

## OPINION EDITORIAL

# Informal Caregiving in Mental Health: Issues of Justice and Relative Invisibility

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An “informal caregiver” can broadly be defined as anyone who partakes in a caring role without financial compensation. These carers are often family or friends of the individual who is cared for. This relationship sets informal carers apart from health professionals and involves an added degree of complexity. Research has found that family carer involvement reduces hospital admissions, burden of care, and relapses while increasing compliance [1-4]. These carers are also able to identify early signs of relapse and significant side effects of medication [5,6]. The magnitude of carers’ contributions to sustaining the healthcare system is exemplified in one study which finds that a conservative estimate of the economic contributions of informal caregivers in Canada is 25 billion dollars annually [7]. Despite invaluable insight and significant contributions, support for informal caregivers remains starkly lacking in mental health care [8].

Although caregiving can be a fulfilling experience, a chronic lack of support can contribute to debilitating stress and burnout [9-11]. Deinstitutionalization, which refers to the widespread closure of psychiatric institutions on a global scale, provides crucial context [12]. The resulting relocation of care to the community has considerably expanded the role of informal carers despite insufficient investment in support for community carers [12]. Overall, the lack of recognition for the unpaid labour of informal carers in welfare reform policies has resulted in a deficit of monetary and institutional support [9]. Thus, economic insecurity presents a significant burden for informal carers. On average, caring for a child with a mental health condition is more expensive

than caring for a child with a physical illness [9,13]. Furthermore, thorough accounts of the costs of adolescent mental health care accumulated by carers usually do not factor in the time spent in caring roles, psychological stress, or time away from work [9].

As central advocates of those they care for, informal caregivers must contend with different contexts that can bring about situation-specific barriers to healthcare access. Within Australia and the United States, carers in rural settings navigate through numerous barriers, including lengthy waitlists, geographical distance and most significantly, inadequate resources [9,14,15]. Close-knit communities can simultaneously act as both an obstacle to care and a source of support. The intimate nature of rural communities allows for emotional and practical support, as well as health information distribution [15]. At the same time, gossip, stigma, and public surveillance can occur through word-of-mouth information flow and hinder access to care [15]. In Global South countries, the burden of mental health is the highest, and yet it is met with the lowest proportion of services [16, 17]. Furthermore, the bulk of health care services are overwhelmed by diseases such as HIV/AIDS, which results in the sidelining of mental health care [17]. Low and middle-income countries lack regulatory bodies, trained practitioners, and legislative frameworks [18]. Overall, inequitable mental health resources can lead to the loss of patient autonomy when families resort to coercive practices such as covert medication or physical restraint due to a lack of alternatives [18]. Ultimately, inequality is perpetuated by neoliberal perspectives which

uphold the duty of individuals to draw upon personal resources to support those they care for [19,20]. Neoliberalism is premised on market-oriented policies, individual responsibility, and the privatization of care so as to avoid public expenditure [19]. By shifting the responsibility of care to communities and family members, government accountability and massive economic gains from unpaid caregivers are obscured while caregivers continue to confront barriers to access [19].

A carer's relationship with those they care for may contribute to and complicate an obligation to provide care. Informal carers must navigate conflicts between a responsibility to attend to the individual they care for and concern for their own well-being [21]. Feelings of guilt commonly characterize caregiving experiences [22]. This tendency to self-blame highlights the extent to which relationships between the carer and patient inspire a sense of duty [22]. For parents who are informal mental health carers, a sense of blame, and thus responsibility, can arise from stigma that extends to their interactions with healthcare professionals. Carers describe judgmental attitudes and behaviours from health professionals who may perceive mental health issues as a reflection of bad parenting [19,23]. Responsibility is underscored in East Asian family ethics derived from Confucianism, which emphasize harmonious interpersonal relationships within a family [24]. Due to these Confucian social norms embroiled into East Asian family dynamics, family carers often harbor a strong sense of responsibility for family members with mental illnesses. For East Asian families in the West, the relational aspects of care may conflict with the western emphasis on individual patient autonomy [24]. Overall, the ambiguity involved in the role of informal caregivers may stem from the neoliberal context which has pushed caring roles to personal networks [19]. By emphasizing personal responsibility, the burdens of care are not seen as a result of unjust structural failure but as inevitable and natural [25].

In summary, informal carers are often left unrecognized by the mental health care system despite the substantial reliance the system has on

them [5,26,27]. In advocating for those they care for, informal caregivers are confronted with significant barriers preventing equitable access to mental health care. It is important to recognize the range of experiences involved in caregiving, including love, joy, hardship and sorrow. By viewing the weight of informal care in relation to systemic injustice rather than as a natural aspect of caregiving, it is possible to take steps towards ameliorating the burdens faced by informal mental health caregivers.

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