

# The Pursuit of Excellence

## Promoting Evidence-Based Nursing Practice in CHRONIC ILLNESS MANAGEMENT

### RESEARCHING THE EXPERIENCE OF LIVING WITH CHRONIC ILLNESS

#### ***What is happening in the Research Unit?***

In the last few years an internationally recognised research program has developed in the RDNS Research Unit. In 1997, CNAs and CNCs Diabetes, together with Professor Tina Koch and Dr Debbie Kralik, commenced a series of collaborative research projects with people who live with chronic illness. The research questions have emerged directly from the practice of district nurses who have realised that most of their clients lived with chronic illness, but had varied self care management approaches which ranged from effective to deficient. Our research interest has focussed on how community nurses can facilitate people living with chronic illness to live 'well', by promoting effective self care management approaches that are both relevant and meaningful to the daily lives of clients.

#### ***Why research the experience of living with chronic illness?***

Approximately 70 percent of RDNS clients live with chronic illness, so it is very important for us to understand what it is like to live with long term illness. If community nurses have an understanding of the process that enables people to incorporate chronic illness into their lives, a substantial contribution will be made to promote chronic illness self care management.

#### ***Who have you researched with?***

Debbie Kralik researched with 81 women living with chronic illness as part of her PhD. In addition, we have convened 11 groups of people (a total of 80 participants). The participants have been:

- Two groups of women living with Multiple Sclerosis and urinary incontinence;
- One group of men living with Multiple Sclerosis and urinary incontinence;
- One group of women living with Multiple Sclerosis exploring issues of sexuality;
- Two groups of men living with Type 2 Diabetes;
- Two groups of women living with Type 2 Diabetes;
- One group of men and women living with arthritis;
- Two groups of men and women living in the community with mental illness.

The participants have been middle class men and women (average age of 52). In each group, our intent was to discover ways that men and women self managed chronic illness, however we wanted the participants to identify and discuss issues that were important to them. An average of seven group

meetings, with each meeting lasting between two to three hours, has been held with each group.

#### ***How has the research been undertaken?***

We have used the work of Dr Ernest Stringer, who visited RDNS in October 2001. Ernie developed principles for Participatory Action Research (PAR) where participants can collaborate in the research process. With the participant's consent, data was generated as the Nurse Consultants and the researcher hand wrote comprehensive notes, and recorded profound statements verbatim, noting participants' gestures and other interactions.

#### ***What have been the findings?***

Dealing with the impact of chronic illness such as Multiple Sclerosis or Diabetes is one of the most traumatic experiences that anybody can undergo. The feelings of disruption, isolation, powerlessness and loss that accompany the impact of chronic illness are a form of "Extraordinariness" that are a great challenge for any of us. But everybody who goes through this process does deal with it - some successfully, others not so. The initial impact of diagnosis is shattering - in fact people describe their world "laying like shattered glass at their feet." Their future becomes blurred and their sense of direction for their lives is distorted in those shattered fragments.

The illness becomes a focal point in their lives and there is a lack of control over the disruption to their lives. They may be confused by all the medical jargon flying about them. Often their physical appearance changes, they feel betrayed by their bodies and daily routines may be difficult.

There is a powerful sense of loss - loss of the ability to work in paid employment; the loss of standard of living; the loss of sexual feelings and sexual practices; the loss of the ability to parent effectively; the loss of spontaneity in life; the loss of control over their lives and their bodies, and changes to relationships.

Self-absorption dominates their perspective on life; however our research tells us that the process of thinking through and turning over these thoughts and feelings is very important to the transition back to "Ordinariness". In this way, people can learn to manage and incorporate the constant and at times unexpected change of chronic illness into their daily lives. The interesting question is what motivates people to learn and develop?

We have found that telling and listening to each others stories is one means of empowering people. In our groups people told of their experiences and listened to others; sharing stories and being 'heard' for the first time

encourages people to take action to control their own lives.

How people see themselves is very important. Being labelled as 'sick' means that how you think of yourself changes dramatically, especially when the body becomes unreliable and does not function in familiar ways. Many women with Multiple Sclerosis for instance talk of a split between their body and their self. Sexual relationships are an area of particular difficulty because in a sexual situation bodily changes cannot be concealed.

We found that people who are in a supportive relationship do better as do those where there is the positive influence of support people. Being acknowledged by others helps being able to build one's new identity. When people describe reclaiming control of their lives, they are not saying they have accepted the illness, rather that they now manage their lives and, through reflection, have developed a changed perception of self. Illness becomes a part of life.

Actively making choices to reshape their lives provides an important sense of progress. It becomes important to learn to 'go with the flow'. Feelings of being betrayed by their body are replaced with a desire to nurture it. People absorb information and learn skills that assist the transition, learning about their illness through daily life experiences and trial and error.

People develop a sense of mastery over and responsibility for their responses to illness. Through the day to day experience of living with illness, people learn that to maintain themselves in Ordinarity means creating a delicate balance in their lives. One participant, Ros, shared her metaphor that maintaining a balance was like being in a small boat. It was paramount that one remained steady because it was easy to capsize the boat, and very difficult to re-establish balance once you were over-board. To become unbalanced may risk a fall into the murky waters of Extraordinarity.

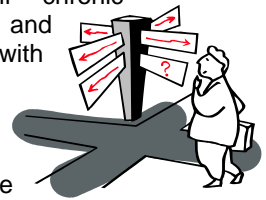
### **How is this research useful to RDNS nurses?**

Understanding the experience of transition in chronic illness is very important for RDNS nurses because it helps us to help people to "self-manage" their illness - to put some power back into their own hands. One important aspect of this research has been that participants have experienced a sense of validation through sharing their illness experiences.

A person living with chronic illness may find him/herself embroiled in a series of disordered and dynamic life events that may result in loss of bodily and social functioning, financial strain, family distress, personal distress, stigma, and threats to the former self-identity.

Be interested in your client's experiences, ask questions, help them reflect on how far they have come in this process of transition and assist in mapping their plans for the future.

If RDNS nurses can understand the process that facilitates people to move toward incorporating chronic illness into their lives, we can make a substantial contribution to enhance their chronic disease self care management and promote direction in their lives with illness.



### **Where can I find out more?**

The findings emerging from the Chronic Illness Research Program have been widely published. Our full publication list is available on the RDNS web site, however some of our chronic illness research publications are listed below. Alternatively Tina Koch and Debbie Kralik can be contacted through the RDNS Research Unit (see contact details below).

*Professor Tina Koch: Director, RDNS Research Unit  
Dr Debbie Kralik: Research Associate, RDNS Research Unit*

### **Our Chronic Illness Research Publications**

Koch T and Kelly S (1999) Identifying strategies for managing urinary incontinence with women who have multiple sclerosis, *Journal of Clinical Nursing* 8, 550-559.

Koch T and Kelly S (1999) Understanding what is important for women who live with multiple sclerosis, *The Australian Journal of Holistic Nursing* 6:1, 14-24.

Koch T, Kralik D and Kelly S (2000) 'We just don't talk about it': men living with urinary incontinence and multiple sclerosis, *International Journal of Nursing Practice* 6, 253-260.

Koch T, Kralik D and Sonnack D (1999) Women living with type two diabetes: The intrusion of illness, *Journal of Clinical Nursing* 8,6 712-722.

Koch T, Kralik D and Taylor J (2000) Men living with diabetes: minimizing the intrusiveness of the disease, *Journal of Clinical Nursing* 9, 247-254.

Koch T, Kralik D (2001) Chronic illness: reflections on a community-based action research programme, *Journal of Advanced Nursing*, 36(1), 23-31.

Koch T, Kralik D, Eastwood S and Schofield A (2001) Breaking the Silence: Women living with Multiple Sclerosis and Urinary Incontinence, *International Journal of Nursing Practice* 7, 16-23.

Kralik D, Brown M, Koch T (2000) Women's experiences of being diagnosed with a long term illness, *Journal of Advanced Nursing*, 33(5), 594 – 602.

Kralik D, Koch T, Telford K (2001) Constructions of sexuality for midlife women living with chronic illness, *Journal of Advanced Nursing*, 35(2): 180-7.

Kralik D, Koch T, Webb C (2001) The domination of chronic illness research by biomedical interests, *Australian Journal of Holistic Nursing*, 8(2): 4-12.

Koch T, Selim P and Kralik D (2001) Enhancing lives through the development of a community based participatory action research program, *Journal of Clinical Nursing*, 11 (1) 109-118.

Kralik D. (2001) The quest for Ordinarity: Transition experienced by midlife women living with chronic illness, *Journal of Advanced Nursing* (in press).

Eastwood S, Kralik D, Koch T (2001) Compromising and containing: self-management strategies used by men and women who live with Multiple Sclerosis and urinary incontinence, *Australian Journal of Holistic Nursing*, (Accepted for publication March 2001).