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# **FROM THE WARD TO THE HOME:**

## **Caring for a Family Member Diagnosed with Schizophrenia in New Zealand**

This thesis presented in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Social Policy and Social Work at Massey University by

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## ABSTRACT

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The research question examined in this thesis is: 'What are the characteristics and complexities of the informal care provided within a family to a member diagnosed with schizophrenia, in New Zealand? This research question is divided into two parts. The first part examines the characteristics and complexities of the unpaid caring work provided to a family member diagnosed with schizophrenia and the second part explores how this care provision is influenced by the social, political, cultural, legal and economic context of New Zealand. This research is important because first, very little is known about the process and interpretation of care provided to a family member diagnosed with schizophrenia and second, New Zealand places great emphasis upon deinstitutionalisation and community care.

Ten women and four of their husbands were invited to participate in this research. These women were the primary informal care-givers of a family member who had experienced the cyclical acute and chronic episodes of schizophrenia. The women's husbands filled a secondary supporting role in relation to the women. The women met to identify themes related to their informal care provision. These themes were translated into an interview guide which acted as a prompt for the researcher while the women and men were articulating their stories of care-giving.

Foremost amongst the findings of this research was that the dominant understandings of care should be extended in order to reflect the informal care provided to a family member diagnosed with schizophrenia. The men supported the women's care provision which reflected their family member's unpredictable, changeable and cyclical symptoms of schizophrenia. It was characterised by the primacy of supervision and monitoring and was provided on a continual (flat-line) basis. It was also established that the women were finding it increasingly difficult to meet their informal caring responsibilities, these responsibilities being increased and extended by the Government's actions to reduce both state expenditure and state caring responsibilities. The

difficulty the women were experiencing in meeting the complex and changing care needs of their family member indicated that a continuum of care needs to be provided. It is argued that a continuum of care will need to include early intervention services, a range of community-based and institutionally-based mental health services, and a review of the definition of 'mentally disordered' contained within the Mental Health (Compulsory Assessment and Treatment) Act 1992. In order to coordinate and provide such a continuum of care, state, community and family caring responsibilities need to be combined, these three caring agents working collaboratively.

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## ACKNOWLEDGMENTS

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When beginning the task of completing this thesis, I had little appreciation of how difficult, and at times, how daunting this task would be. It was the encouragement and support of many people which facilitated the completion of this thesis. It is to some of these people that I now express my appreciation.

The richness and detail presented in this thesis stems primarily from the experiences, feelings, and thoughts expressed by the women and men who participated in this research. Each one of these individuals shared aspects of their lives through telling me their stories of the care they provided to their family member diagnosed with schizophrenia. I acknowledge their commitment to their caring work and wish them well as they face future challenges this commitment will undoubtedly bring them.

Much support, inspiration and sound advice was provided by my supervisors Robyn Munford, Mike O'Brien and Celia Briar. Robyn, as chief supervisor, was a constant presence from the very beginning to the end. Robyn's own involvement with care-giving work, both professionally and personally, provided a standard by which my work could be measured. Mike became my second supervisor when Celia went on sabbatical leave to England.

I gained both a national and local understanding of the complexities of providing care to a family member diagnosed with schizophrenia, in New Zealand, by my involvement with Schizophrenia Fellowship. The assistance and support Schizophrenia Fellowship provided the participants is highlighted in this thesis.

On a day-to-day basis I was given much assistance and personal support from friends and members of my family. Your reward for this assistance and support will be seeing me engage the world with the time I used to spend working on my thesis. The possibilities are endless.

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