

Beyond childhood cancer: Bringing primary carers into focus

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The research associated with this thesis abides by ‘National Statement on Ethical Conduct in Human Research’, developed jointly by the National Health and Medical Research Council, Australian Research Council and Australian Vice-Chancellors’ Committee (2007). The research was conducted according to approval from the Human Research Ethics Committee (Tasmania) Network (Reference number: H 10250).

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Abstract

Childhood cancer is no longer a universally fatal disease. Four out of five children diagnosed with cancer will now survive the disease due to advances in paediatric oncology in recent decades. Much social science research has focused on children and primary carers dealing with childhood cancer through the acute stages of diagnosis and treatment. Emerging data has also examined the long term health and social implications of children and young adult survivors of childhood cancer. However, primary carers of children whose cancer has abated have not been a focus of research attention. In this sociological thesis I investigate the everyday lived experiences of primary carers of children who have survived cancer in an Australian context. I look beyond the medical success story and beyond the ‘back to normal after cancer’ rhetoric by regarding childhood cancer as a significant disruption in carers’ lives.

I paid particular attention to the ways in which carers constructed meaning and responded in the cancer aftermath by drawing on the symbolic interactionism perspective and a constructionist version of grounded theory. Qualitative data from 38 primary carers was conceptualised to represent a new normal. The findings illustrated how pre-cancer identities and taken-for-granted assumptions and expectations are no longer tenable. Carers responded by constructing a new sense of normality, characterised by insidious cancer memories and the knowledge that they had lost control of their child’s life and well-being. With the abatement of cancer the carers gave new meanings to define their self and

situation, and with particular front stages and back stages of interaction according to their insider or outsider audiences. They also developed new understandings of being a carer of a child in remission; by weaving together new meanings of hope and uncertainty with strategies of emphasising everyday life to mitigate the impact of cancer in their lives. The extent of child morbidities deriving from cancer treatment is the most pertinent constraint in shaping everyday life after cancer rather than cancer *per se*.

By examining childhood cancer and its survival from the participants' perspectives, the thesis offers understandings of health and illness as an ongoing social process that sits between the binaries of acute and chronic illness, cancer and survivorship and children and primary care. The findings offer ways to enhance current and future families impacted by childhood cancer, with policy direction to inform health and allied health professionals and cancer support services.

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To my family and those I am blessed to have as close friends, thank you for your support and believing in me. My one regret is how this thesis represents time taken away from those who I love and cherish.

I dedicate this thesis to past, present and future families impacted by childhood cancer; may you be blessed with health and happiness. And finally, I pay my respect to the memories of those who will stay forever young ...

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