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2018

FAMILY CARERS' PREFERENCES FOR SUPPORT WHEN CARING FOR A FAMILY MEMBER AT THE END OF LIFE AT HOME: AN INTEGRATIVE LITERATURE REVIEW

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Background

- Approximately 60% of people wish to die at home.^[1]
- Across Europe there are an estimated 100 million family carers meeting the needs of loved ones at the end of life.^[2]
- Family carers report unmet health and social care needs.^[3]
- Understanding family carer preferences for end of life care is integral to palliative care at home.

Method

An integrative literature review to synthesise the available evidence about family carers' preferences for support when caring for a loved one at the end of life in their own home. To examine what helps family carers cope and their experiences of care provision.

Key search terms

(Palliative care OR terminal care OR supporting care OR end of life care OR domiciliary care OR anticipatory care OR advanced care planning OR death OR dying) AND (Home) AND (Family OR carers OR caregivers) AND (preferences OR experiences OR satisfaction OR support).

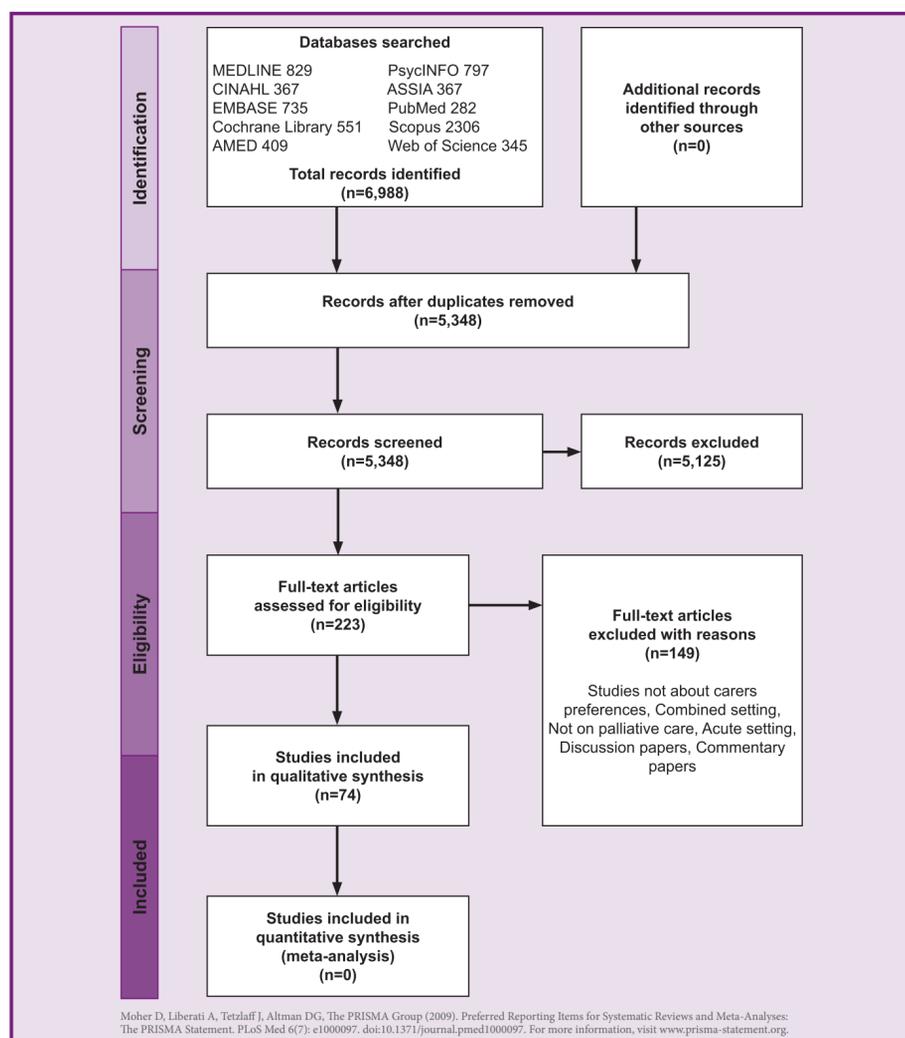


Figure 1: PRISMA Flow Diagram.

Results of searches

5,348 titles and abstracts were screened and 74 articles were included in the final analysis.

Preliminary findings

| Theme: Being a partner in care | |
|--|---|
| Sub-theme: Involvement in decision making and end of life care; shared decision making was important in helping family carers cope. | Sub-theme: Prioritising patients support needs; alongside meeting family carers own psychosocial needs. |
| Theme: Timeliness of transitions of care through the illness trajectory | |
| Sub-theme: Preparedness for transitions; timeliness of access to support from knowledgeable staff and appropriate and co-ordinated services. Access to information and key contacts for continuity of care. Access to support that responds to changing needs. | Sub-theme: Knowing what support can be accessed; competent personnel, respite care, support groups, additional support at the end of life and into bereavement. |

Conclusions

- Family carers, alongside their loved ones, prefer to be involved in planning and deciding about care at home.
- They need information about how the illness trajectory might develop and the support and services available to help them in a timely manner.
- Health Care Professionals should recognise that meeting the needs of family carers is inextricably linked to addressing the needs of their loved ones.

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