

Contraceptive Practices and Awareness among Patients Attending a Rheumatology Clinic at a Tertiary Hospital in North India: a Cross-Sectional Survey

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Abstract

Objective: To provide adequate and effective contraceptive advice, understanding the practices, attitude and knowledge of the patients towards contraception is very much necessary. Yet there is a gaping chasm in the data about contraceptive practices in use by patients suffering from rheumatologic disorders. A volatile interface with (mostly) adverse socio-cultural and economic conditions may have engendered a situation whereby women are, unnecessarily and avoidably, exposed to the hazards of unwanted pregnancies, abortions, stillbirths, malformed babies, and maternal deaths. We planned this study to document the expanse and depth of this chasm.

Study design: This was a single-center, observational, cross-sectional survey carried out at a tertiary teaching hospital in North India and the participants were mostly from urban areas in and around the capital, New Delhi. 65 patients being treated at the hospital's rheumatology clinic filled a pre-designed questionnaire to assess their knowledge, attitude and practice of contraceptive use. Questions also looked at the socio-cultural and economic factors at work in this population. All responses were collated and simple descriptive analysis was done.

Results: Out of 65 patients only 58.5% were currently using any form of contraception. Among the 65, more than two-thirds of the patients were using teratogenic drugs. Yet, only 56% of these were using any form of contraception. Although most (95%) knew about contraception, but the knowledge was generic in nature and not disease-or method-specific. Only about 36% of the patients had received contraceptive advice from their treating physician(s). Importantly, only 35% of the patients on teratogenic drugs had received contraceptive advice. It was heartening to note that most patients viewed contraception positively and wanted to receive more knowledge on this subject.

Conclusions: The study has highlighted, for the first time, the abysmally poor practices and knowledge of contraception in this cohort of patients. More focussed efforts from treating physicians are required to consciously recognise this lacuna in their practice, and educate and empower their patients in modern day contraceptive practices. Policy makers in rheumatology circles must also realise and emphasise the importance of safe and effective contraception for their patients in contemporary guidelines.

Keywords: Contraception, rheumatology, rheumatoid arthritis, systemic lupus erythematosus, cross-sectional survey.

Introduction

Contraceptive advice forms an integral part of rheumatologic consultation since majority of the people afflicted with rheumatic disease lie in the reproductive age group. Personal preferences, socio-economic factors, and education are few other factors that play vital role in acceptance of family planning practices¹. To provide adequate and effective contraceptive advice, understanding the attitude and knowledge of the patient towards contraception is very much necessary.

A number of drugs used in rheumatology are foetopathic and teratogenic like methotrexate, leflunomide and are included in USFDA pregnancy category 'X'. Others like

cyclophosphamide, mycophenolate, chlorambucil, sulfasalazine and azathioprine are category 'D'. Also use of oral contraceptives (OCPs) exerts a marked additive risk of thrombosis in these patients, many of whom might not be aware of their genetic phenotype. Multiple observations have suggested that estrogen influences SLE disease activity^{2,3}, and that oestrogen has an immunostimulatory effect⁴. A slightly increased risk of developing SLE associated with past use of OCPs was demonstrated in the Nurses' Health Study⁵; however, later population-based case-control studies of SLE patients did not identify an association with OCP use^{6,7}. Pregnancy is also known to worsen lupus nephritis and pulmonary hypertension associated with rheumatic diseases which

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are relative contraindications to pregnancy.

As a result, there is growing appreciation of the need for *safe and effective* contraception for patients with rheumatic diseases. Moreover, contraceptive advice is as much a component of good preventive healthcare in rheumatology as it is elsewhere. However, as is the experience in general population in India, the knowledge and actual practice of contraceptive use may be inadequate and mired in myths and other socio-economic-cultural issues. We plan to document and understand contraceptive practice and patterns and the factors hindering safe and effective contraceptive use among these patients using a KAP (Knowledge, Attitude, Practice) survey. A KAP survey is a quantitative type method (predefined questions and formatted in standardised questionnaires) that provides access to quantitative and qualitative information⁸. Focusing on knowledge and attitudes of the respondents, these questions are intended to identify key knowledge, social skills, and know-how commonly shared by a population or target group about particular issues (HIV, malaria, reproductive health, etc.) on which one intends to start a programme and/or activities on health education⁹.

Although numerous KAP surveys, regarding contraception in the general population, have been published worldwide and from India, no scientific studies have been published, to the best of our knowledge, regarding the knowledge, attitude and practice of contraceptive use in patients with rheumatic diseases. We propose to address this lacuna of comprehensive rheumatologic care. The underlying reasons hampering the practice of adequate and safe contraception have to be studied, acknowledged and addressed by doctors caring for patients with rheumatic diseases to deliver better medical care and ensure optimum health and reproductive outcomes in these patients. It may also serve as a wake-up call for policy makers as can be gauged by a simple but shocking observation. Taking Rheumatoid Arthritis as the prototype disease; the word "contraception" *does not even once appear* in the ACR, EULAR or BSR guidelines for management of rheumatoid arthritis! This shows the lack of importance being given to this topic, of huge implications, in physician-patient encounters.

Aims and objectives

1. To assess the knowledge and practice of contraceptive use in patients with rheumatic diseases.
2. To assess the attitude of patients with rheumatic diseases towards various methods of contraception.
3. To assess the factors affecting contraceptive use in these patients viz. education, socio-economic status, cultural issues, etc.

Material and methods

Ours was an observational, cross-sectional study conducted in the rheumatology clinic at a tertiary teaching hospital in the centre of Delhi, a metropolis with a population of almost 20 million (Lok Nayak Hospital associated with Maulana Azad Medical College). 65 patients were chosen, as a sample of convenience. The inclusion criteria were as follows:

- All patients being treated for rheumatic diseases such as, rheumatoid arthritis, systemic lupus erythematosus (SLE), scleroderma, psoriatic arthritis, spondyloarthropathy, etc.
- Males, between the ages of 15 to 55 years.
- Females, between the ages of 15 to 45 years.
- Should be married.
- Willing to give consent.

The exclusion criteria were as follows:

- Widowed / divorced or separated couples.
- Unwilling for consent.

The subjects' written consent was obtained according to the Declaration of Helsinki (most recently at the General Assembly in October 2008), and prior approval of the Institutional Ethics Committee of Maulana Azad Medical College, New Delhi was obtained. After discussion with the patient a pre-designed questionnaire assessing knowledge, attitude and practice of contraceptive use was administered by doctors in the rheumatology clinic. Males were interviewed by a male doctor and females were interviewed by a female doctor. Proper privacy was ensured. Any health or contraceptive concerns were appropriately managed, if required, in consultation with a gynaecologist.

All proformas were collated and analysed. Descriptive statistical analysis was carried out for the data gathered and data was analysed using SPSS software (version 21).

Results

Out of the total of 65 patients enrolled for the study, 63 were female and 2 were male. 48% of the patients were in the age group of 36 to 45 years. The most common diagnoses among the patients were rheumatoid arthritis (60%), and SLE (12.3%). Other diagnoses were psoriatic arthritis, sarcoidosis, hypothyroidism, spondyloarthropathy, scleroderma, vasculitis and Behcet's disease (all between 1.5 to 3 %). The majority of them belonged to the middle socio-economic class (48%). 43% were from the low socio-economic class and 8% were from upper class. 35.4% of the patients had never attended school, 52% had schooled upto various levels and only 12.3% were graduates and

above. Patients included in the study were fairly representative of the population of patients attending the clinic. There were no statistically significant differences between patients included in the study and those not included for the following variables; age, sex, socio-economic class, literacy, geographic area, disease profile, use of teratogenic drugs.

Out of 65 patients only 38 (58.5%) were currently using any form of contraception while the rest, i.e., (27) 41.5% were not using any means of contraception (Fig. 1). The most preferred methods of use of contraception (among the 38 patients) were barrier methods (48%) and ligation (37%). The common reasons to prefer these methods were convenience of use, previous side-effects with other methods and importantly, spousal (husband in almost all cases) choice. Among those not using any means of contraception (27 patients), the reasons were lack of knowledge of contraception and/or it's importance (9 patients), 13 patients said that they did not want to use contraception for various reasons such as hysterectomy, lack of sexual activity, oligomenorrhoea, perceived side-effects, beliefs of non-requirement of contraception as she is 40 plus of age or that she cannot conceive once she has rheumatoid disease. 6 women were trying for pregnancy, and 4 found it difficult to procure contraceptives while 4 were not using it under family or spousal pressure.

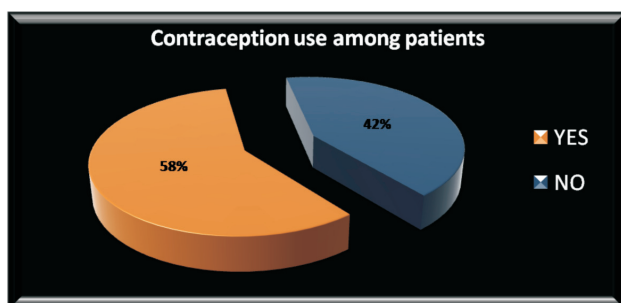


Fig. 1: Proportion of patients using any form of contraception.

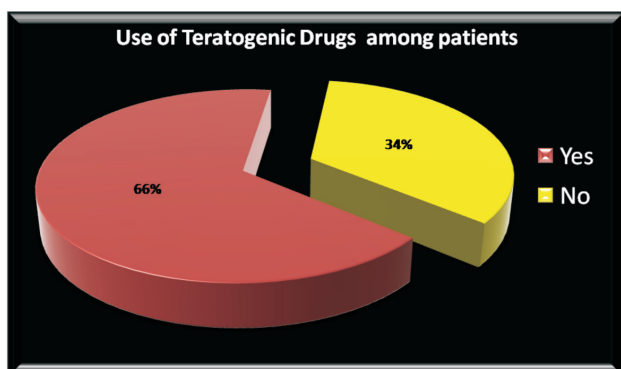


Fig. 2: Proportion of patients using potentially teratogenic drugs (DMARDs).

An important observation was that 43 (66.2%) of the patients were using teratogenic drugs (methotrexate, leflunomide, cyclophosphamide) (Fig. 2). Out of these 43, only 24 (56%) were using any form of contraception, while the rest, i.e., 19 (44%) were not using any contraception (Fig. 3).

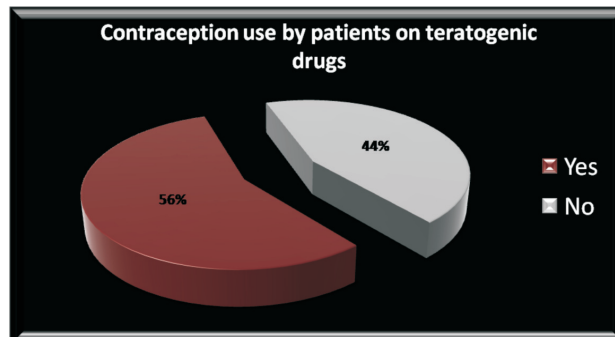


Fig. 3: Proportion of patients on teratogenic drugs.

62 (95%) patients knew about at least 1 method of contraception; most well known methods were oral pills, IUCDs, barrier methods, and ligation in descending order. 3 patients did not know about any means of contraception. The commonest sources of knowledge for these patients were media, friends, doctor, family and spouse, again in descending order. However, the reasons pertained mainly to family planning and only 5% replied that use of contraception could avoid complications of their disease and/or drugs.

Little more than half, i.e., 35 patients (53%) out of 65 knew that some form of contraception should be used by patients of inflammatory arthritides, 32% said that contraception should not be used, while 13% did not have any knowledge on this aspect.

Out of 65 patients, only 11 (17%) knew about the drugs they were taking, i.e., the names and dosages while 50 patients (77%) did not know about the most appropriate method of contraception to be used by them, given their disease and drugs (Fig. 4). 11 (17%) said condom was the

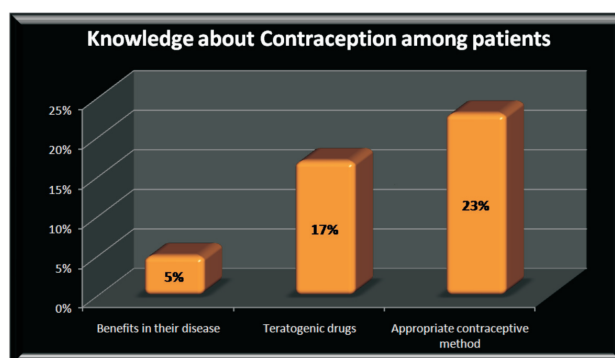


Fig. 4: Proportion of patients who had knowledge of aspects of contraceptive use.

best for them. 29 patients (38%) had no knowledge of the harmful effects of contraceptive use, while the most commonly perceived harmful effects were abnormal menstrual bleeding (23%), infection (8%), and weight gain (8%).

43 (66%) were strongly of the view that contraception should be used while 13 (20%) were unsure. The reasons for their dilemma were as follows: little knowledge of contraception (28%), no knowledge of the benefits of contraception (20%), no knowledge of best means of contraception (18%), concern for safety (16%), and not knowing how to use it properly (10%).

Only about 36% of the patients had received contraceptive advice from their treating physician(s) (Fig. 5). Out of these, only 17 (26%) felt that they had received adequate contraceptive advice. Importantly, only 35% of the patients on teratogenic drugs (15 out of 43) had received contraceptive advice for their treating physician(s) (Fig. 6).

Also, 72% of the patients had not tried to discuss the issue of contraception with their treating physician. The most common reason for not discussing contraception with their physician was that they did not know it was an important issue (35%). Other reasons were shyness (20%), lack of desire to know about it (21%), lack of time in clinic (7%),

and lack of privacy in clinic (7%) (Fig. 7).

52 patients (80%) were willing to receive more information about contraception (Fig. 8). Among the 27 patients not using any means of contraception, 19 (70%) were willing and among the 38 patients using any contraceptive methods 21 (55%) were willing to receive more knowledge about contraception. The preferred modes of education were physician provided (49%), nurse provided (22%), friend/spouse (21%).

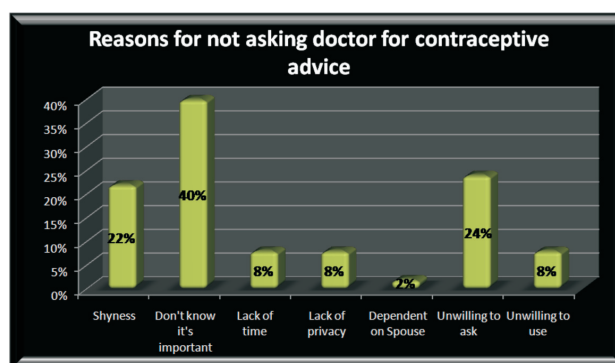


Fig. 7: Various reasons given by patients for not being able to seek contraceptive advice.

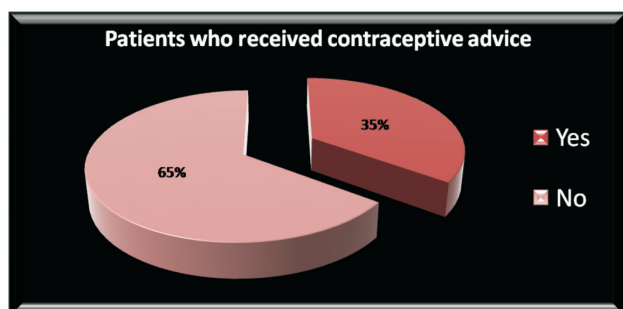


Fig. 5: Proportion of patients who received contraceptive advice from physician.

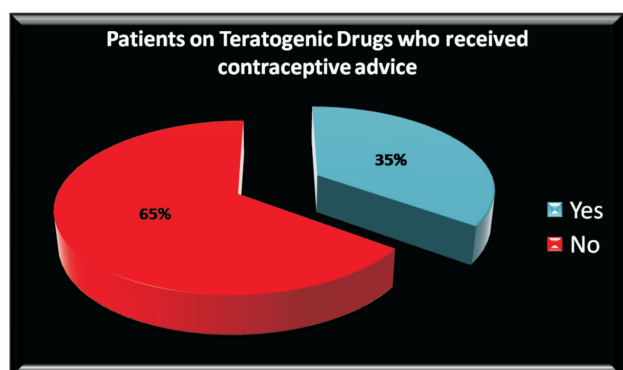


Fig. 6: Proportion of patients, taking potentially teratogenic drugs, who received contraceptive advice from their physician.

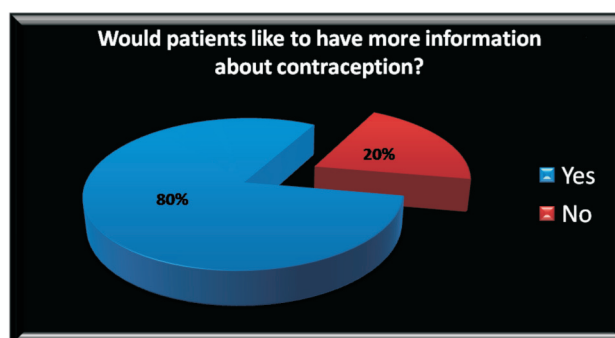


Fig. 8: Proportion of patients willing to obtain more information about contraception.

Discussion

A total of 65 patients of various rheumatological disorders attending the rheumatology clinic were administered the survey questionnaire. As expected, the majority of patients were women. The disease profile also reflected their gender with most patients suffering from rheumatoid arthritis or systemic lupus erythematosus (72%). Also, most of the patients were from the urban and semi-urban areas of Delhi. Another notable demographic was that the majority of women (48%) were of the middle socio-economic class, with an almost equal number (43%) from the low socio-economic class. Most notably, 87% of the women had not attended or completed school. This reflects the fact that almost half of the women were from economically weaker

section of the society and majority were illiterate or semi-literate.

Hence, the survey findings would mostly reflect the knowledge, attitude and practice of contraceptive use among semi-literate women from economically weaker sections in an urban/semi-urban setting in a metropolis of a developing country. *The socio-demographic characteristics and clinical attributes of the study population were representative of the larger population served by the clinic.*

In keeping with the disease profile, almost two-thirds of the women were using teratogenic drugs (methotrexate, leflunomide, cyclophosphamide, mycophenolate) regularly.

Out of the 65 patients, only a little more than half were using any means of contraception. The dominant reasons for this were various beliefs about contraception, lack of awareness about their disease and drugs, about need for contraceptive use, and about appropriate method of contraception to be used. However, strikingly, 44% of the patients on teratogenic drugs were not using any means of contraception.

Although almost all (95%) patients knew about contraception, *per se*, more specific aspects of knowledge were lacking. Their knowledge was limited to family planning benefits (something which has been widely promoted by the government for many decades) of contraception. A more practical knowledge of important personal health issues in the context of their disease, teratogenic drugs, and appropriate methods of contraception was found to be lacking. Only 5% of the patients knew that using contraception could avoid complications of disease flare in pregnancy or harmful effects of drugs/disease on foetus/neonate. Majority of patients did not know about the appropriate method of contraception, given their disease and/or drugs.

Almost 72% patients had not breached the topic of contraception with their treating physician for various reasons. This is an important observation as it reveals that this discussion has to be initiated actively by the physician, in a conscious manner. Yet, only about one-third of the patients had ever received contraceptive advice from their treating physician or nurse. Even among those who had received advice, many felt that it was inadequate. Importantly, only 35% of the patients on teratogenic drugs had received contraceptive advice from their treating physicians.

On the brighter side, 80% patients responded that they were willing to acquire more knowledge about contraception. Among those women not using any means of contraception, 70% were willing to acquire more knowledge, if given by their treating physician or nurse.

Choice of contraceptive use was passively dictated either by husband's choice (condom) or previous obstetric indications (ligation, intra-uterine contraceptive device) rather than an active choice made after studying the pros and cons of their disease and/or drugs.

On the whole, it can be surmised that contraception was perceived to be a very important issue among these women of reproductive age group. More so, because of the unique socio-econo-cultural fabric of Indian society, women are always at a disadvantage and likely to suffer the adverse consequences of unplanned pregnancies, disease flares, and adverse pregnancy outcomes.

There were many false beliefs and knowledge gaps about contraception among the patients. Physician-patient interaction was also found to be inadequate, especially for those women who required to the most, i.e., those on teratogenic drugs.

Fortunately, the attitude towards contraception was quite positive; mostly due to its family planning benefits. This positive attitude reflected in the willingness to use and gain more knowledge about contraceptive use.

In a cross-sectional observational study conducted in the outpatient clinic of a tertiary hospital in India between July-December 2012, 200 married women between 20 - 45 years were interviewed with a pre-designed questionnaire. Efforts were made to identify reasons for the wide gap between knowledge and practice of contraception. All women knew at least one method of contraception but only 48% were using some sort of contraception. Most known method was female sterilisation, least known were injectables and male sterilisation. Common method chosen was female sterilisation (70.8%). None adopted male sterilisation. Reasons for not using contraception were desire to have child (25%), desire for boys (13.4%), worried about side-effects (16.3%), opposition from family members (11.5%), felt pregnancy was naturally spaced (11.5%), no specific reasons (10.5%), couldn't avail contraceptive facilities (5.7%), inconvenient to use (5.7%). Need for educational and motivational activities from doctors and health workers to promote the use of contraception was felt in the study¹⁰.

In another study from a tertiary hospital in India, results were as follows, most of the women interviewed fell in the age group of 21 - 30 years (48%). 91% were married for 5 years. 46% were illiterate and only 17.6% had primary education. Out of 500 women interviewed, 484 (96.8%) had heard/were aware of family planning method (permanent/temporary). Out of 484 women, who had knowledge and awareness of family planning methods about 328 (67.77%) got information from social circle (husband, mother/in laws). The importance of and use of

contraception had been explained by health personnel to 68 (14%) and 88 (18.18%) got it through mass media. Out of 500 women interviewed, 269 (53.8%) were practicing different contraceptive methods. Most of them 135 (50.18%), resorted to tubal ligation as a contraceptive method of choice and the reason being completion of their family in 178 (66.17%). Only 66 (24.5%) women used various methods for spacing. Only 11(4%) women used oral contraceptive pills as a contraceptive method as against 106 (21.9%) women having knowledge about them. The authors concluded that lack of knowledge regarding the various methods of contraception was the reason for not practicing family planning methods¹¹.

In another study from Delhi, out of 492 post-partum women, 56.9 % accepted one of the contraceptive methods during their hospital stay only. The most common contraceptive method chosen was intrauterine device (45.0%). The main reason for non-acceptance of contraception was expectation of a male child¹².

Our study has highlighted, for the first time, the huge gap in knowledge and practice of contraception use by patients of rheumatological disorders. The major barriers to use of safe and effective contraception were lack of knowledge, (illiteracy and lack of counseling), socio-cultural factors like family/spousal pressure, and various beliefs. The most important learning outcome of this study is the need to overcome physician and patient barriers in enlightening patients about their disease and the various aspects of contraception. Talking to patients on this aspect should be practiced by all physicians treating patients with rheumatological diseases. Information can be given out in small steps, at each visit; spouses can be involved. Involvement of interns, nursing staff, and distribution of pamphlets may all help to create awareness among patients and encourage them to ask questions which are specific to their situation. After all, contraception is a very personal issue and can never be generalised!

Although the results of our study were in conformity with other contraceptive KAP surveys done in India, it was a small, single-center study. We did not study the obstetric outcomes among women with rheumatic diseases. It would have placed the contraception issue in better perspective. More data from larger, multi-centric studies may illuminate the finer details of this abyss in clinical practice in patients of rheumatic diseases. We could thus, conclude from our study that:

- Use of (appropriate) contraception was found to be inadequate among patients of rheumatological disorders, especially among patients taking teratogenic drugs.
- Knowledge and awareness of specific issues of

contraception was highly inadequate.

- Less emphasis was given, both by patients and physicians, to this important issue during their interactions.
- Majority of patients had a positive attitude towards the correct practice of and learning about contraception.

Key messages: Our study has provided the first evidence about a vast unmet and neglected need among patients of rheumatological disorders; something oft forgotten by busy medical practitioners. We have generated data (albeit in small patient numbers) to show that contraceptive practices need more attention by physicians, patients and policy makers.

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