

## Promoting Evidence-Based Nursing Practice in SELF MANAGEMENT OF ARTHRITIS

### Self-management from the perspective of people living with arthritis

#### INTRODUCTION

This paper reports the findings of a study that aimed to understand the meaning of 'self management' for community dwelling men and women living with arthritis. In this newsletter we report a small section of the study. The word arthritis means joint inflammation and is often used to refer to a group of more than 150 types of arthritis. These diseases commonly affect the joints but also other parts of the body, including important supporting structures such as muscles, bones, tendons, and ligaments, as well as some internal organs. Pain and restricted movement are the main physical symptoms. It is estimated that there are more than three million Australians living with arthritis and it costs about \$2.24 billion a year in direct health system costs (Arthritis Foundation of Australia 2001). Most importantly, arthritis can exact a major personal and financial toll on the individual and family through pain, disability, reduced self-esteem, and loss of income. Self-management has been promoted as a way of living optimally with the physical and psychosocial effects of arthritis (Lorig and Holman 1993).

#### WHY STUDY SELF MANAGEMENT?

The term 'self management' makes reference to the activities people undertake in order to promote personal health and to detect and treat common health problems. There is an abundance of literature related to the treatment and development, implementation and evaluation of arthritis self management programs. It is important to emphasise that much of this literature however is from the perspective of health professionals and has a patient education focus (Hill 1995; Donaldson et al 2000). The underlying assumption is that if the patient is adequately educated they will successfully self manage arthritis (Barlow et al 1999; Barlow et al 2000). Self-management education programmes are orchestrated for people living with arthritis (Lorig & Holman 1993) and it is accepted that if people know the reasons why and how they should make effective self-management decisions, they will do so (Anderson 1995; Patterson et al 2001).

Self-management is reported as being central to the successful management of the pain and disability associated with arthritis (Lorig & Holman 1993) and people have an improved chance for a rewarding lifestyle when they educate themselves about the disease and take part in their own care (Barlow, Williams & Wright 1999). Research has revealed that patients who take part in their own care report less pain, make fewer doctor visits and enjoy a better quality of life (Lorig et al 1988; Barlow et al 2000). What has not been researched is the perspectives of people who live with arthritis and the way in which they view self-management.

#### WHO PARTICIPATED IN THE RESEARCH?

We researched with nine people who live in the community with arthritis. Participants were six women and three men aged between 48 and 75 years (mean 60 years) and had lived with arthritis from between 4 and 52 years (mean 17 years). People living with arthritis were invited to join the study by responding to pamphlets placed in local pharmacies and a small article in a local newspaper. Information about the study was posted to people who expressed interest. Participants were asked to post the consent form with a story about themselves that provided an introduction to their life and experiences of living with arthritis.

#### HOW WAS THE RESEARCH CONDUCTED?

Two telephone interviews were conducted with each participant. The first was for the purposes of the researcher introducing herself, reviewing the purpose of the research, providing the participant with the opportunity to ask questions and to arrange a suitable time for a longer conversation. It was anticipated that the interview guideline would help to structure and focus the content of each interview (Lavrakas 1993; Barriball et al 1996).

#### WHAT WERE THE FINDINGS?

Participants revealed that self-management is the complex ways in which the individual perceives, manages and takes action in response to the disorder created by the symptoms and disability associated with arthritis. It is important to state that managing pain was the single most important aspect of self-management. Uncontrolled pain can impact on every aspect of one's life. Jon said:

*... it gets me down when I can't control the pain... 'If I didn't have the pain it would make the world of difference... pain is a constant companion. I have to consider it before everything I do.*

The self-managed creation of order is further explained by four themes:

- Recognising and monitoring the boundaries and identifying the possibilities
- Mobilising the resources
- Managing the shift in self identity
- Balancing, pacing, planning and prioritising

We will elaborate on the themes.

#### Recognising and monitoring the boundaries and identifying the possibilities

Monitoring disability and pain are important features of the experience of living with arthritis. When in pain, participants were reminded that their bodies could not consistently be relied upon to do what they wanted. The experience of pain however, was not just a physical event because it can have far reaching ramifications. It can be disordering, disruptive and a constant reminder of personal boundaries and dependencies. Jackie explained:

*The hardest thing I have found to cope with, apart from the pain is the restriction on my activities and the fatigue. Not being able to pick up my grandchildren has been fairly awful, especially if they hold their arms out.*

The taken-for-granted aspects of every day activity are relinquished for a life of close scrutiny. Such scrutiny or monitoring was important however in order to examine the ways that one responds to various activities or events. It creates a familiarisation with boundaries and an identification and understanding of the possibilities. The interpretation of living with an illness like arthritis is an ongoing process because people reinterpret their situation as the illness makes its impact in different ways. For Jan, self-management meant, 'studying yourself and your reaction to activities... work out what your limits are'. Reflecting on life as a way of understanding the boundaries and identifying the possibilities was important because '... you need to know what causes the pain... its understanding and knowing what is happening'. Understanding the boundaries enabled one to know personal limitations and to move forward without constant assault to self-esteem because something could not be achieved. Jim said: 'You've got to do things that are realistic for you...you've got to limit yourself to your capabilities...I take one day at a time...I keep moving and I keep busy.' Jim has learnt to use distraction as a way to control pain, 'I don't notice the pain until I sit down...I let my work overtake the pain.'

### Mobilising the resources

If people regularly display or discuss their pain they fear wearing down other peoples sympathy and placing strain on their social networks. Jackie recognised that she protects others around her from the effects of arthritis (the motivation being the fear of a lack of understanding from others) but there were also protective behaviours that she employed for herself. One of those behaviours was not to talk with others about arthritis, unless in the safety of an individual or a group of people who also experience arthritis. A common element in people's stories was maintaining independence and to work out ways of achieving this. Maintaining independence facilitated a sense of control. Jane talked about, *'keep yourself going for as long as possible and manage your own life'*. Jan said, *'If you want to do something then work out how to do it and what you need to do it... you can usually find a way to get things done'*. While people said there were some activities that they needed to ask for the help of others, there was a focus on knowing what one could do for themselves and mobilising the resources necessary to achieve it. Jo explained:

*I balance what I am doing, I try to be much more efficient and I am conscious about the use of certain joints... this is very much a conscious living... I can't take anything for granted.*

### Managing the shift in self identity

Managing arthritis pain was often a focus point for self-management. Self-management of pain required pharmacological and non pharmacological components. Pain and physical limitation can be a threat to one's integrity and self identity because individuals with arthritis must confront and manage a host of issues associated with daily activities that others take for granted. Reflecting on life before arthritis Jon said, *'could do anything I wanted to without even thinking about it.'* In giving advice to someone else, he said *'I think I would recommend that they build up confidence.... Don't give up on things but replace them with something else'*. Jim has long recognised the place of self-management in his life with arthritis and believes the key is planning. He said *'I plan and I take control... sitting around mopping doesn't do you any good.'*

### Balancing, pacing, planning and prioritising

Daily activities must be paced in order to tolerate or not aggravate the pain and they must balance the undesired side effects of medication against the benefits of pain reduction. Planning and prioritising were closely linked with accepting and managing the action needed for change. Jon said that there had been a positive side to having arthritis because it *'has made me look at change ... made me consciously incorporate change into my life'*. Jon revealed: *'I have to consider everything that I do... if there is an alternative way of doing things then I find it'*. Managing change to create order was the impetus for taking control, *'don't give up, but be prepared to change your lifestyle....don't rely on other people... take action in your own life'*.

Pacing was as important as planning Jackie said, *'I have learned to pace myself and when I am tired, to rest... I have given up on my guilt trips and am learning to live with my arthritis'*. Jackie's arthritis is managed by *'medications, exercise and changing the way I do things'*. *'Managing pain is the main issue for me'*. Jackie has several strategies for managing pain such as *'the application of heat, anti-inflammatory medications, and keeping moving by walking and exercising'*. Rest was important for participants:

*Rest is one of the hardest things...laying down and not feeling guilty when there is someone in the background who is very busy... my husband made me feel guilty at first [when resting] but not now.*

### WHAT CAN COMMUNITY NURSES LEARN FROM THIS RESEARCH?

The journey towards the creation of order in ones life when living with a chronic illness can be long and winding with numerous challenges obscuring the view ahead. This study has thrown light on the convoluted process of self-management of chronic illness. Listening to the perspectives of people living with arthritis raises the awareness of community nurses. Self-management enables the client to take a 'holistic' approach to their own health care rather than be segmented into the bits and pieces espoused by our mainstream health system. Some strategies that community nurses may use with clients to facilitate self-management include:

- Ask the client what they would like to achieve (what is important for them?)
- Provide relevant information based on what they want to achieve (not necessarily what you or the GP would like them to achieve)
- Allow clients the time to come to terms with the information and changes taking place in their lives
- Consider ways to facilitate the client having control. Provide choices to make final decisions
- Engage with them and developing relationships. Find commonalities between you and your client
- Consider their environment and their lifestyle choices
- Search for and identify benefits of self-management. Provide reassurance and positive support.
- Set small achievable goals so the person can see success. Assist clients to reflect on the progress being made or other ways that may be effective in addressing the problem.



*We will let Julie have the last word:*

*"Self-management is about finding a system that works... I am always adapting, planning and prioritising... thinking about ways to change my usual habits. I manage myself. You have got to have that control or you can sit down and let the world go by".*

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*This issue researched by Debbie Kralik and Tina Koch, RDNS Research Unit.*

Contact Details: Research Coordinator, *RDNS Research Unit*, PO Box 247, GLENSIDE SA 5065, Ph: (08) 8206 0111, Fax (08) 8206 0010, Email: [howard.natalie@rdns.sa.gov.au](mailto:howard.natalie@rdns.sa.gov.au), Web: <http://www.rdns.net.au> (newsletter available on website)