

Support for palliative family carers: a review

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Background

- Experiences and context
- Needs
- Barriers to support
- Rewards and coping

(i.e. Funk et al., 2010; Stajduhar et al., 2010)

The aim is to systematically identify and review the literature on *support* for palliative family carers who provide care to a relative living with a serious terminal or advanced chronic illness at home.

Method

Integrative literature review (Whittemore & Knaf, 2005)

Göran Bostam, librarian, Ersta Sköndal University College

Ten electronic data bases (Academic Search, Nursing & Allied etc)

1193 citations (156 duplicates) **1037 citations**

Review in progress

Ex. Academic Search

1) 65 hits 2) 33 3) 13 articles 4) ?# included studies?

Next step - "Grey literature" – national web sites and hand search

What should I do if....?

- Practical support regarding
 - Knowledge about symptoms (ie. pain, nausea, delirium) and provision of care
 - Assistance with symptom control
 - Assistance with hygiene and dressing
 - How to receive extra help when needed

How will I cope if...?

- Emotional support regarding
 - Sensing the possibility to having a choice to decide place of care/death
 - Preparedness to become a carer
 - Bereavement experiences
 - Meaning-making
 - Economic support

Who do I turn to if....?

- Organisational support regarding
 - Adequate communication and information
 - Individual support and support groups
 - Home hospice services, family physician, district nurses, specialist palliative teams
 - Telephone services (24-7)
 - Respite care (24-7)
 - Psychological and/or existential support
 - The importance of the local community/NGO's

Discussion

- A reactive “repair” approach pre-dominates the literature. A proactive support approach is needed.
- Person centred support is needed (but missing)
- How define support in palliative care? (from the perspective of relatives or professionals?)
- Hospice – support form or organisation?
- The context – is it possible to generalize the carer’s individual needs? (socio-economic positions)



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