The purpose of this qualitative study was to examine the process of transformation of personal beliefs, values, feelings, and knowledge (meaning perspectives) underlying occupational change in a small group of clients with rheumatoid arthritis during home-based rehabilitation. A grounded theory approach used to collect and analyze data concurrently included: (1) a sample of five adult clients diagnosed with rheumatoid arthritis in occupational therapy, (2) data collection through 28 semi-directed interviews, and (3) data analysis using the constant comparison method. The study identified meaning perspectives of these clients with rheumatoid arthritis and explored the transformation of perspectives related to the modification of occupational performance. The study suggests that the exploration of meaning perspective transformation by clients and therapists could be a potential part of rehabilitation intervention.


Rheumatoid arthritis is a chronic illness that disrupts the balance in people’s lives across all components of occupation, including work, leisure, self-care, and rest and sleep, believed to support healthy occupational performance (Canadian Association of Occupational Therapy, 1997). Developing a new occupational balance, in particular between rest and other activities, is important for maintaining or improving function, decreasing pain and fatigue, and protecting joints while living with rheumatoid arthritis (The Arthritis Society, 1999; Palmer & Simons, 1991). Clients with rheumatoid arthritis often have difficulty incorporating recommended health behavioral changes that require a new occupational balance in their lives (Gerber et al., 1987). In particular, help-seeking strategies recommended in occupational therapy, such as using social support, instrumental help or pacing or both, often carry associated meaning perspectives (i.e., personal beliefs, values, feelings, and knowledge) that have been identified as barriers to change (Dubouloz et al., 2000). It has been suggested that these barriers can be overcome through a process of transformation of meaning perspectives (Ashe, 2001; Dubouloz, Chevrier, & Savoie-Zajc, 2001; Paterson, Thorne, Crawford, & Tarko, 1999).

Mezirow (1991) developed a theory of transformative learning in adult education that suggests that for a complete and durable change of actions, an individual must transform meaning perspectives through critical reflection. These meaning perspectives are the constituents of a personal paradigm and consist of the core personal values, beliefs, feelings, and knowledge that guide daily actions. The purpose of this study was to formulate a substantive theory of the process of meaning perspective transformation during modification of occupational performance with clients with rheumatoid arthritis who received occupational therapy intervention in their homes.
Background on Rheumatoid Arthritis

Rheumatoid arthritis is a progressive musculoskeletal disease that runs a variable course characterized primarily by synovitis and erosion of the synovial joints of the body. It causes impairment through fatigue and joint-related pain, deformity, stiffness, and immobility (The Arthritis Society, 1999; Palmer & Simons, 1991). Rheumatoid arthritis, identified as the most common chronic inflammatory joint disease, is prevalent in about 1% of the adult population in the United States (Glazier et al., 1996; Sinclair, Wallston, Dwyer, Blackburn, & Fuchs, 1998). The condition is at least twice as prevalent in women as in men (Rasch, Hirsch, Paulose-Ram, & Hochberg, 2003; Symmons et al., 2002), and is a leading cause of disability and loss of productivity and independence, incurring personal, social, and health care costs (Clarke et al., 1997; Lajas et al., 2003) estimated at 1% of the gross national product of the United States in 1991 (Mann, Hurren, & Tomita, 1995). In the United States, seniors with rheumatoid arthritis are the segment of the elderly population most likely to require medical intervention (Rasch et al., 2003). Advanced age and female gender are risk factors for limited positive outcomes related to disability and mortality (Symmons, 2002).

Medical treatment for rheumatoid arthritis is not curative, but aims to control the disease and minimize its debilitating effects (Sinclair et al., 1998). This type of treatment requires that occupational therapy emphasize the goals of adaptation to existing impairment, prevention of further impairment, and maintenance of independent function (Chan, 1998; Driessen, Dekker, Lankhorst, & Van der Zee, 1997). In Ontario, a study showed that 45% of 529 primary care physicians surveyed referred clients with late rheumatoid arthritis to occupational therapy, and those receiving 6 weeks of occupational therapy treatment at home showed improvement in daily function and mobility (Glazier et al., 1996). Occupational therapy treatment emphasizes patient education, the goals of which are energy conservation, joint protection, pain management, and use of safety equipment (Driessen et al., 1997; Mann et al., 1995). Splinting and lifestyle management may contribute to reduction of fatigue and joint pain during the performance of routine daily activities (Toupin & Denford-Nelson, 1993).

Patient Education Research

Research findings have shown that patient education helps change health behaviors to improve health status, but for rheumatoid arthritis clients, changes of behavior are difficult to achieve and maintain (Hammond, 1997; Taal, Rasker, & Wiegman, 1997). It has been suggested that the most effective interventions are related to attitudinal change (Tucker & Kirwin, 1991) and to the needs and beliefs of the client (Donovan, Blake, & Fleming, 1989; Kirwan, 1990; Tucker & Kirwin, 1991). However, to our knowledge, educational programs have included very little exploration of the meaning of personal change that takes place during rehabilitation (Hammond, 1997, Taal et al., 1997). Even though knowledge, attitudes, values, and perceptions have been recognized as predisposing factors for health behaviors (Furst, Gerber, Smith, Fisher, & Shulman, 1987), clients have rarely been encouraged to reflect on their underlying values, beliefs, knowledge, or feelings when changes to habitual conduct of daily activities are recommended (Brady, Kruger, Helmick, Callahan, & Bountagh, 2003; Hirano, Laurent, & Lorig, 1994; Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985; Lorig & Holman, 1993; Toupin & Denford-Nelson, 1993).

Transformative Learning Research

In the field of rehabilitation, the transformative learning process triggered by chronic illness or trauma has been studied in several client populations. Carpenter (1994) investigated a group of 10 clients with spinal cord injury during their rehabilitation process. She concluded that these clients had redefined their conception of self and of disability in establishing a new identity adapted to a new way of living. Similarly, Dubouloz and colleagues (2001) investigated a group of nine clients with myocardial infarct. Findings showed that to establish a new occupational balance in their lives, the participants had to deconstruct and reconstruct old meaning perspectives related to work, self-care, rest and sleep, and personal change. They also had to construct new perspectives on health and self. The newly constructed meaning perspectives empowered participants to successfully modify their balance of occupation by integrating rest, exercise and modified eating habits into their daily lives. In a study of clients with multiple sclerosis, the emergence of a new meaning perspective revolved around the redefinition of self (Dubouloz et al., 2002). A study by Ashe (2001) explored arthritis education groups and desired health outcomes. Ashe reported the existence of an individual transformation process among clients and concluded that the arthritis education group experience contributed to meaning perspective transformation. No documented studies have been conducted on the meaning perspective transformation process of clients with rheumatoid arthritis participating in individual home-based rehabilitation programs.
The purpose of this study was to explore the transformation of meaning perspectives among clients undergoing occupational therapy treatment for rheumatoid arthritis. The research questions were:

1. What were the meaning perspectives (beliefs, personal values, feelings, and knowledge) related to the four areas of occupations (work, leisure, self-care, and rest and sleep activities) among clients with rheumatoid arthritis early in their home care occupational therapy treatment?
2. Did these meaning perspectives undergo transformation during treatment?
3. If so, how did the new meaning perspectives relate to the clients’ modifications of occupational performance?

Methods

This study employed a qualitative research design in the grounded theory tradition of inquiry that is used to generate theories (Glaser & Strauss, 1967; Strauss & Corbin, 1990) and to explore processes (Bengle, 1991; Carpenter, 1994; Dubouloz, 1997). Data collection and analysis were done concurrently using a four-phase cycle of (1) theoretical sampling, (2) data collection, (3) data analysis, and (4) generation of a theoretical model (Strauss & Corbin). The ethics board of the principal investigator’s university approved the study.

Sampling

The theoretical sampling method was used for this project (Glaser & Strauss, 1967; Sandelowski, 1986; Strauss & Corbin, 1990). Participants were recruited from among adult clients with rheumatoid arthritis of either gender at the beginning of their community-based occupational therapy to modify their daily occupational balance. Only clients diagnosed with rheumatoid arthritis within the last year were included, to focus on the evolving occupational modification that occurs at the onset of the condition (Dubouloz et al., 2001). Participants were recruited by occupational and physical therapists at an arthritis society rehabilitation service. One of the authors, a practicing occupational therapist, served as the project coordinator at the clinical site. At a departmental meeting she presented the research project to her peers who introduced the project to a number of their clients for potential participation. These potential participants received a letter of information describing the objective of the study, the methodology, the nature of client participation, and participant rights. Clients interested in participating telephoned the principal investigator for further information. Volunteers who agreed to participate signed a consent form that stressed confidentiality, anonymity, and the rights of the participants.

The study sample initially included five women and one man diagnosed with rheumatoid arthritis in the previous 11 months (average 6 months). The five women ranged in age from 38 to 67 years. Three of the women were formally employed, and two were retired homemakers. The male participant was 79 years of age and retired. During the course of the study, the diagnosis of one female participant was changed to lupus erythematosus, a systemic rheumatic disease of the connective tissues. The data of this participant were included in the analysis since the initial manifestations and impact of lupus in this person were very similar to those of rheumatoid arthritis, as is sometimes the case (Lin, Hsia, Yang, & Horng, 1999; Semble, 1995). Data collected from the male participant were of limited usefulness due to an absence of work activity issues reported by this individual. In addition, his advanced age and confounding medical conditions made it difficult for him to distinguish rheumatoid arthritis-related problems from others. Consequently, data from this individual were excluded from the study.

Data Collection and Analysis

Data were collected using an interview guide that focused on the meaning perspective of the participants in four areas of occupation—work, leisure, self-care, and rest and sleep activities—across the time period of participants’ rehabilitation. The common treatment objective was the provision of information and the encouragement of reflection on the illness, and the adaptation of the participant’s daily living environment and activity to the rheumatoid arthritis condition (Biundo & Hughes, 1997a, 1997b; Melvin, 1982; Palmer & Simons, 1991). Individual, semi-structured interviews conducted by the principal investigator included open-ended questions and suggested prompts to encourage the sharing of experiences and perceptions by participants. Some unplanned probes were used. An example of an interview line of questioning is as follows:

Could you describe what “work” is for you? When you think about yourself working, what comes to mind? What is particularly important (or not) about work, for you? Why? Could you provide some concrete examples? Has your perception of work changed since before your illness? If so, how?

Similar lines of enquiry were followed for leisure, self-care, and rest and sleep activities.

Each participant was interviewed for approximately 1 hour, using the same lines of questioning, from two to seven times during the course of rehabilitation treatment. Interviews were scheduled about 3 to 4 weeks apart, and were held at the location of the participants’ choice. The variation in the number of interviews conducted per partic-
The quantity of results through a process of investigator trian-
view. In each individual case, the nature of the participant’s occupational therapy program, the depth of the data collected, and the level of comfort and acceptance of the self-reflection process by the participant contributed to the decision to continue or terminate interview scheduling.

Each interview was tape-recorded and transcribed verbatim by the research assistant. The analysis was conducted with the assistance of the computer software program ATLAS/ti (Muhr, 1997). The constant comparison method was used to systematically conceptualize, categorize, and interpret data, according to the approach of Strauss and Corbin (1990) that employs three data coding phases: open, axial, and selective.

Open coding, conducted between interviews, consists of selecting units of analysis from the data and organizing them into preliminary categories by repeatedly looking for similarities and differences between data properties and dimensions. The units of analysis consist of single pieces of information related to the phenomenon under study, as reported by participants. In this study, over 500 units of analysis were identified such as “I don’t need anyone around….I’m just so afraid of losing my independence.” Through constant comparison with other units of similar meaning, preliminary categories (open codes) were determined, such as help could make one dependent. New data from subsequent interviews, during which participants continuously updated and refined their input, helped define the emerging preliminary categories. Axial coding is used to find relationships among preliminary categories to further group them into more comprehensive ones. For example, help could make one dependent and resistance to seeking help were coded under “self-help.”

Selective coding is used to identify core categories by applying a similar reduction process to axial coding. In this study, six core categories were identified. Saturation of data was achieved when strong, common, recurring themes were identified in participant responses (Glaser & Strauss, 1967; Morse, 1994).

A second level of analysis consisted of three sessions of the full research team to discuss and confirm the analysis process and the results presented to the team by the principle investigator. The first session was conducted when approximately half the interviews had been completed, and the subsequent two sessions were scheduled at appropriate times as the selective coding process progressed. The purpose of these sessions was to provide increased assurance of the credibility of results through a process of investigator triangulation (Janesick, 1994; Streubert & Carpenter, 1999).

Findings

The iterative data analysis process yielded the following six core meaning categories: Illness, Independence, Activity, Altruism, Self-Caring, and Self-Respect. Illness represented one trigger and the context for the transformative process. Independence, Activity, and Altruism were prior meaning perspectives that were part of the participants’ self-definitions. These three categories actively directed behavior before and during rehabilitation treatment. Self-Caring and Self-Respect emerged as new meaning perspectives, resulting from the transformative process that occurred during the rehabilitation process. Each category is described below at early and later stages of therapy. For each of the six categories, four descriptive elements, each with a potential for transformation, were expressed by participants and identified as: definition (what it was), function (what it enabled), meaning (why it was important), and assessment (how it was evaluated). For each core category, these descriptive elements are presented below, and illustrated by participant quotes.

Category I—Illness

Early in occupational therapy, illness was defined by the participants as an incurable chronic disease that was “staying, rather than just visiting” and that participants had to learn to live with. The nature of this chronic disease was defined as variable. Participants said that they felt different each day. The illness was also described as unpredictable, as its daily manifestation of symptoms, effect on occupational performance, and prognosis were difficult to foresee by participants.

As an invisible illness, rheumatoid arthritis was also defined as difficult for other people to recognize and understand.

The outside world doesn’t seem to be able to grasp that you can look OK on the outside but maybe feel ah…washed out on the inside. They can’t see that. I think society on the whole needs to see you missing an eyeball, or missing a limb to understand a handicap or a disability.

Illness seemed to disable the participants’ sense of personal control and ability to be involved in occupations. Some participants said they felt that they could not control the illness but were controlled by it. It forced a number of personal changes by imposing limitations on what they were able to do: “You suddenly realize that I can’t run after the 3-year-olds anymore.” Participants said they felt redefined by illness.

I don’t like the way, like, a chronic illness sort of colors your personality to someone else. So, I don’t want to be looked at, you know, as someone who has rheumatoid arthritis, I’d rather just be looked at as Darlene.

1 All names are pseudonyms.
Being chronically ill meant that, to themselves and to others, participants had become lazy, different, and for some, abnormal persons.

[...]the arthritis making me like [a] lazy person. I have to take rests otherwise I can’t….Lazy means, I don’t feel like doing things[...]slow.

I’m not the person I was before… the illness has become my identity, whatever….Someone who’s chronically ill….I guess someone that, who has special needs. Or someone who has to be handled differently or, thinks differently now than they used to. Who lives differently than they used to.

Some participants said they felt redefined by the illness, yet they continued to value the independent and active person they were before. These individuals made a very negative assessment of the illness. The condition was seen as an unwanted and overwhelming daily challenge that had a significant impact on their lives affecting their mobility and their ability to work. Uncertainty about the future provoked expressions of anxiety, feelings of shock, disappointment, frustration, sadness, and anger. Two participants said they disliked the changes imposed by the illness and seemed to fear being or being perceived as nonproductive, inactive, or lazy.

What some participants said they found most difficult was the inability to do as well as before, and the unpredictability of the outcome. Perhaps because of this unpredictability, they consistently maintained some hope that the illness or its symptoms would disappear, stay away, or improve: “Well, I mean, it is, it’s with me. It’s not going to go away. I guess. There’s still a little bit of me that says ‘Oh maybe it’ll go away,’ so, we’ll see.”

Later in therapy, a participant expressed that she maintained the same personal values as before her illness. Nevertheless, she recognized that she had to find different ways of functioning to remain independent and active. However, for other participants, the need for functional reorganization remained difficult to accept if it was linked to a redefinition of self caused by illness. When a participant perceived illness as a less central part of self, it appeared to allow that participant to remain fundamentally the same person.

Look, it’s just another part of life like getting a pimple, bad haircut, that’s it. I don’t know if I really have a definition for it. It, it’s certainly not…beating me up. Like there’s more to me than an autoimmune disorder. It’s just, it’s [a] part of me.

In this situation, the illness seemed to be assessed less negatively—as an inconvenient but manageable condition, than for those for whom no alternate meaning was apparent.

**Category II—Independence**

For participants, independence was related primarily to work and self-care occupations. Early in occupational therapy, participants defined independence as being able to do things their own way without help or limitations. All participants said that independence enabled them to be in control and free in their daily lives. They considered this a strongly ingrained core value that had been fought for, and its loss was feared.

Later in therapy, participants continued to strongly value the meaning and function of independence: “I thought seriously about meals on wheels for a while but then the ugly horns come up, ‘Uh, uh, dependency.’” However, for other participants, through self-reflection, the definition of independence was transformed.

So, now instead of being an independently fit person, I’m an independently disabled person (laugh), no…chronically ill person who occasionally needs help, you know. It’s all relative to the position you’re in.

The dimension of “my own way” became more flexible, acknowledging functional limitations and including help from others. In integrating their new reality, participants seemed able to redefine what independence was for them.

**Category III—Activity**

Early in occupational therapy, participants defined activity as “doing something all of the time” and included social, physical, and mental activities. Participants seemed to relate activity primarily to work and leisure occupations. Activity enabled personal satisfaction, enhanced cognitive and emotional well-being, and self-actualizing. It was appreciated as part of the participants’ self-definition, and as desirable and enjoyable.

Well I don’t think it’s good for you to, just sit around and do nothing. I think it’s good to be active and….It’s good for your brain. It’s good for the way you perceive yourself, how you feel.

Later in therapy, the function, meaning, and assessment of activity remained unchanged for participants, but the definition was transformed from “all the time” to “within my means.” The motivation for finding alternate ways to be and remain active developed.

Being active. It’s all the same. Being active, being able to work. Being able to volunteer. Being able to use my brain and whatever. I mean, that’s all still there. But ah, how I’m going to be able to do them[.....]So I just have to learn different roads to get to the same way I want to be.

**Category IV—Altruism**

Early in occupational therapy, all participants defined altruism as taking care of the needs of others, including family,
friends, and coworkers. One participant helped others by being a volunteer or an advocate. Another helped with small tasks at home (e.g., sewing). A third listened and tried to help solve personal problems of others: “I want to be there for my friends. And I am, to talk. If my friends call, I’m there to talk.” As a function, altruism enabled participants to fulfill an expected social role.

It was just a case of when you see a need you just jump in and help. That’s all. Simple as that….I think it’s something that stays with you. I think it’s an automatic reflex. You don’t realize it, you don’t even think about it. You just automatically do it.

Helping others seemed to mean that participants considered themselves as caring, capable, and productive persons. This was appreciated by one participant as an important part of her self-definition, “[…]my character make up is providing help as opposed to asking for help.”

Later in therapy, the definition of altruism underwent a transformation as it became less of a priority. It was redefined as being secondary to some participants’ own needs. One individual expressed this in the following way:

…I don’t need to feel obligated to do anything that somebody else wants to do. It’s OK to say no[…]and I think that is positive in a way because you’re responding to, like I’m responding to my own needs, not to the needs of everyone around me.

Category V—Self-Caring

In the context of daily living adaptation, occupational therapists presented participants with help-seeking strategies for managing rheumatoid arthritis. This appeared to contribute to the emergence of a new meaning perspective of self-caring. Participants defined self-caring as the use of three kinds of assistance: (1) social support—housekeeping and personal care from family, friends and professionals such as meals on wheels; (2) instrumental help—medical “assistive devices” such as grab bars, lifts, and orthoses, and nonmedical “everyday adaptations” such as zippered boots and garden kneepads; and (3) pacing—decreasing the quantity, duration, and speed of activities. Some participants reported that self-caring appeared to enable them to avoid excessive pain and fatigue.

Sometimes you get wrapped up, you keep going. You pay for it the next day with your fingers and your wrists. You do, dearly. Um, but… I’ve learned I’ll get done when I get done today. What I don’t, there’s tomorrow or the next day. I’m kind of actually enjoying it. I don’t feel as exhausted.

Self-caring appeared to enable participants to maintain their ability to do such things as carry on housework, engage in personal care, and perform manual activities like opening containers. The function of self-caring was generally perceived as positive. However, its meaning and assessment appeared strongly interconnected with participant perspectives of illness, affecting participant self-definition. Some participants felt lazy, limited, or dependent. One participant expressed that having to take care of herself meant that she was incapable.

I think really, accepting any of the support services, I was telling the world that I was incapable. I think that’s really what it boiled down to, that I was incapable. And I couldn’t stand that.

This new requirement to address the issue of self-caring was assessed by 1 participant as contradicting her personal nature. “Rarely will I ask for assistance. It’s just my nature.”

Regarding the necessity to seek social support strategies for self-caring, several participants expressed a variety of negative feelings including frustration, anger. They seemed to feel that the experience was imposed and unavoidable: “No way. I’d die before I would knock on anybody’s door.” For 1 participant, self-caring appeared to threaten her independence: “That’s hard, when you’ve been independent…to say, ‘Do you mind?’” Later in therapy, a new meaning for self-caring seemed to emerge that acknowledged a balance between the acts of giving and receiving help.

So it’s a balance there, what they [other people] give to me. [A friend told me] ‘Think of all you do for other people’…in another way maybe they [other people] are helping somebody and they don’t realize it. Somebody’s just trying to help them [patients], like be considerate to them back. Maybe another person’s help is their way of thanking that person…I guess everyone has their own perception, my own is that it [getting help] shouldn’t be a loss of independence.

For some participants, the negativity associated with self-caring had evolved to a realistic response to personal, self-care needs, necessitated by the medical condition. Instead of being socially dependent or incapable, participants appeared to enter into a process of transformation from “dependent” to “interdependent” (i.e., independent with help).

Category VI—Self-Respect

When occupational therapy was initiated, the notion of self-respect received little attention from participants. However, later in therapy, it emerged as a new meaning perspective, particularly as it related to personal opinions and choice.

Respecting one’s own choice….I think it is important. I don’t think you should feel pressured into doing something that you don’t want to do.

The emergence of self-respect seemed to enable some participants to change their views on their relationship with the problems and judgment of others, and empowered them to respond to their own needs.
I probably still worry about it [being seen as lazy]. But, I don’t care as much any more (laugh). I don’t care as much how other people perceive me, I guess.

For one participant, preservation and refocusing of the use of personal energy contributed to a new meaning of self-respect.

Why burn yourself out? Energy’s very precious…You learn that it doesn’t matter if the floor’s not vacuumed, like. In that respect it’s been to my benefit because it’s calmed me. Participants reported that they started to occupy themselves differently. For example, instead of pushing themselves to finish tasks, to get more done, or to maintain high perfectionist standards, they only tackled what they could handle, did things slower, and slept more. The implied meaning of self-respect was that they accepted and valued themselves. Self-respect was positively appreciated as being beneficial. Slowing down made life easier and more relaxed. For one participant, self-respect was linked to pacing and self-actualization.

Pacing myself?...I think it’s more pleasurable now….I tend to take more pleasure in what I do….Instead of thinking about it, I’m actually feeling it. […]Well I hated to sleep my free time away, yeah. But now…I’ll sleep if I want. I get up when I want. And in the end I accomplish as much in a day on a Saturday as if I woke up 3 hours earlier.

Finally, as self-respect developed in one participant, she felt more confident, content, and accepting of herself.

…to me it was almost like this [illness] has been a gift to me because throughout the last however many months it’s been…it’s almost like I have a new self-awareness, a new self-discovery of it. Reassessed myself as a person. Appreciate myself more. Accept myself...maybe, I think I always did accept myself but I think I accept myself with more relish. I’m quite content and happy with the person that I am.

The emergence of the new meaning perspective of self-respect seemed to be a key occurrence that may have interacted positively with the learning, acceptance, and usage of self-caring strategies, a central element of the transformation of the self-caring category.

Substantive Theory

The transformation process of meaning perspectives among participants with rheumatoid arthritis during rehabilitation therapy was the focus of this study. Early in their treatment, the participants shared three core meaning perspectives that they experienced as self-defining values: Independence, Activity, and Altruism. The characteristics of each meaning perspective: Independence—consistently self-reliant, Activity—constantly occupied, Altruism—responding first to the needs of others, illustrate the values that guided participants’ lives. These values appeared to direct their choices of occupations and occupational balance. However, some occupational choices were no longer available to participants due to the constraints imposed by the illness. During rehabilitation, particularly during occupational therapy, participants had to learn self-caring strategies to develop a new feasible occupational balance. At first, self-caring was viewed as demeaning and therefore unacceptable, and this made social support strategies difficult to consider. Seeking help conflicted with the participants’ initial three core meaning perspectives, and became a barrier to the learning of needed self-caring strategies.

Later in therapy, critical reflection based on new knowledge of the illness appeared to be a key element of the transformation process. Critically reflecting on their new situation seemed to enable participants to recognize self-contiuity and self-acceptability in illness, and to encourage the emergence of a new directive meaning perspective of Self-Respect. The meaning of self-respect—accepting and valuing yourself, appeared to encourage reorganization of participants’ personal paradigms. For example, personal limits were acknowledged, and the meaning of self-caring strategies appeared to transform from laziness to personal limitations, from dependence to interdependence, and from incompetence to self-responsiveness.

As a consequence of the appearance of this new framework, the definitions of the core values were transformed. Altruism, as a commitment to helping others on demand appeared no longer to be a guiding principle for behavior. What emerged was a refocusing on valuing and satisfying personal needs. Also, the measure of the value of activity was no longer how busy the individual was. Rather, moderated activity that recognized personal health limitations took on its own value. The transformation of these two core values seemed to enable the participants to accept self-caring strategies—in particular, pacing. For example, interviews revealed that participants readily broke large tasks into a series of smaller, more manageable ones done over a longer period of time, giving rise to a new occupational balance. Parallel to these developments, the definition of independence was broadened to incorporate self-caring strategies that included the use of help. The interplay of these meaning perspective elements appeared to result in the transformation of the notion of dependence to interdependence, making room for the integration of the use of instrumental help and social support.

When participants integrated the rehabilitation strategies of pacing, instrumental help, and social support into their daily occupations, they found that they could still be productive. They also could continue to be active and independent. It became evident to them that in addition to
avoiding pain and fatigue, they could continue to experience self-actualization within their meaningful occupations, guided by the concept of self-respect. As a result, self-caring became acceptable and desirable and appeared to grow as a new supportive meaning perspective in the transformative process.

We propose that the results of this study identified a transformative learning process involving a deconstruction and reconstruction of meaning perspectives in clients with rheumatoid arthritis. Two externally imposed triggers that broke down the coherence between the client's values and actions, and that at first had a negative impact on their self-definition, initiated the deconstruction process. The first trigger, the illness context, conflicted with clients' previously existing meaning perspectives that defined parts of the self (independence, activity, altruism), and appeared to prevent the desired behavioral changes. The second trigger, the rehabilitation context, introduced new behaviors (self-caring) that appeared to be in conflict with the clients' previously existing values and self-definition. The reconstruction process involved interplay between new awareness and critical reflection on the elements of these conflicts, and resulted in the emergence of a new directive meaning perspective—self-respect, on which further transformation of the core meaning perspectives could take place. The reconstruction process contributed to the rebuilding of coherence among personal values and required modified activity imposed by the illness and rehabilitation contexts, suggesting the reestablishment of occupational balance.

Discussion

Mezirow's work (1991) focused on meaning perspective transformation among adult learners when personal crises triggered change. This study considered the condition of clients undergoing home care rehabilitation to attempt to provide further insight into the transformative process. It builds on Mezirow's theory by describing six meaning perspective categories according to their elements of structure identified as their definition (what it was), function (what it enabled), meaning (why it was important), and assessment (how it was evaluated). The results suggest that transformation may take place in one or several of these structural elements.

Current rheumatoid arthritis patient education programs appear to focus primarily on providing disease-related information and generic skills for energy conservation and joint protection, exercise and diet, and personal goal setting, performance feedback, and problem-solving strategies (Brady et al., 2003; Gerber et al., 1987; Hirano, Laurent, & Lorig, 1994; Lorig & Holman, 1993; Toupin & Denford-Nelson, 1993). Exploration of the meaning perspective transformation process related to chronic illness through self-reflection has not yet appeared as a self-management strategy in the rheumatoid arthritis patient education literature. However, a highly developed body of work exists on the health behavior change process of clients in the field of psychology. The closely related concept of "values clarification" for unclear or conflicting values (Kinnier, 1995) has been applied to "motivational interviewing" to address ambivalence to change (Emmons & Rollnick, 2001), and is a key element of the "transtheoretical model" of client stages and readiness for health behavior change (Cancer Prevention Research Center, 2001).

In the field of rehabilitation, authors have identified a transformative process of meaning perspectives. Livneh (1986), in an extensive synthesis of stage models of psychosocial adaptation to physical disability, describes "reintegration or reorganization" involving cognitive acknowledgement, affective acceptance, and behavioral reconstruction as the fifth and final stage of adjustment. Carpenter (1994) developed a three-phased process of transformation that involved "rediscovering, redefining, and establishing" among clients with spinal cord injury. Dubouloz et al. (2001) described a process of "deconstruction and reconstruction" guided by the emergence of a new directive meaning perspective of self-value among clients with cardiac conditions. The present study, conducted in a similar health care environment and with a similar research design, suggests the existence of a comparable transformative process, in which a new directive meaning perspective of self-respect emerged.

The importance of this study lies in its potential clinical implications for therapists and clients, both of whom could benefit from increased awareness of the process of meaning perspective transformation during rehabilitation. Clinicians could encourage client self-reflection during their interventions to guide the discovery of meaning perspectives and meaning perspective transformation of importance to individual clients. We suggest that this self-reflection could be conducted by applying the suggested structure of four elements of a meaning perspective as described in this study. This suggestion could be further explored in a systematic study involving rehabilitation clinicians. Furthermore, results of similar research projects with clients with other conditions could lead to the development of a bank of meaning perspective changes upon which a generalized formal theory of the process of transformation in rehabilitation could be constructed.

Several limitations to this study can be pointed out. The study used individual interviews with participants as the single source of data. The richness and depth of the data...
could have been enhanced through the use of multiple data sources such as personal journals of participants, family member interviews, and focus groups with participants to review the suggested results. Furthermore, longer time-frames to collect data might have produced a more complete description of processes of change, as some authors have suggested that acceptance of the reality of a chronic illness and its consequences, is a slow process often taking more than 2 years (Eberhardt, Larsson, & Nived, 1993; Newbold, 1996). Finally, this study was designed to explore and describe the experience of a small group of participants, which through circumstances of availability included only female participants. A broader sample including both genders and a larger number of participants could be used in future research to extend the findings. It is recognized that there is still a great need for more research on the structure and process of transformation in living with a chronic illness (Paterson et al., 1999).

Conclusion

This study attempted to bring a deeper understanding of the process of transformation of meaning perspectives among clients with rheumatoid arthritis. It provided new qualitative evidence that transformation of meaning perspectives seems to occur. The findings suggest that existing meaning perspectives (values, beliefs, feelings, and knowledge) evolved toward new ones in clients with rheumatoid arthritis during a period of rehabilitation. Although it is not possible to derive how transformation takes place from the results of this study, the process of meaning perspective transformation suggested could be instructive to therapists as it reveals an inner process associated with rehabilitation.

Acknowledgments

This study was funded by a research grant from the Canadian Occupational Therapy Foundation and The Arthritis Society. It was made possible with the kind participation of the research participants who generously shared their time, life experiences, and reflections, and with the collaboration of the Consultation and Rehabilitation Service of the Arthritis Society for Eastern Ontario.

References


