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Family Preparedness for  
Life with a Traumatically Brain Injured Relative

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## ABSTRACT

The numbers of people surviving traumatic brain injury are increasing, as medical technology and crisis management systems improve. The demand for rehabilitation and support services outstrips supply and typically it is the families of individuals with brain injury who step in to meet the shortfall in services. Yet families are rarely prepared for the changes traumatic brain injury brings. It was a premise of this study that well prepared families would be more likely to understand what was required to effectively facilitate their injured relative's recovery, and be more capable of doing so, than families that were not well prepared.

Using an evolving methodology, this three-phase mixed method study set out to investigate family preparation for life with a brain injured relative, focusing on the period where the injured relative was an inpatient at a rehabilitation facility in the Manawatu, New Zealand. Semi structured interviews and a self-administered mail questionnaire were employed to examine the roles performed by family members following their relative's brain injury, and their perceptions of the preparation they received for these roles and for the effects of role performance on their own lives, while their relative was an inpatient at the Rehabilitation Centre.

The study found that family members often played a critical part in their relative's recovery from injury, assuming one or more of the roles of caregiver, case manager and therapist. Consistent with the literature, many family members considered they had not been adequately prepared for these roles during the period of inpatient treatment and suggested many changes were required to the way in which the process of family preparation was approached.

From the experiences reported by family members, an evidence-based model of family preparation was developed to guide family preparation initiatives during the period of inpatient rehabilitation. The model is based on the premise that each family has unique preparation needs, reflecting the different capabilities of their brain injured relative, the family's social capital, and the range of professional and lay services available to the injured relative and the family at any given time. The changes to family preparation proposed in the study include enhanced collaboration between families, practitioners

and agencies, greater inclusion of families in the inpatient phase by practitioners, and the adoption of a more planned approach to family preparation. These changes are largely achievable within existing resource constraints.

## ACKNOWLEDGEMENTS

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