Understanding Social Role Participation: What Matters to People with Arthritis?

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ABSTRACT.

Objective. To assess the importance of different social roles in the lives of people with osteoarthritis (OA), and satisfaction with time spent in roles and role performance, as well as the relationship of demographic, health, and psychological factors to role perceptions.

Methods. Sixty women and 27 men (age 42–86 yrs) with hip or knee OA were recruited from rehabilitation programs and community advertising. Participants completed interview-administered questionnaires measuring demographics, OA symptoms, activity limitations, and well-being (e.g., depression). They also completed the Social Role Participation Questionnaire (SRPQ) assessing the influence of arthritis on role salience and satisfaction across diverse role domains (e.g., close relationships, employment).

Results. Participants reported many salient roles, but low to moderate satisfaction with them related to OA. SRPQ dimensions of salience and satisfaction were distinct; satisfaction with time spent in roles and with role performance was highly correlated (r = 0.83). Lower role salience was associated with being older, having less education and income, and greater illness intrusiveness. Less satisfaction with time spent in roles due to OA was associated with being younger, greater pain, and greater illness intrusiveness, whereas less satisfaction with role performance was associated with greater illness intrusiveness and depression.

Conclusion. This study addresses a gap — the influence of OA on social role participation. It underscores the importance of taking into account individual perceptions of roles, and that these perceptions are
multifaceted. Understanding diverse factors related to social roles may help identify individuals at risk for role difficulties and provide targets for interventions to improve role participation. (First Release June 15 2008; J Rheumatol 2008;35:1655–63)

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The influence of arthritis on diverse social roles such as occupation, relationships with others, leisure, and community involvement has
reflects a movement away from a medical model of health to a biopsychosocial model that focuses on health as an interaction of individual, social, and environmental factors. In research, this is exemplified in the adoption of the World Health Organization's *International Classification of Function* (ICF; 2001) and other conceptual models to guide studies in areas like participation, social outcomes, social integration, and life habits. However, reviews of models like the ICF highlight several challenges for researchers. They include conceptual confusion in definitions of an individual's broader life experiences and distinguishing concepts like "participation" from "function," "activity," and "disability." To deal with these issues, some researchers have suggested combining the activity and participation constructs, while others have called for ways to more clearly differentiate the effects arthritis can have on an individual's life.

Among people with arthritis, interest in social roles is often expressed simply and compellingly — they are what matter in life. That is, despite arthritis, individuals want to engage in roles that are important to them, at the times they want, and in the ways they want. However, much of existing arthritis research emphasizes the influence of the disease on impairment-level variables (e.g., pain) and discrete activities (e.g., dressing, walking), although studies find that role occupancy is also affected. Largely missing are individuals' evaluations of their roles in terms of their perceived importance, as well as the satisfaction or dissatisfaction experienced with time spent in roles and with role performance. Also missing is the relationship of demographic, illness, and psychological factors to role perceptions. By understanding individuals' perceptions of the different roles that matter to them and the factors associated with these perceptions, we have the potential to better guide research and measurement of the impact of arthritis on people's lives, as well as to inform and evaluate health intervention efforts directed toward enabling individuals with arthritis to maintain or regain full and active participation in life.

Current conceptual discussions of social roles stem largely from psychosocial development research, where the selection and maintenance of roles is thought to be integral to identity, well-being, and successful aging. Role participation includes being involved in close relationships (e.g., parenting), social and community interactions, being a student or employee, and participation in leisure pursuits. Roles involve patterns of behavior that are expected, taught, and encouraged within sociocultural contexts. They are undertaken because of a sense of personal value or necessity and they shape identity by answering the question, "Who am I?" Hence, role participation can be defined as involving broad patterns of purposeful
behavior at the level of societal involvement. Roles consist of acts and tasks, but because of their range and diversity, cannot be constrained to a universal list of these acts and tasks. Instead, they are dependent upon context and their assessment is largely subjective.

In emphasizing that the assessment of roles is subjective, there is recognition that the individual decides what matters to him or her and whether goals have been met. Measuring whether a role is occupied (Yes/No) or difficulty with a role provides an incomplete picture of the effect of a disease on role participation from the individual's perspective. For example, socioemotional theory discusses the salience (i.e., importance) of roles and considers time as a critical factor in understanding social role participation. When time is perceived as relatively unlimited, many roles can be pursued, but when time is perceived as limited, as in old age or when health problems arise, individuals reprioritize roles. Arthritis studies also find that roles vary in their subjective importance and that individuals often express upset and dissatisfaction when important roles are forgone or need to be modified. These studies point to the need for role participation in arthritis research to be understood in terms of the salience of roles in a person's life and perceived role satisfaction.

This research examines 3 dimensions of social role participation: (1) role salience (i.e., the importance of roles); (2) satisfaction with time spent in roles (i.e., performing roles as often as desired); and (3) satisfaction with role performance (i.e., performing roles in the ways desired) across diverse role domains (e.g., community interaction, physical leisure, employment, caregiving, intimate relationships) identified from existing arthritis and psychosocial research.

We examined perceptions of different roles in a sample of individuals with hip or knee osteoarthritis (OA). Drawing on research related to socioemotional development and previous arthritis studies, individuals with OA are expected to report relatively high levels of salience across their social roles, viewing many of them as important, but relatively low satisfaction for time spent in roles and role performance because of their OA joint problems. Moreover, the factors associated with role salience and satisfaction are expected to differ. Individuals with OA who report greater pain, fatigue, activity limitations, and psychological distress (i.e., greater illness intrusiveness and depression) should report less satisfaction with time spent in roles and role performance. However, role theory would suggest that role salience should be related less to illness variables and more to factors like life-stage (e.g., age) and resources like education and income. For example, older adults may rate some social roles (e.g., employment) as less important than younger adults. Those with fewer resources may also rate some roles as less
salient (e.g., travel). No age difference in satisfaction with social roles is expected, consistent with studies showing that, despite changes in role importance across the life-course, role satisfaction remains relatively stable36.

MATERIALS AND METHODS

Participants. A purposive sample of individuals with mild to severe hip or knee OA was recruited using community advertising in several newspapers with a broad spectrum of socioeconomic readership characteristics, community centers, and from The Arthritis Society, Ontario Division, which provides rehabilitation services. Respondents were recruited across a wide age range and in urban and rural areas. Participants resided in southwestern Ontario, Canada. Screening questions determining eligibility included whether OA had been diagnosed by a health professional; knee, hip, and/or groin pain in the previous year; and being at least 30 years old. Exclusion criteria included other diagnosed musculoskeletal conditions; acute injuries in the previous year; fibromyalgia; ongoing treatment for chronic back pain or waiting for OA surgery (e.g., joint replacement); or conditions that participants reported resulted in activity limitations in their daily lives (e.g., Parkinson's, multiple sclerosis). Participants with nondisabling comorbidity (e.g., hypertension, diabetes) were included in the study if these conditions did not interfere or physically limit daily activities. To exclude these individuals would have resulted in a highly unrepresentative sample of the population.

A telephone interviewer screened 171 individuals to establish eligibility. Sixty-seven individuals (39.2%) were not eligible because of other musculoskeletal health conditions or chronic disabling illnesses. Of those remaining, 7 were not interviewed because of scheduling difficulties and 10 were excluded after interviewing because of physical or mental health conditions other than OA or English comprehension difficulties. Eighty-seven individuals completed the study.

Procedure. Participants were interviewed at home or at a location of their choice by a trained interviewer using a structured questionnaire. Interviews lasted about 1.5 hours.

The study received ethical approval from the University Health Network institutional review board and all participants provided informed consent.

Social roles. Social roles were assessed using the Social Role Participation Questionnaire (SRPQ), designed for this study. Eleven
social role domains and one global question were assessed drawing on pilot studies, psychosocial role research, existing participation measures, and arthritis studies1–10,24,25,28,36,37 identified from MedLine, Embase, and PsycInfo databases. They were (1) community, religious, cultural interactions; (2) social events; (3) physical leisure; (4) hobbies; (5) casual or informal contact with others; (6) travel or vacation; (7) employment; (8) attending school, continuing education; (9) intimate relationships; (10) relationships with children/grandchildren; (11) relationships with other family; and (12) a global assessment of social role participation. Although participation in some domains does not always involve contact with others (e.g., leisure, hobbies), these domains are shaped by social and cultural expectations. Therefore, they are appropriate to consider as social roles.

Instructions stated we were interested in whether OA joint problems affected people's roles. For each domain, participants were asked about role salience, "To what extent is [the particular social role] important to you" (1 = not at all important to 5 = extremely important). Participants were asked about the importance of all roles, regardless of whether they participated in the role. This enabled data generation on whether roles like employment were valued despite lack of engagement in them. Participants were asked whether they were currently employed, attending school, involved in an intimate relationship, or had children/grandchildren (Yes/No). Individuals not engaged in these roles were asked whether OA joint problems were a factor in not participating in them (Yes/No).

For each social role in which respondents participated, they were asked to rate their satisfaction with time spent in that role and with their role performance (1 = not at all satisfied to 5 = extremely satisfied) focusing on the influence of their OA joint problems on the role. Prior to data collection, questions were administered to 12 individuals and cognitive debriefing discussing the content, wording, and time taken to complete the questionnaire led to modifications of wording and the order of questions.

**Independent measures. Demographics.** Participants' age, sex, marital status, living arrangements (live alone: Yes/No), education, and employment status were collected.

**Arthritis.** Respondents were asked whether they had been diagnosed with hip or knee OA and the duration of symptoms.

**Pain.** Pain in the previous week was assessed using the Short-Form McGill Pain Questionnaire46. Sensory and affective pain was
measured on a 4-point scale (0 = none; 3 = severe). Cronbach's alpha for the scales was 0.74 and 0.82, respectively. A visual analog scale measured pain intensity (0 = no pain; 10 = worst possible pain).

Self-reported health and other chronic health conditions. Self-reported health was assessed with a single item asking respondents to rate their health in the previous week (1 = poor; 5 = excellent). Participants were also asked, "Do you have any other chronic health conditions? (e.g., high blood pressure, emphysema, angina, ulcers, cancer)" (Yes/No).

Activity limitations. The 17-item function in daily living subscale of the Knee and Osteoarthritis Outcome Score (KOOS) or Hip and Osteoarthritis Outcome Score (HOOS) assessed difficulty with everyday activities in the previous week (0 = none; 4 = extreme). Scores are transformed to range from 0 to 100, lower scores indicating greater activity limitations. Cronbach's alpha was 0.96 (KOOS) and 0.94 (HOOS).

Illness intrusiveness. Thirteen items measured participants' perceptions that their illness interfered with life, including health, work, relationships, and self-expression (1 = not very much; 7 = very much); Cronbach's alpha was 0.89.

Depression. Depression was measured with the depression subscale of the Hospital Anxiety and Depression Scale (HADS). Responses are on a 4-point scale (0 = most of the time; 3 = not at all), with scores ranging from 0 to 16. Lower scores indicate greater depression; Cronbach's alpha was 0.77.

Analyses. Frequencies, means, and standard deviations were calculated. Spearman correlations were used to examine relationships among SRPQ questions. Interrelationships among independent variables were examined to avoid potential multicollinearity. Mean scores were calculated for the 3 social role dimensions (salience, time spent, role performance). Because individuals may not engage in all roles, mean scores were calculated if participants responded to at least 9 of 12 role domains. Cronbach's alpha coefficients examined the internal consistency of the 3 SRPQ dimensions. Categorical variables were dummy-coded. Referent categories for gender, education, and presence of other chronic health conditions were men, postsecondary education, and no other chronic health conditions. Prior to multivariate analyses, bivariate analyses (t-tests, analysis of variance, simple regression) examined the association of independent variables to role salience, satisfaction with time spent in roles, and role performance. This contributed to multivariate model-building and
maximized the power of analyses by identifying potentially redundant variables or variables not significantly associated with any of the 3 dependent measures. Variables not significant in any bivariate analyses at a level of at least \( p < 0.20 \) were excluded from multivariate linear regression analyses. Gender was retained in multivariate analyses for control purposes. Separate multivariate linear regression analyses were performed with role salience, satisfaction with time spent in roles, and role performance. Analyses were conducted using SAS version 9.

RESULTS

Respondents were 60 women and 27 men ranging in age from 42 to 86 years (mean 65.6 yrs; Table 1). The sample was relatively well educated and 30% reported an income over $70,000 CAD. Most participants reported knee OA (62%), and nearly 60% reported nondisabling health conditions like hypertension. There was a wide range of pain, fatigue, and activity limitation scores across the sample, with moderate pain and activity limitations reported on average and a third of the sample (33.7%) reporting fatigue most or all days.

Table 1. Sample characteristics (n = 87)

Not all respondents participated in all roles. Overall, 4.6% of the sample reported educational pursuits, 33.3% were employed, 70.1% were involved in an intimate relationship, and 87.4% had children/grandchildren. Salience ratings for employment differed depending on role occupancy (mean 3.5, SD 0.83, for those employed and mean 0.45, SD 0.99, for those not employed; \( p < 0.001 \)). They also differed for intimate relationships (mean 3.4, SD 0.61 vs mean 1.9, SD 1.7) for those involved or not involved in intimate relationships (\( p < 0.001 \)). There were no significant differences in salience scores among those with or without children/grandchildren (mean 3.5, SD 0.53 vs mean 1.5, SD 1.7, respectively; \( p < 0.09 \)) and for those involved or not involved in educational pursuits (mean 2.5, SD 0.58 vs mean 1.3, SD 1.4, respectively; \( p < 0.09 \)). However, the uneven distribution of individuals in these roles limits the power of these analyses for detecting differences.

Figure 1 presents mean role salience scores for the entire sample and satisfaction with time spent in roles and role performance means for those occupying the role across the 11 specific role domains and the global role question. Education was omitted because so few participants were involved in this role. Across the entire sample,
social roles rated most salient included relationships with children, other family, and physical leisure activities. Roles rated less important included paid work and community, religious, or cultural activities. Social roles rated most satisfactory, considering OA joint problems included intimate relationships, employment, relationships with children and other family. Roles rated less satisfactory considering OA joint problems included physical leisure, travel, hobbies, and social events.

Figure 1. Mean social role domain scores for role salience, satisfaction with time spent in roles, and role performance.

Mean salience scores and correlations among the role dimensions for each separate role domain are presented in Table 2. Correlations among role salience and role satisfaction were low across all role domains for both time spent in roles and role performance (r = –0.18 to 0.28). Correlations of satisfaction with time spent in roles and satisfaction with role performance were high for community interaction, travel, casual contact with others, and relationships with other family (r > 0.7), and moderate for relationships with children, employment, physical leisure, and attending social events (r = 0.41 to 0.56; all p < 0.01).

Table 2. Means and correlations among role domains for those occupying social roles.

Prior to regression analyses, total mean scores were calculated for each social role dimension (Table 3). This resulted in missing data for only 2 participants (2.3%). Cronbach's alpha, a measure of internal consistency, was adequate for all dimensions, with salience = 0.74, satisfaction with time spent in roles = 0.83, satisfaction with role performance = 0.85. Correlations among the total mean scores for each dimension revealed that role salience was largely independent of satisfaction with time spent in roles (r = 0.10) and role performance (r = 0.02). Satisfaction with time spent in a role was highly correlated with satisfaction with role performance (r = 0.83, p < 0.001).

Table 3. Means and correlations of social role dimension summary scores.
Bivariate regression analyses of independent variables and the 3 role dimensions revealed that all variables were significantly associated with at least one social role dimension except gender, marital status, living arrangements, and OA disease duration. These variables were omitted from multivariate regression analyses, with the exception of gender, which was retained for control purposes. Separate multivariate regression analyses examined factors associated with role salience, satisfaction with time spent in roles, and role performance (Table 4). Age, education, income, other chronic health conditions, and illness intrusiveness were significantly associated with role salience. Specifically, older adults (p < 0.02), those with secondary school or less education (p < 0.04), and those with less income (p < 0.04) reported lower importance of roles. There was also a trend for those with other chronic health conditions in addition to OA to report lower role importance overall (p < 0.08). Greater role salience was associated with the perception that OA was more intrusive in life (p < 0.02). These variables accounted for 46% of the variance. Less satisfaction with the time spent in roles related to OA joint problems was significantly associated with being younger, reporting more pain, and illness intrusiveness (all p < 0.01). A trend emerged with those reporting lower self-reported health also reporting lower satisfaction with time spent in roles (p < 0.07). The variables accounted for 63% of the variance. Less satisfaction with role performance related to OA joint problems was associated with greater illness intrusiveness (p < 0.03) and depression (p < 0.01) and with a trend for greater pain (p < 0.06). These variables also accounted for 63% of the total variance.

Table 4. Multivariate analyses of variables associated with role salience, satisfaction with time spent in roles, and role performance.

DISCUSSION

Our study addresses a gap in arthritis research, namely, the influence of OA on social roles. Individuals with OA want to maintain participation in meaningful roles despite limitations caused by their disease. Recently, there has been an increased interest in the larger social and cultural environments within which individuals interact. However, reviews of health models like the ICF highlight conceptual and measurement challenges for researchers in assessing these broader life experiences. For example, assessing role occupancy may be too simplistic, identifying only whether a role has been foregone. This can overlook the effects of arthritis in areas like social relationships where roles may not be given up, but may be profoundly
affected by disease. Measuring the extent of role difficulties may be more useful, but does not identify aspects of a role that are important to the individual. To overcome these challenges, the questions developed for this study focused on a single construct — social roles. By drawing on psychosocial development research, we were able to conceptually differentiate social roles from assessments of function and activity. The SRPQ generated a multifaceted view of roles, measuring diverse roles drawn from research and theory within the arthritis, health, and lifespan development fields, and examined the salience of these roles, as well as the influences of OA joint problems on satisfaction with time spent in roles and role performance.

An examination of each of the 12 role domains revealed that although individuals reported a range of highly salient roles in their lives, when they considered their OA joint problems, satisfaction with the time spent in roles and with role performance was often low to moderate. Social relationships were among the most important roles identified by participants, and they reported relatively greater satisfaction with them than physical leisure, travel, and vacation, which were also reported as highly salient. The larger discrepancies (i.e., lower correlations) between salience and satisfaction for some roles and not others likely relate to the physical manifestations of OA and its potentially greater impact on roles like travel and leisure than roles like social relationships, which can be engaged in despite the functional limitations of OA. More important is that measuring both salience and satisfaction provides additional insight into roles that is not apparent from measuring role occupancy or role limitations alone. Specifically, roles rated as highly important, but where there is low satisfaction related to OA, might be those where the greatest upset and distress is engendered and where intervention and treatment efforts should be targeted, compared to roles rated as less salient in a person's life or roles where satisfaction levels are high. Additional research on the implications of differing levels of salience and satisfaction is warranted.

The salience of specific roles was associated with role occupancy. For example, participants who were employed or involved in an intimate relationship rated these roles as more important than those not involved in them. It will be important to examine this finding in greater depth in future research. As noted, previous research has found that individuals may reappraise the salience of their roles over time related to age, resources, or illness. In our study, older adults and those with less education and income reported that roles were less important. Longitudinal research with diverse samples in terms of sociodemographics, disease severity levels, and duration would enable changes in role salience to be assessed along with any
corresponding changes in role satisfaction related to OA. It would also enable a comparison of factors associated with different types of role domains.

In order to examine variables associated with role salience and role satisfaction, total mean scores were created. The internal consistency of the 3 role dimensions was good and correlations between the salience and satisfaction dimensions were relatively low, suggesting that these dimensions are distinct. However, mean satisfaction with time spent in roles and role performance scores were highly correlated. This suggests that the frequency or duration of time spent engaging in roles is related to satisfaction with its performance. Additional research is needed examining whether the dimensions measuring satisfaction should be combined or kept separate. Ratings of these dimensions may respond differently to changes in disease severity or as a result of treatment and intervention. For example, a self-management intervention might enable an individual to perform a role in the way they want, but might not address the fatigue that would allow a person to perform the role as much as they would like. Alternatively, a pharmacological treatment might improve fatigue and enhance the time spent in roles, but may not address the way a role is performed. Additional research is also needed examining the stability, responsiveness, and validity of the dimensions assessed in the SRPQ and comparing it to existing measures of participation.

Different factors were associated with role salience, satisfaction with time spent in roles, and satisfaction with role performance. As noted, perceptions of roles as less important were associated with being older and having less education and income. There was also a trend for those with other chronic health problems to report that roles were less salient on average. Age was also associated with satisfaction with time spent in roles due to OA. However, in this instance, younger participants reported less satisfaction. Psychosocial studies have often reported relatively stable levels of life satisfaction across ages\textsuperscript{36}. However, our findings are in keeping with research suggesting that, although OA is considered normative for older adults, it is perceived as "off-time" or non-normative for middle-aged adults who may perceive less satisfaction with the time they are able to spend in roles as a result of the disease\textsuperscript{37,53,54}. These findings point to the need for greater emphasis, not only on disease factors and their relationship to social roles, but life-stage and psychological perceptions of the meaning of chronic disease at different ages.

Reporting greater pain was associated with less satisfaction with time spent in roles. There was also a trend to report less satisfaction with role performance with increased pain. Poorer self-reported health was
also associated with less satisfaction with time spent in roles. Activity limitations were not associated with role satisfaction. This may be because, although roles encompass tasks and activities, these tasks are so socially and culturally diverse they are distinct from existing measures of activity limitations, which focus on mobility, self-care, and household chores. These findings provide preliminary construct validity that the measure of social roles is distinct from previous measures identifying activity limitations. It also underscores the value of assessing diverse constructs like impairment, activity, and participation to complement one another and to increase the breadth and depth of our understanding of the influence of OA on people's lives.

Illness intrusiveness was associated with the 3 role dimensions, and depression was associated with less satisfaction with role performance due to OA. These findings highlight the importance of psychological appraisals and mood to the perceived importance of roles and role satisfaction. When roles were rated as important, participants were more likely to perceive that their OA was intrusive or disruptive to their life. OA was also perceived as more intrusive when respondents were less satisfied with time spent in roles and role performance. Longitudinal research is needed to disentangle the causal relationships among OA symptoms, role perceptions, perceptions of disease impact, and depression. Role perceptions may be an important mediator in the relationship of OA symptoms like pain on subsequent depression.

Several limitations to this research need to be acknowledged. Although our recruitment strategy enabled us to generalize beyond a clinical sample and was comparable to other OA samples in terms of age, gender, and socioeconomic status of participants, the sample was purposive, small, and relatively affluent, and reported moderate OA symptoms. In particular, social role participation needs to be examined in samples of younger individuals, more culturally and economically diverse groups, with different types, severity levels and duration periods of arthritis, and including a greater range of social, environmental and psychological factors. Additional research examining the interrelationships among impairment, activity limitations, and social roles is also warranted. Longitudinal research comparing individuals with and without arthritis, and those with other types of health conditions, would enable the study of changes in the salience and satisfaction of social roles, as well as hypotheses related to life-stage and its consequences on psychological well-being.

Our study complements and extends existing research in its focus on the larger social environment within which people live and the
influence of OA on people's role participation. Participants identified domains of life that were important to them, as well as areas where their OA resulted in not being able to engage in roles as much as or in the ways that they would like. This can help identify areas of life that should be targeted for self-management or increased intervention efforts. Our research enhances understanding of the effects of OA and underscores the importance of measuring outcomes directed at valued areas of people's lives in addition to symptoms and activity limitations.

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