CareSearch Project
Research Studies Register: Registration Proforma

0116

Study Title: Seeing the unseen: an exploration of reluctance to care in lay carers of cancer patients

Brief description of the study: The aim of this mixed methods study was to gain a clearer understanding of lay carers' reluctance to care (RTC) for patients with recurrent cancer. Survey data from the final 12 months of caregiving were analysed to explore the context of potential reluctance. Spouses perceived greater family support but caregiving had a greater negative impact on their daily activities and social interaction. Non-spouses were more anxious than spouses, but reported greater social support and less negative impact on their finances, daily schedule and health. Females were more anxious and depressed than males, who reported less burden and greater social support. Awareness of the stage of cancer was positively but weakly correlated with anxiety and depression. The results hinted that RTC was experienced by both spouses and non-spouses and was not gender specific. A purposive sample of carers of patients with recurrent cancer were interviewed in-depth, to explore their perceptions and experiences of caregiving and RTC. Complementary data were obtained from a purposive sample of health professionals who interact with cancer carers. Carers and health professionals held diverging perceptions and expectations of the lay caregiving role. Three fundamental dimensions of RTC were identified: the invisibility of the caregiving role, its lack of boundaries and its forced choices. Caregiving is often a sacrificial rather than reciprocal role, but reluctance is seen as an abnormal rather than realistic response to abnormal role expectations. The lay caregiving role seemed to come as a non-negotiable package of expectations which gave carers the autonomy to accept their role rather than the choice to refuse it. Contextual factors which seem conducive to reluctance were overshadowed by carers' commitment to the role, which suggests that their preferences were a lower priority despite the personal cost. There was indirect evidence of reluctance in others: family members distanced themselves from the caregiving situation, and health professionals were distanced from carers by their patient-centredness. The findings were limited by the extent to which carers disclosed reluctance and the extent to which reluctant carers remained in the role, so RTC may have been underestimated. As the need for lay cancer care continues to expand, this topic remains important.

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

	Epidemiology
	Health Services / Health Economics / Quality Improvement
X	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 Cancer Council/Princess Alexandra Hospital Cancer Collaborative Group

Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: Nov 2005 (ethics application)						
Project completion date: Mar 2009 (thesis submission)						
Multi site:	**X**	Yes		No		Not applicable

RESEARCHERS

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Investigator C (Name)

Investigator D (Name)

Investigator E (Name)

Associated publications / reports:

Seeing the unseen: an exploration of reluctance to care in lay carers of cancer patients. PhD Thesis. 2009, The University of Queensland.

Burridge L, Barnett AG, Clavarino A. The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. *Psycho-Oncology* 2009, Jun; 18(6):615-623.

Burridge L, Clavarino A, Winch S. 2007. Reluctance to care: a systematic review and development of a conceptual framework. Cancer Nursing: An International Journal for Cancer Care, 30(2), E9-E19.

Topics (Admin only) Caregivers, Cancer and cancer care