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Adjusting to recent onset of rheumatoid arthritis: a qualitative study

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Abstract

The purpose of this study was to examine men's and women's experiences living with rheumatoid arthritis (RA). Using semi-structured, in-depth telephone interviews, nine women and seven men who were recently diagnosed with RA (disease duration $<$ four years) were interviewed about their experiences adjusting to RA. Line-by-line coding using thematic analysis was used to identify themes. Findings from the qualitative analysis revealed six categories emerging from the data: 1. degree of severity of the impact of the disease, 2. appraisal about what the illness means to me, 3. availability of social support, 4. perception of self-efficacious behaviours, 5. use of coping strategies, and 6. RA's effect on valued life activities. A number of participants described positive thinking about managing their RA; whereas others described negative thinking. Individuals' appraisals and perceptions about their illness coupled with how their illness affected their ability to fulfill their role responsibilities were important in their adjustment to RA. Social support was also identified as key in learning to live with RA. For individuals with RA, the impact of the disease on their ability to maintain normal life is important, and as such it is vital that healthcare professionals have a better understanding of the perceptions and experiences that individuals have living with RA.

Keywords

Adults, chronic illness, patient experience, qualitative, self-management

Introduction

Currently, an estimated 50% of the population (1 in 2 Americans) has at least one chronic illness (Wu and Green, 2000; Center for Disease Control and Prevention, 2010). Chronic illnesses usually affect older adults, so when they affect younger adults, the likelihood for

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disrupting work, family and social roles may be greater. With increasing disability, this may result in the loss of valued roles, which has important implications for the health and well-being of individuals with a chronic illness like rheumatoid arthritis (RA) (Neugebauer et al., 2003; Katz, 2004; Katz et al., 2009).

Of all the chronic illnesses, none is more widespread and disabling than arthritis (Arthritis Foundation, 2008). Approximately 70 million Americans (one in three adults) are affected, with some two million affected by RA (Arthritis Foundation). Research suggests that the most prominent decline in physical functioning among individuals with RA occurs within the first few years of the onset of disease (Sherrer et al., 1986; Van Der Heide et al., 1995). However, the diagnosis of RA can be difficult because it is mostly based on clinical symptoms that may not be present early in the disease (Arnett et al., 1988; Singh et al., 2010). Additionally, radiological findings and the presence of rheumatoid factor (RF) may not be detected early in the disease as is the case in a number of individuals with RA (Singh et al., 2010). Despite this difficulty, early intervention and treatment is important to prevent joint and bone destruction and disability (Singh et al., 2010). Though much of the focus remains on managing disease activity and improving physical functioning, the psychological well-being of patients and their satisfaction with life cannot be overlooked.

Background

There have been a limited number of qualitative studies that have examined adults' experiences and perceptions regarding living with RA. Hughes (2009) found in a sample of nine women and four men that RA resulted in significant lifestyle changes in their occupation, leisure and social activities. Participants reported a decrease in independence and becoming more reclusive and sedentary. Plach et al. (2004) examined the impact of RA on social role experiences among 20 middle and older-aged women. They found that the women reported difficulty balancing multiple roles of wife, mother, homemaker, and paid worker, while concomitantly experiencing the symptoms of pain and fatigue commonly associated with RA. Women reported feelings of disappointment and frustration, (which we conceptualise as role strain) when illness-related symptoms precluded them from meeting family and social expectations and role responsibilities. Role strain, which results from the many demands experienced by individuals as a result of occupying multiple roles (Moen et al., 1995), is defined as the 'felt difficulty in fulfilling role obligations' (Goode, 1960: 483). A theory of role strain hypothesises that there is a fixed amount of time available to adequately fulfill role expectations (Goode, 1960; Rozario et al., 2004). The consequences of having a chronic illness while concomitantly engaging in multiple roles may result in role strain on the individual, making it an important area to examine.

Lempp et al. (2006) examined in a sample of 26 adults diagnosed with RA (mean age 56 years; disease duration range 1–29 years) key personal experiences of living with RA. They found differences in illness experiences in young adults, but not in relation to ethnicity. Study participants reported concerns related to how RA affected their identity in terms of their private (difficulties in relationships) and public (effect on work responsibilities) roles. Study participants also reported concerns related to loss of independence (50% of sample), perceived changes in physical appearance (33% reported changing their physical appearance to accommodate physical restrictions of disease), and loss or change in their social roles (33% reported changes in leisure activities) (Lempp et al., 2006).

The literature also lacks research that examines the lived experience of adults living with RA in the early stages of their disease. A study by Codd et al. (2010) was one of the few we found that examined the qualitative experience of individuals with recent onset RA. They focused on the paid work role in a sample of 10 adults who had experienced RA for less than two years. Participants reported work-specific changes and lifestyle changes in order to maintain paid work. Although the meaning of paid work and the importance of the work role were identified as hugely important to the participants, this study did not examine other roles such as parent or spouse roles that may be equally as significant or relevant.

Study purpose

Because there is a lack of nursing research that has examined the impact of RA on multiple roles (e.g., spouse, parent, paid worker) in adults newly diagnosed, the purpose of this study was to examine the experience of persons living with RA earlier in their disease process. We conducted an inductive study using qualitative data collection methods and analyses to better understand what it was like for adults living with RA. For individuals with RA, the impact of the disease on their ability to maintain a functional life is important, and as such it is vital that researchers and healthcare professionals alike have a better understanding of the perceptions, experiences, and impact of having a chronic illness like RA. In this study, recent onset was defined as being diagnosed with RA less than four years from the start of the study.

Conceptual framework

The theory used to better understand the individual's interpretation of and subsequent responses to living with a chronic illness like RA is self-regulation theory (Leventhal et al., 1980; Clark et al., 2001). Self-regulation theory is a useful framework for examining how individuals adjust to events that occur during a chronic illness like RA. According to Clark et al. (2001), being self-regulating means 'being observant and making judgments based on observation' rather than as a result of convention or custom (p. 770). A model of self-regulation hypothesises that managing one's disease is influenced by an individual's appraisal of his/her illness and is referred to as illness representation, as well as coping strategies the individual uses (Leventhal et al., 1980; Carlisle et al., 2005). Factors that influence illness outcomes consist of both internal and external factors. Internal factors pertain to attitudes, knowledge, feelings and/or beliefs that the individual has about the illness, and the extent to which their knowledge and/or beliefs can affect their illness (Clark et al., 2001). External factors include such things as role models (e.g., health care providers, mentors), and/or interpersonal relationships by which social support is provided, as well as material resources such as availability of transportation or money, all of which influence health behaviour (Clark et al., 2001).

Another important component of the model is the use of management strategies (Karoly and Kanfer, 1982; Clark, 1998). Management or coping strategies refer to those steps the individual takes to control his/her disease (Karoly and Kanfer, 1982; Clark, 1998). These strategies 'may be effective or ineffective; they may be recommended by the health care provider or not' (Clark et al., 2001: 772). According to the model, the coping strategies the individual uses are predicated on the person's judgments about or reactions to their internal and external factors (Clark et al., 2001). For example, a health care provider and/or family member can influence the strategy used. Self-regulation, which includes self-efficacy as part of its model, encompasses abilities that are applied to a specific problem or goal (Clark et al., 2001). For example, how confident is the individual in controlling his/her symptoms, or taking care of his/her RA in general?

Finally, a key factor in disease management is the individual's personal goals. They might include maintaining role responsibilities, having an improved quality of life (illness representation), and maintaining physical functioning (severity of disease). According to Clark and associates (2001), for individuals to be the best manager of their illness they need to improve their self-regulation skills, including internal and external factors so that these influences improve their capacity to be more self-regulating. Nurses and nurse practitioners are the professionals that should assess and assist clients in learning how to self-regulate and cope with the various limitations brought on by a chronic illness such as RA.

Methods

Sample and design

This study is part of a larger quantitative study ($n = 80$) examining the relationship among multiple roles, role stress (role conflict, role overload, and role balance), key psychosocial variables (self-efficacy, social support) and role strain in chronically ill men and women with recent onset of RA. A subset of adults ($n = 16$) participated in semi-structured telephone interviews with the specific goal of answering the original research question from the larger study, which was 'what are the qualitative themes that characterise how men and women conceptualise their experiences with multiple roles and their efforts to manage their disease?' Approximately half of the adults participating in this study scored high on the role strain index in the quantitative study whereas the other half scored low. To participate in the larger study, individuals (18 years and older) had to be recently diagnosed with RA (dx four years or less), and able to read and write English. Individuals who were excluded from the study were those who had been diagnosed with RA for longer than four years, had other co-morbid chronic conditions (e.g., diabetes, chronic obstructive pulmonary disease (COPD)), or were unable to read or write English. This was a mixed methods study. Through the collection of narrative interview data, the criteria for qualitative methodology were met.

Procedures

Permission to conduct this study was attained by the Human Subjects Protection Programme. All the subjects signed informed consent forms, which included information about the study and about their permission to participate as granted by the individuals themselves. The researcher shared information with the participants by mail and telephone. Potential participants were mailed a letter of introduction from the investigator along with a letter of support from the physician. The letter of introduction provided a brief explanation of the proposed study and included a postcard. If the participant was interested, they mailed the postcard back to the researcher with their name, phone number and best time to be contacted. They were asked questions to determine eligibility, and if the prospective participant met the inclusion criteria they were enrolled in the study. The researcher reviewed the consent form over the telephone and the participant was asked if they would be willing to be re-contacted to participate in the telephone interview.

The principal investigator (PI) developed the interview instrument with the help of a consultant with expertise in qualitative methodology. The interview guide contained open-ended questions. An initial pilot study was conducted with a male and a female adult with recent onset of RA to develop and refine the data collection tool. The pilot study indicated a need to make changes to the interview questions in order to ascertain a better understanding of what it is like living with RA. Because of the number of changes made to the data collection tool, to avoid the data being inaccurate or flawed, we chose to not include the two participants' data as part of the total sample for this analysis.

The research interviews lasted approximately 45–60 minutes. The principal investigator was the sole interviewer. Two research assistants were trained to conduct line-by-line coding applying the seven stages of phenomenological analysis outlined by Colaizzi's (1978) methods. The research panel included another researcher with expertise in qualitative methods, a physician with a specialty in RA, and the directors of two academic health care centres and two clinics.

Data analysis of the qualitative study

Of the 80 individuals who consented to participate in the larger study, seven male subjects and nine female subjects (total 16 subjects) agreed to participate in the qualitative portion of the study and were interviewed. An analysis of the interview data is presented here. Prior to inviting subjects to participate in interviews, an initial analysis of the quantitative data was conducted in order to determine which subjects scored low in role strain, and which ones scored high in role strain. The PI re-contacted individuals based on the results of how they scored on the role strain variable (the outcome variable), and was the only one aware of how the participants scored on the outcome variable. This was done to ensure that individuals who were handling their illness well and those who were not were interviewed. The two research assistants and consultant were blinded to the participants' responses to role strain variable. Role strain was assessed by the Positive Affect Scale of the PANAS (Watson et al., 1988) Satisfaction with Life Scale (Diener et al., 1985), and the Center for Epidemiological Studies Depression Scale (Radloff, 1977). These tools were chosen because they measure both positive and negative aspects of well-being. To address issues of redundancy, an index was created by reverse scoring and standardising the scores on the positive effect scale (lack of positive effect) and the satisfaction with life scale (dissatisfaction with life) and standardising the CES-D scale and then adding the three standardised scores together to form an Index of Role Strain. All individuals contacted except one agreed to participate in the telephone interview. Each tape-recorded interview was examined for words that could be linked to positive effect and/or life satisfaction, and negative effect or dissatisfaction with life.

Based on this initial analysis, three men and five women who scored high in role strain and four men and four women who scored low in role strain were interviewed. This allowed for identifying themes that both characterise and differentiate how men and women conceptualised their experiences with RA to better understand how their disease impacted their ability to carry out their role responsibilities.

Trustworthiness of the data

Dependability addresses the issue of reliability and allows the reader to assess the extent to which appropriate research practices have been followed (Shenton, 2004). Dependability of the findings was assured by pilot testing the interview guide, with the researcher and her team consulting a qualitative content expert in the form of writing out memos about the question and answer process regarding individuals living with RA. The themes that emerged were a result of line-by-line coding of every word that emerged from the interviews. Additionally, the PI conducted all of the telephone interviews using the interview guide. Interviews were concluded when no new themes emerged and subsequently saturation was reached.

Credibility pertains to the accuracy of the phenomenon of study and addresses the question of how congruent the findings are (Merriam, 1998; Chiovitti and Piran, 2003). Credibility of the findings was maintained with the researcher asking for clarification of statements made during the interviews as well as re-contacting some of the participants at the end of data collection to clarify and validate study findings with participants. This process also added to the confirmability of the data. Confirmability is associated with objectivity and concerned with relating study findings to the experiences of the participants (Shenton, 2004). In this study, the themes that emerged were linked to the participants' words, and in turn associated to the review of existing literature in order to add to the transferability of the findings. Transferability is the extent to which the findings can be transferred to other settings (Lincoln and Guba, 1995).

Findings

The sample consisted of nine women and seven men with recent onset of RA (mean length of time of having been diagnosed with $RA = 14.35$ months). The mean age was 50 years (range 35–60 yrs). The sample was primarily Caucasian (93.8%), married (87.5%) and had some college education (81%). Seventy-five percent of the sample was employed full- or part-time, and approximately 50% of the sample reported a total household income over $50,000.00. When the sample was further assessed based on their responses to the outcome variable (role strain), the two groups were found to be similar with respect to the demographic variables (refer to Table 1). Findings from the qualitative analysis revealed six themes emerged from the data which all had bearings on their ability to adjust to living with a chronic illness like RA: 1. degree of severity of the impact of the disease, 2. appraisal about what the illness means to me, 3. availability of social support, 4. perception of self-efficacious behaviours, 5. use of coping strategies, and 6. effect of RA on valuable role activities.

Degree of severity of the impact of the disease

When asked what has your experience been like living with RA, all of the participants talked about their symptoms. Degree of severity of disease pertains to the presence of physical (e.g., pain, fatigue, disability) and psychological symptoms of RA (e.g., depressed mood), refers to the respondents' self-assessment of their disease, and includes symptom severity, pain level and degree of fatigue and disability. All of the participants were able to describe their RA symptoms. One participant talked about 'My hand kind of got worse where it would just swell up and I couldn't move the thumb or the forefinger . . . ' Another participant said 'My joints ache, so I prepare for that.' While another said 'it was really, really bad at the beginning. The pain was excruciating.' One individual stated 'I tell you what, it scared me. It just seemed like every joint in my body was locking up.' Another stated 'I mean I was on so much medicine, I felt like a walking pharmaceutical company.'

Table 1. Descriptive statistics of sample

Variable	High Role Strain ($n = 8$)	Low Role Strain ($n = 8$)	X^2 or t	p
Race			1.07	0.30
Caucasian	8 (100%)	7 (87.5%)		
African American	0 (0%)	1 (12.5%)		
Gender			0.25	0.61
Female	5 (62.5%)	4 (50%)		
Male	3 (37.5%)	4 (50%)		
Marital Status			2.28	0.32
Single	1 (12.5%)	0 (0%)		
Married/partnered	6 (75%)	8 (100%)		
Divorced	1 (12.5%)	0 (0%)		
Education Level			1.48	0.69
High school graduate	2 (25%)	1 (12.5%)		
Some college	4 (50%)	3 (37.5%)		
College graduate	1 (12.5%)	3 (37.5%)		
Post college	1 (12.5%)	1 (12.5%)		
Total Household Income			4.30	0.37
Less than 10,000/yr	2 (25%)	0 (0%)		
10,000–19,000/yr	1 (12.5%)	0 (0%)		
30,000–39,999/yr	1 (12.5%)	1 (12.5%)		
40,000–49,999/yr	1 (12.5%)	0 (0%)		
50,000–99,999/yr	3 (37,5%)	5 (62.5%)		
Declined to answer	0 (0%)	2 (25%)		
Employment status			6.97	0.14
Unemployed	2 (25%)	0 (0%)		
Part-time	1 (12.5%)	2 (25%)		
Full-time	3 (37.5%)	6 (75%)		
Disability	1 (12.5%)	0 (0%)		
Retired	1 (12.5%)	0 (0%)		
Age (years), mean (sd)	51.38 (8.7)	48.63 (12.54)	0.51	0.62
Length of time of diagnosis (months), mean (sd)	13.63 (10.28)	15.13 (9.34)	−0.305	0.77

Appraisal about what the illness means to me

Appraisal of the illness emerged when the participants discussed how they thought about their chronic illness. Patients formed meanings about their illness, which were based on their knowledge and beliefs about their body and illness. It also includes such things as their body image and fear of the future. One participant stated 'I was more active person prior to this [RA] hitting me.' Another responded 'I mean it's like I could be fine today and tomorrow I can hardly move.' One participant reported 'I feel like my whole body is falling apart,' and another stated 'I feel like an invalid.' Another reported 'morning is so hard, when I first get out of bed . . . if you let any disease rule you, you will really be in trouble.' Another stated 'What I felt was . . . I felt inadequate. I felt like, um the things I used to do I couldn't do so I wasn't up to par.' One person said 'I get down because I think about what is going to happen five years from now.' Finally another stated 'most people don't understand what a person goes through.'

Availability of support

Availability of social support refers to a network of family, friends, neighbours, and community members that is available in times of need to give emotional, physical, and financial assistance. The respondents fell into two categories. Either they described having support or lacking available support. Participants were asked who is able to help you the most/least with coping with RA. One respondent who identified receiving support stated 'I need many breaks at work, and my boss tells me to take it easy when I need to.' Another stated 'One day I couldn't get up I just sat there and bawled my eyes out and called her [daughter], she came over from Indiana and helped me get out of my tub.' Another stated 'they [family] just pitch in and do it for me . . . my family and my wife's family are good that way and then the ones at our church'. Another person said 'He [husband] is very supportive of me . . . and pretty much said if you need to quit your job that is fine. We'll do what we have to do to get you better.' On the other hand another person said 'my friends and family like they don't really want to do much and stuff cause they're like you're too slow' while another stated 'it's like they got too much to do than to fool with me you know'.

Perceptions of self-efficacious/self-regulating behaviours

Perception of self-efficacious/self-regulating behaviours fell along two types of responses, those who expressed the belief that they could handle their illness symptoms (i.e., pain, fatigue), and those who indicated they could not. For those who possessed expectations of self-efficacy, they described taking direct measures to alleviate and/or minimise their illness difficulties. In contrast, those who did not express self-efficacious beliefs felt less able to handle their illness. One respondent stated 'Well I mean I've lost a lot of strength, and if I can't do it, I can't do it. I don't know how to explain. Until you've been there you don't know.' In contrast 'I try to think about the positive. I try not to be negative . . . and this condition will take you down a road you do not want to go so I try to look on the bright side of everything.' Another stated 'Ever since I was diagnosed I tried to just convince myself that no matter what, um, I'm able to do the things I want to be able to do and I try not to even think about the fact that I have arthritis . . . I'm just you know any other normal healthy person.' Another stated 'You have, the things that used to you can still do it, you just have to just have to figure out a different way to do those things.'

Use of coping strategies

Use of coping strategies refers to the specific things the individual did to manage his or her illness. This included both cognitive and/or behavioural attempts to manage demands that strain the person's personal and/or social resources. The participants responded in one of two ways, those who were able to identify and implement problem-solving approaches and those who were not. One participant stated 'I'm a pretty active person . . . I just don't believe in letting anything [RA] control me. RA does not define who you are . . . to me it's a mindset . . . you've got to look at things positive.' Another stated 'I have to kind of accept it and just do the best that I can with it [RA]. Learn to ask for help which I'm not very good at doing that. Where I wouldn't ask people for help, now I do.' One participant reported 'What has been most helpful to me (laughter) a sense of humor.' Another stated 'I had to try to make adjustments, um at work, I delegate more.' On the other hand one participant stated 'I just know that without it [medication], I mean I'm just, there's nothing I can do.' While another stated 'I don't cope very well, cause I get so aggravated. I can't really say that I have found anything helpful in coping with RA . . . I mean just the knowledge of what I have and what the outlook that's not helpful because it's depressing.'

RA's effect on valued life activities

RA's effect on valued life activities pertains to those activities that are viewed as important and provide meaning and purpose to the individual (Katz and Neugebauer, 2001). This included the degree to which RA impacted on the participants' role-related responsibilities. All of the participants were able to describe how RA affected their family, work, and social roles. One participant stated 'I've lost two jobs because of it [RA]. It's really just hindered my life period, my whole life style.' Another stated 'It [RA] seems like it's affecting me more now than it ever has, like you know go out and fish or hunt you know.' Another reported 'It [RA] affects my work and you know getting to spend time with my son.' While another stated 'I love to get out in the woods and walk and that has pretty much been eliminated.' Finally another stated 'I would say mostly my work is affected by my RA.'

Discussion

The six themes that emerged from the qualitative analysis of the data: 1. degree of severity of the impact of the disease, 2. appraisal about what the illness means to me, 3. availability of social support, 4. perception of self-efficacious/self-regulating behaviours, 5. use of coping strategies, and 6. RA's effect on valued life activities described the participants' experiences with learning to live with RA. An analysis of the data revealed that those individuals who responded in the affirmative to role strain indicating that they were experiencing distress or dissatisfaction with life displayed a more negative outlook or thinking than those who scored low in role strain. They expressed difficulty in managing their illness, and being controlled by their illness, and described less available social support, use of fewer coping strategies, and were less likely to describe efficacious behaviours for managing their disease. For those individuals who scored low in role strain, they displayed a more positive outlook or thinking about their illness. They appeared to be handling their illness by finding ways to manage their disease. They described an availability of social support lacking in the other group, an increased use of coping strategies, and a greater perception of being able to handle their illness. Zautra et al. (1995) examined perceptions of quality of life in males and females living with RA and found that 'positive and negative affective states were influenced by the disease processes associated with RA' (p. 406). Findings from their study showed that patients who were experiencing more pain and disability [activity limitations] reported more negative affect than those who were not.

The investigators found the use of the self-regulation model to be useful in explaining individuals' experiences with living with RA. The self-regulation model proposes that an individual's cognitive representations of illness threat (illness representation) influence the selection and performance of strategies to cope with the illness. According to Leventhal et al. (1980), the attitude that a client has towards coping with symptoms of RA influences the outcome, as seen in the case of a participant who was able to maintain their employment even if the symptoms sometimes were difficult to control. In this study, participants talked about their RA experience by expressing what their illness represented to them. This appraisal, which according to self-regulation refers to illness representation, has implications for how well an individual may or may not manage their RA. A growing body of research supports elements of the self-regulation model from the early work of Glasgow and Hampson (1995) to the works of Scharloo et al. (1999), the latter being the only rheumatoid arthritis study that examined the five dimensions of illness representation as well as coping strategies and illness outcomes. Scharloo et al. found that there was little impact of illness representation on coping strategies. To that end the latest research to study the ability of the self-regulation model to represent illness threat was the work of Carlisle et al. (2005). In their research, avoidance and resigned coping partially met the relationship between symptom identity and disability. The same explanation is given in the research conducted by Carlisle as the one we found when the individual is more negative towards their illness; it would be because they are in greater pain and have higher levels of disability. While this explanation is consistent with the self-regulation model, the quantitative studies have not been able to show the representation through a regression analysis.

Qualitative methods lend themselves to explore data from the individual's point of view, giving the mentioned words credibility. We can ascertain that when the individual focuses on the RA disease and symptoms he/she may feel isolated from family, friends, and community and thus experience less enjoyment impacting negatively on illness outcomes. We can almost select two groups: those individuals who cope by utilising a self-regulation mechanism of coping and those who do not. Carlisle and colleagues (2005) makes a case for active coping and passive coping indicating that avoidant coping is more specific than many of the definitions of passive coping. This is potentially more clinically useful as it should be easier to identify, and as practicing nurses we would be able to help people with RA identify why they avoid situations, and the effects this has on negative outcomes for them.

Research suggests that social support is beneficial for both the physical health and psychological well-being of individuals living with a chronic illness (e.g., Demange et al., 2004). According to the self-regulation model, social support is an important factor that influences health behaviours (Clark et al., 2001). In our study, participants talked about the support available to them and their satisfaction or dissatisfaction with it. Participants typically identified spouses and family members as the individuals most helpful to them. The quality of the relationship may be particularly relevant for the health of RA patients. If nurses establish early meaningful relationships with their chronically ill clients, they potentially could find individuals affected by RA adjusting in a more positive way to early stages of the disease. Longitudinal studies of RA patients have shown that perceived available support at time of diagnosis predicted functional status, pain, and disease activity at follow-up three and five years later (Evers et al., 2003a; Evers et al., 2003b).

The acceptability of social support may hinge on its significance to the recipient's self-confidence or esteem. There is growing evidence that psychosocial variables like self-esteem and self-efficacy may influence important symptoms of chronic illness (e.g., functional status, psychological well-being, pain) (Lefebvre et al., 1999). Self-efficacy, according to Bandura (1977), is the notion that one has the capability to manage the demands of a difficult situation, such as managing the symptoms of RA. As such, self-efficacy beliefs provide individuals with a sense of agency to motivate their learning through use of self-regulatory processes like self-evaluation and goal setting (Zimmerman, 2000). In this study, a portion of the participants were able to articulate a belief that they could successfully cope with their illness. They expressed confidence in their abilities to manage the challenges of arthritis. It is likely, therefore, that the participants who expressed higher levels of self-efficacy might also possess higher levels of positive thinking and lower levels of negative thinking. This is consistent with the findings of Lefebvre et al. (1999), who found that patients who rated their arthritis self-efficacy as high reported lower levels of negative mood and pain and higher levels of positive mood. Lau-Walker (2004) found in a sample of cardiac patients a significant relationship between illness representation and generalised self-efficacy. Meanwhile, those who perceived more consequences associated with their heart condition reported lower levels of self-efficacious behaviour. In our study, there were a number of participants (approx. 50% of sample) who expressed having low levels of efficacious/self-regulating behaviours, suggesting that they had greater difficulty in managing their disease. These results suggest that self-efficacy may be an important factor in understanding the daily experience of individuals living with RA. It is possible then that higher levels of positive thinking and lower levels of negative thinking (i.e., about their RA) may allow individuals to be more efficacious and therefore better able to meet their role-related responsibilities, thus adding to the robustness of the transferability of the data.

Valued life activities is the term identified by Katz and her colleagues (e.g., Katz and Neugebauer, 2001; Katz and Morris, 2007; Katz et al., 2008) to describe ‘a broad range of life activities (e.g., hobbies, working, leisure activities, taking care of family)’ (Katz and Neugebauer, 2001: 265). Neugebauer et al. (2003) examined the effect of physical impairment on valued life activities in individuals with RA. They found the greater the physical impairment; the greater the effect it had on valued activities (Neugebauer et al., 2003). In our study, we found the participants identifying activities that corresponded to the domains outlined in Katz and Neugebauer’s article (2001). When we examined the impact of illness on multiple roles, we found that all of the participants were able to describe how RA had affected their family, work, and social roles. Most respondents talked about how their RA affected their ability to participate in activities associated with work, parenting, and leisure. In earlier work conducted by Katz (1995), she examined life activities over a five-year period among individuals with RA and healthy controls, and found individuals with RA lost approximately 10% of the activities they had valued. The greatest losses occurred in paid work, parenting, leisure and social activities. Our findings are consistent with Katz (1995) in that participants identified intrusion by their illness on their role responsibilities, and identified the most significant intrusions affecting their work, parenting, and leisure roles.

Limitations of the study

There are limitations to the study. First, the interviews were conducted over the telephone. As a result, we missed out on assessing nonverbal cues, which may have implications for understanding the context of meaning of the subjects’ words. Second, though clarification was sought during the interviews by the interviewer, some participants were re-contacted up to six months after data collection was completed. This time lag may have affected the rigour of the study findings. Third, because the larger sample from which we drew our participants was a convenience sample, made up of predominantly middle and upper middle-class, Caucasian adults, the generalisability and transferability of the findings beyond the sample are limited.

Relevance to clinical practice

How individuals appraise their illness, coupled with how their illness affects their ability to fulfill their role responsibilities, has implications for their adjustment to RA. Similarly, social support and self-efficacious behaviours were found to aid individuals in their adjustment to RA. To assist individuals in better managing their illness, healthcare providers need to do a better job of assessing how individuals are coping with and making sense of their illness experience (Ramjeet, 2003). Nurses and other healthcare providers can learn from those who are managing their illness well, and share this information with other patients. It is important that individuals with recent onset of RA do not feel isolated or alone, particularly since managing their illness can be a challenge. Additionally, developing more collaborative relationships with patients and providing them with the risks and benefits of various treatment options will allow clients to make the decisions about what they believe will work best for them.

Conclusions

here are few studies that have examined individuals' experiences with living with a chronic illness like RA, and even fewer studies that have examined RA in newly diagnosed individuals. By interviewing individuals early in their illness, nurses and other health care providers can gain a better understanding of the challenges adults face in managing RA. More qualitative research is needed, however, to examine the experiences of adults living with rheumatoid arthritis. Additional research is needed to examine rheumatoid arthritis among ethnic minorities and lower socioeconomic adults who may face even more difficult challenges living with and managing a chronic illness like RA.

Key points

- For those individuals who scored low in role strain, they displayed a more positive outlook or thinking about their illness than those who scored high on the role strain variable.
- Among most respondents, RA affected their ability to participate in work, parenting, and leisure activities.
- Social support and self-efficacious behaviors were found to aid individuals with their adjustment to RA.

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Conflict of interest statement

None declared.

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