CareSearch Project Research Studies Register: Registration Proforma	0076

Study Title: The Partners and Caregivers Study: A longitudinal study of the psychosocial outcomes of the partners/caregivers of cancer survivors.

Brief description of the study: The purpose of the Partners and Caregivers Study is to assess the psychosocial well-being and financial impact of caring for or living with a cancer survivor over the first five years post-cancer diagnosis.

Partners/caregivers were referred to this study by eligible cancer survivors participating in a Cancer Survival Study conducted by the research team. The Cancer Survival Study participants were recruited through the Central Cancer Registries of NSW and Victoria. At six to eight months post-diagnosis, in addition to their own survey, Cancer Survival Study participants were sent a separate package to pass on to their partner/caregiver, with an information letter and consent form inviting them to participate in the Partners and Caregivers Study. Consenting partners/caregivers are subsequently surveyed at six months, one, two, three and a half, and five years post-cancer diagnosis of the cancer survivor, in parallel with the Cancer Survival Study participants. Partners'/caregivers' psychosocial outcomes of interest include anxiety, depression, quality of life, unmet needs, social support, coping, and financial and employment impact. In addition, if the cancer patients for which they are caring becomes deceased during the 5-year study period, partners/caregivers are asked to complete a modified post-bereavement survey twice nine months apart to assess predictors of poor bereavement. Currently, data analysis of the Wave 1 (6 months post-diagnosis) is underway. Psychometric analysis of the Supportive Care Needs Survey for Partners and Caregivers (SCNS-P&C), the tool used to measure partner/caregiver unmet needs, has been undertaken using the Wave 1 data. A paper reporting the psychometric assessment is under editorial review.

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

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

Project details:

Funding source (Optional): Cancer Council NSW

Has the study received ethics approval?	**x**	Yes		No		Not applicable
Project starting date: 1/08/05						
Project completion date: In progress						
Multi site:		Yes		No	**x**	Not applicable

RESEARCHERS

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Investigator E (Name)	
Associated publications / reports: Girgis A, Lambert S, Lecathelinais C. The Supportive Care Needs Survey for Partners and Caregivers of Cancer Survivors: Development and Psychometric Evaluation. CANCER (Under editorial review).	
Topics (Admin only) Cancer and cancer care, Caregivers	