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The Caregiving Bind: Concealing the Demands of Informal Care Can Undermine the Caregiving Identity

Helen Moore, Alex Gillespie



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The Caregiving Bind:**Concealing the Demands of Informal Care Can Undermine the Caregiving
Identity****Abstract**

Disagreements and misunderstandings between informal caregivers and care-receivers have been widely reported, but the causes are unclear. The present article compares the views of people with acquired brain injury and their main informal caregivers (28 dyads, $n = 56$). First, we report a quantitative analysis finding that the majority of disagreements were about caregivers' identity. Caregivers saw themselves as less confident, less intelligent, more embarrassed, more independent and more overprotective than care-receivers rated them to be. Caregivers understood the care-receivers' ratings but disagreed with them. Second, we report a qualitative analysis focusing on how caregivers felt themselves to be perceived by significant others. Caregivers felt that the care-receiver, family members, the general public, health services and even friends often have negative views of them. The 'caregiving bind' is proposed as a cause of caregivers' negative identity. It arises when caregivers try to protect the care-receiver's identity by concealing the extent of informal care provision, with the unintended consequence of undermining the prospects of the caregiver receiving positive social recognition for the challenging work of caregiving. The caregiving bind has implications for therapy and points to the potential of friends and health services to provide caregivers with positive social recognition.

Keywords: UK; informal care; acquired brain injury; disagreement; misunderstanding; identity

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