

## Non-Monetary Costs of Informal Caregiving in Dementia: The Caregiving Burden

### Custos Não Monetários da Prestação Informal de Cuidados na Demência: Sobrecarga do Cuidador

**Keywords:** Caregivers; Dementia

**Palavras-chave:** Cuidador; Demência

Pires C *et al*<sup>1</sup> studied the financial costs of informal caregiving of people with dementia (PwD). Their work also highlights the caregivers' psychosocial burden, an often-neglected topic which we would like to explore further. Personal experience of caregiving in dementia may have a significant impact on the mental health of informal caregivers. Caregivers of PwD experience high levels of depression, anxiety, adverse physical and psychosocial outcomes.<sup>2</sup> Despite its potential negative effects there is substantial variability in the levels of stress and burden experienced.<sup>3</sup> Indeed, tolerability of caregivers to the diagnosis of dementia and to known contributing factors to caregiver burden (CB) may differ across different cultures.<sup>2</sup>

Factors associated with CB are varied including both caregiver and patient-related factors (Table 1). Patient-related factors include behavioral and psychological symptoms of dementia (BPSD), severity of cognitive impairment, level of functional dependence and patient safety.<sup>3</sup> BPSD are a heterogeneous group of highly prevalent symptoms. Although presenting in virtually all subtypes and stages their impact is more clearly discernible in frontotemporal and Lewy body dementia.<sup>4</sup> Amongst BPSD, apathy and psychomotor

agitation/aggressivity are the most common, with the latter causing the highest levels of caregiver stress. This may explain the fact that CB appears to be greater in caregivers of male patients who tend to present higher levels of aggression.<sup>4</sup> Humor elation and euphoria are the least distressing symptoms.<sup>4</sup>

Caregiver-related factors contributing to CB encompass a wide range of personal, psychological and social variables. The role transition to becoming a caregiver implies taking on a series of new responsibilities. Adjustment to the new role profoundly impacts home environment, leisure activities, family and social relationships. The resulting emotional strain makes the individual more vulnerable to develop caregiver exhaustion. Considering individual variables, gender and kinship were not found to influence CB.<sup>4</sup> Decision-making regarding living arrangements and admission to long-term care facilities is one the most relevant factors with caregivers developing feelings of guilt, failure and betrayal.<sup>2</sup> In case of admission to a long-term care facility or even death the caregiver's role does not cease, involving legal, financial and healthcare decisions. Healthcare-related aspects include decisions regarding the withdrawal of invasive life-support measures, which often prove particularly challenging.<sup>2</sup> Early interventions should target both patient and caregiver and are aimed at increasing dementia awareness, planning of end-of-life care and provision of caregiver training programs. Online caregiver training programs (such as the iSupport tool- [https://www.who.int/mental\\_health/neurology/dementia/isupport/en](https://www.who.int/mental_health/neurology/dementia/isupport/en)) can provide accessible and personalized advice by empowering caregivers and promoting resilience.<sup>5</sup>

**Table 1** – Factors associated with caregiver burden

PwD-related	Caregiver-related	Other
Level of dependence and personal safety	Caregiver roles (work, home, social)	Care setting placements
Dementia characteristics (subtype of dementia, BPSD)	Caregiver education	End-of-life care
Level of cognitive impairment	Personality traits	Financial capacity
Sex (male)	Coping strategies	Available social support

PwD: people living with dementia; BPSD: behavioral and psychological symptoms of dementia

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