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Brenda Jane Duchene California State University - San Bernardino

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CAREGIVERS' EMOTIONAL EXPERIENCES REGARDING THEIR ADOLESCENT'S SUBSTANCE ABUSE PROBLEM

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

by

Cindy Reyes

Brenda Jane Duchene

June 2015

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Approved by:

Dr. Thomas D. Davis, Faculty Supervisor, Social Work

Dr. Rosemary McCaslin, M.S.W. Research Coordinator

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ABSTRACT

The primary aim of this investigation was to explore caregivers' emotional experiences regarding their adolescent with substance abuse problems. These researchers systematically examined the literature on caregiver stress and found a large body of studies on caregivers of persons with mental illness, severe medical problems including cancer, HIV/AIDS, and developmental disabilities. Yet, an absence of research was found on caregivers including parents of adolescents with drug and/or alcohol problems. Based on the findings on investigations with other types of caregivers, these researchers expected caregivers of adolescent substance abusers to report high levels of emotional and psychological distress. Like caregivers of persons with psychiatric problems, it was expected that caregivers would report feelings of hopelessness, anger, anxiety, worthlessness, depression, apathy, alienation, etc. It was also expected that caregivers would express feelings of failure as parents, guilt for not caring better for their adolescents, and frustrations with how this problem can affect the complete family system. A total of 12 caregivers, including parents, of adolescents with drug and/or alcohol problems were interviewed using a semi-structured interview composed of 20 questions related to their experience of caring for an adolescent with these problems. The interview was designed by these researchers and was based on a systematic review of the literature as well as the clinical experiences of these researchers. The study is considered a

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gualitative-ethnographic study and attempted to capture the personal and intimate challenges confronted by caregivers. The results yielded five salient themes that emerged from the interviews. They were: stress, hurt, disappointment, failure, and hope. In addition, "mini-themes" were also identified. The themes were distance, resistance, guilt, helplessness, and shame. As a result of these findings, recommendations for reaching out to caregivers, the provision of psychological assistance for caregivers, and future research were presented. In addition, the results led the researchers to discuss the challenges of caregivers, especially minority caregivers, in caring for and parenting adolescents with these problems. The results also prompted more questions that require further study. Finally, the researchers also made a series of recommendations for mental health and substance abuse professionals, especially social workers, in the assessment and treatment of families with this problem. In the end, it is the contention of these researchers that substance abuse problems among adolescents are not only an individual issue, but a family issue that requires intervention at the family systems level. Overall, the findings from this study supported the researchers' assumptions that caregivers of adolescents with substance abuse problems would report high levels of stress, depression and worry, and also economic problems.

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This study would not have been possible without the support and guidance of the two members of the faculty advisory committee. To Dr. Rosemary McCaslin who reviewed the rough draft of this project and provided us with significant feedback in order to improve it. To Dr. Tom Davis who also developed many hours of his time and was patient in reviewing, editing and giving us feedback on this project from inception to completion. We also want to express appreciation and gratitude to Dr. Roberto Velasquez, retired professor of psychology from San Diego State University, who spent countless hours reading, reflecting and providing us with invaluable direction and technical advice. Most importantly, his encouragement and support throughout this entire process is appreciated. We would also like to acknowledge and thank the Masters of Social Work Program at the California State University of San Bernardino. Finally, we thank Garett Staley, the program director at Touchstones, the adolescent substance abuse treatment program in Orange, California, for allowing us to conduct our research at her facility.

DEDICATION

I dedicate this thesis project to my mother, Elvia Cantu, who struggled as a single mother to get me to where I am today. Thanks to her, I have been successful in accomplishing my career goals and am the person I am today. Also, I extend appreciation to my husband, Victor Reyes, who supported and encouraged me to grow as a person. Last, but not least, I thank my family, the Ortiz and Cantu families, for their constant words for encouragement and support. (Cindy Reyes)

Le dedico este proyecto de tesis a mi madre, Elvia Cantu, que ha batallado como madre soltera para conseguir traerme a donde estoy hoy en día. Gracias a ella, he tenido éxito en en el logro de mi metas profesionales y soy la persona que soy hoy. También, deseo expresar mi agradecimiento a mi esposo, Victor Reyes, quien me apoyó y animó a crecer como persona. Por último, pero no menos importante, le agradezco a mi familia, las familias Ortiz y Cantú, por sus constantes palabras de aliento y apoyo. (Cindy Reyes) I dedicate my thesis to my loving husband Gerald Duchene, who has been my best friend and advocate thank you for being there for me throughout the entire MSW program, words cannot express my appreciation. A special feeling of gratitude and dedication to my sons and daughter, Ruben, Gerald Jr. Irena, and Michael, whose words of encouragement and support kept me reaching for my goals. To my family, Paula Hernandez and Dana Henderson, who have never left my side and are very special to my heart. (Brenda Duchene)

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CHAPTER ONE

Caregivers, whether they are parents, grandparents, or foster parents, of adolescents with alcohol and/or drug problems, face many different types of challenges including significant emotional stress, depression and hopelessness, guilt and fearfulness, desperation, loneliness and social alienation, health concerns, and marital distress. Similar to caregivers of persons with several medical and mental health conditions (e.g., cancer, HIV/AIDS, stroke, schizophrenia, post-traumatic stress disorder, and autism), these caregivers undergo tremendous emotional and psychological strain, as well as economic distress, as they have to endure years and years of having to care for an adolescent who is actively using alcohol and/or drugs (Harpin, 2005).

In addition, like the caregivers for persons with medical illnesses (Blake, 2008; Calhoun, Beckham, & Bosworth, 2002; Draper, Bowring, Thompson, Van Heyst, Conroy, & Thompson, 2007; Garro, Thurman, Kerwin, & Ducette, 2005; González Salvador, Arango, Lyketsos, & Barba, 1999; Hansell, Hughes, Caliandro, Russo, Budin, Hartman, & Hernandez, 1998; Lecavalier, Leone, & Wiltz, 2006; Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Sherman, Edwards, Simonton, & Mehta, 2006), these caregivers also have to struggle with the unpredictability of an adolescent's behaviors which can take

the caregivers through a psychological "roller-coaster ride". In turn, this type of a challenge can often lead to not only severe stress, but also mental illness and even substance abuse in caregivers. This can also lead to "burn out" which often causes caregivers to give up and walk away from their adolescent.

On a daily basis, these parents are pressed to not only care for themselves and manage their own lives and families including other children, but also keep vigilance over adolescents who are actively using different types of substances and the resulting consequences that are usually problematic and dangerous. They worry about whether their adolescents are going to die because of a drug overdose, be killed or severely injured in an accident, prostitute themselves in order to maintain their habit, become drug dealers in order to support their addition, or end up in prison. They also worry about their adolescent's education, especially if that adolescent is no longer attending on a regular basis or if they are about to be expelled. They also worry about whether their adolescent is going to run away or disappear for extended periods of time or whether the adolescent will also develop mental illness as a result of using (and abusing) substances.

For many parents or caregivers, the toll of parenting this type of adolescent can be significant and can affect lingering psychological and physical effects. For example, in addition to dealing with the substance abuse problem, they also have to deal with other key issues that are part of the adolescent period of development including puberty, identity and sexual

development, life and relationship choices, peer associations, etc. Many caregivers may eventually need psychological treatment because the strain of caregiving is overwhelming and emotionally costly.

In addition, families, both immediate and extended, are also affected by a family member's substance abuse problems and the family as a system may undergo many changes, often dysfunctional and pathological. Many families become disjointed, disorganized, and disengaged, while others become highly enmeshed and lose psychological boundaries. Thus, there is significant "collateral damage" in families with a family member who has drug and/or alcohol problems, whether the member is an adult or child. For example, younger children may also begin to view the adolescent with substance abuse problems as a "role model" and may also begin to experiment with substances as well as take on oppositional or defiant behaviors. Also, in many families, substance abuse may be intergenerational having begun with parents or grandparents, and thus may become a problem over several generations.

Economically, families are also known to suffer because of a family member actively using substances, whether alcohol or other different types of drugs. In many families, the abuser often steals from the family, especially if the drug or substance is costly. In other cases, families often go into debt when trying to assist their family member through specialized mental health and substance abuse treatment. In other cases, families are often stuck with bills and costs associated with incarceration, harm to others (e.g., restitution),

and legal costs. It is not unusual for families to become bankrupt in attempting to seek a "cure" for their adolescent's substance abuse problems. In other cases, economic strain may cause parents to experience their own emotional and relationship problems to the point of divorce.

Our systematic review of the research literature indicates that while there is a wealth of studies on minors, especially adolescents, with substance abuse problems, from prevalence and epidemiology investigations to specific primary and secondary interventions to empirically-derived treatments (Aarons, Brown, Hough, Garland, & Wood, 2001; Burrow Sanchez, 2006; Deas & Brown, 2006; King, Ghaziuddin, McGovjern, Brand, Hill, & Naylor, 1996; Kaminer, 1994; Newcomb & Bentler, 1989; Segal, Morral, & Stevens, 2014; Tapert, Aarons, Sedlar, & Brown, S. 2001; Tarter, 2002; Whitbeck, Hoyt, & Bao, 2000), there remains a lack of research on the caregivers or parents of adolescents with theses problems.

As a result, these researchers extended their literature search to include the effects of adult substance on family strain as well as studies on caregivers of adolescents with other types of behavioral, medical, and emotional problems (Hu, Lin, Yen, Loh, Hsu, Lin, & Wu, 2010; Kuo & Operario, 2009; Lin, Lin, & Wu, 2010; Moretti, Holland, Moore, & McKay, 2004; Parker, & Benson, 2004; Rotheram-Borus, Leonard, Lightfoot, Franzke, Tottenham, & Lee, 2002; Ungar, 2004). Research studies on caregivers of children, especially adolescents, with these types of problems suggest that caregivers

are overly taxed on an emotional level and often develop their own psychological problems in attempting to cope with the burden of caring for an adolescent with one or more medical and/or psychiatric problems.

While there are many commonalities between among caregivers of adolescents with substance abuse issues and those with adults with drug and alcohol problems as well as medical problems, there are also many unique differences. For example, in the case of the caregiver for an adolescent with substance abuse problems, they are typically the biological parent or grandparent, while caregivers for adult substance abusers can range from a spouse to an adult child or friend to a government sponsored caretaker. Moreover, there continues to remain an absence of research studies on how caregivers effectively cope with the stress of having to parent an adolescent who has such problems, and in which the problems can range from mild to severe to catastrophic. This stress can manifest itself at different levels of the caregiving process, from initially finding out that an adolescent has problems with substances to having to manage the negative outcomes of substance abuse including poor academic performance, school absence, oppositional and defiant behaviors, criminality, incarceration, gang involvement, and sexual acting-out. This stress can also manifest itself when the parent is dealing with the adolescent who may be deceptive and/or who is in denial about their problem.

It is the contention of these researchers that the stress associated with the caregiving of adolescents with substance abuse problems is similar to other stress in other types of caregiving (see Chapter Two). For example, we believe that caregivers who care for adolescents with substance abuse problems can experience such high levels of psychological stress so as to be affected at both physical and psychological levels, and in turn may lead to "caregiver burn out". Caregivers can develop various medical conditions as a result of stress including high blood pressure, headaches, ulcers, and irritable bowel syndrome. They can also develop various DSM-V conditions including Major Depressive Disorder, Generalized Anxiety Disorder, and Panic Disorder. In this manner, the stress experienced by caregivers of adolescents with substance abuse problems parallels that experienced by caregivers of persons with Alzheimer's disease, cancer, stroke, HIV/AIDS, traumatic head injury, paralysis, etc. (Bodnar & Kiecolt-Glaser, 1994; Dwyer, Lee, & Jankowski, 1994; Empeno, Raming, Irwin, Nelesen, & Lloyd, 2011; Radziewicz, 2001; Vedhara, Shanks, Anderson, & Lightman, 2000; Wright, Clipp, & George, 1993).

As social workers, it is our contention that we must not only consider the role of caregivers in the treatment of substance abuse disorders in adolescents, but also consider the mental health status of the caregivers who have to handle the day-to-day crises. In addition, there is also a cultural element that must always be recognized in the caregiving of persons with

medical conditions that logically extends to the caregiving of culturally- and linguistically-diverse adolescents with substance abuse problems (e.g., Aranda & Knight, 1997; Ho, Weitzman, Cui, & Levkoff, 2000; Ramos, 2004).

Restated, this investigation considers the factors that are likely to account for the "stress" or agony experienced by caregivers who are placed in the difficult role of caring for a child with substance abuse disorders. Since these researchers are interested in the psychological mechanisms related to successful coping which leads to caregiver resilience, it is first important to study the emotional issues that these caregivers face on a daily basis. Ultimately, the goal of these researchers is to develop interventions that would promote long-lasting resilience in caregivers. Our review of the literature on caregiving in general did identify diverse programs and interventions that are employed to strengthen both coping and resilience. These have primarily focused on the caregivers of persons with medical and psychiatric problems (see Chapter 5).

Problem Statement

Today, as the rates of substance abuse amongst adolescents from diverse cultural, economic and social backgrounds continue to increase to epidemic proportion, more and more caregiver, including parents, are being placed in the difficult situation of having to care for an adolescent with these problems (Mayes & Truman, 2002). In particular, these caregivers are likely to

encounter high levels of distress because they have to care and parent an adolescent who has substance abuse problems and which can also include an element of mental illness or what is called a "dual diagnosis" (Bukstein, Brent, & Kaminer, 1989; Costello, Erkanli, Federman, & Angold, 1999).

As previously noted, these caregivers are often placed in the difficult situation of having to worry about their adolescent on a continuous basis as they fear that the adolescent may die of an overdose, run away from home, enter the criminal justice system, or drop out of school. Thus, caregivers are likely to have severe interruptions in their daily routines including staying up all night waiting for their adolescent to come home. In addition, the caregiver has to also manage the affairs of the rest of the family unit and can include responsibilities associated with parenting and economic support. Thus, like caring for an elderly parent, a child with autism or mental retardation, or an adult with Alzheimer's disease, the work is never ending, tiring, and potentially threatening to one's mental and physical health.

Oftentimes, at the beginning of the detection of a substance abuse problem in an adolescent, the caregiver experiences high level of distress because they do not know where to begin the process of seeking help or assistance for their adolescent. Many confront barriers related to the family (e.g., denial of the problem), community, and health care system. Even today, with all of the major changes in substance abuse and mental health care, especially for minors, there remain many problems in accessing the most

beneficial services for an adolescent. Thus, an additional stressor is imposed upon caregivers, that of having to find the most effective form of assistance for the adolescent and the family.

Purpose of the Study

Drug or substance abuse by adolescents continues to have a major impact on the health and well-being of young people and poses a serious parental management problem for parents and families (Henggeler, Clingempeel, Brondino, & Pickrel, 2002; Johnson & Pandina, 1991; Liddle, Dakof, Parker, Diamond, Barrett, & Tejeda, 2001; Mayes & Truman, 2002; Ozechowski, & Liddle, 2000; Waldron, 1997). The problems associated with the use of substances are far reaching and include criminality, sexual actingout, and ending school prematurely. As noted previously, the effects can be acute or chronic, and can change the family system, from a healthy functioning system to one that is dysfunctional and destroyed.

The purpose of this investigation was to examine a small group of caregivers, most of whom were parents, of adolescents with substance abuse problems. Using past research on caregiver stress related to caring for sick and mentally ill persons, this study considered the feelings, opinions, and attitudes of caregivers who are responsible for an adolescent with drug and/or alcohol problems. In this study, the researchers' primary aim was to document the emotional challenges faced by this specific group of individuals.

It is important to highlight a recent research study by Fisher and colleagues (2006) who examined 591 adolescents between the ages of 12 and 17, as well as one parent of each adolescent. The main purpose was to determine how much knowledge the parents had of their child's use of substances. Using the parental form of the Semi-Structured Assessment for the Genetics of Alcohol (C-SSAGA), the results indicated that only half (50%) of the parents of children who were actively using substances knew that their child was using. This suggests that caregivers are usually not likely to know that a child is using substances and that they do not appear to monitor this potential problem on a regular basis. In other words, most parents are not vigilant of substance abuse problems among their children, and thus, undergo significant trauma when they find out or are informed by a third party that their child has such problems.

CHAPTER TWO

Introduction

Chapter Two presents a discussion of the key research literature that is related to the topic being investigated in this study- stress in caregivers of adolescents with substance abuse problems. As noted in Chapter One, there is a virtual absence of research on the specific emotional and psychological challenges that caregivers have to confront in caring for and parenting an adolescent with drug and/or alcohol problems.

While the research literature on adolescent substance abuse does consistently suggest that families and caregivers can be negatively impacted by their adolescent's substance abuse problems, as their lives can become chaotic and disorganized, there is an absence of studies, quantitative or qualitative, that examines the many feelings and emotions that caregivers experience as they go through the different phases of managing the reality of an adolescent who is impaired because of substance use. There is also scant research on the many challenges that caregiver experience in attempting to adjust their lifestyles to such a stressful, emotionally draining and enduring event. It is important to note that a child's substance abuse problem can not only last for years during the periods of childhood and adolescence, the

problems can linger well into adulthood and can be livelong problems for caregivers even beyond their period of caregiving.

Thus, it is our contention that caregivers are not only stressed during the time they care for their adolescent with active substance abuse problems, they can remain stressed for most of their lives if an adult child continues to use substances well into adulthood. For example, many caregivers have to change or modify their lifestyle, career, relationships, and daily routine because they now have to monitor their adolescent's behaviors on a continuous basis. Moreover, they have to be on constant guard for the worst case scenarios including death. Thus, the quality of life and wellness for the caregiver is compromised as the focus changes to the adolescent with substance abuse problems and away from the caregiver.

This chapter is divided into three key subsections that are related to the topic that is being studied in this investigation. The first subsection considers the theories that guide the conceptualization of this study while the second subsection considers the prevalence of substance abuse among adolescents, with a special emphasis on how this problem affects the caregivers as family members. The final subsection discusses the importance of the family in addressing the issue of substance abuse in a family member who is a minor.

Theories Guiding Conceptualization

It is important to note that every research study, whether qualitative or quantitative, should be anchored in a theory or set of concepts, assumptions and/or ideas that guide the research process from beginning to end. At the same time, studies should also be a reflection of the researchers' own experiences within the field including their own clinical experiences and observations with the target groups(s) that is being studied. The following are some of the researchers' assumptions about the psychological, emotional and even physical consequences of parenting an adolescent with substance abuse problems:

- The process of caring for a child, especially an adolescent with substance abuse problems, can be very stressful, painful, worrisome, time-consuming, and frustrating. An event such as this can impact the life of a caregiver in many distinct ways, especially in disturbing the daily routine of the person. From our personal experiences with family members, we recognize the high levels of distress and strain experienced by caregivers and families of persons with medical, psychiatric, and/or developmental disabilities. Caregiving can be very time-consuming, often requiring a full-time commitment.
- The process of caring for an adolescent with substance abuse problems is not only a problem for the caregiver, but for the complete family and thus a "systemic issue." Thus, not only is the caregiver

affected, but also the family. Similar to families with adult members who are substance abusers, families of adolescent substance abusers can be torn apart because of this problem and can develop their own negative reactions to a sibling's problems. Thus, the issue needs to be understood from both a caregiver and family point of view. In this investigation, we examined the caregiver distress and strain in coping with an adolescent with such problems, yet we recognize the need for comprehensive research on "caregiving families" and the consequences of helping out an adolescent family with substance abuse issues.

The process of caregiving can trigger lots and lots of issues for the caregiver including feelings of regret, guilt, anger, anxiety, tiredness, anguish, frustration, sadness, worry, incompetence, shame and embarrassment, and inferiority and failure. The caregiver is also likely to experience different feelings and emotions depending on the status of the adolescent. Thus, caring for an adolescent with substance abuse problems can result in an "emotional roller-coaster ride" with constant changes in mood and affect, which can be exhausting. If the adolescent is in a period of sobriety, the caregiver is likely to feel positive, calm, and happy, but when the adolescent relapses, the caregiver is likely to go into crisis. Thus, we believe that caregivers are likely to experience

turmoil, "ups and downs," and/or an "emotional rollercoaster ride" in the process of caring for an adolescent with substance abuse problems.

- The caregiver is likely to go through different stages of managing an adolescent's substance abuse, from the beginning when they first learn about the problem to more advanced phases when the adolescent is using multiple drugs or substances, or is beginning to have legal problems. In many ways, these stages are similar to those that many persons undergo after the death of a loved one or when a loved one is diagnosed with a severe and life-threatening illness. For example, they are likely to experience a period of denial at the very beginning when they learn that their adolescent is using substances, and like the death of a loved one, may experience various periods of denial prior to reaching a level of acceptance.
- As note previously, the life of a caregiver of an adolescent with substance abuse problems, like the life of a caregiver for persons with severe mental retardation or dementia, changes in dramatic ways, and usually for the worst as they initially struggle to gain some sense of balance and homeostasis. As a result, many caregivers may experience break-ups in relationships and friendships and may find themselves isolated from others including family and community. They may also feel as though no one understands their struggle and thus feel alienated by others.

- There is a need for support programs and interventions for caregivers of adolescents with drug and/or alcohol problems. Our review of the literature indicates that caregivers are in dire need of assistance, including spiritual and religious assistance. Like other caregiver many caregivers of adolescents with substance abuse problems are likely to fall back on spirituality, formalized religion, and/or prayer as a means of gaining some peace of mind as they struggle with their adolescents Others may find ways that are unhealthy and even dysfunctional, and may even experience their own issues with substances or other types of problematic behaviors. For example, it is not unusual for caregivers to experience the break-up of an intimate relationship with a partner or spouse.
- As researchers, we strongly believe that social learning theory can be used to understand the origin of substance abuse in different populations including children and adolescents. We believe that a critical mechanism in the addiction process in adolescents focuses on the reinforcement that occurs at both biological and interpersonal levels, and that mechanism grounded in both operant and classical conditioning, combined with social learning theory devised by Albert Bandura can help to understand how substance abuse develops. At the same time, we also acknowledge the research literature that has considered the genetic components to addiction and substance abuse

as well as research on substance abuse across generations of families. Moreover, we also believe in the Theory of Reasoned Action as a theory that supports general social learning theory in understanding substance abuse in adolescents and even in understanding how caregivers can learn to modify their reactions related to stress and coping. We will discuss the strengths of this theory in the next chapter.

One final assumption on the part of these researchers is that culture and language are critical in all aspects of mental and substance abuse health care, and that any understanding of caregiver's stress has to be understood within the context of these two key factors. For example, we believe that caregiving can be governed by culture and that there are differences between cultural and racial groups in how caregiving is expressed, whether it is with persons with Alzheimer's disease or adolescents with substance abuse problems. Also, we believe that language can mediate the expression of different types of psychopathology, ranging from substance abuse to severe mental illness, and as such, must be acknowledged when working with caregivers from diverse cultural and linguistic backgrounds.

As researchers, these are some of the conceptualizations that guide this research study. The following literature supports our contentions which were studied through our investigation with the caregivers.

Adolescents with substance use and abuse problems are known to exhibit deviant behaviors that can be examined and understood through social learning theory (Ford, 2008). Thus, deviance is believed to be a learned behavior that is modeled by social peers that provide normative definitions and that reward deviant behavior (Ford, 2008). For example, smoking by adolescents who use other types of substances is a very common phenomenon, and is typically witnessed in adolescent and young adult peer group relationships. Many youthful substance abusers may use cigarettes as well as other substances, notably marijuana, as a "gateway drug" which can also lead them to poly-substance abuse.

The research that was guided by Akers (1985) indicated that social learning theory concentrated on the impact of socialization and normative influences of significant others (Ford, 2008). Social learning theory builds on classic theory (Sutherland, 1948) which integrated elements of psychological behavior with the modeling and learning process. The theory stated that there are four key components to social learning theory: differential association, imitation, definitions, and differential reinforcement (Ford, 2008). First, differential association area of concern is the direct interactions with others (Ford, 2008). Second, the modeling of behavior is either positive or negative and as a result it is either being rewarded or punished, depending on the behavior. Negative behavior that is punished will more than likely not be imitated and

good behavior will be modeled, but it depends on the characteristics of the model and the behavior being observed that will determine if the adolescent will imitate the behavior (Ford, 2008).

Third, definitions are attitudes and behaviors that people attach meaning to (Ford, 2008). Ford (2008) noted that "to predict deviant behavior social learning theory focuses on a balance of definitions that are favorable and unfavorable of deviant behavior" (p. 303). Definitions can be used to rationalize deviant behavior or give good reason for the involvement in this type of behavior. Fourth, differential reinforcement is based on predicted and actual outcomes of behavior (Ford, 2008). Deviance is learned when behavior is rewarded and outweighs the punishment as they are given positive reinforcement verses those who view taking drugs as a negative reinforcement (Ford, 2008).

The Theory of Reasoned Action, mentioned in the previous chapter, based on the understanding of attitudes and predicting social behavior. This theory was first developed in the late 1960's by Fishbein, and later revised by Fishbein and Azjen. The premise of the theory is that persons intentionally behave in a certain way because there is a "pay-off." This theory is activated by a causal sequence materialized in attitudes, beliefs, and social norms which affect individuals in their decisions and are initiated by two types of beliefs (Sarver, 1983). First, it is a person's beliefs about performing or not performing a specific act and the consequences of that act (Sarver, 1983).

Second, it is a person's beliefs about whether other people agree or disagree with the decision to act out or not to act, and what he/she would think others would want him/her to do (Sarver, 1983).

This theory also indicates reasoned action reflects behavior that is determined by a person's intention to perform the act based on the behavior and the attitude which can be influenced by friends and family (Sarver, 2008). The subjective norms are the way in which the person perceives what they think others would want them to do. Rational process involves the way in which the entire sequence is carried out leading from the beliefs to the specific behavior in which a person will use the information and come to a decision (Sarver, 1983). The theory of reasoned action is a process of sequential stages preceding the last stage. When the stages are completed, the result is behavior based upon the "theory of reasoned action."

Prevalence and Severity of Substance Abuse among Adolescents

According to the National Center for Addiction and Substance Among Adolescents (2005), there was an increase of 212% between 1992 and 2003 in non-medical prescription drug use among adolescents between the ages of 12 to 17 years old (Ford, 2008). Information from school based surveys suggested that marijuana and non-medical prescription drugs have increased and illicit drugs have declined among adolescents (Ford, 2008). This is but one aspect of the growing substance abuse epidemic in the United States today.

Substance abuse among adolescents is a significant public health concern that affects 10% of adolescents between the ages of 12-17 years in the United States, and up to 7% can meet the diagnostic criteria for specific DSM-V substance use disorders at any given time (Burrow-Sanchez, Minami, & Hops, 2015). There is a large number of adolescents who are in dire need of treatment (1.8 million) which far outweighs the number (150,000, or roughly 8%) of adolescents who actually get placed in outpatient or inpatient treatment services (Burrow-Sanchez, et al, 2015).

Latino youth appear to be in greater need of the most effective treatment because they have a higher rate of substance use disorders (14%) when compared to White (12.7%) or African Americans (7%) counterparts (Burrow-Sanchez, et al, 2015). Latino adolescents are more likely than White adolescents to experience legal involvement and be referred for substance abuse treatment ordered by the criminal justice system (Burrow-Sanchez, et al, 2015).

While this study did not specifically focus on the Latino/a population, including caregivers, it is important to note that this population is now the largest and fastest growing ethnic minority group in the United States, consisting of 51 million people with a third of the population being under the age of 18 and at risk for substance abuse (Burrow-Sanchez, et al, 2015). Also,

it is expected that by 2050, the population will increase to upwards of 128 million and comprising up to one-third of the total American population. It is estimated that Latinos, as a group, will continue to be a relatively young population with significant at-riskness for substance abuse disorders.

Usher, Jackson, and O'Brien (2005) analyzed substance abuse patterns among adolescents. They also studied the importance of integrated health services and specialized intervention for those teens that misuse drugs. According to theses researchers, adolescent substance abuse is problematic, multidimensional, and highly complex, with negative implications for family members, school, health and the community. Their analysis was based on adolescents who have histories of substance abuse and who have accompanying medical disorders. Moreover, they also practice high risk behaviors such as sexual promiscuity, possession of weapons, and higher rates of risk-taking behaviors that result in accidental injuries. The researchers stressed that if addiction occurs at younger ages without the knowledge of caregivers, the impact to caregivers is likely to be more severe and prolonged.

Usher, Jackson, and O'Brien (2005) indicated the seriousness of drug use among adolescents and impact families' inability to cope at higher rates. They argued that the family strength model provided information which can be useful for families as it provides specific familial behaviors that can increase the resiliency of family members and why some families have the ability to cope and others do not (Usher, Jackson, & O'Brien, 2005).

The National Center on Addiction and Substance Abuse (CASA) at Columbia University conducted research on adolescents (defined as being under 18 years of age) and found that 1 out of 4 Americans adolescents began using drugs, alcohol and cigarettes before the age of eighteen (CASA, 2009). CASA also noted that 1 out of 4 teens using alcohol and other drugs (AOD) before the age of eighteen will become addicted (CASA, 2009). This poses significant problems for families, in particular parents or guardian (which will be referred as caregivers), on whom the burden of this behavior falls.

Furthermore, the report by CASA stated that "with drug abuse rates in teens rising [around the world] every year due to peer pressure, depression, family problems, and an over glamorization of drugs and alcohol in today's culture" (CASA, 2009) caregivers do not know how to prevent their teen from abusing drugs and/or alcohol. For instance, mothers have reported harmful patterns of criminal activity among their adolescents using marijuana. Furthermore, substance use has been linked to accidental injury and death due to overdose (see Jackson, Usher & O'Brien, 2006). Caregivers feel vulnerable and unable to cope with the issues surrounding their adolescent substance abuser and are heartbroken with the loss of the adolescent they once knew. Thus, it is essential to provide these caregivers with guidance so that they do not lose hope in their battle to stop their adolescent from using drugs and/or alcohol.

Bertrand et al., (2013) also suggested that substance abuse problems are complex with early onset of use being linked to a greater risk of continued use in adulthood. Lack of parental monitoring has also been associated with increased levels of substance utilization and poor treatment outcomes. On the other hand, parental monitoring reduces maternal psychological distress, such as anxiety, depression, irritability and cognitive problems, as well as improves parenting practices, which, as a result, reduce, substance abuse among adolescents. Overall, not only is the addicted adolescent affected, the people living around them are also affected. Both, the addict and his/her loved ones, live a life of daily struggles, confusion and frustration. Therefore, providing caregivers the right resources to help their adolescent with their addiction can also prevent harm within the community.

Usher, Jackson, and O'Brien (2005) addressed issues that are and will continue to affect adolescents. Some teens are at a high risk behavior for misuse and are susceptible to drug addiction and many will develop problems associated with the misuse of various drugs. The findings of Usher, Jackson, and O'Brien (2005) suggested a growing trend of teens using drugs between the ages of 14-18 years of age. Family members often have a difficult time trying to cope with an adolescent that is delinquent and has a drug addiction. Adolescents are curious and like to experiment and they are often provoked by peer group activity.

The Role of Family in Adolescent Substance Abuse Treatment

According to Springer and Orsbon (2002), many of the risk factors indicating whether adolescents are at risk for substance use revolve around the dynamics of the family. Therefore, family is an essential factor when treating adolescent substance abusers. Multifamily therapy groups (MFTGs) have been found to be effective in many populations across a variety of settings in involving families in treatment (Springer & Orsbon, 2002). For this reason, Springer and Orsbon (2002) presented a theoretical overview of the MFTG model. Moreover, they described and illustrated the model by implementing it with substance abusing adolescents and their families.

Techniques and interventions are also integrated in the MFTG model. Springer and Orsbon (2002) briefly described three from four modalities: a.) solution-focused, b.) structural family therapy, c.) interactional, and d.) mutual aid approach. In addition, it emphasized MFTG as being a significant component of the therapeutic process from which teens and their family members can benefit. Furthermore, MFTGs, along with careful planning, can certainly support adolescents and their families through treatment stages.

Bertrand et al. (2013) stressed the importance of the parent-adolescent relationship as well as the mental health of parents when considering interventions for substance abuse. Bertrand et al. (2013) examined the association between changes in adolescents' substance use and parenting practices, changes in mothers' mental health and their parenting practices,

and parental use of services offered by substance abuse treatment centers. The participants were 147 adolescents (ages 13-18 years old in a substance abuse treatment program) and 69 mothers (Bertrand et al., 2013). The adolescents were assessed soon after they were admitted into treatment as well as being followed up six months and nine months later. The adolescent patients perceived an association between better maternal mental health and greater parental warmth. Finally, more self disclosure from the adolescent in addition to parental warmth was associated with the decrease of the adolescent's substance abuse.

Bertrand et al. (2013) stressed that family therapy does not influence the rehabilitation process, but rather it is the various types of family therapy interventions, as well as the different types of family involvement, that are effective in the adolescent's treatment. The study also examined the relationships between parenting practices, mother's mental health and substance use of adolescents in treatment. There was a limitation, with the father's mental health and parenting practices not included in the study. Also, they did not use a control group, therefore it cannot be ignored that adolescent's drug use may in fact have gotten better without attending drug treatment. Replicating this study in populations where there are multiple ethnicities would be beneficial because there would be greater cultural differences.

Gruber and Taylor (2006) examined increasing researcher's and treatment provider's acknowledgement of the part that family and family functioning has in order to comprehend the occurrence and impact of substance abuse. It gave attention to the following subjects: how substance abuse occurs in the families, families and the perpetuation of substance abuse, how substance abuse harms families and adolescents, substance as a treatment and recovery resource, family as a preventive resource, risk and resiliency. Bertrand et al. (2013) also suggested strengthening the family perspective in the following areas of substance abuse research and treatment: a.) incidence, prevalence and impact of substance abuse, b.) substance abuse as related to the functional characteristics of the family, c.) developmental stages of family substance abuse and recovery, d.) families as the unit of measurement in the study of substance abuse, e.) families as resources for developing strategies to combat alcohol and drug addiction, and f.) family risk and protective factors related to substance abuse.

Bertrand et al. (2013) highlighted the impact and effects that substance abuse brings on the family and its members. The goals of most addiction services are aimed at the individual drinker or drug user while family members and other support members are neglected or not recognized as key players. Thus researchers are too focused on the substance user rather than on the possible essential outcomes that result from family involvement. Bertrand et al. (2013) also focused on other family relations and structures rather than just

focus on parent and child/adolescent issues. They provided recommendations to raise attention on family in substance abuse research because substance abuse is not merely the problem of the adolescent but also the problem of the entire family

Typically, when parents find out their adolescent is using drugs or alcohol they are shocked and surprised. They also become scared, depressed, and anxious. They also quickly realize that they are not knowledgeable about substance use or abuse and about available resources in their community. In turn, this results in either increased levels of motivation to learn about the problem or fear and disinterest which pushes for giving up and losing hope. Thus, Gruber and Taylor (2006) emphasized family involvement being necessary in order to progress in providing better quality of care and to make certain that all adolescents and their families needing substance abuse treatment and recovery receive "accessible, appropriate, and quality treatment, as well as menu of recovery services and support" (p. 75). They also highlighted what family involvement really should be and why it is important in the caregiving process of an adolescent with substance abuse problems.

There are many adolescents who meet the DSM-V alcohol and/or drug dependence criteria. Therefore Gruber and Taylor (2006) developed and enhanced collaboration with families and recovery professionals to meet the substance abuse treatment and recovery needs of these adolescents.

Examples family involvement included attempts in improving family communication in treatment to adolescents.

Our review of the literature indicated that parents who care for a child with severe medical illnesses such as cancer can also experience many stressors that are similar to those caregivers with adolescents with substance abuse problems. These stressors, along with the strain of caring for a child with cancer, may have long-term debilitating effects on one's health as well as financial implications for caregivers. Granek's et al. (2014) found that "financial stress was the most pronounced burden that single parents caring for a child with cancer faced" (p.191). Caring for a child with cancer meant being a fulltime caregiver resulting in not being able to work, either for a short while or for a long period of time, in a context of an already unstable financial situation. Overall, the most prominent stressors for the caregivers included "financial, caregiving, and workload strain and was the combination of these multiple stressors that caused the distress rather than any one stress on its own" (Granek et al., 2014).

In addition to caregivers of a child with cancer, caregivers of an adult relative with serious and persistent mental illness also experience major stress. Marquez and Ramírez-García (2013) examined a sample of Latino caregivers and found that despite the high levels of family involvement, the role of caregivers in treatment engagement and retention was overlooked, just as is the case with caregivers of adolescents with substance abuse problems.

Thus, future research is needed that examines family caregivers' role in treatment for both populations because they play a key role in their lives. In their study, Marquez and Ramírez-García (2013) also found the factors that impede Latinos from reaching out to mental health services. Even though they may pursue services for their relatives, there are economic barriers that stand in the way of these caregivers (Marquez & Ramírez García, 2013). The dominant barrier to mental health services for these Latino caregivers was affordability of services followed by linguistically-competent services. They reported having sought services from mental health professionals only when relative reached an alarming behavior or for emergencies such as inpatient hospitalization.

Oruche et al. (2015) argued that family members with an adolescent with a disruptive behavior disorders, such as oppositional defiant disorder and conduct disorder, also experience challenges that are extremely stressful. They stated that even though "most empirically supported treatments for disruptive behavior disorders are family-based, the emphasis is typically on the behavior of the child rather than on the life challenges and resultant distress experienced by the family members" (Oruche et al., 2015, p. 149). They recruited 15 families (primary caregivers) of adolescents with disruptive behavior disorders from a public community mental health center to conduct in-depth interviews to investigate the challenges that caregivers have in living with and caring for adolescents. They fund that the caregivers' challenges

were "overwhelming, demanding, and unrelenting" (Oruche et al., 2015, p. 149).

The most prominent challenges were the following: "(a) managing the adolescents' aggressive, defiant, and deceitful behaviors, and (b) interacting frequently with a number of child-serving agencies" (Oruche et al., 2015, p. 149). This meant that the families experienced stressors that produced changes in boundaries, roles, patterns of interactions, values, and/or goals within the family that lead to financial, emotional, and social hardships affecting all family members. It may or may not be possible for families to manage these hardships without having to disrupt the family system. In addition, if there are too many demands on the family that exceeds their capabilities in order to meet the needs of the adolescent, the family may experience stress and possibly result in altering the family functioning.

Smith and Estefan (2014) argued that families with substance abusing relatives experience "physical and psychological stress symptoms including depression, anxiety, substance disorders, and trauma" (p. 424). They also argued that the emotional responses of family members progressed as the addition did. They stated that "families experiencing addiction endure considerable stress-related behaviors including insomnia, anxiety, and depression; isolation and suicidal ideation; betrayal and resentment; frustration and disarray; grief and loss; and shame and guilt" (Smith & Estefan, 2014, p. 425).

Caregivers who have children with autism spectrum disorder (ASD) reported increased stress levels and other mental health issues due to the demanding care of the recipient. In addition, these parents also suffer from anxiety and depression than their counterparts whose children have other disabilities (De Andre's-Garcia, Ana-Gonzalez, Romero-Martinez, Moya-Albiol & Gonzalez-Bono, 2013). Prolonged exposure to stress can affect the health of the caregiver as there are higher levels of cortisol released from the adrenal glands in the body causing health related complaints (De Andre's-Garcia, et al, 2013). Thus, it was found that caregivers compromised their own health in efforts to care for their offspring with ASD disabilities.

Studies were conducted between groups of 41 parents of offspring's with ASD and a group of 37 non-caregiver parents. The results of the study indicated a dysregulation in both immune (measured by immunoglobulin levels) hormonal stress induced (measured by cortisol levels) responses in the caregiver group complaining of stress and fatigue compared to the noncaregiver parents (De Andre's-Garcia, et al, 2013).

As noted throughout this investigation, caregivers can provide care for family members such as grandparents, parents, uncles, aunts, siblings, disabled children and the elderly. Family caregivers take on this role to care for others without adequate training or expertise, little knowledge of resources, and are unfairly expected to provide quality care for these individuals without any help from others (Ansari et al, 2013). Unfortunately, in the process of

caregiving, this person begins to ignore their health in order to provide care and meet the needs of the patient. The family caregiver experiences many challenges that also affect their psychological well-being. For example, the emotional and physical stress that can manifest itself in many ways such as frustration, depression fatigue, anger, guilt, and loneliness (Ansari, et al, 2013). Stress, and burn out, is commonly observed in a caregiver when they no longer have the time, energy and resources to effectively perform the care giving tasks (Ansari et al, 2013).

According to the Women's Health Project, female caregiver's have higher levels of stress than males, with approximately 75% of women reporting emotional and physical distress and accompanied by financial burdens (Ansari et al, 2013). Yet, family caregivers have found coping strategies to help them deal with caregiving stress including religious faith (Ansari et al, 2013).

Summary

This purpose of Chapter Three was to provide a discussion on the literature most relevant to the study of caregivers of adolescents with substance abuse problems. While there is a shortage of research on the specific emotional challenges of this type of caregiver, the researchers were able to draw from studies with other types of caregivers who care for persons with medical and psychiatric problems. This review also helped the

researchers prepare their instrumentation for collecting data on the 12 caregivers considered for this investigation.

CHAPTER THREE METHOD

Introduction

Chapter Three describes the methodology used in this study to address the problem statement in Chapter One. This chapter is organized into six subsections beginning with the study design and proceeding to data analysis. This study is considered to be a qualitatively-based investigation because its primary mode of data collection was through the use of semi-structured interviews with the participants. At the same time, this study infused an ethnographic perspective because these researchers consider the role of culture to be a fundamental concept in the understanding of human behavior including attitudes, feelings, and opinions. More importantly, it is the belief of these researchers that every time that a social worker works with a client, irrespective of age or target problem, they are using an ethnographic approach in understanding the experience (e.g., world view) of that client.

Moreover, the overall context of this study was phenomenological and focused on intimate personal experiences and challenges that could only be addressed through the use of a semi-structured interview where the participant is given significant leeway to respond to questions, with an allowance for elaboration, honesty, and genuineness. These researchers contend that by the very nature of the discipline, the bulk of social work always involves an

ethnographic approach since the social worker has to work with persons within their environment and in doing so, are able to better understand the unique experience of that person (i.e., micro versus macro levels).

Study Design

The primary aim of this investigation was to explore the experiences, attitudes, and feelings of caregivers toward adolescents with substance abuse problems. As noted in Chapter One, there is an absence of research on caregiver's experiences and feelings toward having an adolescent with such problems. In particular, very little is known about how caregivers feel in having to parent an adolescent whose life is affected by substances.

As previously noted in Chapter One and Two, these investigators believe that caregivers, whether they are parents or not, are presented with many stressful, difficult and painful challenges and problems related to caring helping their adolescent attain sobriety and an increased quality of life. Given the absence of research on this topic, and given our interest in sampling a culturally-diverse group of caregivers, we chose to implement an ethnographic approach in this investigation. Field research with small samples of subjects can often yield as much information as large scale quantitative studies. Thus, in this inquiry, we used a semi-structured interview process as the focal point of the research design.

Study Participants

Participants, who identified themselves as caregivers of adolescents with substance abuse problems were recruited from Touchstones, which is a residential inpatient treatment facility in Orange, California. The facility is a non-profit substance abuse treatment program that has been in existence for approximately 28 years and has contracted with the County of Orange for many years. The focus of the program is the treatment of substance abuse disorders in adolescents ages 11 to 18. The program has 22 beds for patients with an average length of stay of 6 months. The program is composed of various units that are staffed by diverse substance abuse and mental health professionals. The overall mission of Touchstones is to offer treatment and relapse-prevention services to families and youth from diverse cultural, linguistic, and economic backgrounds.

Specific recruitment procedures will be discussed in the Procedures subsection of this chapter in greater detail. But, it is important to note that recruitment of caregivers was conducted through the use of a recruitment flyer which was posted in the lobby of Touchstones by these investigators for approximately one month. In addition to the posting of the recruitment flyer, caregivers were also notified of this study by program staff and letters that were either given or mailed to caregivers. In addition, the first author previously completed an internship at the facility, which also facilitated the recruitment process and the completion of this investigation.

A total of 12 participants were recruited for this study. Given the small sample size, and the qualitative nature of this study, the concept of "statistical power" was not considered in this investigation. Also, given that sampling was primarily conducted through advertising at the facility, the sample was considered a "sample of convenience" and not a random sample.

It is important to note that a recruitment flyer (see Appendix A) was posted in the lobby of the facility by these investigators for approximately one month. Participants were also notified of the study through program staff and letters (see Appendices B and C). Also, a total of 12 participants were targeted for this study. Given that sampling was primarily conducted through advertising at the facility, the sample can be a "sample of convenience" and not a random sample.

Participants had to meet the following criteria for participation in this investigation:

- All participants had to be caregivers of adolescents who were currently placed as patients at the substance abuse treatment facility.
 "Caregivers" included biological and non-biological parents, adoptive parents, stepparents, foster parents, or relatives who had legal custody of the adolescent patient.
- 2. All participants had to be adults over 18 years of age.
- 3. All participants had to possess the ability to be interviewed in either English or Spanish, at the conversational level.

 All participants had to possess the ability consent to participation in this investigation, and thus had to understand the consent forms in English or Spanish.

Data Collection Instruments

The primary semi-structured instrument used for this investigation was designed by both of these investigators and was based on: a.) knowledge gained from conducting a systematic review of the literature on this topic, b.) past experience in interviewing culturally- and linguistically-diverse persons in different practicum experiences, c.) knowledge of diverse cultures and types of questions that are considered culturally-appropriate or sensitive, and d.) knowledge on the preparation of semi-structured interviews for qualitative research. A second instrument, the Parental Stress Scale (Appendix H), was also administered to each of the participants. This instrument is composed of 18 items which are answered according to a five-point likert scale, ranging from strongly agree to strongly disagree. This instrument was administered in English or Spanish and was primarily used to assist these researchers in developing the key themes that were embedded in the semi-structured interviews for each participant. The scale was not scored nor used for any additional data analysis.

A total of 16 items were designed by these investigators as well as an opening and follow-up prompt (see Appendix G). The instrument was

designed to actively engage the participants or "caregivers" to discuss the challenges, problems, attitudes, feelings, and opinions related to caring or parenting an adolescent with substance abuse problems. As can be observed, the items or questions were designed and placed in a logical order that would make each question relevant to one another. That is, the investigators attempted to place items in a sequence that would ease the transition from one question to the next, and would offer the greatest probability of obtaining the most useful data. On average, interviews lasted one hour. All interviews were tape recorded and transcribed for analysis and interpretation.

It is important to note the items for this interview were purposely chosen to contain significant face validity. It is also important to note that due to time constraints, these researchers were not able to pilot test the interview instrument or examine its psychometric properties including reliability and validity. Also, the Spanish translation of the interview is embedded within the instrument (see Appendix G)

Procedures

The procedures section of any study should inform interested parties in the key steps taken to conduct the investigation. That is, the procedures section should clearly describe the steps so that other researchers can replicate this study. As discussed in previous subsections of this chapter, this investigation was conducted through the administration of a semi-structured interview to 12 caregivers of adolescents with substance abuse problems. The procedure of this study involved the following steps:

- 1. These investigators received approval for this study from the School of Social Work Sub-Committee of the Institutional Review Board of the California State University of San Bernardino. Documents, available in English and Spanish, included in the proposal were the recruitment materials including flyers and letters, contact information release forms for the researchers to have consent to obtain the potential participants' contact information to set up an interview appointment, consent forms describing the purpose of the study and how data would be obtained including confidentiality, the tape recording of interviews and subsequent destruction of the interview tapes, reminder letters of the scheduled appointment date and time for the potential participant's' interview, interview instrument with the questions for the potential participants, and the debriefing statements summarizing how the participant's contribution to the study will be useful and how to go about obtaining a copy of the findings.
- Once approval for the study was obtained, these investigators began to advertise for participation in the study by placing flyers (see Appendix A) at the treatment facility and by sending agency recruitment letters (see Appendix B) to caregivers, including parents and guardians, of adolescent patients with substance abuse problems. Staff members at

the facility also gave recruitment letters to caregivers. These investigators also requested from the staff that they advertise the study to the caregivers of patients.

- 3. Caregivers who were interested in the study signing the contact information release form (Appendix C) and staff at the facility in turn notified these researchers. The researchers called the caregivers and informed them of the study as well as scheduled an appointment at the treatment facility in Orange, California. A letter to reminder participants of their appointment with the researcher (see Appendix D) was mailed out to the caregivers.
- 4. At the beginning of the interview with each participant, the researchers thoroughly explained the purpose of the study and the need for consent to participate. Once the participants agreed, the informed consent forms (see Appendix E) were given to the participants.
- 5. Once the consent form was signed by the participant, the actual interview was initiated. It was explained to each participant that the interviews would be anonymous and that no identifying information such as names, addresses, or phone numbers would be included in the study report (i.e., thesis). Also, it was stated to each participant that the data, including the answers to interview questions, would be aggregated for analysis, thus guaranteeing anonymity. The interviews proceeded with the interview questions (see Appendix G) asked by

these researchers. In addition, the parental stress scale (see Appendix H) and the demographic information form (see Appendix F) were completed by the participants.

6. At the end of the interviews, each participant was thanked for their participation and given the debriefing statement (see Appendix I) which stated that they could receive a brief report summarizing the results of this investigation after June 2015 upon request. In addition, a gift card with a value of ten dollars was given to each participant as an incentive for participation.

Protection of Human Subjects

As noted in the previous subsection of this chapter, these researchers complied with all aspects of the protection of human subjects or participant. An informed consent form was prepared both in English and Spanish which stated the primary aim of the study, the benefits and risks of participation, and the option to end participation at any moment during the study without penalty. In addition, the interviewers noted in the consent that all audio recordings of the interviews would be placed in a secure place and that only they and their research advisor would have access. It was also clearly stated to each participant that approval for this study was secured from the Institutional Review Board at the California State University, San Bernardino.

Data Analysis

As noted in the previous subsection on instrumentation, the data was collected using a semi-structured interview. The items were all written as questions or interrogatories and allowed for significant variation in responses by each participant. Using this approach allowed for the accommodation of unstructured data and its interpretation. Thus, the answers to the interview questions were analyzed according to key common themes. Furthermore, only basic inferential statistics, such as number of similar responses or themes across different participants, apply to this study. Using this approach allowed for the accommodation of unstructured data regarding the sample was calculated including the gender, age and ethnicity of each caregiver. This is crucial because of "generalizability" of the results.

Summary

This chapter describes the methodology employed by these researchers to answer the research question or statement of the problem. An attempt was made by these investigators to clearly describe every aspect of the methodology so that other researchers may be able to replicate this study in other similar settings. Also, these investigators always considered the concept of generalizability of the findings as the study was designed and conducted.

CHAPTER FOUR RESULTS

Introduction

As described in Chapter Three, these researchers analyzed the interview data by examining the content of each response provided by each participant for each question. Thus, common themes were considered across all items of the semi-structured interview. The five most salient themes that emerged from the interviews were stress, hurt, disappointment, failure, and hope. In addition, a group of important mini themes were also found by these researchers by using the Parenting Stress Scale and then seeking these themes in the answers provided in the semi-structured interview. It is important to note that both of these researchers independently analyzed the responses to determine themes and then met together to compare both differences and similarities. Overall, the degree of agreement between both investigators is considered high as agreement was quickly reached on the five key themes.

Presentation of the Findings

Prior to discussing the key themes that were found amongst the participants regarding their caregiving of adolescents with substance abuse problems, it is important to provide a summary of the sociodemographic characteristics of the sample employed in this study. It is also important to state the results can only be specifically generalized to this sample or those with similar characteristics.

Sociodemographic Characteristics of the Sample

A total of twelve caregivers of adolescents with substance abuse problems were involved in this study as participants. The caregivers' ethnic/racial background was the following: 67% were of Latino/a background, 25% were White or Caucasian, and 8% were of mixed ethnic or racial background. Sixty-seven percent of the caregivers were mothers, 17% were grandmothers, and the remainder was a father and a sister (16%). The age range for the caregivers was 27 to 63 years, with an average age of 44 years. The age range for the adolescent with substance abuse problems was 13 to 17 years, with an average range of 16 years. The caregivers reported other children in their home ranging in age from 3 to 16 years, with an average of 10 years. In summary, the sample was primarily composed of Latina females and mothers with additional children at home.

Results of Semi-Structured Interview of Caregivers: Key Themes

Tables 1-6 present the results of the semi-structured interviews conducted with caregivers or participants of this study. As noted in the previous section, these investigators analyzed the responses of each caregiver to determine key themes or issues that were identified by most participants. In total, five key themes were identified as well as additional subthemes that were found to be related to the challenges faced by caregivers in parenting an adolescent with substance abuse problems. It is important to note that the themes were devised by examining statements at face value and not attempting to "read more" that was specifically stated by the respondents. Again, it is essential to note that these themes were jointly determined by these investigators. The following tables identify the specific theme, samples of comments made by the caregivers, and subtypes of these themes. In analyzing the data, it was evident that salient subtypes for each theme did emerge, and are thus noted on the tables.

Table 1 presents evidence for the first key theme found by the caregivers' responses. The theme is identified as "stress" and relates to caregiver statements related to the difficulties in parenting, caring, and managing an adolescent with substance abuse problems. In the first theme, four different subtypes of stress were identified: personal, parenting, family, and economic/financial.

Table 1.	Stress	Themes as	Reported b	y Caregiver(s)
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Parent's Statements/Responses	Stress Subtype
The major source of stress in my life is my adolescent's addiction.	Personal
Having an addicted adolescent has been a financial burden.	Financial/ Economic
It is difficult to balance different responsibilities because of my adolescent's addiction.	Personal

The behavior and actions of my adolescent are often	Personal
stressful to me.	
I feel overwhelmed by the responsibility of being a parent.	Parenting
Caring for my addicted adolescent sometimes takes more	Personal
time and energy than I have to give.	
Having an addicted adolescent has meant having too few	Personal
choices and too little control over my life.	
I sometimes worry whether I am doing enough for my	Parenting
addicted adolescent.	
Every night I am worried that my adolescent may overdose,	Parenting
get raped or arrested, or be involved in deviant behavior.	_
My adolescent's addiction has negatively impacted the	Family
entire family.	

Table 2 presents evidence for the second key theme found by the caregivers' responses. The theme is identified as "hurt" (i.e., being hurt by the adolescent) related to parenting, caring, and managing an adolescent with substance abuse problems. In the second theme, three different subtypes of hurt were identified: personal, emotional, and behavioral.

Parent's Statements/Responses	Hurt Subtype
It is a heartbreaking experience as a caregiver to have an addicted adolescent.	Personal
It is the worst experience I have had in my life.	Personal
It is a living hell for me every day.	Personal
My addicted adolescent is not an important source of	Emotional
affection for me.	
I don't find my addicted adolescent enjoyable.	Emotional
I noticed a dramatic, negative change in my adolescent's	Behavioral
behavior.	
My adolescent became very violent, lazy and disobedient and refuses to go to school.	Behavioral
We are no longer like mother and daughter, we are more	Personal

like enemies.	
There is no longer any communication or respect between	Behavioral
US.	

Table 3 presents evidence for the third key theme found by the

caregivers' responses. The theme is identified as "disappointment" (e.g., being

disappointed as a caregiver for parenting an adolescent with substance abuse

problems). In the third theme, two different subtypes of disappointment were

identified: personal, economic, and behavioral.

Table 3. Disappointment Themes as Reported by Caregiver(s	Table 3.	Disappointment	Themes as	Reported b	v Caregiver(s
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Parent's Statements/Responses	Disappointment Subtype
Having an addicted adolescent does not give me a more	Personal
certain and optimistic view for the future.	
I am dissatisfied as a caregiver.	Personal
I am not happy with my role as a caregiver.	Personal
The behavior of my addicted adolescent is often	Personal
embarrassing to me thus I isolate myself from other	
caregivers.	
I wish I had someone professional to help me.	Personal
I am not able to get professional services because I have to	Economic
pay out of pocket and I don't have the money.	
Why did it have to happen to me?	Personal
Family should be included in the adolescent's treatment	Economic
and services should be at low cost so we can afford them.	
I was shocked when I found out my adolescent was	Personal
abusing drugs and/or alcohol.	

Table 4 presents evidence for the fourth key theme found by the

caregivers' responses. The theme is identified as "failure." In the fourth theme,

two different subtypes of failure were identified: personal and general. In the

case of personal failure, the focus was on the caregivers and how they felt

they have failed in the parenting of an adolescent with substance abuse

problems.

Parent's Statements/Responses	Failure
	Subtype
How did he get out of my hands?	Personal
It's my fault because I'm always working.	Personal
What did I do wrong in raising my adolescent?	Personal
I ask myself why it happened to me. What did I do wrong?	Personal
What did I fail in?	
I don't feel satisfied as a parent.	Personal
There hasn't been a specific turning point when things	General
really started to get significantly better.	

Table 5 presents evidence of the fifth key theme found by the caregivers' responses. The theme is identified as "hope." In the fifth theme, three different subtypes of hope were identified: personal, religious, and other(s) directed. In the case of personal hope, the focus was on the caregiver's hope tinged with both guilt and regret, while they considered the use of prayer and involvement in church as being important in managing the difficulties of having an adolescent with substance abuse issues. The personal subtheme focused on both positive and negative aspects of hope for one's personal fate as a parent, especially if they had to do their life over again as parents. The strongest aspect of this subtype of hope was the unending or continuous support of caregiver's for their adolescent, which included a level

of acceptance for their adolescent's decision to use substances. Also

embedded within this subtheme was a sense of optimism that caregivers had

for their adolescent in spite of their problems and poor outcome at this

moment in their lives.

Table 5. Hope Themes as Reported by Caregiver(s)

Parent's Statements/Responses	Hope Subtype
There is little or nothing I wouldn't do for my addicted adolescent if it was necessary.	Personal
If I had to do it over again, I might decide to have children despite the fact that my adolescent is an addict.	Personal
Church has helped me overcome this problem.	Religious
It could be worse but I am pretty optimistic that things will get better.	Personal
I am doing everything possible to help my adolescent.	Personal
She is my daughter and I have to go forward with her.	Personal
I would like for professionals to help us more than to judge us.	Others
My advice to other caregivers is to not give up on your adolescent, don't be an enabler, have patience, get closer to your adolescent, communicate with him or her, look for professional help right away and tell them you love him or her.	Personal/ Others
Through prayer you will survive this crisis.	Religious

Table 6 presents evidence for additional "mini themes" that were

deemed important by these investigators. The themes are distance,

resistance, guilt, hopelessness, and shame. These responses represent other

aspects of surviving the difficult challenge of having an adolescent with

substance abuse problems, and like those previous five themes, are the types

of issues that parents/caregivers bring to therapy for themselves or conjointly with their adolescent.

Table 6. Mini Themes as Reported by Caregiver(s)

Parent's Statements/Responses	Subtype
I don't feel close to my addicted adolescent.	Distance
I do not enjoy spending time with my addicted adolescent.	Resistance
It is my fault that this is happening.	Guilt
I can't do anything to help him.	Hopelessness
People shame me for my adolescent's addiction.	Shame

Summary

In summary, the results presented in this chapter reflect different aspects of caregivers' attitudes toward parenting an adolescent with substance abuse problems. The responses were analyzed at face value and the themes were derived by considering the most important "message" found within each sentence or response. Overall, the results reflect the challenges confronted by one unique group of caregivers.

CHAPTER FIVE CONCLUSIONS AND RECOMMENDATIONS

Introduction

Chapter Five discusses these researchers results gained from this study. In addition, they discuss the strengths and limitations of this study. They also provide recommendations for mental health and substance abuse professionals, especially social workers, within the context of providing psychotherapeutic assistance to the caregivers of adolescents with substance abuse problems. Recommendations for reaching out to caregivers, the provision of psychological assistance for caregivers, and future research are also presented.

Results from this Study

The five most salient themes or factors that emerged from the interviews were stress, hurt, disappointment, failure, and hope. In addition, "mini themes" were also identified. The themes are distance, resistance, guilt, helplessness, and shame. As can be noted on each of the six tables, the comments or responses by the participants were emotionally charged, honest and genuine, and related to their emotional reactions and feelings about having to have the difficult responsibility of having to care for an adolescent with drug and/or alcohol problems. In all themes that were identified, it is important to note that these themes related to how the caregiver felt about the care and parenting of their adolescent.

<u>Stress</u>

The first theme, stress, was seen to be related to personal, parenting, family, and economic/financial stress. A review of the responses and comments by the caregivers suggested a sense of lack of control over their lives, limitations or feelings related to being "stuck" and unable to make changes in other aspects of their life including maintaining a sense of balance, feelings of being overwhelmed and having an external locus of control, and financial problems. The caregivers also described concern and worry over the family unit and how the problem of an adolescent with substance abuse issues affected the rest of the family. Overall, high levels of stress were reported. Hurt

The second theme, hurt, was seen to be related to personal, emotional, and behavioral aspects of being hurt by the identified patient. Responses focused on feeling heartbroken for having an adolescent with drug and/or alcohol problems to feeling that this responsibility and role was extremely negative. This theme also reflected feelings of disrespect on the part of the caregiver and a desire to distance oneself from that adolescent. The caregivers also talked about being hurt because of their disappointment in their adolescent for not being productive in life. Collectively, the results

suggested that the caregivers often felt so hurt and frustrated that they would have wishes of not relating to their adolescents.

Disappointment

The third theme, disappointment, was closely related to the second theme of hurt and reflected personal and economic disappointment. The disappointment considered feelings of embarrassment, shame, pessimism, and victimization (e.g., "why me?"). The comments also reflect disappointment and negativity toward being a caregiver, financial challenges, and even a cry for help (e.g., "I wish I had someone professional to help me.").

<u>Failure</u>

The fourth theme, failure, was composed of personal and general feelings of failure. That is, this theme suggested constant worry, rumination, and concern about being a failure as a caregiver or parent. Moreover, the responses reflected negative feelings, which reflected a perception of failure and inaction, guilt, and dissatisfaction about being a parent.

<u>Hope</u>

The fifth theme, hope, reflected the following subthemes: personal, religious, and other(s) directed. Unlike the four previous themes, this theme suggested that in spite of significant challenges in parenting an adolescent with substance abuse problems, including feeling burnt out, depressed, anxious, and hopeless, the participants reported some feelings of hope. That is, despite wanting to give up on their adolescent, or to distance themselves

from their adolescent, they noted that they sought solace in religion including prayer.

Mini Themes

Lastly, these researchers found several related mini themes including distance, resistance, guilt, helplessness, and shame, suggested feelings of ambivalence in caring for an adolescent with alcohol and/or drug problems. This was also observed by the researchers who witnessed the participants struggle in responding to the interview questions. Their demeanor was often inconsistent, doubtful, confusing, and unclear. This ambivalence is to be expected in caregivers, especially after years and years of struggling with the care of such an adolescent. In many ways, these comments served to express the "love-hate" relationship that often occurs when caring for a family with these types of problems. Moreover, caregivers shift from having hope to hopelessness, especially if the adolescent cannot maintain their sobriety and relapse.

Discussion

The five most salient themes or themes that emerged from the interviews were stress, hurt, disappointment, failure, and hope. In addition, "mini themes" were also identified. The themes are distance, resistance, guilt, helplessness, and shame. As can be noted on each of the six tables, the comments or responses by the participants were emotionally charged, honest and genuine, and related to their emotional reactions and feelings about having to have the difficult responsibility of having to care for an adolescent with drug and/or alcohol problems. In all themes that were identified, it is important to note that these themes related to how the caregiver felt about the care and parenting of their adolescent.

Strengths of this Study

This study has several strengths. As noted in Chapters One and Two, there is scant research on the concerns, issues, problems, and challenges that caregivers face on a day-to-day basis with adolescents who have mild to severe problems with one or more substance. Thus, this study could serve as a model for conducting larger and more systematic investigations on caregivers who have adolescents with substance abuse problems. The strength in employing a qualitative method in this study was that the participants were given greater magnitude to share their feelings at the most intimate level, which usually not the case with more quantitative-oriented studies. For example, the participants cried, laughed, smiled, and emotionally retreated during the interviews. For the researchers, this was "ethnographic moment" in which we were allowed to enter the world of a parent or caregiver at very intimate levels. This is usually not the case in quantitative research studies, where there is usually an absence of emotions.

Limitations of this Study

There are several limitations to this study. First, this study employed a very small size of participants and thus the results have limited generalizability. In the case of this investigation, the results can only be generalized to the twelve participants, but the findings do reflect the many emotions, feelings, and challenges that caregivers experience in parenting an adolescent with substance abuse. Moreover, these emotions parallel the emotions experienced by caregivers of persons with severe mental illness, Alzheimer's disease, and cancer.

A second limitation to this study is that the inter-rater reliability between these two investigators was not formally examined and instead, the method for identifying the key themes was based on deliberations between the investigators. In future studies, it would be important to determine inter-rater reliability to better assure the validity of the themes.

A third limitation relates to the semi-structured interview and the sociodemographic data collection sheet. While the interview was devised by the researchers, based on their clinical experience and a systematic review of the literature, the researchers did observe that more and more questions about caregiving did arise during the interviews with the participants. That is, we found that some of the questions were almost identical and/or overlapped. In a large scale quantitative study, use of theme analysis will assist in empirically validating key themes. With regard to the sociodemographic data sheet, more relevant data should have been collected. For example, no data was collected on marital status, level of education, socioeconomic status, immigrant status, level of acculturation, or history of substance abuse, criminality, or other problems in the family of origin. In retrospect, collection of this data would have enhanced the validity of the obtained data.

A fourth limitation is that the semi-structured interview used in this investigation did not undergo any type of formal back-translation. This procedure is considered the standard for translating psychometric instruments, whether they are paper-and-pencil objective tests or semi-structured interviews. Instead, the two researchers, who are bilingual, conducted a translation. The process employed by these researchers focused on preparing a translation that would be easy to understand by both English and Spanish speakers. Future studies should not only use the back-translation technique in the linguistic adaptation of an interview instrument, but also a pilot study to determine if the translation is correct for the target sample. Accompanying this limitation was the fact that the Parenting Stress Scale was not scored or used in the data analysis. It was employed to assist the researchers in determining the themes produced through the semi-structured interview, but the responses of the Parenting Stress Scale were not quantified to determine degree of parental stress.

A fifth limitation is that this study did not consider using measures of caregiver stress in order to better understand the intensity, frequency, and

duration of moments of distress or strain. Should this study be replicated by other researchers, it is important to emphasize that some objective and measures of stress, anxiety, and depression such as those by Beck (e.g., Beck Hopelessness Scale), should be infused as these issues were repeatedly discussed by the twelve participants (Lin, Lin & Wu, 2010).

Finally, these researchers did not consider the role of peer and family influences on the substance abuse behaviors of adolescents and the relationship with caregiver stress (Windle, 2000).

The following are also limitations to this study:

- Participants were recruited from only one site, which was an inpatient treatment facility for adolescents with alcohol and drug problems in the city of Orange, California. Thus, generalization of these results can only be to the caregivers associated with this facility, and caution should nonetheless be exercised.
- 2. The instrument for this study, a semi-structured interview, which was composed of 20 questions, was devised by these researchers and was not pilot tested nor was it evaluated for reliability and validity. Yet, it is important to note that the questions were based on existent research literature and were designed to have face validity.
- Data analyzed for this investigation was based on the collective responses of the 12 participants in the study, and required qualitative thematic analysis. Thus, one could challenge the themes that were

"discovered" by these researchers, or another researcher who was to analyze the data may have found different emerging themes. Therefore, it is important to acknowledge that interpretation of data is more likely to be subjective and reflect the researchers' world views.

4. Bias may have been introduced during the interview process as part of the interviewer and interviewee interaction, and thus the participants may have been careful in how they responded to the interview questions. Other forms of unintended bias may have also been introduced into this study during the interview because of a desire on the part of the caregivers to appear socially desirable, competent, and responsible.

Recommendations for Social Work Practice, Policy and Research

As minority researchers and professionals, we are particular concerned about the role of social work in the identification, assessment, and treatment of substance abuse disorders in minority communities across America. It is our belief that social workers need to continue to examine both the "micro" and "macro" aspects of substance within the context of ethnicity, race, poverty, class, political disenfranchisement, unemployment, and the family. In particular, we are very concerned about the psychological and emotional effects of substance abuse on caregivers. In this study, for example, we observed that while caregivers possessed high levels of resilience and strength in coping with a problem that often appears to have no clear solution, the caregivers clearly appeared to be psychologically overwhelmed, tired, emotionally worn out or "burned out", frustrated and overburdened, frustrated, and depressed. Thus, there is a need for interventions in the form of support groups, therapy, and other forms of assistance that can help caregivers alleviate the stress that they encounter on a daily basis.

In this study, these researchers also observed that many caregivers reported or alluded to medical conditions that have been exacerbated by their worry and concern over their adolescent's substance abuse. Some participants indicated that the stress of managing a adolescent with substance disorders has caused them to seek out medical treatment or to find outlets to manage the negative effects of such stress. While none of the caregivers spoke of using substances as a means of coping, it was evident that there did exist substance abuse problems in the families of these caregivers beyond that of the affected youth. In addition, the caregivers alluded to marital and relationship problems of their own as a result of having to care for their adolescent, and also noted that disagreements between themselves and their partner or spouse were quite common, especially in negotiating parenting styles. Some of the caregivers easily admitted to minimize their adolescent's substance abuse problems, especially at the beginning, when the problem came to light, while others expected the adolescent to have such problems at some point in their young life.

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It is clear from these researchers' observations that some of the caregivers may have met the DSM-5 diagnostic criteria for certain types of disorders, especially those related to mood and anxiety disorders. Many of the caregivers would repeatedly describe recurring and enduring symptoms that suggested moderate to severe depression, especially if their adolescent had more than a substance abuse condition. It appeared to these researchers that those caregivers whose adolescent had dual diagnoses or multiple diagnoses were likely to be even more distressed. We observed that the perceived and experienced stress among caregivers appeared to increase exponentially as a function of the complexity of their adolescent's problems. For example, in one case, we observed that the caregivers of a youth with polysubstance abuse, oppositional-defiant disorder, conduct disorder, and attention deficit hyperactivity disorder was extremely overwhelmed and emotionally taxed, and appeared to require immediate mental health treatment.

Recommendations for Reaching Out Parents/Caregivers

Based upon our findings, these researchers make the following recommendations for reaching out to parents and caregivers of adolescent with substance abuse problems:

1. There is a significant need in all communities, irrespective of socioeconomic status and race/ethnicity, for diverse

organizations that work with adolescents with substance abuse problems to reach out to caregivers and parents who are in significant distress.

- 2. There is a need for diverse mental health organizations to also reach out distressed caregivers as they have for those who care for elders, persons with mental illness, and severe medical illnesses. Over the past 20 years, a lot of mental health resources have been extended to this community of caregivers, and now is the time to reach out to caregivers of adolescents with drug and/or alcohol problems.
- 3. There is a need for adolescent drug treatment programs, whether inpatient or outpatient, to also assist in identifying and detecting mental health concerns amongst caregivers and to offer diverse resources for assisting them in their personal and emotional struggles. These researchers observed that many of the participants in the study gave the impression that they were "alone" or isolated, burned-out, and felt misunderstood by peers and family who were not involved in the caregiving of an adolescent with substance abuse problems.

Recommendations for Psychotherapy with Distressed Caregivers

Based upon our findings, these researchers make the following recommendations for psychotherapy with distressed caregivers of adolescents with substance abuse problems:

- There is a need for individual psychotherapy with a cognitivebehavioral perspective in light of the feelings, thoughts, opinions, and ideas that the participants shared with these researchers. A review of the comments made across all of the themes by the caregivers indicates that feelings of hopelessness, anxiety, disappointment, low self-esteem, poor self-efficacy, pessimism, anger, frustration, and worthlessness can be effectively addressed through cognitive-behavioral approaches.
- 2. There is a need for caregivers to also be involved in family therapy with the identified patient (IP) who is the adolescent with substance abuse problems as well as the rest of the family. This can also include the involvement of extended family especially in the case of Latino and African American families. Focus should be on understanding the effects of the IPs problems on the family system including the effects on every family member's roles, issues of anger, disinterest, and disappointment held by individual family members, and faulty patterns of communication amongst all members (Garner, Godley, Funk, Dennis, Smith, &

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Godley, 2009; Parker & Benson, 2004; Szapocznik, & Williams, 2000).

3. Both individual and family therapy should also emphasize the need for the caregiver(s) to engage in self-care activities that will lessen distress, depression, and anxiety, and increase quality of life and wellness. As noted throughout this study, caregivers can not only develop mental health problems but also medical or health problems. Therapy should also focus on relieving the caregiver of stress by re-distributing responsibilities amongst the rest of the family members, including caring for the IP (Mark, Song, Vandivort, Duffy, Butler, Coffey, & Schabert, 2006).

Recommendations for Future Research on Distressed Caregivers

As noted at the beginning of this investigation, there is a major need for more research on the caregivers of adolescents with substance abuse problems. Our systematic review of the literature yielded very minimal research on this population, which is highly at-risk for developing significant levels of distress. Thus, studies need to focus both on the psychological and health problems that can develop while caregiving.

There is major need for research across culturally- and linguisticallydiverse caregivers of adolescents with substance abuse problems. Research on caregivers of persons with medical and psychiatric conditions indicates that while caregiving can be very rewarding, it can also have dire consequences on the caregiver. Research also indicates that different cultural groups manage their caregiving responsibilities in different ways and frequently based on their responsibilities indifferent ways and frequently based on their beliefs about the role of the caregiver in the life of the patient. In this study, the majority of the participants were Latinas. While groups were not compared by ethnicity or race, it is important to conduct such studies in the future.

As noted in the Chapter Three and in the "strengths of this study" subsection in this chapter, there is a need for both quantitative and qualitative studies on caregivers who have adolescents with substance abuse problems. Quantitative studies should focus on patterns of coping and resilience among large groups of caregivers, as well as employing empirically-based instruments that tap into problems such as depression, hopelessness, and anxiety, while qualitative studies should focus on the "feelings" and "emotions" of the individual experience of caregiving and parenting an adolescent with drug and/or alcohol problems. Collectively, both types of studies can offer the best means of understanding this phenomenon, caregiving adolescents.

Conclusions

The results of this investigation were found to support the researchers' contentions that the caregiving of adolescents with substance abuse problems can be emotionally challenging, especially as it relates to stress. This study,

through the use of qualitative methods that also included an ethnographic perspective, yielded findings that reflected some of the key concerns or themes that can emerge when caring for an adolescent with alcohol and/or drug problems. More importantly, these results suggest the importance of mental health care and support for these caregivers. This support can occur in many ways including financial support. A common complaint amongst the participants was that caregiving was economically draining. They noted that these economic challenges were likely to not only affect the quality of life for the caregivers, but also their family members'. Yet, the study also documented the love that caregivers have for their adolescents in spite of the high levels of stress that these adolescents caused them. In the end, it is clear that these caregivers are in dire need of support from different institutions ranging from churches to mental health programs to drug and alcohol treatment facilities.

APPENDIX A

RECRUITMENT FLYER

GOT A TEEN EXPERIMENTING WITH DRUGS

AND/OR ALCOHOL?

JOIN THE STUDY OF

THE CAREGIVER'S EXPERIENCES:

SHARING YOUR OWN UPS AND DOWNS

OF HAVING YOUR ADOLESCENT

EXPERIMENTING WITH DRUGS AND/OR

ALCOHOL

Ask your counselor for details or call Cindy: 714-605-7646 or Brenda: 760-755-9469

¿TIENE UN ADOLESCENTE EXPERIMENTANDO CON DROGAS Y/O ALCOHOL?

PARTICIPE EN EL ESTUDIO LAS EXPERIENCIAS DEL CUIDADOR: COMPARTIENDO SUS PROPIAS ALTAS Y BAJAS DE TENER A SU ADOLESCENTE EXPERIMENTANDO CON DROGAS Y/O ALCOHOL

Hable con su consejero/a para obtener más detalles o llame a Cindy: 714-605-7646 o a Brenda: 760-755-9469 APPENDIX B

AGENCY RECRUITMENT LETTER

Dear Caregiver:

I am sure you have experienced many challenges as you sought to work effectively with your son or daughter who has a substance abuse problem. It can be very difficult for you.

As professionals working with adolescents diagnosed with substance abuse, we would like to know more about how your adolescent's experimenting with drugs and/or alcohol has been like for you. We believe that by learning this information, we can help professionals provide better services to families.

The student researchers at the University of California, San Bernardino are conducting a study called "The Beliefs of Caregivers About Having An Adolescent Diagnosed With Substance Abuse" through its Masters of Social Work Program. This study is designed to hear your concerns, feelings, reactions, insights and suggestions, as parents of an adolescent experimenting drugs and/or alcohol. The findings from this study will help all professionals do a better job working with families and their adolescents.

Please consider participating in this study. You will be invited to share your story about

being a caregiver of a teen diagnosed with substance abuse. The researchers want to hear your worries, reactions, and find out from you what helped you cope.

Of course, your participation is voluntary, and anything you share will be kept confidential.

If you would like to participate or learn more about the study, please complete the enclosed form and give it to your Touchstones counselor. A researcher will contact you upon receiving the attached contact information release form.

Thank you for considering this request.

Garret Staley, LCSW, MPA, CCS Program Director Estimado Cuidador:

Estoy segura que ha experimentado muchos desafíos en el intento de trabajar efectivamente con su hijo o hija que tiene un problema de abuso de sustancias. Puede ser muy difícil para usted.

Como profesionales que trabajamos con adolescentes diagnosticados con el abuso de sustancias, nos gustaría saber más acerca de como la experimentación de su adolescente con drogas y/o alcohol ha sido para usted. Creemos que al obtener esta información, podemos ayudar a los profesionales ofrecer mejores servicios a las familias.

Las investigadoras estudiantiles de la Universidad de California, en San Bernardino están llevando a cabo un estudio llamo "Las Creencias de Cuidadores Acerca de Tener Un Adolescente Diagnosticado con el Abuso de Sustancias" a través de su programa de maestría de trabajo social. Este estudio está diseñado para escuchar sus inquietudes, sentimientos, reacciones, ideas y sugerencias, como cuidador de un adolescente que experimenta drogas y/o alcohol. Los resultados de este estudio ayudaran a todos los profesionales hacer un mejor trabajo con las familias y los adolescentes.

Por favor considere participar en este estudio. Sera invitado a compartir su historia acerca de ser un cuidador de un adolescente diagnosticado con abuso de sustancias. Las investigadoras quieren escuchar sus preocupaciones, reacciones y averiguar por usted lo que le ayudo a adaptarse a la enfermedad de su hijo o hija.

Por supuesto, su participación es voluntaria, y cualquier cosa que comparte se mantendrá confidencial.

Si desea participar o aprender más sobre el estudio, por favor complete la forma incluida y entréguela a su consejero/a de Touchstones. Una investigadora se pondrá en contacto con usted al recibir la forma.

Gracias por considerar esta petición.

Garett Staley LCSW, MPA, CCS Program Director APPENDIX C

CONTACT INFORMATION RELEASE FORM

Contact Information Release Form

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Name of parent/s	ep-parent/family member/guardian:
Phone Number: _	Best time to call:

Address: ____

I give my permission to the agency staff to release my phone number to Cindy Reyes and Brenda Duchene, researchers and 2^{nd} year graduate students, and to Dr. Thomas D. Davis, faculty advisor, so that they may contact me about volunteering to be interviewed for the research study. This study is about what it is like for caregivers to have an adolescent diagnosed with substance abuse.

I understand that this information will not be given to anyone else, including the Touchstones, and that any information I provide in the course of an interview will be kept strictly confidential. My participation will not affect the services that I am currently receiving from Touchstones.

Name

Date

Agency Staff Member:

Name

Date

Title

Forma Para Autorizar la Información de Contacto

Por favor imprima

Nombre del padre/padrastro/miembro de la familia/tutor:
Dirección:

Número de teléfono: ______ Mejor hora para llamar: ______

Yo doy mi permiso al personal de la agencia para liberar mi dirección y número de teléfono a Cindy Reyes y Brenda Duchene, investigadoras y estudiantes graduadas de 2 ° año y a Thomas D. Davis, asesor de la facultad, con el fin de que me puedan contactar acerca del voluntariado para ser entrevistado/a para el estudio de investigación. Este estudio es acerca de lo que es para los cuidadores tener un adolescente diagnosticado con abuso de sustancias.

Yo entiendo que esta información no se le dará a nadie más, incluyendo el personal de Touchstones, y que cualquier información que proporcione en el curso de la entrevista será estrictamente confidencial. Mi participación no afectará los servicios que actualmente estoy recibiendo de Touchstones.

Nombre

Fecha

Miembro del Personal de la Agencia:

Nombre

Fecha

Titulo

APPENDIX D

APPOINTMENT REMINDER LETTER

Appointment Reminder from the Researcher

Dear_____,

Thank you for offering to participate in our study. I have your appointment scheduled for:

Time and Date: _____

The purpose for conducting this research is to find out what it is like for caregivers to have an adolescent diagnosed with substance abuse. Because your son/daughter is currently involved with Touchstones, we feel that you have much experience and wisdom to share with us.

The information that you share will be confidential. Neither you nor anyone else interviewed will be personally identified. Any details identifying you will be removed, and your interview information will be combined with that of other caregivers. Your information will not be used for any other purpose beyond this study. Insights from the study will be used to help therapists, counselors, and other professionals better understand the caregivers and adolescents they work with. None of these professionals, including those at Touchstones, will have access to your responses.

Should you decide not to participate, you are free to withdraw at any time and for any reason. No one in the treatment program will be told of your decision not to be a part of this study.

Please feel free to call me at any time about any questions or concerns that you may have or if you need to reschedule your appointment.

Thank you very much for your interest in our study. I look forward to meeting with you.

Sincerely,

Cindy Reyes Researcher 714-605-7346 Appointment Reminder from the Researcher

Dear_____,

Thank you for offering to participate in our study. I have your appointment scheduled for:

Time and Date: _____

The purpose for conducting this research is to find out what it is like for caregivers to have an adolescent diagnosed with substance abuse. Because your son/daughter is currently involved with Touchstones, we feel that you have much experience and wisdom to share with us.

The information that you share will be confidential. Neither you nor anyone else interviewed will be personally identified. Any details identifying you will be removed, and your interview information will be combined with that of other caregivers. Your information will not be used for any other purpose beyond this study. Insights from the study will be used to help therapists, counselors, and other professionals better understand the caregivers and adolescents they work with. None of these professionals, including those at Touchstones, will have access to your responses.

Should you decide not to participate, you are free to withdraw at any time and for any reason. No one in the treatment program will be told of your decision not to be a part of this study.

Please feel free to call me at any time about any questions or concerns that you may have or if you need to reschedule your appointment.

Thank you very much for your interest in our study. I look forward to meeting with you.

Sincerely,

Brenda Duchene Researcher 760-755-9469

Recordatorio Para la Cita de la Investigadora

Querido/a _____,

Gracias por ofrecerse para participar en nuestro estudio. Su cita es el:

Hora y Fecha: _____

El propósito de este estudio es averiguar cómo es para los cuidadores tener a un adolescente diagnosticado con el abuso de la sustancia. Porque su hijo o hija está involucrado/a con Touchstones, sentimos que usted tiene mucha experiencia y sabiduría para compartir con nosotras.

La información que usted comparte será confidencial. Ni usted ni nadie más que sea entrevistado será identificado personalmente. Cualquier detalle que lo/la identifique será eliminado y la información de su entrevista será combinada con la de los demás cuidadores. La información obtenida durante la entrevista no será utilizada para otros propósitos que no sean para el estudio. Su información también será utilizada para ayudar a terapeutas, consejeros y a otros profesionales a mejor entender a los cuidadores y adolescentes con los que trabajan. Ninguno de estos profesionales, incluyendo al personal de Touchstones, tendrá acceso a sus respuestas.

Si usted decide no participar, es libre de retirarse en cualquier momento por cualquier razón. Nadie en el programa de tratamiento será informado sobre su decisión de no participar en el estudio.

Por favor llámeme a cualquier hora sobre cualquier pregunta o preocupación que tenga o si necesita cambiar su cita.

Muchas gracias por su interés en nuestro estudio. Espero reunirme con usted.

Sinceramente,

Cindy Reyes Researcher 714-605-7346

Recordatorio Para la Cita de la Investigadora

Querido/a _____,

Gracias por ofrecerse para participar en nuestro estudio. Su cita es él:

Hora y Fecha: _____

El propósito de este estudio es averiguar cómo es para los cuidadores tener a un adolescente diagnosticado con el abuso de la sustancia. Porque su hijo o hija está involucrado/a con Touchstones, sentimos que usted tiene mucha experiencia y sabiduría para compartir con nosotras.

La información que usted comparte será confidencial. Ni usted ni nadie más que sea entrevistado será identificado personalmente. Cualquier detalle que lo/la identifique será eliminado y la información de su entrevista será combinada con la de los demás cuidadores. La información obtenida durante la entrevista no será utilizada para otros propósitos que no sean para el estudio. Su información también será utilizada para ayudar a terapeutas, consejeros y a otros profesionales a mejor entender a los cuidadores y adolescentes con los que trabajan. Ninguno de estos profesionales, incluyendo al personal de Touchstones, tendrá acceso a sus respuestas.

Si usted decide no participar, es libre de retirarse en cualquier momento por cualquier razón. Nadie en el programa de tratamiento será informado sobre su decisión de no participar en el estudio.

Por favor llámeme a cualquier hora sobre cualquier pregunta o preocupación que tenga o si necesita cambiar su cita.

Muchas gracias por su interés en nuestro estudio. Espero reunirme con usted.

Sinceramente,

Brenda Duchene Researcher 760-755-9469 APPENDIX E

INFORMED CONSENT FORM

Informed Consent

Informed Consent for Caregivers Participation in the Qualitative Study "Caregivers' Emotional Experiences Regarding Their Adolescent's Substance Abuse Problem"

What is the purpose of this study?

The purpose of the study is to look at caregivers' emotional experiences related to adolescents with substance abuse problems. Much research has been done about the adolescent's substance abuse, but there is very little information attempted to capture the personal and intimate challenges confronted by caregivers themselves. We are interested in learning about what you, as a caregiver, have felt as your son or daughter has gone through this type of recovery. Thus, the emphasis will be on you, not your adolescent's experience, and we are hoping to gather information so that professionals can better serve families like yours.

What will I have to do?

After signing a consent form, participate in a 1 hour in-depth conversational style interview, which will be tape recorded.

What are the benefits?

- Your help will assist the researchers and professionals who work with parents and adolescents to better understand what it is like for caregivers to have an adolescent diagnosed with substance abuse.
- From what you and others share, professionals will be better able to provide effective services to these families.
- You and the other caregivers will have access to the findings of this study upon request during the Spring Quarter of 2015.

What are the risks?

You may at one point or another find it uncomfortable to talk about issues related to your adolescent's substance abuse. You have the right to control what is talked about. If the interview is too uncomfortable, you can end it at any time for any reason.

Is it private?

- The researcher will ask about your experience of having an adolescent diagnosed with substance abuse. She will not be sharing your specific responses with anyone connected with the agency program. Your information will be completely confidential. A false name will replace yours on the short information form and in the typed copy of the interview. Only the researcher and her advisor will have access to the data.
- Under HIPPA, there is a special protection for the research information that identifies you. It states that we do not have to identify you, even under a court

order or subpoena. However, as mandated reporters, we are obligated to report any suspected harm to yourself or others.

• Once the completed study is accepted, any material containing identifying information will be destroyed, including the audiotapes, notes, and transcripts. In addition, none of your personal information will ever be available to the staff of any adolescent recovery programs, including those at Touchstones.

Can I quit if I want to?

Participation in this study is voluntary. You may withdraw from it at any time. There is no penalty now or in the future for you or your adolescent if you decide to withdraw. Furthermore, your participation or withdrawal from the study will not affect your services with Touchstones.

Is there any compensation?

Upon request, you will be provided with the findings of the study once the project is complete. You will also have the satisfaction of sharing your story as well as knowing that your contribution will help other families like yours. In addition, you will receive a gift card with a value of ten dollars as an incentive for your participation.

Approval of Research

This project has been approved, as required, for research involving humans by the School of Social Work Sub-Committee of the Institutional Review Board of the California State University of San Bernardino.

Participant's Permission and Responsibilities

I agree to be part of this study. I have fully read this consent form. I have had all of my questions answered. By marking below, I freely give my consent to participate in this project. I am aware that I have the right to withdraw at any time for any reason.

If I have any questions or concerns about this research I will contact:

Dr. Thomas D. Davis Researcher Faculty Advisor tomdavis@csusb.edu 909-537-3839

Participant's Mark

Date

Consentimiento Informado

Consentimiento Informado para la Participación de los Cuidadores en el Estudio Cualitativo "Las Experiencias Emocionales de los Cuidadores Acerca del Problema de Abuso de Sustancias de su Adolescente"

¿Cuál es el propósito de este estudio?

El propósito del estudio es mirar las experiencias emocionales de los cuidadores relacionadas al abuso de sustancias de adolescentes. Se han realizado muchas investigaciones sobre el abuso de sustancias de los adolescentes, pero hay muy poca información que captura capturar los retos personales e íntimos confrontados por los propios cuidadores. Estamos interesados en aprender acerca de lo que ustedes mismos, como cuidador, han sentido mientras su hijo o hija ha pasado por este tipo de recuperación. Por lo tanto, el énfasis será sobre usted, no la experiencia de su hijo, y esperamos poder reunir información para que los profesionales puedan servir mejor a familias como la suya.

¿Qué tendré que hacer?

Después de firmar un formulario de consentimiento, participar en una entrevista en profundidad estilo conversacional de 1 hora, que será grabada.

¿Cuáles son los beneficios?

- Su ayuda asistirá a las investigadoras y profesionales que trabajan con padres y adolescentes a comprender mejor lo que es para los cuidadores tener a un adolescente diagnosticado con abuso de sustancias.
- De lo que usted y otros compartan, profesionales serán mejor capaces de proporcionar servicios eficaces a estas familias.
- Usted y los otros cuidadores tendrán acceso a los resultados de este estudio a petición durante el trimestre de primavera de 2015.

¿Cuáles son los riesgos?

Es posible que en un momento u otro resulte incómodo hablar de temas relacionados con el abuso de sustancias su hijo o hija. Usted tiene el derecho de controlar lo que se habla. Si la entrevista es muy incómoda, puede terminar en cualquier momento y por cualquier motivo.

¿Es privado?

• La investigadora le preguntará acerca de tu experiencia de tener un adolescente diagnosticado con abuso de sustancias. Ella no compartirá sus respuestas específicas con cualquier persona que esté relacionado con el programa de la agencia. Su información será totalmente confidencial. Un nombre falso sustituirá el suyo en la forma de información corta y en la copia escrita a máquina de la entrevista. Sólo las investigadoras y su asesor tendrán acceso a los datos.

- Bajo HIPPA, hay una protección especial para la información de investigación que lo identifica. Declara que no lo/la tenemos que identificar, incluso bajo una orden judicial o citación. Sin embargo, como reporteras del mandato, estamos obligadas a reportar relatar cualquier sospecha de daño a usted mismo o a otros.
- Una vez que el estudio completado es aceptado, cualquier material que contenga la información que lo/la identifica será destruido, incluyendo las cintas de audio, notas y transcripciones. Además, ninguna de su información personal nunca será disponible para el personal de cualquier programa de recuperación de adolescentes, incluyendo aquellos de Touchstones.

¿Puedo renunciar si quiero?

La participación en este estudio es voluntaria. Usted podrá retirarse de ella en cualquier momento. No hay ninguna sanción ahora o en el futuro para usted o su hijo o hija si usted decide retirarse. Además, su participación o retiro del estudio no afectará sus servicios con Touchstones.

¿Hay alguna compensación?

A petición, se le proporcionará un resumen de los resultados del estudio una vez finalizado el proyecto. También tendrá la satisfacción de compartir su historia, así como saber que su contribución puede ayudar a otras familias como la suya. Además, recibirá una tarjeta de regalo con un valor de diez dólares como incentivo para su participación.

Aprobación de la investigación

Este proyecto ha sido aprobado, como requerido, para la investigación con seres humanos por la escuela de la Escuela de Trabajo Social del Subcomité del Consejo de Revisión Institucional de la Universidad del Estado de California de San Bernardino.

El permiso y las responsabilidades del participante

Estoy de acuerdo en ser parte de este estudio. He leído completamente este formulario de consentimiento. He tenido todas mis preguntas contestadas. Marcando abajo, libremente doy mi consentimiento para participar en este proyecto. Soy consciente que tengo el derecho de retirarme en cualquier momento y por cualquier motivo.

Si tengo alguna pregunta o inquietud acerca de esta investigación me pondré en contacto con:

El Dr. Thomas D. Davis Investigador Asesor de la Facultad tomdavis@csusb.edu 909-537-3839 Participant's Mark

Date

APPENDIX F

DEMOGRAPHIC INFORMATION FORM

Demographic Information Form

Name:
Address:
Phone Number(s):
May the researcher identify herself and the study when calling? Yes No
Your age:
How do you define yourself ethnically? White or Caucasian Black or African American Hispanic or Latino American Indian or Alaskan Native Asian Native Hawaiian or other Pacific Islander Other Race Mixed Race
Age of adolescent:
Ages of other children in the home:

Your relationship to the adolescent: _____

Formulario de Información Demográfica

Nombre:	
Dirección:	
Numero(s) de teléfono:	
¿Puede la investigadora identificarse ella misma y al estudio al llamar?S	lí <u>N</u> o
Su edad:	
¿Cómo se define étnicamente? Blanco o Caucásico Negro o Afroamericano Hispano o Latino Indio Americano o Alaska Nativo Asian Nativo Hawaiano u otros Isleños del Pacífico Otra raza Raza Mixta	
Edad del adolescente:	
Edad de otros niños en el hogar:	

Su relación con el adolescente: _____

APPENDIX G

INTERVIEW QUESTIONS

Interview Questions for the Caregivers' 1 hour Interview

This interview schedule served as a guide during the actual interview. The researcher asked these questions after a briefly explaining the purpose of the study as well as reminding the participants of their right to refuse to answer any questions or withdrawal from the interview at any time for any reason.

Opening prompt: "I am interested in knowing about your experience of having an adolescent experimenting with drugs and/or alcohol."

- 1. Please tell me what brought your son/daughter to Touchstones?
- 2. What was it like for you as a caregiver when you found out that your adolescent was experimenting with drugs and/or alcohol?
- 3. What thoughts and/or concerns ran through your mind as you learned about your adolescent's substance abuse?
- 4. Did you notice any changes in attitude and/or behavior in your adolescent?
- 5. When you feel stressed, depressed and/or hopeless how you deal with the situation?
- 6. Have you had feelings of isolation because other parents do not have kids in treatment or experimenting with drugs and/or alcohol?
- 7. Do you feel financially burdened due to the legal fees you have to pay for your son/daughter?
- 8. Have you felt physically ill as a result of your adolescent's addiction?
- 9. Do you find that you receive support from the following: friends, family, church, school or any other support groups?
- 10. Do you feel that you have enough professional social services from your community?
- 11.

11. Have you ever attended any AA, NA, or Al-Anon meetings to help you cope? If so, how have these meetings impacted you?

12. How has your relationship with your adolescent changed since he/she began experimenting with drugs and/or alcohol?

- 13. Was there a specific turning point when things really started to get significantly better for you as a caregiver? If yes, please tell me about that,
- 14. What advice would you give to caregivers of an adolescent who just found out that their adolescent abuses drugs and/or alcohol?
- 15. What advice would you give to professionals, such as counselors, family therapists, program personnel, who work with a new adolescent and his/her family?
- 16. Are there any other comments or insights that you would like to share with this interviewer regarding your coping with an adolescent with substance abuse problems?

These interview questions were developed by the researchers.

Preguntas Para La Entrevista De 1 Hora Para Los Cuidadores

Este conjunto de preguntas/afirmaciones sirvió de guía durante la entrevista. La investigadora pregunto estas preguntas/declaraciones después de brevemente explicar el propósito del estudio así como recordar a los participantes de su derecho de negarse a responder cualquier pregunta o a retirarse de la entrevista en cualquier momento y por cualquier motivo.

Indicador de apertura: Quiero saber de su experiencia de tener un adolecente en su hogar que está experimentando con drogas o alcohol. Quisiera saber sus opiniones, sentimientos, y actitudes.

- 1. Por favor dígame lo que trajo a su hijo/hija a Touchstones.
- 2. ¿Cómo fue para usted como cuidador cuando se entero que su adolescente estaba experimentando con drogas y/o alcohol?
- 3. ¿Qué pensamientos y/o preocupaciones pasaron por su mente al enterarse del consumo de sustancias de su adolescente?
- 4. ¿Noto algún cambio de actitud y/o comportamiento en su hijo/hija?
- 5. Cuando se siente estresado/a, deprimido/a y/o desesperanzado/a ¿cómo maneja la situación?
- 6. ¿Ha tenido sentimientos se aislamiento debido a que otros padres no tienen hijo/hijas en tratamiento o experimentando sustancias?
- 7. Siente una carga financiera debido a los costos legales que usted debe pagar por su hijo/hija?
- 8. ¿Se ha sentido físicamente enfermo/a a consecuencia de la adicción de su adolescente?
- 9. ¿Cree que recibe el apoyo de los siguientes: los amigos, la familia, la iglesia, escuela o cualquier otro grupo de apoyo?
- 10. ¿Considera que tiene suficientes servicios sociales profesionales de su comunidad?
- 11. ¿Alguna vez ha asistido a alguna reunión de AA, NA o Al-Anon para ayudarle a adaptarse? Si es así, ¿cómo le han afectado estas reuniones?
- 12. ¿Cómo ha cambiado su relación con su hijo desde que él/ella comenzó a experimentar con drogas y/o alcohol.

- 13. ¿Había un punto decisivo específico cuando las cosas realmente comenzaron a hacerse considerablemente mejores para usted como un cuidador? Si la respuesta es sí, por favor platíqueme sobre esto.
- 14. ¿Qué consejo le daría a los cuidadores de un adolescente que se acaban de enterar que su adolescente abusa de drogas y/o alcohol?
- 15. ¿Qué consejo le daría a los profesionales, como consejeros, los terapeutas familiares y el personal de programas, que trabajan con un nuevo adolescente y su familia?
- 16. ¿Hay algo más que quisiera compartir sobre su experiencia de tener un hijo/a con problemas de alcohol y/o drogas?

Estas preguntas de la entrevista fueron desarrolladas por las investigadoras.

APPENDIX H

PARENTAL STRESS SCALE

Parental Stress Scale

The following statements describe feelings and perceptions about the experience of being a parent/caregiver of an adolescent who is addicted to drugs and/or alcohol. Think of each of the items in terms of how your relationship with your adolescent (and his/her drug and/or alcohol addiction) typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 =Strongly Disagree 2 =Disagree 3 =Undecided 4 =Agree 5 =

Strongly Agree

- _____1. I am happy in my role as a parent/caregiver.
- _____2. There is little or nothing I wouldn't do for my adolescent if it was necessary.
- _____ 3. Caring for my adolescent sometimes takes more time and energy than I have to give.
- 4. I sometimes worry whether I am doing enough for my adolescent.
- _____ 5. I feel close to my adolescent.
- _____ 6. I enjoy spending time with my adolescent.
- _____7. My adolescent is an important source of affection for me.
- _____ 8. Having an addict adolescent gives me a more certain and optimistic view for the future.
- 9. The major source of stress in my life is my adolescent's addiction.
- 10. Having an addict adolescent leaves little time and flexibility in my life.
- _____11. Having an addict adolescent has been a financial burden.
- _____12. It is difficult to balance different responsibilities because of my adolescent's addiction.

- _____13. The behavior of my addict adolescent is often embarrassing or stressful to me.
- _____14. If I had it to do over again, I might decide not to have a child(ren).
- _____15. I feel overwhelmed by the responsibility of being a parent/caregiver.
- _____ 16. Having an addict adolescent has meant having too few choices and too little control over my life.
- _____ 17. I am satisfied as a parent/caregiver.
- _____ 18. I find my adolescent enjoyable.

This scale was adapted from Berry and Jones (1995).

Escala de Estrés Parental

Las siguientes afirmaciones describen sentimientos y percepciones sobre la experiencia de ser padre/cuidador de un adolescente que es adicto/a a las drogas y/o alcohol. Piensa en cada uno de los artículos en términos de cómo es su relación con su hijo/hija (y su adicción con las drogas y/o alcohol) típicamente. Por favor, indique el grado al que está de acuerdo o en desacuerdo con los siguientes artículos colocando el número apropiado en el espacio proporcionado.

1=Muy en desacuerdo 2=En desacuerdo 3=Indeciso 4=De Acuerdo 5=Muy De Acuerdo

- _____1. Estoy contento/a con mi rol de padre/cuidador.
- _____ 2. Hay poco o nada que no haría para mi hijo si fuera necesario.
- _____ 3. Cuidar a mi hijo/hija a veces toma más tiempo y energía que tengo que dar.
- _____ 4. A veces me preocupo si estoy haciendo lo suficiente para mi hijo/hija.
- _____ 5. Me siento cerca de mi hijo/hija.
- _____ 6. Me gusta pasar tiempo con mi hijo/hija.
- _____7. Mi hijo/hija es una fuente importante de afecto para mí.
- _____ 8. Tener un hijo/hija adicto/a me da una visión más segura y optimista para el futuro.
- 9. La fuente principal de estrés en mi vida es la adicción de mi hijo/hija.
- _____ 10. Tener un hijo/hija adicto/a deja poco tiempo y flexibilidad en mi vida.
- 11. Tener un hijo/hija adicto/a ha sido una carga financiera.
- _____12. Es difícil equilibrar las diferentes responsabilidades debido a la adición de mi hijo/hija.
- _____13. El comportamiento de mi hijo/hija adicto/a suele ser embarazoso o estresante para mí.
- _____ 14. Si lo tuviera que hacer de nuevo, tal vez decido no tener hijos.

- _____15. Me siento abrumado por la responsabilidad de ser un padre/cuidador.
- _____ 16. Tener un hijo/hija adicto/a ha significado tener muy pocas opciones y muy poco control sobre mi vida.
- _____ 17. Estoy satisfecho/a como un padre/cuidador.
- _____ 18. Mi hijo/hija me parece agradable.

Esta escala fue adaptada de Berry and Jones (1995).

APPENDIX I

DEBRIEFING STATEMENT

Debriefing Statement

This study you have just completed was designed to investigate caregivers' beliefs, feelings, experiences, reactions, and suggestions as a caregiver of an adolescent with a substance abuse problem. In other words, the investigators wanted to explore how caregivers of adolescents with a substance abuse problem describe their caregiving experiences and to understand their contextual life stressors. The findings of this research study will provide your voice and concerns as there is very little information in the literature about caregivers' own experiences about having an adolescent diagnosed with substance abuse. The study will also help professionals understand your coping skills and strengths as a caregiver with an adolescent who abuses drugs and/or alcohol in addition to eliminating the shaming and accusing that you experience for your adolescent's substance abuse. Ultimately, the results from this research study will help all professionals do a better job in working with caregivers and their adolescents.

Thank you for your participation. If you have any questions or concerns about the study, please feel free to contact Dr. Thomas D. Davis at (909) 537-3839. If you would like to obtain a copy of the findings of this study please visit the Pfau Library located at the California State University of San Bernardino or Touchstones after September 2016.

La Declaración De La Entrevista

Este estudio que acaba de completar fue diseñado por Cindy Reyes y Brenda Duchene para investigar los cuidadores creencias, sentimientos, experiencias, reacciones y sugerencias como un cuidador de un adolescente que ha sido diagnosticado con abuso de sustancias. Los resultados de este estudio de investigación proporcionarán su voz y preocupaciones ya que hay muy poca información en la literatura sobre las experiencias de los cuidadores acerca de tener un adolescente diagnosticado con abuso de sustancias. El estudio también ayudará a profesionales a entender sus habilidades de adaptación y fortalezas como un cuidador con un adolescente que abusa de drogas y/o alcohol además de eliminar la vergüenza y la acusación que experimenta a causa del abuso de sustancias de su adolescente. En definitiva, los resultados de este estudio de investigación ayudarán a todos los profesionales a hacer un mejor trabajo al trabajar con los cuidadores y los adolescentes.

Gracias por su participación. Si usted tiene alguna pregunta o inquietud acerca del estudio, por favor no dude en ponerse en contacto con el Dr. Thomas D. Davis al (909) 537-3839. Si desea obtener una copia de los resultados de este estudio, por favor visite la biblioteca Pfau ubicado en la Universidad del Estado de California de San Bernardino o Touchstones después de julio de 2015.

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ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:

Assigned Leader: Cindy Reyes

Assisted By: Brenda Jane Duchene

2. Data Entry and Analysis:

Team Effort: Cindy Reyes and Brenda Jane Duchene

- 3. Writing Report and Presentation of Findings:
 - a. Introduction and Literature

Team Effort: Cindy Reyes and Brenda Jane Duchene

b. Methods

Team Effort: Cindy Reyes and Brenda Jane Duchene

c. Results

Team Effort: Cindy Reyes and Brenda Jane Duchene

d. Discussion

Team Effort: Cindy Reyes and Brenda Jane Duchene