Alcohol and drug use disorders have devastating physical, mental, and socio-economic consequences not only for patients but also for their families. It is a critical public health concern for which the global burden far exceeds the difficulties experienced by many of the 250 million drug users, or the two billion alcoholic drinkers worldwide. Their illness substantially affects the quality of life of other family members, including financial security, mental health, social networks, and productivity. The cost approaches 2 per cent of the gross domestic product of some index countries.

Family involvement with the disease of addiction was self-evident to social workers who, in the early 20th century, did their work in clients' homes and could see directly how families function, but has only recently received proper scientific attention. Psychiatric research on caregiving has increasingly recognized the price paid by families of individuals with mental health problems and their contribution to the care process. However, the analysis has traditionally been limited to relatives of individuals with mental disorders like schizophrenia, bipolar disease, or dementia, and investigations on drug and alcohol use have been slowly following the path. The delay is perhaps due to a difficult progression from focusing on the role of the family in generating or exacerbating the drug user’s problems, through identifying family members as recipients of care, to learning what they can offer to the management of addiction. Still today, primary challenges remain the broadening of the substance abuse treatment attention from the individual to the family and its active participation in the recovery process.

In this issue, Mattoo and colleagues report on the burden endured by caregivers of men with alcohol and opioid dependence in India. Their results confirm the existence of high rates of subjective and objective burden, if compared across cultural boundaries and socio-economic conditions, or with different psychiatric diseases. In particular, the finding that living in a rural environment, together with earning a lower income, was associated with greater family burden offers important elements of reflection. As the level of education of caregivers or patients did not play a significant role in the perceived burden, we may assume that access to treatment and social support are important components to enable coping with the burden of a chronic disease. Indeed, beyond the initial evidence of how having a family member with an alcohol or drug problem affects family functioning and leads to increased risk of developing patterns of physical and behavioural problems, we observe a reduction of medical cost and utilization by the family when that individual receives treatment for his problems. In addition, international families of patients with chronic psycho-behavioural conditions seem to give increasing significance to the personal and political benefits of organizing not only to learn and understand how to cope with the problem but also to help foster a social response. It has been demonstrated that in the daily routine of living with substance dependence and other chronic psychiatric illnesses, lack of perceived social support by family caregivers is an important predictor of subjective caregiver burden if external support from the family is lacking, and of objective burden if other family members are of little help.

It is important to keep in mind the complex role that families play in substance dependence. The assistance they provide is multifaceted, including direct care, financial assistance, and management of illness symptoms, as well as helping directly their relatives’ engagement and retention in treatment. As they can be
a source of help to the treatment process, they also must manage the consequences of the addictive behaviour. Family members are concerned about the substance abuse behaviour of the individual, but they also have their own problems. At times, complementary or mirroring problems may crystallize the relationship into a codependent dimension, where the ‘non-ill’ member becomes overly concerned with the difficulties of the other, and renounces to his/her own wants and needs. Of course, this concept can lead to the risk of pathologizing otherwise normal caring functions, particularly those that have to do with empathy and self-sacrifice. In a potentially highly unstable ‘role play’, members often must change their conventional family roles or add new, often-inappropriate functions in order to adapt to the unpredictable, unreliable and sometimes demanding behaviour of the substance abuser. The individual typically engages with searching or using substances most of the time and is often incapacitated by the effects of alcohol or drugs, which leaves him/her unable to fulfill any responsibility in the family. Vacant roles may be redistributed and some family members, especially children, might have to bear excessive responsibilities. To further complicate the picture, caregivers or other burdened members of the family often do not know how to ask for help, or refuse to do so because of shame and fear of social stigma. The effects of the burden often extend beyond the nuclear family. Extended family members may share feelings of concern, fear, anger, embarrassment, or guilt; they may wish to ignore or defend from the individual abusing substances. Furthermore, the effects on families may continue through generations. Trans-generational effects of substance abuse may have a negative impact on role modelling and concepts of normative behaviour, which damages the relationships between generations and continues to influence family functioning well beyond the life of the ‘sick’ member, especially among those cultures where the extended family is an important reference point. Thus, providing services to the whole family can improve treatment effectiveness and contribute to social prevention and cost containment, as in families with alcohol or substance abuse single members often are connected not just to each other but also to any of a number of public agencies, such as social services, criminal justice, or child protective services.

Although issues of caregiver burden are receiving increased attention, there is still a strong need for studies on the burden of alcohol and drug use, in particular investigations based on large sample sizes and control groups. Given the fact that primary caregivers represent a diverse group of relationships, future research should also determine if there are differences related to specific types of relationships and roles in the family. More epidemiological and longitudinal studies and studies from different cultures are needed to gain a better understanding of generic and specific factors that influence the relationship between family and mental health. Significant challenges concern both the study of caregiving, and clinical practice and health policy. In research, further study on caregivers’ ways of coping should identify effective strategies and focus on resources more than deficits. The estimate of financial burden will face the complexity of calculating immaterial costs and assessing the impact of service structures on burden. Quality of findings could be enhanced by further improving conceptual clarity and by the agreement on a few standard instruments for the measurement of caregiver burden to facilitate comparison. On the practical level, strategies to improve communication between families and health providers can be better developed if primary care physicians receive adequate training to operate a much needed function of substance abuse screening and routine management. Finally, an active involvement of families in the therapeutic process and the correct response to their needs can only be fully achieved with a transition from an acute model of brief treatment of alcohol and drug use problems, to a more comprehensive chronic care model, assigning equal importance to family members and the individual in both treatment and continuing care phases.

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References


