

Carers of Cancer Patients: A sociological understanding of their emotional and support service experiences

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This project will be completed in 2009–10. The following is a summary of research outcomes. Study findings indicate that time is a central factor in carers' need and experiences. Some cancer carers experienced little control over their time as they managed multiple roles –working, parenting, caring for elderly relatives and caring for their spouse. In particular, they had little time to experience or interpret their feelings. Carers who experienced more control over their time had more time to feel, more time to reap the benefits of caregiving – growing closer to their spouse – and more time to experience the confusion associated with the contradictory roles of being a carer and spouse.

These differences in what can be called 'time sovereignty' explained much of the variation in carers' support preferences. Those who had control over their time tended to prefer emotion-focused support; those who did not, tended to prefer practical support. For the latter, a central problem was the accessibility and efficacy of financial aid and respite programs.

The findings also indicate that medical personnel rarely recognise spouses as carers in need of inclusion and information on treatment and psychosocial support. Carers' accounts suggest that this neglect may be having a detrimental impact on carers' wellbeing.

Based on these findings, this report makes the following recommendations which provide a frame of action for Cancer Council ACT and Cancer Australia:

1. Make a variety of emotional support options known and/or available to support those time-sovereign carers who are confused about their emotions, but do not feel comfortable in support groups.
2. For time-poor carers, make practical support easier to obtain and more widely known as this would improve their ability to cope with their time poverty.
3. An institutional need is for cancer nurses within the medical system, following the successful model put forward by breast care nurses, to lessen the burden on carers and ensure carers are provided with relevant information and guidance.