

Chronic illness self-management: taking action to create order

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Background. This paper presents research that was framed by our early understandings about the ways that people incorporate the consequences of illness into their lives. The word ‘transition’ has been used to describe this process. We believed self-management to be central to the transition process but this assertion required further research, hence this paper.

Aim. The research aimed at understanding the way in which people who lived with chronic illness constructed the notion of self-management. While the participants of this study were living with arthritis, the focus was on understanding the meaning of self-management rather than the experience of living with the symptoms of arthritis.

Approach. Data were generated when nine people living with arthritis were invited to write an autobiography about their life and experiences of living with illness. Two telephone interviews were recorded with each participant and then the research group (researchers and participants) convened for a discussion meeting.

Findings. In contrast to health professionals who identify self-management as structured education, participants identified self-management as a process initiated to bring about order in their lives. Creating a sense of order, or self-management, had four key themes (i) Recognizing and monitoring the boundaries, (ii) Mobilizing the resources, (iii) Managing the shift in self-identity, (iv) Balancing, pacing, planning and prioritizing

Conclusions. People learned about their responses to illness through daily life experiences and as a result of trial and error. They reconfigured their daily lives and reconstructed their self-identity by exploring their personal limitations or boundaries. Self-management of chronic illness has been considered as both structure and

process, however it is the process of self-management that we contend is central to the experience of transition.

Relevance to clinical practice. Clinical nursing intervention for people with a long term illness may be enhanced when self-management is approached from a broad, contextual perspective and self-management processes are integrated into clinical practice. The challenge is for nurses to embrace processes in nursing practice that will facilitate interactions with clients without obstructing the diversity of perspectives, create an environment conducive to learning and engage individuals in identifying self-management strategies that have meaning in their lives.

Key words: chronic illness, community nursing care, self-care, self-management, transition

Introduction

Over the past 5 years a chronic illness research programme has been developed which has involved collaboratively researching with 180 men and women who live in the community with adult onset chronic illness (Koch *et al.*, 1999, 2000, 2001, 2002a,b; Kralik *et al.*, 2000, 2001a,b; Koch & Kralik, 2001; Kralik & Koch, 2001; Eastwood *et al.*, 2002; Kralik, 2002). Within the context of this chronic illness research programme, a study was recently completed that aimed to explore the meaning of self-management for people living with chronic illness. The study focused on understanding the meaning of self-management to men and women living with arthritis. Clarifying this focus is important, because the study did not seek to explore the experience of people living with arthritis. Self-management was assumed to be a familiar concept for these people, given that those organizations that support them had embraced an Australian wide-structured, self-management programme (Arthritis Victoria, 2002).

In this paper, the emerging theoretical concerns from the chronic illness research programme and the meaning of self-management as perceived by people who have a chronic illness will be outlined. The study was granted ethics approval by the organizational ethics committee and names used in this paper are pseudonyms.

Transition thesis

This study is framed by our early understandings about the ways people incorporate the consequences of illness into their lives. The word 'transition' is used to describe this process and other research on the concept of transition has come from nurses where the focus has been on the experience of transition during a life crisis (Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994; Meleis *et al.*, 2000). Our research interest has been on understanding

the experience of transition in chronic illness (Koch & Kralik, 2001; Kralik, 2002).

Research on a similar construct (transformation) in chronic illness (Paterson *et al.*, 1998; Thorne & Paterson, 1998; Paterson *et al.*, 1998) seems closely aligned to the present work. Transformation occurs when the burden of illness is replaced by the perception that it has enhanced the quality and meaning of life, by enabling people to experience life in a way that was previously inaccessible (Lamendola & Newman, 1994; Finfgeld, 1995; Halldorsdottir & Hamrin, 1996). This research contradicts these findings because we contend that living with chronic illness is a constant process that includes being vigilant of bodily responses, careful planning of daily activities and learning new strategies. Furthermore, we believe self-management to be integral to the transition process but this assertion requires further research.

Self-management

The term 'coping' is used interchangeably with self-management. Coping is a complex construct with many definitions, however a distinction is drawn here by adopting the definition of coping as being a state of tolerating, minimizing, accepting or ignoring things that cannot be mastered (Richardson & Poole, 2001). The term 'self-management', however, makes reference to the activities people undertake to create order, discipline and control in their lives.

Self-management has been reported as enabling people to minimize pain, share in decision making about treatment, gain a sense of control over their lives (Lorig & Holman, 1993; Barlow *et al.*, 1999), reduce the frequency of visits to medical doctors and enjoy a better quality of life (Lorig *et al.*, 1998; Barlow *et al.*, 2000).

Although self-management is assumed to be relevant across chronic illness, the literature is predominately focused on arthritis. The focus of this literature is the treatment, development, implementation and evaluation of self-management

programmes (Barlow *et al.*, 1999; Barlow *et al.*, 2000). The majority of the literature is about the Arthritis Self-Management Program (ASMP) which is a 6-week course developed by Lorig *et al.* (1998) at Stanford University. It is based on concepts of self-efficacy and behaviour change and is 'taught' in a group format with a 'train the trainer' approach. These self-management education programmes were initially designed for people living with arthritis (Lorig & Holman, 1993), but more recently the authors argue for the programme's applicability across chronic conditions.

Motivation to absorb the education provided by the programme assumes that if people know the reasons why and how they should make effective self-management decisions, then they will do so (Anderson *et al.*, 1991; Paterson *et al.*, 2001). Authors report self-management to be central to living successfully with arthritis, because people have an improved chance for a rewarding lifestyle when they educate themselves about the disease and take part in their own care (Lorig & Holman, 1993; Barlow *et al.*, 1999). Much of the chronic illness self-management literature is from the perspective of health professionals (Hill, 1995; Donaldson *et al.*, 2000). However, relying on a prescriptive, education-focused, professionally driven programme assumes that if individuals are provided with adequate education, they will self-manage illness.

People with arthritis have used a variety of creative and innovative strategies to relieve symptoms or manage the consequences of the disease (Boisset & Fitzcharles, 1994; Eisenberg, 1996; Peck, 1997; Bath *et al.*, 1999; Jordan *et al.*, 2000; Taylor, 2001). The long-term and progressive nature of arthritis provides the individual with an important role in managing their condition (Jordan *et al.*, 2000; Taylor, 2001). However, much of the literature assumes that self-management means the same to all people, and researchers (Paterson *et al.*, 2001; Thorne & Paterson, 2001) have contested the meaning ascribed to self-management. It has been identified that there are many factors influencing the way people self-manage long-term illness, in particular the meaning they ascribe to the self-management process (Thorne & Paterson, 2001).

Participants

People living with arthritis were invited to participate in the present research by responding to a brief article placed in a community newspaper. Information about the study was posted to people who expressed interest. Participants were nine community dwelling people with arthritis, several that also had other illness or disability including diabetes, osteoporosis, palsy, depression and stroke. Participants were

six women and three men aged between 48 and 75 years (mean 60 years) who had lived with arthritis from between 4 and 52 years (mean 17 years).

Data generation

Data generation commenced when participants were asked to write or record an autobiography about their life and experiences of living with illness.

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 convenient time for a longer conversation. In order to support our research strategy, it was noted that the telephone interview has achieved credibility in the research literature as a legitimate means of data generation (Oskenberg & Cannell, 1988; Oppenheim, 1992; Lavrakas, 1993; Barriball *et al.*, 1996).

One participant requested a face-to-face interview and that conversation was recorded in the person's home. The second telephone interviews lasted for an average of 85 minutes. The questions for the interview were semi-structured to ensure the same questions were asked of each participant. The questions were: 'what were your experiences of seeking medical help?; what was it like when you received a diagnosis?; what implications did you think this illness would have for your life?; how did you perceive the people around you coped or reacted to your diagnosis?; how do you live with arthritis?; what are the sorts of things that help you to live with arthritis?; could you share an experience that you will never forget because it best describes what it means to live with arthritis?; what was important for you before arthritis and what is important for you now?; how has life changed for you?; and what advice would you give to a friend who has just been diagnosed with arthritis?'. It was anticipated that the interview guideline would help to structure and focus the content of each interview (Lavrakas, 1993; Barriball *et al.*, 1996). Participants stated that telephone interviewing was convenient, not intimidating, not time consuming and overcame the difficulty with mobility that some participants experienced. Notes were taken during the telephone interviews and transcribed as soon as possible.

Data were also generated when participants and their partners attended a dinner meeting where they were invited to discuss and provide feedback on the preliminary research findings. This meeting was recorded and transcribed. The first author conducted telephone interviews and facilitated the dinner meeting with participants. While quotes from individuals have been used to explain the findings, the self-management

constructions have emerged from analysis of the collective transcripts and stories told by the participants.

Data analysis

This inquiry comprised three data sets, those being the participants' written stories, interview transcripts and data from the group meeting with participants. Recurring constructs across the data sets were located by a constant comparative approach. Distinctive features and common themes, issues and concerns from each of the data sets were preserved and discussed by the authors. Feedback to participants and validation of the emerging constructions occurred in the group meetings.

Findings

This study revealed self-management to be a multi-dimensional construct involving complex processes where the purpose was to create order from the disorder imposed by illness. Four themes emerged which were titled: recognizing and monitoring the boundaries; mobilizing the resources; managing the shift in self-identity; balancing, pacing, planning and prioritizing.

Recognizing and monitoring the boundaries

Pain for the person with arthritis was a 'companion' and managing it and the associated restriction in movement and strength were the motivating factors of self-management. Not being able to free oneself from pain can impact on every aspect of a person's life as Jon explained:

...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.

Pain created the boundaries in everyday activities and would remind participants that their bodies could not consistently be relied upon. Pain created disorder and disruption, and was a constant reminder of boundaries and dependencies.

The taken-for-granted aspects of every day activity were relinquished for a life of close scrutiny. Such scrutiny or monitoring was important, however, to allow examination of the ways that one responds to various activities or events. Monitoring created a familiarization with boundaries and identification and understanding of what may be possible. 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.

As an alternative to lifting up her grandchildren, Jackie came to understand that quality time could be spent with the children when they sat together reading or engaging in other activities.

The interpretation of living with an illness was an ongoing process because people reinterpreted their situation as the disease made 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'.

Recognizing the boundaries as well as identifying the possibility of achieving daily activities in other ways was pivotal to a sense of independence. It was important however, not to relinquish the advantages gained. Jane said, '...once you stop doing activities you can't get them back'.

Understanding the boundaries involved an exploration of one's personal limitations and enabled a sense of progress 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.

Mobilizing the resources

Mobilizing the resources meant identifying, understanding and making the most of what was available to help one to live well. Resources could be psychological, physical and material. Mobilizing the resources incorporated protective behaviours. Jackie recognized that she protected others from the effects of arthritis (the motivation being the fear of a lack of understanding from others) but she also employed protective behaviours for herself. One of these was not to talk with others about arthritis, unless in the safety of an individual or a group of people who also experienced arthritis. Participants suggested, that if they displayed or discussed their pain on a regular basis, they might place strain on their social networks. Lack of involvement in everyday activities may force people to withdraw from others, which can lead to a

sense of isolation. Interactions with others were a way of reinterpreting and understanding events. It was a validating experience to hear the stories of others and to be given the opportunity to share their own.

A common element in participant's stories was maintaining independence and identifying and learning 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 assistance with, they focused on knowing what they could do for themselves and mobilizing 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.

James felt he was missing out on active play with his grandchildren. He thought about ways he could mobilize the resources to create possibilities for active play. James said, 'I've made a trolley so I can pull the grand-kids around.' This enabled him to feel a valuable part of their quality playtime. However, compromising and planning was evident in the conversation as he said, 'I usually find other ways of doing things'.

Managing the shift in self-identity

The participants experienced physiological symptoms as well as convoluted, contextual disruption to their work and family relationships and future plans, which for some, led to a profound loss of self and shifts in identity. The experience of learning to live with chronic illness involved a process of shifts in self-identity as the individual grasped the sense of self that was before illness intruded on their life. Kralik (2002) conceptualized this transitional process as the quest for 'Ordinariness'. This quest involved people developing an altered perception of self such that illness may become a part of life. Shifts in self-identity, when living with chronic illness and the struggle for self-preservation, involved an ongoing process of negotiation and verbal accounting or story telling (Charmaz, 1983; Kelly, 1992; Kralik, 2002). Shifts or disruptions in self-identity may be influenced by past and present life experiences as well as experiences with the illness as participants questioned who they were with arthritis.

The participants revealed that the assault to self-identity from the experiences of living with arthritis were profound. They endured a significant shift in their perception of self,

and the way in which they experienced their changed body. ...Jan said 'I feel ugly, I am self-conscious about my body and I hate the look of my hands'. This in turn impacted on the way they presented themselves to others.

Jo described one of her most desperate times when she was watching an outside sporting event and found herself to be stranded:

unable to step up one small step and being stuck when it was getting dark...everyone had gone inside. I spent hours crying after I was rescued and can still visualize the feelings surrounding the event.

Jo's assault to her self-identity culminated by the devastation at feeling helpless and dependent was evident in her story.

Life with the companionship of pain and associated physical restrictions and changes associated with arthritis was draining to confidence and self-esteem. Disclosure to others may not be an option when bodily changes such as twisted fingers told the world that arthritis was present. Jane said, 'I don't like to look at my fingers...I think they are disgusting'. Jane's choice to disclose or not disclose her arthritis to others was reduced, as arthritis became physically visible.

Participants experienced that others viewed them with suspicion, until a firm medical diagnosis of arthritis was made. Josie explained:

About 10 years ago I went and saw a doctor, first time I'd actually gone to someone to see about why my hip was in such agony. I could hardly walk, went to the doctor and he said I had to have X-rays. Did that, went back to him the next day, next thing he's telling me I'm a liar, I've had a miraculous recovery and there is no pain, there is nothing in the X-ray. So in other words the pain which I experienced was my imagination and there was nothing the matter with me... I've never ever been back to that doctor's surgery since. That stopped me from seeing the doctor. Doctors have got no kind of consideration for the kind of pain [I have]... I didn't find out till later that arthritis doesn't actually show on X-rays. I think why didn't he do something else rather than call me a liar? I wasn't asking for medication, I just wanted to know what the pain was and what I could do to ease it.

Self-management of pain required pharmacological and non-pharmacological components. Life with the companionship of pain and associated physical restrictions and changes was a threat to one's integrity and self-identity because individuals with arthritis confronted and managed a host of issues associated with daily activities that others may take for granted. Reflecting on life before arthritis Jon said, 'I 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'.

Arthritis created disorder in the control of the body and threatened the sense of self. Self-management to Jackie meant having the confidence to take 'control...I have to manage myself'. Control referred to the exercise of power over management of both her environment and arthritis and to feel secure about that control. Confidence came from developing a consciousness about the place that arthritis had in one's life.

Coming to terms with the shifts in self-identity was a process of 'becoming'. Jan's advice was 'don't let arthritis dominate your life, but try to combine it in your life'. Jackie suggested that self-management enabled her to promote an 'holistic' approach to her health rather than be segmented into the 'bits and pieces' espoused by the bio-medical model.

Balancing, pacing, planning and prioritizing

Jim had long recognized the place of self-management in his life with arthritis and believed the key is planning. He said 'I plan and I take control, sitting around moping doesn't do you any good.'

Daily activities were paced in order to tolerate or not aggravate the pain and to balance the undesired side-effects of medication against the benefits of pain reduction. Planning and prioritizing 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 also 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.

Jackie revealed the importance of pacing, '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 was managed by 'medications, exercise and changing the way I do things'. 'Managing pain is the main issue for me'. Jackie had several strategies for managing pain such as 'the application of heat, anti-inflammatory medications, and keeping moving by walking and exercising'.

Jackie revealed that she was always planning, pacing and working out what was important for her:

There are lots of things that I can't do such as kneeling down or bending over, so this effectively cuts out long periods of gardening,

which was something I was keen to do when I retired...However I find other ways of doing things.

Rest was important for participants, however it proved difficult to find a balance between activity and rest:

I go as stiff as a poker if I stand for too long'. '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.

The feeling of guilt when resting was overcome with the gaining of confidence at self-managing arthritis. Jackie revealed that, by managing guilt, she effectively managed her arthritis because it provided her the opportunity and permission 'to do what is right for me. I am learning to make myself number one because I am the person that is going to look after me the best'.

Josie felt that she had developed confidence to understand her bodily responses:

I know what's the matter with me, I know my body, I'll do what I feel I need to do, when the pain is so bad I use a hot pack and I take it easy until it goes away and I've learnt to live that way.

For Julie:

... self-management is about finding a system that works...I am always adapting, planning and prioritizing... 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.

Self-management was not a linear, consistent process rather it is grounded in the personal and social context of people's lives. At times self-management meant the management of a crisis, other times it was like 'smooth sailing' as Jo explained:

Over the past 13 years I have floundered often, stopped medications often, not coped often but I have always been able to bounce back...I seem to get over my bad bouts faster and manage better as the years go by and my skills improve.

The impact of arthritis on daily life needed to be clearly understood in order to balance, plan, pace and prioritize. The major reason for change in Jackie's life was because the 'spontaneity of life has gone...you just can't get up and go...I plan everything I do'. Arthritis impacted on the activities that Jim once enjoyed, 'I used to like dancing and walking but they are just a dream now.' However, Jim used his creative management skills to look at other possibilities in his life:

I've come to the fact that I can't do it but there are other ways to enjoy things...you have to think ahead and plan all the time... you can't leave anything until the last minute.

The meaning ascribed to self-management for people living with arthritis was contextual and involved finding ways to live daily life optimally, by creating order from the disruption and disorder imposed by, and associated with the pain and physical restrictions of illness. The meaning of self-management for participants did not involve education by health professionals nor necessarily the adherence to medically prescribed treatment regimes.

Discussion

This research has revealed that the assumptions of what constitutes self-management of a chronic illness such as arthritis requires re-evaluation. The prescriptive and perhaps oppressive nature of self-management, as being the adherence to prescribed medical treatment plans has little meaning for people living with illness. Freire (1976) described prescription:

One of the basic elements of the relationship between oppressor and oppressed is prescription. Every prescription represents one man's choice upon another, transforming the consciousness of the man prescribed to into one that conforms to the prescriber's consciousness. Thus the behaviour of the oppressed is a prescribed behaviour, following as it does the guidelines of the oppressor. (p. 23)

Thorne & Paterson (2001) identified the importance of placing disease education within context and suggested that health professionals may complicate the learning process with rigid ideas as to what constitutes successful self-management.

We contend that self-management of chronic illness can be both a structure and a process. Health professionals have created structures in the approach to patient education whereby people are positioned as passive subjects absorbing information. In contrast, participants in this study have revealed that self-management is a dynamic, active process of learning, trialing and exploring the boundaries created by illness.

Self-management of chronic illness was more than 'doing' but was entwined with a sense of 'being' and 'becoming'. Self-management fluctuated as life and the illness itself presented new challenges. It was a process that involved identifying one's psychological and physical responses to illness and constantly planning, pacing and managing daily life as a means of creating order.

Burks (2001) presented a concept analysis of intentional action. In support of Burks (2001), the participants in this inquiry revealed that the action to initiate order was not a single act but rather an evolving combination of processes

carried out over a period of time, in stages and with the possibility of repetition. This seems important for health professionals to acknowledge and to convey acceptance to clients who experience the convoluted nature of chronic illness self-management.

Our findings were supported by the work of Taylor (2001) who explored the elements of self-care for people living with arthritis, and revealed the highly contextual nature of the way people learn to incorporate illness into daily life. In accord with Thorne & Paterson's (2001) work, this study revealed that participants learning to self-manage were motivated to become advocates of their own day to day needs, and were conscious of bringing illness issues into the foreground in order to regulate self-management decision making.

Implications for nursing practice

Despite the evidence of cost benefits and improved health outcomes for individuals who participate in established self-management programmes, they reach only a small percentage of people living with arthritis or other chronic illnesses (Keysor *et al.*, 2001). The cost of participating in such programmes, transport to venues, confidence in attending group meetings in an unfamiliar environment may all be prohibitive factors.

Acute care and community nurses in particular come into frequent contact with people who have a long-term illness and are therefore in a prime position to facilitate self-management. Clinical nursing intervention for people with a long-term illness such as arthritis may be enhanced when self-management is approached from a broad, contextual perspective and self-management processes are integrated into clinical practice. The authors challenge nurses to embrace processes in nursing practice that will facilitate interactions with clients without obstructing the diversity of perspectives, create an environment conducive to learning and engage individuals in identifying self-management strategies that have meaning in their lives.

While effective chronic illness self-management interventions have been identified, these interventions have usually been developed in one disease population. There is growing global interest of self-management interventions that are appropriate and meaningful across chronic diseases (Kralik *et al.*, 2001b). The development of the self-management strategies may lay with understanding what is important for individuals living with illness so that a holistic approach (that is inclusive of biomedical understandings) lays the framework rather than the segmented bio-medical model and particular disease categorization.

Conclusion

We contend that self-management is central to understanding the transition process. In addition self-management of chronic illness has been considered as having elements of both structure and process. Patient education may provide a structure for people to absorb passively, whereas the process of self-management involved learning about their responses to illness through daily life experiences and as a result of trial and error. A sense of mastery and responsibility for their responses to illness developed. People claimed the empowering process of taking responsibility for living well with illness by questioning the direction of their health care and making choices about every facet of their health care. People reconfigured their daily lives and reconstructed their self-identity as they explored their personal limitations or boundaries. They chose whether to disclose (if obvious markers such as a wheelchair are absent) their condition to others. Where previously they perceived their world to be shattered, self-management allowed pieces of their life with illness to fit into place.

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Contributions

Study design: DK, TK; data analysis: DK, TK, KP; manuscript preparation and literature review: DK, TK, KP, NH.

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