International Observatory on End of Life Care

Family Carers in Palliative Care: high impact, low priority

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Family carers: high impact

Family carers in palliative care:

What theories, models and assumptions do we hold about carers?

How do these models influence the types of support offered in palliative care settings?

Evidence from an evaluation of carer’s support services

What theories, models and assumptions do we hold about carers?

Common assumptions about carers:

- Female
- Related to the cared-for person
- Co-habiting
- Engaged in care-giving tasks
- Care-giving impacts on the health, wealth and emotional well-being
- Need support

Concepts of 'role'

- Contradictory role expectations
- Lack of identification with the role
- Lack of clarity in the role
- Feelings of ambivalence

Traditional 'burden' model

- Drawn from the psychological literature
- Deficit model
- Construes carers as overburden by tasks of caring
- Caring is measured in terms of tasks (predominantly physical, nursing or domestic roles)
- The impact of caring is measured in terms of deficits – loss of health, income, employment, opportunities for social engagement.
- Little recognition of positive aspects of care giving
- Little recognition of pre-existing and current relationships
- Typically carers are regarded as 'vulnerable' and in need of 'support'.

The transactional model of stress and coping

- Offers a psychological model based on individual appraisal of threat and coping responses
- Emotion focused and problem focused coping
- Emphasis on cognitions (thoughts) and 'coping' abilities
- Accounts for the variability of response to care giving
- Indicates the types of supportive interventions that may be required which include education and information to enable carers to deal with 'problems' and challenges and emotional support or relaxation strategies to help deal with personal distress.

(Hudson P. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. *Palliative and Supportive Care*. 2003;1(4):353-65)

A social relationship model

- Carers are seen as citizens with rights and responsibilities; this raises important challenges for public policy, the economy and the wider social fabric.
- Care giving is seen within existing social and family relationships, dependencies and dominance (Family Systems theory)
- Carers are seen as resilient and remarkable.
- The meaning of care giving can only be understood within the wider social and cultural context in which it is situated.

Rather than interventions focused on individual coping:

- Carers need to be protected from health and social care systems that actually increase rather than lessen the burden of caregiving.
- Carers' economic and financial security is not always given the priority it deserves.
- Carers' social inclusion requires increased attention.

(Payne S. Resilient carers and caregivers. *In:* B Monroe and D Oliviere (eds).
Resilience in Palliative Care – Achievement in Adversity.
Oxford University Press, Oxford, 2007, 5, 83-97)

How do these models influence the types of support offered in palliative care settings?

(Payne and Hudson, 2009)

	Information / Education / Training	Social support	Therapeutic support
Interventions directed at carers	Information on: bereavement/grief Grants / finance Moving & handling	Drop-in centres Lunch clubs Walking groups	Counselling Complementary therapies Groups
Interventions directed at patients and have secondary benefit for carers	Information on: Disease process Managing symptoms Self care strategies Healthy eating / relaxation	Respite Day care In home sitting services	Counselling Complementary therapies Physiotherapy

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Evaluation of the Help The Hospices Major Grants Programme for Carers of those who are Terminally ill

Sheila Payne, Terri O'Brien, Mike Nolan and Christine Ingleton

Funded by Help the Hospices

Help the Hospices

Aims and objectives of the evaluation

- The extent to which the funded services are working towards extending and increasing the provision of support services for carers, and evaluating the quantity and quality of these
- Identifying improvements in addressing inequity of access to services for carers including issues of social exclusion, cultural diversity and economic disadvantage
- Examining the processes and models used by the funded services, and identifying transferrable lessons across funded services working in different organisational sectors
- The extent to which funded services influence policy and practice both locally and nationally and are sustainable

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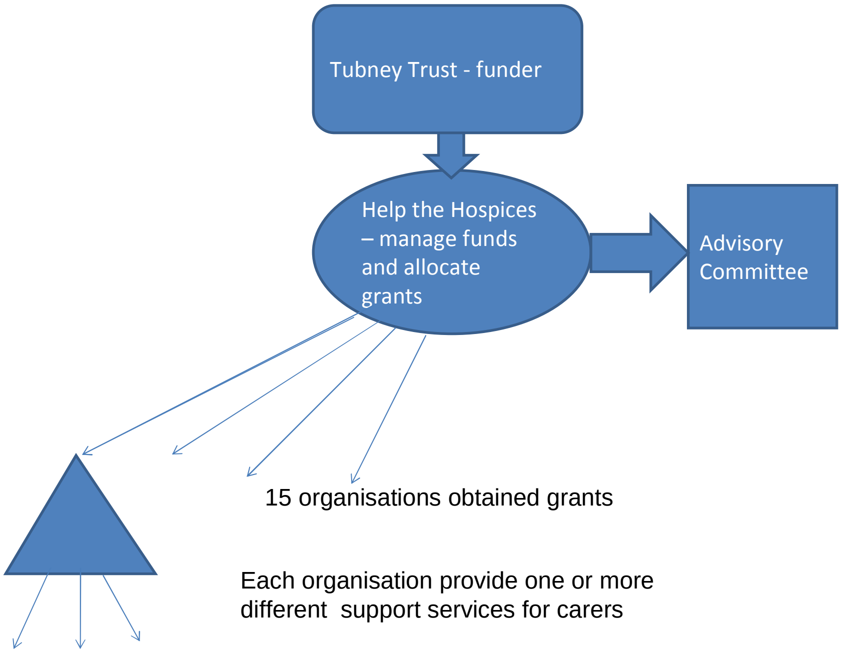


Tubney Trust - funder

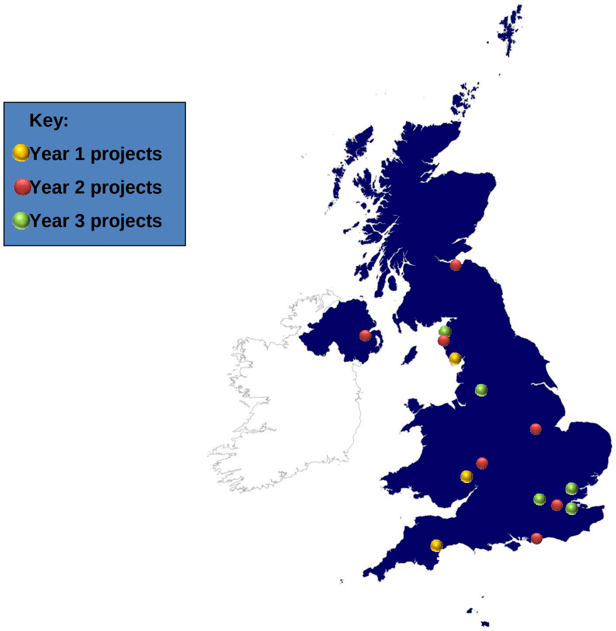
Help the Hospices – manage funds and allocate grants

Advisory Committee

15 organisations obtained grants

Each organisation provide one or more different support services for carers

The organisations and projects



Methods used in the evaluation

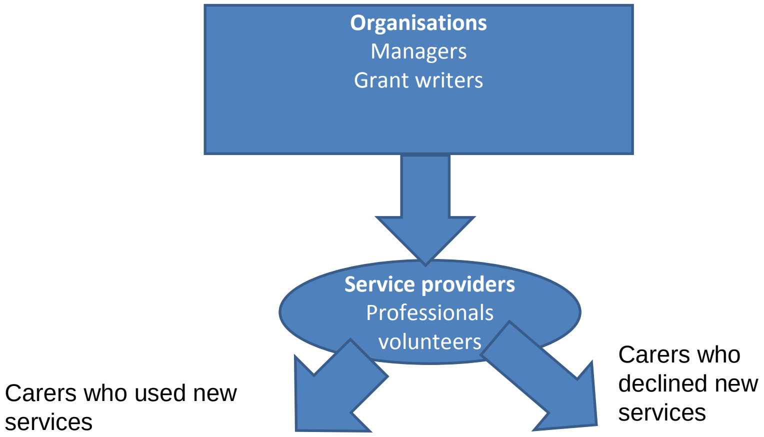
A Formative Evaluation approach:

structure, process and outcomes

Ingleton, Field and Clark (1998) “Issues in Research: Formative Evaluation and its Relevance to Palliative Care” in Palliative Medicine 1998; 12. 197-203

Sources of data

1. Interviews with project workers
2. Documentary analysis
3. Carers’ questionnaire
4. Interviews with 20 carers at two project sites



Organisations
Managers
Grant writers

Service providers
Professionals
volunteers

Carers who used new services

Carers who declined new services

Research participants: project workers and carers

Projects	Number of projects	Number of service providers interviewed	Numbers of carers interviewed	Service users (carers) questionnaire returns
Year 1	3	13	-	15
Year 2	7	20	10	44
Year 3		8	7	5
Totals	15	41	17	65

Findings: Types of services

Multifaceted services:

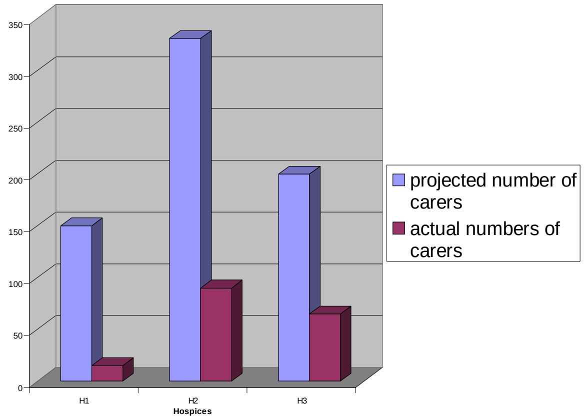
direct services (bereavement support groups, advisory services, complementary therapies)

Indirect services (volunteer recruitment and training, volunteer sitters)

Types of activities in the services

- Information /education/training
- Social support
- Therapeutic support

Year 1 projects: numbers of anticipated and actual carers using the services



Findings: organisational challenges

- Delays in starting the project (13 out of 15 projects)
- Laying the ground work (11 out of 15 projects)
- Difficulties relying on external partners for referrals (10 out of 15)
- Complex referral systems (7 out of 15 projects)
- Project workers leaving the organisation or moving to new posts (7 out of 15 projects)

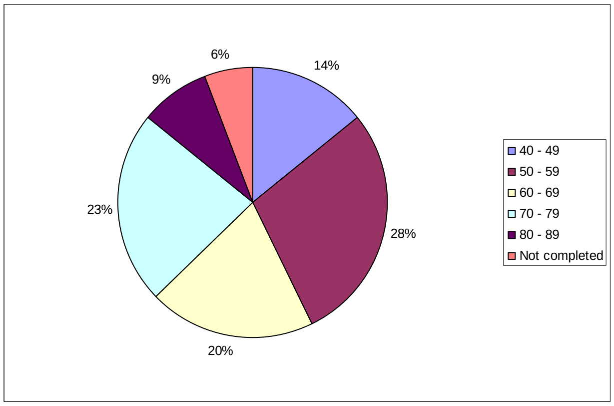
Findings: successes

- All projects were eventually implemented
- Recruiting more volunteers (2 out of 15 projects)
- Successfully targeting carers in rural areas (4 out of 15 projects)
- Successfully linking up with other services (15 out of 15 projects)
- Some services continuing beyond the project (sustainability of services) (6 projects have completed 4 are continuing some of their services)

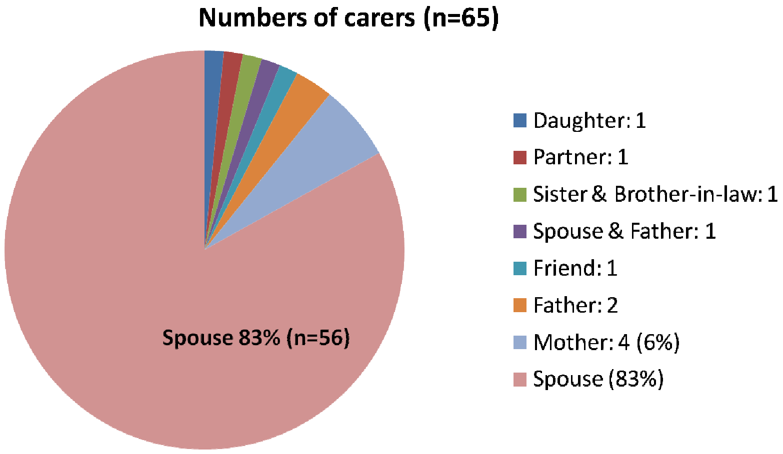
Description of sample of carers answering the questionnaire:

- 100% (n= 64) of Carers described themselves as White British
- 80% (n=53) are female
- 20% (n=13) are male

Age of carer respondents



Who are you caring for?



Views about services

- 91% (n= 50) of Carers said the services were relevant to their needs
- 72% (n= 45) had heard about the service from their local hospice
- 49% (n=23) said the service could be improved
- 51% (n=24) did not think the service could be improved (n=47 carers answered this question)

Helping to relieve feelings of social isolation

- ‘I felt isolated and alone prior to the Carers services offering me support’
- ‘Excellent service; I was on my own prior to this and felt isolated’
- ‘It makes me realise I'm not alone - and actually makes me feel 'stronger minded' after a chat and meal’..’

Gaining confidence knowledge and social support

- ‘I was out of my depth when I was asked to come to a 6 week course. This has given me confidence to continue to care for my partner.’

- ‘It has given a bit of life back to me and I am grateful for the excellent services you provide for us. Thank you’

- ‘This service has enabled me to get advice and put some normality into my life’

Summary findings from carer interviews

- Carers are a diverse group
- Caring can be burdensome if the person is chronically sick – long death
- Caring regarded as a privilege if the illness is of short duration - short death
- These services are often part of a larger support package for carers
- Carers often choose services that they *want* rather than *need*

Reasons given for declining services

- No perceived need for the services by carers
- The person they are caring for doesn't want them to go
- Tried the service but didn't like it
- Not the kind of service on offer that the carer wanted
- Would like the service later when the person they are caring for has died

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Future research

- Needs to be a clearer rationale for the support services offered.
- How will the 'right' support be provided to the 'right' person at the 'right' time, in the 'right' format, place and amount?
- Needs to be better assessment to ensure that carers are offered support that empowers them and does not promote dependency .
- Support needs to be cost effective.

Methodological challenges:

- Recruitment of carers to research

  - if carers are construed as vulnerable then they need 'protection' from researcher, if they are critizens they need to make up their own minds as adults.
- Gate-keeping – patients and staff
- Competing priorities
- Short intervention time – small window of opportunity to offer support

Thank you for listening

International Observatory on End of Life Care

Observatory Events of Interest:

(www.eolc-observatory.net)

Observatory Summer School 2010

Running over a period of two weeks, the purpose of the Summer School is to provide an ‘advanced introduction’ to social research methods relevant to end of life care. The course is ‘advanced’ in the sense that you will be taught by expert researchers who will develop your knowledge of selected methodologies to a high level. It is also an ‘introduction’ in that it assumes no prior knowledge of research methods in the social sciences and is aimed at those at an early stage in developing their own research.

Potential students should contact Jo Gluth
(**Tel**: 01524 5923309 **Email**: lj.gluth@lancaster.ac.uk), for further information.
You can also visit our website: http://www.eolc-observatory.net/education/school2007.htm

Masters/Diploma/Certificate in Health Research

The IHR postgraduate programme in Health Research is designed for those who want to refine their understanding and research skills in relation to the broad domain of health, illness and disability through a flexible online distance learning course. For face-to-face postgraduate courses in health research please see our courses page.

The programme provides students with guidance related to their chosen pathway of study.

Health Research, Disability Studies, **End of Life Care**, Intellectual Disability, Public Health

Further information is available from to Gluth
Tel: (+44)1524 503309

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