Understanding what affects psychological morbidity in informal carers when providing care at home for patients at the end of life: a systematic qualitative evidence synthesis

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

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Introduction

Being a carer for a family member or friend at the end of their life can have an impact on the carer's mental health. This includes depression, anxiety, stress and feeling overwhelmed. If carers feel unable to cope, they may be less able to look after their relative or friend. The mental health of carers must be a priority to help them feel better, cope, and support patients. This review summarises information from research into things that carers say are important for their mental health, to help us understand how we may be able to maintain or improve carers' mental health.

Methods

We worked with six carers in a Review Advisory Panel to search for studies on carers' experience published between 1 January 2009 and 24 November 2019 and identify common themes from identified studies. Themes were put into a table of themes and subthemes, assessed by the carers, and compared with other literature to identify factors that caused carers to have poor mental health, and ways to help carers feel better.

Results

We found six themes that indicate how caring for those at the end of life can affect mental health. These include: the impact of the patient condition and seeing the patient decline; the impact of caring responsibilities; carers' relationship with the patient; finances; carers' feelings and experiences such as lack of control or confidence when caring; and support from other family, friends and health-care professionals. Strategies to improve mental health were linked to the final two themes, including how to manage carers' views and experiences of their situation and how to gain appropriate support.

Conclusions

This study describes factors that lead to poor mental health and ways to improve mental health when caring for someone at the end of life. Further work is needed to use this information to inform policy and service delivery.