

What factors are associated with informal carers' psychological morbidity during end-of-life home care? A systematic review and thematic synthesis of observational quantitative studies

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Plain language summary

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Background

Family carers are central in supporting patients nearing end of life. However, their own mental health may often suffer as a result. It is important to understand what makes carers' mental health better or worse, to support them appropriately and help them stay in good health.

Aim

To synthesise what is known about what can affect carers' mental health during end-of-life caregiving.

Method

We identified research literature (1 January 2009–24 November 2019) that looked at factors that may make carers' mental health better or worse when supporting someone nearing end of life. We focused on adult carers of adult patients cared for at home. Researchers worked with the help of a carer Review Advisory Panel to group similar factors into themes. This report presents research that used numerical measurements (for instance, surveys) to investigate factors related to carers' mental health.

Results

Findings from 63 studies were grouped into seven themes: (1) How the patient was: worse patient mental health and quality of life related to worse carer mental health. (2) How much caregiving affected carers' lives: greater impact, burden and feeling tasks were difficult related to worse mental health. (3) Relationships: good relationships between family members and between carer and patient seemed important for carer mental health. (4) Finance: having insufficient resources may affect carers' mental health. (5) Carers' internal processes (carers' thoughts and feelings): feeling confident and prepared for caregiving related to better mental health. (6) Support: carers' mental health seemed related to support given by family and friends and to getting sufficient, satisfactory support from formal services. (7) Background factors: older carers seemed generally to have better mental health, and female carers worse mental health overall.

Conclusions

Factors that may affect carers' mental health are many and varied. We therefore need a broad strategy to help carers stay in good mental health during caregiving.

