Male Veterans Coping With the Pendulum Swing of Rheumatiod Arthritis Pain: A Qualitative Study

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Abstract

This study describes the physical, psychological and social context of rheumatoid arthritis (RA) pain from the male veterans. A qualitative, descriptive design was employed using a purposive sampling to ensure representation of male veterans. Interviews were conducted with 12 male veterans of the VA Greater Los Angeles Healthcare System. Socio-demographic characteristics, clinical profiles and descriptors of rheumatoid pain experienced by male veterans' since their diagnoses were gathered. Interviews were audio recorded and transcribed verbatim. Grounded Theory analysis techniques were used to identify concepts related to living with RA Pain. Six concepts related to RA pain adaptation emerged. Three concepts were associated with movement (keep moving, consequences of not moving, staying physically active) and three were related to emotion (thinking positive thoughts, doing jobs, focusing on male identity). The "keep moving" concept explained coping with chronic RA pain through three activity types: physical, cognitive and socio-economic activities. These activities fluctuated in intensity depending upon the disease stage and RA symptoms. The forward and backward pendulum swing described the unpredictable course and pain coping strategy of the veterans. Further studies are recommended to determine the transferability of our findings to other populations and to confirm the impact of continuous motion as an effective pain management strategy for RA.

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Introduction

Males' response to rheumatoid arthritis (RA) may vary due to factors such as genetic predisposition, gender differences, morbidity and mortality. Chronic pain is a pervasive symptom among persons with RA, yet optimal methods to manage RA pain, particularly for males, remain unclear (Heiberg & Kvien, 2002; Parker & Smarr, 1992). It is estimated that approximately 3% of males within the Veteran Administration (VA) have RA (Mikuls, 2006). The significance of studying RA in male veterans is that males have significantly higher risk (than females) for having specific shared genotypes (HLA-DRB1), epitope positive

rheumatoid factor (RF), and anti-cyclic polypeptide (anti-CCP) citrullinated auto antibodies, all of which predispose men to poor outcomes, such as pain and disability and early mortality (Jawaheer, Lum, Gregersen & Criswell, 2006; Nagyova, Stewart, Macejova et al., 2005; Doran, Pond, Crowson et al., 2002; Mottonen, Paimela, Leirisalo-Repo et al., 1998). Although the causal role of gender-related hormones on diseases has not been fully explored (Wiesenfeld-Hallin; 2005), there is evidence to support that RA susceptibility (Laivoranta-Nyman, Luukkainen, Hakala et al., 2001) and disease course (Del Rincon, Battafarano, Arroyo et al., 2003) differ between males and females (Tengstrand, Ahlmen,

Hafstrom et al., 2004), particularly in RA males who smoke (Jawaheer, Lum, Gregersen & Criswell, 2006).

Male experiences with pain and their coping mechanisms of RA pain are poorly understood. Data from interviews of 12 males with RA (Lack, Noddings, & Hewlett, 2011) revealed that RA pain was an influential factor to disease adjustment. Lack et al data suggested that when RA results in loss of personal power and control, patients experience distress, which they may not exhibit to their clinicians. Although RA pain were influencing factors to disease adjustment, Lack and team did not report specific pain coping mechanisms that men used. There remains a gap as to how men manage RA pain. This study ventured to answer this research question.

Methods

Design

This qualitative study was a cross-sectional, descriptive study designed to elicit information on the RA experience and pain management among adult male veterans. A purposive sampling method was used.

Sample

Twelve participants, aged 36-75 (mean age 58), were recruited from the VA Greater Los Angeles Healthcare System (VAGLAHS), where predominantly adult male veterans receive care. Participants were identified via recruitment flyers posted at seven primary care and two rheumatology clinics. Inclusion criteria included: (a) age 18 years and older, (b) male, and (c) having a diagnosis of RA (positive RF serology [anti-cyclic citrullinated peptide]). The survey instrument, containing several openended questions, was administered by the project researcher. Our goal was to gather details how male veterans with managed RA pain and capture their overall experience how they cope with the disease. Initial questions, such as, "tell me how you define your pain", "what is it like when the RA is at its high or low", "can you please describe what is it like to live with RA pain", "please tell me about your personal recipe in managing your pain", and "at times, what seemed to have worked before no longer does". Other example questions, "please tell me what has been your experience when the prescribed interventions seem to have lost their effect".

Data collection and analysis

Individual semi-structured interviews were administered to the 12 male VA patients in designated rooms at the VA in Los Angeles, CA. Each interview was one hour in duration and was audio recorded for data collection and analytic purposes. Socio-demographic characteristics and descriptors of rheumatoid pain experienced by male veterans since their diagnoses were gathered as were self-described strategies employed to manage RA pain. Clinical profiles (measures of pain and treatment regimens) were obtained from medical chart reviews. Interviewers were audio recorded and transcribed verbatim. Data saturation (no new categories emerging from interviews) signaled recruitment closure (Corbin, & Strauss, 1990).

Incentives in the form of a \$20 grocery certificate were provided to each participant. The purpose of the study, participants' voluntary involvement, and confidentiality were explained to each subject; participant consent was obtained. The Institutional Review Boards of the authors' primary affiliations approved the study.

Data analysis followed Grounded Theory methodology (Strauss & Corbin. 1998). Common themes were identified and categorized into major groupings. Three coders reviewed the transcripts and its resulting themes/categories to establish inter-rater reliability. Coders designed sketches and maps of categorical links for clarification which were used to confer with the participants to clarify and validate participant's responses (Creswell, 1998). The researcher informed the participant of potential future contact to confer the meaning of his responses if and when clarification was necessary. This phase of the data collection was referred to as 'member checking' (Creswell, 1998) to assure that categories represented participants'

experiences. This method of interview is consistent with grounded theory method of data collection and analysis.

Medical Record Results

Participants. Twelve veterans participated in the study. Sixty-six percent were Caucasians, 16% were African Americans, 8% were Hispanics, and 8% were Asians. The majority of males had some college education (59%), were retired and/or held part time work (75%); earned an annual income of < \$25,000 (75%), were married (75%), were homeowners (83%), were enlisted in the Army (92%), were non-officers (100%) and did not have any service-connected disabilities (67%).

Medical chart reviews provided clinical information on each participating veteran. Participants had an RA diagnosis for an average of 13 years. All (100%) had reported anti-cyclic citrullinated peptide antibody, which is a specific measure to confirm RA diagnosis. The mean pain score at the moment of assessment was 2 on a visual analogue scale of 1-10, which translates to "mild" pain such as tender and swollen joints. RA was reported by participants as present in five of 28 small joints of upper body. The majority of sample had bone erosions (83%), a family history of RA (50%), and were under combination therapy of biologic agents and oral disease modifying anti-rheumatic drugs (70%). All were using over the counter pain agents (100%); none were current smokers and 58% were alcohol drinkers.

Interview Results

Veterans Pain Experience Prediagnosis: The Painful Road to Diagnosis. The path to early diagnosis was perceived to be unforgettable. Veterans' understanding of their pain prediagnosis era revealed clusters of physical, psychological and emotional experiences (Table 1). Physical symptoms were described as having 'a bad and long flu', being 'beat-up and tired', feeling 'stiff all over' or 'sore all over', 'walking on sharp eggshells', having 'chills' and 'painful warmth but not a fever'. Psychological and

Table 1

Veteran's Experience and Description of RA Pain Type of Experience and Sample Quotes from Interviews

Painful Road to Diagnosis

- "The pain was making me limp especially when it was not diagnosed....he said that I will probably be in a wheelchair within five years..., a lot of fear ...very scary to not know what was going on with my body." (37 year old, fireman)
- "I kept complaining to my private doctor said, "Well, welcome to senior's citizen's world" ... I was cut short at 58" (58 year old, handyman)

Descriptions of Pain: Complexity of day-to-day Pain as a constant companion

- "I don't know if there is a definition of pain; pain is a very personal thing." (75 year old, salesman)
- "... stress involved with being sick all the time...not being able to communicate...like loneliness." (58 year old, driver for errands)
- "Pain is like a sibling, you have it there but is not always there... a possibility that it can come back." (75 year old, salesman)

Flare-up Pain: The Unpredictable Intrusions

- "It's mental, it is like having a sibling, you know it's there, sometimes visits without being invited." (60 year old, personal trainer)
- "... when it flares, the whole body hurts; sensitivity and aching in the joints...it puts you in a fetal position." (59 year old, stock trader)

emotional descriptions included feeling 'down', 'frustrated', 'mental', (which meant an irrational mind frame, and needing to 'go into a shell', an inward thing) especially during failed efforts to take the edge off their pain. Males described these symptoms as triggers that motivated medical attention and finally led them to receiving their diagnosis of RA. Pain was a key part of the pre-diagnosis phase of their disease experiences.

Veterans' Descriptions of Pain. The experience of pain has been a lingering companion in males' day-to-day lives, prompting participants to describe pain unique to the masculine perspective. Men perceived that pain experience is a personal matter, and being stoic while in pain is 'manning up', an expectation of what men are supposed to do. An experience of differential pain (Table 1) depicted complexity in the day-to-day pain versus intense pain during RA flares.

Core Categories: Pendulum Swing of Pain and Rheumatoid Arthritis

The core explanatory category of pain that emerged in this study was described as the adaptation to the pendulum swing of RA pain. The pendulum swing was described as the movement of pain that changes from the non- or low-pain experience to the high-pain experience (that can exceed the pain experience), only to return unexpectedly back to the non- or low-pain state and then swing again to exceed the pain experience. Six concepts related to RA pain management or adaptations were identified. Three of the concepts were associated with movement (keep moving, consequences of not moving, stay physically active) and three were related to emotion (think positive thoughts, doing jobs, a focus on male identity).

Managing or adapting to the pain of RA was described as a process to 'keep moving' as a means of successfully preventing or controlling the RA symptoms. On a day to day basis, males reported activities important to 'manage flareups' and to 'protect self and others.' The concept of a clock pendulum was voiced by one of the participants as it symbolized the constant swing in pain level that the RA produced. This rhythm of the swing was disrupted by the sporadic occurrence of forceful and painful events. The extreme ends of the pendulum symbolize the extreme consequences of progressive RA, and the episodic flare-ups carry forceful swings at the pendulum endpoints. That centered balance is the 'keep moving' component where males described that they 'normally' lingered when not in pain. However, according to the participating males, the extreme ends of the pendulum are their fate.

Male veterans shared that because they frequently experience emotional consequences from RA pain, they are forced to make adaptations in their daily living, specifically forcing them to maintain positive thoughts and to retain one's identity in the face of their experience with RA. Keeping busy to retain a "sense of self" was a frequent coping activity that involved "doing jobs" such as social activities and on-going communication with others. Retaining a focus on one's identity was an important factor in coping with RA, as male identity was paramount for RA adaptation to occur.

'Keep Moving'. To maintain the "balanced pendulum," physical activities were perceived by males as an effective strategy to manage pain and RA progression. Table 2 summarizes subcomponents of "keep moving" as the following: 'Stay active', 'Think positive thoughts' and 'Doing jobs.' Being able to 'keep moving' was perceived as key to maintaining and returning to their normal state and for controlling their pain experience. The phrase, "The key is to keep moving, you can't stop," describes strategies that evolved as ways for males to adapt to pain and prevent the consequences of not moving. A flare up was considered a pendulum swing that disrupts from their norm to the edges of pain and debility.

Consequences of Not Moving: Edges of the Pendulum Swing: In the males' words, 'freezing up', 'rusty joint syndrome', 'gnarly hands', 'crooked fingers', being 'in wheelchair for life', moving 'permanently handicapped' and 'dying

Table 2

Perceived Types of Keep Moving as Method of Pain Management Perceived role and sample quotes from interviews

Keep Moving (Major Theme)

- "I keep moving so that I don't freeze to death." (65 year old caretaker).
- "You can't stop. I rarely ever use the word can't." (60 year old personal trainer)
- "I don't do anything, just move around and it goes away." (68 in-home caretaker)

Subcomponents: Stay active' (Physical component)

- "Staying active is the key. The more that I exercise or physically moving around, the less the pain bothers." (59 year old stock trader)
- "Get up in the morning. It's the key. You can sit and watch TV and let your life rot." (60 year old, personal trainer)

'Think positive thoughts' (Cognitive component)

- "The best way to deal with pain is put it aside, deal with it, do everything I can to overcome ... You just have to embrace it basically." (75 year old salesman)
- "I truly try not to let it (pain) affect my mood with people." (58 year old, chauffer)
- "Then I couldn't run (manage) the rheumatoid. I started doing the prayer, I believed he would help me get through it." (75 year old foster grandparent)

'Doing jobs' (Socioeconomic and masculine component)

- "I keep moving to do jobs; it puts a little money in my pocket." (68 year old hearse driver).
- "I tend to get my hopes up to high...do the things I used to do. Everybody...want to go back to work. They want to join society again." (58 year old chauffeur)
- "...my grandkids... live with me so they need me right now... And I'm hoping that I can give them a normal life." (75 year old foster grandparent)
- "... males have to subdue more pain because they have to work." (60 year old personal trainer)
- "...I try to psych myself if it is painful. I... about my daily operations...I still have a job to do and I can't skip a job." (37 year old fireman)

in a chair' described the physical consequences of not moving. Males understood that if ceased, the outcome would be a progressive anatomical change and 'freeze in place' would occur. Freezing up meant that important function of joints (e.g., hands, leg, shoulder or hip joints) would no longer be possible. Others believed 'rusty joint syndrome' as a condition of rot and deterioration of their hands, legs and other body parts. Before the "rust" takes over, males viewed conditions of 'gnarly hands' to mean disfigured fingers, wrists and other body parts as harbingers of the 'rusty joint syndrome'. The ongoing path to 'rusty joint syndrome,' in the male's view, is ultimately complete dependency on family members or others to perform simple tasks such as feeding, dressing, bathing, and/or walking. These were outcomes that would eventually lead to being bound to a wheelchair until death, as the males believed to be their fate if moving, even though painful, completely ceased. These negative consequences were events that males would rather prevent by 'keep moving'. As long as they were able to kept moving without intrusions of flare up events, they were able to perform normal daily physical activities.

'Stay Physically Active'. Routine physical activities such as exercise and machinery use were examples of the concept 'keep moving'. Some males found stationary bikes and treadmill were preferred ways to maintain physical mobility and to stay active. While physical

exercise was key for some participants, this type of moving was decreased during intensive pain experiences or RA flare-ups. Staying active by 'keep moving' or avoiding strenuous activities during RA flares recurred as a common strategy to manage pain depending on the level of pain. Males believed that 'staying active' was an effective method to prevent RA disease progression and subsequent pain experience. Balancing levels of physical activities to stay active required males to adjust to temporal changes of their RA disease course and to adapt to challenges by adjusting, avoiding, or discovering newer forms of physical activities.

'Think Positive Thoughts'. "Keep moving" was not unique to the body; it also included one's mind- specifically cognitive thoughts. Cognitive activity functioned as pain distractions, dissociation and control over situations while maintaining positive thinking. Keeping busy in order to 'keep [your] mind off pain', describes males' cognitive ability to be able to engage in exercising 'mind over matter'. Thinking positive thoughts were effective adaptations to distract the physical sensations of pain. Table 2 summarizes data that describes the males' experience of 'mind over body' and ways to displace pain.

Emotional dimensions of 'keep moving' also emerged. Males described how pain limited their ability to actively engage with others, however, they felt that positive thinking and being around the company of family members offered some level of comfort. Males engaged in cognitive thinking activities by positively and experiencing simple pleasures of life as they participated in family outings, despite the physical limitations of RA. Feeling depressed because of pain, males shared, drove them into isolation which prevented them from having feelings of joy. Therefore, 'positive thinking' was shared as an effective approach to combat depression.

'Doing Jobs'. Doing jobs or engaging in activities and social events were identified as socio-economic and gender properties of 'keep moving'. 'Keeping busy by doing jobs' was described as a method for males to 'put a little money in the pocket and to talk to people'. The importance in keeping busy at paid jobs in order

Table 3

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Striving to Keep a Job

- "...when I got hired (into a new job) I didn't tell them I was having any problems (RA diagnosis). I didn't tell them that I was on any medication...I still have a job to do and I can't skip a job...maybe at a different angle." (37 year old fireman)
- " major depression because I couldn't go to work and it was my goal in life to work until I'm 67 years old and bow out but it got cut short... severe depression...goal to work but I got cut short at 58." (58 year old handyman)
- "I ended up staying and worked to the end of the shift...concern ... dangerous to have someone like that still working on the job and may not be able to do what they're supposed to do." (58 year old chauffeur)

A Focus on Manhood

- "I'm from an old school...you support the company and work for them, you're loyal. You're only a number and if you don't produce, you're fired. I have to shovel as much dirt as my fellow so it is equal. This is a man thing." (75 year old salesman).
- "...have to support the family and have to get up in the morning and go to their work. Man-up as my father would say." (60 year old personal trainer).

to meet work demands also facilitates the process of social interaction and keeps one's mind off the pain. Being a man, they felt, meant having to physically demonstrate their masculinity by providing for the family. By working, males felt they were engaging in activities that fit their image of being males. Keeping busy in jobs, despite having pain, was important to their manhood. Males share that being without a job would eventually lead to emotional distress such as depression, isolation and 'going into a shell'.

Males supported the concept that activities, such as practicing 'mind over matter' and 'doing jobs to keep busy' do co-exist. By keeping positive thoughts in order to continue doing the necessary duties helps to fulfill their masculine identity. Most males held various part time jobs (Table 3) as ways to support their family even though they often experienced job loss due to their symptoms of RA. 'Wanting to do a job', 'striving to keep a job', 'dreaming of one (a job)' robustly resonated among the males. Whether they were formally working or not, makes supported the goal of having a job to maintain males roles (supporting a family) and male identify (masculinity). Adjusting to and accepting less physically demanding work was a major event for males, because it meant doing jobs that they would not otherwise experience if they did not suffer from RA. Job loss or change occurred at varying periods of their disease course. The actual event of losing their primary job reportedly led most into premature retirement, financial hardship, and a severe emotional state. All males reported that they wanted to continue working as long as they could. Although most reached retirement from primary jobs or military duty, the males believed that family duties were full-time work in itself. Some became parents again, this time, caring and providing for dependents, which in itself was considered full-time work for a male.

A Focus on Male Identity. Males expressed a desire to retain and regain their masculine identity and pursuing and retaining employment were fundamental to this goal. Males in our study, however, were often unable to secure and retain a job because of the negative effects of

RA. Explaining that males were supposed to 'subdue more pain because they have to work', participants revealed that they suffered from blows to their masculine identity due to poor employment experiences. Persistent job loss ruined their perceived male image and seeded and exacerbated psychological and emotional burden.

Males felt torn between two sides of their manhood, fearing a job-related injury due to their RA, yet unwilling to give up their 'mediocre' jobs because they have to support the family. In their view, working in physically demanding jobs identified with being a male, however, RA intruded to such value. The males wanted to return to their previous jobs but were unable to because that meant being required to perform physically demanding activities such as 'climbing up stairs, ladders', 'being on feet all day', and 'carrying heavy objects', that were impossible to perform given their RA diagnosis. They understood that these activities would cause more pain and potentially lead to further physical damage than already sustained from RA.

Discussion

A substantive theoretical scheme was generated through Grounded Theory methodology to describe the meaning of pain in the males' lives. Physical (keep moving, staying active) and cognitive (think positive thoughts) strategies were methods that offered tolerable control of their RA pain and a better quality of life. Because few male-based interventions for RA sufferers exist this study adds to the body of knowledge regarding veteran males and RA pain management and experiences.

Our study revealed that males balanced physical activities with RA pain and protected themselves from bodily harm by limiting activities that demanded physical energy and endurance. They avoided prolonged standing or sitting during disease flares as these, the males believed, could cause 'frozen joint syndrome', increased stiffness, and pain. Asking for help from others as ways to manage pain is a form of selfmanagement behaviors. Most males in our study did not ask for help from others, which was also documented in other studies (Katz, 2005). Male participants in this study displayed selfmanagement behaviors through a combination of physical and cognitive adaptations that they reported to be effective in managing their RA pain.

Males in this study experienced chronic pain, and their suffering often led to limited day-today physical activities. However, similar to other studies (Ahlmen, Nordenskiold. Archenholtz et al., 2005; Katz, 2005), the emotional component of physical activity was also discussed when participants reported emotions of happiness ('thinking positive thoughts') when physical activities were independently performed. Males in this present study similarly reported happiness when they independently engaged in their day-to-day physical activities, and some perceived physical independence as an important measure of how well they managed RA. Physical independence, along with reduced pain, stiffness, and increased mobility, muscle strength and grip force were factors that participants perceived to be important outcomes of RA treatment. These factors were similarly reported in a study by Ahlem et al. (2005).

The personal impact of RA on female identity, such as changes in body image and deformities, has been reported (Lempp, Scott, Kingsley; 2006; Shaul, 1994), however, this study did not support concerns of body image changes for males.

Consistent with recent qualitative studies that explored the meaning of pain, the complexity of RA and constant adaptations to manage RA (Sleath, Callahan, Devellis et al., 2008; Lempp, Scott, Kingsley; 2006; Dubouloz, Laporte, Hall et al., 2004; Kralik, Koch, Price et al., 2004; Fair, 2003) in quantitative studies (Motivala, Khanna, FitzGerald, & Irwin, 2008; Pincus, 2005; Keefe, Smith, Buffington, 2002; Bradley, Alberts, 1999), participants in this present study provided clear examples of daily experiences with managing chronic RA pain.

Similarities with the concept of 'keep moving' are found in other qualitative and quantitative studies (Katz, 2005; Ahlmen, Nordenskiold, Archenholtz, 2005; Lempp. Scott, Kingsley, 2006; Pincus, 2005; Plasqui, 2008; Rose, 2006). 'exercise', 'Physical capacity', 'physical function' and 'self-efficacy for physical function' were similar concepts used and were well established in relevant theoretical schemes within qualitative research approaches.

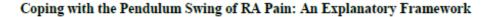
Findings from qualitative studies that focused on RA (Ahlmen, Nordenskiold, Archenholtz, 2005; Dubouloz, Laporte, Hall et al., 2004; Fair, 2003) also supported concepts related to 'keep moving'. For example, in one qualitative study, the notion of 'physical capacity' (similar to 'keep moving') emerged from the analysis of Ahlmen's data (2005), which described the meaning of RA treatment outcome from the perspectives of 25 patients with RA. The authors included 'physical capacity' themes, which represented both physical and psychological properties but not the socioeconomic properties as found in this present study of male veterans. Their study participants disclosed the importance of mobility, beliefs of physical disability, feeling unhealthy and functional loss; these reports were consistent with the findings of males' description of limited physical capacity, functional loss because of pain and stiffness.

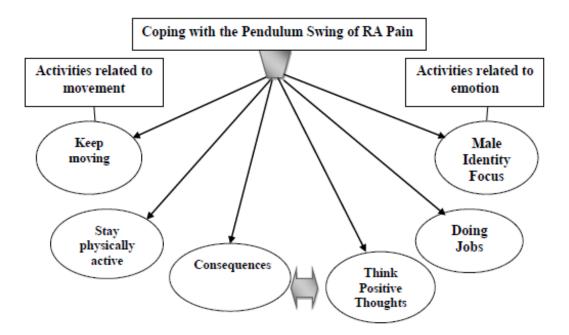
The importance of pain relief during the early phase of RA and the experience of suffering through pain was also reported in earlier RA studies (Dildy, 1996; Lineker, Badley, Charles et al., 1999; Mancuso, Paget, Charlson, 2000). Findings of a telephone interview method with RA groups mentioned 'keeping mind off' pain and other symptoms as groups with RA used self-management behaviors. such as 'accommodation', 'active remediation', 'asking for help', or pushing oneself to keep going (Katz, 2005). This present study found similar evidence in ways to "keep going."

Our study suggests that the theoretical scheme shown in Figure 1 has explanatory power of coping with the pendulum swing of RA pain in

male veterans. The full explanatory power of this scheme, however, will not be realized until future inquires are executed, presumably the evaluation of physical, cognitive and socioeconomic outcomes of 'Keep Moving' program on males with RA. Prospective studies among community-dwelling males (non-veteran) with RA are needed to determine whether the themes discussed in this manuscript are found to be similar or different in other groups.







Although this study had several strengths, several limitations with regard to the research process are noted. Firstly, as a nurse, the researcher's concurrent role as a direct care provider to some men in this study may have influenced the way in which the males responded to the interview questions. Previous interactions between the researcher (as a nurse) and the participants may have biased their viewpoints about pain, intensity assessment, and management of pain. Secondly, the interviewer was female which may have impacted the way in which males responded to interview questions. Thirdly, the interviews involved personal and private disclosures about pain experiences, hence, personal pain management styles might not have been fully captured for reasons of personal and privacy concerns among the male participants.

The "keep moving" concept highlighted in this study explained how males cope with their chronic RA pain through three activity types: cognitive and socio-economic physical. activities. These activities may fluctuate in intensity depending upon one's stage in the disease course and current RA symptoms. The forward and backward swing of a pendulum is depicted to describe the concept of the unpredictable course and pain coping strategy of the veterans. Further studies are recommended to determine the generalizability of our findings and to confirm the impact of continuous motion as an effective pain management strategy for RA. It is also recommended to identifying any differences in coping strategies by gender and by veteran and non-veteran status. Further research on the RA experience from perspective among males will add to our body of knowledge

regarding pain management and the experience of males with RA.

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