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# Support for informal carers and families

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# Why are informal carers so important?



- 7+ million carers in Britain – by 2011 will be 13 million
- Increasing number of older people
- Many provide <80 hours care a week
- Save taxpayer money:
  - family carers contribute \$196 bill/year through unpaid caregiving to US health care system (Arno et al, C. The economic value of informal caregiving” Health Affairs 1999; 18:182-188)
  - £57 billion/year in UK (Government Actuaries Office)

# Key highlights from work at KCL

8 years of study

- Who / what is a carer?
- Reviewing the evidence base
- Testing interventions to support informal caregivers
- Testing the effect of patient services on informal caregivers
- Studying sleep in caregivers (Malik)
- Studying caregivers from different cultures (Koffman)
- Developing short form measures to assess caregiver burden (a new 6 item burden inventory)

# Central concept: ambivalence and identity

- Based on qualitative interviews with caregivers
- Carers **may not** self identify .....
  - *“part of love, duty and a relationship. Both ‘hell and a joy”*
  - *“not as bad off as ‘real’ carers”*
  - *“Something strange happened, I can’t even pinpoint it now: something just flipped inside me and I lost my own identity; I was the girl whose fiancé was dying of cancer and I didn’t know who I am”*

*Harding R, Higginson I. Support Care Cancer. 2001 Nov;9(8):642-5.*

# Appropriate help: services and barriers

- Carers believe having nurse at home abnormal
- Lack credibility to be 'real' service recipients
- More comfortable contacting services for person cared for than for themselves:
  - *“When I just can't cope with his tears and nightmares they can just come in and counsel him and look after him, and that's where they succeed, not when I have my own fears and nightmares”*

Harding R, Higginson I. Support Care Cancer. 2001 Nov;9(8):642-5.

# Systematic literature review of interventions to support caregivers

- 22 studies describing interventions:
  - home nursing care (4)
  - respite services (3)
  - social networks and activity enhancement (2)
  - problem solving and education (3) and
  - group work (10)
- Of these, 9 were delivered solely to carers (i.e., were targeted services)
- Only 6/22 had been evaluated, only 2/22 used a randomized control trial (RCT; grades IB).

*Harding R, Higginson IJ. Palliat Med. 2003 Jan;17(1):63-74.*

# Evaluation of a Short-Term Group Intervention for Informal Carers of Patients Attending a Home Palliative Care Service

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## **Abstract**

*Despite evidence of high psychological distress and unmet needs, evaluated interventions for informal caregivers in palliative care are few. This study involved an observational outcome evaluation of attendees, and a comparison group, in specialist home palliative care. The measures included carer psychological status and patient physical status at baseline, 8 weeks, and 20 weeks. Qualitative data were collected regarding content, satisfaction with, and impact of intervention. Process data described the uptake, resources, and group activity. The intervention combined informal multiprofessional teaching with facilitated peer exchange and support, and was delivered over 6 sessions of 90 minutes per*

# Intervention 1: the 90 minute group

- Developed following literature review, qualitative work with caregivers and staff consultation
- Aimed to promote self-care by combining informal teaching with group support
- Six / five weekly sessions each of 90 minutes
- Single group facilitator introduced multiprofessional input
- Changing weekly speaker (welfare benefits advice, occupational and physical therapy, clinical nurse specialist, and aromatherapy)
- Group discussion of the weekly themes
- Maximum of 12 carers.
- Initially focused on patient issues in order to provide legitimacy for attending
- To enable attendance, transport for carers and a patient-sitting service were provided when necessary.

*Harding R et al J Pain Symptom Manage. 2004 May;27(5):396-408.*

# Findings 90 minute group

- Uptake 40/170 caregivers - ie 24%
- Carers were less likely to accept if they were in paid employment (OR = 0.26,  $P = 0.06$ )
- More likely to accept if they utilized avoidance coping (OR = 1.13,  $P = 0.04$ ) or their patient had worse physical status (OR = 2.1,  $P = 0.03$ )
- Attendees described support and knowledge gains from the multiprofessional input and peer group.
- Most relied on social comparison processes to appraise their situation.
- Attrition prevented further analysis

## Thoughts

- Group useful but uptake low despite transport etc
- Attrition – possibly too long

*Harding R et al J Pain Symptom Manage. 2004 May;27(5):396-408.*

## Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care

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**Background:** Family caregivers are often responsible for providing significant support to relatives who require palliative care at home. However, evidence suggests that family caregivers have limited information, resources or support to prepare them for such a role. Furthermore, family caregiving can be associated with negative physical, financial and psychosocial outcomes. **Purpose:** This project sought to examine the utility of a group family caregiver psycho-educational programme focused on preparing primary family caregivers for the role of supporting a relative with advanced cancer at home. **Method:** The education programme consisted of three consecutive weekly sessions presented in a group format, conducted at six home-based palliative care services across metropolitan and regional Victoria (Australia). Participating caregivers were required to complete a set of self-report questionnaires measuring caregiver competence, preparedness, optimism, rewards, social support, burden and information needs, at three time points: commencement of the programme (T1), upon completion (T2) and 2 weeks later (T3). Caregivers were also asked to report on the relevance, acceptability and content of the programme, as well as any barriers to access. **Results:** Sixteen education programmes were conducted, with 74 caregivers attending the first session. Forty-four caregivers completed all three data collection sets. Following the intervention, a significant positive effect was found for the following outcomes: pre-

# Informal carers - next steps

- Evaluation of modification of psycho-educational intervention
- 3 sessions
- Feasibility study to conduct initial randomised controlled trial
- Test
  - Psycho-educational support
  - Recruitment
  - Randomisation
  - Outcome measures

# References

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