CHAPTER II

REVIEW OF LITERATURE

Introduction

Being a family disease, addiction affects the family as a whole. The current study is an attempt to understand the psychosocial conditions of mothers who are the caregivers of substance dependent young adults. A serious examination of existing literature in the field is necessary for planning the different stages of research.

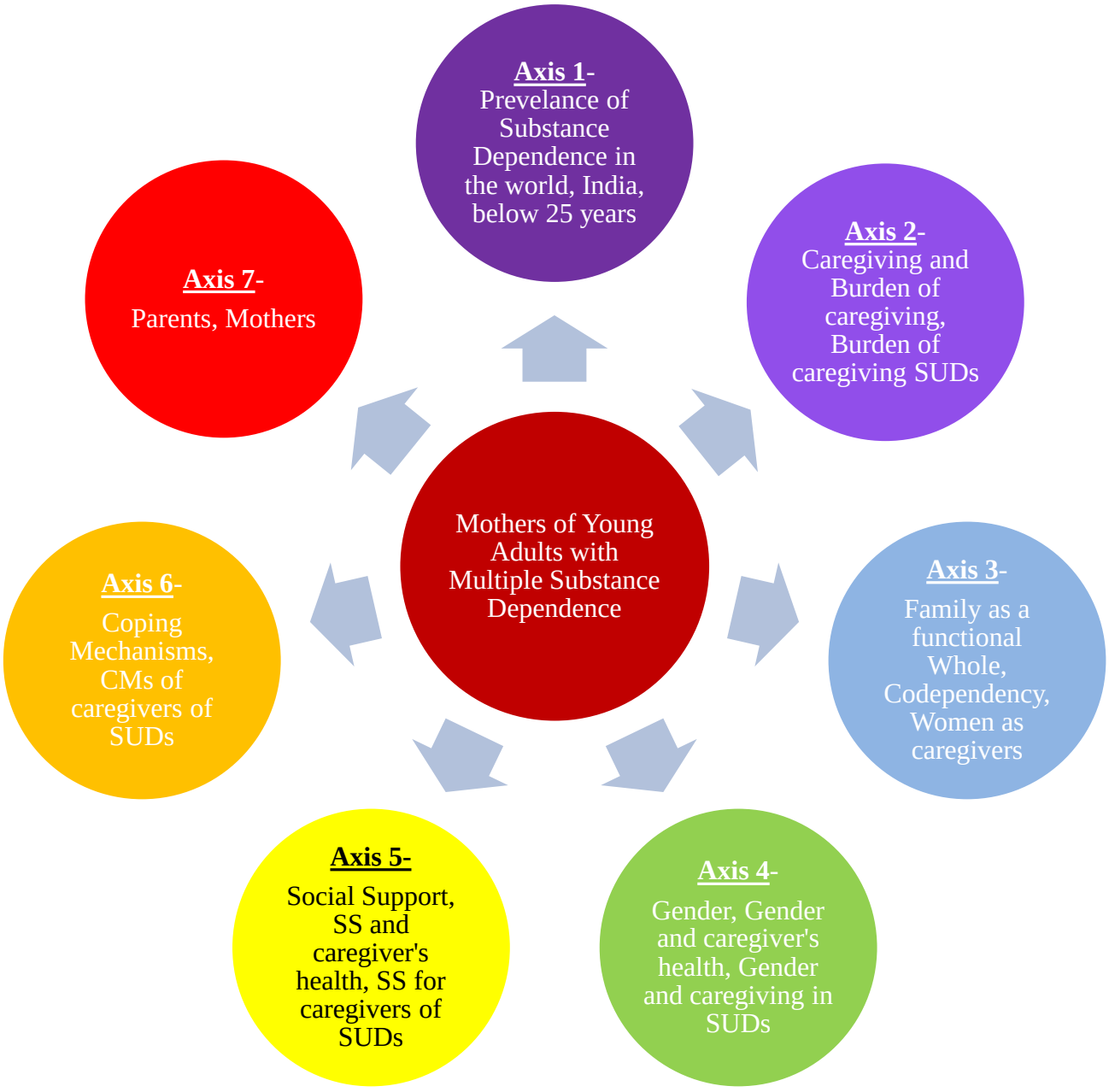
Considering the abundance of information available on the topics of addiction, caregiving, family, young adults and middle aged women, the researcher found it appropriate to view the problem from different directions and dimensions, in order to form a comprehensive picture of the situation. The central context – mothers of substance dependent persons – was cut across different axes, alignments and magnitudes, according to various influential variables. The researcher studied each axes in detail, following the rule of general to specific.

On Axis 1, the incidence and prevalence of substance use disorders in the world was studied. The spread of substance use in the world and India's record in that background was examined. The second axis was of that of caregiving. The concept of caregiving across boundaries of physical, psychological and behavioral disorders in varying magnitudes was studied. This axis comprised of the factors relating to caregiver burden also. On the next axis, family and it's dynamics under the influence of substance dependence was brought to focus. The changes happening in the various subsystems of family as a whole were emphasized. On axis 4, the role of gender in

determining the caregiver distress was considered in detail. In the succeeding axes, variables of social support and coping mechanisms were plotted and deliberated. Parenthood or parenting was considered on a separate axis, distinct from family, for the betterment of conceptualization and understanding the changes happening in parental subsystem after the advancement of dependence.

Diagrammatic Representation of RoL

Figure 2 - Diagrammatic Representation of Review of Literature



The following stands the compilation of the extensive review of literature.

Axis 1

The Prevalence of Substance Use and Related Disorders across the World

World Health Statistics 2020

World Health Statistics 2020 states that there has been inadequate progress in prevention and control of non-communicable diseases causing premature mortality and in reducing its risk factors. Tobacco use and harmful use of alcohol are considered to be one among the four main contributing factors for non-communicable diseases. Even though global trends show steady decline in the use of tobacco and alcohol, meticulous analysis bring forth solid concerns. There is a steady decline in the age of initiation of psychotropic substances and substance use disorders caused by them.

World Drug report 2022

World drug Report 2022 warns a post-2008 Great Economic Crisis like situation or even worse condition as compare to it. COVID- 19 lockdown and its restrictions have shattered the world economy. It rendered many people jobless, homeless and support-less. Unemployment, poverty and other mental health challenges, lead disadvantaged people to engage in harmful patterns of drug use and suffer substance use disorders and turn to illicit activities linked to drugs.

Epidemiology of Substance Use Disorders in the World

World Drug Report 2022 states that around 284 million people around the world used drugs in the year 2020, which amounts to 5.6 per cent of the total population. In the past two decades,

drug use increased more rapidly in developing countries (28 %) as compared to developed countries (7 %). Drug use is more widespread in developed countries than developing countries, but, drug use disorders are more prevalent in lower income countries as compared to their higher income counterparts. Emergence of around 500 new variants of new psychotropic substances into the drug market complicates the identification, seizure, diagnosis and management of disorders caused by them.

Prevalence of Substance Use Disorders in India

Substance use Disorders, including alcohol use disorder, moderate to severe use of tobacco and use of other drugs was prevalent in 22.4 percent of the population above 18 years, in all the surveyed states in India, according to National Mental Health Survey, 2015-16, conducted by NIMHANS. Alcohol use disorder was identified among 4.6 percent of the population. 0.6 percent of the people were found to have other substance use disorders (substances other than tobacco or alcohol). These other substances include cannabis products, opioid drugs, stimulant drugs, inhalant substances and prescription drugs. As the substance use and mental health has bidirectional influence, high prevalence of SUDs in India is of serious concern.

Young People and Substance Dependence

Data showing the use of licit and illicit drugs across the world (World Drug Report 2020, National Mental Health Survey 2015-16, published data by National Institute on Drug Abuse, 2019, SAMHSA 2019) confirm that adolescents and young adults are more affected by substance use disorders due to the usage of substances other than alcohol and tobacco. It is difficult to obtain the actual data of drug use in the world in view of noncooperation from various countries, as stated by World Drug Report. However, from the available information, there is a growing

trend among the young adults across the world to initiate substance use behavior at a much younger age (12-13 years) and to develop substance use disorder towards the beginning of third decade of life.

Axis 2

Caregiving and Burden of Caregiving

Concept of Caring or Caregiving

Care giving is defined by Oxford dictionary as an activity or profession of regularly looking after a child or a sick, elderly, or disabled person. There is a lack of consensus on the definition of caregiving, with reference to different parts of the world and different characteristics of the recipient of care (Kent et.al, 2016). In simple words, caregiver is an individual (paid or unpaid) in the social network of a person, helping the person in performing activities of daily living (Gruber et.al, 2006). Care givers can be formally trained professionals or informal relatives or acquaintances of the person cared for. Large majority of informal care givers are family members of the person having caregiving needs.

Caregiving is studied through wide ranges of diseases and conditions across the world. Glance of existing literature on caregiving shows that focus was on caregivers of elderly, terminally ill persons, disabled persons, and chronic psychiatric or neurological conditions. Families of persons with substance use disorders are reaching to scientific attention probably in the previous two decades. Glimpses of such studies related to caregivers are condensed below.

Caring Persons with Terminal Illnesses

Cancer, Chronic Obstructive Pulmonary Disease, Chronic Heart Failure, chronic liver disease, chronic renal failure, AIDS, other neurological illnesses like muscular dystrophy, leading to progressive death are termed as terminal illness. Caregivers of terminal illnesses are studied extensively. Most of the studies document their stress, physical and psychological disorders, social isolation, financial burden etc.

Family based caregivers manage a wide range of responsibilities in their personal and familial life (Ates, G. et.al 2018) while caring patients receiving palliative care. They fulfill multiple roles and expectations within different settings. This has immediate consequences on caregivers' every-day lives. The mixed method study, conducted on the family based caregivers (N =156) of terminally ill patients from five countries revealed that the needs of caregivers are almost similar. The emotional experiences and the burden undergone by them are mostly underrated by quantitative methods (Herden- Eerden et.al., 2014, Caress et.al., 2009, Bijnsdorp et. al., 2020)

Financial burden and depression was reported among the family based caregivers of terminally ill patients (Emmanuel et.al, 2000) from six study centers in United States of America. Significant majority of carers were found to have moderate to severe depression and high level of financial burden.

Review of literature on the family care givers of motor neuron disease revealed that the caregivers experience substantial burden and distress at varying stages of their caregiving life (Aoun et. al., 2012). The institutional and social support received by the informal caregivers was found to be minimal as compared to their material and emotional needs (Mockford et.al., 2006).

Several negative emotional consequences were also documented in qualitative research studies (Pinquart & Sorenson 2003, Oliver & Turner 2010)

A longitudinal study of primary caregivers of refractory breast cancer patients documented psychological morbidities like depression and anxiety (Grunfeld E et.al 2004). Economic and occupational burden was also reported in similar studies (Areia et.al, 2019; Cassileth et.al 2015, Guldin et.al 2012, Zarit, 2004) conducted on family members of cancer patients.

The scenario of caregiving HIV-AIDS affected persons is also identical. Family based caregivers are found to report high degrees of social occlusion, in addition to financial, social and emotional distress (Madiba & Ntuli 2020). Care givers are also reported to experience grief, prolonged grief reaction, depression, anxiety and sleep disorders.

Caring Persons with Chronic Psychiatric Illness

Chronic psychiatric illness is considered to be one of the main debilitating disorders causing distress and burden to family members and community as a whole. WHO estimates 7.4 percent of global Disability Adjusted Life Years is caused by psychiatric and behavioral disorders. Living with and caring for such persons pause a great challenge in front of the family based care givers. It involves a considerable amount of time, energy and money of the caregivers for a long period. The caregiving tasks are often unpleasant, psychologically stressful and physically exhausting (Schulz & Martire, 2004).

Schizophrenia, Bipolar Affective Disorders, certain personality disorders and organic disorders are generally considered as chronic psychiatric illness, even though the treatment outcome varies according to a multitude of factors.

A qualitative study from Uganda by Olwit et.al (2015) grades the life of caregivers of persons having chronic psychiatric illness as chronic sorrow and details their psychological conditions including symptoms of moderate to severe depression, anxiety, grief, insomnia and other stress related disorders.

A descriptive study on the family based care givers of schizophrenia patients coming to the outpatient department of Thanjavore Medical College Hospital (Stanley, Balakrishnan & Ilangovan 2017) revealed high levels of anxiety and depression. The study highlighted that caregiver burden was severe and quality of life was low. Similar findings were reported by various research studies across the globe (Bademli 2017, Gourdasian et.al, 2018, Hosseini et.al 2010, Ranjan & Kiran 2016)

Care givers of patients with schizophrenia and bipolar affective disorder in Nepal were studied by Sharma et.al (2018). The study reports high level of emotional and financial burden in addition to high scores of depression and anxiety.

Studies done among the caregivers of persistent psychiatric disorders in India exposed somatization disorders, depressive disorders, anxiety, post-traumatic stress disorder and other adjustment disorders (from report submitted to ICMR by Chadda, 2003; Murthy, 2011; Ampalam et.al 2012; Steele A et al, 2010; Arun et.al, 2018). Care givers of persons with episodic illnesses like recurrent depressive disorder were also reported to have depression and anxiety symptoms, synchronized with the patients, and accentuated by stigma and other social factors (Chai & Mahadevan, 2018).

Caring Persons with Substance Use Disorders

Substance use disorders (or drug addiction, in simple words) have been a matter of concern for ages. According to International Classification of Disorders- 10, Substance use disorders include acute intoxication, harmful use, withdrawal, dependence, and substance induced psychosis.

Caregiving persons with substance use disorders is a widely studied topic across the world. With the rise in incidence and prevalence of addiction, the problems faced by the caregivers have also increased. A study conducted by Shekhavat et.al (2017) in a medical college hospital, Kota, Rajasthan, revealed that the wives of the dependent persons showed features suggestive of severe depression, anxiety and burden.

A study on the existing literature on the physical and psychological wellbeing of caregivers of substance dependents (Settley, 2020) revealed the extend of psychological distress experienced by caregivers and emphasized on the complexity of their needs. This meta-analysis spreads light on the research studies published in the electronic media and print media in the past ten years. The study stated that caregivers of substance dependents were mostly family based and were close relatives of the patients. Most of the literature speaks about the care giver burden in terms of financial, social and emotional burden.

Similar to the caregivers of persons with chronic psychiatric illness or persons with terminal illnesses, the care givers of substance dependents also experience high level of anxiety and depression, helplessness, social isolation, guilt and shame (Gruber & Taylor, 2006; Jackson, Obrien & Usher, 2006; Smith & Esthefan, 2014)

The social functioning and support perceived by the family is less focused in the literature. There is dearth of studies exploring the help seeking behavior of the family members and the availability-approachability factors of institutional and other governmental benefits.

Families with Young Substance Dependents

Addiction massively affects families, through the areas of family functioning, family dynamics, role relationships and social functioning (Barnard 2007; Conyers 2003). Substance abuse in one of the family members affects other family members also. Gruber and Taylor (2006) pronounce the need for family perspective in the treatment of substance use disorders.

In the context of adolescents and young adults abusing substances, the responsibility of caregiving befalls on the parents. Parenting styles, personality attributes, substance taking behavior, interpersonal relationships of the parents and early attachment patterns are considered as contributory factors in adolescent substance abuse (Usher, Jackson & O'Brein 2005).

Parents of young substance dependents undergo high degree of anxiety and stress, as evident from the published literature (Sheff, 2009). The lived experiences of parents were studied by a limited number of researchers worldwide. Choate (2015) studied the life experiences of parents through qualitative approach, grounded theory and recorded the impact on family functioning, social interaction, physical and mental health, and coping styles. Another qualitative research by Reyes & Duchene (2015) on caregiver's emotional experiences reflects on stress, hurt, disappointment, failure and hope as main themes evolved during the interviews.

Burden of Caregiving

Concept of Caregiver Burden

Caregiver burden is the stress which is perceived by caregivers due to the home care situation. This subjective burden is one of the most important predictors for negative outcomes of the care situation – for the caregivers themselves as well as for the one who requires care (Grabel et.al, 2014).

There is no International Classification of Disorders -10 code for caregiver burden. Zarit et.al (1986) defines it as "the extent to which the caregivers perceive that the caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning". This definition summarizes the multidimensional aspect of caregiver burden. Burden of caring in the context of psychiatry, is defined as the presence of problems, difficulties and adverse life events that affect the lives of significant others (care givers) of psychiatric patients (Platt S. 1985).

Two dimensions of caregiver burden are identified by authors- Objective burden which includes the effects on the household and financial trouble and effects on health, children, family routine and leisure time and subjective burden which includes subjective experience and perception of burden (Pai & Kapur, 1981; Thara et.al, 1998; Sarkar et.al, 2016)

Scientific literature points out that the family caregiver burden infringes upon multiple domains of functioning of the caregiver including physical and mental health, social relationships and financial life. It is also found to be associated with psychological morbidity and negative attitude towards the patient (Chang et.al, 2018; Chan & Leow, 2011; Kate et.al 2013; Jagannathan et.al 2014; Shiraishi & Reilly 2019).

Awad & Voruganti (2008) examined the historical development of the concept of care giver burden. This concept was initially used in the context of chronic and terminal physical illness like cancer and neurological disorders. Gradually, the research was extended towards psychiatric illness causing permanent disabilities and dysfunctions like schizophrenia and dementia. Caregiver burden associated with substance use disorders have gained attention of scientific community in the past two decades, after the focus of treatment of addiction shifted from the patient to the family.

Burden on Families Caused by Psychiatric Illnesses

Caregiver burden is found to have similar features in physical and psychiatric disorders characterized by anxiety, stress, depression, guilt, economic and social consequences (Tamizei et al. 2019). Glanville & Dixon (2005) observes that caregivers of persons with schizophrenia and other chronic psychiatric disorders experience high level of subjective burden and distress, accompanied by occupational and social restrictions. Granden et.al (2008) states that family members of persons with persistent psychiatric illness experience high emotional burden due to the functional loss of both the patient and other significant family members.

Bhimani, R. (2014) studied the burden of caregiving among caregivers of Parkinson's disorder and the results emphasized the presence of moderate to severe burden, lack of training in providing basic care, lack of social support and community based services.

Burden on Families Caused by Substance Use Disorders

Addiction and substance use disorders have similar course and outcome trajectories as compared to chronic psychotic disorders like schizophrenia, mood disorders, dementia and certain personality disorders (Mattoo et. al, 2019). The concept of caregiver burden is introduced relatively recently to the parlance of substance use/misuse. Earlier, addiction was perceived as faulty behavior pattern rather than a primary illness. The medical model and bio-psycho-social model envisages addiction as a disorder. The family members of substance dependents were initially seen either as a causative factor or as a maintaining force in management of drug addiction. In the past two decades, with the practice of family focused therapeutic interventions, caregiver burden also gained worth in scientific research.

Substance dependence is considered as a family disease, as it affects the others in the family also, in terms of occupational and social functioning, physical and emotional distress and financial burden (Lennox et. al, 1992; Holder & Galanter, 1998).

Biegel et al (2007) observes that literatures on substance abuse in the past decade have studied the role of families as causative and perpetuating factors and also role of families in the treatment of substance dependents. But, very few studies have been done to understand the influence of substance dependent and his/her dependence pattern on the families or primary caregivers.

A Polish research (Maciel, et.al, 2018) on caregivers of substance dependents under treatment from a hospital, revealed moderate to severe levels of burden. The study was conducted on 115 female caregivers whose relatives were under treatment in a deaddiction program. Burden was measured using Zarit Burden Interview. Significant differences were found in relation to place of treatment and kinship, but not in relation to the type of drug (alcohol or cannabis).

A research study from Iceland, on the family members of persons with substance use disorders (Olafsdottir, Hrafnsdottir & Orjasniemi, 2018) revealed that majority of the family members had severe depression, severe anxiety and serious stress. The study sample was 143 individuals taking part in a family therapy group for families having substance dependents. Family members included parents, spouses, children and siblings of the substance dependent. The study indicated no significant difference in gender, in the experience of anxiety and stress. This study was supported by similar studies and reports (Kenneth, Leonard & Eiden, 2007; Denning 2010; Dawson et.al, 2007; Lander et. al, 2013) from the Scandinavian countries were substance dependence is relatively high, as compared to other western countries (Eurostat., 2019). These studies also documented decreased intimacy and increased domestic violence in families with substance abuse.

A cross- sectional study from Brazil (Marcon et.al, 2012), on the burden and quality of life of caregivers of drug addicts reported high level of depression, burden and low score of Quality of Life. The study was conducted at four psychosocial care centers for alcohol and drugs in four different municipalities in Brazil. The sample size was 109, following the stratified random sampling. The tools used were translated versions of 36- item Short- Form Health Survey, Beck Depression Scale and Caregiver burden Scale. Caregivers were predominantly women and were unemployed. High prevalence of domestic violence also was documented in this study.

One of the important studies done by a Portuguese psychologist and his colleagues (Soares et.al, 2016) on the informal family based caregivers of addicts was reviewed by the researcher. The study titled ‘Depression, distress, burden and social support in caregivers of active verses abstinent addicts’, examined 120 informal caregivers of drug/alcohol addicts, who received treatment from Minho Medical Centre for deaddiction. A cross-sectional transversal design was

used. The tools used were Beck's Depression Inventory, Brief Symptom Inventory, Caregiver Reaction Assessment and Portuguese version of Instrumental and Expressive Social Support Scale. The study gave evidences that the caregiver depression and burden was significantly correlated with the abstinence and deaddiction treatment of the addict.

Family structure and outlook in Indian context is different from western and other developed countries of East Asia and Oceania (Sarkar, Patra & Kattimani, 2016). Indian society lays importance in familial bonds and interdependence rather than personal autonomy (Avasthi A. 2010). The concept of 'personal space' is rather limited in India, and 'enmeshment' and 'over-involvement' are common in Indian families. Meta-analytic studies of literature from India, suggest that alcohol dependence and intimate partner violence are closely correlated (Rao V, 1997).

Studies done in India differs slightly to Western in the sense that burden experienced by the family members did not differ significantly across different drug groups, whereas it was recorded higher in rural community. Dual diagnosis and comorbidity were found to escalate the family burden (Mattoo et. al.,2013; Ganguly, Sharma & Krishnamachari, 1995).

A descriptive comparative study on the burden of caregivers of schizophrenia, alcohol dependents and opioid dependents revealed moderate to severe burden in all the three groups (Chandra, 2004). Severe caregiver burden was reported in the wives of opioid dependents by study conducted by Nebhinani et.al (2013). This was a study on the wives of injecting and non-injecting opioid users.

Study done on the spouses of alcohol dependents (Mattoo et.al 2013) showed high prevalence of depression, indicating high family burden. A huge majority of 95% of families with alcohol or

opioid dependents reported moderate to severe burden, as documented by a series of studies done in Postgraduate Institute of Medical Education and Research, Chandigarh. These studies were done on the patients and families seeking deaddiction and related services from the aforesaid center. The respondents were divided into three groups- caregivers of alcohol dependents, caregivers of opioid dependents and caregivers of persons with alcohol and opioid dependence. Compared to opioid and alcohol and opioid dependence groups, more often the alcohol dependence group was older, married, currently working, having a higher income and with the wife as a caregiver. Family burden was moderate or severe in 95-100 per cent cases in all three groups and more for 'disruption of family routine', 'financial burden', 'disruption of family interactions' and 'disruption of family leisure'. Family burden was associated with low income and rural location.

One of the cross sectional studies among the caregivers of substance abusers (Kaur et. al, 2018), explored the role and burden of caregivers of patients seeking treatment from Government Medical College Hospital, Amritsar. The study revealed that more than half of the caregivers (n=349) developed stress while caregiving. None of the respondents of this study were trained caregivers, neither did they knew about help seeking from professionals and services provided by the government. Similar results were put-up by Sharma et.al (2019) with his study on family burden in substance dependence (a tertiary care hospital based study) from Faridkot, India. Here, the primary caregivers (n=150) were assessed on the basis of Family Burden Interview Schedule. The results indicated that 99 percent of the caregivers had moderate to severe objective and subjective burden.

A descriptive study by Shyangwa, Tripathi & Lal (2008) in a medical college hospital, Nepal, on the burden experienced by 30 caregivers of intravenous drug users and alcohol dependents found

increased burden in both the groups, however, the burden was more with intravenous drug users than with alcohol dependents. The study also reported that the spouses of the dependents reported higher degree of burden as compared to other family based caregivers like parents, children and siblings.

A study conducted in south India (Ramanujam V. et al. 2017), on 200 alcohol dependents and their caregivers, receiving treatment from a private medical college hospital brought out an alarming statistics of moderate to severe burden among nearly 95 percent of the caregivers. 80 percent of the caregivers reported gross interference in family routine and family interaction patterns as the dependent caused disruption in the general atmosphere of the house. 58 % of the caregivers showed symptoms of depressed mood, loss of sleep and death wishes, secondary to dependents' alcohol intake. Significant correlation was also recorded between the dependency and severity of burden.

A similar result was reported by Swaroopachary et.al (2018) who conducted a cross-sectional hospital based study on alcohol dependents and their caregivers receiving treatment from a tertiary care hospital in Telengana. Sample size was seventy patients and their female caregivers. Burden was assessed with the help of Family Burden Interview Schedule. The result indicated severe burden among the caregivers. There was significant correlation between severity of dependence and burden.

In a study (Malik et.al, 2012) conducted in a rural village of Punjab, involving 83 primary caregivers of patients with substance dependence, it was recognized that majority of the caregivers (77.5 %) had moderate burden, on Family Burden Interview Schedule. Burden was especially evident in the areas of finance, routine activities, family leisure, and family

interaction. Family burden was found to have temporal association with the number of substance, type and duration of dependence. Higher proportion of burden was seen in caregivers of illiterate patients of reproductive age group, of lower socioeconomic status, having multiple and longer duration of substance dependence, and had relapsed many times.

A comparative study of burden perceived by the wives of persons with alcohol dependence and heroin dependence was done at Medical College Hospital, Kota, Rajasthan. The study (Shekhavat, Jain & Solanki 2017) used Burden Assessment Schedule to assess the burden and found out that wives of both the groups experienced moderate to severe burden.

Axis 3

Family as a Functional Whole

Changes in Family Dynamics after Development of Dependence

Alcohol and drug addiction judder the family functioning and dynamics in many ways. This may be evident from disarrayed family structure and relationships, failure in controlling the additive behavior, increasing helplessness against addiction and family life centered on the dependent (Barnard 2007). Many authors have described the changes in family dynamics after the drug dependence of one of the family members as ‘overturning’ the basic family structure, ‘family fracturing’, ‘confusing’ and ‘family destroying’ (Oxford et.al 2005)

Methodical review of literature on the family of substance dependents brought about evidences for change in family dynamics after the prominence of substance use pattern in the family.

Authors describe that other members of the family live in a warped environment wherein inconsistent behaviors abound and rules fade. Substance dependence and related activities become the center of the family's functions and all other members are occupied in keeping the family secret and equilibrium (Dore et.al 1996). Boundaries become either too rigid or virtually nonexistent resulting in isolation or enmeshment of family members. Changed roles and performances are an attempt to maintain homeostasis roles, but result in continued addiction of the dependent and permitting of the dependent's maladaptive patterns of behavior. The family members and the dependent, applies the defense mechanism of denial, repression and regression to camouflage the reality of addiction (Issacson, 1991). The three main rules defining the family interaction pattern are "don't trust", "don't feel" and "don't talk". Consequently, the family members have difficulty in expressing emotions, processing problems and resolving them. The basic emotions generated are anger, shame, guilt and despair. These are never expressed effectively in family atmosphere and get bottled up. The outcome is family conflict, chaotic interactions, defective communication, skewed power dynamics and total family disruption (Gustavsson & Rycraft 1994).

Studies on alcoholic families have exposed marital disruption, ruined family rituals, poor cohesion, blurred boundaries within and across different subsystems, dysfunctional communication-interaction pattern and defective power distribution (Preli, Protinsky, & Cross L 1990).

The patterns of interaction across and within different subsystems in alcoholic families were studied by Suman & Nagalakshmi (1995). They compared the interaction patterns of 40 alcoholic families with 10 non-alcoholic families using family interaction scales. The outcomes gave evidences that the alcoholic families had poor communication patterns, spouse abuse and

poor role functioning. Spouses of alcoholics mentioned greater dissatisfaction in the areas of family functioning. Strong alignment was found between the alcoholic's wife and children (inter-generational alignment). Absence of division of labor in the parental subsystem caused role strain in mothers. Instrumental and expressive leaders were found to be the wife of alcoholic, even though the power and authority was skewed towards the male alcoholic.

The entire family structure and functioning is affected in drug abuse situations, but, the significant family member who assumes the caregiver role is the most burdened from this process (Kaur et. al, 2018; Rose, Mallinson & Gerson, 2006; Townsend et. al, 2006). The assistances provided by the caregivers are multifaceted, including personal, financial, management of illness symptoms and retention of the abuser in the treatment process.

The effect of Substance Use Disorders on a family or a significant family member depends up on the severity of the disorder, comorbidities (physical and psychiatric), behavior/personality of the substance dependent, support available for the family and the coping skills of the family members (Daley, 2013).

Many studies and reports document the adverse effects of substance use disorders on family system and functioning (Daley & Douaihy, 2010; Klostermann & O'Farell, 2013). Highlighted effects are emotional burden, economic burden, relationship distress, family instability, and effects on children and parents. Parents of adolescents and young adults with substance dependence may feel guilty, helpless, frustrated, angry, or depressed (Daley, 2013).

Maina et.al. (2021) did an exploratory qualitative research on the relatives of persons with substance use disorder in order to comprehend the families' experiences due to substance dependence and also to understand the resources needed to help them. She interviewed 21

participants with different relationships with the substance dependent, using an interview guide. Out of the participants, 17 were women, and four were men of which two had a sister, four had a brother, eight had a parent, six had a dependent, and one participant had a grandparent with substance dependence. Out of the thematic analysis of the qualitative responses, four themes evolved which are – grieving the loss, living in dread and despair, living in perpetual crisis, and mitigating the effects of substance use in the family. The study also recommended that entire treatment of substance use disorders should include re-integration of families as an essential objective, along with dissemination of information about deaddiction treatments.

Parents' Involvement, Reaction and Needs in Connection to Adolescent Substance Dependence

Fisher et.al (2006) noted that parents were frequently unaware of their child's initiation of substance use behavior, and sometimes may be misdirected to believe that the problem is due to some other cause. Jackson, Usher and O'Brien (2007) described parental reactions in the context of adolescent substance dependence as moving from suspicion, to knowledge, to enabling and then to confrontation. They may try to control the unwanted behavior in their own possible ways, by denying, by minimizing and normalizing, by neglecting the substance use as a part of adolescent experiments.

An ethnographic qualitative research on the emotional experiences of the parents of adolescents and young adults with substance use disorders was conducted at a residential treatment facility in California by Reyes & Duchene (2015). The researchers conducted in-depth interviews with 12 caregivers using interview schedules. The process of data collection was done in a series of interviews with the same respondent and the collected information were recorded and analyzed.

Qualitative data analysis techniques were used. The study identified five main themes- stress, hurt, disappointment, failure and hope. The mini themes which were reported by the respondents were distance, resistance, guilt, helplessness and shame. These themes were suggestive of the burden undergone by the caregivers while caring the young substance dependent.

A qualitative study on the needs and experiences of parents of adolescents with substance dependence by Chaote (2011) concluded that the parents oscillate through a cycle of reactions and responses towards their child's unwarranted behavior. These reactions are toleration or normalization, engagement or control, and withdrawal or isolation. Throughout the life, the parents struggled to understand the actual problem and reported significant day-to-day challenges in relation to substance taking behavior of their adolescent dependent. Some of these challenges were conflicts with law and public, shame, guilt, road traffic accidents, hospitalization etc.

Concept of Codependency

Codependency refers to psychological behavioral problems that enable drug users and their family members to engage in mutually destructive habits and maladaptive coping strategies to maintain a sense of balance or homeostasis (Steinglass, 2009). Codependent family members display an intense need to help compared with family members without codependency (Rotunda, West & O'Farell, 2004). Therefore, it is a multidimensional problem influenced by a variety of factors that may begin in childhood with a compulsive need to assume a caretaker role and may produce paradoxical affective links that reinforce the drug user's maladaptive behavior patterns.

Family members, focusing on the problems caused by the dependent individual, forget their own problems and culminate in codependency. This concept is stress generating and demanding for

change of patterns of conduct. The abuser eventually becomes unable to fulfill the roles and responsibilities and the codependent member has to fulfill the vacant roles (Cullen and Carr, 1999).

Codependent family members often have difficulty setting boundaries and asserting their own needs because of low self-esteem, poor emotional control and self-blame. This not only allows the drug user to continue their addiction but also prevents family members from seeking help for themselves and their loved ones (Noriega et.al 2008).

A Brazilian study reported work and emotional overload, self-negligence, and medication use associated with high codependency among family members who sought the help of a support hotline (Bortolon et.al 2017). In addition, these families exhibited difficulties in communication, in interaction style and behavior control and problem resolution.

Rusnakova, M (2014) postulated a process model for codependency focusing on the experiences and behaviors of codependents. These phases of codependency- namely- denial, anger, rescuing, sadness, hatred and reconciliation- were characterized by a set of thoughts and emotions. After the phase of reconciliation, the codependent once again enters in to the stage one following the relapse of the substance dependent. The researcher studied seven caregivers of substance dependents using in-depth interviews, using life history-case study approach of qualitative research. The participants of the study were deliberately selected by the researcher from different life experiences in caring substance dependent close relatives. Six out of seven caregivers were females.

Women as Caregivers- Victim of Burden

Report submitted to Ministry of Social Justice and Empowerment and UNDCP (Shankardas et. al 2001) states that, within the family, it is often the woman, in the role of wife or mother who is most affected by the individual's substance use, and has to bear a significant part of the family burden. Such impact becomes even more obvious in a developing country like India, where women are already disadvantaged. Domestic violence, crime, increased trafficking, and risk of HIV were recognized as possible outcomes of individual drug use. One of the major burdens the women faced was the burden of blame – blame for the drug use in the family member, blame for hiding the issue from others, and blame for not getting timely treatment. Thus, the woman often became the victim of not just the drug abuser but also the society. Drug abuse magnifies violence within marital relationships. Most women suffer abuse silently, responding with humiliation, frustration, helplessness, and suicidal thoughts. Shame and embarrassment force many women to withdraw to themselves and suppress their hurts, leading to emotional breakdown and other psychiatric morbidities.

Provided the cultural and societal background of India, where females are ascribed secondary position as compared to male counterparts in family and community, victimization of female members can be visualized in families with substance dependence too. Family based women caregivers are found to have more physical and psychological disorders (Mattoo et.al, 2013; Ramanujam V. et. al, 2017; Swaroopachari et.al 2018; Sharma et.al, 2019), more psychiatric morbidity (Dandu, Bharathi & Dudala, 2017; Mammen, P. M., Thilakan, P., Solomon, S. (2015); Sedain, 2013; Bagul et.al, 2015), higher levels of subjective burden (Nebhinani et.al, 2013; Chandra, 2004), lower quality of life (Loganathan & Murthy, 2011) and more restricted social functioning (Singh A., 2010).

As the family-based caregivers do not receive any formal or informal training, at least in India and other developing countries, the caregivers are not able to deal with the problem effectively, cannot reach out for professional assistance and sometimes find help seeking as defaming or disrespecting the dependent family member (Nebhinani et.al 2013).

Wives of Substance Dependents

Noori R et.al (2015) studied the associated parameters of anxiety and depression among the wives of Iranian male drug dependents. The study was conducted among 237 Iranian women divided into three groups: 1. non-drug-dependent wives who had non-drug-dependent husbands (Group I), 2. non-drug-dependent wives who had drug-dependent husbands (Group II), and 3. drug-dependent wives who had drug-dependent husbands (Group III). The levels of anxiety and depression were measured through the Hospital Anxiety and Depression Scale (HADS). Linear regression was applied for determination of anxiety and depression predictors. The study concluded that spousal drug dependence was a predictor of anxiety and depression.

A qualitative research done by Joolaee S et.al (2014) among the wives of addicted men in Iran, explored the needs and expectations of the spouses. The study was carried out in a deaddiction clinic, affiliated to Tehran University of Medical Sciences. The sample size was 56 and the method of data collection was in-depth interviews with the respondents (duration 45 min to 130 min). The needs emerged from the study were support for the treatment of addicted husband (as the first priority), instrumental and financial needs, emotional needs and information needs. Spouses expect support from family, government and community.

A study done by Dawson et.al (2007) found that women who lived with a substance-abusing partner had much worse states of health, with more anxiety, stress, physical illness, and significant impairment of their overall quality of life as indicated by lower family incomes and higher levels of domestic abuse.

Indian literature also pinpoints that wives of substance dependents experience high level of burden and stress due to the dependence of their husbands. Evidences can be derived from the series of studies done by Mattoo S and his colleagues (2013) on the spouses of substance dependents, Swaroopachari et.al (2018) on the caregivers of alcohol dependents and Shekhavat, Jain & Solanki (2017) on the wives of heroin dependents, which are discussed in the previous pages.

A descriptive, cross-sectional, tertiary care hospital-based study, conducted by Sharma et. al (2019) on the wives of substance dependent individuals revealed high degree of subjective and objective burden. The study was done among 150 beneficiaries and their wives of the Drug De-addiction and Treatment Centre, Department of Psychiatry, Guru Gobind Singh Medical College, Faridkot. The translated version of Family Burden Interview Schedule (Punjabi) was used as the main tool of data collection. The results indicated that 35% caregivers had severe objective burden, while 65% had moderate objective burden. 74% had severe subjective burden and rest had moderate subjective burden. Objective burden had correlation with monthly family income, monthly expenses on substance, number of substances, type of substances and treatment history. The family burden was associated neither with age, education, occupation, or duration of dependence of the patients nor with family type, background, caregiver's age, education, or occupation.

Another significant study on the wives of persons having alcohol use disorders was conducted by Dandu, Bharathi & Dudala (2017) at a government tertiary center in Thirupati, Andra Pradesh, to evaluate the presence of psychiatric morbidity among the respondents. The sample size was 101 male alcohol dependents and their female spouses. Spouses were screened using the General Health Questionnaire- 28 item version, and those who were found positive were interviewed separately to diagnose according to International Classification of Disorders- 10. The study results indicated psychiatric morbidity among 66 percent of the wives. Majority of the reported disorders were dysthymia, and recurrent depressive disorder, adjustment disorders, panic attacks, and generalized anxiety disorder. 85 % of the wives were affected by physical or verbal violence from their husbands. Similar finding were also reported by some other Indian as well as foreign authors (Bagul et.al, 2015; Ponnu, Pradeep & Susan, 2015; Sedain, 2013; Steinglass 1981; Nayak et.al, 2010; Kishore, Pandit & Raghuram, 2013)

Children of Substance Dependents

Evidences from empirical research prove that substance dependence during pregnancy can harm fetal development (Salo & Flykert 2013). Infants born to opioid dependent mothers are more likely to develop cognitive developmental delays. Children of parents with SUDs are at increased risk for abuse or neglect, physical problems, poor behavior/impulse control, poor emotional regulation, conduct or oppositional disorder, scholastic backwardness, and psychological issues like depression, anxiety, and substance abuse (Daley, 2013).

Siblings of Substance Dependents

When an adolescent uses alcohol or drugs, siblings in the family may find their needs and concerns ignored or minimized while their parents react to constant crises involving the

adolescent who abuses drugs. The neglected siblings and peers may look after themselves in ways that are not age-appropriate, or they might behave as if the only way to get attention is to act out (Brook & Brook, 2001).

Axis 4

Gender

Gender Perspective in Caregiving

In the Indian milieu, caring of old and ill is done largely inside the subshells of family (Shankar & Rao 2005). Institutional treatment and rehabilitation facilities are under-developed and insufficient, considering the spread and extend of persons requiring institutional care. National Mental Health Survey (2015-16) reports a 10.6 % prevalence of mental disorders currently in Indian population, requiring active intervention. This data indicates the extend of gap between the need and availability of institutional care facilities.

Navidian and Bihari (2008) observe that availability and accessibility constraints of mental health care delivery systems in the developing and under-developed countries restrict the provision of care to the household. Data shows that more than 90 % of the persons above the age of 18, with psycho-social disabilities, in the rural areas, are cared in the households (Shah et.al, 2013; Kumari et.al, 2009; Sreeja et.al, 2009). In urban areas, persons receiving residential institutional care vary from 20 per cent to 35 percent, as recorded in various studies done across the country (Barman & Chakravorty, 2012). This background signifies the caregiving functions done by the large assembly of home- based care givers.

Pinquart & Sorenson (2019), after reviewing 109 published literatures in the past two decades, establishes that women constitute the bulk of providers of informal care, world-wide, irrespective of urban-rural demarcations. This is pertaining to the caregiving of elderly, and those with physical and mental disabilities. While providing care, the women undergo emotional, physical, social, and financial burden, which in turn compromise their quality of life, self-worth and independence (Viana et.al., 2013; Pompili et.al., 2014).

Considering the culture and tradition of India, caregiving is considered as a familial ritual and obligation. Usually, women assume the responsibility of caring, in the families. Most of the Indian researches ally with the predominance of female care givers in relation to persons having mental health needs (Patel et.al., 2006; Balaji et.al., 2012; Kate et.al., 2013; Chatterjee et.al 2014) and in elucidate the mental health issues of women caregivers.

Gender

World Health Organization (2020) designates gender is a social construct. Gender refers to norms, behaviors, functions, roles and expectations of women, men, girls and boys that are socially created, maintained and preserved. It varies from society to society and changes over time. Political status, economic class, ethnicity, physical and mental disability, age, etc. modify gender roles. It is hierarchical and non-egalitarian, producing disparities that intersect with other social and economic inequalities (WHO Gender Studies, 2020).

Influence of Gender on Health

Lindsey (2010) explains the influence of gender on health and wellbeing of an individual. She states that gender influences personal experience of health and access to healthcare. It also

influences a person's help seeking attitudes, behaviors and practices. Many Indian authors support the gender-based discrimination prevalent in the parlance of health care (Das, Das & Das, 2012; Fikree & Pasha, 2004; Loganathan & Murthy 2011; Patel et.al, 2006; Shidhaye & Patel,2010). Gender roles, inequality and discrimination faced by women put their health and well-being at risk.

Women face greater barriers than men to accessing health information and services (Hunt, 2003; Addlakha, R., 2008). These barriers include restrictions on mobility; lack of access to decision-making power; lower literacy rates; discriminatory attitudes of communities and healthcare providers; and lack of training and awareness amongst healthcare providers and health systems of the specific health needs and challenges of women. Women also face high levels of violence rooted in gender inequality. Rigid gender norms – especially those related to masculinity – can also affect men's health and wellbeing negatively. For example, specific notions of masculinity may encourage boys and men to smoke, take sexual and other health risks, misuse alcohol and not seek help or health care. Such gender norms also contribute to boys and men perpetrating violence – as well as being subjected to violence themselves. They can also have grave implications for their mental health (Das, Das & Das, 2012).

Influence of Gender in Caregiving

Researches describing the vivid experiences of caregiving, particularly through gender lens and qualitative approaches are very few in low- and middle-income countries (Mathias et.al 2018). Recent studies on caregiver experiences (in India) have largely been quantitative, descriptive/diagnostic, gender- neutral and passive, missing the nuances of gender sensitivity and

caregiver life experiences (Mathias et.al 2015; Kumar & Gupta, 2014; Chadda, 2014; Kate et.al 2013).

A qualitative research was done by Mathias et.al (2018) in the rural population of India to explore and elucidate the experiences of men and women as caregivers of persons with psychosocial disabilities. The study was conducted in two administrative blocks of western Uttar Pradesh. Method of data collection was in-depth interviews with the respondents at their homes, each interview duration maximum of ninety minutes. The interview was guided by a semi structured interview schedule to probe experiences of social connectedness and support, stress, caregiving responsibilities, gender relations, and social inclusion within the respondents' households and communities. Collected data were analyzed inductively and thematically. Nine themes under three meta themes emerged from the analysis. The main themes were – high stress, bleak to bright horizons, self-blaming to self-affirming, embodiment (or somatization) of stress, losing and keeping friends, social judgment to social support, experiences of violence, togetherness and new gender relations. The study established that the males and female caregivers had different caregiving experiences. Predominantly women experienced the negative end of the experience spectrum, while men tended to locate themselves on the more positive end. Women experienced more stress, bleak views, social judgment and higher degrees of violence, whereas men got more acceptance and support from the society and initiated violence/acted as perpetrators.

Women caregivers generally experienced greater stress levels as compared to their male counterparts, for the following reasons: women work more hours in caregiving, perform heavier manual caregiving tasks, have fewer opportunities for respite, and have fewer social interactions outside the house in a context where it is more socially acceptable for men to devote time to

leisure activities (Addlakha, 2008; Jagannathan et.al, 2014). Women are often unable to utilize positive coping strategies like reaching out for help, ventilation of emotions through emotional support seeking, quality time for self to improve self-worth and self- appreciation etc. adding to their distress and burden. This impact is visible in their poorer quality of life (Kate et.al., 2013).

Men receive more social support than female caregivers, as observed by many researchers from the country and abroad (Kate et.al., 2013, Kumar & Gupta, 2014). Men tend to ask support for household and caring activities from their informal support providers more than that done by women. Men get more acceptance in doing so from the society, as caring and household chores are considered 'feminine', while these activities done by women are normalized or minimized. (Gupta et. al., 2015)

Embodiment is the term used to denote the way in which biological, psychological and social experiences are fused into body or physique. Personal experiences of distress and illness are filtered and modified by society and culture to present them as somatic syndromes (Kirmayer & Sartorius, 2007). The society accepts the expression of distress as bodily aches, pains and other complaints (Grover & Ghosh, 2014). Krieger's eco-social theory (2001) also uses social dynamics of acceptance and control to explain etiology of psycho-somatic and somatization disorders. Somatization disorders, depressive disorders, psychosomatic disorders, sleep disorders and adjustment disorders are some of the common disorders seen among the female caregivers of persons with psychosocial disabilities. All these disorders are internalizing disorders, in which the individual internalizes his/her conflicts or problems, by employing neurotic or mature defense mechanisms. As society allows women to express vague bodily complaints and ailments more than any other psychological, social or psychiatric difficulties, the prevalence of somatization is more among women care givers (Sharma N., 2014).

Gender Differences in Caregiving Persons with Psychosocial Disabilities

In the huge arena of home based of caregivers of elderly and other persons with psychosocial disabilities (including intellectual disabilities, developmental disabilities, physical disabilities, terminal illnesses, chronic psychiatric and neurological illnesses, and substance use disorders), numerous studies were done in the past two decades. Considering the abundance of literature, only significant studies, meta-analyses, and reviews of literatures were studied by the researcher. The selected literature was reviewed on the basis of a few main themes- viz. time spent on caregiving, types of tasks, role strain, reasons for providing care, burden, and psychological morbidity. Following were the major findings:

a) Women spend more time in care giving than men (Yee & Schulz, 2016; Pinquart & Sorensen, 2016, Miller & Caffaso, 1992)
b) Tasks associated with personal care (including bathing, dressing and managing incontinence) were done mainly by women care givers, while no particular distinction was noted in the carrying out of tasks related to management of everyday living (Dupuis et.al 2014).
c) Many studies have found that female caregivers experience greater role-strain and role-conflict than male caregivers (Martin, 2017; Houde, 2012; Dupuis et.al 2014). Female caregivers encounter pressure in enacting multiple roles. Role conflicts arise when conflicting demands are made from the caregiver. Role-strain occurs when one is unable to meet the expectations and obligations of multiple roles. Role-overload sets in when these competing demands overwhelm the person's ability to carry out his/her role. This might lead to role-captivity, which refers to the caregivers' feelings of being trapped in

their roles. This give rise to physical problems, fatigue, burnout, depression and other emotional disturbances.

d) Several authors have identified emotional and social connectedness of women towards their family members, as well as their sense of family obligation as the basis for their reason for caregiving (Guberman et.al 2013).

e) Extensive literature review done by Pinquart & Sorensen (2016) stated that women caregivers experience greater subjective burden as compared to males, at least in certain domains of burden. Women also experience lower level of subjective wellbeing and physical health.

f) Meta-analytic reviews revealed the high prevalence of depression and somatization disorders among the female caregivers (Yee & Schulz, 2016).

Impact of gender on caregiving is interceded and confounded by various other factors including the patient's characteristics, personality of the caregiver, severity of the illness and associated physical, social and psychological problems and disabilities, composition of the family, caregiver's demographics, relationship with the patient, and effect of culture and ethnicity (Chakrabarti, 2017).

Gender Differences in Caregiving Persons with Substance Use Disorders

The review of literature on the caregivers of persons with substance dependence, pointed out that the majority of the caregivers are females- either wives or mothers (Swaroopachari et.al 2018; Sharma et.al, 2019; Dandu, Bharathi & Dudala, 2017; Ponnu, Pradeep & Susan, 2015; Sedain, 2013; Bagul et.al, 2015; Nebhinani et.al, 2013; Chandra, 2004). Guberman et.al., (2006) observed that women initiate the process of caregiving as they are the first victim and primary

target of all household processes and rituals. Women are seen prey to domestic violence and disharmony arising out of substance dependence. In most of the studies, the persons suffering from addiction are males and their caregivers are females (Barnard, 2005).

Axis 5

Social Support of Caregivers

Social Support

Social support is well-thought-out to be one of the vital aids and assistances that the society reserves for its members. It can also be considered as the care provided by the community.

Concept of Social Support

Cohen & Wills (1985) defined social support as the perception and actuality that one is cared for, has assistance available from other people and that one is a part of supportive social network. These supportive resources can be emotional (e.g., nurturance), informational (e.g., advice), or companionship (e.g., sense of belonging); tangible (e.g., financial assistance) or intangible (e.g., personal advice). Social support can be measured as the perception that one has assistance available, the actual received assistance, or the degree to which a person is integrated in a social network.

The concept of social support is studied and theorized by a number of authors, sociologists, psychologists and social workers. It is thus very difficult to derive a widely accepted definition

and to synthesis the constructs incorporated in the concept (Taylor, 2011). Still, following are some of the important theories and thoughts postulated by various authors.

The four main functions of social support, according to Wills (1985) are emotional support (love, trust, empathy, etc.); tangible support (or instrumental support consists of concrete and direct ways of support); informational support (useful information and advices) and companionship support (also called belonging, it is seen as the presence of companions to engage in shared social activities).

Barrera (1986) distinguishes two components of social support – received support and perceived support. Received support (or enacted support) refers to specific supportive actions given/offered by support providers, whereas perceived support is simply the recipient's subjective judgment about the provision.

According to Wills (1998), social support can be measured in terms of structural support and functional support. Structural support is the degree of extend to which a person is connected within a social network through family relationships, memberships in clubs etc. functional support is the degree of assistance that members in this social network can provide such as emotional, instrumental, informational and companionship supports.

Influence of Social Support on Physical Health

The association between social support and physical health variables are well demonstrated through researches. There is abundant literature regarding the connection of social support with psychosomatic disorders, cardiovascular disorders, auto immune disorders and life style diseases (Callaghan & Morrissey, 2013).

Influence of Social Support on Mental Health

Social support and mental health are studied widely by many researchers and there is ample evidence to show that social support improves mental health and wellbeing of a person (Gurung, 2006). Taylor (2011), through his comprehensive review of literature regarding social support and a variety of psychological distress and psychosomatic disorders, pointed out that social support helps people reduce psychological distress like anxiety and depression. Social support enhances psychological adjustment in chronic or terminal diseases like cancer, stroke, HIV/AIDS and coronary artery disease. During acute stress, social support can act as both problem- focused and emotion- focused coping strategy. Social support is found to have reducing effect on chronic pain disorders also.

People with low social support report more sub-clinical symptoms of depression and anxiety as compared to those with high social support (Penninx, et.al 2015). People with low social support are also found to have higher prevalence of PTSD, anxiety disorders, depressive disorders and eating disorders. Among persons with schizophrenia, those with low social support were found to have more symptoms. Low social support is also associated with suicidal ideation and increased substance abuse.

Models and Theories of Social Support on Health

There are two models conjecturing the impact of social support on health. They are buffering hypothesis and direct effect hypothesis. Buffering hypothesis by Cohen and Wills (1985), proposes that social support protects people from the bad effects of stressful life events. In direct effect hypothesis, people with high social support are found to have better health than people

with low social support, regardless of stress (Berrera, 1986). The evidences to support both the hypothesis are poor (Thoits, 1995).

Stress and coping- social support theory (Lozarus and Folkman, 1986), developed to explain buffering hypothesis suggests that social support promotes adaptive appraisal of the stress and improves coping. Relational regulation theory, developed by Lakey & Orehek, E (2011) explains the main effect of perceived support on mental health. According to Life- span theory (Uchino, 2009), social support develops through the life span, especially in childhood attachment with parents.

The social support- health model indicates that social relationships have beneficial effects on physical and psychological health and well-being (Dennis, 2017). Interaction with a supporting group, for sharing experiences and for improving understanding about their own condition can favor health outcomes and better integration with the environment.

Gender and Social Support

Literature identifies gender differences both in seeking and providing social support (Wills, 1998). Women provide more social support to others and are more engaged in their social networks. Women are also more likely to seek out social support to deal with stress. Studies indicate that there is no significant difference in seeking informational and instrumental supports, but emotional support is more sought by women.

Research data suggests that women benefit more from social support than men (Schwarzer & Leppin, 2009). Taylor and her colleagues (2011) gave a biological cause for this difference. They differ in their response to stress (fight or flight versus tend and befriend). Married women seek

social support more from their spouses as compared to married males. It is also noted by the social psychologists that men's behaviour are asocial mostly, with less regard to the impact of their coping upon others (eg. Substance intake, aggression). Women are more prosocial, with greater regard for the impact of their coping upon others. This may explain why women are more likely to experience psychological issues (such as anxiety, depression). There are basic differences in the perception and processing of stressors between males and females.

Culture and society plays a nurturing and defining role on how gender influences the social support and health of an individual (Schwarzer & Leppin, 2009). Gendered notions and expectations also influence the social support. Restrictions which the society holds on women limit them in seeking emotional, instrumental and informational support. Women are also restricted to keep structural social supports, during different stages of their life span. These factors, along with multitude of others, reduce the social support perceived and appreciated by women. Thus, in a given situation, women experience more stress, as compared to men.

Social Support for caregivers

Social support plays an important role in management of caregiver's burden and any stressors in life (Fink, 2015). It is an important factor in caregiving severely mentally ill persons. Caregivers may have various barriers in obtaining support because of stigma and ignorance. Pearlin et.al (2015) observes that the level of care that the caregiver gives to the impaired relative depend on the nature of support he/she receives from other people in their interacting environment.

Support Networks and Support Functions in the Context of Caregiving

The two dimensions of social support- social networks (or structural social support) and support function (tangible and intangible social support) relate to each other. Social network influences the access of and utilization of received functional support (Thoits, 1995). This relationship is applicable to caregivers also. The benefits of social support are regulated by the forms of social support, sources and the match with the types of problems faced by the caregiver (Pearlin et.al, 2015). The task-specificity model of Litwak (1985) clarifies the links between support networks and support functions. Members of a support network may provide different functions of support, and substitution of tasks theoretically occurs among groups whose structure most closely matches the tasks of the other.

Social Support for Caregivers of Persons with Substance Dependence

Orford and his colleagues (2010) designed and postulated the 'Stress strain coping support-model' to understand of the experiences of family members living with a substance dependent close relative. This model suggested that living with a substance abuser is stressful, the stress leads to strain, family members try to cope or respond to their situation and they experience differing levels and quality of social support.

Social support as an attribute influencing the caregivers of substance dependents has not been researched much, in the Indian context, as compared to that with caregivers of other psychiatric disorders. Some of the important Indian studies done on social support experienced by the caregivers were particularly on spouses of substance dependents (Mattoo et. al 2013).

A study was done by Gupta et.al (2014) on the wives of alcohol and opioid dependent men receiving deaddiction treatment from a tertiary government medical college hospital. The aim of the study was to assess psychiatric morbidity, social support and coping among the wives. Two groups each of 50 members were formed on the basis of alcohol and opioid dependents in their spouses. Psychiatric morbidity was assessed with the help of General Health Questionnaire and MINI. Social Support Scale and Coping Resources Inventory were also used. Social support score was poor in both the groups and the most common defense mechanisms used were denial and internalization.

Another research reviewed was that done by Bhowmick et.al (2001) on spouses of individuals with alcohol and drug dependence. The study was aimed to examine the relationship between social support, coping and co-dependence in the wives of people having alcohol and drug dependence. Wives of thirty males each of alcohol and drug dependence were studied by administering social support Scale, Coping Resources Inventory and Co-dependence Assessment Questionnaire. 49 respondents out of 60 were found to be codependent. Wives also recorded low coping resources and social support.

Social support as perceived by the parents of youth with substance use disorders is not understood in detail. Evidences from literature regarding the caregivers of other psychiatric disorders and similar psychosocial disabilities suggest that social support in various dimensions is the vital need of caregivers, and when provided can improve their well-being indicators (Dennis, 2017).

Axis 6

Coping Mechanisms of Caregivers

Coping Mechanisms

Coping is an individual's willful attempt to overcome a potentially dangerous situation or threat, which is not otherwise familiar or usual or which is under the person's control (Kato, 2015). It is the basic characteristic of a living organism, not restricted to human beings. From an evolutionary perspective, the better the person is able to cope with the stressors and challenges from the external environment, higher is the chance of the person to survive and get accommodated into the environment. Coping mechanisms are also seen as indicator to well-being and self-actualization.

Concept and Definition of Coping

Coping means to apply one's own conscious effort, to solve personal and interpersonal problems, in order to try to master, minimize or tolerate stress and conflict (Lazarus & Folkman, 1984).

Behavior scientists define coping as a behavioral reaction to an aversive situation that induce physiological stress reactions including fight/escape response or distress response and/or other neuro-endocrine responses (Wechsler, 1995). According to cognitive- behavioral scientists, coping can be viewed as thoughts and behaviors mobilized to manage the internal and external stressful situations (Venner, 1988). The varying ways of dealing with a stressor are called coping styles or coping strategies or coping mechanisms. They are relatively stable and determine a person's response to stress.

Zeidner & Endler (1996) defined coping strategies as tools and techniques used to handle difficult emotions, decrease stress, and establish or maintain a sense of internal order. They are behavioral and psychological efforts that people employ to master, tolerate, reduce or minimize stressful events.

Wechsler (1995) applies coping strategies adopted by animals to human behavior and coping studies. He incorporated the escape-remove-search-and-wait strategies to the coping mechanisms shown by human beings. People tend to get rid of the aversive stimulus by increasing the distance to that stimulus or by avoiding the event/stressor or by withdrawing themselves from the stressor. This type of coping behavior is called escape strategy. In another set of responses, people can act up on and try to remove/resolve/reduce the stressor. These behaviors are called fight or removal strategy or active coping strategy. If person tends to find-out possible ways of solving the problem or reducing the stress, in case, the individual's own resources are unsatisfactory, then those behaviors are called search coping strategies. In some other cases, the person resorts to 'not to do anything' or 'just wait for the external stressful condition to improve by itself'. This is called wait strategy or passive strategy.

Types of Coping Strategies

There are different ways of classifying coping strategies based on diverse perspectives, as postulated by psychologists and behavior theorists of dissimilar orientation (Folkman & Moskowitz, 2004).

According to Folkman and Lazarus (1988), the coping strategies are categorized into four groups, namely- problem focused (include active coping, planning, restraint coping, and suppression of competing activities), emotion focused, which aims to reduce the negative

emotions associated with problem (include positive reframing, acceptance, turning to religion, and humor), support seeking (seeking emotional and instrumental support from community) and meaning making in which the cognitive strategies are used to derive meaning from the situation .

Weiten (1989) speaks about appraisal-focused (adaptive cognitive strategy in which the person modifies the way s/he think, eg- denial, distancing, humor), problem- focused (adaptive behavioral strategy in which the person finds out more information about the problem and learns new skills to solve the problem), emotion- focused (seeking social support, reappraising the stressor in a positive light, accepting responsibility, avoiding and self- control) and occupation-focused coping.

According to another classification (Coppens et.al, 2010) coping strategies are divided into reactive coping (reaction following the stressor) and proactive coping (aiming to neutralize future stressors). Adaptive and maladaptive coping styles are also identified (Compas et.al, 2017) based on the mental health outcome.

Comparison among Different Types of Coping Strategies

Different types of coping are beneficial at different occasions of stressful situations. The effectiveness of each coping mechanism can only be determined based on the outcome or impact on health of the individual (Folkman & Lozarus, 1988). If the problem focused coping strategies are used more, the distress decreases (Higgins & Endler, 1995). Emotion focused and avoidance focused coping strategies may be dysfunctional as they tend to divert from understanding or managing the stressors, which leads to increased physiological and psychological distress. Active coping strategies produce better emotional adjustment to chronically stressful events than do avoidant coping strategies.

Gender and Coping Strategies

Gender differences in coping strategies are the differences in which men and women manage stressors. Studies indicate women tend to use emotion-focused coping more and tend-and-befriend response to stress, whereas men tend to use problem focused coping and fight-or-flight response more (Wang et.al, 2007; Jonker & Greef, 2009; Davis, Matthews & Twamley, 1999). Social norms and standards play an important role in adoption or choice of coping strategies by males and females. As society encourages males to be independent and aggressive, they tend to follow more individualistic and action oriented methods of coping. On the other hand, society, through the process of socialization, frames females to be more submissive and dependent. Females are fortified to use more social support, deny the reality, resort to religion and assume responsibility of the fault. These are all emotion-focused or avoidance focused coping strategies.

Females are required by cultural stereotypes to play caregiver role, which is not generally enacted by males. When males assume responsibility of caregiving, they get more societal endorsement, while women's efforts are normalized. Women often have to pay the cost in terms of unfulfilled expectations, resulting in depletion of physical and psychological resources to cope (Jonker & Greef, 2009).

Socioeconomic Status and Coping

Taylor (2006) and Carver (2011) observe that avoidant coping strategies are used more by people of low socio-economic background because threats from the environment may overwhelm the personal resources of individuals or the stressors from outside may be largely uncontrollable. People with higher position in socioeconomic ladder, with more education, employment and opportunities, deploy active coping strategies and task oriented styles. This is substantiated by

Carver (2013) in his study on 168 Andrew hurricane survivors. He found that self-distraction, denial and religion were negatively correlated with education and income.

Coping in the Context of Health

Coping exercises a significant role in the health and healthy practices of people (Carver, 2011). People with maladaptive coping mechanisms are more likely to engage in health-risk activities, like substance abuse, more prone to treatment non-compliance and relapse. People suffering from lifestyle diseases and terminal illnesses are found to use emotion-focused coping strategies more. The use of emotion focused and avoidant mechanisms tend to aggravate the severity of their illness and use of meaning making, humor, and passive coping mechanisms like meditation reduces the severity (Taylor, 2006; Goodkin et.al, 2008; Kemney, 2001 and Ironson et.al, 1994).

Coping mechanisms based on avoidance are associated with a stretch of psychosomatic disorders, psychological distress and psychiatric disorders like depression, anxiety, PTSD and somatization disorders (Compas et.al, 2017).

Coping in Caregivers

Role of coping skills in determining the mental health, burden and social adjustment of caregivers is well established by the studies of Venner, (1988) and Jonker & Greef (2009). They point out that avoidance coping strategies are crucial in development of burn-out, burden and depressive features, while, problems focused strategies reduce the caregiver stress. Meaning making coping, social integration, seeking out help/information, learning new skills etc. play a protective and preventive role for caregivers.

Caregivers who employ coping strategies without acceptance-based coping styles are found to develop anxiety and depression in the long-run. But, reverting to acceptance based strategies, help them to ameliorate their stress, as evident from the work of Higgins & Endler(1995) on the caregivers of various disorders.

In India, one of the most commonly used coping styles followed by caregivers is drawing strength from religious activities (Malhotra & Tapa, 2015; Chandonkar, et.al, 2018; Govindappa & Pankajakshi, 2014; Shah et.al (2017)). This can be viewed as an active coping strategy, provided the religious and spiritual inclination of informal family based caregivers of rural India. This aids the caregivers in better planning, receiving more support from the society and enriched acceptance of the situation/stressor/caregiver status. This also helps them in receiving more instrumental support and advice from others and developing positive reframing practices such as seeing something good in what is happening. Some caregivers reframe their caregiving experience as an opportunity to pay-back the love and care they received or as opening to attain spiritual salvation.

Social Support and Coping among Caregivers

Coping mechanisms used by the caregivers are influenced by the social support they receive from their family and society (Gangiwale et.al, 2016; Jonker & Greef, 2009; Kate et.al, 2013). This is particularly seen in the case of elderly spousal caregivers of dementia patients and caregivers of children with developmental disabilities (Iavarone et.al, 2014; Gupta et.al, 2012). The caregivers who receive emotional and instrumental support from the other (normal) family members are seen to use adaptive coping mechanisms, active coping and pro-active coping and successful in reducing their stress due to caregiving functions. On the other hand, the caregivers

who lack support from their family members are found to exhibit dysfunctional coping techniques like self-blaming, resorting to substance abuse, denial, withdrawal, emotion focused coping, aggressive outlet of emotions etc. These maladaptive coping mechanisms deteriorate the mental and physical health of the caregivers and also degrade the quality of care provided by them.

Coping Strategies Adopted by Caregivers

A multitude of coping strategies are employed by the caregivers of persons with different psycho-social dysfunctions/disabilities, according to their demands and needs. A study done by Chandonkar et.al (2018) on caregivers of mentally ill persons showed that most commonly used coping style is religious coping and the least used is denial and withdrawal based coping. Most of the caregivers practiced active coping mechanisms, by searching for more information about the illness and various ways of treatment.

One of the important studies done on the coping mechanisms of caregivers of children with developmental disabilities (Gangiwale et.al, 2016) was reviewed by the researcher. The study titled 'Quality of life and coping strategies of caregivers of children with physical and mental disabilities' was done on 116 caregivers of disabled children. Parents of children with autism, cerebral palsy, ADHD, LD, Down's Syndrome, Epilepsy and Mental retardation were included in interviewed. WHO- QoL Brief and Brief- COPE inventory were used to collect data. Active emotional coping was used by most of the caregivers. This was followed by problem focused coping. Both these coping were beneficial for the caregivers in reducing their distress and improving their QoL. The caregivers validate the information and support provided by organizations like special schools in improving their QoL and coping.

‘The emotions and coping strategies of family members with terminal cancer’- a qualitative study conducted on the caregivers of terminal cancer by Grbich et.al, 2018, was another study reviewed by the researcher to understand the coping mechanisms used by caregivers of terminal illness. A stage-by-stage iterative approach was used for a period of 18 months for data collection. Sample size was 20. A minimum of three and a maximum of six monthly sessions were done with each caregiver. Seventeen patients died within the 15 months of data collection. The coping mechanisms during three stages-initial diagnosis, through the experience of caregiving and post bereavement were explored. Each caregiver had a story and length of coping mechanisms she used during the whole spectrum of experience. Being a qualitative study, the research was able to bring the fathom and plurality of coping mechanisms used by the caregivers.

Cooper et.al (2008) opined that the caregivers of Alzheimer’s Disease exhibit strategies that are mainly task-focused; they seem to be more prone to “go toward” the patient, both in the behavioral and emotional sense. The caregivers of chronic neurological and cardio-vascular disorders used emotion focused coping strategies. (Folkman & Lozarus, 1988).

Coping Strategies Adopted by Caregivers of Substance Dependents

Oxford & Gutherie (1968) conducted an empirical investigation on coping behavior of wives of alcoholics to reveal five interpretable components which they labeled attack, withdrawal, protection, acting out, and safeguarding family interests. There are studies exploring the coping styles used by the wives of alcoholic clients. Some of such studies have specifically focused on the determinants of coping styles used. Most of these studies were conducted in the last two decades of twentieth century. Such studies in current Indian context are lacking.

Some prominent researches on the coping behavior of wives of substance dependents in the western context were done by Orford and colleagues from 1996 onwards. One important study needing special mention was that titled 'Tolerate, engage or withdraw: A study of the structure of families coping with alcohol and drug problems in SW England and Mexico City'. This study was successful in bringing forth three main categories of coping seen in the caregivers, namely- tolerate, engage, and withdraw. This lead to the development of a scale to assess the coping styles of wives – Orford's Coping with Drinking Questionnaire- which stands basic to many researches among spouses of substance dependents. Engaged coping is a form of coping in which the wife of alcoholic gets vigorously engaged with her husband through active interaction (arguments, throwing the drinks, restricting the availability of the drink and discussing the negative consequences with the husband). The withdrawal coping involves avoidance of the drinker, active involvement in other self-regulating activities and gaining independence. Tolerant coping is inactive coping by putting up with the problem.

Groenewald & Bhana (2017) conducted a qualitative study on mother's experiences of coping with adolescent substance abuse which came up with some important findings. The research was conducted by using multiple case study approach using phenomenological perspective. Data collection was done through one-to-one interviews of 16 mothers. The mothers used both problem focused and emotion focused coping in the three main categories of tolerating, engaging and withdrawing with the dependent child. Their coping strategies were also influenced by individual and relational factors like subjective distress and mother-adolescent relationship.

A study conducted in Nepal, among the wives of alcohol dependents by Pandey & Shrestha (2020) using modified version of Orford's Coping with Drinking Questionnaire revealed that most of the wives adopted withdrawal based coping as compared with other two categories. The

study was descriptive and exploratory in design and was done on 162 samples. Avoidance, discord, fearful withdrawal and sexual withdrawal were the most common coping components among the wives. The study was limited in the sense of generalizability.

Seeking help is often a difficult process. Marshal (2013) reported that many family members try to cope on their own for a long time before they look for help, and that they feel ashamed when they do so. Family members are reluctant to open the problem up to anyone other than those living in the immediate household. Orford et.al (2010) observes that the reluctance to seek support is related to feelings about what it means to be a good caregiver and the shame that the parent might feel if it was known outside the family.

Coping strategies used by the family members of Indian population are studied sparsely. Almost all such studies were done among the spouses of alcohol or opium dependents. Most of those studies were quantitative and descriptive, limiting the array of responses and the gravity of the experiences (Sharma et.al., 2016).

Coping strategies of spouses of alcohol dependents were studied by Pandey & Shrestha (2020). They conducted a descriptive and exploratory study on the wives of alcohol dependents at Gokarneswor, Kathmandu, Nepal, using the Orford's Coping with Drinking Questionnaire. The results indicated that most of the wives used withdrawal coping, and tolerant coping was least used. Barman, Hiramoni (2019) was another expert researcher who established that socio economic factors (like education, employment, income, type of family) also influenced the coping strategies of wives of alcoholics. He studied 200 wives on the basis of Orford's Coping with Drinking Questionnaire and found out that engagement coping was more used as compared

to tolerant and withdrawal coping strategies. The coping strategies used by the respondents were not similar to those used by the respondents of Pandey & Shrestha (2020) study.

Sharma, N. et.al (2016) conducted a similar study on the wives of alcoholics to understand the problems experienced and the coping strategies used them. The tools used were problems of wives questionnaire and translated version of CDQ. Engagement coping was used more as compared to tolerant coping, which was in turn used more than withdrawal coping.

Coping strategies used by the wives of alcoholics depend on the family atmosphere, behavior of the husbands and personality of the wives (Sebastian, Chinnu & Suja, 2020).

Another significant study was done by Banerjee, Bora & Deuri (2017) on the wives of persons with alcohol dependence. The study was descriptive and exploratory in design. The objectives of the study were to understand the coping strategies and perceived social support of the respondents. The sample size was thirty and the tools used were Ways of Coping Scale and Multidimensional Scale for Perceived Social Support. Adaptive coping such as positive reappraisal, seeking social support and problem solving were used more in comparison with escape avoidance coping. Perceived social support was also high among the wives.

Coping strategies adopted by wives of substance dependents were explored by Singh (2010). He conducted an exploratory and descriptive study on hundred wives of substance dependents. Interview schedule was used as the tool of data collection. Qualitative data was also used in the study. The results suggested that wives tried to control spouse's addiction by explaining, arguing, controlling the environment, taking to religious healers, reporting to local leaders etc. Reporting to Police was not common. Divorce was the least preferred.

Nanjudaswamy, et.al (2020) studied stress, coping strategies and domestic violence in wives of alcohol dependent individuals. The research design was exploratory and descriptive. Sample size was seventy five and tools of data collection were perceived stress scale, coping with drinking questionnaire and domestic violence questionnaire. Avoidance, discord, fearful withdrawal and sexual withdrawal were the most common coping components identified. Domestic violence influences coping styles adopted by the spouses.

Another descriptive study was done to assess the level of stress and coping strategies among wives of alcoholics at selected settings by Devi, Rajsankar & Kokilavani, in 2013. They studied seventy wives using questionnaires prepared by themselves. They observed that active coping strategies were employed by most of the wives.

An exactly opposite result was derived from the study of Chandrasekaran R. & Chitraleka V. (1998), wherein they found that avoidance coping was seen more among wives who are shy and passive. They suggested that modes of coping are related to personality of the wife and situational attributes.

Rao & Kuruvila (1992) studied the coping behavior of wives of alcoholics in detail and proposed that female partner starts behaving like an addict after a period of time. Coping can be viewed in ten distinct behavioral actions: Discord, avoidance, indulgence, competition, anti-drink assertion, sexual withdrawal, fearful withdrawal, taking special action, and marital breakdown. Similar findings were stated by Chakravarthy & Ranganathan (1985) who found that 10 styles of coping behavior were used, of which discord, fearful withdrawal and avoidance were mostly used.

A community participatory study on wives of alcoholics was carried out by Govindappa & Pankajakshi (2014). Community based survey approach was used. Wives employed active

coping techniques like forcing husbands to abstain, controlling their finances and availability of alcohol. But husbands increased the usage of other substances.

Coping Strategies Adopted by Mothers of Young Substance Dependents

The coping strategies adopted by the mothers of young alcohol or substance dependents are not studied essentially and particularly in Indian context. A study done by Hoeck and Van Hal (2012), on experiences of parents of substance abusing young people attending support groups, the coping mechanisms used by mothers of such people are uncovered. It was a qualitative case study of 12 parents. The study records that, initially most of the mothers (9/12) tried to limit the drug use by making some rules about the usage, by exercising punishment or control. This can be seen as a form of engagement with the dependent. Some mothers tried to cover up the drug abuse, gave money to prevent crime or were too frightened to do anything. This is a form of extreme tolerance. After joining the support group, some mothers reported that they were able to distance themselves by engaging in alternative activities and that they began to see to see the problem more logically. These are signs of withdrawal or adaptive coping.

The review indicates that the coping patterns of mothers of young substance dependents have still to be explored.

Axis 7

Parents of Persons with Substance Dependence

Parents of Substance Dependents

The latest global data of substance use/abuse indicate increasing number of adolescents and older children starting to use psychoactive substances and lowering of age of initiation (World Drug Report- 2020). Legalization of cannabis and certain other psychoactive substances in countries like Canada and Uruguay has intensified the usage among the youth. Epidemiological studies from India (National Mental Health Survey, 2015-16) also indicate the prevalence of substance abuse among adolescents and young adults in India. This drift bestows the responsibility and obligation of caregiving on the parents.

Review of literature (published online) on the parents of adolescents and youth, indicate that most of the studies were focused on the etiological perspective (Reiter, 2018; Daley, 2013; Barnard, 2007; Cook, 2001; Zimic & Jakic, 2012; Volk et.al, 1989). Some researchers also focused on interventions to incorporate parents in the treatment programs. (Csiernik, 2016; Klostermann & O'Farrell, 2017; Logan & Marlatt, 2018; McGillicuddy et.al 2018; Usher, Jackson & O'Brien, 2005; Szapocznik et.al 2015; Waldron, 1997). There were only few studies describing the emotional experiences, subjective and emotional burden of parents, social and familial functioning of parents, stigma, coping, and quality of life (Oxford et.al, 1998; Gruber & Taylor, 2006; Baer et.al., 2007; Crowley & Whitmore 2007; Hoeck & Van Hal 2012; Choate 2015; Conyers 2017; Jackson & Mannix, 2012; Reyes & Duchene, 2015; Sawatzky & Fowler-Kerry, 2010; Usher, Jackson & O'Brien, 2017; Zohhadi, Templeton & Velleman, 2014).

Reiter (2018) studied in detail about the substance abuse and the family and published a book titled 'Substance Abuse and the Family', in which he described conflicts undergone by the parents with substance dependence, parental conflicts, personality of the parents and parental substance abuse leading to substance abuse in children. Zimic & Jakic (2012) also have described similar observations in their article 'Familial risk factors favoring drug addiction onset' in Journal of Psychoactive Drugs. Family was viewed in family systems perspective by Volk et.al (1989). In the article on 'Family systems of adolescent substance abusers' in journal Family Relation, they strongly proposed that relations were rigid and enmeshed in families with substance dependent members.

Velleman & Templeton (2009) identified seven areas of family functioning that are impacted by addiction. They are roles, rituals, routines, finances, communications, conflict and social life.

Another important reference was the works done and documented by Usher, Jackson & O'Brrien (from 2005 to 2017). They looked at families with adolescent and youth substance dependents. They document that the experiences of parents across wide range of youth's life- schooling, health, family and social relationships, the effects of which mostly are long term, far-reaching and irreparable. The parents get entrenched themselves in the problems before they become recognized. The duty of managing or resolving the problems falls largely to the parents (Jackson & Mannix, 2012).

Usher and his co-researchers identified eight major themes in how families experienced serious substance abuse in a youth: the process of confirming suspicions; struggling to set limits; dealing with consequences of the drug use on the family; living with blame and shame; trying to keep the child safe; grieving the loss of the child that was; living with guilt; and choosing self-

preservation. Barnard (2005) also found similar wide-ranging impacts in families having youth and adolescents who abuse alcohol/drugs for at least four years in the recent past.

One of the important studies done by Jackson, Usher, & O'Brrien (2006) was a qualitative study on parental perspective of the effects of adolescent drug abuse on the family. The study was done on eighteen parents of drug abusing young people. The findings revealed that the family relationships were fractured and split as a result of the ongoing destructive and damaging behavior of the drug abusing young person. Five themes were identified that captured the concept of fractured families: Betrayal and loss of trust, Abuse, threats and violence, Sibling anger and resentment, Isolated, disgraced and humiliated, and Feeling blamed. The parents perceive that their children (youth) as 'complex, demanding, overwhelming and highly stressful'. They experienced 'ongoing turbulence' in the family and described as being "torn between wanting to provide support for their drug affected child and needing to ensure a stable environment for their other children whose peaceful use of the family home was affected".

One of the noteworthy researches done on parents of substance abusing young people was that by Hoek, S & Van Hal, G in 2012. This was a small scale qualitative study on twelve parents, focusing on their experiences concerning having a substance abusing son/daughter and attending the support group. The study title was 'experiences of parents of substance abusing young people attending support groups. Semi-structured in-depth interviews were carried out with the participants based on previously fixed key themes. Most interviews were conducted at the homes of the participants. Average duration of interviews was 100 minutes. All the interviews were audio- recorded and transcribed. Thematic analysis on the basis of principles of grounded theory was done on the collected information. The main themes on which the data were categorized were –discovery of the drug use of their son/daughter, levels of parent's knowledge about drugs,

communication with son/daughter, sources of information and support, feelings of stress, joining support group, and coping strategies. Majority of the parents (9/12) interviewed were women. All the parents displayed signs of stress and strain. The core emotions that parents had to deal with were feeling worried and anxious (12/12), uncertainty (12/12), low and depressed (11/12) mood, and helplessness and despair (10/12). Most parents also mentioned feeling guilty (9/12). Furthermore, parents' self-image and self-confidence were undermined by their experiences (10/12). Some of the parents (5/12) were victims of physical violence. All parents indicated that home and family life were threatened by the drug abuse. In addition, majority of the parents mentioned strain in their relations with other family members due to the substance abusing son/daughter.

Another path-breaking study in the field was that by Orford and his colleagues (1998) on the parents of alcohol and drug abusing youth. The study was conducted to explore the ways family members cope with drinking or drug problems. 207 family members from separate families of two different socio-cultural group (Mexico and South West England) were interviewed with the help of semi-structured interview schedule and coping questionnaire. Nine distinct ways of coping were identified from the results of interview, which could be described in terms of three broad coping positions- tolerate, engage or withdraw. These conclusions challenged some previous assumptions of behavior oriented family scientists about functional and dysfunctional ways of coping in the families.

Smith & Estefan (2014) did a comprehensive review of published researches from 1937 to 2014 and captured narratives on the experiences of mothers with alcohol and/or drug dependent children. They described that addiction had profound impact on families, but there were barriers

to disclosing or talking about the problems. Divulging the family secrets was seen as harmful, which reinforced the need to protect the secrets. They also felt that the mother carried the heavier burden, as there is a lot of social pressure to be successful in the role of primary caregiver. This work was further carried forward by Smith and her colleagues through studies on the narratives of mothers supporting their adolescents through the process of recovery from addiction. They detailed the experiences of four mothers using life-study approach and phenomenological approach.

Parents found themselves in conflict over how to react and manage the behaviors arising from the substance dependence (Butler & Baud, 2005; Barton, 2011; Rees & Wilborn 1983). Denton & Kampfe (2014), after reviewing available published literature on families and substance abuse from 1956 onwards came to a conclusion that communication between parents was damaged which made problem-solving more challenging as the youths' behaviors grew beyond their management.

Pasek & Vondraskova (2017) proposed that parents of drug abusing youths undergo a cycle of stages characterized by certain psychological reactions (consisting of emotions and cognitions) through their life-long process of caregiving. They are as follows: 1) shock 2) grievance 3)anger 4)guilt 5)negotiating 6)feeling of shame 7)sadness and feeling of fear 8)resignation 9) distastefulness and disgust 10)reconciliation 11)anticipatory anxiety and undue optimism and finally returns to shock when the relapse occurs.

Crowley & Whitmore (2007) describes that substance dependency in youth is different from adult experiences as adolescents and young people have difficulties in analyzing the future

consequences as the development and maturity of brain is not complete. Their beliefs and attitudes reflect their developmental stage; and their physiological responses are reflective of physical development. Concurrent mental health disorders often emerge in the adolescent stage of development, which may complicate the parents' understanding of the issues.

Mothers of Young Substance Dependents

An extensive review of existing literature on the caregivers of substance abusers/dependents was done by the researcher in order to study the male-female representation of caregivers in the researches and reports. In almost all the studies, female caregivers/samples outnumbered that of males (Shekhavat et.al, 2017; Settley, 2020; Gruber & Taylor, 2006; Smith & Estefan, 2014; Mattoo et. al, 2019; Olafsdottir, Hrafnsdottir & Orjasniemi, 2018; Marcon et.al, 2012; Nebhinani et.al, 2013; Kaur et. al, 2018; Shyangwa, Tripathi & Lal, 2008; Ramanujam V. et al. 2017; and so on). This over-representation of women in the research samples jolted curiosity in the researcher and lead to further exploration of reasons and factors influencing this. A Multitude of social, political, psychological and economic factors was contributing to the women's ascribed role as caregiver. This included, not exclusively, the factors like socioeconomic profile, gender, familial and social support, personality, coping and resilience of women caregivers.

Further, from the works of Chaote (2015), Hoeck & Van Hal (2012), Reyes & Duchene (2015), Smith & Estefan (2017), Jackson & Mannix, (2012), Crowley & Whitmore (2007), Conyers (2017), Jackson & Mannix, (2012), Sawatzky & Fowler-Kerry, (2010), Groenewald & Bhana (2017) and Usher, Jackson & O'Brien, (2017), it could be deduced and inferred that mothers who

are the primary caregivers of young substance dependents are in a pitiable plight, needing support from the professional health care providers.

Even though scientific data indicated mothers as more vulnerable and having more distress, they were also pronounced as more influential, supporting and resilient than other family based caregivers of substance dependents (Gruber & Taylor, 2006; Smith & Estepan, 2014; Reyes & Duchene, 2015). Stewart & Brown (2018) has particularly mentioned that including mothers in the treatment of adolescents and youth can improve the treatment outcome as mothers show more perseveration and patience to keep the dependent in therapy, while other significant relatives lose hope. Still, studies focusing on the psychological morbidity, burden, social support, and coping mechanisms of the mothers is deficient, especially in Indian context.

General Characteristics of Mothers of Young Adults

As per the operational definition of the term ‘young adult’, used in this study, the dependents belong to an age range of 18-24, including the lower and upper limits. Their mothers fall in the age group of 40-60, ie. Middle age. Women of middle age are characterized by certain common biological, psychological, social underpinnings. The gradual deterioration of health, changes in the external appearance, hormonal alterations leading to cessation of reproductive functions, and menopause are some of the physical changes. Psychological vicissitudes are changes in attitudes, beliefs, values, patterns of interaction, problem solving skills, coping skills and the boundless experiences. Social changes include the changes in roles and expectations from the society as a spouse, mother, daughter and sibling and as a working women / entrepreneur.

Hurlock (2004) viewed middle-age as a period of transition, stress and evaluation. It demands adjustment to new interests, values, roles and responsibilities and new patterns of behavior, of which, adjustment to changed roles and responsibilities is deemed as most challenging.

Kimmel (2010) stated three major crisis middle-aged women undergoes- parenthood crisis, dealing with aging parents and dealing with death of spouse/ or separation and divorce. The parenthood crisis is when the women realizes that their children are not meeting the social standards of performance or when they fail to perform according to the general expectations of the society, in terms of education, occupation, and socio-occupational functioning.

Mothers of Young Substance dependents

The aforesaid general characteristics are applicable for the mothers of young substance dependents, in addition to the 'caregiver' status. There are plenty of studies in the western literature exploring the health, physical and mental status of parents of teen-aged substance dependents. But there is only flimsy information regarding the mothers in particular, and their physical, psychological and social state of affairs. In addition, there is no valid record/ study on their lived struggles and experiences in the Indian context. However, the available literature can be summarized as follows:

Physical and Psychological Health

As discussed in the previous pages, studies have shown that the primary caregivers of adolescents and young adults with drug abuse suffered from multiple health problems (Ray et.al, 2007). The common physical diseases reported in them are cardiovascular disorders, uterine

cancer, depressive disorders, sleep disorders, anxiety disorders, somatization disorders and so on. Svenson (2019) noted that, there is a steady decline in the health related help seeking behaviors of primary caregivers after the progression of dependence in the family members. This reveals that the caregivers with time start to neglect their physical and psychological health and focus exclusively on the problems emerged out of dependence. Similar patterns are visible in the health status of codependent family members of substance dependents. (Cullen& Carr, 2007; Carson & Baker, 2014). Codependent family member, in the case of young adult is his/her mother.

Social Functioning

The researcher could not identify any particular study about the social functioning of mothers of young substance dependents, but certain factors of social functioning (social support, stigma, social isolation and access to social welfare provisions) has been studied sparsely. Reyes & Duchene (2015) reported that the mothers were found to isolate themselves from social gatherings. Authors like Chaote (2015), Hoeck & Van Hal (2012), Jackson, Usher, & O'Brrien (2006), Smith & Estefan, (2018), Groenewald & Bhana (2017) have also reported similar experiences of mothers who withdraw themselves from their social support providers, especially friends and relatives, in an attempt to hide the problem of addiction in their wards or as losing their interest in earlier pleasurable activities. From their narrations, the shrinking of regular repertoire of activities, social contacts and recreation activities could be interpreted.

Quality of Life

Studies on Quality of Life of mothers of young adults with substance abuse and related disorders are lacking, but QoL of caregivers of substance dependents are documented to be very poor by

various studies. However, there is wide discrepancy in the tool used for assessing QoL, by different researchers.

A study done on the QoL of caregivers of adolescent illicit drug users in Brazil (Marcon et.al, 2017), showed poor QoL among all the caregivers. It was a descriptive study on 109 caregivers of drug addicts, receiving psychosocial care from government centers. QoL was assessed with the help of Medical Outcomes Study 36 – Item Short-Form Health Survey- SF-36. This outcome was supported by the researches done by Copello, Velleman, & Templeton, (2005). But , in their studies they used WHO- QoL or its brief versions.

The concept of QoL is not seen in Qualitative studies, where in detailed descriptions of the life experiences itself is studied through narratives, case studies, in-depth interviews using grounded theory, phenomenological, ethnographic or epistemological approaches (La Rosa, 2005).

Challenges Faced by Mothers of Young Substance Dependents

Following through the narratives of mothers documented by Smith and Estefan (2017), Reyes & Duchene (2015), Chaote (2015), Groenewald & Bhana (2017) and Hoeck & Van Hal (2012), it can be summarized that the challenges faced by the mothers of substance dependents are multi-facet and multifactorial. Some of them can be composed as three main themes- blaming (from others), overcoming the guilt and self-blame, coping with her (own) emotions.

In addition to these main themes, she has to confront with stigma and isolation from the society (Govindappa & Pankajakshi, 2014; Parsakarathy, 2013; Singh, 2010). Restricted social support and instability in financial resources are some of the other prominent challenges (Bhowmick et. al, 2001; Fink, 2015; Taylor, 2011; Gururaj et.al, 2006).

Lack of recognition, validation of emotions, lack of competence of general health care workers including doctors and insufficient resources (human and welfare oriented) were some of the pitfalls from the part of service providers reported by the mothers during interviews (Chaote, 2015, Hoeck & Van Hal, 2012)

Unique Qualities of Mothers of Substance Dependents

McArdle (2016) noted that mothers kept on trying to help their drug-abusing son/daughter whatever it may take, while fathers, from a certain stage, judge it more appropriate to distance themselves. He has also validated the role of mothers in regulating the drug-related behavior of young people. Kaufman (2015) found out that mothers were having an enmeshed relationship with their drug abusing son, while fathers were having disengaged relationship with their daughter or tried to be brutal towards her. Fathers sometimes responded by increasing their alcohol consumption.

Mothers' Experiences of Caregiving

Review of qualitative studies done on parents of adolescents and youth receiving psycho-social treatment for addiction revealed the spectrum of experiences through which caregiving mothers pass by, as the dependence and codependence progress. Chaote (2011) concluded that parents dithers through toleration or normalization, engagement or control, and withdrawal or isolation.

Summary

The entire review of literature can be summarized as follows:

Axis 1 Prevalence

The prevalence of substance use disorders have increased considerably in the post Covid-19 period. This is attributed to many factors like relaxation of lockdown restrictions, economic damages caused by Covid-19, unemployment and mental health challenges. 22.4 percent of Indian population has substance use disorders including alcohol, tobacco and other drugs. Recent studies point out that the age of initiation to psychoactive substances has lowered to early adolescence (12-13 years). Age of developing dependence has also sunk to late second decade or early third decade.

Axis 2 Caregiving and Burden of Caregiving

The concepts of caregiving and burden were studied in this section. The concept of caregiving is recently introduced to the field of substance use disorders. The researcher reviewed caregiving in different contexts and understood that the act of caregiving is demanding and challenging in all contexts, but it is more challenging in the context of substance use disorders. Similarly, the concept of burden was also studied in varied backgrounds. The burden of family based caregivers or family members of substance use disorders is not widely studied abroad as well as in India. However from the available research data, it is clear that the family members of substance dependents suffer severe to extreme burden. The burden experienced by mothers of persons with substance dependence is not yet studied in Indian context.

Axis 3 Family as a Functional Whole

Substance Use Disorders quaver the family structure and functioning in multiple ways. It impacts the role relationships inside the family, weakens the communication patterns, alters boundaries within and between different sub-systems, revises the power distribution and shatters the dynamic equilibrium existing in the families. Research data gives evidences for marital disruption and family conflicts as a result of predominance of substance use in one of the members of the family. Even though the entire family is affected by the dependent's substance intake, the primary care giver is the most affected. Usually, the primary caregiver is wife or the mother of the substance dependent. Wives and parents of the substance dependent is often trapped in vicious circle of codependency and undergo severe burden. In developing countries like India, women are underprivileged. This marginalized status makes them more vulnerable to domestic violence and physical-psycho-social hazards.

Axis 4 Gender

In India, caregiving is considered as a family ritual and obligation, which is usually done by the female folk of the family. So, in most of the researches, regardless of the type of the disease, female caregivers outnumber male counterparts. Many Indian authors state gender based discrimination in context of health care delivery and health practices. Women face greater barriers than man in accessing health care facilities. These barriers are mostly socially constructed. Role of gender in determining the gradation of life experiences of a female primary caregiver is rarely explored in developing countries like India, where social norms and structures play decisive role in individual's life. In substance use disorders also, majority of the caregivers are females –either wives or mothers.

Axis 5 Social Support of Caregivers

The influence of social support on physical health and mental health are well established through researches. There are two main models – buffer effect hypothesis and direct effect hypothesis – stating the impact of social support on health. Gender differences are identified in both providing and seeking social support. Women provide and seek more social support as compared to males and women are also found to benefit more from social support than males. Gendered notions and expectations also influence social support. It plays an important role in managing caregiver burden. There is scarcity of literature studying the social support enjoyed by the parents of substance dependents.

Axis 6 Coping Strategies of Caregivers

Different types of coping strategies are beneficial at different occasions of stressful events. The effectiveness of each coping strategy can only be understood looking on its influence on health of the individual. Studies indicate that there are gender differences in coping. Social norms and standards also influence the coping strategies employed by males and females. Socio-economic status also influences the coping styles of a person. Role of coping skills in determining the mental health, burden and social functioning experienced by the caregivers is studied in various researchers in various contexts. Tolerate, engage and withdraw are the main coping methodologies adopted by many of the caregivers of substance dependents, globally. Coping patterns of the parents of young substance dependents in Indian context is not subjected to serious scientific exploration. Help seeking behaviors of the parents, for their children and for themselves, has also to be understood deeply.

Axis 7 Parents of Persons with Substance Dependence

Most of the studies done about the parents of persons with substance dependence are focused on etiological perspective. There are some studies emphasizing the importance of involving parents in the treatment team. Researches concentrating on the struggles, needs and challenges of parents while caregiving their offspring with substance dependence are very few. The traumatic experiences of the parents are wide ranged and their consequences are mostly long-term and irreparable. Some qualitative researches explore the experiences of parents with youngsters as substance dependents. Majority of the respondents in these studies were women. They give evidences for the abuse and humiliation undergone by the mothers. Such studies in Indian context are very rare. Barriers in treatment/engagement of the parents, diverse needs and expectations of mothers, coping patterns and strengths of parents have to be understood in depth in order to empower mothers to lead their youngsters through the path of recovery.

The summary of findings from the comprehensive review can be briefed as follows:

a) Substance use disorders in adolescents and youth is a pressing problem affecting the parents.
b) Quantitative studies are less effective in detailing the lived experiences of parents, emphasizing the significance of qualitative and mixed approaches
c) Mothers of young substance dependents exhibit more stress and needs more attention
d) Studies focusing on the psychological morbidity, burden, social support, and coping mechanisms of the mothers is lacking.

Conclusion:

Life of mothers along with the substance dependent sons or daughters is challenging and over-draining of physical, psychological and social resources. In-depth study and analysis is essential to understand the complexities of their lived experiences. Both qualitative and quantitative researches are needed to fulfill this objective. Studies focusing the strength, coping and resilience aspects of mothers are essential in order to validate the efforts of mothers. New indigenous models supporting the caregivers have to be evolved and scientifically tested in order to ensure comprehensive treatment of substance use disorders.