was told that because of his intellectual disability they do not think that their facility would be able to help him…I asked if they know of any other place, they had no answers…I’ve been calling different places… I just take him to the family doctor for advice.” C5 received, “he is not eligible, or they’re understaffed…cannot meet his needs…could not accommodate.” C6, “we cannot figure out what to do…my mother denied he had a disability…she didn’t want him to feel the stigma of being different…now he’s older with a disability...my mother is deceased.” C7, “I have tried for many years to find treatment services…if one has no intellectual disabilities there are services…there are even services for mental illness…just not for people that have intellectual disabilities.” C8, “my sister…she’s in the medical field, she knows people…it’s like a counseling program…he attends every week to see how he is doing.”

Core Theme 2: Adversity

For caregivers, seeking services seemed to begin with acceptance that loved ones were (a) intellectually disabled, (b) held cognitive limitations, (c) would possibly need care for the span of their lifetime, (d) might face negative attitudes from peers and others, and ideations related to education, occupation, socialization, relationships, and finding normalcy by societal standards. For example, C1, C3, C5, C6, not able to accept that their child was born with an intellectual disability, each experienced how denial led to a delay in seeking services. C1 "her mother refused to believe that she had an issue," C3 and C6, culture and stigma played a role in delaying treatment. As C3 explained, "At first, I didn't want to admit my son is different… being Latino, I am supposed to be the strong father...to protect." C6, "my mother would not even consider my brother as having any disabilities, especially cognitive. She was told before we left Italy to come to the United States of his disability…she was afraid of labeling…of cultural beliefs, that people would talk…now she's deceased, he's 52, and we're trying to get assistance...the way the system works…I don't know." Culture was not an issue for C5, "I never thought I would be a single parent and never thought I would have a child with a disability and then I found I had both."

Core Theme 3: Family History of Alcohol Use and Abuse

Family history of alcohol use and or abuse was addressed by C1, C3, C4, C5, C7, and C8. C1 and C4 discussed parents' use of alcohol, C1, "her father drank and continues to drink heavy… alcohol abuse runs in both sides of the family." C4 "both my parents were alcoholics…they are now deceased." According to C1, C3, C5, C7, and C8, extended family members such as grandparents, aunts, and uncles, and other relatives who had contact with intellectually disabled family members used alcohol. C5 expressed, “we came from generations of alcoholics, I am in recovery myself.” C7 detailed that, “my uncles on both sides and paternal grandfather were drinkers,” she also shared, “almost all of our aunts and uncles use alcohol” C8 indicated, “a lot of people in my family abuse alcohol, they drink too much, but don’t think they do.”

Core Theme 4: Extended Carers

Family dynamics can include siblings and extended family such as grandparents, aunts and uncles, nieces and nephews, and others. Family can also consist of, foster parents, unrelated guardians, and others who assume the caregiver role. However, for the purpose of this study, extended family means related to immediate family as C1, C2, and C8 assumed the parts of caregivers to supplement care when the immediate family was unable or deceased. In the three cases, the recipient's parents were deceased, C2 and C8 had no siblings, C1, two siblings intellectually incapable, and one sibling unavailable, none had children (Rossetti & Hall, 2015; Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014; Williamson & Perkins, 2014). C1, “I grew up with her...like a big sister...I don’t want to see something happen to her.” C2, “I know I didn’t have support to fall back on so I want to do everything in my power... to be that person,” and C8, “He’s my uncle...been drinking since he was about 17 years old...he lives with me...me and my sister both take care of him.”

Core Theme 5: Holistic Health of Caregivers

Parents when having children might expect that during the developing years of their child’s life from birth to adulthood, issues associated with the different stages of development might include behavioral problems, which is ofttimes discussed before children arrive as to how to discipline. So, with the birth of a child with intellectual disabilities, parents might not be prepared for difficulties related to cognitive functioning with limitations that can present as added stressors (Hill, 1945). As parents expect children to mature and become independent, individuals, children diagnosed with intellectual disabilities might present just the opposite, placing unexpected stressors on the family unit. Concurrent sub-themes expressed by caregivers were stress, worry, hopelessness and helplessness, anger, and self-blame. Six and eight reported hypertension, stomach issues, headaches, exhaustion, and one in remission from cancer. Eight of eight communicated stress related to caring as a major factor. Although health issues of stress and emotions were overwhelming at times, at no time during interviews did caregivers express that family members were burdensome, in contrast, each informant expressed “I was not able to do enough.”

Core Theme 6: Guilt and Shame

As caregivers expressed frustration with a lack of services, frustration was not an issue with caring or directed towards family members receiving care. Caregivers (as stated in theme 5) express feelings of failure. Eight of eight expressed feelings of failure, C1 “I can’t help,” C2 “I just want to keep her safe,” C3 “I feel like a failure…I cannot protect him”, C4 “we (informant and wife) want to make sure he is safe, I’m his father, and I’m supposed to protect him,” C6 “I have not done enough… I feel I cannot protect him from himself.” C2 and C4 expressed family member’s safety, while C3, C5, C6, C7, discussed protecting, as C8 shared “I have to be there for him it’s what I do.”

Core Theme 7: Caregivers’ Support System

Caregivers in the midst might not understand that self-care is as important as care provided to family members (Park, Lee, Chun, Ivins-Lukse, & Park, 2018). Informants shared their thoughts on self-care as expressed by C2, C6, and C8 is that family takes care of family and they reach out to each other. C3, C4, and C5 sought self-help groups such as Al-Anon, while C1 sought no support, citing “lack of time,” and C7 announced that faith and meditation were high on her list, but shared, “I have sought talking therapy in the past when overwhelmed.” At the time of interviews, eight of eight focused on family member care and not making strides in self-care.

Core Theme 8: Motivation

According to Ruben Hill (1949), families in crisis or overwhelmed by issues either adapt or implode. Motivating factors for caregivers to continue seeking treatment services were, (a) caregivers’ fear of self-ability to care in the future, C1, C3, C5, and C7 expressed fear of dying. Sub-theme, “what will happen when I am not here?” “Who will care...” these sentiments were expressed in the same terminology. C2 and C8, co-caregivers and under the age of 30 held no fears or worries of future care, and C6 expressed that with many siblings, future care should not be a problem, “because there are so many of us and because he is older…” The motivating factor appeared to be love for their family members.

Core Theme 9: Endurance

With the knowledge and understanding of the difficulties that obtaining treatment services have presented, caregivers appeared more determined to stay the course. Caregivers also informed that wary of who will care if they do not, sub-themes established were: (a) love (also motivational factor), (b) continued need for services, (c) age of caregivers, (d) and as stated in theme eight “when I’m gone...who will care?” One prevailing factor appeared to be faith.

Core Theme 10: Resilience, Determination

Caregivers although frustrated, exhausted, fearful, and at times feeling overwhelmed, still held a sense of gratitude for family members with intellectual disabilities, seeing the joy in sharing a life together as C2 expressed “I have learned to be patient, I have become a more patient person… I know my niece is not the only one,” C8 “this is what families do…” Attitudes seemed to be a factor as eight of eight informants held positive attitudes towards providing care to family members and did not see the necessity of seeking services as a negative. A common theme was that eight of eight had to work outside of the home, five of eight also had children to support, and in all five cases, caregivers’ children became co-caregivers, and C4 and C6 with deceased parents became the main caregivers, which often happens with siblings (Hill, 1945, 1947).

Step 5: At this point and with completion of the analysis, I created individual textual-descriptions of caregiver’s experiences through descriptive meanings using quotes verbatim as presented by informants, and as a means to ensure accuracy of informant’s authentic voices

Step 6: I constructed a description of individual structural expression as a researcher/instrument, I used the informant’s textural content and with varied imagination, I reconstructed the caregiver's lived experiences in seeking substance abuse treatment for intellectually disabled family members abusing alcohol. Further examination of data in this hermeneutical phenomenological study unearthed categories of (a) stress, (b) worry, (c) hopelessness/helplessness, (d) anger, and (e) self-blame, which appeared to re-cycle or treadmill (see Table 3 and Figure 2), these categories provide a deeper understanding as to how caregivers experience the phenomenon of obtaining treatment services.

Step 7: In order to have a better understanding of each individual’s contextual description, I created a chart highlighting documentation from each informant of similarity, differing, and/or contradictory. This charting helped in the verification of core or common themes as represented in the interview process.

Table 3

Categories of Interest (Cyclic)*

Categories	Subcategories	Manifestation
Stress	Physical, emotional, mental	Health issues, hypertension, headaches, stomach, worry
Worry	Emotional, psychological	Fear, hopelessness/helplessness
Hopelessness/helplessness	Anguish, desperation, loss	Exhaustion, anxiety, feeling overwhelmed, anger
Anger	Frustration, guilt	Inadequacy, isolation, self-blame
Self-blame	Inept, inability to provide	Guilt, stress

*Symptoms appeared to re-cycle.

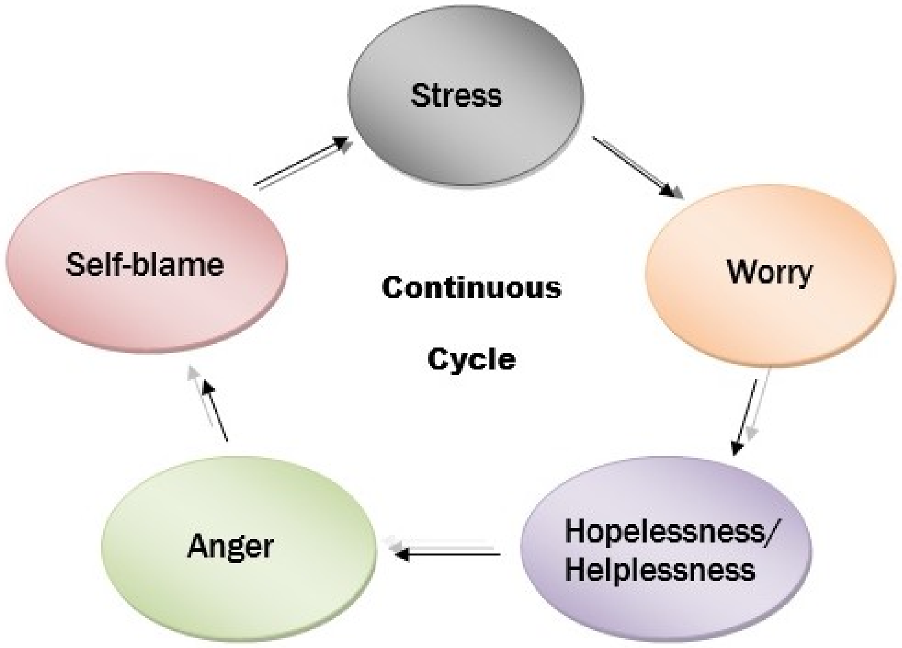


Figure 2. Cyclic categories.

Evidence of Trustworthiness

Results

Major findings of this hermeneutical phenomenological study presented ten significant core themes: (a) finding substance abuse treatment services, (b) adversity, (c) family history of alcohol use and abuse, (d) extended carers, (e) holistic health of caregivers, (f) guilt, shame, (g) caregivers support system, (h) motivation, (i) endurance, and (j) resilience, determination. In addition, findings of this hermeneutical phenomenological study revealed categories of (a) stress, (b) worry, (c) hopelessness and helplessness, (d) anger, and (e) self-blame.

The core questions essential to the study were designed with specificity of purposive and criterion base to assist with unearthing the perceptive meaning from the caregivers' perspective interpretations. The two research questions deemed essential to this hermeneutical phenomenological research study were:

RQ1: How do caregivers experience seeking substance abuse treatment services for family members with intellectual disabilities abusing alcohol? With the responsibility of assuming the caregivers' role experiences in seeking treatment services for family members classified intellectually disabled posed challenges as there was no clear direction known or understood by family carers (Hill, 1945, 1947). In addition, diversity in age seemed to present a role in perception as two informants under the age of 30 who were also co-caregivers felt less stress and or stressors, and reported no medical, emotion, or physical symptoms as depicted by those over age 30.

Caregivers found that although most service agencies contacted for treatment appeared sympathetic, none presented positive answers, solutions, or referrals. Two of the eight recipients of care were adolescents and placed in teen programs with the general population of peers. Eight of eight sought family physicians for advice in their search for adequate services. Lack of assistance presented as frustration, anger, fear, and hopeless and helpless feelings led to ideations of failure on the part of the caregiver. Caregivers also expressed the need to protect intellectually disabled family members abusing alcohol from use and abuse in the present moment, but also worried about the future and who would provide care when they were no longer able, available, or deceased. Having an understanding of experience in seeking services led to question two.

RQ2: How do caregivers interpret experiences related to seeking substance abuse treatment services? Informant's experiences, although similar in expectations to the phenomenon of study, and vital to interpretation held differences in levels of focused attitudes towards prospective outcomes. Perceptive ideations varied dependent upon age, culture, and relationship. For instance, as noted caregivers under the age of 30 who co-cared for family felt less stressed and more optimistic than those over the age of 30. Cultural perspectives led to a lack of motivation in seeking services sooner as stigma related to cultural ideations presented obstacles and appeared attached to beliefs, thoughts, and ideations of mental illness, which in some cultures is taboo (Cantwell et al., 2015; Werner & Shulman, 2015). Denial was also a major factor in, if, or how informants moved towards treatment as carers who denied intellectual disabilities in family members seemed to delay the process of seeking treatment service. In addition, caregivers' relationship to the recipient was diverse, from immediate family members such as parents and siblings to extended family, to include cousins, aunts (parent siblings), and nieces and nephews, which presented as urgency or lack thereof and how the treatment was obtained or not. Stigma, for instance, played a major role for two of eight in delaying treatment, and/or not seeking treatment and was based on cultural beliefs, comprehension of need, and cultural ideations. However, in the interim, eight of eight caregivers expressed that their understanding was that in-community substance abuse treatment services were to assist individuals in finding sobriety. However, seven of eight who sought treatment for family members were surprised at agencies' refusal to treat and the lack of knowledge of how to provide services for intellectually disabled individuals abusing alcohol. Anger and frustration were concurrent emotions expressed as caregivers realized that treatment might not be available to loved ones because of their disability.

Carers of adolescents in teen programs did not express a higher quality of care as one of the two adolescent recipients received individual counseling and monitoring of behaviors, but was kept isolated in the home environment by caregivers round-the-clock. The second teen not able to meet the standards of the program and feeling bullied by non-intellectual disabled (non-ID) cohorts in the program dropped out and was also placed on home care. Both were isolated from peers as a means of ensuring sobriety. Caregivers of the adolescents informed that in order to keep them safe, the teens were homebound and kept away from peers so as not to fall under the influence, thus providing information of the diverse perceptive attitudes of how to keep family safe from environmental and social factors.

Summary

This chapter includes the findings of a hermeneutical phenomenological research study through gathered data collected through a face-to-face structured interview with eight informants in the Northeastern, United States. Participant selection was through *purposiv*e and *criterion* samples to meet the necessary criteria of the study. Data gathered revealed ten core themes. The findings in this hermeneutical phenomenological study and with the use of van Kaam's method data analysis, ten core themes emerged from informants' descriptive authentic voices and transcribed, listed, eliminated, and clustering of invariant constituents took form and held constant. Exploration of data in this hermeneutical phenomenological study uncovered categories of (a) stress, (b) worry, (c) hopelessness and helplessness, (d) anger, and (e) self-blame. Chapter five consists of (a) background, (b) interpretation of research findings, (c) limitations, (d) implications for social change, (e) recommendations for future studies, (f) implications of this study, and, (g) a conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

Caregivers look to community support for assistance when trying to obtain treatment for intellectually disabled family members (Findlay et al., 2015; Irazabal et al., 2016; Salamone-Violi et al., 2017). In some cases, family and primary physicians become the immediate sources, but they might not have the knowledge of where to refer intellectually disabled individuals abusing alcohol for assistance or treatment (Manthorpe et al., 2015). As a researcher, my interest was to have a deeper understanding of how caregivers not only obtain but also perceive seeking treatment services for intellectually disabled family members abusing alcohol. Given that caregivers usually comprise of parents as the primary source of care for individuals diagnosed intellectually or cognitively impaired, detection of criterion might not be noticeable during the infant stages, but possibly at the start of the school years (Martins & Couto, 2014; Mitchell et al., 2016; Pryce, Tweed, Hilton, & Priest, 2017). Siblings are usually groomed to become secondary carers and oftentimes experience similar issues of stress-related symptoms as parent caregivers (Balcı, Kızıl, Savaşer, Dur, & Mutlu, 2019; Jacobs & MacMahon, 2017; Sonik, Parish, & Rosenthal, 2016). I looked towards the collected data in hopes that responses would provide answers to the experiences of the phenomenon studied (Moustakas, 1994). The results of this hermeneutical phenomenological study supplied information that filled some of the gaps not explored by prior research. However, the outcome also presented knowledge that further study is needed in order to gain a comprehensive understanding as to the phenomena of (a) caregivers’ lived experiences and perceptions in seeking substance abuse treatment for intellectually disabled family abusing alcohol, (b) intellectually disabled individuals abusing alcohol, and (c) ideology of substance abuse treatment services for people with intellectual disabilities (Slayter, 2016; Spassiani et al., 2017).

The purpose of this hermeneutical phenomenological study was to explore how caregivers experience obtaining substance abuse treatment services for intellectually disabled family members abusing alcohol. With the use of structured interviews in informal settings, eight informant caregivers shared their lived experiences of caring for and seeking treatment services for family members with intellectual disabilities. Informants provided in-depth, information-rich data that assisted with a comprehensive understanding of the phenomenon of the study. This chapter consists of an interpretation of research findings and a discussion of the limitations, implications for social change, recommendations for future studies, implications of this study, and a conclusion.

Interpretation of the Findings

Core themes developed through the gathered data, transcriptions, and descriptive interpretation of this hermeneutical phenomenological study. As the researcher, I discovered 10 themes of significance: (a) finding substance abuse treatment services, (b) adversity, (c) family history of alcohol use and abuse, (d) extended carers, (e) holistic health of caregivers, (f) guilt, shame, (g) caregivers support system, (h) motivation, (i) endurance, (j) resilience, determination (see Table 2). Even though thematic congruence appeared to correlate within the population of the study, there is potential for bias because I formed my interpretations through my own understanding (Ashworth, 2015; Moustakas, 1994). Also, because findings were unique to each informant, the same conclusion might not be true with different populations (Moustakas, 1994). However, with the diversity of informants' ethnicity, culture, and gender, similarities are reflected in themes. The only differences were in the age of informants, as informants under age 30 appeared to be less stressed and did not report physical or medical symptoms related to phenomenon (Hill, 1945, 1947; Pryce, et al., 2017). Core themes to follow (see Table 2).

Core Theme 1: Finding Substance Abuse Treatment Services

One constant during interviews was the difficulty in obtaining treatment services for family members diagnosed with intellectual disabilities abusing alcohol. The obstacles appeared in trying to understand where to begin, or who to turn to, as informants sought advice from the family doctor or primary physicians for advice (Salamone-Violi, et al., 2017; Slayter, 2010, 2016; Slayter & Steenrod, 2009). Contacting community servicing agencies also proved futile as caregivers were informed that family members (a) did not meet criteria, (b) agencies were not knowledgeable or equipped to service people with intellectual disabilities, (c) were understaffed, (d) waiting lists were too long, and (e) if accepted, were treated as mentally ill with medication and placed in treatment with the general population (Quintero, 2011; Ting To, 2014). Even with difficulties in finding community assistance, informants understanding the limitations of an intellectually disabled family member abusing alcohol continued to advocate for substance abuse treatment services (Spassiani, 2017).

Core Theme 2: Adversity

Caregivers had to first accept loved one's limitation of (a) being intellectually disabled, (b) having cognitive limitations, (c) possibly needing care for their lifetime, (d) might face negative attitudes affecting areas of education, occupation, socialization, relationships, and finding normalcy by societal standards (Mak & Cheung, 2008). Accepting the facts and possibilities associated with a cognitive disability, and with the understanding that finding treatment services for intellectually disabled family members abusing alcohol, caregivers sought alternatives when faced with difficulty (Rogers, 2015). Options were (a) moving beyond culture and fundamental beliefs to seek help from outside of cultural communities, (b) co-cared with help from extended family members, (c) 24-hour family care, limiting independence, and (d) possible group home placement as a last resort (Simpson, 2012; Yu et al., 2009).

Core Theme 3: Family History of Alcohol Use and Abuse

A family history of alcohol use and or abuse appeared to play some role in alcohol use in some families of the intellectually disabled and needs further investigation (Jones, Steele, & Nagel, 2017). Social and family behaviors can often have an impact on children in the developmental stages of growth as they try to emulate, mimic, or impress role-models in their environments (Sharma & Sharma, 2017). Informants felt the need to share family dysfunction as possibly influencing behaviors associated with intellectually disability and alcohol abuse.

Core Theme 4: Extended Carers

Caregivers ranged from parents and siblings, to include extended family members. In defining their role as family caregiver, each informant expressed obligatory beliefs and values or love as the deciding factor for taking on the role (Bhatia et al., 2015; Burke et al., 2015; Pryce, et al., 2017). Also, medical, educational, issues of employment, relationships, and socialization were important, but not a top priority to carers. In this study, caregivers under age 30 were also co-caregivers and did not convey health-related issues, yet did report experiencing stress. Extended family informants shared in-depth emotional attachments to intellectually disabled family members and shared the need to help (Pollack & Bagenstos, 2015). In some cases, carers appeared acting out of past emotional self-expression of needing help and finding none, wanted to ensure assistance to a family member in need (Spassiani, 2017).

Core Theme 5: Holistic Health of Caregivers

One theme that emerged among caregivers over the age of 30 was self-neglect. Informants seemed knowledgeable about taking some measure of self-care as important, but did not appear able to find or make time for self. Therefore, hypertension, exhaustion, lupus, cancer, and other medical issues were under medical care as a means of staying healthy. However, providing care was more important to the carers than all other major health issues (Mitchell, et al., 2016). Concurrent sub-themes expressed by caregivers were stress, worry, hopelessness and helplessness, anger, and self-blame and informants over age 30 reported stress-related symptoms. In sharing lived experiences, many opened to the notion that self-care was important and discussed the need to follow through to remain or regain a healthy lifestyle (Alpuente, Cintas, Foa, & Cosentino, 2018).

Core Theme 6: Guilt and Shame

A major category and theme was self-doubt caused by (a) inability to help family members to stop abusing alcohol; (b) allowing association with negative role models, including family; and (c) the inability to obtain treatment services, which led to self-blame. This issue also crossed age lines, as carers over age 30 felt a deeper sense of guilt and disappointment in themselves (Cantwell et al., 2015). Guilt was a constant theme, as was shame for some, which started before family members began alcohol use; it started with the denial of an intellectual disability and then denial of alcohol abuse (Werner & Shulman, 2015). Guilt and shame also seemed to play a part in the aggressiveness of seeking care, as feelings of guilt/shame increased, so too did levels of stress to find treatment (Pierron-Robinet, Bonnet, Mariage, & Puyraveau, 2018; Weber, 2011).

Core Theme 7: Caregivers' Support System

What was apparent from the information gathered was that caregivers understood the need for supportive services, but none were actively involved during interviews (Zakrajsek et al., 2014). Caregivers ignored their need for supportive services, as none were seeking supportive services, but reaching out only to family, friends, and some remained isolated. Even though supportive services were available, such as Al-Anon, counseling/therapy, informants did not contact these services because guilt influenced how caregivers sought help or as a follow-through to maintain proper holistic wellness. Guilt appeared to stem from the inability to find services to treat alcohol abuse. Caregivers expressed that they could not find supportive services connected to family member's alcohol abuse (Doehring, 2015). Carers, not knowing where to find services, turned either to family, spouse, or isolation (Findlay et al., 2015: Martins & Couto, 2014; Robinson, et al., 2016). There was a consensus that community services available did not meet caregivers' needs and or intellectually disabled family members' needs for substance abuse treatment or caregiver assistance. Caregivers might not understand that self-care is as important as care provided to family members (Park et al., 2018).

Core Theme 8: Motivation

One of the motivating factors for caregivers to continue to seek substance abuse treatment services for family members abusing alcohol was love (Thackeray & Eatough, 2015; Thorkildsen et al., 2015; Thorkildsen & Råholm, 2018). Each informant expressed a narrative of loving and caring for their specific family members in need. Fear seemed another factor, as family members over the age of 30 worried about future care of their loved one; fearing the unknown possibilities led to increased worry, pushing towards resolution (Pryce et al., 2017). According to Hill (1949), families in crisis or overwhelmed by issues either adapt or implode.

Core Theme 9: Endurance

Caregivers seemed unaware of their ability to unravel the multifaceted world created by their pursuit of services. Even though frustration and worry were prevalent, so too was the underlying fear that if they as family members did not continue the search, then possibly no one would (Pollack & Bagenstos, 2015). With the difficulties with obtaining treatment services, caregivers appeared more determined to stay the course (Watson, 2006, 2007). Faith seemed to be the substance that kept caregivers from giving up or giving in to the fears and frustration for present and future care of their loved ones.

Core Theme 10: Resilience, Determination

Informants seemed unaware of their tenacity in seeking services, which in some ways, made them resilient. At the point of the interview, not one of the eight participants had given up on finding services for their intellectually disabled family member abusing alcohol (Hill, 1945, 1947). Even though informants reported many obstacles including mental, emotional, and physical health issues, for caregivers, the end goal was to find services that would meet their loved one's needs. In their determination, caregivers over the age of 30 put their own needs on hold and focused solely on their family members (Park et al., 2018; Rosino, 2016).

Limitations of the Study

Conducting a hermeneutical phenomenological study exploring behaviors of intellectually disabled individuals abusing alcohol and their caregivers attempts at finding treatment services can be daunting, especially for carers who want to share personal matters and possibly experience a cathartic release through sharing of information (Bazzano, et al., 2015; Moustakas, 1994; Newman et al., 2010). One limitation of the interview process was sampling size (Moustakas, 1994; Suri, 2011). In order to delve into the lived experiences of informants, the population size had to be limited so as not to become overwhelmed (Cleary et al., 2014; Gentles et al., 2015; Moustakas, 1994; Palinkas et al., 2015). A second limitation was restrictions set by the cooperating organizations as to where to post the Request Letter from Site to Conduct Study (see Appendix D), which extended the time needed for the recruitment process. Third, informant recall and truthfulness of shared information is a potential limitation.

Recommendations

The limited scope of this hermeneutical phenomenological research study included caregivers of intellectually disabled family members abusing alcohol and how caregiver/informants experienced the phenomenon of seeking substance abuse treatment services. This hermeneutical phenomenological study presented an in-depth analysis of how caregivers perceived the role of caring and advocating for treatment services. To further explore the lived experiences of this phenomenon, I recommend replicating the study to compare or extend knowledge of similar or differing groups. A comparative analysis may broaden the vision of program developers and stakeholders to include intellectually disabled alcohol and substance users and their caregivers in future planning of services. An advanced view of the paths taken by caregivers to obtain services and deferring to the needs of intellectually disabled alcohol/substance abusers with limited cognition apart from non-intellectually disabled and mentally ill individuals might narrow the gap and extend available services. Because this study only included information pertaining to caregivers seeking treatment services for intellectually disabled family members abusing alcohol, I also recommend the use of regression analysis to further explore the relationship between dependent and independent variables, resulting expectations, and outcomes of the studied phenomenon.

Implications

With this study, and continued research, exposure of the often-times complicated understanding of the special needs of adults with limited cognition and the identifying of these limitations might inform stakeholders, servicing organizations and agencies, and substance abuse treatment developers to widen the scope on this vulnerable population and their caregivers (Carroll Chapman & Wu, 2012; Schmidt, 2016; Slayter, 2010, 2016; Slayter & Steenrod, 2009). In addition, the public, especially those providing care to individuals with intellectual disabilities, should be aware that a vulnerable population of alcohol abusers exists that many might not have given credence to as becoming users (McGillicuddy, 2006; Quintero, 2011). As intellectually disabled children mature into adults and move into the general population, and without proper supervision, issues such as alcohol abuse that affect non-ID might amplify in the lives of individuals with intellectual disabilities, thus caregivers become necessary (Hermans, Wieland, Jelluma, Van der Pas, & Evenhuis, 2013). This study is important as it might shed light on two populations generally overlooked when developing services of treatment, caregivers, and individuals diagnosed, misdiagnosed, and/or not diagnosed with intellectual disability abusing alcohol.

I have come to understand that not enough is known about intellectual disabilities in general, to include in the medical and educational fields as books and articles reviewed seemed to struggle with answers, and this might be where steps need to be taken for discussion. Growing up in a family with six intellectually disabled siblings ranging from mild to moderate, I have been blessed with the ability to recognize cognitive limitations almost immediately. However, when working in the field of substance abuse and mental health, and through personal experience, I have come to the collusion that intellectual disability is not a high priority issue in our local, state, and/or governmental systems (ADA, 2016; Gostin & Gable, 2010). While funding has increased in areas of special education (SE), this educational pathway has not worked as well as expected and has put added stress on teachers and others workers in the school system because of poor understanding as to how to teach a specialized group of children (İlik & Sari, 2017;

Vygotsky, 1978, 2017). One reason for this is that as children move through the system, not all reach their potential and many never catch up to peers of the same age and grade level (Beld et al., 2018). From my social worker's perspective, this process can give a false sense of security and mislead children, and their parents into believing that these children are moving forward, but might not be on the same standard grade level tract as non-SE, which may present opposing results.

One issue I find with the label of SE is that the term used to assist children with additional help in the educational process does not always determine actual grade levels. If parents do not know the exact grade level or keep school records there might not be any true understanding of the child's real grade or comprehension levels, thus causing problems in adulthood when in need of services. In my practice and by doing hundreds of assessments, 85% of clients reported SE but did not know at which grade level, and of the 85% more than 50% were below the eighth-grade level and most under fourth grade in learning curves. Even referring agencies did not classify individuals as intellectually disabled, but as mentally ill or no classification at all. Yet, many clients were on probation, attached to youth and family services, homeless, and or living on their own. Eighty-five percent were alcohol/substance users, and of the 85%, none was ever referred to an organization that provided services to individuals with intellectual/cognitive disabilities, not through the educational system, the legal system, or in the medical field, even occupational where many testing scores were retrieved from also lacked in recognition for referrals (Gilmour & Wehby, 2019). My question is: How can we as a nation or as human service workers overlook a population as vulnerable at times as children and the elderly? Human rights laws enacted and mandated to protect the intellectually disabled and disabled, are in some ways the very laws that at times do not protect them (ADA, 2016; Goodey, 2015; Gostin & Gable, 2010; Prebble, et al., 2013). Example: if there is a need for substance abuse treatment, intellectually disabled individuals can refuse treatment even if cognition is the obstacle. Caregivers must become legal guardians in order to have a say in treatment or treatment options. In addition, individuals with intellectual disabilities living with caregivers are also at risk when caregivers are no longer able to care for them or die (Irazabel, et al., 2016; Pryce, et al., 2017; Ryan, et al., 2014).

At this point, unless affiliated with servicing organizations, intellectually disabled oft times become homeless, and are forced to fend for themselves, which might prove almost impossible given the lack of comprehension, cognitive limitations, and understanding of how community systems work. Without supervision many experience (a) homelessness, (b) isolation, (c) misdiagnosis and or classified as mentally ill, or, not diagnosed at all, and, (d) fall into negative behaviors and come to harm (Caton et al., 2012; Coyle et al., 2014; Gawryszewski & Monteiro, 2014). Stepping into a world foreign to their understanding could lead to imitating peer behaviors with positive and or negative consequences, which brings me back to education (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2012). Issues affecting intellectually disabled individuals have to be at the forefront as equal to children, and the elderly. Education is the key and the medical and educational fields should be the leaders as both are the initial out of family organizations that provide care and observe children through the developing years (Vygotsky, 2017). Higher education should implement studies of the intellectually disabled and issues related to their curriculums.

Conclusion

Caregiver informants experienced obstacles in finding substance abuse treatment services for intellectually disabled family members abusing alcohol. Informants who had knowledge and experience in caring for intellectually disabled family provided detailed information that through careful examination of the data ten themes and sub-themes emerged to include five cyclic categories of (a) stress, (b) worry, (c) hopelessness/helplessness, (d) anger, and (e) self-blame. In this hermeneutical phenomenological study eight of eight informants reported stress/stressors as a factor of self-blame, which led back to stress. Six of the eight informants experienced increased stress of mental and emotional, and reported medical issues. Eight of eight were not seeking or receiving any out of family support during interviews as caregivers either relied on family when under stress, or isolated. Six of eight informants and over the age of 30 held negative ideations of the future care of family members, whereas two informants under the age of 30 and as co-carers experienced less concern for long-term planning of care. Eight of eight although frustrated in not finding treatment services, did not deter from their search, however, they did believe that stress was beginning or would eventually affect their health and well-being of the family unit. The results of this hermeneutical phenomenological study will provide program developers, stakeholders, and community agencies a window into the needs of people with intellectual disabilities abusing alcohol and their caregiver's struggle to find services, while supplying an in-depth understanding and insight of reasons to develop treatment services that support individuals with intellectual disabilities and their caregivers in a holistic manner. Thus, providing caregivers with easy access to appropriate substance abuse treatment services for family members with intellectual disabilities and alcohol abuse.

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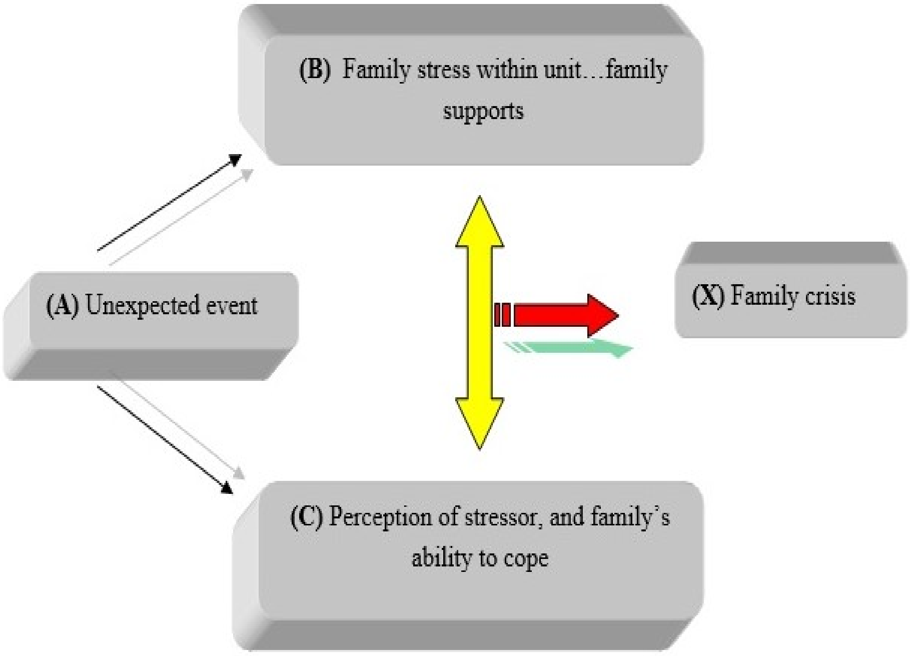
Appendix A: Hill's ABCX Model of Family Stress



Appendix B: Interview Questions

1. What has been your experience in finding substance abuse treatment services available for your family member with cognitive disabilities abusing alcohol?

2. What has been your experience in accessing services that support your family member’s needs?

3. What kind of supportive services are available to you as a caregiver of an intellectually disabled family member abusing alcohol?

4. How has the process or experience thus far affected your perception of seeking services?

5. How have you experienced the supportive services for your family member, particularly at the beginning of those services?

Appendix C: Email to Organizations

Date:

Dear Sir/Madam,

My name is Mariam Nicoll and I am a doctoral student/licensed social worker at Walden University, with concentration in Human Services – Clinical Social Work. I am in the process of dissertation. I am researching how caregivers experience obtaining substance abuse treatment for intellectually disabled family member(s) abusing alcohol. I would like to have a follow up phone call to give detail on the topic and process to my research study, and reasons why I am reaching out to your organization. I thank you in advance for your time and consideration.

Mariam Nicoll, PhD (candidate), LSW
Walden University

Appendix D: Request Letter from Site to Conduct Study

Mariam Nicoll, PhD (candidate), LSW

Walden University

Organization A (same as for Organization B- different address)

April 30, 2018

Dear Sir/Madam,

I seek your help in accessing about 5-10 of your parents/guardians who care for your clients who have intellectual disabilities and alcohol abuse (IDAA) problems. As a doctoral candidate at Walden University who is preparing a research proposal for a PhD in Human Services – Clinical Social Work, and an experienced licensed social worker, pending approval, I will interview parents/guardians who care for clients with IDAA for purposes of understanding experiences relating to initial contacts with behavioral health services.

This potential study, tentatively titled, Caregivers' Supportive Role for Obtaining Substance Abuse Treatment Services to the Intellectually Disabled Alcohol Abuser, includes potential benefits that might assist in the development and collaboration of community services that address substance abuse in conjunction with intellectual disabilities while working as a unit to assist caregivers and individuals with IDAA. I do not anticipate any potential harm to participants. I fully intend to use careful consideration and take all necessary precautions to address potential problems or negatives with immediacy throughout the interview and study. Participation is voluntary, and participants will be able to opt out of the research at any time without question or consequence.

Pending your approval, as well as approval from Walden University Institutional Review Board and faculty and staff, I seek from you a list of potential parents/guardians with contact information to assist in the recruitment process. I will not use names of participants or your organization in my study to protect confidentiality and anonymity. I will furnish you with the results of this research as the findings may be particularly helpful.

Please let me or my dissertation chair know if you have questions about my request.

Sign

Appendix E: Criteria of Inclusion

1. Must be over the age of 18
2. Have/had experience as caregivers seeking treatment services for intellectually disabled family member(s) abusing alcohol,
3. Have good comprehension skills cognitively and of the English language
4. Not having serious mental, emotional, is not pregnant, or physical health issues.

Appendix F: Informed Consent Form

You are warmly invited to take part in a research study about caregiver's understanding in finding substance abuse treatment services for intellectually disabled family members abusing alcohol. I am inviting people over the age of 18, who speak and understand English, are not pregnant, and do not have major health problems to join and be part of the study. I got your name and contact info from Organization A. The organization has no part in this study and will not know if you took part. This form is called an "informed consent" allowing you to understand this study before deciding if you want to come aboard.

I, Mariam Nicoll am a doctoral student at Walden University and will conduct this study. You might already know me as a licensed social worker, but this study is not part of my job, but part of my college studies.

Background Information:

The reason for this study is to understand the steps caregivers take when looking for treatment services for intellectually disabled family members abusing alcohol in the community.

Procedures:

If you agree to be in this study, I will ask you to:

- Sit for one question and answer interview session. Session will take about one hour (5 minutes for brief introduction of study, 30-45 minutes for interview of questions and answers, and 10 minutes for any questions that you might have for me).
- I will use a tape recorder to make sure I accurately transcribe your responses.
- I will only ask questions that are part of the research study.

Here are some sample questions:

- How do you understand the steps you need to take in finding substance abuse treatment services for your intellectually disabled family member abusing alcohol?
- How have you experienced finding substance abuse treatment services?

Voluntary Nature of the Study:

This study is voluntary, meaning that you have a choice to take part. You are free to say yes or no to this invitation. No one at Organization A will know if contact was made for this study. If you decide to be in the study now, you can still change your mind later. You can stop at any time. I will contact you to let you know if you were selected for the study. (This is only necessary if too many are recruited).

Risks and Benefits of Being in the Study:

For this study, risks could be that you might have some emotions or feelings connected to your everyday life, such as feeling emotional, or becoming upset. Being part of this study would not give risk to your safety or wellbeing.

You might not see any benefits to you, but the study might help others have an easier time finding treatment services and community services who work with substance abuse treatment, and services that help with the needs of caregivers and individuals with intellectual disabilities abusing alcohol.

Payment:

There will be no payment for being part of this research study.

Privacy:

Only I will have access to your information and your part in this study. I will not share your name or where we met for interview and will not use your information for anything other than this study. Information entered into computer program, will be coded as letters and numbers, and will be kept on a removable computer disc. No names will be used at any time during or after study to protect your privacy. I will keep tape recording and removable disc in a locked cabinet for six months after study and then I will destroy tape. Information kept on the removable computer disc will be kept in a locked container for a period of at least 5 years, as required by the university and then I will destroy disc.

Contacts and Questions:

You can ask any questions you have now. Or if you have questions later, you can email me at (mariam.nicoll@waldenu.edu). If you want to talk privately about your rights as being part of this study, you can call the Research Participant Advocate at my university at 612-312-1210. Walden University's approval number for this study is **01-04-19-0041443** and it expires on **January 3, 2020.**

I will give you a copy of this form to keep.

Obtaining Your Consent

If you feel you understand the study enough to make a choice about joining, please let me know by signing below.

Printed Name of Participant (you) ______________________________

Date of consent (date signed by you) ______________________________

Participant's Signature (you) ______________________________

Researcher's Signature ______________________________

This has been approved by the Institutional Review Board of WALDEN UNIVERSITY as acceptable documentation of the informed consent process and is valid for one year after the stamped date.

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