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Social Role Experiences of Women Living With Rheumatoid Arthritis

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This study was designed as the qualitative arm of a larger quantitative study (N = 156) of the relationships among social role quality, physical health, and psychological well-being of women living with rheumatoid arthritis (RA). A subset of 20 midlife and late-life women from this larger sample participated in semistructured interviews with the specific aims of investigating how fulfilling they found social roles to be, including their spouse, mother, worker, and homemaker roles, while contending with RA, and what circumstances made social role experiences more positive. The results of the current follow-up qualitative study illustrate how difficult it can be to fulfill social roles during exacerbations of the illness in their formative adult years. The circumstance that best facilitated their positive experience in social roles was the unburdening of social role obligations as they grew older. Implications for nursing practice are discussed.

Keywords: women; social roles; arthritis; chronic disease

Of the more than 2.1 million Americans diagnosed with rheumatoid arthritis (RA), most are midlife and older women (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2003). RA-related

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symptoms, such as pain, joint stiffness, and fatigue, and associated disability, have a significant impact on everyday tasks, family relationships, and social activities (Fyrand, Moum, Finset, & Glennas, 2001; Gornisiewicz & Moreland, 2001; Katz & Yelin, 1995). Despite advances in drug therapy, progressive functional impairment remains a common problem. The majority of individuals with RA must alter their lifestyles, and almost 32% are too disabled to work 10 years after disease onset (Wolfe & Hawley, 1998).

The burden of RA bears on emotional as well as physical health. Fears of helplessness and uncertainty about the future are heightened by unpredictable disease flare-ups and subsequent physical deformities (Mahat, 1997; Read, McEachern, & Mitchell, 2001). Altered functional ability gives rise to feelings of disablement, uselessness, and apprehension about premature aging (Griffith & Carr, 2001; Kamwendo, Askenbom, & Wahlgren, 1999; McPherson, Brander, Taylor, & McNaughton, 2001). Progressive inability to perform valued activities and sustain family and social roles brings about depressive symptoms and feelings of stress (Katz & Yelin, 2001; van Lankveld, Naring, van't Pad Bosch, & van de Putte, 2000). When physical decline precludes a woman's ability to meet household and nurturing activities, the onus of RA extends to the entire family as members shift roles to maintain family functioning (Medeiros, Ferraz, & Quaresma, 2000; Revenson & Gibofsky, 1995). The effect of RA on social roles and responsibilities appears to be more problematic for women than for men. Women with RA have greater difficulty maintaining paid employment and tending to family and household obligations than do men, and women also report less satisfaction with sexual relations, and more emotional distress (Dowdy, Dwyer, Smith, & Wallston, 1996; Lapsley et al., 2002; Majerovitz & Revenson, 1994; Yelin, 1992).

In summary, discomforts and progressive disability appear to limit women's ability to carry out social, occupational, and leisure activities in the face of RA and, therefore, increase their vulnerability for

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impaired well-being. Given these morbidity problems, it is important to learn more about women with RA and their experience in social roles so that appropriate and effective interventions might be planned. With this in mind, a large quantitative study (N = 156) was undertaken to examine relationships among social role quality, physical health, and psychological well-being in midlife and late-life women diagnosed with RA (M age = 59, SD = 11, range = 39 to 87). Results from this larger study are reported elsewhere (Plach, Heidrich, & Waite, 2003). The conclusion reached from this larger study was that women with RA who had positive social role experiences had less depression and more purpose in life, despite physical difficulties, than those who did not have positive social role experiences. Given these promising results, a qualitative follow-up study was designed to explore in greater depth the nature of social role experiences for women living with RA. A subset of 20 women from the original sample of 156 was purposively selected to participate in semistructured interviews with the specific aim of investigating their insider views on how fulfilling they found particular roles to be, including spouse, mother, worker, and homemaker, while contending with RA. A second specific aim was to better understand what circumstances made social role experiences more positive for women living with RA. The results of this follow-up qualitative study are reported here.

METHOD

The setting for the larger quantitative study of women living with RA included several metropolitan communities in a Midwestern state. The convenience sample of 156 participants was recruited from private physician offices, health clinics, and community newsletters. Inclusion criteria were that participants be female, carry a diagnosis of RA, and be able to read and write English so that they could complete written survey instruments about social role quality, physical health, and psychological well-being. The purposive sample of 20 participants who took part in this qualitative follow-up study consisted of women who had previously participated in the quantitative study and had given their permission to be contacted again for any subsequent investigations. (Of the original sample, 85% gave permission to be contacted again.) The purposive sample was chosen using two criteria: length of time since diagnosis and age. We wanted to

include women in the qualitative study who had enough years since their diagnosis with RA to have a long-lasting subjective experience of the illness that they could tell us about. Because the first couple of years of an illness such as RA involve adjusting to the diagnosis and initial treatment regimens, women who had lived with a diagnosis of RA for 3 years or longer were selected. Because results of the larger study had indicated a difference in the level of depression between midlife and late-life women living with RA, we also wanted to ensure similar numbers of midlife and late-life women in the qualitative study.

The 20 participants ranged in age from 39 to 86 years (M = 61), all but one was White. More than one half were married, reported a yearly household income of at least U.S.\$30,000, and had lived with RA for more than 10 years (Table 1). Eight women had children who were still living at home. Nine worked outside the home, 10 were retired, and two categorized themselves as disabled.

Semistructured interviews were conducted in private, conveniently located places, mostly in participants' homes. The interview guide consisted of open-ended questions about what it was like to live with RA and what it was like to carry out their social roles. Interviews varied in length from 45 min to 90 min and were audiotaped and transcribed verbatim. Institutional Review Board approval was obtained for all study procedures.

We used qualitative content analysis (Lofland & Lofland, 1995) to find common patterns and themes within participants' characterizations of their social role experiences. In the initial coding, the researchers divided the data according to the social roles discussed: spouse, mother, worker, and so on. Labels were then assigned to units of meaning. The second level of coding involved reading all the labeled descriptions of what it was like being a spouse, and then identifying the context and circumstances of positive spouse role experiences. This second level of coding was repeated for each social role.

Then, as we sorted, aggregated, and synthesized the data further, we looked for themes that represented the relationships among codes. The last analytic step was to identify major categories of experience that represented the relationships among the themes. In the process, each woman's experience was systematically compared and contrasted with experiences of the other participants. Analytic memos and diagrams were created to show how initial codes related to one another, how themes fit together, and what major categories

Characteristic	n	%	
Age			
39 to 65 years	11	55	
66 to 86 years	9	45	
Ethnicity/Race			
White	19	95	
Hispanic	1	5	
Marital status			
Married	12	60	
Widowed	4	20	
Divorced	3	15	
Single (never married)	1	5	
Yearly household income			
Less than U.S.\$10,000	1	5	
\$10,000 to \$30,000	7	35	
More than \$30,000	12	60	
Length of time since RA diagnosis			
3 to 5 years	5	25	
6 to 10 years	4	20	
More than 10 years	11	55	

 Table 1: Demographic Characteristics of Participants (N = 20)

Note: RA = rheumatoid arthritis

began to emerge (Miles & Huberman, 1994). Trustworthiness and rigor were strengthened throughout the analysis as the three researchers met at regular intervals to compare and discuss coding and reach consensus on what was represented in the data. Our findings are presented with ample verbatim excerpts from the women's interviews for readers to judge their veracity.

RESULTS

No Roles Left Untouched by RA

Our data indicated that as women with RA moved through adulthood they struggled to balance multiple roles as spouse, mother, worker, and homemaker, while at the same time contending with fatigue, pain, and disability imposed by RA. No roles were left untouched. The midlife women in the sample were embroiled in social role dilemmas as they raised school-aged children, worked

full-time jobs outside the home, tried to have satisfying relationships with their husbands, and did all in their power to keep the house clean and the family well fed. The late-life women in the sample recalled such dilemmas from earlier in their lives and recounted them in their interviews; however, they spoke from a standpoint wherein adult children were no longer dependent on them, they were retired, conflicted marriages had either ended or settled into a tolerable routine, and their households were calmer. When reflecting on their formative adult years living with the disease, however, these late-life women told stories very similar to the younger participants.

When illness-related symptoms precluded women's capacity to meet family expectations and social role norms, they felt frustrated and disappointed. Although most described a tremendous capacity to cope with the symptoms of RA and strive to maintain as much normalcy in their lives as they could, they still experienced guilt and lowered self-esteem when family expectations exceeded what their illness allowed them to do. They were determined to fulfill their roles and maintain relationships as expected, yet they lacked the energy to take care of themselves as they focused on doing right by others.

Stories from all the women in the study illustrate these social role dilemmas. The midlife women talked about what it was currently like, and the late-life women talked about what it used to be like being spouse, mother, worker, and homemaker.

For instance, in their role as spouse, many of the women had felt inadequate at times due to the RA:

I remember coming home from work and being exhausted and laying down and resting, which was what I was supposed to do. And I remember my ex-husband coming in and slamming pots and pans around because he thought I should be up cooking his dinner. I pushed and pushed myself. I figured maybe I wasn't doing all that I should be doing. I thought maybe I was lazy. Maybe just because I have rheumatoid arthritis doesn't mean that I should be allowed to lay down. I lived with that a long time. I kept trying to be everything—go to work all day, come home and clean, have his food ready, be his sex kitten at night.

As far as the wife part of it, that was difficult because I really couldn't be a wife with all the pain and everything that I had. My husband tried to be as supportive as possible, but he admitted to me that he resented my sickness. He resented that I could not do all the things that I used to do.

I think the fatigue probably does more to a relationship than the immobility. Because sometimes I just don't have the energy to be in a relationship. I just don't have the energy to listen to his concerns or deal with his emotions. I get through the day. I don't have anything else to give.

Women's role as a mother with RA was no less troublesome:

My kids had a hard time dealing with my pain, and they didn't understand what it was. They tell me now that when they were little they just remember me screaming a lot with pain and being in bed. I feel bad. That's not much of a childhood. It makes me feel bad that they feel that's what their childhood was all about.

I tried to do the mother things even when I was sick. I tried to be there for the kids when they came home from school. Even though I was in bed, they still felt comfortable coming after school or after dates to sit and talk with me. But, one of my daughters, who was a teenager at the time I was most sick, has never really gotten over going from the closeness we had to all of a sudden my not being available to her the way she really wanted me to be.

My kids have always seen me with arthritis. Sometimes I wish they knew me before I had rheumatoid arthritis. I'm very grateful they help me when I need it, but it makes me feel sometimes like I'm not a full mom like I want to be. Because instead of me caring for them, they're caring for me.

Because of the RA, women suffered losses in their role as worker, too.

Let me tell you what I lost—I lost my profession. I loved it. I was a beautician, and I can't even do my own hair today. When I had to quit my job, I was already starting to lose my speed and my dexterity, and I was dropping things a lot. I was dropping my combs, dropping my brushes.

They compensated as best they could at their jobs.

I have a tendency to do much more than I should at work, because I want to make sure they know I can do my job even though I have rheumatoid arthritis. I sometimes have trouble setting limits when I think people expect too much of me as an employee. Then, I don't have the energy to keep up my volunteer work at the church.

Their work role in the household as a homemaker was affected as well.

I've always been in charge in my home, and everything was just a certain way. Now that I am fighting with this disease and trying to cope with everything, I keep going as much as I can. It's what everyone expects. But, I get really tired and sometimes I lay down on the couch. Then my family says I'm lazy. I also feel guilty about not cooking much anymore.

It's frustrating because I can't keep the house the way I would like it to be kept. And I read booklets from the Arthritis Foundation. There are so many platitudes: "Let it go. Don't worry about it. Just relax." It sounds so easy, but it's difficult in reality to watch dust pile up, dirt pile up. It's very difficult. It makes me angry when healthy people tell afflicted people how they should feel.

Women felt badly that their families were so deeply affected by their illness over the years.

My rheumatoid arthritis affects my whole family. Everybody is pulled in. That compounds it, and I feel worse, because I don't want to see them held back by me. It gives me a sense of guilt over something I can't control, and that bothers me very much.

I get frustrated because I tell my family over and over, "I can't do this. I can't do this." And it's like they don't hear me. It's like they don't get it. And to have to keep repeating your limitations, you feel like you're whining or you're being a victim. And I don't like taking that role.

The emotional and physical effects of the RA tended to isolate them from friends as well.

With rheumatoid arthritis, there's just no avenue to let out your feelings. It all just stays inside. It makes me lonely and isolated. I isolated myself a lot from people. I did not have the energy, and people didn't understand. I stopped going out. I lost a lot of friends.

In general, these data suggest that dealing with the ramifications of RA during midlife negatively affected the quality of women's social roles. The impact of RA on women's lives seemed to have a domino effect. Discomfort and dysfunction affected their ability to perform in social roles. Their self-image of who they were in relation to others became shaken. Family dynamics changed as roles shifted and realigned to accommodate the intrusion of RA. Relationships became strained and altered. Some social roles, such as being a professional in the workplace, an active church member, or a dependable friend, were lost.

Benefits of Growing Older and Wiser With RA

There was evidence of positive social role experiences in the data as well. Most of these stories came from the late-life women in the sample who had discovered that growing older helped them better balance the restrictions of RA and find meaning and strength in their daily lives. For the older women in this study, RA seemed to be less problematic as their lives were less referenced by the needs of growing families and demanding careers. The busyness of younger years that had often rendered them physically and emotionally exhausted was now behind them, and they contended with fewer daily hassles and pressures. Although they were not free from the pain and limitations that accompanied the disease, many appraised their lives positively. As one participant put it, "I have rheumatoid arthritis, it doesn't have me."

As the following quote illustrates, many of the older women in the study were able to set aside multiple social role responsibilities to focus on the one role that gave them the most pleasure.

My house doesn't look like it did 10 years ago. I clean it a lot less now too many aches and pains. There are some things I can't get done, like I used to decorate for every season. Well, I don't do that anymore, and nobody misses it except me. Oh, there are uncomfortable moments, and the fact that I can't do some things, that does bother me. But, on the whole, my husband and I are able to do a lot, go out to eat, visit friends. We traveled to Florida last year. It is easier now that the kids are grown, and I don't have to struggle with work anymore.

RA seemed less overwhelming than it had been earlier in life because they could slow down and adjust plans to accommodate discomforts, unlike in their younger years when everyday responsibilities dictated that they carry on despite severe fatigue and pain.

Now that I'm older, I feel like I don't have to work so hard to please everyone, to do everything no matter how sore I am. I get to do what I want to do. If I want to get dressed and go out shopping, I'll do that. Some days I really hurt, so I just stay home. I don't like any demands, anybody saying, "Wednesday we'll go here," or "Thursday, you gotta do that." I had people telling me what to do for years, but not anymore.

At their age, these late-life women with RA were freed from juggling family and work responsibilities, and they had more time to reflect on their lives and negotiate around their health problems. They resisted self-pity and found new meaning and purpose in their life circumstances:

I don't mind getting older. I think I know myself better. I'm more creative. I'm more productive, maybe not physically, but spiritually and psychologically. RA makes me slow down, and I'm able to be in the moment and appreciate it. When I was younger, I was always trying to get to the next moment, the next thing, taking care of everybody and everything: the kids, my husband, my employer. Now I'm reclaiming myself. I wouldn't wish RA on anyone, but it has changed me—and not really for the worse.

Rheumatoid arthritis has changed my lifestyle, but I think there is more quality. Instead of all the physical things, I read, write, and pray more. It has brought out a different side of me and helped me to find other gifts.

Some were even able to identify a positive legacy they were leaving as a result of having RA:

A plus with this is that my children don't feel awkward around people who are disabled. Most people grow up never knowing how to deal with somebody who is disabled. My children grew up learning how to do for me, and that's good.

My granddaughter told her mother, "Mama, if you ever get sick, I'll take care of you like you take care of Grandma." It's good for kids to see that sometimes people need help that way.

One woman reflected back on her life, not discounting the difficulties posed by the illness, but finding serenity in her role accomplishments:

I am 73. I had my first serious bout with rheumatoid arthritis at the age of 9, when I was completely immobile. At age 35, another bout with it lasted years. But I kept moving, raised the kids and all. Now at 73, I consider myself in remission, although there are still problems. I have had a total hip replacement, a total knee replacement, and all my joints are lumpy and stiff. But, I'm very thankful to the Lord for all the blessings I've received and for helping me through my problems. So, what I do is volunteer for the Rheumatoid Arthritis Foundation when they do their fund drive every year. It makes me feel like I'm contributing.

DISCUSSION

Similar to other research, findings from this study highlight the deleterious effects a chronic, debilitating illness such as rheumatoid arthritis can have on social role activities and psychological health for women (Brown & Williams, 1995; DeVillis, Patterson, Blalock, Renner, & DeVellis, 1997; Katz & Yelin, 1995; Plach & Heidrich, 2002; Plach & Stevens, 2001; Walsh, Blanchard, Kremer, & Blanchard, 1999). No role was left untouched by RA. When limited in their ability to perform their spouse, mother, worker, and homemaker roles, women in the current study felt angry, sad, and sometimes useless. During active exacerbations of their illness in their formative adult years, the social roles women with RA tried to fulfill became even more difficult, and they were exhausted. According to these data from midlife and late-life women, the circumstance that best facilitated their positive experience in social roles was the unburdening of social role obligations as they grew older. Achieving older age helped women in the current study to shed a portion of the contentious social role responsibilities they had earlier in life and gain wisdom about their illness and its effects on their lives and the lives of their families. They seemed better able to balance the constraints of RA without the multiple role obligations of earlier years. Late-life women with RA had the time and energy to negotiate around their health problems, pursue more of their own interests, and contribute to their own well-being and that of their families and society in ways that gave meaning and purpose to their lives.

These findings bear some similarity to findings by Dildy (1996), Neill (2002), and Shaul (1997), in that they seem to indicate that women with RA go through a process of adaptation over time in which they learn to balance resources and demands, and that they are able through a process of personal transformation to achieve success in managing their lives despite their limitations. The turning point, however, seems to be the unburdening of social role obligations that are at conflict with women's RA-related pain, fatigue, and disablement. For these participants, that turning point, which pointed the way to more positive role experiences, came with advancement in age. The clinical implication in these findings lies in pursuing ways to help women with RA to reach a positive plane in their social role experiences while they are still in their formative adult years. The ordinary arrangements of family and work life are often characterized by ineq-

uity that consistently disadvantages women (Robinson, 1998), so any work in this area must address this broader social concern.

It may be that experiencing RA at one developmental stage in life's trajectory is more problematic for emotional well-being than it is at a different developmental stage. For example, experiencing physical limitations from RA may be perceived by late-life women as somewhat consistent with their same-age peers whose activities have slowed because of the aging process. Whereas, experiencing these same physical limitations at midlife may make women feel dissimilar from same-age peers whom they perceive as boundlessly energetic and achievement oriented. In the larger quantitative study of women with RA (N = 156), we found these kinds of differences between latelife and midlife women. Despite significantly more health problems, late-life women fared better than their younger counterparts from a psychosocial perspective, reporting more role satisfaction and less depression (Plach, Napholz, & Kelber, 2003a). We found similar differences in a previous quantitative study with women with heart disease (N = 157). Regardless of the extent of physical health problems, late-life women had less anxiety and depression, and more positive well-being and role satisfaction than midlife women (Plach, & Heidrich, 2002; Plach, Napholz, & Kelber, 2003b).

Feminist researchers suggest that women use a process of repatterning to juggle competing family, work, and personal demands. With this process, they reorganize activities to reduce or overcome the negative effects of role demands (Wuest, 2000). Perhaps nurses could help women with RA mitigate the effect of RA on social role expectations by providing education about repatterning strategies, such as relinquishing and replenishing (Wuest, 2000). Relinquishing is the process of consciously deciding which activities to give up, giving women a sense of control that helps to offset stressors associated with uncontrolled losses. For example, a woman might choose to stop hosting major family events. With replenishing, women learn to pay attention to themselves, attending to their physical, emotional, intellectual, and social needs. In this instance, a woman might choose to join a book club to develop new knowledge and increase her social network.

Such strategies hold little potential for success unless women and their families are involved in intervention. Family dynamics play a major part in whether women with RA feel fulfilled and satisfied in their social roles (Nyman & Lutzen, 1999). Often family members are not present for education sessions in the physician office or clinic setting, and an opportunity is missed to teach the family how they can best give physical and emotional support to their loved ones. By encouraging patients to bring a family member with them to clinic appointments or by scheduling in-hospital education at times when family members are available, nurses can provide family-centered education about the effects of RA on functional ability and help family members plan strategies to realign role responsibilities and expectations. By working with the family to determine realistic and flexible role expectations and modifications, nurses can help keep a woman's important roles intact. Family-centered education may help to maintain family balance and optimize women's emotional well-being. Such interventions need to be tested.

A support network or support group of peers could help women living with RA feel safe expressing and responding to the emotional and physical turmoil imposed by the presence of RA in their everyday lives as spouses, mothers, workers, and homemakers. Participating in a support group provides an opportunity to share illness experiences with like-minded women contending with similar challenges to their well-being (Ruffing-Rahal, 1998). One outcome may be to help women with RA move toward accepting fewer responsibilities and feeling less guilt about not attending as closely to the needs of others (Charmaz, 2002). Support groups can also provide education, and when facilitated by a community health or rheumatology advanced practice nurse, participants can receive consultation and self-care information, ask health-related questions, and learn about other health and community resources (Ruffing-Rahal, 1998). According to latest recommendations for our nation's health, evidence-based arthritis education should be an integral part of an individual's management of their arthritis (Office of Disease and Health Promotion, 2001). A viable strategy to meet this objective would be the development of multidimensional support groups facilitated by advanced practice nurses. Clinic and office nurses could refer and encourage women's participation in support groups.

Caution is warranted in generalizing from the findings of the current qualitative study. The experiences of these predominately White women cannot be taken as representative of women from other ethnic/ racial groups. Further research about women with RA would benefit from a sampling strategy that optimizes ethnic/racial diversity so that similarities and differences in women's experiences with RA could be explored and the design of future interventions made culturally competent. Although the findings cannot be generalized to all

women with RA or similar illnesses, the information derived from naturalistic studies such as this one may be transferable to other women in similar situations (Lincoln & Guba, 1985). For example, there may be some applicability to other women living with chronic illnesses that are debilitating, have pain and fatigue associated with them, and have a clinical course that involves exacerbations and remissions. Larger studies involving women with varying diagnoses, as well as longitudinal designs, might allow for examination of the varied day-to-day circumstances of women's social roles with changes in disease trajectory over time.

In summary, women with RA contend with many challenges in their social roles as they live with RA. Findings from the current study help to shed light on women's everyday experiences with the negative psychological and social sequelae of RA. This elucidation of qualitative data about the social context of women's lives provides a fuller appreciation of women's experiences of illness and adds information about the impact of chronic, disabling illness. A challenge for nurses is to incorporate insights provided through women's accounts of social role experiences into care plans and clinical practice (Brown & Williams, 1995) so that women can be helped to engineer the best possible everyday well-being.

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