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## Lived Experience of Caregivers of Relatives with Alcohol and Opiate Dependence (A phenomenological study)

Akwasi Duah  
*University of Massachusetts Medical School*

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Lived Experience of Caregivers of Relatives with Alcohol and Opiate Dependence  
(A phenomenological study)

A Dissertation Presented  
by  
AKWASI A. DUAH

Submitted to the Graduate School of Nursing  
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Graduate School of Nursing

*Lived Experience of Caregivers of Relatives with Alcohol and Opiate Dependence*

A Dissertation Presented

By

Akwasi Duah

Approved as to style and content by:

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Donna Perry

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Carol Bova

---

Danny G. Willis

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Date

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Joan Vitello PhD, RN, NEA-BC, FAHA, FAAN  
Dean & Professor  
University of Massachusetts Worcester  
Graduate School of Nursing

## **Dedication**

To my mother, Kate Asantewaah Acheampong. I have come this far because of all the sacrifices you made for me. To my lovely wife Afua Ampomaah Bonsu and children; David Duah, Darren Duah and Daniel Duah.

Also to all the participants who shared some of their “inner most secrets” to make this study possible.

## Abstract

Substance abuse is a relapsing chronic illness. In 2014, an estimated 27 million persons reported using illicit drugs in the United States (SAMHSA, 2014). Substance abuse negatively impacts societies, productivity, healthcare costs and families. Families play an important role in relapse prevention and sobriety. With adequate family support, substance abuse positively responds to treatment. Many individuals (about 66 million Americans) play the role as an informal caregiver for a relative with chronic illnesses such as substance abuse but few studies exist on the caregiving experiences. What we know about the family caregiving experience is restricted to data from quantitative studies which do not explain the complexities and competing challenges that exist. Different approaches are thereby needed to deepen our understanding of the family caregiver burden of living with a relative with substance abuse problems. Such studies will enable us to understand the original experience and moment of learning of a relative's substance abuse problems, decision making and support that follows thereafter. This moment calls for major decision making and encounter with treatment services.

The purpose of this study was to explore the lived experience of caregivers of relatives with alcohol and opiate dependence. This study utilized Max van Manen's (2014) Phenomenology of Practice. Ten participants (N=10) were recruited for this study. Van Manen's guided existential inquiry was used in the analysis of experiential material collected through interviews. Four main themes emerged from the data: (1) Being in the moment: the extension of the self; (2) The dawn of reality: the being of acceptance; (3) Deciding in the moment: the healthcare experience; (4) Uncertainties and struggle: a lifelong process. These themes described how the participants: experienced, accepted and processed a relative's substance abuse problem, encountered treatment services and experienced the uncertainties and struggles involved in

caring for a relative with substance abuse problems. Two main findings emerged from these themes; the impact of guilt and stigma on seeking care and the need to see addiction as a disease instead of as a moral character failure. This calls for coalitions with stakeholders to decrease stigma, enhance acceptance process and increase access to treatment.

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*If I were to tell you where my greatest feeling, my universal feeling,  
the bliss of my earthly existence has been,  
I would have to confess: It has always, here and there,  
been in this kind of in-seeing,  
in the indescribably swift, deep, timeless moments  
of this divine seeing into the heart of things.  
(Rainer Maria Rilke, 1987)*

## Chapter 1

### State of the Science

#### Specific aims

Substance abuse is a relapsing chronic illness. In 2014, an estimated 27 million persons (10.2 percent of the population aged 12 or older) reported using illicit drugs in the United States (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). This shows an increase in the last decade from 8.3% in 2002 to 10.2% in 2014 (SAMHSA, 2014). Of the 27 million persons, 7.1 million persons met criteria for substance abuse disorder. Substance abuse is currently on the rise with a concerning impact on families, societies, productivity and healthcare costs. Addiction, with adequate support often responds to treatment with long term lifestyle modifications.

Many individuals in the United States find themselves as an informal caregiver (unpaid) for a family member with chronic illness (Rospenda, Minich, Lauren, Milner, & Richman, 2010). It is estimated that about 66 million Americans claimed providing unpaid care as a family caregiver to at least one relative or friend (Family Caregiver Alliance, 2007). This includes all carers and does not differentiate those caring for persons with substance abuse. Caregivers today

have an increased level of responsibility because more adults with disabilities and chronic conditions are living at home (Collins, 2011). Caregivers have a key role in supporting family members/relatives with substance abuse and mental illness, but their contributions are frequently undervalued by mental health nurses and other health clinicians (McCann & Lubman, 2011). Caregiving for a loved one with a chronic condition including substance abuse has benefits including personal fulfillment and relief of suffering (American Association of Retired Persons [AARP], 2011, Collins, 2011). However, caregiving also has its associated stressors/burden.

Previous studies on the construct of burden of care have investigated several determinants and factors that have been attributed to the caregiver's perception of burden of care (Zegwaard, Aartsen, Cuijpers, & Grypdonck, 2011). Extant literature has put forth strong evidence between these determinants and burden of care in the family of the affected individual (Vaingankar, Subramaniam, Abidin, He, & Chong, 2012). Though studies on the burden of care of chronic illness on families have focused on individual conditions such as anxiety, depression, bipolar disorder, schizophrenia, dementia, and cardiovascular diseases (Vaingankar et al, 2012, Manneli, 2013), few studies exist on the burden of care of substance abuse on families. What we know about this phenomenon is restricted to data from quantitative studies which do not explain the complexities and competing challenges that exist. These studies do not explicate how relatives are affected by the singularity, alterity and vulnerability of the phenomenon of living with a loved one with addiction. They do not tell us how people experience this phenomenon differently. The majority of caregiving burden relating to substance abuse rests on family members; however, little is known about their problems and experiences (Usher, Jackson, & O'Brien, 2007).

In order to deepen and contribute to our understanding of this phenomenon different approaches are needed. There is the need to design studies that focus on the relatives pre-reflective experiences. Inquiry that focuses on a caregiver's pre-reflective experience "tries to grasp attentively the living sense of the experience before we have lifted it up into cognitive, conceptual or theoretical determination or clarity" (van Manen, 2014, p. 39). This will allow us to explicate the original sources of the lived experience; "for .....there is nothing more meaningful than the quest for the origin, presentation, and meaning of meaning (van Manen, 2014, p. 27). Such studies will enable us to be aware and comprehend a deeper multifaceted understanding of the phenomenon of addiction.

Understanding the experiences of caregivers of family members with substance abuse is important not only for the caregivers themselves but because of their role in relapse prevention and treatment. Evidence suggests that effective methods involving increased participation of the family are needed in treatment and relapse prevention (Peterson, 2010). The family is recognized as the most protective factor (Diaz, Brands, Adaf, Giesbrecht, Simich, Wright, 2009) and the primary source of continuous care because when treatment fails, they assume the caregiver role as the providers of last resort (Clark, 2001). Acquiring a better understanding of the family burden has become increasingly important as families adopt a major role in the care of their relative (SAMHSA, 2010). Studies that aim at sound understanding of this phenomenon and its determinants and risk factors are necessary. This calls for a multi-factorial approach to understand the multiple concepts involved in caregiving in families of the addicted individual. Therefore we need to know more about the burden of addiction from the perspectives of family caregivers.

The purpose of this research is to explore the lived experience of caregivers who have a relative with opiate and/or alcohol dependence problems. The study will use van Manen's phenomenology of practice (van Manen, 2014). Using the phenomenology research approach will allow access to this human phenomenon with the purpose of reaching findings and discoveries not captured by other approaches. Knowledge gained from this study will enable us to design clinical interventions which are multidimensional for effective caregiver assessment, strategies to offset this burden, increase family involvement and supportive services to prevent relapse and sustain sobriety. Also, understanding these complex experiences will enable effective healthcare interventions to be designed. A continuum of care with a variety of integrated supportive and ancillary services that address the multiple needs of this population may improve their chances of recovery and their quality of life (SAMSA, 2010). The following research questions will be explored

1. What is it like to live with and care for a relative with opiate and/or alcohol dependence?
2. What alliances, resources, and supports does the family caregiver receive from healthcare providers?

### **Background and Significance**

Current trends in substance abuse treatment suggest the importance of involving families. The role that families play in treatment intervention and relapse prevention is invaluable (Valleman, Templeton and Copello, 2005). There is a dearth of methodologically sound research as it pertains to this area (Valleman et al, 2005). To effectively involve families in substance abuse treatment, it is important to design studies that aim at understanding the experiences family caregivers go through as they care for their relatives with substance abuse. Such studies will also deepen our understanding of the role family caregivers play in relapse prevention and



sustenance of sobriety. Since addiction is a chronic illness, understanding the experiences of family caregivers of persons with chronic illness will offer some insight into this phenomenon. It is thereby important to discuss the literature on what is known about family caregivers in general. This will be followed by a discussion on the literature of the family caregiver burden of persons with substance abuse.

### **Substance abuse**

Chronic illness such as substance use has a significant impact on families and societies as a whole (Brown, Biegel, Tracy, 2011). There has been a recent resurgence in alcohol and drug use (Manson, 2011, Torvik, Rognum, Ask, Roysamb, Tambs, 2011). Alcohol has been reported to be the most abused substance in the U.S with 136.9 million Americans reporting current alcohol use and about 16.5 million Americans classifying themselves as heavy alcohol users (National Association of State Alcohol and Drug Abuse Directors, 2015). In 2012, about 21.5% of Americans seeking treatment for a substance abuse related disorder reported alcohol as their primary substance of choice (National Association of State Alcohol and Drug Abuse Directors, 2015). Also, an additional 17.5% of Americans seeking treatment reported alcohol alongside a secondary drug of choice (National Association of State Alcohol and Drug Abuse Directors, 2015). In 2013 about 169,000 Americans reported using heroin for the first time with more than 500,000 Americans meeting criteria for dependence on heroin (SAMHSA, 2013). Admissions to medical treatment for heroin and drug rehabilitation services increased by 16% from 2010 to 2012 (National Association of State Alcohol and Drug Abuse Directors, 2015).

Substance use is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, and continued use despite harm and cravings (Graham, Schultz, Mayo-Smith, Ries, & Wilford, 2003). It is important to note that alcohol and

drug use is a chronic medical condition. Both of these problems share similarities with other chronic illnesses such as diabetes, asthma or hypertension. Addiction is similar to other chronic illness because they all: have distinct biological and behavioral patterns which should be addressed, require long term processes of repeated treatment episodes for restoration of optimum functioning, have the possibility of relapses, and need the support of family members and participation in programs for the sustenance of recovery (National Institute on Drug Abuse (2008). However, addiction is different from other chronic illness as it relates to societal stigma, legal consequences of drug use, and guilt/shame.

### **Family caregivers in general**

Advances in healthcare technologies including the management of illness for the past 50 years have lengthened the lifespan of adults with chronic illness. Caregiving for chronically ill adults has been transferred back to the home setting. This has been attributed to shorter hospital stays, aging U.S population, increase in home care technology, and changes in insurance reimbursement for care at home (Collins, 2011). Families who assume these critical roles as caregivers often have minimal support or preparation thereby being burdened by these roles (Ducharme, Levesque, Lachance, Kergoat, Legault, Beaudet, & Zarit, 2011, Schumacher, Beidler, Beeber, & Gambino, 2011). A family caregiver is a friend or relative who provides unpaid assistance to persons with a chronic or disabling condition (Family Caregiver Alliance, 2007). Burden in this study refers to the experiences (both negative and positive) of caregivers as they care for their relative with alcohol and opiate abuse problems and their encounter with the healthcare system.

It has been estimated that demand for family caregivers is expected to rise by 85% in the next decade (American Association of Retired Persons, 2011). A typical family caregiver in the

U.S is a woman, under age 75, spends about 20 hours per week providing care, is employed fulltime, and earns lower wages (Family Caregiver Alliance, 2006). In 2011, the economic value of informal caregiving was an estimated cost of \$450 billion if services had been provided by a paid formal caregiver (American Association of Retired Persons, 2011) .This exceeds all federal and state Medicaid spending in 2009 and accounts for approximately 2.9% of U.S total Gross Domestic Product in 2009 (American Association of Retired Persons, 2011). Family caregivers today have an increased level of responsibilities because more adults with disabilities and chronic conditions live at home than ever before (Collins, 2011).

### **Exploring the Literature on Family Caregiving**

#### **Criteria for search**

The purpose of this review is to examine the literature on the lived experience of caregivers of relatives with alcohol and opiate dependence. The databases of PubMed, CINAHL and PsycINFO were utilized in this comprehensive literature search. The inclusion criteria were; a research article written in English, relevance to the purpose statement and published between 1992 and 2012. The Substance Abuse and Mental Health Administration (SAMHSA) was founded in 1992. SAMHSA is a government agency with the mission and vision of developing contracts and grants to reduce the impact of substance abuse and mental illness on America's communities. Many studies on substance abuse and mental illness were funded during this era.

#### **Results**

Three main themes describing the burden of substance abuse on caregivers were identified in this review. These are: subjective burden, objective burden, and addiction as a chronic relapsing disease. Subjective burden is the social, psychological and emotional impact experienced by caregivers (Weitzenkackmp, Gerhart, Charlifue, Whiteneck, & Savic, 1997).

Objective burden is the physical effect of the day-to-day tasks caregivers undertake for their family members (Sales, 2003). Although there are some overlaps between subjective burden and objective burden, making this distinction in this study is necessary for the clarification, organization and understanding of the literature. Addiction as a chronic illness is characterized by relapses and remissions.

### ***Subjective burden***

Subjective burden reported by caregivers of substance abusers includes; guilt, anxiety, depression, stigma, and worry. Subjective burden was seen as an important concept among this population. A caregiver's suspicions and first realizations of a family member's abuse problems are compounded by doubts until a behavior change in the addicted person's life becomes more apparent to confirm a substance abuse problem (Usher et al, 2007). A parent's early attempt to confront this situation or set limits is often met with lies, resistance, and a break in communication (Usher et al., 2007). This proves to be difficult as caregivers report feelings of guilt and desperation (Usher et al., 2007).

Caregivers often have the notion that society perceives them as responsible for their child or family member's substance use. This usually leads to guilt and shame. Also, the substance abusing child/family member sometimes blames the caregivers in their immediate environment for their problems (Usher et al., 2007). In a secondary analysis of data (N=164), Brown et al (2011) noted that caregivers of women with substance use experience worry and stigma as they respond to the complex emotional and behavioral problems of their care recipients. They further noted that, almost half (45%) of these caregivers are unlikely to ask for help thereby making them more vulnerable to increased risk of additional burden. In a prospective study (N=349), Sattar, Padala, McArthur-Miller, Roccaforte, Wengel & Burke (2007) made the claim that,

caregivers of alcoholics reported being burdened by care recipient behaviors of irritability, agitation, disinhibition, and elation. Not only are these behaviors stressful, but they are readily observable by other persons in the care recipient environment.

Losing a family member, especially a child, to drugs is very devastating. Carers usually grieved the loss of a child and the future expectations. These shattered dreams lead to increased guilt as parents see their role as a failure (Usher et al, 2007). The death of a substance abusing child as a result of drug use usually leads to a very intense guilt and immense responsibility for the premature death of the child (Usher et al, 2007).

Caregivers reported feelings of embarrassment, loss of control and being stigmatized. Family members with a higher perceived burden of care experienced more symptoms of anxiety and depression (Vaingakar et al, 2012). Family members with available emotional support from others reported greater well-being and fewer burdens. The impact of substance abuse on families has consequences. Parents had to deal with stealing behaviors of children, verbal and physical abuse by the substance-abusing child/family member, and at times caregivers getting involved in the care and responsibilities of other substance abusers associated with the child (Usher et al, 2007). Psychological distress, perceived quality of life, lack of social support, and lack of family communication are predictive of subjective burden (Moller-Leimkuhler & Wiesheu, 2012).

In a cross sectional study (N=109), Macon, Rubira, Espinosa and Barbosa (2012) reported that about 50% (N=109) of caregivers of illicit drug users reported an increase in depressive symptoms which limited their overall ability to provide the needed care. In a related exploratory cross sectional survey study (N=164), Biegel, Ishler, Katz and Johnson (2007) reported that predictors of caregiver burden of users of illicit drugs include worry, stigma and displeasure. In this study caregivers reported that, the frequency and greater behavioral problems of the care

recipient predicted higher levels of worry. Increased levels of anxiety, worries, feelings of extreme depression and mood swings were high among caregivers of illicit drug users. Lack of caregiver support and care recipient behavioral problems further contributed to an increased sense of burden. This increase burden may lead to caregiver depressive symptomatology.

Family caregiving also has effects on the quality of life of caregivers. Main determinants of quality of life reported by participants were psychological health, social relationships, loss of time from work, financial loss, limited time for leisure and socializing, health effects from distress, chronic medical conditions, increased use of tranquilizers and antidepressants, and disruptions in family as a result of addictive behaviors (Salize, Jacke, Kief, Franz and Manni, 2012, Marcon et al, 2012, Biegel et al, 2007). These alterations in quality of life often lead to disruption in family processes (Biegel et al, 2007).

### ***Objective burden***

Objective burden to family caregivers include financial and time commitment. Studies have reported that family caregivers spent between 16% and 19.8% of their income on non-medical expenditures directly related to their family member's substance abuse (Clark, 1994, Salize et al, 2012). Also, family caregivers spent between 21.2 and 32.3 hours per month providing informal care (Clark, 1994, Salize et al, 2012).

An exploratory research study by Salize et al (2012) showed that families of alcoholics (N=48) spent about 19.8% of their total pre-tax family income on non-medical expenditures directly related to their family member's alcoholism. Also, the average time spent caring for the addicted family member was estimated at about 32.3 hours per month (Salize et al, 2012). This informal care is seen as an additional financial burden. In a related study, Clark (1994) reported that families (N=127) spent about 16% of their monthly income in providing financial support to

their care recipients. These caregivers spent about 21.2 hours monthly in assistance to their care recipients (Clark, 1994).

Time spent in assisting a care recipient reduces available time for work thereby lowering family earnings. In a secondary analysis of data to explore the relationship between family support and substance use (N=174), Clark (2001) reported that care givers often have relatively low income but spent a high proportion of that in support of a relative with addictive problems. It was also noted that caregivers reported providing about 50 hours per month of direct assistance relative to tasks of daily living for care recipient.

### ***Relapsing disease***

Brown and Lewis (2002) have proposed four stages of a developmental model of recovery. These are: active alcohol/drug use, transition to recovery, early recovery, and ongoing recovery. This model exemplifies the chronic and potentially relapsing nature of substance abuse. It depicts how the family caregiver burden might be different at each of the different stages of recovery. This is consistent with van Manen's (2014) singularity, alterity and vulnerability of human experience, which are discussed in chapter 3.

- ***Stage 1: Active alcohol/drug use:*** This is the first stage of the developmental model. In this stage, the affected family member is actively abusing substances. Impaired parental functioning may be a symptom of the family. Children might see the parent actively abusing substances and are also adversely affected by this use. This stage is depicted by chronic relapses.
- ***Stage 2: Transition to recovery:*** In this stage, the family is in chaos due to the addicted family member's substance use being out of control. Other family members feel

frightened by these changes. Usually a significant life event may be a vehicle to transition to recovery.

- **Stage 3: Early recovery:** At this stage, the addicted family member has realized that recovery is possible and is learning lifestyle skills that are not addictive. This stage is depicted by a decrease in impulses to abuse substances and the family environment may be calm and less chaotic. However, an underlying fear of relapse could create increased anxiety and tension. Also, significant others and children might feel neglected due to the recovery family member's presence in 12 steps and support groups. As Diamond (2002) noted, in families where addiction becomes the central organizing principle, the addictive substance is usually triangulated into relationships and deep rooted disagreements of unresolved trauma are often deflected into the use of the addictive substance. In this instance, when this substance is taken away, underlying issues which were masked during the active drug use are brought into perspective. For example, ineffective communicative patterns underlying family structures as a result of substance use are questioned when the addictive substance is taken away. In such a case if a new effective communication pattern is to be introduced into the family structure, the old pattern must give way to a new pattern. In this process of change, certain tenets of the old pattern are questioned leading to a chaotic family environment.
- **Stage 4: Ongoing Recovery:** Recovery is internalized, prolonged abstinence is archived, possibility to relapse is decreased and family systems begin to re-build.

Even during the phase of recovery, there is a constant fear of relapse that caregivers go through. Recovery itself is fraught with many meanings. There is the meaning of recovery as an objective outcome which is evident by a point devoid of



illness (Resnick, Rosenheck & Lehman, 2004). A more recent term or meaning refers to a subjective orientation a person attaches to hope, freedom of choice, and personal abilities irrespective of illness or health (Resnick et al, 2004). Recovery is a lifelong process which is perpetuated by hope, healing, empowerment, and connection (Resnick et al, 2004).

### **Study Rationale and Innovation**

Advancing knowledge of caregiver burden is important not only to support family caregivers but in order to improve outcomes (preventing relapse and sustaining sobriety) for substance abusers. Addiction, as with any other disease can be debilitating to families. The struggles, fears and uncertainties families go through as a result of addictive behaviors of a family member and even the destructive effects on the addicted family member are all phenomena with deeper meanings. The impact of substance abuse on individuals has been well documented but little is known about the burden of substance use on caregivers. Understanding addiction and its toll from the perspectives of caregivers will contribute to effective and efficient ways of involving them in the care of this population. Research is needed to understand this burden in order to identify strategies to offset caregiver stressors for improvement in health outcomes (Collins, 2011). “Acquiring a better understanding of the family burden has become increasingly important as families adopt a major role in the care of their relative” (Vaingankar et al, 2012, p.219).

Most caregivers reported subjective burden as the major area of concern. These feelings that are experienced during caregiving are also dependent on the persons’ appraisal of the situation. Subjective burden in caregiving has been noted for negative health sequelae and is as important in predicting treatment outcomes (Weitzner, Jacobsen, Wagner, Friedland & Cox,

1999). This demands that a thorough caregiver assessment which is multidimensional is needed to gather pertinent information about the caregiving experience to determine the needs, resources and strengths.

This study will explore the primordially of the human phenomenon of caring for family members with addiction using van Manen's phenomenology of practice (2014). This includes the original experience and moment of learning that a relative has an addictive behavior and the acceptance, decision making and support that follows thereafter. This moment calls for major decision making, encounters with treatment services, and the burden of care. Insights will be gained by reflecting on these experiences thereby allowing for deeper understandings of dimensions of meanings of the extraordinary and mostly ordinary decisions that relatives encounter. Knowledge gained from this study will provide insight to support the design of clinical interventions which are multidimensional for effective caregiver assessment, strategies to offset this burden, increase family involvement and supportive services to prevent relapse and sustain sobriety.

### **Conclusion**

Since the family is recognized as the most important protective factor in substance abuse treatment, future qualitative research is needed to address this theme (Diaz et al, 2009). The strong value given to family support also underscores the importance of exploring secondary stigmas in the coping process including gaining social support and engaging in risk reduction (Salter, GO, Gregowski, Rudolph, Latkin, Celentano, Quan, 2003). The protective factors seen in families necessitate the importance of designing studies that aim at finding ways to support families of the addicted individual. Therefore, this study will explore the family caregiver burden

of persons with alcohol and/or opiate abuse as it relates to their experience, decision making, and the alliance, resources and support available from healthcare providers.

## **Chapter 2**

### **Conceptualizing Family Caregiver Burden: the organizing framework**

#### **Introduction**

##### **Phenomenology and theory**

Phenomenology is both a philosophic and a research methodology (Bogdan & Bikled, 1992). “Phenomenology does not offer us the possibility of effective theory with which we can explain and/or control the world; rather it offers us the possibility of plausible insights that bring us in more direct contact with the world” (van Manen, 2014, p. 66). “Phenomenology studies the world as we ordinarily experience it or become conscious of it before we think, conceptualize, abstract, or theorize it” (van Manen, 2014, p. 65). As an example, in studying the caregiver burden of addiction, it is important to describe directly ways how this phenomenon arises and how it presents itself in the life of the caregiver. “It is the experience that is the ultimate bearer of meaning, not some theory, linguistic formation or abstractive construction” (van Manen, 2014, p. 65).

The philosophical underpinnings of this method will be used as an underlying framework; since “phenomenology reflection and analysis itself is sometimes referred to as theorizing and theory” (van Manen, 2014, p.67). These philosophical underpinnings will be further presented and explained in the next chapter. However, since the concept of family caregiver burden will be the focus of this study, it is important to clarify this concept for a better understanding of its usage in the literature.

##### **An overview of burden as a concept**

Burden as a concept has been commonly used in research studies as an outcome and/or predictor (Chou, 2000). However, burden as used in caregiver research lacks a general

acceptable operational/conceptual definition. There is thereby the need for a further clarification of this concept to ascertain its attributes and delineate its boundaries. Recent trends in involving families in the care of their relatives have become increasingly important to further study the burden families go through in the provision of care. Research studies on this concept cannot yield meaningful and significant results for practice if caregiver burden lacks conceptual clarification.

The purpose of this chapter is to provide a concept evaluation on family caregiver burden, its meaning to the caregivers of relatives with drug/alcohol addiction, its definitions, essential attributes, outcomes and future recommendations for conceptual work. It will also be determined whether this concept is matured to be used in nursing. The Morse, Mitcham, Hupcey & Tason (1996) criteria for concept evaluation will be the guiding framework. Morse et al's (1996) criteria is based on these four questions; is the concept well-defined, are the characteristics/attributes identified, are the preconditions and outcomes of the concept described and demonstrated, and are the conceptual boundaries delineated?

### **Literature Review**

Hilemain, Lackey & Hassanein (1992) defined a caregiver as a person who is unpaid to provide physical help or supports a person to cope with a disease. This definition refers to all caregivers other than nurses or other healthcare team members providing care for a fee. The Merriam-Webster dictionary defined burden as "bearing of a load". Burden in this sense is seen as something that is harsh, uncomfortable, overbearing, tormenting, intimidating or oppressive. This implies that providing care for a sick relative could be uncomfortable, overbearing, tormenting, or even oppressive to the caregiver. Braithwaite (1996) commented on caregiver burden as a situation where the care recipient's needs conflict with the caregiver's basic needs.

Lawton, Kleban, Moss, Rovine & Glicksman (1989) defined caregiver burden as “an external demand or potential threat that has been appraised as a stressor” (p. 61).

### **Historical perspective**

Grad & Sainsbury (1966) have been purported as the first to introduce the concept “family burden” in the scientific literature in their study of how communities care for the mentally ill. They noted that, the 1959 Mental Health Act (1959 Chapter 72 7 and Eliz 2) in the United Kingdom which came into force in 1960 led to an increase in community care of the mentally ill as opposed to psychiatric hospitals. Fifty years ago, President J.F Kennedy delivered a historic address to Congress on the state of the country’s mental health system. This federal initiative led to the closure of many state hospitals and state funded outpatient clinics with the hope that these will be “supplanted by the open warmth of community concern and capability” (Torrey, 2013, para 1). It is surprising to note that, despite this initiative of community re-integration of mentally ill persons from state hospitals, federal and state funding of community resources for the mentally ill have not been enough (Torrey, 2013). Torrey has stated that when President Ronald Reagan in 1981 decided to cut funding to Community Mental Health Centers (CMHC), not only was he killing these programs but rather, he was “disposing of the corpse” (Torrey, 2013, para 5). The enactment of the Americans with Disabilities Act (1999) seeks to re-integrate persons with mental illness into community settings rather than having them segregated in institutions. States are to make available community based long term psychiatric care (American with Disabilities Act, 1999). These major events led to families providing the needed care for their mentally ill relative.

Within nursing, the concept “family caregiver” did not appear in the discipline’s literature until the late 1980’s with studies done by researchers such as Archbold (1983), Philips

& Rempusheski (1986), and Bowers (1987). Pepin (1992) reported that the late entrance of the discipline into family caregiver's research was probably due to the fact that the focus of the discipline in that era was steered towards the conceptualization of nursing as a professional practice discipline. In as much as these were necessary important aspects of nursing in this era, it also led to a delay in the identification and clarification of important concepts critical to the discipline.

### **Defining the caregiver burden**

Nibert (2005) reported that, in the late 1950's, caring for a family member at home by a family caregiver was common. Early writers such as Hoeing and Hamilton (1966) expounded and dichotomized this concept. They divided burden into subjective and objective. Subjective burden was seen as the feelings associated with caregiving as family caregivers fulfilled their associated functions. Objective burden signified the experiences of events coupled with negative caregiving.

To accentuate the meanings of caregiving explicated by Hoeing and Hamilton (1966), Zarit, Reever and Bach-Peterson (1980) explained burden as the "extent to which caregivers perceived their emotional, physical, social life and financial status as a result of caring for their relative" (p. 261). Burden was thereby seen as a subjective perception and it involves the feelings and emotions attached to caring for the sick/impaired family member. Subjective burden is the social, psychological and emotional impact experienced by caregivers (Sales, 2003). Perceived subjective burden is also seen as the "caregiver's attitude or emotional reaction to the caregiver's experience" (Montgomery, Gonyea & Hooyman, 1985, p. 21). Objective burden is seen as the physical effect of day to day tasks caregivers undertake for their family members (Weitzenkmp

et al, 1997). It is also “the extent of disruptions or change in various aspects of caregivers’ life and household (Montgomery et al, 1985, p. 21).

Conceptually, the distinction between the objective and subjective burden is unclear as most studies have failed to make a clearer distinction between these two. However, studies that provide a deeper understanding of this concept are necessary for clarification of this distinction. Such studies provide the evidence of effective caregiver assessment and interventions. Also, clarifying and explicating burden into dimensions will enable future studies to develop instruments to measure this concept. For clarification of the concept of family caregiver burden in this study, burden will be dichotomized as objective and subjective.

A more recent trend in the literature takes a broader approach in the conceptual clarification of the burden of care (Chou, 2000). Perhaps the broadest definition of caregiver burden now encompasses “the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for a chronically ill or impaired individual” (Chou, 2000, p. 399).

### **Critical Attributes**

A characteristic feature of a concept is that its distinct attributes emerge in the literature repeatedly. Review of the literature and definitions revealed some distinct characteristics of this concept. These attributes emerged as a result of its frequent use in the literature.

### **Subjective/Objective perception**

The effect of a phenomenon on family caregivers may be different. This van Manen (2014) claimed as the “singularity of experience”. The ability of a caregiver to organize and use resources available based on the interpretation of demands of the sick person (Romeis, 1989) is



very critical to the perceived subjective/objective burden. This evaluation process is weighed in light of the level of impairment of the sick person.

### **Multidimensional phenomena.**

The care giver burden has been claimed to have a multidimensional characteristic (Chou, 2000). Its dimensions include but are not limited to physical, financial, psychological and social (Chou, 2000). It also covers other domains such as spirituality of the caregiver (Woods, Haberman & Packard, 1993). Caregivers may not necessarily perceive all these dimensions at one time (Chou, 2000) and burden has been purported to change in relation to the sick family member's demands, level of impairment and resources available to the caregiver. A caregiver's adaptation to this burden is also purported to change over time as new coping skills/problem solving skills are developed to effectively deal with competing situations and demands (Perlick, Clarkin & Sirey, 1995). Moreover, inadequate resources to meet the demands of caregivers may make caregivers feel burdened (Chou, 2000) and lead to emotional feelings of being overburdened (Corbin & Strauss, 1988).

### **Pre-Conditions/Outcomes**

For family caregivers to feel burdened there should be certain pre-disposing conditions. These are factors that heightened or lessen feelings of perception of a concept (Walker & Avant, 1988).

Social demographics play an important role in the perception of the burden of care. A caregiver's gender plays a crucial role in how burden is perceived. Chou (2000) purported that; burden of care is experienced by women and men differently because of societal/sex roles of genders. A typical care giver in the U.S is a woman under age 75, spends about 20 hours per week in caregiving, is employed full time and earns lower wages (Family Caregiver Alliance,

2006). This explains that women are likely to experience more feelings of burden than men in caregiving. Perceived burden of care also depends on caregiver's financial resources. Example, a caregiver with adequate financial resources might be able to assess the necessary services for the care recipient. Financial aspect of caregiving may be less of a burden.

A caregiver's income determines how many services can be purchased to alleviate caregiver burden (Loomis & Bote, 1995). Access to resources lessens the burden of care. Moreover, filial relationships, race, culture and readiness to help are all preconditions that affect the burden of family caregiving. Caregiving decisions are made based on varying cultural values (McCubbin, 1993). For example in cultures with the extended family structure as its underpinnings, caregivers may perceive less burden as there might be some assistance or support from other family members.

### **Outcomes/Consequences**

The burden of family caregiving has both negative and positive consequences/outcomes. A number of studies (Marcon et al, 2012, Biegel et al, 2007, Brown et al, 2011, Coppel, Burton, Becker and Fiore, 1985) have reported caregivers being burdened by the psychologic problems of increased anxiety, depressive symptoms, worry and guilt. Family caregivers are more likely to report poor psychologic health compared to non-caregivers with a matched age (Monsen, 1999, Ostwald, 1997). Also the psychological and/or the physical state of the caregiver correlate with the psychologic health of the care recipient (Chou, 2000). Caregivers' negative feelings and personal distress may lead to care recipients' withdrawn behaviors or mood disturbances (Bennett, 1994, Corbin & Strauss, 1988). Evidence suggests that caregivers' increased responsibilities may negatively impact their physical and mental health. The deterioration of caregivers' health can result in poor health outcomes of care recipients (Grady & Rosenbaum,

2015). Further, deterioration of care recipient psychologic health has a multiplier effect on the overall physical/psychologic health of caregivers (Chou, 2000). Family conflicts coupled with the financial cost of caregiving to families are outcomes of family caregiving. Caregivers usually spend a considerably amount of time in caregiving thereby limiting their work hours and hence their income.

Caregiving also has an overall impact on healthcare spending. The economic value of informal caregiving if these services were provided by a paid caregiver is estimated at \$450 billion in 2011 (AARP, 2011). This exceeds all federal and state Medicaid spending in 2009 and it accounts for approximately 2.9% of U.S total Gross Domestic Product (G.D.P) in 2009 (AARP, 2011).

Family caregiving overall also has positive effects. Review of the literature has reported positive conceptualization of caregiving as caregiver esteem, uplifts of caregiving, caregiver satisfaction, finding or making meaning through caregiving, and gain in care giving experience (Hunt, 2003). These positive effects of caregiving may lessen the burden of care. This important aspect of family caregiving will be explored in this study. For these reasons, this study will explore a conceptual definition that includes both positive and negative dimensions associated with burden of care.

### **Related Concepts/Boundaries**

Competing concepts of family caregiver burden are: caregiver strain (Pearlin, 1994; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Archbold, Stewart, Greenlick, & Harvath, 1990), caregiver stress (Cohen, Kamarck, & Mermelstein, 1983; Nolan, Grant & Ellis, 1990), and hassles of caregiving (Kinney & Stevens, 1989; Kinney, Stephens, Franks, & Norris, 1995). The line among these concepts is blurred. Caregiver burden however is a much broader concept

which encompasses the hassles, strain, and stress of caregiving. These concepts have been noted in the literature as not caregiver burden (Chou, 2000). For example, hassle, strain or stress can be used as descriptors of caregiver burden.

### **Conclusion**

Based on Morse et al's (1996) criteria for concept evaluation, it can be deduced that family caregiver burden is not a mature concept. Though the characteristics/attributes have been identified, outcomes and preconditions described or demonstrated and conceptual boundaries delineated, it is evident in the literature that there is a dearth of research studies and a lack of a general acceptable definition of the concept. There is agreement in the discipline of nursing of the importance of paying greater attention to the needs of family caregivers. Future studies should focus on the cultural/gender differences, quality of care/quality of life of family caregivers, support, multiple concepts involved in caregiving, and development of physiologic/self-report measuring scales.

The use of qualitative research methods can contribute to the maturity and advancement of concepts. Qualitative approaches can enhance ongoing development of theories and hence knowledge in nursing (Finfgeld-Connett, 2006). Phenomenological studies provide one of the avenues for developing the knowledge base of the discipline in caregiver research. Such studies provide a deeper understanding of the sources of support, multiple concepts of caregiving, and decision making that family caregivers encounter in the care of their sick relative. Also, understanding the various multifaceted layers involved in caregiving will enable nurses to develop strategies, better understand the burden of care and the importance of involving families in the care of their relative. This study will further refine this concept and provide a deeper

understanding of the burden of care of family caregivers as it relates to caring for the relative abusing alcohol and opiates.

### Chapter 3

#### The Method of Phenomenology of Practice

*This text is an invitation to openness, and an invitation of openness to phenomenologies of lived meaning, the meaning of meaning and the originary sources of meaning.*

(van Manen, 2014, p. 15)

This study utilized a qualitative methodology; phenomenology of practice as described by Max van Manen 2014. Phenomenology of practice is an interpretive form of inquiry which combines philosophical, philological, and human science methods. The main purpose of this study was to provide insight by exploring and identifying the eidetic meaning of the family caregiver burden of addiction from the perspectives of family members. An overview of phenomenology of practice as described by van Manen will be discussed in this chapter, including approaches to this method and a description of the proposed study. It is important to note that Phenomenology of Practice is a new method of research and there are few published studies in the literature. However, utilizing this approach in this study adds to existing methods in developing knowledge in nursing. The philosophical underpinnings of this method are more applicable during data collection and analysis. For example the approach of “wonder” can only be applied by the researcher during the moment of encounter with the research participant. In wonder what is ordinary becomes extra ordinary when data is analyzed with a reflective gaze.

#### Phenomenology of Practice

Phenomenology of practice is an interpretive inquiry that addresses and provides the “practice of professional practitioners as well as the quotidian practices of everyday life” (van Manen 2014, p. 15). This implies that, the meaningful aspect of a phenomenon is of value to

practicing practitioners. As van Manen (2014) postulated, “Phenomenology of practice is for practice and of practice” (p. 15). Our understanding of the eidetic meaning of a phenomenon enhances our practical understanding of that phenomenon. The phenomenological research value of phenomenology of practice: “reflects on and in practice, and prepares for practice” (van Manen, 2014, p.15). By this, the focus of this qualitative methodology is not technicalities and instrumentalities (van Manen, 2014). In as much as a research methodology should be methodical and organized; phenomenology of practice provides an approach with methodological guidelines yet is not mechanistic. This method is appropriate for this study because it seeks to uncover the eidetic meaning of the human phenomenon of addiction from the perspectives of family caregivers: the moment caregivers learned of a relative’s addiction problems, acceptance and nature of support, and the decision making processes that follow thereafter as they seek to care for their relative. The philosophical underpinnings of this methodology suit this study because it allows for innovation, and resourcefulness in seeking meanings of the phenomenon under study. Phenomenology of practice embodies the “ontology, epistemology and axiology of thought and thoughtful action” (van Manen, 2014, p.15).

### **Phenomenology as a Method**

Phenomenology as a method abstemiously reflects on structures of lived experience (van Manen, 2014). This notion ascribes to reflection that is devoid from “theoretical, polemical, suppositional and emotional intoxications” (van Manen, 2014, p.26). This calls for a prereflective account of human experience that is prior to meditation or theoretical reflection (van Manen, 2014). The phenomenological method of assessing human consciousness prereflectively is not a prescribed approach consisting of multiple steps or a series of rules (van Manen, 2014). Phenomenology as a method is not just a technique or a set of procedures but an

approach sensitive to and suiting a particular phenomenon of interest. By this, there is not one phenomenological method but a “concept of method” that expresses “to the things themselves” (Heidegger, 1927, 1962, p. 24, Husserl, 1913/1982, p. 35). This requires the application of a unique phenomenological approach to explore what is given in a lived experience. As Heidegger 1975/1982 claimed “when a method is genuine and provides access to the objects, it is precisely then that the progress made by following it and the growing originality of the disclosure will cause the very method that was used to become necessarily obsolete”. (p. 328). Phenomenology is seen as a “method of methods” (van Manen, 2014).

Pathos, as van Manen claimed is what drives the phenomenological method; “being swept up in a spell of wonder” about how a phenomenon appears, shows, presents, or gives itself to us (van Manen, 2014, p. 26). For a phenomenon to give itself, one has to be in a state of wonder. “Phenomenology is more a method of questioning than answering, realizing that, insights come to us in that mode of musing, reflective questioning and being obsessed with sources and meanings of lived experience (van Manen, 2014, p. 27). In a state of wonder, the extraordinary is seen in the ordinary, when we hold daily existence with our phenomenological gaze (van Manen, 2014). By this, wonder is not amazement, marveling, admiration, curiosity or fascination (van Manen, 2014). Wonder is thereby letting yourself be in a state where the phenomenon under study presents itself or speaks to the inquirer. Phenomenological study thereby begins in a state of wonder (van Manen, 2014). This state of wonder is accentuated in a phenomenological reflection and analysis which occurs in the approaches of epoché, reduction and vocative.



### **The Philosophical Methods (Epoché and Reduction)**

The epoché/reduction has been considered to be a great discovery of Husserl and is seen as the basic method of phenomenology (van Manen, 2014). This phenomenological method is complicated and has been explained and understood in various ways as is evident in the philosophical literature. The methods of the epoché and reduction “are the great ways to gain access to the meaning structures of a phenomenon” (van Manen, 2014, p. 216). Reduction is taking up a reflective attitude towards the way we experience the world. As Merleau-Ponty (1945/1962) pointed out, “I posit of knowledge when...I adopt a critical attitude towards it and ask ‘what I am really seeing’. The task of radical reflection....consists, paradoxically enough, in recovering the unreflective experience of the world....and displaying reflection as one possibility of my being” (p. 280).

Lived experience, which is understood as the world we live through, takes root in the attitude of reduction. However, this attitude in questioning lived experience to gain insight into a phenomenon is analytical, tentative and rigorous. This attitude of questioning is situated in wonder; a quest to uncover/unravel the threshold of a phenomenon (van Manen, 2014).

#### **Gestures of the reduction**

As has been noted, reduction as a construct has been understood in many ways as evident in the philosophical literature. Reduction is achieved when the epoché and the reduction proper amalgamate. Epoché referenced back to Greek skepticism. Epoché, as commonly understood means lying aside, setting aside, stepping back, forfeiting or taking away anything that obstructs how a phenomenon gives or shows itself. A more commonly misunderstood term; “bracketing” relates to suspending judgments about the world (natural attitude). When the phenomenological attitude is brought in, beliefs, opinions and theoretical perspectives are suspended and a

phenomenon is given purely devoid of abstraction or conceptualization (reduction proper).

Epoché is essential in that it allows an understanding that enables a gaining of insight into a phenomenon (wonder).

### **Approaches to epoché-reduction.**

The basic idea of the epoché-reduction is to reflect on the world as we live it in the natural attitude (van Manen, 2014). Epoché-reduction opens “oneself to experience as lived-how certain phenomena and events are constituted and give themselves in lived experience” (van Manen, 2014, p. 222). As noted, epoché (bracketing or suspending beliefs) and reduction (reflection) have been fraught with so many meanings which are confusing and complex (van Manen, 2014). Epoché and reduction can thereby be “distinguished for their heuristic and methodological usefulness” (van Manen, 2014, p.222). The methodological moments of epoché-reduction are; wonder, openness and concreteness, which will be described further below;

#### **Heuristic epoché-reduction: wonder**

Wonder lies in the heart of awakening a profound sense of interest in a phenomenon (van Manen, 2014). As van Manen (2014) opined, “wonder overwhelms but should not be confused with curiosity, fascination or admiration” (p.223). Wonder is seeing the unusual in the usual, the extraordinary in the ordinary, strange in the familiar (van Manen, 2014). Wonder encapsulates a phenomenon by bracketing the everyday taken for granted natural attitude to awaken an insightful true sense and understanding of a phenomenon of interest (van Manen, 2014). Wonder thereby becomes a quest to explore meaning.

#### **Hermeneutic epoché-reduction: openness**

This method involves “bracketing all interpretations and explicating reflectively whatever assumptions seem to need attention in writing the research text” (van Manen, 2014, p. 224). It is

important to be aware of beliefs, assumptions, preunderstandings of frameworks, theories that relates to the political, psychological and ideological nature, and motivation of the research question (van Manen, 2014). It is imperative that one must be open genuinely to the preconceptions and preunderstandings of the phenomenon under study. To arrive at this, there should be a critical self-reflection to overcome subjective inclinations, and private feelings of the phenomenon under study (van Manen, 2014). Notwithstanding this, “forgetting one’s preunderstanding is not really possible and therefore these various assumptions and interest may need to be explicated so as to exorcise them in an attempt to let speak that which wishes to speak” (van Manen, 2014, p.224). Anything that will impede the understanding of the phenomenon under study needs to be brought to “bare” through a critical self-reflection/awareness. This will lead to a reflective gaze free from expectations or inclinations.

### **The experiential epoché-reduction: concreteness**

In epoché-reduction, “experiential reduction suspends abstractions in favor of concrete experiential facilities” (van Manen, 2014, p.225). By this, all abstractions, theorizations and constructions are suspended to enable a concrete experience of the phenomenon under study. Abstractions, theorizations, conceptions and thematizations that overlay a phenomenon need to be stripped away to enable the phenomenon to be seen in a non-abstracting way (van Manen, 2014). In bracketing theoretical meanings, it is important “not to ignore it but to examine it for possibilities of extracting phenomenological sensibilities” (van Manen, 2014, p. 226).

### **The methodological epoché-reduction approach**

In this method, all conventional techniques are bracketed and the researcher “invents an approach that might fit most appropriately” the phenomenon under study (van Manen, 2014, p. 226). This requires “sensitive interpretive skills and creative talents from the researcher” (van

Manen, 2014, p.226). A rationality that is flexible is necessary in inventing an approach in the study of a phenomenon that embodies a scholarly creativity and original manner (van Manen, 2014). This requires “heuristic attentiveness, creative insight, interpretive sensibility, linguistic sensibility, and scholarly preparedness and tact (van Manen, 2014). An experiential account gained from the phenomenon is a “concrete plausible example of a possible human experience” (van Manen, 2014, p. 227). Phenomenology allows access to the participants’ inner life to gain insight into their feelings and experience of a particular phenomenon in a particular moment (van Manen, 2014).

### **The eidetic reduction; eidos or whatness**

This involves the grasping of insight which is essential in gaining meaning of a phenomenon (van Manen, 2014). The eidetic reduction “seeks to describe what shows itself in experience or consciousness and how something shows itself” (van Manen, 2014, p. 229). This enables what is distinct about the phenomenon under study to be revealed. By this method, subjective meanings are bracketed to allow a meaningful possible variant of the phenomenon (eidos). The eidos from a Husserlian perspective make a phenomenon what exactly it is (van Manen, 2014). This is accomplished by comparing the phenomenon under study to related but different phenomenon (van Manen, 2014). In this study, the phenomenon under study, which is caregiver burden, was compared to related phenomenon such as caregiver stress, caregiver strain, hassles of caregiving etc. These comparisons were deduced from the literature and participants’ understanding of these concepts.

### **The Philological Methods: The Vocative**

This method relates to phenomenological writing (text). This text is the vocative process of the research. Vocative as in the word “vicare” means to call. Max van Manen (2014) has outlined

these moments of the vocative; lived thoroughness, nearness, intensification, pathic and epiphany.

### **Revocative method: lived thoroughness**

This method involves bringing the experience vividly into presence. This was done through including real life experiential material, anecdotes, expressive narrative or qualitative imagery (van Manen, 2014). In this manner, the experience of the phenomenon is placed concretely in the real life world (van Manen, 2014). This enables readers to unreflectively recognize the phenomenon experientially.

### **The evocative method: nearness**

The evocative method “lets the text speak to us in an addressive manner so that its reverberative meanings seduce us to attentive recognition” (van Manen, 2014, p. 249). In this sense the experience is taken from its theoretical perspective into the reader’s immediate presence through anecdotes. The anecdote is “the most common device by which people talk about their events” (van Manen, 2014, p.250).

### **Structure of anecdote**

The following outline has been suggested by van Manen (2014) for gathering narrative material or for editing lived experience descriptions:

1. An anecdote is a very short and simple story
2. An anecdote usually describes a single incident
3. An anecdote begins close to the central moment of the experience
4. An anecdote includes important concrete details.
5. An anecdote often contains several quotes (what was said, done, and so on)
6. An anecdote closes quickly after the climax or when the incident has passed.

7. An anecdote often has an effective or “punchy last line”; it creates a punctum.

**The invocative method: intensification**

The aim of the invocative method is to intensify “the philological aspects of the text so that the words intensify their sense and sensuous sensibility” (van Manen, 2014, p.260). Invoke comes from the word “invocare” meaning to “call upon, to summon, to appeal, to implore, to conjure, to bring about, to call forth by incantation” (van Manen, 2014, p. 260). This was achieved through phenomenological text that enabled words and phrases to bring forth their full value. This allowed the phenomenological meaning which was embodied within the text to show itself.

**The convocative method: pathic**

This method “aims for the text to possess the (em) pathic power to appeal ---- so that its life meaning speaks to, and makes a demand on the reader” (van Manen, 2014, p. 267). The phenomenological text explicates meaning and also illuminates the reader’s understanding of the meaning.

**The provocative method: epiphany.**

This method “articulates the kind of ethical predicaments that are suggested in the phenomenon that is being studied, and what are the active normative responses (advice, policies, tactful practices...)” (van Manen, 2014, p.281). To provoke, from the word pro-vocare means “to call forward, to challenge, to incite, to stir up, to arouse to feeling, to quicken, to excite” (van Manen, 2014, p. 281). A phenomenological text must call forth, challenge, stir up, or excite actions. Its transformative effect enables the reader to grasp emerging meaning with insightful understanding of the phenomenon. That is, the formative value of phenomenology is expressed in this method: “what it does with us”.

## **Human Science Methods**

Phenomenology of practice relies on human science empirical methods in the collection of experiential data for insightful phenomenological meaning. In as much as this type of approach is employed by other qualitative methodologies, when used in phenomenology, it assumes a distinct feature. Empirical methods used in phenomenology aim “to gather pre-reflective experiential accounts” (van Manen, 2014, p. 311). Empirical methods outlined by van Manen that can be utilized in research include but are not limited to: personal descriptions of experience, lived experience descriptions (written accounts), interviewing for experiential accounts, observations, anecdotes, and narrative stories. The interview method may also be used to collect lived experience descriptions for anecdotal accounts. It is of worth to note that, phenomenological interviews and observations require the researcher to adapt the phenomenological attitude as exemplified by epoché and reduction. These philosophical underpinnings were accounted for during data collection. Due to time and ethical constraints and nature of the research question, in the proposed study the interview and observation method was the primary source for collecting experiential materials. The approach followed in this study will be described below.

## **Sample and Setting**

The aim of phenomenological studies is to collect experiential material of the phenomenon being studied. Since phenomenological studies do not allow for empirical generalization, it is non sensical to seek for a larger sample size (van Manen, 2014). Sample size in phenomenological studies should be enough to “gain examples of experientially rich descriptions” (van Manen, 2014). In determining the sample size of a phenomenological study, the answer should not be based on some kind of statistical criterion but on the nature of the

phenomenological question (van Manen, 2014). It is important to note that a phenomenological study should “gather enough experientially rich accounts that make possible the figuration of powerful experiential examples or anecdotes that help to make contact with life as it is lived” (van Manen, 2014, p 353). A larger sample size may produce too many transcripts which may lead to shallow reflection (van Manen, 2014). It has been recommended that researchers interview 5-25 individuals who have all experienced the phenomenon (Polkinghorne, 1989). A sample size of ten is usually enough to gather rich experiential material of the lived experience thereby allowing for a deeper reflection. Ten participants were recruited for this study.

Employing phenomenal variation enabled cases rich in information to be captured for saturation.

A purposive sampling technique was used to identify participants for this study.

Phenomenal variation; a type of purposive sampling (Sandelowski, 1995) was utilized to identify caregivers of persons with alcohol and/or opiate abuse. This type of sampling included variation in length of diagnosis, time of diagnosis, and length of caregiving. This allowed for rich experiential material. Snowballing technique as described by Polit and Beck (2008) was utilized to ask previously interviewed participants to recommend other family caregivers who may be interested in study. Approximately ten participants were recruited from two hospital-based mental health centers within a health care system in the Northeastern United States. The researcher obtained permission from the health system’s Institutional Review Board to use these centers as data collection sites. Van Manen’s approach allows the researcher to be resourceful by identifying participants with rich experiential materials. Clients seeking care are usually brought to these centers by persons providing caregiving in terms of emotional and/or physical support. These persons were targeted as the accessible population. Alcohol was the most common abuse substance among these clients seeking care. Study flyers was handed to caregivers of persons



with alcohol and opiate dependence inviting them to participate in the study. These recruitment procedures were followed;

- Researcher was available to describe study and recruitment procedures to staff.
- Study flyers were given to staff (therapists, nurses, social workers, and counselors) to be handed to caregivers of persons with substance abuse who might be interested to participate in this study.
- Study flyers were made available in the waiting rooms of these centers (outpatient and inpatient psychiatric treatment centers).
- Caregivers interested were asked to call the researcher on a designated number.
- Researcher explained purpose of study to prospective participants, voluntary nature of participation, answered any questions and concerns, and set up interview.
- Informed consent was obtained prior to interview. This was done through a fact sheet.
- A number was assigned to participants to protect confidentiality and anonymity.

An interview method of collecting data was used and it was conducted in participant's home or in other places deemed necessary and safe. Semi-structured in-depth phenomenological interviews were utilized with each participant. Also, field notes and participant observation were utilized. These took into account events and processes observed during data collection, participants' body language, facial cues, and non-verbal language when certain key moments of this experience were being explored.

### **Inclusion criteria**

Primary caregivers were defined as persons who identify themselves as providing primary support in terms of treatment decisions, financial, emotional, and/or physical support to a loved one with substance abuse problems. Primary caregivers are persons who have close relatives

with opiate and/or alcohol problems. Close relatives are: wife, husband, son, daughter, or son or daughter in-law. These close relatives were not necessarily living with the primary caregiver.

Inclusion criteria include:

- Primary family caregivers providing physical and emotional support to persons with opiate and/or alcohol abuse.
- English speaking and 18 years or older.
- Cognitive capacity to give a written informed consent to participate in the study.  
Cognitive capacity was determined by a mini mental status exam.

#### **Exclusion criteria**

- Caregivers of persons whose primary drugs of choice were not alcohol and/or opiate.
- Non English speaking.
- Less than 18 years.
- Non family caregivers.
- Individuals without the cognitive capacity to provide informed consent. Also, caregivers who were chemically impaired were excluded from the study.

### **Procedure**

#### **Human Subjects Protection**

Institutional Review Board (IRB) approval was obtained from the healthcare system and informed consent was obtained from all study participants. Participants were provided an explanation of the purpose of the research, procedures, risk and benefits, voluntary nature of participation, and procedures to be used to protect confidentiality.

Qualitative interviews were utilized, taking into consideration interview burden on participants. This topic explored a sensitive area of participants' lived experiences. During the

interview, the emotional state of participants was assessed and participants was made aware that, they are not obliged to discuss anything that would make them feel uncomfortable. If a participant became emotionally upset during the interview, the following procedures were to be followed:

- First, the interview will be stopped. Researcher is a psychiatric registered nurse and thereby is trained and knowledgeable to do an initial assessment on an emotionally distraught person.
- If it is deemed that a participant is emotionally distraught with suicidal or homicidal ideation/intent, emergency care will be sought by calling 911. Researcher will stay with client to provide emotional support and the rationale for the need of this intervention until help arrives. Participant will be responsible for all cost of services.
- If a participant denies any suicidal or homicidal intent or ideation but is emotionally distraught without any psychosis, agitation or irritability, participant will be offered to be sent in a taxi cab to the nearest emergency room for further evaluation and care. Researcher will pay for the cost of the taxi services. Any other cost associated with the services at the hospital will be the responsibility of the participant.
- If a participant is not distraught but is emotional and tearful, he or she will be reminded of the voluntary nature of their participation in this research. Participants will be encourage to seek counselling and therapy with their healthcare providers.
- Also, participants were made aware of the availability of professional counseling services and other psychiatric emergency services. Participants will be referred to these services if the need arises. Participants were made aware that study does not provide payment for these services.

These protocols were developed but not utilized in the study.

### **Interview Approach**

Phenomenological interview is a “means for exploring and gathering experiential material (van Manen, 2014, p. 314). This mode of interview aims for a pre-reflective account of experiential material in the form of stories, narrative materials or anecdotes (van Manen, 2014). The purpose of the phenomenological interview is not socio-psychological /personal opinions, interpretations or cultural narratives but just a mode of getting people to narrate their lived experience of the phenomenon under study. A challenge of phenomenological interview is to get participants to actually narrate their experiential account pre-reflectively (van Manen, 2014). The following modes as explicated by van Manen (2014) served as a guide for the interview process.

**Where:** conducting an interview in a formal setting such as university offices or specifically interview room is not always the best method for accessing pre-reflective experiential materials (van Manen, 2014). Participants are best able to share their experiential accounts prereflectively if the environment is conducive. In this study, participants were allowed to choose a place that is conducive and safe. Researcher was open to places such as homes, or other settings that feel right to the participant and provide a quiet private environment to conduct the interview about this sensitive topic.

**Who:** If the phenomenon being studied touches on fragile and sensitive topic (such as in this study), the researcher should be personable in order to develop rapport and to win the trust of participant (van Manen, 2014). In this study a therapeutic relationship of personal sharing and friendliness were developed before seriously easing into the topic of interest.

**When:** Interviews should not be arranged or done in a haste or rush (van Manen, 2014). Time and anniversary of significant events are crucial in accessing participants’ pre reflective

experience. As van Manen (2014) emphasized “it usually takes a bit of time before one may then ease into a more focused questioning.....good interview takes time (van Manen, 2014, p. 315). Participants were allowed to choose a time and schedule of the interview. The phenomenological interview should be seen as a conversation (van Manen, 2014). Conversational interviews require the “right kind of tone and atmosphere” (van Manen, 2014, p. 315). Atmosphere for such interviews are better done in the evening than early morning (van Manen, 2014). This was taken into account when scheduling interviews. Additionally, recruitment was not done during the winter holiday season as this is typically a sensitive period for families.

**Why:** The phenomenological question (research question) will be the central focus of this interview. By this, the question under study should instill a sense of wonder and openness to the phenomenon (van Manen, 2014). The purpose of this is to let the instilled wonder animate the conversation.

**How:** The interview was taped as described earlier. Also, it was important to clarify some concepts (caregiver burden) being used in this study and to generate explorative questions about this phenomenon using language that is understandable to the study participants.

The research question should always be the focus of the phenomenological interview. Also during the interview, the researcher should be aware of emerging stories of the phenomenon and to ask for experiential material that is detailed and rich (van Manen, 2014). In this study the researcher stayed close to the lived experience by asking for concrete examples. For example, specific instances, situations, events, how when, what exactly happened, events following thereafter, what was said and not said etc. Participants were asked to give real life experiential accounts of the caregiver burden. To achieve this, participants were asked to describe a “key moment” of the phenomenon: the caregiver burden of addiction. It was imperative not to ask for

interpretations, speculations or explanations to prevent exploring the narrative to its fullest extent. There was a self-critique and self-awareness, insightfulness, honesty, openness, curiosity and quizzical attitude. As a healthcare provider of persons with addiction problems, it was important to acknowledge these experiences. At the start of this study, a journal was kept about suppositional, political, ideological and theoretical knowledge about the topic under study. Also, a reflective journal highlighting thoughts and feelings was kept throughout the study.

### **Data Collection**

This study collected experiential material of the lived experience of caring for a loved one with alcohol and opiate dependence problems. This was done through the interview process by asking participants to describe this experience with examples and personal stories.

### **Data Management**

All interviews were audiotaped and transcribed verbatim. A professional transcriptionist was used. Each participant's interview was assigned a code. Each transcript was labeled to correspond with the assigned code number. For easy access, electronic copies of the transcripts was stored on an encrypted research drive which was purchased through the University of Massachusetts Medical School. Descriptive statistics were used to summarize demographic information. Demographic information collected included gender, age, race, length of diagnosis, and occupation etc. This was used to describe caregivers' characteristics.

### **Data Analysis**

#### **Reflecting on experiential material**

Max van Manen has explicated various methods to reflect on experiential material which was utilized in the study. These are,

***Thematic reflection;*** meanings embodied in the text of the interviews were be attended using macro and micro thematic levels. At the macro thematic level, these texts were attended as a whole. Micro thematic level selectively attends to passages, phrases, words of the text. The aim is to gain new insights into invariant and variant meanings of a phenomenon.

***Guided existential reflection;*** insight into the phenomenon of addiction was gained through exploring meanings and possibilities other than some predestined formula or mechanical way of doing things. Heuristic life world themes such as corporeality (lived body), temporality (lived time), spatiality (lived time), relationality (lived other), and materiality (lived things) were explored.

***Linguistic reflection;*** close attention was paid to the language participants used to describe the phenomenon of addiction. This involved reflecting on the sources of words (etymology) and conceptually exploring similarities and differences in meanings of words.

***Exegetical reflection;*** texts were read with sensitivity and criticality. Here, related phenomenological literature was explored to seek meanings.

### **Methodological Rigor**

Max van Manen's (2014) criteria for evaluative appraisal of phenomenological studies was used to establish methodological rigor. This includes the components of heuristic questioning, descriptive richness, interpretive depth, distinctive richness, distinctive rigor, strong and addressive meaning, experiential awakening, and inceptual epiphany. These will be described below.

#### **Heuristic questioning**

Phenomenological text should induce and incite a sense of wonder and questioning (van Manen, 2014). Wonder is achieved during the data collection and analysis process. To induce

wonder, participants were asked to give concrete examples of the phenomenon (what this is) that is unique (does this exist) of the lived experience focusing on “that instant when an insight arises that is totally unique to a certain example” (van Manen, 2014, p 353).

### **Descriptive richness**

Phenomenological text should contain rich and “recognizable experiential material” (van Manen, 2014, p. 355). Recognizable experiential material should be narrative and is that which is essential or universal about the phenomenon.

### **Interpretive depth**

Phenomenological text should offer “reflective insights that go beyond the taken-for-granted understandings of everyday life” (van Manen, 2014, p. 356). Data collected and text deduced from the data should show reflective quotations and extraordinary insights.

### **Distinctive rigor**

Phenomenological text should be guided by a critical self questioning. This was achieved by including experiential material that has a distinct meaning of the phenomenon being studied.

### **Strong addressive meaning**

Phenomenological text should offer a strong embodied meaning of the phenomenon. This was achieved through text that attends to our embodied, communal, temporal, or situated self (what phenomenology does to us).

### **Experiential awakening**

Phenomenological text should awaken primordial understanding through vocative and persuasive language.



## **Inceptual epiphany**

Phenomenological studies should offer the possibilities of deeper understanding of the phenomenon. This awakening should provide insight for professional practice, human actions, ethics and life meanings.

### **Summary**

This research study utilized the van Manen phenomenology of practice method. Phenomenology is not just a research method but more also a philosophy (Dowling, 2005). As a research method, phenomenology seeks to explore a phenomenon as it is lived. Exploration of a human phenomenon allows it to “lay bare and exhibit the ground of a phenomenon yet while preserving it in its entirety” (Heidegger, 1927/1962, p. 23). It is a “direct and primitive contact with the world” (Merleau-Ponty 1945/1962, p. vii). Phenomenology in the context of practice thereby allows a phenomenon to be understood not only in a scholarly capacity but in a way that provides insight for practice and thoughtful communication (van Manen, 2014). It is “a philosophic method for questioning” (van Manen, 2014, p. 29). “And the critical questioning of the meaning and pursuit of the originality or inceptua; source of lived experience assures an openness that is a condition for discovering what can be thought and found to lie beyond it “ (van Manen, 2014, p. 40-41). Understandings and insights gained produced pathic existentialities giving us glances into the singularities of possible human experience (van Manen, 2014). Phenomenology as a method involves philosophical (reduction), human science (gathering experiential material) and philological (writing phenomenological text; the logos) (van Manen, 2014). A distinctive feature of phenomenology of practice is its focus on reflection, singularity of experience, and moment of human phenomenon.

Phenomenology allows the researcher to transcend or suspends previous knowledge in order to understand a phenomenon at a much deeper level (Meleau-Ponty, 1962). It is an attempt to approach a “lived experience with a sense of newness to elicit rich and descriptive data” (Creswell, 2007, p, 262). As a healthcare provider for persons with addiction and substance abuse problems, it was necessary to acknowledge and attempt to bracket these experiences. A research study using phenomenology is successful if it touches on the lived experience, which is very distinct from theoretical explanations (Colaizzi, 1978).

*Looking at human behavior is like running into a cloud  
whose origins and direction is unknown.*

*You can see the cloud, dynamic and three dimensional,  
but when you reach out to grab a handful to test,  
you come away with nothing visible but a clenched fist.*

*You may be buffeted by the forces within the cloud that moves on,  
still visible and dynamic and still three dimensional and you think*

*" I can see the cloud, I can feel the forces it contains,  
but how do I study it when it refuses to lend*

*itself to anything more than a fleeting encounter". (Wright, 1966).*

## **Chapter 4**

### **Findings**

#### **Introduction**

As Chinn and Kramer (2011) noted, the phenomena that are of concern and central to the discipline of nursing “are rather elusive-phenomena that nurses know exist and deal with on a daily basis yet are difficult to describe and fully understand” (p. 152). Understanding this as a discipline and relating it to our knowledge development will enable us to re- focus on the substance of the discipline. Scholars of the discipline should raise philosophical questions about the phenomenon central to nursing. The importance of philosophical thinking cannot be overlooked in a discipline’s knowledge development. Philosophically inclined discourse arouses dialogue, reflection and intuition which enhance knowledge development (Meleis, 1987). The

central focus of the discipline requires a new revision of the discipline's knowledge development to focus on the substance of the discipline (Meleis, 1987). The substance of the discipline consists of phenomenon and concepts unique to the discipline of nursing (Donaldson & Crowley, 1978). The phenomenon of caregiver burden as it relates to alcohol and opiate addiction is no exception. Patient centered care with a focus on family involvement, dignity and respect, and information sharing has emerged as an important concept in this century as it relates to healthcare. Acquiring a better understanding of the family burden has become increasingly important as families adopt a major role in the care of their relative (SAMHSA, 2010).

Max van Manen's (2014) phenomenology of practice qualitative design was used to explore the lived experience of family caregivers who have a relative with opiate and/or alcohol dependence problems. Phenomenology thus becomes "the study of a possible human experience, not just an individual person's experience" (van Manen, 2013, p. 37). This chapter discusses the findings of the study.

### **Sample**

A total of ten (10) family caregivers participated in this study (N = 10). Purposive sampling techniques were used to identify participants for this study. Phenomenal variation, taking into consideration length of diagnosis, time of diagnosis, length of caring, relationship, type of substance use, was utilized to allow for the collection of rich experiential material. Data was collected between January and July of 2016.

Demographic data collected include: age, ethnicity, gender, marital status, occupation, hours spent per week caring for relative, duration of caregiving and length of diagnosis. These are outlined in Table 1 with a brief description provided below.

Hours spent per week caring for a family member ranged from 3-40 hours (mean=10.7). On the question of the number of years spent caring for a family member with alcohol and/or opiate abuse, participants reported mean years of 12.4 (range 4-40 years). Sixty percent (n=6) reported alcohol as their relative's primary drug of abuse, whilst forty percent (n=4) reported heroin as their primary drug of abuse. It is important to note that, of the participants interviewed, only fifty percent (n=5) reported that their relative were diagnosed by a psychiatrist with an alcohol and/or opiate abuse problems.

**Table 1**

Demographic Information (N = 10)

Category	Number	Percent	Mean	Range
Age			55.5	31-69
Gender				
Male	1	10%		
Female	9	90%		
Ethnicity				
Caucasian	10	100%		
Marital Status				
Married	7	70%		

Single	1	10%
Widowed	2	20%
Employment		
Employed	8	80%
Retired	2	20%
Caregiver		
Relationship		
Son	3	30%
Daughter	1	10%
Brother	2	20%
Husband	1	10%
Father	1	10%
Mother	1	10%
Son-in-law	1	10%

### **Being of Reflection**

The methods of guided existential inquiry of lived relation (relationality), lived body (corporeality), lived space (spatiality) and lived time (temporality) were employed in the analysis

of data. In writing the phenomenological text (the vocative), the moments of lived thoroughness, nearness, intensification, pathic and epiphany were explored. By this, the phenomenological writing text included experiential materials in the form of quotes with insightful meanings. As previously pointed out, this text should explicate meanings and illuminate the reader's understanding of the meaning of the human phenomenon of caring for family members with addiction. This was made possible by collecting rich and experiential data. To achieve this, the researcher suspended judgements, beliefs, opinions and theoretical perspectives (Bracketing). For example, before each interview, the researcher, being a professional caregiver of persons with addictive problems, made bare his own knowledge (beliefs, opinions etc.) of the phenomenon under study in order to explore any further meanings. Having worked as a psychiatric nurse in the emergency room, the researcher understood how it was for family caregivers to bring their relatives to the emergency room to seek treatment for substance abuse disorder. During an interview with a participant, the researcher suspended any beliefs or opinion related to this phenomenon and explored this experience further, which led to newer insights previously not known by the researcher.

### **Findings**

Four main themes emerged from participants' interviews. These are: Theme 1. Being in the moment: the extension of the self. Theme 2. The dawn of reality: the being of acceptance. Theme 3. Deciding in the moment: the healthcare experience. Theme 4. Uncertainties and struggle: a lifelong process.

## **Theme 1**

### **Being in the Moment: the extension of the self**

Theme 1 describes how the self experiences and relates to the phenomenon of the caregiver burden. It explores the meaning of relating to the other (Relationality-Lived self-other) and how the self is experienced in living with a relative with alcohol and opiate abuse problems.

In the moment of the experience, the caregiver suspects the existence of a problem that is usually “something” and confronts the relative (the other). The caregiver is then convinced and made to believe by the other of the non-existence of such suspicions. However, that “something” being questioned is usually corroborated by certain behaviors evident in the relative. Caregivers in the moment of everydayness of life usually failed to notice this as a sign of a deep rooted problem. In the moment of everydayness, what is unusual in the usual, extraordinary in the ordinary, and strange in the familiar failed to make itself known to the caregiver. The moment of everydayness depicts the prereflective mode of human consciousness. In this prereflective mode (natural attitude), caregivers rarely question the world around them; thereby, the “being” of the totality of the world is taken for granted. In the natural attitude thoughts have been so accustomed to the everydayness of life that phenomenon are usually experienced without much concern or doubt. A participant stated:

I knew something wasn't right, and I would ask him about it, and he would just completely lie to me. And he's very, very smart..... really quite brilliant and manipulative, so he would lie to me and I would just believe him even though.....he wasn't acting right or money was going missing or he wasn't behaving correctly...



Three features emerged from this theme; Suspicions, Disbelief and Secret. These three subthemes reflect how the self (Caregiver) processes and experiences the phenomenon of family caregiver burden as it relates to the other.

### *Suspicions*

Before the recognition of a problem, caregivers may suspect its existence but were unable to bring such an issue forth into consciousness. This might be due to the fear of the unknown or categorizing a relative with addiction problems. These suspicions may arise due to the pre-existence of a supposedly mental health disorder seen in a relative in the moment of the experience. The pre-existence of certain mental health disorders may precipitate addictive behaviors. Several participants reported this as a precursor or usually a precipitant of the existence of the phenomenon of addiction upon further reflection. Caregivers expressed a fairly significant assumption of a relative's diagnosis of a mental illness or behavioral expressions of the probability of the existence of such a disorder. This depicts a possible projection of the occurrence of substance abuse: a contemplation of an unconscious being of relative likely to take form consciously. Here, caregivers unconsciously predict the occurrence of the addiction.

A participant with a son with opiate abuse stated:

All right. So it's, it's very hard for me to separate out kind of his dual diagnosis. Because....he was diagnosed with ADHD when he was four, so he had a fairly significant....you know, issue with ADHD.....when we got the diagnosis we knew that...I mean, we sort of...obviously we're dealing with a diagnosis, but always sort of projecting out the worst...one of the worst possible scenarios, or the thing that we wanted most to try to avoid.....

Moreover, caregivers might also use this as an unconscious adaptation to reject any unpleasant feelings associated with the possibility of addiction and to attribute the occurrence of these addictive behaviors to certain crises that happened within the family. Here, the caregiver presents an acceptable explanation unconsciously when suspicions arise. A participant of a brother with opiate abuse stated:

I think he was, he was never diagnosed with ADHD but I definitely believe he had that. And I believe he was just depressed too 'cause we had some...a cousin that died when we were young. She was hit by a car and that was really tough on him, he was a very emotional person. And then we had an uncle that had actually overdosed too and we were really close with both of them.

In other instances, the co-occurrence of a possible mental illness and substance abuse heightened the burden of care. When the caregiver is a child, it had significant effect on childhood experiences. This led to a misunderstood self. The self comes to a moment where there is a struggle to comprehend what it was like to be raised by a mother with alcohol abuse problems. The more intimate the relational experience or a supposedly intimate relationship with the relative with substance abuse problems the more difficult the burden. A participant of a mother with alcohol abuse stated:

So my relative was my mother, and as long as I can remember she abused alcohol. And she also...I think it's a good likelihood that she probably had some mental illness too that was also never diagnosed. I can say now that it was really hard, really, really hard, to be raised by an alcoholic, probably mentally-ill, mother. At the time growing up, I didn't understand.

At times, signs of the possibility of the existence of the phenomenon might be present but caregivers unconsciously repressed these unwanted feelings about the relative from conscious awareness. Personifying addiction as a thief that steals at an unexpected time shows the unconscious awareness of the understanding of how the phenomenon manifests itself. Reflection illuminates perspectives later in life. A mother of a daughter with opiate abuse problem stated:

Because it's just like a thief in the night, because it steals people when they least expect it. Now that I look back, I see signs and symptoms that addiction was there. But I overlooked them as part of not wanting to think that it was a problem, and thinking that it was just experimentation or recreational use that a lot of teenagers or college students go through. I wasn't looking at this as I would look at someone now. I looked at it as, "It's just a phase. She's a young adult. Everyone tries it," and didn't want to realize or didn't realize that it was really an abuse problem leading and led to addiction.....and I thought up until that point that things were going in the right direction. You know, I had given her the tools that she needed in life. Started off, sent her to the best of schools, private schools, Catholic schools. She made it into college. Very intelligent.

In other instances, caregivers project unconsciously the possibility of the existence of substance abuse in the family member based on the existence of certain behavioral patterns or knowledge base coupled with a family history of alcohol abuse. When the phenomenon manifested to the caregiver, it was more like a self-fulfilling prophecy as reported; what has been repressed unconsciously finally becomes conscious or was made bare. A participant stated:

So in some way I feel like we've been living with a potential...we had been living with a potential for opioid or alcohol abuse, and both my husband and I

have family.....we don't have a problem, but our family. We have ...you know, family who have a history of alcohol problems, on both my husband's side and my side. So, so I think that, for both of us, that was a real fear. And I think as a nurse.....who has worked with individuals and families who have substance abuse, I think I was even probably more sensitive to the potential trajectory. So, you know, I don't think it was any different once we realized he was experimenting with drugs. It was kind of like.....a self-fulfilling prophecy, but it happened so gradually that we just...you know, it just became part of the thing we were expecting.

Initially, the awareness of the existence of such a problem might not be obvious until the exhibition of certain bizarre behaviors by the relative which defiles certain family norms. These heightened the caregiver suspicions. Several participants stated:

I guess w-...we didn't pay enough attention in the beginning. You know? We were just either oblivious to it, or we didn't want to see it. And I think not wanting to see it was part of it. I think my husband saw it before I did. And I know that many times he peed right there where he stood, and my husband would, you know, tell him, you know, "Come on." You know, "Give me a break." You know, "Get upstairs and do what you have to do," he said. And so that's when we knew that, you know, that was bigger than we knew. I knew that he drank, but I didn't know it was an issue. He worked every day, worked hard, and came home and everything was fine.....until he started stumbling up the stairs and doing things that we weren't able to accept.

But he came home on some drugs. I mean, he was...he could barely stand up, and it was, it was sort of like, like your worst nightmare. You're absolute worst nightmare. And it was just terrible. We had to call the police, and he had to face the music, so to speak. And that was devastating...and you don't look forward to calling the police on your children...

So he...as time went on, he...that changed, where he would...when we started spending more time together, he would start ruminating and trying to pick fights with me. And that's when I realized he was drinking, 'cause he'd get in this mood to pick a fight. And again I didn't pay attention to what he was drinking, 'cause he acted like he was very capable, you know, sober. So in those early days I didn't have any warning.

In other cases, other close relatives or friends confirm caregivers' suspicions. This is normally very disappointing to family members as this further confirmed their fear of the problem. Participants stated:

I don't think he...he to this day would not tell you he has a problem with alcohol, but it is quite obvious that he does. I did not know how bad it was, or that he was drinking all the time, until his wife would start to tell me things, and then all of a sudden I would know. Because he hadn't lived in our home for a while...and so I, I didn't see what was happening with him.....I think it was, again, as I said, when he... when he got married, and then I was starting to hear from his wife and actually see things that were happening. And it affected his work a little bit. And my husband heard from other people that he came in to work and he was smelling like alcohol.

And then, you know, we tried...I tried everything to help him. He just...he said he wanted it but never really pursued any of the help. And then his friends one night called me because they were concerned about his behavior at a restaurant. And then they ended up telling me that he started using heroin and he's been using it for a few years.

### **Disbelief**

The bringing into awareness consciously of that which has been suppressed unconsciously by caregivers of their relatives' addictive problems is usually met by disbelief, which is characterized by charged emotions, upset feelings, surprise, hopelessness, helplessness and vulnerability.

Disbelief is often met with denial as caregivers tend to escape the unpleasant feelings by ignoring that the phenomenon of addiction exists. The belief that they are invincible or privileged to be inoculated from the phenomenon of addiction leads to anger and feelings of being violated. A mother of a daughter with opiate abuse problem stated:

I was angry and I was extremely emotional and upset. I felt like...that this could not happen to us, that this should not happen to her, that how could this possibly be? So my initial emotion was anger and violation and almost disbelief.

The surprise and disbelief of the existence of such a phenomenon is compounded by the initial belief that the diagnosis of a substance abuse disorder or the exhibition of substance abuse behaviors is a "moral character defect". This presumption confirmed the societal challenges that exist in the classification of substance abuse as a disease. In other instances, a substance abuse disorder can be seen as a "fatal illness". This mental image of substance abuse disorder is used to justify the societal belief that, there is no treatment for substance abuse and a diagnosis is seen as

a “death sentence”. Also, caregivers may also feel as a moral failure themselves as a result of their relative’s addiction. The unseeing of this mental picture is a struggle and challenge encountered by the self. Participants stated:

So I was taken by surprise, and as well as...I felt hopeless and helpless because it wasn't anything medical. I didn't look at it medical. I looked at it as morally that she made some bad decisions that led her into this. I believed at that point that it was a moral character defect, as opposed to the disease that I now know it is.

When I first found out about her addiction, I felt extremely vulnerable. So when I found out that her substance use was at that degree, it was very disheartening, and I felt that we failed somewhere along the line. I believe that I still remember the initial time of going into that emergency room and seeing her on the stretcher and having her cry, and I believe that it was just so devastating. It was like someone just told me that she had a fatal illness.

And then I had that other person who was present in the home, but was distant from the rest of us, my brother and my fa-...my father and myself, and was off in a corner, sort of wrapped around her bottle, and there was no way to get in between her and her bottle. And everything she had went into that bottle, and that bottle went into everything that she had. I thought maybe I would be able to fix that. I would be able to...if I did something better, smarter, faster, more worthy of her attention, that I could make her behave differently. So as...from a very young age, that is exactly what I tried to do. I tried to make her be different than who she was, and I tried to make her behave differently than she behaved.

## **Secret**

Caring for a family member with addiction problems is relational. Hence for confidentiality or the covering of the problem to exist, conscious efforts are made by the caregiver or even by the substance abuse relative to conceal it.

For a secret to be kept and hidden, caregivers must distort reality as it relates to the presenting phenomenon and present it as “something” that conforms to the social norms. Here, to conform to social norms, substance abuse must be presented as a socially acceptable problem. Substance abuse then becomes a socially defined construct. Caregivers live in two opposing selves: A socially constructed conforming self, and a self of conscious reality of the phenomenon. To illuminate, a participant stated:

Well, it was pretty devastating, and in the beginning it was so difficult that I wouldn't even share it with anyone. I held it all in and dealt with it by myself. I didn't even share it with immediate family members because I didn't want her to be judged, and I just didn't want to hear all the negative that I believed I would hear. So I covered up initially and acted as though she had a medical problem. I even remember one time, when she was hospitalized, that I said that she had a kidney infection because I couldn't fathom saying that it was substance abuse and letting it out. I felt that it was a secret at that time.

## **THEME 2**

### **The Dawn of Reality: the being of acceptance**

The acceptance of a human phenomenon of addiction of a relative is seen as a process. This theme describes how participants process and accept a relative's substance abuse problems. Four features emerged from this theme; being of reality, stigma, guilt and acceptance as an



insight. The moment of learning that a relative has an addictive behavior is accentuated by the feelings of shame, guilt and stigma.

### **The being of reality**

Acceptance as a “being” of reality is a process that happens over time. Acceptance begins with the recognition of a situation or phenomenon which usually has “uncomfortable” feelings. Here, the self struggles to bring into awareness or come into terms with the reality of the situation. Acceptance as a “being” manifests itself through acknowledgement. However, the everydayness of a phenomenon may temporarily blur this process and hence acceptance. The acknowledgement of a phenomenon of addiction as a normal part of life and the prevailing social conditions may lead to a normalization of the phenomenon. Participants stated:

No. No, nobody. There was never any...and back then too, nothing was ever said. Nobody ever spoke of...alcoholism, divorce, you know, sex. Those things weren't talked about. I mean, I'm going back 50 years. Those type of things weren't discussed. It wasn't...not like today.....so nobody ever said...., “I think you have a drinking problem,” because everybody drank. The priest drank. The grandmothers drank. The aunts and uncles drank. Everybody drank. The kids drank.....you gave the priest a jug of booze for Christmas. Just...alcohol made the world go round. That's pretty much how it...in my eyes, that's how you saw it. Everybody drank.

Caregivers may be aware of the existence of a phenomenon of addiction but consciously decide not to bring into awareness its acceptance. This may be due to how the phenomenon presents itself or what it signifies. Realization thereby does not necessarily lead to acceptance. Participants stated:

I think at first it was difficult for me to accept that he had a problem, and for a long time I probably didn't realize it. It took a long time for me to realize and accept that. It still is difficult. I think the worst part is wanting his happiness and wishing that he would choose a different path, that it was not...I just thought he should be able to stop.

And I think that that's another part of this whole equation that's difficult, is that you're always thinking this back and forth thing. "Oh, he doesn't really have a problem." "Oh, he does have a problem." And obviously we knew he had a problem, but in the back of your head sometimes you don't want to accept that easily

### **Stigma**

The acceptance of a substance abuse disorder of a relative was usually tied to societal stigma. Stigma then becomes a hindrance in the acceptance process. Stigma is not looking beyond a person's current human existence and personality state. It considers a person's addictive behaviors as a character defect. Participants stated:

A lot of people, they look at drug addicts and they're just like, "Oh they're just, you know, some loser drug addict." But they don't really, like, look past the fact that he...you know, they are a human being and there's a reason why they're a drug addict and that just because their personality is a drug addict doesn't mean that's who they were before. So it's tough.

Societal stigma may manifest itself in a form of an unpleasant experience where the victim's behavior becomes a marker of what is not acceptable in the society. A participant stated:

And it was sort of...you know, if you think about the sort of traditional, like, town drunk, always...you know, there's always sort of people snickering behind a closed door. "Oh, yeah. That's just the town drunk." Well, that's sort of how my family was. Like, everybody else considered their own drinking an acceptable level, but my parents' was excess

Stigma may also assume the form of an objection implicitly expressed towards the relative by others. Caregivers might feel the phenomenon has been personified to represent something that is contagious. Participants stated:

They immediately said, "No, he can't be in our home." Like, "He's not welcome in our home." And I'm, like, "Well, he doesn't have the plague." You know? Like, it's not contagious. And I was embarrassed. I felt like I was stupid and should have known better and that kind of stuff.

### **Guilt**

Guilt is a common component in the acceptance process. Guilt is an intense unpleasant feeling of remorse or responsibility family caregivers experience regarding the relative's addictive behaviors. It is often a precursor to acceptance. A participant stated:

And my husband had wanted him to move out. I wasn't able to do that because I worried. He wasn't real street smart, and I worried what would happen to him if he had to move out. And maybe, maybe if I had been able to tell him, "You have to live on your own. You have to take care of yourself and you, you can't depend on us anymore for shelter," maybe it would have been different. Maybe it would have been good.....

Certain events in the relative's life may be perceived as a cause of developing the phenomenon or addictive behaviors; a precipitant of guilt. Inability by the caregiver to have put in place measures that could have prevented this event intensifies guilt, hence hindering acceptance. Participants stated:

I felt as a parent, or parents, or her family, that we did something wrong to create this. Sometimes I have the guilt, only because I've found out along the way that there was an early childhood sexual trauma that I did not know about. So I do still sometimes feel a level of responsibility for not recognizing that, that that happened as, as a child.

But you always...there's always this thing in the back of your mind that goes on, like, "Oh, maybe it was..." You know, and you find some ridiculous thing, like in pregnancy, or this moment here, or maybe if he hadn't had that teacher, or...you always are looking or scanning for s...w...you know, something you could have done differently that would have switched...you know, would have made the switch, like this would have changed the trajectory. But you can't find anything. I guess it's...like guilt? I suppose it's guilt, but it's even worse than guilt. It's like looking for something you can't find.

Also, inaction of caregivers as it relates to an early treatment intervention was perceived to heighten the level of guilt. A participant stated:

There was one time when we almost called the police. But then we didn't because we were afraid of what would have happened. And...so in that respect, that was another way we probably aided and abetted him, because we maybe kind of protected him from a situation.

When guilt is overcome, acceptance is brought into conscious awareness. Detaching oneself from the phenomenon may be a necessary start of this process. A participant stated:

It's very painful for me because I've had to detach myself in order to be able to cope...well enough, and there were times when, as a mom, I just became very, very depressed. You know, he's my son. He's my...only son, and.....you don't want to see your children fail.

Acceptance may also be mediated by seeking information to learn about and understand the phenomenon of addiction. Knowledge enlightens perspectives about addiction thereby minimizing the unpleasant feelings of remorse and responsibility. Being knowledgeable about the manifestation of addiction lessens the burden of guilt and hence acceptance. A participant stated:

But back then it was a total...like a disgrace, and it was guilt and shame, and I didn't feel that I could divulge that to any family members 'cause I felt that they would judge her and me. I didn't realize that it wasn't about what we had done. It was about her addiction.....before I became as knowledgeable as I am about addiction, it was a lot of guilt and shame and not being able to accept it as the disease that it is..... it was extremely difficult, because I felt that I as a parent ...may have failed.

### **Acceptance as an insight**

Acceptance finally happens when caregivers seek for education that leads to personal growth as it relates to substance abuse. Psychoeducation pertaining to the phenomenon of addiction can lead to insightful meanings of how the phenomenon presents itself. Here, family caregivers become aware of disease symptomology, counseling, supportive interventions, resources and

problem solving strategies to cope. They may also feel supported by health care providers and/or society. A participant stated:

Well, in the beginning I really had a hard time wrapping my head around this, so I realized that I needed to get appropriate support and education around this. And I did seek that help out, and through that I was able to wrap my head around what this was all about. So as I moved through the process and I got...became more educated about addiction, it became a lot easier to be able to take care of her and help her through it. And that has been an extremely strong support for me, to be able to accept this, and deliver care, and accept this as the disease that it is, as well as...I rely strongly on my faith. I think that having educated myself in the area, now I feel much more able to share it. As I move forward I treat this as though she has a chronic illness, and I support her with her illness..... is that you need to look at this like it's a disease, that it's a sickness, and that you need to try to move forward with gaining as much knowledge as you can about it, understanding how to move forward, understanding what the best things are to do to help them stay healthy.

Further, caregivers learned to cope and live with their relative despite the presence of substance abuse. Here, change of a relative's substance use is likely not possible and caregivers learned the skills and problem solving to accept the phenomenon as it presents itself. Here, compromises are made and the burden becomes bearable. A participant stated:

And so those final years he drank, but he was much more livable because he knew better than to drink a lot of hard stuff, and if he did, he knew better than to talk to me. He never did get off of alcohol, but we learned how to just dance around it.

At times, acceptance comes in the form of acknowledging that a relative's motivation and readiness to change are processes beyond the control of a caregiver. Having hindsight into past perspectives and insight into one's current perspective provides opportunity for the caregiver's personal growth. A participant stated:

You know, I can give advice. I can give advice, but it's up, it's up to them whether or not they want to seek the help and, and do what they need to do to get better. And I'm a very firm believer that until they're ready, there's nothing you can do. So that's...you know, you can look back and see all the things you didn't do and regret that, but you can't change it. You can only do better for somebody else.

Acceptance also serves as a catalyst to change behavior and perspectives regarding caring for a family member with substance abuse. Being through this experience provides a transformational process where the caregiver becomes compassionate in their approach to other addicts. A participant stated;

Well, I can't say it changed my life. It changed the way I feel, changed the way I feel about him. Well, I think it changed the way I, I look at other people and, and other issues. And, you know, I'm probably a lot more sympathetic to people with alcohol or abuse issues than I ever was.

### **THEME 3**

#### **Deciding in the Moment: the healthcare experience**

This describes how healthcare is experienced in relation to a family member with addiction. This theme describes how participants encounter and experience the healthcare system as their relative with a substance abuse problem seek care. Four features emerged from this

theme; deciding to medicate or not, the being of treatment, seeking alternatives, and being of respect.

### **Deciding to medicate or not**

Family caregivers reported an association between the healthcare experience and medication prescription. Caregivers were initially expecting an experience for their loved one that was less invasive, that which expresses the discharge of feelings and emotions therapeutically; a cathartic experience. Participants stated:

It's just that they were so quick to throw so many drugs at him, and even ones that, when I read all the side effects and the dangers and the cautions, no one was paying attention to. And that, I thought, "Oh, my God." You know, all this man needed probably was some good talk therapy and get this whole thing, you know, out in the open, rather than, "Let's drug him. Let's drug him some more. Let's give him some more drugs, 'cause those are doing things."

That's one of the things I think, in modern medicine they're too quick to give out pills. Pills. "Oh, and here's some more pills." "Oh, you're getting anxiety from it? Here. Here's another pill." "Oh, you can't sleep? Here's another pill." You know? And so all these pills just made his health worse.

There was usually a decisive moment where caregivers are torn between either to medicate or not to medicate. These two choices are primarily presented to them as they seek care for their family member. However, psychoeducation about the condition and other evidence based practice guidelines may be what they seek but healthcare providers often overlooked these. To caregivers, the encounter with the health care system should enable them to make informed decision. Participants stated:



A lot of...well, you know, I think one tension that always occurred was the question of medication. Young children, you know, taking this med. Then that didn't work, so then they were on another med. And at some point y-...it's like their, their eyes are glazed over. They're so heavily medicated. And you...and it's, like, "Ugh." So that was always a tension.

But again, there was always this pressure that we should be doing...trying more medications, and I think we were pretty reluctant to really get into heavy meds at such a young age. So...I think that was the biggest tension with healthcare providers in terms of their support-...educating us about the condition and, you know, state-of-the-art whatever.....whatever the thinking was at the time.

They don't do the education. "So these are all habit-forming, I want to let you know.....That's another thing that people...I think docs need to educate and not just give directions. So, like, "This is your med." write the directions. Educate them. Yeah. Maybe that will prevent some of the problems.

### **The being of treatment**

Caregivers expressed their frustrations with the healthcare system as they seek care for their relatives. Here, they encounter some of the bureaucracies and hindrances that have embedded and tangled the system of care. The chronic nature of the disease and the negative feelings expressed unconsciously by healthcare providers towards persons with this disease further compound the process of accessing care. Participants stated:

But he came, came to my house, and so the options were limited, and it's hard to get treatment centers when you've been through that cycle so many times. They don't really particularly want to take you.

And it was tough because you didn't...I didn't really want to go get him 'cause I knew he needed the help but the hospital was refusing to keep him 'cause he said he felt safe and, you know, he wouldn't, he wouldn't admit that he was suicidal or depressed or anything. So they let him go. And it was just the fear that, you know, you're letting him go just so he could use again.

The frustrations in seeking care for their relatives are also manifested when there was an actual attempt to contact healthcare facilities. The resultant reality of the availability of treatment services/facilities and other resources became evident. Care is sought but to the dismay of caregivers, resources are limited; a mismatch of reality. A participant stated:

I helped him one...it was like one of the last times he overdosed before he passed. He was really.... wanted help so we called...I helped him call, like, 50 different detox programs and no one had a bed, no one would take his insurance, you know. It was just like, it was the runaround. And then after that he just got frustrated and he was, like, well no one wants to help me so why should I help myself?

However, a court mandate due to an adverse event may facilitate healthcare access. In such a case and with this mandate, seeking care and accessing resources become much easier. A participant stated:

And then after that wasn't successful he, we couldn't find a bed for him and he refused to go to the hospital. And then he happened to.....like nod off while he was driving and got into an accident and he got arrested and that's when the courts systems forced him into a two week detox program.

By encountering the healthcare system, caregivers were expecting to be involved in the care of their relatives. At times, the family caregiver initiates a call but some participants described being ignored by providers. This was sometimes attributed to privacy laws and hospital policies.

Participants stated:

They never, they never involved anyone in the family. They never called us, never asked us any of our opinion. Yeah, we, we called a couple times... to see if we could talk to the social worker or the doctor to explain to them that this was...this has been like an ongoing issue. And that he needs longer treatment, needs more help but no one was interested in calling us back. They just looked at it as like a court, a court order and when he was done, he was done.

No. They never contacted us. They never...he never said that they wanted to talk to us. I didn't...he really wasn't there long enough to really...you know.....40-some-odd years old, we didn't get involved in, in the medical part of it at all. And I don't know. You know, at the time, you know, all these... HIPAA and whatnot.

Caregivers' encounters with the health care system as they sought care for their relatives often led to self-transformational processes. In some cases this process of self-discovery might even lead to caregivers deciding on a career in healthcare to advocate and effect change.

Participants stated:

I really feel strong about making the medical field and then hopefully the general population really understand and look at this as a disease, start using terminology that reflects disease, "remission" and "exacerbation" instead of negative connotations like "clean" and "dirty," because that kind of stuff sends negative messages.

And I actually entered into the field of addiction because of it, because I saw the subservient care that was being delivered, and I felt that I needed to become a part of this, to help. So through her addiction, it brought me into working in human services.

I think it's made me want to go into nursing and help people that have substance-abuse problems. I think...because there's so many nurses that don't understand that alcoholism and addiction is a disease, just like heart disease is a disease. I think that has made...just opened my eyes and made me realize, "Wow, these people need help." And if you can help somebody to stay clean, even for a period of time, you're helping them. And they're going to...if they relapse they'll probably get clean again. And then if they relapse...and some day it might stick. For some people it takes.....multiple times, and some day it might stick. So I feel like, you know, that it's made me want to go into this type of nursing, because I was already in the business of the nursing. Might as well help people with mental illness and addictions

### **Seeking alternatives**

In as much as the healthcare system is the means utilized in addressing concerns about a family member's addiction, other caregivers viewed it as not the only resource or the place where they can find answers. Other resources were sought to supplement care. In some instances, a book, as a resource, may provide insight into the phenomenon of addiction. Although most caregivers sought alternative sources of healthcare, these resources may not be an alternative but rather complimentary. Participants stated:

So, yes, wonderful people from the healthcare sys-...healthcare. I'm not sure that's the only arena that you ha-...that you need to access. I'm not sure they have all the answers. We certainly look to the healthcare system for most of the answers for most illnesses, right? But I don't think...I don't see that they have all the answers. 'Cause trust me. I think if they had all the answers, I think I ..... would have found them

So that's...we have a friend, another friend, whose son is my daughter's age. She's...34. He has a problem with heroin, and has been in and out of all kinds of things in the past year and a half. They gave us an excellent book called "Addict in the Family". And we've been reading that, and that's given us a lot of insight.... And the book is...has been very helpful, and we both read it that weekend, and it gave us some strength. It made us.....sad, but boy, it was, like, textbook. All the behaviors, all the issues. It was so in, in our face. It was just...amazing.

Further help is sought from other sources such as spiritual groups or psychosocial therapy sources. Spirituality was an important concept. Further, alternative resources were beneficial both for the family member with the addiction as well as family caregivers, such as Al-Anon.

She does attend regular substance abuse therapy and individual therapy, but her...the strongest asset that she has found to help her is through church and through spirituality and through God, attending Bible groups, going to the church and being around people that are extremely supportive to her.

I did seek some counseling...through a social worker. Who was very...I was very fortunate to find her. She was a very good match for me, and it was a good

support, and I saw her for about a year. And then I haven't done anything since then. I have a wonderful network of close friends.

Participants also described self-help groups like Alcoholics Anonymous and Al-Anon as important supports. The importance of social support cannot be overlooked.

What helped me was my own individual therapy. I've done therapy and also I went to Al-Anon after he came home from detox and we were still together. I went to Al-Anon because Al-Anon teaches you how to have boundaries for yourself and take care of yourself, because obviously the other person isn't going to. They're going to take care of their needs, but they're not going to take care of you. So Al-Anon teaches you how to put yourself first, and if you want to move forward and have a healthy relationship, that'll help you do that. But if you, if you can't have a healthy relationship with that person, then you have a healthy relationship with yourself. So Al-Anon was helpful. And, and a lot of people there had multiple people in their life that were alcoholics and addicts. I just had one, so I could learn a lot.

I'm glad you brought that up, because I think AA was the most positive thing he got involved in. And it's...that's the thing, that he was so proud to get his coins. And we ended up going to one of the...when he got his 100th day or whatever it was, we went to one of those meetings. And that was a real eye-opener. It was, like, "Wow. I'm glad I never had to do this." You know? It was...but he found friends there. He had a good sponsor. And, and like I said, he still goes to the meetings. I don't think he goes as often as he used to, but he goes when he needs it.

## Being of respect

Family caregivers reported respect as an important component in the delivery of care. Being respected as perpetuated by family caregivers means being acknowledged. This means opinions, values, beliefs, concerns, etc. of family caregivers matter. This component of care as reported varies across healthcare facilities. This is manifested as a conditioned consciousness that anytime care is sought, its existence is brought into awareness; it becomes a “demand thing”. Participants stated:

The treatment facilities varied from place to place as far as the quality of care that was delivered and the respect that was delivered to her and myself and our family.... So that became a major job that I took on. Any time that she had to enter into either an emergency room or a treatment facility, I demanded respect for her and our family. And it wasn't always easy.

And I also remember being...not being treated with respect in that emergency room when I was trying to ask questions.....And it still stands out to me. The caregivers in that facility were so disrespectful to me when I arrived there as her parent to bring belongings, that it just resonates in me today that...the importance of how important it is to treat families of people with addiction with respect.

And very negative connotation like, “This won't be necessary. This isn't necessary. This is not a five-star.” So it was extremely upsetting to me at that point, that I was looking for someone to nurture me and help me. Instead it was embarrassing and insulting.

In demanding respect, caregivers go through a process of seeking education and increasing knowledge base of care-related issues regarding addiction. This knowledge base enabled them to

assume an advocacy role for their relative. Being able to access service as it relates to addiction can be tied to ability to seek help and importantly being able to navigate the system efficiently due to knowledge of how the system works. Participants stated:

I believed that she was treated subserviently, as well as I was, in the beginning.

But as I moved through the process, gained knowledge and education, I now, and maybe a couple years into it, realized that I had to become an advocate and I had to not allow healthcare-givers to treat us subserviently

I think I was able to step out of the box easier because of my profession, and able to seek help. But I think the average person not in the medical field may not be able to access services, and it's extremely important for the family to be taken care of, as well as the person with substance abuse.

In accessing care, addiction was viewed as the "hidden disease". A disease is purported to be hidden when it has a negative connotation or is judged as a moral failure by society.

It's the hidden disease, and they pass judgment, and they still look at it like the person is willfully doing it to themselves, so they don't offer a lot of support.

Although my major support has been my actually, my mother.

In other words, family caregivers feel supported and listened when healthcare providers treat them with dignity and respect. Dignity and respect start when addiction is considered as a disease and not as a social character defect. A participant stated:

We've had some pretty good luck with her primary care doctors being on board with addiction as a disease. We have a family practice physician for years that I saw, as well as my daughter, who definitely treated us with dignity and respect.



## THEME 4

### **Uncertainties and Struggles: a life long process**

This theme describes how the phenomenon of addiction is experienced by family members; the burden of care. Here, caregivers described the uncertainties and struggles involved in caring for a relative with substance abuse problems. This experience may be described as a life-long process. Lived experience of the human phenomenon of addiction (lived time) thereby becomes a process where the fear of the unknown, blame etc. all become an embodiment of the future, insights and meanings leading to personal growth. Four features emerged from this theme; how it affected us, the burden we carry, the being of insight-it has shaped who we are, and the constant fear of relapse/unknown.

#### **How it affected us**

The effects of substance abuse on the caregiver become more pronounced on how the self struggles to relate to the other. This may be manifested by a struggle to maintain and sustain a trustful relationship with others especially where the caregiver is a daughter and the relative is a mother. Moreover, where the caregiver is a partner, it affects future trustful relationships with future partners. Participants stated:

I struggled with everything. I struggled with my relationships. I definitely struggled with my relationships with women, because I didn't have that primary relationship with my mother. I had great relationships with males, male friends, male family members, male teachers. I struggled with my relationship with women.

It's not nice to say that I don't trust people, but I'm way more cautious about who I bring into my life, especially with men. I'm way more cautious about, if I'm

dating, what kind of guys I'm dating, you know, what kind of jobs they have, what kind of family they come from. Like, I won't, I won't ever date anybody with a history of substance abuse, even if they have 15 years clean. I won't ever do it, ever. Not interested.

Further, caregivers may view the effects of caring for family members with addiction on the self as wasted years. Time may have been spent on the substance-abusing relative thereby ignoring the needs of family caregivers. Participants stated:

But sometimes it contributed very negatively, and I had a lot of wasted years. I'd say the entire...from 25 to 35, that was a wasted decade for me. And there's no part of that, there's not a minute in 10 years, that I would repeat.

I'm resentful that I'm in my 30s and single. I feel like I was with him for over six years and it was just a big disaster.....But that's...those are still feelings I'm working through, feeling, like, cheated and, you know, like my...a big portion of my life was just spent on him, and I didn't get anything in return except for trouble and pain.

Furthermore, when a child is involved in the caregiving experience, the effects of the phenomenon of addiction become evident in their growth and development. Caregivers may also grieve their childhood as a result of the burden of addiction. Grieving here implies loss of the childhood experience. Participants stated:

I think this whole experience has stunted her development. It really has. She's 17, but she acts like 14. I think emotionally she's just not there. A very anxious person. She can play instruments. She's got a lot of talent. However, she doesn't apply it because I think her self-esteem is low. And I think the anxiety, the self-

esteem is a little disabling because of this experience with her dad. So...and I think it'll always affect her. Now I'm worried because he has such a family history, that we've talked to her and told her...when she was younger we started educating her about alcohol and saying, "This is something that you're probably allergic to".

My brother...from the time I was in kindergarten I can remember getting up, making myself a cup of coffee, and getting myself off to school by making a peanut butter sandwich, putting it in a bag and getting myself dressed in the same clothes that I wore every single day, because I didn't have a parent getting myself ready for school. So for a lot of years I think I struggled with that and, and grieved the way that I grew up.

Effects of the burden of addiction on the self are not limited to the present but also future endeavors. Caregivers may be more considerate but there is the need to constantly explain the self or the justification of past behaviors. Participants stated:

I've been much better with my money. Like, now I have a new car, but a lot of my bad credit and stuff came up yesterday when I bought a new car, and I had to explain to them on the phone, the bank. "You know, you had a car repossessed three years ago. What happened?" Like, that's mortifying to me. And I said, "Well, you know, I was engaged to someone with a substance-abuse problem and I couldn't pay my bills. But I've been on the right track since." So it's embarrassing, 'cause that stuff keeps coming up.

## **The burden we carry**

Caregivers reported an ongoing burden as it relates to the needs of their relative. Burden reported encompasses support ranging from financial to other needs critical to the daily existence of the relative. Financial support was the most reported burden and it varied among caregivers.

Financial support may be provided in the form of assisting relatives engage in treatment or supporting living expenses necessary to prevent relapse and maintain sobriety. It may also be provided in the form of occupational rehabilitation. Participants stated:

Absolutely about everything. So if my mother lost her job, I would pay for her to take some kind of educational course, to be retrained in something else. I did this from the time that I was probably...I can remember being 20 years old and sending her to get...paying for her BLS and for her certified nurse assistant training, so that she could find a new job.

I definitely try not to enable her, but I do try to support her, because I think substance abuse is also dual diagnosis. If she is having a hard time or struggling, I try to make sure that she stays in contact with support groups and encourage her to.....reach out to her treaters, her physicians, her groups. I also support her financially if she needs help. I don't support any drug use. However, I have had to support her, subsidize her living situation at times, when she's not able to handle a full-time job and able to pay for all of her primary needs. I still always am there for support to help her re-engage in treatment or to get emergency services, but I have to at some point take a step back and allow her to see the destruction that's going on.

In other instances, relatives become completely dependent on the caregiver for all financial support as they may not be able to be financially independent due to their drug use. Caregivers might unknowingly support their drug use. A participant stated:

So he put me in a lot of unsafe situations, but...it didn't matter to him. He was getting what he needed. But I would have, like, drug dealers call my phone looking for money and, you know, he'd just take my Visa and run off, take my car. So, yeah, you feel very taken advantage of, or I, I did. I did. I felt used. So as the partner you're supporting their habit and everything else financially. You're putting a roof over their head 'cause they can't work. I always...I helped him out and he would call me crying, talking about how bad he felt about, you know, what he's done and I'd like help him through that and, you know, if he needed a place to stay, I would give him a place to stay. If he needed food, I'd give him food.

The burden of financial support was noted to be a major stressor. This is a need that caregivers may have to constantly revisit. Caregivers may decide to curtail financial support but may be unable. A participant stated:

He did get into a situation where he would, would face legal issues. We did not totally bail him out, but we supported him financially at the time because he was not in a situation to be able to afford attorneys' fees and things like that.....And now we're in a position where we know he's struggling, and financially struggling, and we've made a decision that we are not going to do that, that he has to face the consequences of his actions and he's got to do this himself...before we can...It is not the first time. But every other time we have kind of gone back and

forth. We'd say, "We're not doing this anymore." "We're not doing this anymore."

And then we'd get sucked in and we'd help him a little bit.

Due to the chronic nature of the phenomenon of addiction, the way the phenomenon presents itself may be manifested by constant need for treatment. A participant stated:

Oh, yes. He was in many programs, in and out of them. You know, he just cycled through. He'd come out. He was in jail, jail a number of times, I mean that's not really a program, for drunk-driving. And he tried lots of rehab facilities, in-patient stays, you know, residential programs. He would get it. He would practice it. But then when he would get out, not long after he would relapse.

Burden may also assume the form of blame where the relative addict projects his or her "woes" unto the family caregiver. The relative may use manipulation as a tool. A participant stated:

And I think part of that is because we have been hurt so much.....that maybe that has given us enough strength to say if he really feels that way and he really blames us sometimes for a lot of the things...he manipulates us and makes us feel like we're at fault for things that have happened.

### **The being of insight-It has shaped who we are**

The uncertainties and struggles family caregivers go through as they provide care for their relatives with alcohol and or opiate problems often lead to insightful meanings. In this case, caregiver burden as an experience becomes a self-transformational process.

Compassion, as a being of insight may be portrayed as a response to the burden of others. A participant stated:

I can say that this experience gives me much more compassion for people who are in similar circumstances. Am I really grateful for the life that led me to that?

Now I am. But for many years, particularly the years in my 30s when I was also actively drinking, I would say these experiences had contributed really poorly to my quality of life.....30s was not the quality of life that I have now in my 50s.

Family Caregivers may assume a non-judgmental attitude towards persons with substance abuse. Experiences with an addicted relative informed attitudes towards others going through a similar situation. Participants stated:

So I think that's one of the things it did for my life, is to teach me patience, lots of patience. So I learned that I never would judge someone with an addiction as poor character, because I know from my own husband. He didn't have poor character. He was a hard worker, he was helpful, he was caring, and you just had to remember when he'd had too much to drink, that's not really him. That wasn't him. I grew a lot because, first of all, of course early on I learned that alcoholism is not a choice, that people fall into it for various reasons. One, in looking at him, I realized his environment, having come from a background where men were expected to go and relax with a drink with the other men. And then from his experience in Vietnam, which gave him a lot of demons that he was trying to make peace with.

But I've learned to look past the addict and, and actually look, you know, at who they really are and why. I...when I work with addicts I try to figure out why they became an addict. Because you don't really wake up one day and say, "I want to use drugs and become an addict for the rest of my life." A lot of times most of

them are, you know, underlying depression or some type of trauma. Something that got them to, you know, get into this addiction and I like to look at that and try to help them with coping with what is really the problem before they start working on their addiction. 'Cause you can't really work on the addiction if you don't work on the underlying problem.

### **The constant fear of relapse/unknown**

Due to the chronic nature of addiction, there is the fear of the unknown. Caregivers are usually consumed in the "what if's" of an undesirable event. Participants stated:

That phone call that, that, that he's in the hospital or he.....died. He was reckless so, you know, it was just like if he didn't come home for a night or, you know, sometimes he wouldn't come home for a few days and it's, you know, we...like, I'd call all his friends to see where he was to make sure he was okay. 'Cause there was a bunch of incidents where he would OD. And he came back but...You, you know, when you're always concerned for them, when they're not home, if they didn't come home for the night, when you're worried about getting that phone call.

So if the phone rings at an odd time, or sometimes just when I see her name come up on my phone, I get anxious because I'm not sure if it's going to be a good thing or a negative thing. So it definitely puts an emotional strain on, on me. That's an immediate panic, because I worry about overdose all the time.....So it, it kind of always made you feel like you were living on the edge and waiting for the next shoe to drop.



The constant fear of relapse becomes more evident in the notion of addiction as a chronic relapsing disease. Here, sobriety does not necessarily mean the absence of the disease. Chronic relapse does not also portray the absence of sobriety. Relapse and sobriety, a key moment of this phenomenon, is a life-long process. Participants stated:

That's the way I look at addiction with my daughter, because it can go on long periods of remission or sobriety, and then all of a sudden it can come back, just like the sleeping giant. So I look at it like it's there forever, and there's going to be good times and bad times. But it's definitely taken a big piece of my serenity, because it's a constant, a constant thing in the background, 24-7, that you realize that you have a child that's sick.

When he calls, we're listening for that clear voice we know when he's in good shape, and we know when he's not. And his siblings are the same way. Like, they're so hurt by, you know, knowing that he's, like, going down this direction that they know is not good.....And so he has sounded good, and it's great. But you...when you go through this stuff, you have to brace yourself, that it, it could any time turn.

Addiction becomes a disease that caregivers always consciously bring into awareness.

Participants stated:

It kind of takes over your life. You know? The a-...the addiction and the problems. And it, it becomes...you almost get to the point where it's so much in your head that you obsess over it. It's awful. It's awful. You know, you shouldn't have to spend so much time worrying about it and thinking about what's going to happen.

But...I think that it is...it's something that...I'm going to carry around with me until I go.....to my grave. And so it has brought a lot of sadness. And I guess... what I would like to have in my life, is to know that there's hope somewhere. I would like to be able to feel hopeful again. So that's a difficult thing to, to deal with..... my biggest fear, that he would drink himself to death or walk in front of a car .....

## **Chapter 5**

### **Discussion and Implications**

#### **Introduction**

The purpose of this study was to explore the lived experience of caregivers of family members with opiate and/or alcohol abuse problems. This study was situated in Max Van Manen's phenomenology of practice. Participants described their experiences of living with and/or caring for the relative with a substance abuse problem. Four main themes emerged from this study. Participants reiterated the importance of sharing their stories as addiction was mostly seen as a hidden disease. The roles that families play in the recovery and sobriety of a substance abuse relative is very important. This chapter discusses the findings of this study in relation to the philosophical underpinnings, and prior empirical literature. Implications for practice, future research, health policy and limitations of the study will also be discussed.

#### **Philosophical Underpinnings**

The philosophical tenets of van Manen's phenomenology of practice supported the themes identified in this study. The philosophical underpinnings of this method provided an underlying framework in understanding the family caregiver burden of a relative with alcohol and/or opiate abuse problems; the moment caregivers learned of a relative's substance abuse problems, and the acceptance, decision making and support that follow. The four main themes identified in this study support the methods of guided existential inquiry of lived relation (relationality), lived time (temporality), Lived space (spatiality), lived material things, and lived body (corporeality) as proposed by van Manen.

Lived relationality is “the lived relation we maintain with others in the interpersonal space that we share with them” (van Manen, 1990, p 104). The relationship between the self and the other depicts an experiential moment. Fundamentally, the phenomenon of living with a relative with addiction problems becomes a relational experience. Here, the self struggles to accept the existence of such a problem. Extension of the self is perpetuated by the sacrifice and dedication that ensued in the moment of the experience. Each participant (the self) experiences this moment differently. Acceptance of a substance abuse disorder takes time which can be assisted by family psychoeducation.

Acceptance becomes a temporality (lived time). Being, as a construct has been described by Heidegger (1962) as time. Time thereby becomes a fluid in which being occurs. The being of acceptance is perpetuated by becoming aware (awareness) and Telos. Telos is described by van Manen (2014) as the “wishes, plans and goals we strive for in life” (p. 306). Telos becomes a goal-oriented purpose, an ultimate end. Becoming aware of a family member’s addictive behaviors is very devastating. Here, caregivers place themselves in two worlds (spatiality-lived space); a world of shattered dreams and that of future expectations as in seeing the caregiving role as a failure. Acceptance thereby vindicates itself in the “womb” of time. Acceptance as a “being” of reality becomes “momentarily” and an “enduring” process. Insight, a precursor to acceptance comes in a moment but also its endurance is subject to the test of time.

A phenomenon is experienced in relation to “things” (lived material things). This experience of a “thing” has a direct impact on the self. As van Manen (2014) claimed “Thus, in our encounter with the things, we experience the moral forces they exert on and in our lives” (p. 307). Of note, “how are things experienced and how do the experience of things lead to insightful meanings of phenomenon” (van Manen, 2014, p. 307). The healthcare experience

thereby becomes a thing that cannot be separated from the self. It becomes an extension of the self and mind. The disrespect and resentment faced by caregivers as they encounter the healthcare system becomes a thing that is being kept. Experience becomes personal or strange. For things “can disappoint us or reflect our disappointment back to us (van Manen, 2014, p. 307). As Heidegger (1971) pointed out”...the thingly character of the thing does not consist in it being a represented object, nor can it be defined in anyway in terms of the objectness, the over-againstness, of the object” (p. 167). As has been previously noted, the experience of a thing (health care system) should lead to insightful meanings. These insightful meanings are translated into terminology that reflects positive connotations (“relapse and sobriety” not “clean and dirty”) consistent with current research trends of addiction as a disease.

Corporeality-Lived Body depicts how the phenomenon is experienced in relation to the body or self. This body corporeality or embodiment is regarded by some phenomenologists as the motif fundamental to the understanding of human phenomenon (van Manen, 2014). In the human phenomenon of addiction, the whole body is involved in the uncertainties and struggles as this becomes a life long process for the family caregiver. This translates to how the body becomes aware, recognizes and converges on the human phenomenon of addiction. As van Manen (2014) noted, “we may look at our own body in the same appraising manner as we look at some elses’ body- however, this look is not the same, since we perceive our own body with our own body” (p. 304).

This object/subject experience of the body as it relates to the human phenomenon of addiction shows how people experience the same phenomenon differently (singularity of experience). Uncertainties and struggles of the human phenomenon of addiction depicts how the body is engaged in the world in bringing into awareness or the incarnate of fears, anxieties etc. of

living with a relative with addiction problems. The “being” of a life long process (Temporality-Lived Time) explores experience of time in relation to the human phenomenon of addiction (lived experience). As van Manen (2014) implied, “even the clock has a lived sensibility of time.....a number or display on a digital time piece shows time as differently from an analogue time piece....A clock.....with an analogue face shows time as movement in space when the hands slowly but determinately sweep across the dial. We tell time if it is glancing how far the hands of the clock have to go for lunch time to start” (p. 306).

### **Findings and prior empirical Literature**

This study explored the caregiver burden of addiction of a relative with alcohol and/or opiate addiction abuse problems. It showed how the burden of care is experienced differently taking into consideration the challenges and complexities involved in caring for the relative addict. Four main themes emerged from this study. Out of these themes, two major findings relating to the family caregiver burden of addiction were noted. These are caregiver burden of guilt and stigma, and addiction as a disease. These findings will be discussed in relation to previous studies of caring for family members with alcohol and/or opiate abuse problems.

#### **Caregiver burden of guilt and stigma**

Guilt and stigma are the defining characteristics that distinguish addiction from other chronic illnesses. This study builds on existing knowledge of the role stigma plays in the acceptance process. Stigma as a multi-faceted construct (Sercu & Bracke, 2016), is seen as a subjective burden. It has been reported that stigma against substance abusers is one of the main barriers to treatment delivery, and public health outcomes (U.S Department of Health and Human Services, 1999, Birtel, Wood & Kempa, 2017). Kessler, McGonagle, Zhao, Nelson, Hughes, Eshleman (1994) claimed that, due to the comorbidity of substance abuse disorder with

other psychiatric disorders, substance abuse stigma is one component of psychiatric disorders stigmatization. Further, it has been asserted by Rasinki, Woll & Cooke (2005) and Room (2005) that public attitudes expressed towards substance abusers differ from those with mental illness. To buffer this claim, Barry, McGinty, Pescosolido, & Goldman (2014), Parcesepe & Cabassa (2013) and Link, Struening, Rahau, Phelan & Nuttbrock (1997) reported that, individuals with substance abuse problems are likely to be more stigmatized than individuals with mental illness. This is due to societal view of addiction as a moral failure or personal choice rather than a disease. In their systematic review of 28 studies, Van Boekel, Brouwers, Van Weeghel & Garretsen (2013) reported that healthcare professionals also had negative attitudes towards persons with substance abuse. One thing that was clear was the impact stigma had on the caregiving experience by heightening the burden of care.

Categorizing addiction as a moral failure may discourage use but stigmatization may prevent early identification and treatment thereby affecting the health of users (Ahern, Stuber, & Galea, 2007), leading to an increase in the burden of care. Participants reported certain bizarre behaviors exhibited by the addicted family member defying family norms that may bring into awareness the existence of the phenomenon of substance abuse. As Usher et al (2007) reported, the realization of the existence of the phenomenon of addiction in the family member is compounded by doubt until the exhibition of certain behaviors which apparently confirm a substance abuse problem. As they reported, these lead to guilt as any attempt to intervene and provide any needed direction is met with resistance. This further heightened the burden of care.

There was the difficulty in discussing their loved one's substance abuse problem with other family members and friends. Here, family caregivers make conscious efforts to keep it as a secret for fear of societal stigma. The guilt of being responsible for their relative's addictive

behaviors or a failure as a parent or caregiver further intensifies symptoms of anxiety, worry, and depression (Usher et al, 2007, Vaingakar et al, 2012, Marcon et al, 2012, Biegel et al, 2007), hence heightening the negative effects of the burden of care. Participants also reported that stigma was a hindrance in the acceptance process. Moreover, feelings of guilt related to consequences of use could hinder successful treatment and recovery (Ehrmin, 2001). All these coupled with caregivers' self-blame for being the cause of relative's substance abuse problems heightened the burden of care.

### **Addiction as a disease**

There has been increasing evidence for the past two decades that addiction, is a disease of the brain (Volkow, Koob and McLellan, 2016). Addiction as reported by participants in this study is known as the "hidden disease"; a disease that has negative social connotations or seen as a moral failure. Substance abuse as a disease, lacks dignity and respect, a defining characteristic of a chronic disorder. The concept of addiction as a disease continues to raise societal questions (Volkow et al, 2016). Although family members expressed preference for a disease-focused view rather than a moral failure, Reinerman (2005) points out that this can be a "double-edged sword" and the disease model can also perpetuate a contradictory discourse, "a humane warrant for necessary health services and legitimation of repressive drug policies" ( p. 307). However, this discourse yields progressive effects if drug use becomes a public health concern rather than criminal law (Reinerman, 2005). Such a discourse is gradually yielding positive results in some communities in the United States. It is important to note that, conceptualizing addiction as a disease has provided the evidence for cutting-edge treatment interventions, preventive measures and viable public policy (Volkow, 2016).



Brown and Lewis (2002) stages of development model of recovery depicts the differences in family caregiver burden of substance abuse and the chronic relapsing nature of substance abuse as a disease. The differences in the family caregiving and the burden of care are consistent with the singularity, alterity and vulnerability of van Manen's (2014) philosophy of phenomenology of practice. Findings of this study demonstrated the fears, struggles and uncertainties encountered by family caregivers as they provide care to their relatives. This experience was reported by participants as a life long process.

Addiction as a chronic relapsing disease provides insight into the burden of care. The way the disease manifests itself may be a precipitant to the burden of the fear of the unknown. Burden reported in this study is ongoing and it ranges from financial support to other critical needs. Financial support being the most reported burden is consistent with prior literature findings. Family caregivers spent a significant portion of their income and time directly on relative abusing substances (Clark, 1994, Salize et al, 2012). In providing financial support, participants reported unknowingly supporting the relative's drug use.

### **Implication for Practice**

Participants provided several insightful recommendations for assisting family caregivers. These recommendations seek to enhance healthcare providers' understanding of family needs and the caregiver's burden. Findings of this study suggest that caregiver needs including support may be different at each stage of the caregiving experience. This finding is consistent with Raymond's (2016) qualitative descriptive study of Parents Caring for Adults with Serious Mental Illness. During the initial stages of the experience, caregivers' encounter with the healthcare system and their needs are usually focused on support and nurturing. Focusing the initial healthcare experience on providing information about the disease and treatment process is

necessary in decreasing the guilt and pain associated with the burden. Further, caregivers reported utilizing the healthcare system, especially through the emergency room, as the first point in accessing care. Having a dedicated specialized addiction service team as a centralized referral center is needed in addressing needs of caregivers and their relatives. The shortage of addiction specialists and other ancillary staff is critical in providing efficient treatment. The United States is currently faced with a shortage of these staff coupled with limited number of beds available for treatment. Policies to arouse interest in this specialty including expansion of student loan forgiveness programs with the aim of increasing staff to bridge the gap in treatment.

The Role of the 12-Step programs in addiction treatment and services cannot be underscored enough. Participants reported meeting places as dilapidated; meetings being held in back rooms, basements and not the nicest places. Meetings being held in dignified places and medical facilities are advised. These 12-Step programs need to be incorporated into the medical field as with other support groups. Addiction is a disease and as supported by the American Medical Association has not been fully understood by society. It is seen as a moral failure. Dignifying addiction just like any other disease and affording it the respect it needs to enable substance abusers and especially family caregivers to share their experiences is necessary. Participants reported the need for a change in terminology that reflects addiction as a disease; remission and exacerbation and refraining from negative connotation such as “clean” and “dirty”.

The recent crisis in opiate overdose requires an integrated approach involving family caregivers. This approach is necessary in educating caregivers about this crisis and life saving measures. Also, most caregivers reported access to information regarding their relative in treatment as problematic due to privacy laws. In order to encourage caregivers to be active

participants in their relatives' care and assume advocacy role, privacy reforms are necessary. Additionally, there is a need to educate substance abusers about the importance of family support in achieving and maintaining sobriety.

### **Implication for Research**

The results of this study add to existing knowledge on the family caregiver burden of a relative with opiate and/or alcohol abuse problems. Support is an important concept in the caregiving role as it relates to substance abuse. Participants of this study were mostly Caucasian. Racial and cultural/ethnic differences in the support family caregivers provide for their relative with substance abuse problems require further inquiry. Exploring these differences as to how support is conceptualized, identifying the nature of support, and needs of family caregivers at various stages of the experience are areas deserving further investigation. These studies should identify the sources of support; for example, spiritual groups, family members, friends and how these can be utilized to lessen the burden of care. It is important to recognize that various cultures and ethnic groups' concept of illness especially substance abuse may be different from the western culture. Support given may be affected by how substance abuse is conceptualized; as a disease or moral character defect.

Stigma and guilt, defining characteristics of chronic illnesses play important roles in the acceptance process. Acceptance may lessen or heighten the burden of care. Studies focusing on how stigma is conceptualized among family caregivers of relatives with substance abuse problems are needed. Such studies should focus on identifying strategies to increase public awareness of addiction as a disease, decrease stigma and enhance the acceptance process.

### **Implications for Health Policy**

A recent surge in drug overdoses has provided a window of opportunity in bringing public awareness of the extent of substance abuse and the burden of care. Awareness may reduce stigma and guilt thereby enhancing the acceptance process. Building coalitions to increase awareness of substance abuse and the burden of care with mental health advocates and other stakeholders such as AARP, NAMI (National Alliance on Mental Illness), AL-Anon Family Groups, Healthcare for All (Massachusetts), Family Caregiver Alliance etc., is important. Due to the scope and nature of this problem, addressing it at the local level offers many advantages. At the local level, increasing awareness may be addressed through the involvement of key community stakeholders, for example, healthcare professionals. Local campaigns with more modest goals are more effective and likely to achieve positive results (Freudenberg, Bradley and Serrano, 2009). Providing awareness includes but is not limited to providing public education on the societal forces, genetic susceptibility and environmental factors that influence substance abuse and its impact on families.

Policies to increase access to healthcare for substance abuse and related services through the Mental Health Parity Act and the Affordable Care Act is important. These policies should consider a comprehensive approach to care. Integration of primary care and behavioral care may improve access to care, treatment and overall effective management of substance abuse as a disease (Volkow et al, 2016, Saitz, Jo Larson, LaBelle, Richardson and Samet, 2008). These policies may make available resources for family caregivers as a tool to decrease the burden of care.

### **Limitations**

Participants recruited for this study reside in a large urban area and were of limited racial or ethnic backgrounds. Experiential materials that were gathered from family members of a loved one with substance abuse might not be similar to other ethnic or racial groups in rural areas or other geographic areas. Further, the sample lacked cultural diversity as it relates to gender and ethnicity. All of the participants were Caucasian (n=10) and majority of them were female (n=9). The study demographics do not reflect the gender and ethnic differences in family caregiving and how burden and support are conceptualized among other population groups.

Moreover, in the moment of the experience (during the interview), things are brought into focus. In this moment, it was important to explore the phenomenon further to seek for deeper meanings. However it was also important to balance this exploration to avoid emotional distress for participants. In this moment of the experience, researcher was unable to explore phenomenon for some of the deeper meanings as it would have caused additional emotional burden on the participants.

### **Summary**

This study explored the caregiver burden of family caregivers who have relatives with opiate and/or alcohol abuse problems using van Manen's (2014) phenomenology of practice. Four themes emerged from the data. The themes identified examined the singularity, alterity and vulnerability of the human phenomenon of the family caregiver burden of substance abuse. Two major findings; caregiver burden of guilt and stigma, and addiction as a disease were identified from these four themes. These major findings supported prior empirical literature on the family caregiver burden of substance abuse.

This research study explores a very sensitive topic as it relates to the caregiver burden of substance abuse. Participants shared some of their deepest secrets devoid of any theoretical or suppositional inclinations. Despite these private feelings of the phenomenon of substance abuse, participants expressed the importance of sharing their stories to increase societal awareness of substance abuse and the burden of care, and to provide a framework for conceptualizing addiction as a disease. Conceptualizing addiction as a disease informed public policies and health (Volkow, 2016).

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## APPENDIX

### Interview guide

This is a flexible guide that will be used to structure the scope of the interview process. As has been explained in the methodology section of this dissertation, the philosophical underpinnings of Phenomenology of Practice do not rely on mechanistic means for assessing human consciousness but rather allow for resourcefulness and innovation on the part of the researcher. The response of a participant to an initial question will determine the nature of further probing questions taking into consideration the burden of these question on the participant.

1. Can you tell me what is it like to live with and/or care for a relative with alcohol or opiate abuse?
2. How did you find out that your relative is abusing drugs?
  - What was it like for you?
  - What was your initial reaction?
  - Can you describe in detail with a specific moment of this experience that still resonates with you?
  - What was said, what happened thereafter?
3. Can you describe the moment that you learnt your relative has addictive problem?
4. How has your encounter with the health care system been?
  - Who initiated treatment for your relative?

- Any specific examples of structures that needs to be improved in the delivery of care? (Please include specific examples as it relates to your case...it can be stories)
5. What is the nature/structure/kind of support that your relative needs/receiving from you?
  6. Describe what you do as the primary caregiver for your relative?
    - How did you assume the caregiver role?
    - How did you prepare for this role?
  7. As a primary caregiver, do you receive any support from other family members, community resources or support groups?
  8. In what ways have you grown or developed from this experience of caring for your relative?
  9. What has the meaning of the experience of caring for your family member been for your life?"

### **Demographics**

Name:

Age:

What ethnicity do you use to describe yourself:

What gender are you:

What is your marital status:

Occupation:

How many hours a week do you spend caring for your relative:

How long have you been caring for your relative with alcohol and/or opiate problems:

How long has your relative been diagnosed with alcohol and/or opiate dependence/abuse: