



The University of Sydney

Sydney Nursing School

Doctor of Philosophy project Laynie Pullin

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Title: Living with and providing support to people with spinal cord injury: experiences of long-term family carers.

Background

A literature search conducted in 2009 revealed that little is currently known about long-term family care-giving in this context, particularly in relation to the experience of carers of people with spinal cord injury who are beyond 5 years post injury. There is a dearth of qualitative research in this area. A long-term family carer is defined as a family member who has been living with, and providing “active support” to, a person with a spinal cord injury for 10 years or more.

Aims & Methods

This project aims to explore the life experiences of partners and other long term family carers living with and supporting people with spinal cord injuries. It will also explore long-term family carers’ perceptions of how they are currently supported by health and other community-based services. A qualitative approach is used to explore participants’ experiences. Framed within a grounded theory approach (Charmaz,2006), in-depth interviews and small focus groups will be used for data collection. Concurrent data analysis will involve the development of theoretical conceptualizations of participants’ experiences. On-line blog interactions will be used if theoretical sampling is needed to develop the researcher’s emerging categories. The purpose is to obtain data to further elaborate on emergent themes of interest (Charmaz, 2006).

Potential Significance

The project may make a significant contribution to the carer/health/rehabilitation arena and will provide rich data for relevant policy makers. Results may provide new information about another important group of long-term family carers whose experiences are currently not well understood.ⁱ

Progress & timeline 2010-2011

1. Literature review and community services review completed in 2009.
2. HREC Approval for Study given July 14, 2010.
3. Recruitment commences August 2010.
4. September 2010: Data collection to commence
5. July-Sept 2011: Data analysis to be completed

ⁱ Charmaz, K. (2006) *Constructing grounded theory: a practical guide through qualitative analysis*, London, Sage.