

The Impact of Substance Use Disorders on Families and Carers: A Scoping Review

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ABSTRACT

Substance Use Disorder (SUD) is a persistent and global public health and social problem. This scoping review explores and describes the impact that Substance Use Disorders (SUDs) have on families and carers. It draws on 36 research articles published between January 2007 and August 2021. The review findings are presented according to three themes, namely (1) the impact of SUDs on families/ carers, (2) the burden on carers, and (3) coping responses to living with a person with SUD. The evidence indicates that SUDs in a family affects almost all domains of family members' and carers' lives, suggesting the need to develop targeted harm reduction interventions that could reduce vulnerability and help restore the bio-psychosocial well-being of family members and carers.

Keywords: Substance Use Disorders, Carers, Family members, Caregiver burden, Quality of life, Harm reduction interventions, Scoping review

INTRODUCTION

Globally, an estimated 36 million people live with a substance use disorder (SUD) (United Nations Office on Drugs and Crime [UNODC], 2021), a medical diagnosis of the health condition that arises from the harmful use of alcohol and other drugs (Sher & Vergés, 2016). First introduced in the 1950s, the Diagnostic and Statistical Manual of Mental Disorders (DSM) has been revised five times, evolving from what

Strong and Busch (2013) describe as a language for researchers to one in which a particular medicalized view of decontextualized individuals predominates. In the most recent DSM (i.e., DSM-5), substance use disorder (SUD) is understood as a mental disorder in which the use of one or more substances leads to impaired control, social impairment, risky use, and pharmacological dependence (American Psychological Association [APA], 2013) as well as inducing physical and other mental disorders (Hartney, 2022).

As useful as an individual medicalized

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diagnosis of harmful substance use may be for condition identification, its contribution to therapeutic (or indeed criminal and other) responses is less clear; amongst other things, because it does not direct attention toward the physical and mental health, economic and social harms for families and caregivers exposed to SUD (Tabeleáo, Tomasi, & Quevedo, 2014).

Therefore, the rationale for conducting this scoping review was to explore and describe research findings on the impact that SUD has on the carers of people who use substances harmfully (henceforth, PwSUD carers) to develop and evaluate context-specific, evidence-based harm reduction interventions. In this study, PwSUD carers are defined as informal caregivers, such as a relative, spouse, partner, significant other, or friend providing care for a person with SUD (Jackson, 2012). It should be emphasized that in this scoping review, all carers are treated as equally important to inform the program design and development for all PwSUD carers.

This scoping review focused on peer-reviewed literature across the globe on the impact of SUDs on PwSUD carers between January 2007 and August 2021. The scoping review formed part of an extensive intervention research study that commenced in 2017. Hence, articles from 2007 (a decade before the study) up to 2021 (when the intervention was designed) were considered to inform the research process.

MATERIALS AND METHODS

Identifying the research question

The following question directed

this scoping review: *What is the impact of SUD on carers of people with SUD?*

Study Design: Scoping Review

This is a scoping review of available evidence on the impact of SUD on PwSUD carers. It seeks to summarize and describe in detail the findings and range of research as well as identify research gaps in the available literature. A scoping review is “a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge” (Colquhoun, Levac, O'Brien, Straus, Tricco, Perrier, Kastner & Moher, 2014, p. 292).

To undertake the review, the authors were guided by five of Arksey and O'Malley's (2005) six-stage methodological framework, and subsequently enhanced by Levac et al. (2010), namely: (1) identify the research question to guide the scope of inquiry; (2) identify studies from multiple sources that are relevant to the research question; (3) study selection guided by inclusion and exclusion criteria based on the research question; (4) chart the data obtained from the included studies; and (5) collate, summarize, and report the results. Consultation with researchers, experts in the field of interest, and research participants, for additional inputs, was excluded (Levac et al., 2010) because the focus of the scoping review was to map available literature on the identified topic.

Identifying Relevant Studies

The databases of Google Scholar, PubMed, Family and Society Studies Worldwide, Social Work Abstracts, Africa-wide Information, Latin America and Iberia database, and the Southern African Bibliographical Information Network (Sabinet) were systematically searched for peer-reviewed journal articles published in either English or Afrikaans between January 2007 and August 2021. Quantitative, qualitative, and mixed method studies that referred to the impact that harmful substance use, including SUD, has on PwSUD carers were included. Systematic reviews, narrative literature reviews, policy documents, and gray literature were excluded. The above-mentioned databases were selected to cover international biomedical literature from PubMed, as well as social science literature, e.g., Family and Society Studies Worldwide, and Social Work Abstracts. Africa-wide Information and Sabinet were searched to cover and include (South) African literature – the continent where the authors reside. Furthermore, the Latin America and Iberia database was also searched to include studies from the global South that meet the study goals. Search terms included: effects OR impact OR influence AND families OR relatives OR family member OR caregivers OR carer AND substance use disorder OR substance abuse OR dependency OR addiction AND alcohol abuse OR alcohol dependence. The subject directory “NOT” was used to exclude studies on smoking, tobacco, cigarettes, and nicotine. Studies that focused on nicotine were not considered

for this review because service delivery within the (South) African context is directed towards alcohol, medicine, and illegal drugs.

Information Sources and Search

An initial total of 3545 articles (N = 3545) were obtained from the aforementioned databases. These were subjected to a three-phased selection process. During the first phase, the titles of all the articles were screened by the first author using the following inclusion criteria: (1) focus on SUD or substance abuse, (2) focus on families and carers of people with SUD, and (3) the effect or impact of substance abuse/ misuse on carers or families. Titles that fulfilled any two of the above criteria or which the first author was uncertain about were included. In the second phase, abstracts of the selected titles were reviewed taking into consideration the research question as well as inclusion, and exclusion criteria. Articles that were then selected for inclusion reported on the impact of SUDs on families and/or carers, irrespective of whether these were based on the perceptions and experiences of people with SUD or their families and/or carers. Those that were excluded did not relate to the impact of SUD on families and/or carers. A total of 75 articles were advanced to the third, and final, selection phase where the authors read through the full articles. Of these, a total of 39 journal articles were excluded because they did not meet the inclusion criteria, *inter alia* no full text was available (n = 4); they were systematic reviews (n = 5), or their content did not relate to the research question (n = 11). The

remainder (n = 19) were excluded as they focused on co-morbid disorders, risk, and protective factors, harm to the substance user, and family interventions. Accordingly, a total of (n = 36) articles were ultimately included in this scoping review. Neither a quality appraisal of the selected 36 articles nor an assessment for author bias was conducted since this

is a scoping review and not a systematic review (cf. Tricco et al., 2016). Figure 1 shows a flow diagram of the selection process informed by the Preferred Reporting Items for Systematic Reviews extension for Scoping Reviews (PRISMA-ScR) (Peters et al., 2020).

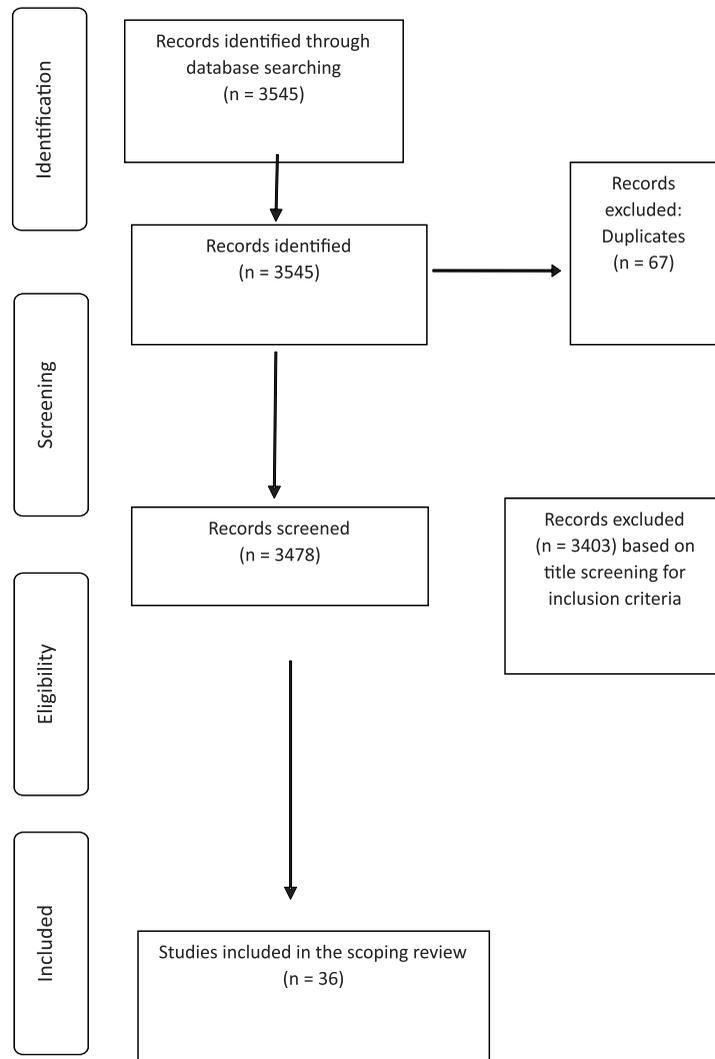


Figure 1: Flow diagram of the selection process informed by PRISMA-ScR

Collating, Summarizing, and Reporting the Results

The first author created a structured table with the charted data that sets out the studies' approaches and characteristics *inter alia* the country and setting where the study was conducted, the study population, the sample size, the research approach, and key findings. The charted data were then examined and interpreted using Creswell and Poth's (2018) thematic analysis spiral. Data were read and tabulated and ideas that emerged during this process were noted (Steps 1 and 2, Creswell & Poth, 2018). The data were then interpreted and classified (Step 3, Creswell & Poth, 2018) yielding three main themes, namely: (1) The impact of SUD on families and carers, (2) the burden on carers, and (3) Coping abilities of family members/ carers of a person living with SUD. The development and assessment of interpretations as well as the representation and visualization of data (Steps 4 and 5) are presented in the results and discussion.

Trustworthiness

The trustworthiness of this scoping review was enhanced by ensuring its credibility, transferability, and dependability. Credibility was ensured by adopting a well-established research method of Arksey and O'Malley (2005), and through frequent consultation among the authors (i.e., peer debriefing) (Nieuwenhuis, 2020). Transferability was enabled by providing a detailed description of the research procedure and process (Nieuwenhuis, 2020). Dependability was achieved by

providing a detailed account of the research design and its implementation, detail on data gathering, and the analysis process (Nieuwenhuis, 2020).

Research Ethics

The research protocol for conducting this scoping review was approved by the Research Ethics Committee of the University of Pretoria, South Africa (GW20180512HS).

Findings

All of the studies were conducted in countries classified by the World Bank as high- and upper/ lower-middle-income countries (Hamadeh, Van Rompaey & Metreau, 2021). Thirteen studies were from high-income countries, namely the USA (n = 5), and Australia (n = 2), and one each from Chile, Germany, Netherlands, Portugal, Denmark, and Sweden; thirteen studies were from middle-income countries, namely Brazil (n = 7), South Africa (n = 3), Trinidad and Tobago (n = 1), and Vietnam (n = 2). In the remaining studies, Iran (n = 2) and India (n = 7) are classified as lower-middle-income countries. One study re-examined existing data from 26 countries on gender and country differences in the negative consequences of drinking alcohol. Study populations ranged from substance users and family members (n = 6) to caregivers/ significant others/ family members of the people with SUD (n = 9) to people with SUD in treatment (n = 4) or in recovery (n = 1). One study included school learners (adolescents) and their parent(s)/ caregiver(s). Two studies included school learners (adolescents) and their parent(s)/

caregiver(s). Some studies exclusively focused on female family members and spouses of people with alcohol or psychoactive substance dependence (n = 9).

Twenty-four studies were quantitative, using instruments such as the *Perceived Caregiver Burden Scale* (Stommel et al., 1990), the *Zarit Burden Interview Scale* (ZBI) (Zarit et al., 1985), and the *Caregiver Burden Scale* (CBS) (Gerritsen & Van der Ende, 1994) to determine caregiver burden. Analytically, one study ran a logistic regression to determine whether family members of persons with SUD were more vulnerable to medical conditions. Another longitudinal evaluation implemented repeated observations over time to determine the effectiveness of a family-based adolescent substance abuse prevention program, specifically its impact on improving parental mental health and family functioning. The multi-country study involved multi-level analyses of survey data to explore gender and country differences

concerning the consequences for family members or caregivers of people with harmful alcohol use. Twelve studies were qualitative and focused on gaining an in-depth understanding of the impact of SUD and alcohol dependency on families. Semi-structured interviews were conducted to gain an understanding of the lived worlds of the participants.

Other data that were extracted include findings on the physical, psychological, and social impact of SUD on PwSUD carers, the burden that carers are faced with, and the coping abilities of PwSUD carers.

The Impact of SUDs on Families/Carers

From the studies in the scoping review, the following sub-themes were generated to describe the impact of SUD on families and carers: the physical impact of SUDs on families/ carers, the psychological/ emotional impact of SUDs on families/ carers, and the social impact of SUDs on families/ carers.

The physical impact of SUDs on families/ carers.

Several studies identified SUD-associated family stressors that were linked to physical effects (Kraus et al., 2009; Li et al., 2013; Maharaj et al., 2017; Ray et al., 2009). These included declining physical health, weakness, dehydration, hypertension, migraines, ulcers, acid reflux, and lowered immunity (Biegel et al., 2007; Melo et al., 2019; Mangueira & Lopes, 2016; Soares & Pereira, 2015). Carers of people with SUD also reported chronic conditions such as heart disease/ attack, cancer, Type 2 diabetes, and arthritis (Soares & Pereira, 2015). SUD in the family was also found to lead to interpersonal violence and injuries (Dandu et al., 2017; Kraus et al., 2009; Marcon et al., 2012). Generally, family members of people living with SUD reported significantly more physical complaints (Shamsael & Cheragi, 2019), including sleep disturbances and ignoring their physical health (Sharma et al., 2016).

Psychological/ emotional impact of SUDs on families/carers.

In terms of psychological well-being and mental health, family members of people living with SUD were prone to

insomnia and anxiety, distress, loss, grief, internalized blame and shame, anger, depressive symptoms, irritable moods, feeling fear, disappointment, and a sense of worthlessness and powerlessness (Hellum et al., 2021; Hlungwani et al., 2020; Hussaarts et al., 2011; Li et al., 2013; Manguiera & Lopes, 2016; Marcon et al., 2012; Ray et al., 2009; Richert et al., 2018; Schultz & Alpaslan, 2016; Usher et al., 2007). These family members experienced greater depression (Mammen et al., 2015; Shamsael & Cheragi, 2019) and a greater number of psychiatric morbidities such as depressive and anxiety symptoms (Gandhi et al., 2017; Shah et al., 2017) in comparison to the general population, as did caregivers, with 39% of carers (n = 82) in one study being at risk for major depressive disorder (Biegel et al., 2010). Family members also reported feeling frustrated, and constantly feeling emotionally drained and exhausted by the daily challenges that arise from their relatives' behaviors (McCann et al., 2019). SUD generally diminished family members' quality of life (QOL) (Li et al., 2013).

Social impact of SUDs on families/carers.

Several studies (Kraus et al., 2009; Li et al., 2013; Maharaj et al., 2017; Ray et al., 2009) found that SUD-linked job instability, unreliability, failure to fulfill marital or parental responsibilities, challenging interpersonal relationships, and financial strain caused by income loss and the struggle to cover treatment costs and legal and drug debts (McCann,

2019) stressed family relationships. The greatest vulnerability in a study by Reis et al. (2017) is substance users' access to work and income resulting in financial constraints. These led to severe familial disruption, including tension in the family, deterioration in family relationships, dissatisfaction with their relationships with the user, low marital satisfaction disturbed family dynamics, marital conflict, and disruption in family routine, interactions, and leisure (Chaturvedi et al., 2019; McCann, 2019). Violence as a result of the substance user's uncontrolled and unpredictable behavior was found in several studies which creates fear, insecure living environments and lack of security in households, and possible further social isolation due to feelings of shame (Dandu et al., 2017; Hellum et al., 2021; Maghsoudi et al., 2019; Melo et al., 2019; Rodrigues et al., 2018; Shah et al., 2017).

SUD in the family was also found to have broader societal consequences for members, including stigmatization, loss of social standing, humiliation, and embarrassment, criminality, imprisonment, and lack of tangible support (Droege et al., 2015; Hlungwani et al., 2020; Kumar Mattoo et al., 2013; Lee et al., 2015; Li et al., 2013; Maharaj et al., 2017; Manguiera & Lopes, 2016; Rodrigues et al., 2018; Schultz & Alpaslan, 2016; Shamsael & Cheragi, 2019; Tshweneagae et al., 2016). Social isolation in the family results from the fear of stigmatization (Maghsoudi et al., 2019). Rodrigues et al. (2018) indicate reduced use of services due to stigmatization by health professionals. Other barriers to accessing professional

services include a lack of information related to addiction, being unaware of available services, having limited support networks, and feeling dissatisfied with professional support (Dias et al., 2020; Reis et al., 2017). They rather seek religious help, join self-help groups and engage in psychosocial therapy, and increased spiritual practices (Melo et al., 2019; Rodrigues et al., 2018)

Burden on Carers

The impacts on family members of people with SUD as described above bring with it a substantial burden for family members (Kumar Mattoo et al., 2013) and is an outcome of the effects of SUD on families. In this paper, 'burden' is defined as 'an objective or subjective impact, pressure, or overload on carers' (Da Silva et al., 2012, p. 270). An analysis of the studies found that they reported on predictors of burden, the subjective and objective nature of burden, vulnerability to a burden, and coping strategies.

Predictors of burden.

Predictors of burden were found to be feelings of shame, anger, and general tension that include feelings of responsibility, exhaustion, facing problems difficult to resolve, injuries, and lack of time (Marcon et al., 2012). Other predictors of burden include behavioral problems of the person with SUD (such as theft, violence, crime, limited access to work and income), and the lack of perceived social support, both formal and informal (Biegel et al., 2007; Moore et al., 2011). Greater

behavioral problems of the person with SUD predict higher levels of burden (Moore et al., 2011). The behavioral problems of the person with SUD are unpredictable and uncontrollable which leads to adverse effects and distress resulting in the carer pursuing more responsibility in the household to restore the equilibrium. These were found to often negatively affect caregivers' perception of their QOL and compromise the relationship with the user (Marcon et al., 2012). Other family relationships are also characterized by tension and dysfunctional dynamics due to the care being provided to people with SUD (De Oliveira & De Oliveira Lopez, 2016; Li et al., 2013; Maharaj et al., 2017). Families of people with SUD especially experience challenges related to familial functioning within the domains of cohesion, communication, support, and organization (Burstein et al., 2012 in Schultz & Alpaslan, 2016).

Subjective and objective burden.

Some studies distinguished between subjective and objective carer burden (Biegel et al., 2007; Moore et al., 2011). Subjective burden included worry, stigma, and displeasure (feelings/emotions) while objective burden included impact/disruption to the family. It is noteworthy that Biegel et al. (2007) found that behavioral problems of the person with SUD are the only predictor of more than a single type of burden. Problematic behavior reported in their study included managing money, boredom, over-dependence, irritability, dishonesty, mood swings, being anxious or worried, and displaying feelings of

depression or extreme sadness. The carer, therefore, has increased responsibility towards the family due to the turbulences resulting from the problematic behavior of people with SUD. Using the *Zarit Burden Scale* to assess the impact of care activities on social, physical, and emotional well-being as well as the economic status of caregivers, two studies (Biegel et al., 2007; Moore et al., 2011) found that family carers experienced moderate levels of two types of subjective burden, namely worry, displeasure and lower levels of stigma and low levels of objective burden (impact).

Vulnerability to burden.

Vulnerability to the burden of care is not equally distributed. Being female is a universal socio-demographic characteristic associated with higher levels of burden, with the stressors related to SUDs caregiving in women being significantly linked to increased burden (Biegel et al., 2007, 2010; Moore et al., 2011). Other socio-demographic characteristics found to be associated with care burden vulnerability are having lower levels of education, living in low-income and rural communities, having pre-existing physical health problems, and caring for people with alcohol and opioid dependence (Kumar Mattoo et al., 2013; Tabeleáó et al., 2014).

Coping Responses to Living with a Person with SUD

Some common, maladaptive coping responses among family members and carers who live with people who have

SUD include self-distraction, denial, venting negative emotions, starting to use substances themselves, behavioral disengagement, and self-blame (Carver, 1997 in Moore et al., 2011). Understood as maladaptive coping because they heighten a person's levels of stress and anxiety (Carver, 1997 in Moore et al., 2011), these kinds of responses were found to increase as behavioral problems, risky lifestyle, dysfunctional family relationships, and other stressors increased (Biegel et al., 2010; Moore et al., 2011; Schultz & Alpaslan, 2016; Sharma et al., 2016; Usher et al., 2007). However, more adaptive coping including avoidance of the person with SUD and being supportive by finding a treatment or other solutions (Schultz & Alpaslan, 2016) was not found to moderate the burden of care as a family coping only functions as a partial mediator of familial well-being (Soares & Pereira, 2015). The most commonly employed coping strategies of families include withdrawal coping (avoidance and focusing on own life) and engaged coping styles (talking about the drinking, pleading for not drinking, and arguing); tolerant coping was less used which include actions such as enabling and making excuses on behalf of the person with SUD (Sharma et al., 2016). Seeking assistance to deal with SUD-related problems in the household is also a coping response in an attempt to improve well-being and reduce burden. Families rather access support from religious entities, self-help support groups, and psychosocial therapy (Melo et al.; 2019; Rodrigues et al., 2018). They are less inclined to access professional

SUD services due to a fear of stigmatization by health professionals or a lack of knowledge of available services (Dias et al., 2020; Reis et al., 2017; Rodrigues et al., 2018).

DISCUSSION

The multidimensionality of SUD makes it both a chronic mental disorder in which there are treatment lapses and recurrence and a social condition that has negative ramifications for the health and well-being of family members and carers of people who use substances.

The evidence from this scoping review indicates that living with and/ or caring for a person with SUD triggers or exacerbates physical illness and disease among family members and carers. It also causes them social, psychological, and emotional harm that impinges on the individual and collective quality of life. Many suffer from heightened anxiety and stress, reduced social standing, and disrupted interpersonal, working, and community relationships. Many also have low self-esteem, feel worthless and powerless, and are often unable to implement effective coping strategies. Moreover, because of the neurological nature of the disorder, the harmful effects of SUD on family members and carers are often enduring, repetitive, and cumulative (Lindeman et al., 2021).

Family members and carers remain largely neglected or marginal to therapeutic responses directed towards people with SUD even though interventions are often recommended by the reviewed studies. Beyond

reiterating their call to address the impacts of living with and caring for a person with SUD, this scoping review surfaces possible domains for intervention. It highlights that the burden of care is extensive, is borne predominantly by women, and is at its most onerous when there are behavioral problems in people with SUD (cf. Moore et al., 2011). Coping strategies are often maladaptive, add to familial stress, individual anxiety, and carer burden (cf. Carver, 1997 in Moore et al., 2011), and need to be considered with other variables to reduce the burden of care.

By distilling stressors, the nature, extent, and socio-demographic characteristics of the burden of care as well as the coping responses of family members and carers, it is possible to target and respond to their vulnerabilities in ways that empower, sustain, and help restore their psychological well-being and general health.

For interventions to reduce the SUD burden of care, three things need to happen. The tenets of harm reduction need to be extended to family members and carers of people with SUD. The harms associated with SUD need to be assessed. The identified harms of SUD on carers and family members need to be addressed to help them improve their well-being and quality of life. Van Wormer and Davis (2018) and Stein and Manyedi (2016) state that harm reduction has long been considered a practice in the field of addiction because it is evidence-based and focuses on informed decision-making based on people's needs and abilities to make small, incremental changes that reduce their vulnerabilities. It

furthermore empowers them to act in ways that contribute to improving their health and well-being (Van Wormer & Davis, 2018:321; Stein & Manyedi, 2016:836). Beyond substance use, precepts of harm reduction are also embedded in different clinical medicine, allied health, and psychology disciplines and fields and increasingly are being considered as an approach to professional practice in social work (Valharia et al., 2017). There is a need for multi-professional, multi-sectoral mobilization and cooperation. This requires that clinicians and healthcare workers are equipped to identify the context of SUD burden of care to better respond to carers' and family members' physical (cf. Kraus et al., 2009; Li et al., 2013; Maharaj et al., 2017; Ray et al., 2009) and mental health conditions, including injuries caused by interpersonal violence (cf. Hlungwani et al., 2020; Hussaarts et al., 2011; Li et al., 2013; Manguera & Lopes, 2016; Marcon et al., 2012; Ray et al., 2009; Richert et al., 2018; Schultz & Alpaslan, 2016; Usher et al., 2007). Similarly, it requires social workers, and social auxiliary workers, including counselors, to have a deeper understanding of the SUD burden of care to provide services to and facilitate carers' and family members' abilities to cope better with the deterioration in interpersonal relationships, financial strain, and stigmatization that comes with living with a person with SUD (cf. Kraus et al., 2009; Li et al., 2013; Maharaj et al., 2017; Ray et al., 2009). It also requires that all interventions are organized in a way that enables inter-professional cooperation

and patient/ family-centered care coordination (Hugo et al., 2020). There is also a need to identify or create harm reduction interventions that concretely address the SUD burden of care for family members and carers.

Implications for Practice

There is a need to reorient social, health, care, and allied services, both within and beyond the field of SUD, to meet the service needs of carers of people with SUD.

Practitioners and systems need to know what a harm reduction approach to SUD burden of care entails. This, in turn, requires that meaningful interventions are identified or generated and then tested and applied in a targeted way to address the needs of carers and other vulnerable family members. The wide range of existing therapeutic expertise across a range of disciplines and fields can contribute significantly to this process.

Practitioners also need to know how a harm reduction approach to SUD to reduce the burden of care, can be practiced. This involves exposing them to further education and training to develop skills and competencies that may be lacking.

Implications for Future Research

The scoping review points to the need for further research in several areas. The SUD burden of care and the health and social impacts of harmful substance use on family members and carers in low-income countries and poor communities within middle and high-income countries is not well elaborated. There also is a

need to get a deeper understanding of SUD's burden of care effects on self-efficacy and agency over time to understand their impact on the life chances and overall health and well-being of individuals affected by SUD. There is a need to investigate the multiplicity of non-SUD harm reduction interventions to ascertain their potential relevance for family and carer SUD burden relief. There is an imperative to designing and testing harm reduction interventions to determine their efficacy in addressing the SUD burden of care and the physical and mental health of family members and carers.

CONCLUSION

Limitations of this scoping review include possible errors in the interpretation of the strength of evidence because the quality of studies was not appraised (Goldstein, Venker & Weng, 2017). Some findings may have been missed even though several databases were consulted, as only one search per database was conducted and only studies published in English and Afrikaans were included. Consultation with relevant stakeholders such as professionals in the field of SUD working with families was also precluded from the scoping review. Despite these limitations, the scoping review generated a synthesis of evidence on the topic, with broad findings from a wide range of studies that drew on a variety of designs and methodologies. Generally, it found that PwSUD carers face particular substance use-related

stressors that lead to poor physical and mental functioning, marginalized daily living, and a compromised QOL. Despite evident health and care needs, they remain largely neglected or marginal to therapeutic responses directed toward people with SUD. This needs to change. By distilling stressors, the nature, extent, and socio-demographic characteristics of the burden of care as well as the coping responses of family members and carers, this scoping review found that there is a possibility to develop targeted harm reduction interventions that could reduce PwSUD carers' vulnerability and help restore their bio-psychosocial well-being.

REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)*. Washington, DC: APA.
- American Psychological Association. (2010). *Family members of adults with substance abuse problems*. <http://www.apa.org/pl/about/publications/caregivers/practicesettings/intervention/substanceabuse.aspx>
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32. <https://doi.org/10.1080/1364557032000119616>
- Biegel, D. E., Ishler, K. J., Katz, S., & Johnson, P. (2007). Predictors of burden of family caregivers of women with substance use disorders or co-occurring substance and mental disorders. *Journal of*

- Social Work Practice in the Addiction*, 7(1/2), 25-49. https://dx.doi.org/10.1300/J160v07n01_03
- Biegel, D. E., Katz-Saltzman, S., Meeks, D., Brown, S., & Tracy, E. M. (2010). Predictors of depressive symptomatology in family caregivers of women with substance use disorders or co-occurring substance use and mental disorders. *Journal of Family Social Work*, 13(2), 25-44. <https://doi.org/10.1080/10522150903437458>
- Canadian Centre on Substance Abuse (CCSA). (1996). *Harm reduction: Concepts and practice: A discussion paper*. <http://www.ccsa.ca/pweb/cgi/fastweb.exe?getdoc+view1+General=507+6++harm%20reduction%20defined>
- Center for Substance Abuse Treatment. (2012). Brief interventions in substance abuse treatment. In *Brief Interventions and Brief Therapies for Substance Abuse*. Rockville (MD): Substance Abuse and Mental Health Services Administration (US). <https://www.ncbi.nlm.nih.gov/books/NBK64950/>
- Chaturvedi, R., & Maheshwari, S. K. (2019). Marital satisfaction among wives of alcoholic husbands residing in selected villages. *Int J Therapeut Appl*, 36, 1-5.
- Colquhoun, H. L., Levac, D., O'Brien, K. K., Straus, S., Tricco, A. C., Perrier, L., Kastner, M., & Moher, D. (2014). Scoping reviews: Time for clarity in definition, methods, and reporting. *Journal of Epidemiology*, 67(12), 1291-1294. <https://doi.org/10.1016/j.jclinepi.2014.03.013>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: choosing among five approaches* (4th ed.). Sage.
- Dandu, A., Bharathi, S., & Dudala, S. R. (2017). Psychiatric morbidity in spouses of patients with alcohol related disorders. *Journal of family medicine and primary care*, 6(2), 305
- Da Silva, L. B. L., Ivo, M. L., De Souza, A. S., Pontes, E. R. J. C., Pinto, A. M. A. C., & De Araujo, O. M. R. (2012). The burden and quality of life of carers of sickle cell anaemia patients taking hydroxyurea versus those not taking hydroxyurea. *Rev Bras Hematol Hemoter*, 34(4), 270-274.
- Dias, L. M., Alves, M. d. S., Pereira, M. O., de Melo, L. D., de Assis, Camila Cristina Gregório, & Spindola, T. (2021). Health personnel, family relationships and codependency of psychoactive substances: A phenomenological approach. *Revista Brasileira De Enfermagem*, 74(1), 1-9. <https://doi.org/10.1590/0034-7167-2020-0309>
- Droege, J. R., Stevens, E. B., & Jason, L. A. (2015). Children's impact on adult's substance use problem awareness and treatment optimism: The role of harm. *Journal of Drug Education*, 45(3/4), 185-194. <https://doi.org/10.1177/0047237915612172>
- Dussailant, F., & Fernandez, M. (2015). Alcohol's harm to others' well-being and health: A Comparison between Chile and Australia. *Alcohol and Alcoholism*, 50(3), 346-351.

- <https://doi.org/10.1093/alcac/agv002>
- Flyckt, L., Fatouros-Bergman, H., & Koernig, T. (2015). Determinants of subjective and objective burden of informal caregiving of patients with psychotic disorders. *Int J Soc Psychiatry, 61*(7), 684-692. <https://doi.org/10.1177/0020764015573088>.
- Gandhi, R., Suthar, M., Pal, S., & Rathod, A. J. (2017). Anxiety and depression in spouses of males diagnosed with alcohol dependence: a comparative study. *Archives of Psychiatry and Psychotherapy, 4*, 51-56.
- Goldstein, A., Venker, E., & Weng, C. (2017). Evidence appraisal: a scoping review, conceptual framework, and research agenda. *Journal of the American Medical Informatics Association, 24*(6), 1192-1203. <https://doi.org/10.1093/jamia/ocx050>
- Graham, K., Bernards, S., Knibbe, R., Kairouz, S., Kuntsche, S., Wilsnack, S. C., Greenfield, T. K., Dietze, P., Obot, I., & Gmel, G. (2011). Alcohol-related negative consequences among drinkers around the world. *Addiction, 106*, 1391-1405. <https://doi.org/10.1111/j.1360-0443.2011.03425.x>
- Hamadeh, N., Van Rompaey, C. & Metreau, E. (2021). *New World Bank country classifications by income level: 2021-2022*. <https://blogs.worldbank.org/opendata/new-world-bank-country-classifications-income-level-2021-2022>
- Hartney, E. (2022, January 27) DSM 5 Criteria for Substance Use Disorders. *Verywellmind*. <https://www.verywellmind.com/dsm-5-criteria-for-substance-use-disorders-21926>
- Hellum, R., Bilberg, R., & Nielsen, A.S. (2021). "He is lovely and awful": The challenges of being close to an individual with alcohol problems. *Nordic Studies on Alcohol and Drugs, 39*(1), 89-104. <https://doi.org/10.1177/14550725211044861>
- Hlungwani, E. N., Ntshingila, N., Poggenpoel, M., & Myburgh, C. P. H. (2020). Experiences of parents with an adolescent abusing substances admitted to a mental health institution in Giyan, South Africa. *Curationis, 43*(1), 1-9. <https://doi.org/10.4102/curationis.v43i1.2139>
- Hugo, J., Maimela, T., Janse van Rensburg, M., Heese, J., Nakazwa, C. E., & Marcus, T. S. (2020). The three-stage assessment to support hospital-home care coordination in Tshwane, South Africa. *African journal of primary health care and family medicine, 12*(1), e1–e10. <https://doi.org/10.4102/phcfm.v12i1.2385>
- Humeniuk, R., Henry-Edwards, S., Ali, R., Poznyak, V., & Monteiro, M. (2010). *The assist-linked brief intervention for problematic substance use: a manual for use in primary care*. http://act-eassist.org.au/pdfs/Brief_Interventi

- on_self_training_manual.pdf
 Husaarts, P., Roozen, H. G., Meyers, R. J., Van de Wetering, B. J. M., & McCrady, B. S. (2011). Problem areas reported by substance abusing individuals and their concerned significant others. *The American Journal on Addictions*, 21, 38-46.
<https://doi.org/10.1111/j.1521-0391.2011.00187.x>
- Kraus, L., Baumeister, S. E., Pabst, A., & Orth, B. (2009). Association of average daily alcohol consumption, binge drinking and alcohol-related social problems: Results from the German Epidemiological Survey of Substance Abuse. *Alcohol and Alcoholism*, 44(3), 314-320.
- Kumar Mattoo, S., Nebhinani, N., Kumar, B. N. A., Basu, D., & Kulhara, P. (2013). Family burden with substance dependence: A Study from India. *Indian Journal of Medical Research*, 137(4), 704-711.
- Lee, S. J., Li, L., Lin, C., & Tuan. L. A. (2015). Challenges facing HIV-positive persons who use drugs and their families in Vietnam. *AIDS Care*, 27(3), 283-287.
<https://doi.org/10.1080/09540121.2014.963015>
- Li, L., Tuan, N. A., Liang, L., Lin, C., Farmer, S. C., & Flore, M. (2013). Mental health and family relations: Correlated reports from people who inject drugs and their family members in Vietnam. *International Journal of Drug Policy*, 24(6), 1-11.
<https://doi.org/10.1016/j.drugpo.2013.06.007>
- Lindeman, S. K., Titlestad, K. B., Lorås, L. & Bondas, T. (2021). An unknown invisible intrusion. Impact of an adult family member's problematic substance use on family life: a meta-ethnography. *Drugs: Education, Prevention and Policy*.
<https://doi.org/10.1080/09687637.2021.1943316>
- Maghsoudi, J., Alavi, M., Sabzi, Z., & Mancheri, H. (2019). Experienced Psychosocial Problems of Women with Spouses of Substance Abusers: A Qualitative Study. *Open Access Macedonian Journal of Medical Sciences*, 7(21), 3584.
- Maharaj, R. G., Motilal, M. S., Babwah, T. Nunes, P., Brathwaite, R., Legall, G., Reid, S. D., Canavan, M. E., & Bradley, E. H. (2017). National Alcohol Survey of household in Trinidad and Tobago (NASHTT): Alcohol use in households. *BMC Public Health*, 17, 347-355.
<https://doi.org/10.1186/s12889-017-4266-z>
- Mammen, P. M., Thilakan, P., & Solomon, S. (2015). Pattern of psychiatric morbidity in spouses of patients with alcohol dependence syndrome. *Journal of Evolution of Medical and Dental Sciences*, 4(71), 12309-12316.
- Mangueira, S. O., & Lopes, M. V. O. (2016). Clinical validation of the nursing diagnosis of dysfunctional family processes related to alcoholism. *Journal of Advanced Nursing*, 72(10), 2401-2412.
<https://doi.org/10.1111/jan.12999>
- Marcon, S. R., Rubira, E. A., Espinosa, M. M., Belasco, A., & Barbosa, D. A. (2012). Quality of life and stress in caregivers of drug-addicted people.

- Acta Paulista de Enfermagem*, 25(2), 7–12.
- Marlatt, G. A., & Witkiewitz, K. 2010. Update on Harm-Reduction policy and intervention research. *Annual Review of Clinical Psychology*, 6, 591-606.
- McCann, T. V., Polacsek, M., & Lubman, D. I. (2019). Experiences of family members supporting a relative with substance use problems: a qualitative study. *Scandinavian Journal of Caring Sciences*, 33, 902-911.
<https://doi.org/10.1111/scs.12688>
- Melo, C.F. & Cavalcante, I.S. (2019). Codependency in relatives of alcohol addicts. *Journal of Fundamental Care Online*, 11:304-10. DOI:
<http://dx.doi.org/10.9789/2175-5361.2019.v11i2.304-310>
- Moore, B. C., Biegel, D. E., & McMahon, T.J. (2011). Maladaptive coping as a mediator of family stress. *Journal of Social Work Practice in Addiction*, 11(1): 17-39.
<https://doi.org/10.1080/1533256X.2011.544600>
- Nieuwenhuis, J. (2020). Analysing qualitative data. In K. Maree (Ed.), *First steps in research* (3rd ed., pp. 118-153). Van Schaik.
- Peters, M. D., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., ... & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI evidence synthesis*, 18(10), 2119-2126.
<https://doi.org/10.1097/XEB.0000000000000277>
- Ramlagan, S., Peltzer, K., & Matseke, G. (2010). Epidemiology of drug abuse treatment in South Africa. *South African Journal of Psychology*, 16(2), 40-49.
- Ray, G. T., Mertens, J. R., & Weisner, C. (2009). Family members of persons with alcohol or drug dependence: Health problems and medical cost compared to family members of persons with diabetes and asthma: Family members of persons with AODD. *Addiction*, 104(2), 203-214.
<https://doi.org/10.1111/j.1360-0443.2008.02447.x>
- Reis, L.M. & Oliveira, M.L.F. (2017). Social vulnerability in families living with long-term addictive behavior. *Acta Paulista de Enfermagem*, 30(4), 412-19.
- Richert, T., Johnson, B., & Svensson, B. (2018). Being a parent to an adult child with drug problems: negative impacts on life situation, health, and emotions. *Journal of Family Issues*, 39(8), 2311-2335.
<https://doi.org/10.1177/0192513X17748695>
- Rodrigues, T., Sanches, R., Oliveira, M., Pinho, L. B., & Radovanovic, C. (2018). Feelings of families regarding drug dependence: in the light of comprehensive sociology. *Revista brasileira de enfermagem*, 71(suppl 5), 2272–2279.
<https://doi.org/10.1590/0034-7167-2018-0150>
- Schultz, P., & Alpaslan, A.H. (2016). Our brothers' keepers: Siblings abusing chemical substances living with non-using siblings. *Social Work/Maatskaplike Werk*, 52(1), 90-

112. <https://dx.doi.org/10.15270/52-1-481>
- Shah, V. A. S., Behere, P., Mishra, K.K., Sharma, A. & Kumar, K. (2017). Psychiatric Morbidity among Spouses of Men with Alcohol Dependence. *International Journal of Recent Surgical and Medical Sciences*, 3(1), 10-14.
- Shamsael, F., & Cheragi, F. (2019). The impact of substance abuse on family members' mental health status. *Current Drug Research Reviews*, 11(2), 1-6.
<http://doi.org/10.2174/25899775511666190319162901>
- Sharma, N., Sharma, S., Ghai, S., Basu, D., Kumari, D., Singh, D., & Kaur, G. (2016). Living with an alcoholic partner: Problems faced and coping strategies used by wives of alcoholic clients. *Industrial Psychiatry Journal*, 25(1), 65.
- Sher, K. J., & Vergés, A. (2016). Introduction and overview. In K. J. Sher (Ed.), *The Oxford handbook of substance use and substance use disorders*. Oxford University Press.
- Strong, T., & Busch, R. 2013. DSM-5 and Evidence-Based Family Therapy? *Australian and New Zealand Journal of Family Therapy*, 34(2), 90-103.
- Soares, A., & Pereira, M. G. 2015. Cortisol, family coping and burden in informal caregivers of addicts. *International Journal of Psychology and Neuroscience*, 1(1), 114-134.
- Tabeleão, V. P., Tomasi, E., & Quevedo, L. (2014). Burden on relatives of people with psychic disorder: levels and associated factors. *Revista De Psiquiatria Clinica*, 41(3): 63-66.
<https://doi.org/10.1590/0101-60830000000012>
- Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K., Colquhoun, H., Kastner, M., et al. (2016). A scoping review on the conduct and reporting of scoping reviews. *BMC Medical Research Methodology*, 16(1), 15.
<https://doi.org/10.1186/s12874-016-0116-4>
- Tshweneagae, G. T., Mzolo, M. P., & Sibanda, S. (2016). Am I supporting his addiction: The dilemma of having an adolescent son on drugs. *African Journal for Physical Activity and Health Science*, 23(1), 69-76.
- Vakharia, S. P., & Little, J. (2017). Starting Where the Client Is: Harm Reduction Guidelines for Clinical Social Work Practice. *Clinical Social Work Journal*, 45, 65–76.
<https://doi.org/10.1007/s10615-016-0584-3>
- United Nations Office on Drug and Crime. (2021). World drug report 2021. United Nations Publication, Sales No. E.21.XI.8.
- Usher, K., Jackson, D., & O'Brien, L. (2007). Shattered dreams: Parental experiences of adolescent substance abuse. *International Journal of Mental Health Nursing*, 16, 422-430.
<https://doi.org/10.1111/j.1447-0349.2007.00497.x>
- Yuen, E., & Toumbourou, J. W. (2011). Does family intervention for adolescent substance use impact parental wellbeing? A longitudinal evaluation. *The Australian and New Zealand Journal of Family Therapy*, 32(3), 249-263.