

The needs of carers of blood cancer survivors: are there differences between Australia rural and urban dwellers?

As cancer treatments are increasingly delivered on an outpatient basis, the burden on partners, relatives and friends or support persons increases. Such people play a critical role in helping cancer patients manage their care. This can take a toll on support persons' own health and wellbeing. Support persons of blood cancer survivors who often undergo treatments over a long period of time may be at particularly risk. It is important to understand the unmet needs of cancer support persons. An 'unmet need' is an issue which is not adequately addressed by existing health care or support services. Needs may relate to wanting more information, requiring practical support or being able to manage emotional or social needs.

For support persons (and cancer survivors) living in rural areas, there are additional burdens of greater distances to treatment centres, less access to health care providers and support groups, and financial costs associated with having to relocate for treatment. No studies have compared the unmet needs of support persons living in rural areas with those in urban areas.

We surveyed over a thousand support persons (792 urban and 193 rural) of adult blood cancer survivors living across five Australian states. Support persons completed the 78-item Support Person Unmet Needs Survey (SPUNS) which measures the level of unmet need experienced by support persons over the past month across six domains: *Information and Relationship Needs, Work and Financial Needs, Needs for Access and Continuity of Care, Personal Needs, Emotional Needs and Needs relating to the Future*. Each item is scored from zero to four, with '0' representing 'no unmet need' and '4' representing 'very high unmet need'. The majority of support persons in our study were female (67%), aged over 60 years (56%) and the spouse or partner (84%) of a blood cancer survivor. Twelve percent reported having a previous diagnosis of cancer themselves and half of all support persons experienced other non-cancer health problems.

Sixty-six percent of support persons reported at least one 'moderate to very high' unmet need, with a quarter of participants reporting six or more 'high/very high' unmet needs. The most commonly reported needs related to information ("trying to find information about what type of financial help is available & how to obtain it"), personal and emotional issues (eg. "dealing with feeling stressed"; "not sleeping well"), and needs relating to the future (eg. "worry about the cancer getting worse"). There were no differences in the proportion of rural and urban support persons

who had 'some' or 'many' high unmet needs though a higher percentage of support persons in rural (76%) compared with urban areas (64%) had 'at least one' high unmet need. Those from rural areas were more likely to report trouble finding information about financial assistance, obtaining assistance and being able to meet costs associated with care. This is likely due to the greater financial burden imposed by living a great distance from treatment centres. One in three support persons from rural areas had to relocate temporarily while the cancer survivor underwent treatment and 40% reported extensive travel times (2 to 5 hours). Rural support persons were also more likely to report having to take time off work, having less income and using up their savings.

This research shows that support persons living in rural areas of Australia are particularly vulnerable to financial-related unmet needs and highlights the importance of greater efforts to ensure that health care services help with relieving this financial burden by prioritising rural patients' preferences regarding the timing of treatment and proactively provide information about travel subsidies, transport and financial support.

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[A national study of the unmet needs of support persons of haematological cancer survivors in rural and urban areas of Australia.](#)

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