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DELAY IN HELP SEEKING BY PATIENTS WITH RHEUMATOID ARTHRITIS: DUE TO SELF-MANAGEMENT OF SYMPTOMS

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ABSTRACT

Introduction: Rheumatoid arthritis (RA) is a chronic systemic autoimmune inflammatory disease that affects mainly the small joints of the hands and feet. RA is one of the most common inflammatory joint diseases and causes premature mortality, disability and compromised quality of life. RA is widely prevalent throughout the world. RA affects approximately 1% of the adult population in general, but this percentage increases with age. Women suffer three times more often than men in rheumatoid arthritis.
The authors discuss one class of barriers in help seeking of RA which are due to Self-management of symptoms (patient would try self-managing the symptoms at first) before seeing the doctor.

Aims & Objectives: The aims and objectives of the study are to identify the time interval between onset of symptom and presentation to a health care provider (rheumatologist) among early RA patients and to analyze delay in help seeking due to self-management of symptoms RA before seeing the doctor.

Materials & Methods: The study tool consisted of a predesigned pretested questionnaire. Data collected were fed in Microsoft Excel and the analysis was carried out using standard statistical software Stata 15.1.

Results: Majority of participants tried to self-manage symptoms by consulting with non-doctors, exercise, limiting movement, supporting joints and altering diets before consulting doctor. There was a significant association between consulting a pharmacist, altering diet and supporting his joints with splints/ tube-grip with treatment delay ($p \leq 0.05$).

Conclusion: The RA patients may be educated not to self-manage symptoms of RA risking treatment outcome without consulting GP/rheumatologist.

KEYWORDS : ACR, EULAR, GP, help seeking, rheumatologist

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic systemic autoimmune inflammatory disease that affects mainly the small joints of the hands and feet. RA is one of the most common inflammatory joint diseases and causes premature mortality, disability and compromised quality of life. RA is widely prevalent throughout the world[1-2].RA affects approximately 1% of the adult population in general, but this percentage increases with age. Women suffer three times more often than men in rheumatoid arthritis. The incidence of this chronic disease ranges between 0.1 and 0.3/1000. RA usually manifests between the ages 20 and 50, and is more prevalent amongst females, with a sex ratio ranging from 2:1 to 4:1[3,4].

The joints most commonly involved in RA are the wrists, small joints of the hands and feet. As the disease progresses, larger joints such as the ankles, knees, elbows, and shoulders frequently become affected. RA is a polyarthritis. Joint involvement is classically bilateral and symmetrical.

Risk factors leading to the development of RA include obesity, smoking, high red meat consumption, a previous blood transfusion and an adverse pregnancy outcome. Protective factors include the oral contraceptive pill and adequate fruit intake. The signs and symptoms of RA are weight loss, fever, fatigue, malaise, depression and severe cases of cachexia. They generate high degree of inflammation and may precede onset joint symptoms .Excess mortality is predominantly due to cardiovascular disease.

According to the European League Against Rheumatism (EULAR) recommendations from 2016, each patient with persistent swelling in at least one joint should be referred to a rheumatologist and examined within 6 weeks of the onset of symptoms, and effective treatment should be started by the end of the 12th week[5]. Rheumatoid arthritis usually requires lifelong treatment, including various medications, physical therapy, education, and possibly surgery. Treatment is aimed at relieving symptoms and preserving joint function[6].Starting treatment within 12 weeks of symptom onset doubles the chance of achieving remission, and the necessity to use biological medicinal products in RA treatment decreases from 32.2% to 10%[7].

OBJECTIVES

1) To identify the time interval between onset of symptom and presentation to a health care provider (rheumatologist) among RA patients.
2) To analyze delay in help seeking due to self-management of symptoms RA before seeing the doctor.

MATERIALS & METHODS

This hospital based cross sectional study was undertaken in the Department of Rheumatology KIMS, Bhubaneswar from December 2016 to October 2018. The study population was patients diagnosed as rheumatoid arthritis by a rheumatologist.

SAMPLE SIZE

Considering the prevalence of help seeking behaviour as 31%(8) in Rheumatoid arthritis with 95% confidence level and the desired level of precision as 6% and 10% non-respondents, the optimum sample size calculated was 250.

The Inclusion criteria were patients aged 18 to 65 years diagnosed with early rheumatoid arthritis using 2010 American College of Rheumatology(ACR) / European League Against Rheumatism(EULAR) criteria.

The study tool consisted of a predesigned pretested questionnaire including details about a) Demographic profile (Age, sex, marital status, BMI and socio-economic status) b) Time interval between onset of symptoms and reported to a doctor and c) Questionnaire on actions taken to manage symptoms before first visit to doctor and their association with delay in help seeking.

All the analysis was carried out by using standard statistical software Stata 15.1.

RESULTS

The study of medical help seeking behavior Rheumatoid arthritis patients attending Rheumatology OPD in a tertiary care hospital-Bhubaneswar included the patients who attended the Rheumatology

OPD & diagnosed clinically as early Rheumatoid arthritis. A total number of 250 Rheumatoid Arthritis patients enrolled in this study. The results are analyzed and presented as per the objective in the following tables.

TABLE-1: SOCIO-DEMOGRAPHIC PARAMETERS OF PARTICIPANTS

Age (Mean Age in yrs)	Male		Female		Total	
	42.96±18.49		48.20±12.51		47.59±13.40	
Sex	Male N=29	% 11.60	Female N=221	% 88.40	Total N=250	
BMI	Obese N=94	% 37.6	Not-obese N=156	% 62.4	Total N=250	
Marital Status	Married N	%	Unmarried N	%	Widowed N	%
	227	90.80	22	8.80	1	0.40
Social Economic Status	N=0 Upper %	N=175 Upper Middle %	N=44 Lower Midde %	N=27 Upper Lowr %	N=04 Lower %	Total N
	0.00	70.00	17.60	10.80	1.60	250

Table -1, depicts the socio- demographic characteristics (Age, sex, marital status, BMI & Socio-economic status of the study participants.

TABLE-2 TIME INTERVAL BETWEEN ONSET OF SYMPTOMS & REPORTED TO A DOCTOR

SEX	N	%	TIME INTERVAL			
			≦ 6 weeks		.> 6 Weeks	
			N	%	N	%
MALE	29	11.6	6	2.4	23	9.2
FEMALE	221	88.4	25	10.0	196	78.4
TOTAL	250	100	31	12.4	219	87.6

Table -2, depicts the time interval in between the onset of symptoms and reported to a doctor. Only 2.4% of the patients who were male reported to doctor within 6 weeks of onset of RA symptoms and 10% of the patients who were female reported to doctor within 6 weeks of onset of RA symptoms.

TABLE- 3 ACTIONS TAKEN TO MANAGE SYMPTOMS BEFORE FIRST VISIT TO DOCTOR

Question	Response	Delayed		Not Delayed		Total	P value
		N	%	N	%	N	
Initial treatment tab from chemist	Yes	6	66.67	3	33.33	9	0.087*
	No	213	88.38	28	11.62	241	
Spoke to pharmacist before doctor	Yes	6	60.00	4	40.00	10	0.016**S
	No	213	88.75	27	11.25	240	
Consulted other health care professional	Yes	131	89.12	16	10.88	147	0.385*
	No	88	85.44	15	14	103	
Control by altering diet before doctor	Yes	104	88.14	14	11.86	118	0.049*S
	No	115	87.12	17	12.88	132	
Post symptoms tried to exercise/ movement	Yes	81	86.17	13	13.83	94	0.594*
	No	138	88.46	18	11.54	156	
Spiritual help to manage symptoms	Yes	15	78.95	4	21.05	19	0.269**
	No	204	88.31	27	11.69	231	
Control symptoms by limiting movement	Yes	136	85.53	23	14.47	159	0.190*
	No	83	91.21	8	8.79	91	
Supported his joints with splints or tube-grip	Yes	61	78.22	16	20.78	77	0.007*S
	No	158	91.33	15	8.67	173	
Water baths to relieve symptoms	Yes	103	86.55	16	13.45	119	0.337*
	No	116	88.55	15	11.45	131	
	TOTAL	219	87.60	31	12.40	250	

*Pearson λ 2 test **Fisher's exact test S- Significant($p \leq 0.05$)

Table-3, actions taken to manage symptoms before first visit to doctor and its association with delay in help seeking. Speaking to pharmacist, trying control by altering diet and supporting joints with splints or tube-grip before doctor were found to statistically significant($p \leq 0.05$).

DISCUSSION

All the study participants are ≥ 18 yr of age. The mean age of the total study participants is 47.59±13.40 years, of which mean age of male is 42.96±18.49yrs & female participants is 48.20±12.51 yrs(Table-1). Similar study also reveals in their study that the participants having mean age of the was 46.5±9.2 years as reported by Resorlu H et al[9].

The age profile is very nearer to other studies as Simons et al had subjects with mean age are 58 yrs[10].

The study by Hussain W et al, shows in their study from symptoms to diagnosis: An Observational Study of the Journey of Rheumatoid Arthritis Patients in Saudi Arabia that the mean age of the study participants was 43.3±12.0 years[11].Out of the total study participants, female participants 221(88.40%) are more as comparable to male counterpart 29 (11.60%). The study by Hussain et al(11)participants notably, the majority of these patients were female (84.8%) was found in their study, which is quite similar to this current study . Similar kind of study participants -female (96%) & male (29%) were found in the study by Iversion et al[12].

Among the study participants maximum were found to be non-obese 156 (62.4%), whereas obese were found to be 94 (37.6%)(Table-1). The risk of development of rheumatoid arthritis (RA) could be affected by immune activation in obesity. Other two studies reported no statistically significant associations between BMI or BMI categories and RA.[13,14].

The results from the Nurses' Health Study indicated a stronger association between obesity and RA development at a younger age.[15] Maximum study participants were married (90.80%), unmarried(8.80%) and widowed (0.40%)(Table-1). Similar study participants also found in Hazes JMW et al(16) as married (79%), unmarried (16%) and widowed (5%).

In a study on Marital Status in Rheumatoid Arthritis byLars Hellgren[17] reported that no significant differences in marital status was found among the rheumatoid arthritis.

Socio economic status was assessed based on income, education and occupation and divided patients into five groups as per revised Kuppuswamy and B G Prasad socio-economic scales for 2016 [18]. Most of the study participants belong to upper middle socioeconomic status (70%), followed by lower middle (17.60%) & lower class (1.60%). None of the study participant has attained upper socioeconomic status (Table-1).

Patient delay was defined as the period from the onset of symptoms to the time that help was sought from a healthcare professional who could prescribe disease modifying treatment. As according to the European League Against Rheumatism (EULAR) recommendations from 2016, each patient with persistent swelling in at least one joint should be referred to a rheumatologist and examined within 6 weeks of the onset of symptoms, and effective treatment should be started by the end of the 12th week[19].

Among these females 196 (78.4%) of them took >6 weeks of time to report to a doctor after the onset of symptoms as compared to males 23 (9.2%). Both in males and females in total 219 (87.6%) have took >6 weeks time to report to a doctor, whereas only 31(12.4%) have reported within <6weeks of onset of symptoms(Table-2). In a study by Raciborski F et al [20] reported that after the onset of symptoms of rheumatic disease, 28% of patients delayed seeing any doctor for 4 months or longer; 36% of patients waited 4 months or longer for a referral to a rheumatologist; majority of the patients (85%) made an appointment with a rheumatologist within a month of receiving a referral and 25% of patients waited 4 months or longer to see a rheumatologist. In an another study by Mota et al reported that a significant reduction in diagnostic delay, probably reflecting a stronger awareness of the importance of early diagnosis in North America and Europe which is not a reality in Latin America (LA). [21]. The study by Hussain W et al shows in their study on from Symptoms to Diagnosis: An Observational Study of the Journey of Rheumatoid Arthritis Patients in Saudi Arabia observed that the mean time from onset of symptoms to first physician visit was 6.2±5.5 months[22].

The study by Smolen JS et al reported that rapid attainment of the targeted end point is critical, and to achieve the treatment goal of remission or at least low disease activity within the time frame of 6

months[19]. Like any other disease, the RA patient's journey involves 3 distinct stages: onset of symptoms to consultation (lag1), consultation to rheumatology referral or definite RA diagnosis (lag2), and diagnosis to proper treatment (lag3). These lag times have been of interest to rheumatologists and have been reported by numerous studies[23,24] with some studies focusing specifically on the factors that contribute to these delays and measures undertaken to overcome these.

Patients with RA often do not seek the advice of rheumatologists at the onset of their symptoms and non-rheumatologists fail to refer RA patients to rheumatologists soon enough. In Saudi Arabia, although patients consulted with physicians at a mean of 7 months after the onset of RA symptoms, very few subjects initially sought a consultation with rheumatologists, who were ultimately responsible for diagnosing most RA patients [22].

Table-3, describes the action taken to manage symptoms before first visit to the doctor. In this study majority 88.38% of the study participants though they do not tried to control their arthritis symptoms by bringing tablet from the chemist still they delay their primary treatment from the doctor, whereas only 11.62% did not delay their treatment. The cultural background may have influenced the type and extent of use of complementary and alternative management strategies including dietary manipulation, heat, physical therapies, traditional medicines, and prayer in rheumatoid arthritis [25,26].

Many of the study participants spoke to pharmacist about their symptoms before the start their treatment from a doctor and they 60% delay their treatment, whereas 40% did not delay their treatment. Advice from a chemist sometimes gives consolation to the study participants. In this point of view majority 88.75% of study participant though they do not spoke to a pharmacist, still they delayed their treatment, whereas only 11.25% did not delay their treatment. When the onset of RA was slow, people were more likely to use alternative therapies to self-manage[27]. The onset of RA symptoms and treatment delay influenced by various factors such as RA disease severity and help seeking behaviour of the patient[25,28].

The main aim of this study was to quantify total treatment delay at the various stages before they consult at rheumatology doctor and to verify and elaborate the existing knowledge on delay practised by the study participants. The study participants tried to manage their symptoms other type of health care professionals without a rheumatologist and they (89.12%) delay their treatment, whereas only 10.68% did not delay their treatment. Participants look for information to share responsibility for decision making and get advice and reassurance from non- medical professionals.

The study participants identified a number of sources of information they would access for further information about the symptoms they were presented with, including people such as friends, family, colleagues, and non-medical healthcare professionals (e.g. pharmacists or physiotherapists), written materials such as books, magazines, information leaflets and the internet. The subthemes extracted relate to the reasons why participants thought they would or would not utilise these sources of information[29].

In this study the study participants tried to control their arthritis symptoms by altering their diet before consult a doctor and in this connection they delayed their treatment (86.17%), whereas 13.83% did not delay their treatment. Various dietary plans for RA have been reported since long and are being repeatedly projected[30] ,such as medically supervised 7–10 days fasting[31],vegan or Mediterranean diets (MDs)[32].

We hereby discuss the reported dietary interventions that clearly indicate clinically and statistically significant and beneficial long-term effects for relieving symptoms, delay in disease progression and associated damages in RA patients. These kinds of diet information lead to treatment delay in rheumatoid arthritis. A diet including intake of only fruits and vegetables, eliminating any animal product or by-products is vegan diet. This has been repeatedly reported to be clinically beneficial for disease remission in RA patients[33].

Study participants are always interested in alternative treatments to relieve their debilitating condition. The other aspects of self-taking care by the study participants that, they first began exercise and keep moving after getting the symptoms of arthritis and they delayed (86.17%) the treatment; whereas (13.83%) did not delay their treatment. Exercise is an essential component of medical and surgical management of inflammatory joint diseases. Nevertheless, rheumatologists traditionally have recommended exercise restriction or exercise programmes limited to non-weight bearing isometric exercises and range of motion exercises owing to concerns about aggravating joint inflammation and accelerating joint damage in patients with RA[34].

Eight Participants in the de Jong study, on the other hand, had average disease duration of 6 years. Many reports have shown that a delay in initiating DMARD treatment can adversely affect various disease measures years later [12,35] .

Study participants also started spiritual support as prayer and religious guidance to help them to manage their symptoms and 78.95% participants delay their treatment whereas 21.05% did not delay. On the other aspects, neither the study participant have took any guidance spiritual practice or prayer but still majority of them delay their treatment (88.31%), whereas only few 11.69% did not delay their treatment. In patients with rheumatoid arthritis, the most frequently cited triggering factor for disease onset was a psychological factor or life-event. Patients with rheumatoid arthritis hold a core set of beliefs and apprehensions that reflect their level of information about their disease and are not necessarily appropriate. Personal belief in a treatment may per se lead to an improvement, and total blinding of the patient and observer to the treatment is necessary in tests of healing. It has been speculated that the therapeutic effect of healing is a result of the "channelling" of a so far unidentified form of energy from an undefined source, via the healer to the patient. The central claim of spiritual healers is that this process facilitates self-healing in the patient. Spiritual healing includes several categories, including "therapeutic touch" and "intercessory prayer," and the healing may be attributed to God, spirits, universal forces or energies, biological healing energies residing in the healer, or self-healing powers or energies thought to reside latent in the healed organism[36]. Patients dedicated to spiritual healing could be explained as a "placebo effect"[37]. Spirituality-based strategies are commonly used to cope with chronic pain. Chronic pain patients with a variety of conditions (e.g. musculoskeletal pain, cancer, or sickle cell) usually report that religiousness and spirituality are important in their life[38], evaluated the role of daily spiritual experiences and daily religious/spiritual coping with pain in the experience of individuals dealing with rheumatoid arthritis.

Other practices to get rid of the pain symptoms, the study participants tried to control by limiting how much they move and it was found that 85.53% of study participants delay their treatment whereas 14.47% did not delay their treatment. Sometimes the study participants support the joints, like splints or tubi-grips to relief from pain and by putting these grips 78.22% participants delay their treatment whereas 20.78% did not delay their treatment.

These studies dealt with the following: working wrist splints , resting hand and wrist splints , special shoes and insoles. There is evidence that wearing working wrist splints statistically significantly decreases grip strength and does not affect pain, morning stiffness, pinch grip, quality of life after up to 6 months of regular wear[39].

Lastly the participants 86.55% also practices warm water bath to relieve their joint pain and delay their treatment whereas 13.45% participants did not delay their treatment. Similar study reported that the management of impaired morning function is based primarily on non-pharmacological approaches, including simple or short exercises, application of heat or a hot shower or bath, and delaying activities until later in the day[40].

The limitations of the study are that sample consisted mainly of participants from a particular area of coverage and men were relatively underrepresented (1 male for every 7.6 females) instead of normally observed 1:3 ratio in RA.

CONCLISION

RA patients may be educated not to self-manage symptoms of RA risking treatment outcome without consulting GP/rheumatologist.

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