

## A Call for Community Compassion: Recognizing and Supporting the Wellbeing of Caregivers in Alcohol Use Disorder Rehabilitation

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### Abstract

*This research delves into the multifaceted challenges faced by Alcohol Use Disorder (AUD) caregivers in India, examining the impact on their Quality of Life (QOL). The study reveals physical, psychological, social, and environmental impacts. The caregiver's enhanced QOL is a crucial determinant of successful treatment at the micro level and holds wide ranging effects on public health and the economy at the macro level. Recognizing and addressing caregivers' needs is vital for a comprehensive response to the AUD epidemic, advocating a paradigm shift towards family-centered treatment approaches to foster a society that values and supports caregivers.*

### Introduction

Across the globe and among all societies, the role of caregivers is critical. The act of caregiving is not unfamiliar, but the term “caregiving” is relatively not that old, with the first recorded use of the word in 1966 (Caregiving, 2010). Caregiving is “the process of helping another person who is unable to do for themselves in a holistic manner” (Hermanns & Smith, 2012). In the context of chronic psychological illness, caregiving can be perceived as providing an elevated level of support that exceeds the limits of ordinary care. The concept was originally introduced in the context of schizophrenia and coincided with their deinstitutionalization (Leff et al., 1990).

In India, about 90% of persons having chronic mental illness reside with their family members (Chadda, 2014). Due to a deficiency in well-established professional services within both public and private sectors in India, attributed to a scarcity of trained personnel and infrastructure, the familial support system assumes a critical role in the care of individuals with mental illnesses. In the cultural context of India too, the family structure is characterized by interdependence, with family members being the primary individuals engaged in the caregiving process. The primary caregivers engage in multiple roles in order to give care to persons with mental illness (Honea et al., 2008) and may get multifaceted range of impacts on their overall well-being which may include impact on physical health, social impacts, financial strains and psychological impact.

Worldwide, most studies on caregivers have been conducted among caregivers of the elderly population with dementia or chronic physical illnesses, followed by studies among caregivers of schizophrenia. Fewer studies have been conducted on caregivers of individuals dealing with Alcohol Use Disorder (AUD) and other psychiatric conditions. (Caqueo-Urizar et al., 2014). “AUD is a medical condition characterised by an impaired ability to stop or control alcohol use despite adverse social, occupational, or health consequences” (NIAAA,2020). Lasting changes in the brain caused by alcohol misuse perpetuate AUD and make individuals vulnerable to relapse. Alcohol, a widely consumed psychoactive substance, is often overlooked as a drug due to its availability and social acceptance. However, alcoholism remains a significant global health concern. In India too, alcohol misuse represents a public health problem and it needs to be given adequate attention. As per the 2019 report on Substance Use in India, 14.6% (16 crore) of individuals aged 10-75 use alcohol, with 2.9 Crore being dependent users. In Punjab, the alcohol use rate exceeds 28%, ranking it as the third-highest in the country, and among children, it's 6%, three times the national average. As per the National Mental Health Survey (2016), AUD prevalence in India was 4.6%. Projections indicate that by 2050, alcohol-related factors could lead to the loss of 258 million life years, 552 million Quality-Adjusted Life Years, and an economic loss of INR 97.9 lakh crores (1.45% of India's GDP) (Jyani et al., 2019).

However, beyond the direct health implications, AUD's ripple effects extend to caregivers, particularly family members. As caregivers navigate the challenges posed by their loved ones' AUD, the intricate dynamics of caregiving can significantly influence their own Quality of Life (QOL), representing an essential facet in understanding the broader impact of AUD on both patients and their support systems. QOL stands as a multidimensional and subjective measure, encapsulating an individual's perception of their overall well-being and satisfaction in various facets of life. According to “World Health Organisation (WHO), QOL is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHO, 2012). The WHO framework for understanding QOL incorporates four primary domains viz Physical Health, Psychological Well-being, Social Relationships and Environmental Factors, each representing a distinct facet contributing to an individual's overall well-being.

### QOL of AUD Caregivers

The WHO's comprehensive approach to QOL acknowledges the interplay of these dimensions, recognizing that a person's well-being is a complex and interconnected tapestry. As a result, the WHO's concept of QOL serves as a valuable framework for evaluating and enhancing the overall welfare of individuals, providing a foundation for research, policy development, and interventions that aim to improve the QOL on a global scale. As we navigate the intricate landscape of QOL, the WHO's encompassing framework provides a global lens, emphasizing the interconnected nature of well-being. Extending this perspective to the specific challenges faced by AUD caregivers, the nuanced dimensions of QOL affected by their caregiving responsibilities can be uncovered. Hence as we explore the intricate aspects of challenges confronted by caregivers of individuals with AUD, these effects can be classified into four specific categories: physical, psychological, social, and environmental.

1. Physical effects: The physical health of AUD caregivers is often significantly impacted due to the demanding and stressful nature of their responsibilities. Numerous studies conducted in India have shed light on the adverse effects of caregiving on the physical well-being of

individuals providing support to those with AUD. Sen et al., (2016) highlighted that caregivers often face elevated levels of stress, sleep disturbances, and compromised immune function, leading to increased vulnerability to various health issues. The burden of managing the unpredictable behavior and health complications associated with AUD patients can contribute to caregivers neglecting their own health needs. Additionally, Kumar Goit et al., (2021) found a correlation between the duration of caregiving and the physical health of caregivers, indicating that the longer individuals fulfill the caregiving role, the more susceptible they become to chronic health conditions. These findings underscore the urgent need to recognize and address the physical health implications faced by AUD caregivers, emphasizing the importance of targeted interventions and support systems to safeguard their overall well-being.

2. Psychological effects: The psychological well-being of caregivers supporting individuals with AUD is profoundly impacted by the demanding nature of their caregiving responsibilities. Numerous studies conducted in India have illuminated the psychological toll on these caregivers. Gohil et al., (2016) found that caregivers often grapple with heightened levels of stress, anxiety, and depression, attributing these mental health challenges to the unpredictable behavior and emotional strain associated with caring for someone with AUD. Arya et al., (2017) indicate a significant prevalence of caregiver burnout, characterized by emotional exhaustion and a diminished sense of personal accomplishment. The constant vigilance required in managing the complexities of AUD, coupled with societal stigma and limited support systems, contributes to the deterioration of caregivers' psychological well-being. Recognizing and addressing these psychological challenges becomes imperative to ensure the holistic well-being of both caregivers and those undergoing AUD treatment.
3. Social effects: The caregiving role for individuals with AUD in India significantly impacts the social relationships of caregivers, as suggested by studies in the region. Kumar Goit et al., (2021) underscore that caregivers often experience strained interpersonal relationships

due to the stigma associated with AUD, leading to isolation and social withdrawal. The demanding nature of caregiving responsibilities can result in a reduction of time and energy available for maintaining social connections, as highlighted by Murthy, (2016). Moreover, the erratic behavior and emotional challenges associated with AUD patients can strain family dynamics and relationships, further exacerbating the social toll on caregivers. Recognizing and addressing these social challenges is vital for fostering a supportive environment that acknowledges the complexities of caregiving for individuals with AUD, promoting resilience and well-being within the caregiving network.

4. Environmental effects: The environmental QOL for caregivers of individuals with AUD in India is substantially affected by the unique challenges posed by their caregiving responsibilities. Vadher et al., (2020) indicates that the caregiving environment is often characterized by heightened stress levels, financial strain, and disruptions in daily routines, all of which contribute to a diminished QOL. The lack of awareness and societal understanding of AUD can lead to a hostile social environment, exacerbating the burden on caregivers. Furthermore, Kumar et al., (2021) suggest that the inadequate availability of support services and mental health resources compounds the environmental challenges faced by caregivers. The confluence of these factors underscores the need for comprehensive interventions and societal awareness campaigns to create a more supportive and conducive environment for caregivers grappling with the multifaceted consequences of providing care to individuals with AUD.

### **Role of caregiver wellbeing in treatment process**

At a deeper level, the improvement of the QOL for caregivers of individuals with AUD is intricately linked to the dynamics of the caregiver-patient relationship and the broader societal fabric. The caregiver's well-being is not merely a personal matter; it serves as the linchpin in the complex web of interactions within the caregiving ecosystem. When caregivers experience an enhanced QOL, it influences the emotional climate of the caregiving environment. Reduced

stress, improved mental health, and greater overall well-being contribute to a more stable and supportive atmosphere for both the caregiver and the individual with AUD.

### Micro Level: Impact on Patient Treatment

The enhanced physical health of caregivers, resulting from an improved QOL, intricately intertwines with the treatment process for individuals with AUD. Caregivers often face elevated stress levels and compromised immune function when supporting those with AUD. As caregivers' QOL improves, marked by reduced stress and enhanced overall well-being, their physical health strengthens. This plays a pivotal role in the treatment process at the micro level, equipping healthier caregivers to provide consistent and effective support, navigate challenges, and sustain the demands of caregiving. The caregiver's improved physical health becomes a cornerstone for creating a stable and supportive environment, significantly influencing the success of AUD treatment.

Similarly, the enhanced psychological well-being of caregivers, stemming from an improved QOL, crucially influences the treatment process for individuals with AUD. As QOL improves, marked by reduced psychological distress, caregivers navigate challenges more effectively, fostering open communication and adherence to treatment plans. This positive psychological atmosphere significantly impacts motivation and engagement, enhancing the overall effectiveness of AUD treatment.

Additionally, improved social relationships of caregivers, resulting from an enhanced QOL, play a pivotal role in positively impacting the treatment process for individuals with AUD. Caregivers with an uplifted QOL cultivate stronger social connections, creating a supportive ecosystem that acts as a buffer against the isolation and stigma associated with AUD. This positive social context facilitates reduced caregiver stress, promoting an atmosphere conducive to the patient's recovery.

Moreover, the improved environmental well-being of caregivers, stemming from an enhanced QOL, significantly contributes to the positive treatment process for individuals with AUD. Operating in an environment characterized by reduced stress levels, financial stability,

and a more organized daily routine, caregivers create a positive atmosphere crucial for the success of AUD treatment.

In conclusion, the overall improved QOL of caregivers serves as a linchpin in positively contributing to the relapse prevention and continued recovery process of individuals with AUD. This holistic approach, addressing physical, psychological, social, and environmental aspects, creates a resilient foundation for sustained recovery. Caregivers, as role models, influence the adoption of constructive strategies, reducing reliance on alcohol and fostering a conducive environment for ongoing healing. The interconnectedness of caregiver well-being and patient outcomes underscores the significance of a comprehensive and holistic approach to AUD treatment.

### **Macro Level: Impact on Public Health and Economy**

Zooming out to the macro level, the improved QOL of caregivers has far-reaching implications for public health and the country's economy. A holistic focus on caregiver well-being aligns with broader public health strategies. As caregivers experience better physical and mental health, they are more likely to engage in healthier lifestyle practices, indirectly promoting public health by setting positive examples within their communities. Additionally, the reduction of caregiver stress and burnout contributes to lower healthcare costs associated with treating caregiver-related health issues.

From an economic perspective, caregiver well-being is intimately tied to workforce productivity. When caregivers experience an improved QOL, they are better equipped to balance their caregiving responsibilities with professional commitments. This, in turn, contributes to a more productive and engaged workforce, minimizing the economic impact of absenteeism and reduced productivity due to caregiver-related stress. Furthermore, by recognizing the societal impact of caregiver support, countries can make informed policy decisions that prioritize caregiver well-being, fostering a healthier and more productive nation overall. Therefore, at the macro level, the improved QOL of caregivers becomes a strategic investment in both public health and the country's economic prosperity.



In summary, the improved QOL for caregivers is a strategic investment with wide-ranging effects on individual well-being, public health, and economic productivity. This enhancement not only encourages healthier lifestyles and mitigates caregiver stress but also results in lower healthcare costs and a more engaged workforce. Acknowledging the societal significance of caregiver support allows for informed policy decisions, ultimately fostering a healthier and more prosperous nation. The positive outcomes stemming from the enhanced QOL of caregivers act as a driving force for comprehensive benefits, highlighting the interdependence of individual, societal, and economic well-being.

### Conclusion

In a broader perspective, AUD poses a widespread challenge, carrying extensive consequences not just for those directly impacted but also for the caregivers who bear the responsibilities of providing support. This paper has shed light on the profound impact of AUD on the QOL of caregivers, unveiling a complex web of physical, psychological, social, and environmental challenges. Recognizing that the caregiver's improved QOL serves as a catalyst for positive outcomes at both micro and macro levels is pivotal. Beyond the immediate caregiving environment, the enhanced well-being of caregivers resonates through communities and contributes to public health and economic resilience. As we confront the magnitude of the AUD epidemic, a paradigm shift is imperative. Social stakeholders must redirect their focus from patient-centered approaches to inclusive family-centered treatment strategies. By acknowledging and addressing the comprehensive needs of caregivers, we not only enhance the treatment landscape but also foster a society that values the interconnected well-being of all its members. This call to action is an invitation for collective efforts, encouraging a shift towards compassionate and family-centered approaches that recognize the integral role caregivers play in the journey towards recovery from AUD.

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