CareSearch Project Research Studies Register: Registration Proforma	0115

Study Title: Home-based care for advanced cancer patients: the impact on family carers

Brief description of the study: This mixed methods study explored the experience of lay carers of patients with advanced cancer. Longitudinal data were collected during the cancer trajectory, and some carers completed post-bereavement surveys. Qualitative interviews were conducted with a sub-sample of carers during bereavement, and with palliative care nurses from hospital and community settings. The carers identified many unmet support needs related to care of the patient, mostly tangible. Support was inaccessible due to lack of information or ineligibility, or a lack of that particular type of service. During the patient's final year of life, female carers experienced significantly higher levels of depression and anxiety than men. During this period, men reported significantly higher levels of tangible support than women, but women reported significantly higher emotional/informational support than men. Anxiety and depression increased for most carers who were interviewed after the patient's death, but there was little change in their perceived support. Carers in the qualitative sub-study reported more favourable support from family and friends than from health care professionals and agencies. Carers reported gaps between their expectations and the support they received, which added to their burden of care; but they made little mention of the need for respite, in contrast to the RNs. The role of the RN toward lay carers seems to be split between generalists and palliative care specialists. Both patients and carers prefer the support of a palliative care nurse, but nurses in this specialised field are under-supplied, particularly in the community setting. RNs who provide palliative care wish for more time; respite, equipping and backup for carers; improved inter-agency links; and more palliative care nurses and specialty training.

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
	Health Services / Health Economics / Quality Improvement
	Qualitative, Observational or Descriptive
X	Mixed Method
	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

Project details:

Funding source (Optional): Queensland Nursing Council

Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: July 2002 (grant application)						
Project completion date: March 2004 (final report)						
Multi site:	**X**	Yes		No		Not applicable

RESEARCHERS

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Associated publications / reports: Home-based care for advanced cancer patients: the impact on family carers. Final Report. March 2004. School of Population Health, The University of Queensland.	
Topics (Admin only) Caregivers, Cancer and cancer care, Setting of palliative care	