

The Unmet Health and Social Care Needs Of Older Caregivers: A Systematic Review

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Background: There has been rapid growth in the number of older caregivers (OCs) age 65 and over in the UK and many deliver more than 50 hours of care each week. OCs may have their own support needs arising from their caring role and age-associated health issues however cuts to social care spending mean fewer are qualifying for support.

Aim: To identify and describe the unmet health and social care needs of caregivers aged 65 and over in the UK.

Methods: Searches of 12 health and social care databases, nine carer and chronic disease websites and five journals were undertaken plus reference list checks. Qualitative Metasummary was used to synthesise findings.

Results: A total of 4407 records were identified, 10 papers from nine studies satisfied the inclusion criteria. Unmet needs were identified in eight domains described below:

<p>Psychosocial needs</p>  <ul style="list-style-type: none"> • Feelings of isolation and even imprisonment. • Family and friends didn't understand the realities of life as a caregiver and friends had be lost. • Lack of recognition from health and social care staff meant support wasn't offered. • Being 'left in the dark' and 'ignored' was common. 	<p>Service needs</p>  <ul style="list-style-type: none"> • Barriers to access included Inflexible, costly and unsuitable services. • OCs 'battled' with social service with some wanting more of the support they were already receiving. • Statutory services were described as infrequent and impersonal to OCs needs. 	<p>Information needs</p>  <ul style="list-style-type: none"> • OCs had little knowledge of available services and how to access them. • Poor information provision left OCs feeling let down, increased their despondency in available services and hindered forward planning.
<p>Future care planning needs</p>  <ul style="list-style-type: none"> • Crises and physical demands caused OCs to question their ability to continue their role and worry about the future yet, few OCs had made any plans. • Many OCs continued to care as there appeared no alternative or because they lacked trust in others to care for their dependent. 	<p>Physical health issues</p>  <ul style="list-style-type: none"> • The demand of caring was thought likely to exacerbate OCs already deteriorating health. • Priority was given to fulfilling the needs of care recipients, at the expense of OCs own health. • Some resumed caring too soon after hospitalisation and found their own long-term conditions worsening. 	<p>Constancy of care</p>  <ul style="list-style-type: none"> • The relentlessness of providing 24-hour care left some OCs in a state of perpetual exhaustion and extreme fatigue. • OCs had little time to maintain relationships and partake in desired activities. • Caring for a dependent at the terminal stage of illness and for those with a severe disability or dementia disrupted sleep.
<p>Reluctance to utilise services</p>  <ul style="list-style-type: none"> • Some OCs showed reluctance to utilise services characterised by poor uptake and delays accessing available support. • Some only sought help after a crisis or when all other avenues had been exhausted. • OCs reported engaging in complex and unpleasant tasks, enduring great difficulties, and still not approaching services. Some were averse to asking their children for assistance. 	<p>Financial needs</p>  <ul style="list-style-type: none"> • Additional costs were incurred by OCs for the sake of their care recipient, particularly for travel. • Some OCs had difficulties accessing financial assistance. • Some OCs were not aware that their dependent may qualify for Attendance Allowance and not all had attempted to claim. This was replicated with Carer's Allowance. The 'overlapping benefits rule' which precludes those receiving a state pension from claiming it was viewed as unfair. 	



Conclusion: Of national significance, the findings show the unmet needs of OCs in the UK is an understudied topic. OCs are diverse in character with wide-ranging support needs, hence personalised carer's needs assessments are vital for this population. More should be done to actively identify OCs and target support. Helping them recognise their caring role may be an important first step. Changes to ensure services are accessible, flexible and sufficiently available to meet OC's needs are required. Further research focused on the support needs of this specific population is recommended.

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