ESTIMATE THE EDUCATIONAL NEED ON KNOWLEDGE OF RHEUMATOID ARTHRITIS IN THE RANGE OF THEIR OWN DISEASE AND ITS SELF-CARE IN A VIEW TO DEVELOP A SELF-CARE MODULE

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INTRODUCTION

Health is more than just a means of living longer. The real purpose of health is to allow a more satisfying and meaningful life, to enjoy a higher quality of life. Higher level of quality of life is always doubtful in the chronic illness like Rheumatoid arthritis1. RA is a chronic, progressive, systemic, autoimmune disease associated with inflammation of the synovial joints and, eventually, joint destruction, functional disability, and a reduced quality of life.2 RA affects 1% population worldwide.3 The reported prevalence of RA in India was about 0.75 percent in 2004, and has risen to 1.0 percent in 2007. Women have incidences 2.5-3 times higher than men.4 As the current treatment neither prevents nor cures rheumatoid arthritis (RA), the main management aim is to reduce the impact of the disease on patients’ lives by improving quality of life and reducing disability.5 Knowledge is an essential element of treatment which allows patients to take care of themselves, to undertake every day activities and to make decisions essential from the point of view of health. Over the past two decades, a growing emphasis has been put on arthritis self-care strategies to help patients with RA cope with the consequences of the disease. In order to manage the disease on a day-to-day basis, patients need a formal body of knowledge and skills.6 Every day rheumatoid arthritis (RA) patients make many decisions about managing their disease. An online, computer-tailored, self-management program can support this decision making, but development of such a program requires the active participation of patients.

ABSTRACT

Introduction: Rheumatoid arthritis (RA) is a chronic, autoimmune disorder that results in significant pain, disability and excess mortality if untreated or inadequately treated.1 As the current treatment neither prevents nor cures rheumatoid arthritis (RA), the main management aim is to reduce the impact of the disease on patients’ lives by improving quality of life and reducing disability.5 Increasingly, patients are turning to internet, websites and chat rooms for advice, and some of these may be of poor quality7. A need based patient education can help them adjust their treatment regimens and attain the self-care management skills necessary for dealing with the consequences of the disease.

Methods: This descriptive study estimated the educational need on knowledge of Rheumatoid arthritis in the course of their own disease and its self-care in a view to develop a self-care module. A total of 60 subjects were selected by purposive sampling technique in a selected tertiary care hospital, Bangalore. A self-prepared questionnaire was administered to estimate the educational need on knowledge of Rheumatoid arthritis in the course of their own disease and its self-care.

Results: The results showed the knowledge on course of Rheumatoid arthritis, and its self-care. The mean and standard deviation of the knowledge score was 13.12 ±3.728. It reflected the extreme need for information on course of disease and it’s self-care. Out of the ten demographic variables there were three variables ie educational status (0.008), income (.014) and duration of illness (.018) had significant association at < 0.05 level of significance with the knowledge.

Conclusion: Receiving a health information on management of Rheumatoid arthritis is highly important in day to day management of this chronic illness.

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A descriptive study measured the need for information about rheumatoid arthritis (RA) among 600 patients who were randomly selected with RA. A Questionnaire surveys were mailed to RA patients. The response rate was 57.3%. The need for information was very high. Information seeking preference scores (median 82.5, interquartile range 80.0-92.5) were significantly higher (P< 0.001). Need for information were higher in women than men. Participants’ RA knowledge scores were on average only moderate, a finding that supports their desire for more information. Now a days, Increasingly, patients are turning to internet, websites and chat rooms for advice, and some of these may be of poor quality. Rheumatology nurses have an important role in educating patients with rheumatoid arthritis. A need based patient education can help them adjust their treatment regimens and attain the self-care management skills necessary for dealing with the consequences of the disease

Table 1 Description of demographic characteristics of the study subjects

| S.NO | Variables | N   | %  |
|------|-----------|-----|----|
| 1    | Age       |     |    |
| a.   | 20-35 years | 10  | 16.7 |
| b.   | 36-50 years | 27  | 45.0 |
| c.   | 51-65 years | 15  | 25   |
| d.   | More than 65 years | 8   | 13.3 |
| 2    | Sex       |     |    |
| a)   | Male      | 18  | 30.0 |
| b)   | Female    | 42  | 70.0 |
| 3    | Religion  |     |    |
| a)   | Hindu     | 44  | 73.3 |
| b)   | Muslim    | 6   | 10.0 |
| c)   | Christian | 10  | 16.7 |
| d)   | Others    |     | -   |
| 4    | Marital Status |    |    |
| a)   | Married   | 53  | 88.3 |
| b)   | Unmarried |     | - |
| c)   | Widow     | 6   | 10.0 |
| d)   | Divorced  | 1   | 1.7 |
| 5    | Educational Status |   |    |
| a)   | Illiterate | 23  | 38.3 |
| b)   | Primary   | 16  | 26.7 |
| c)   | Secondary | 13  | 21.7 |
| d)   | Higher secondary | 3  | 5.0 |
| e)   | Graduate  | 5   | 8.3 |
| 6    | Occupational Status |   |    |
| a)   | Heavy worker | 9   | 15.0 |
| b)   | Moderate worker | 5   | 8.3 |
| c)   | Sedentary worker | 13  | 21.7 |
| d)   | Unemployed | 33  | 55.0 |
| 7    | Monthly Income of The Family | | |
| a)   | Less than Rs. 10000 | 7   | 11.7 |
| b)   | Rs. 10001 – 20000 | 34  | 56.7 |
| c)   | Rs. 20001 – 30000 | 8   | 13.5 |
| d)   | More than Rs. 30000 | 11  | 18.3 |
| 8    | Type of Family |       |    |
| a)   | Nuclear family | 52  | 86.7 |
| b)   | Joint family | 8   | 13.3 |
| 9    | Duration of Illness | | |
| a)   | Less than 1 year | 9   | 15.0 |
| b)   | 1-2 years | 9   | 15.0 |
| c)   | 2-3 years | 9   | 15.0 |
| d)   | More than 3 years | 33  | 55.0 |
| 10   | Area/Location | | |
| a)   | Urban | 36  | 60.0 |
| b)   | Rural | 12  | 20.0 |
| c)   | Suburban | 12  | 20.0 |

A descriptive quantitative research design was adopted for this study. The objectives of the study were to estimate the knowledge on Rheumatoid arthritis and its self-care, to associate the demographic variables with the knowledge on Rheumatoid arthritis and its self-care and to develop a self-care module. The setting of the study was Rheumatology OPD of tertiary care hospital, Bangalore. In this study, 60 subjects were selected using purposive sampling technique and they were investigated using a self-prepared questionnaire. The tools used for the study were demographic proforma, structured questionnaire on Knowledge on Rheumatoid arthritis and its self-care. The demographic proforma of the subject includes age, sex, religion, marital status, educational status, occupational status, monthly income, type of family, duration of illness and area of residence. And the questionnaire consisted of 35 questions with 9 aspects which includes disease condition, medication, heat and cold therapy, diet, rest and exercise, joint care and lifestyle modification, stress reduction and coping, sexual activity, adherence to therapeutic regimen and follow up. ethical clearance from Institutional Ethics Committee and written informed consent from the participants of the study was obtained.

RESULTS

Data was analyzed using SPSS. The descriptive and inferential statistical methods used for analysis were mean, standard deviation, number, percentage, percentile score, Mann-Whitney ‘U’ test and Kruskalwallis test.

The data presented in table -1 shows out of sixty respondents, forty five per cent of the subjects were in the age group of 36-50 years. Nearly three fourth of the patients were Hindus viz. 73 per cent. In this study, the female and male ratio was 3:1. Regarding the educational status, illiterates were nearly 38 per cent and graduates were about eight per cent. Most of the patients (88%) were married. Nearly half of the patients were unemployed viz. 55 per cent and only 15 per cent were heavy workers. Nearly half of the patient’s (56%) monthly income of the family was between Rs.10001-20000. Around 87 per cent were belonged to nuclear family. Fifty five per cent of the patients were suffering from, this illness for more than three years. About 60 per cent of the patients were residing at urban areas.

The data presented in table -2 showed the knowledge on course of Rheumatoid arthritis, and its self-care. The mean and standard deviation of the knowledge score was 13.12±3.728. It reflected the extreme need for information on course of disease, management and self care. There were 10 sample scored 25 percent score and 12.5 fall in 50 percent score and 15 in 75 percent score.

The data on the Table-3 showed the association between the demographic variables and the knowledge. The commonly used ANOVA (Kruskalwallis) helped to identify the association. Out of the ten demographic variables there were three variables ie educational status (0.008), income (.014) and duration of illness (.018) had significant association at < 0.05 level of significance.
Rheumatoid arthritis is a chronic condition but it is not usually life threatening. Because of the inherent unpredictability, patients tend to perceive that they have less personal control over their health than other patients. Rheumatology nurses have an important role in helping them to achieve a control. Control can be achieved by having awareness of self care to bring about desired outcomes. Self care, or self management, means taking a proactive role in treatment and maintaining a good quality of life. The present study focused on the assessment of knowledge on course of disease and self care among patients with RA. The active participation of the subjects helped in development of self care module.

In this study, forty five percent of the subjects were in the age group of 36-50 years. It reflects the prevalence of rheumatoid arthritis is common in this age group. This was supported by Lynda Martin. The female and male ratio in this study was 3:1. The above fact was supported by Kragg. About 55 per cent were unemployed and some of the patients were unemployed due to the effects of illness. This was supported by Katz.

Work disability among people with RA is significantly higher than in the general population. In a study of 90 employed patients with RA, showed that two-thirds of people with RA lose an average of 39 working days each year. Work-related limitations are common. A survey reported the barriers were, Pain adversely affecting ability to work (63%), Physical limitations restricting duties (62%), Fatigue adversely affecting ability to work (60%), Excessive sick-time absenteeism (33%), Barriers related to travel to work (13%), Lack of understanding and/or support from employer (12%), Lack of specific adaptations (4%), Problems with colleagues (2%), Lack of family support (2%). Patients can suffer from productivity and activity impairment.

Knowledge is an important prerequisite for an individual to implement behavioural changes towards the prevention and control of chronic diseases. In this study the mean and standard deviation of the knowledge score was 13.12 ± 3.728. The score reflected the extreme need for information on course of disease, management and self care. It is consistent with the study by Neame which also focused on the need for education.

Regarding the association between knowledge and demographic variables of the subjects, out of ten demographic variables there were three variables had significance. They were also supported by the other studies ie educational status and/or support from employer (12%), Lack of specific adaptations (4%), Problems with colleagues (2%), Lack of family support (2%). Patients can suffer from productivity and activity impairment.

CONCLUSION
Rheumatoid arthritis cannot be cured, but people can be helped to adopt self-management technique and changing of lifestyles will reduce disease symptoms to some extent and maximise the quality of life.

**DISCUSSION**

Rheumatoid arthritis is a chronic condition but it is not usually life threatening. Because of the inherent unpredictability, patients tend to perceive that they have less personal control over their health than other patients. Rheumatology nurses have an important role in helping them to achieve a control. Control can be achieved by having awareness of self care to bring about desired outcomes. Self care, or self management, means taking a proactive role in treatment and maintaining a good quality of life. The present study focused on the assessment of knowledge on course of disease and self care among patients with RA. The active participation of the subjects helped in development of self care module.

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