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Original article

“Disease knowledge index” and perspectives on reproductive issues: A nationwide study on 398 women with autoimmune rheumatic diseases

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ABSTRACT

Objective: The reproductive choices of women affected by rheumatic diseases (RD) can be influenced by several factors, including the quality of physician-patient communication. We conducted a survey on reproductive issues aiming at exploring the unmet needs of women with RD during childbearing age.

Methods: We administered 65 multiple-choice and 12 open-answer questions about pregnancy counselling, contraception, use of drugs during pregnancy and other women reproductive issues to 477 consecutive women with RD aged 18–55 years followed-up in 24 rheumatology centres in Italy. Analysis was restricted to 398 patients who received their diagnosis of RD before the age of 45. According to the RD diagnosis, patients were subdivided into 2 groups: connective tissue diseases ($n = 249$) and chronic arthritis ($n = 149$).

Results: At the time of interview, women in both groups had a mean age of 40 years. Nearly one third of patients in each group declared not to have received any counselling about either pregnancy desire nor contraception. A smaller family size than desired was reported by nearly 37% of patients, because of concerns related to maternal disease in one fourth of the cases. A "Disease Knowledge Index" (DKI) was created to investigate the degree of patients' information about the implications of their RD on reproductive issues. Having received counselling was associated with higher DKI values and with a positive impact on family planning.

Conclusion: Italian women of childbearing age affected by RD reported several unmet needs in their knowledge about reproductive issues. Strategies are needed to implement and facilitate physician-patient communication.

1. Introduction

Rheumatic diseases (RD) are chronic inflammatory systemic diseases often affecting women of childbearing age. Therefore, fertility, contraception, and family planning are topics of crucial interest for the quality of life of these patients [1]. For a long time, pregnancy has been discouraged in patients with RD because of concerns about negative impact on maternal disease and the chance for poor gestational outcome. In the last decades, knowledge about the relationship between pregnancy and RD and the use of drugs during pregnancy have significantly improved [2], allowing an increasing number of women with RD to develop their family plans [3]. In this setting, counselling of women with RD during their reproductive age is certainly a key point and should be part of the physician-patient communication [4,5]. The present study aimed at capturing the unmet needs of women with RD in Italy through a questionnaire investigating the different aspects of women's health, such as family planning, pregnancy and contraception.

2. Methods

This study was designed as a multicentre retrospective patients-based study. Twenty-four centres participated in the study, among 30 centres that were invited (all of them were affiliated with the Italian Society for Rheumatology, SIR). Each centre was asked to collect data from 20 consecutive women aged 18–55 years, who had a documented diagnosis of rheumatic disease (RD), and received their follow-up care in the outpatient clinic located at each participating centre.

The study was approved by the Ethical Committee (EC) of the University Hospital in Brescia (ASST Spedali Civili) as coordinating centre. Subsequently, it was approved by the local EC at each centre. Data were collected in September 2015 using a self-reported questionnaire, comprising 65 multiple-choice and 12 open-answer questions developed by the research group revising a survey conducted in Eastern Europe [6] and subsequently revised and approved by female representatives of three Italian Patient Associations. The questionnaire included demographic information (age, diagnosis of RD, year of diagnosis) and six main sections:

- counselling about contraception and pregnancy;
- knowledge about the implications of RD on reproductive issues;
- family size and pregnancy desire;
- pregnancy outcomes before and after the diagnosis of RD;
- patients' knowledge about the use of drugs during pregnancy;
- children's follow-up.

Overall, 477 questionnaires were collected. Among these, the analysis proposed in this paper focuses on patients with a diagnosis of Connective Tissues Diseases (CTD) and Chronic Arthritis (CA), excluding 27 patients with Systemic Vasculitis and 8 patients with non-inflammatory RD. The CTD group comprised: Systemic Lupus Erythematosus and/or Antiphospholipid Syndrome (SLE/APS), Dermato-Polymyositis (DM-PM), Undifferentiated Connective Tissue Disease (UCTD), Mixed Connective Tissue Disease

Box 1: Questions and answers considered for the creation of the ''Disease knowledge index'' (DKI).

Can women with rheumatic diseases get pregnant? Yes.

Is it possible that disease activity can worsen during pregnancy? Yes.

Can women with rheumatic diseases breastfeed? Yes.

Can women with rheumatic diseases have healthy children? Yes.

Do you think that the children of women with rheumatic diseases carry a higher risk of having general health problems? No.

Does the offspring of women with rheumatic diseases inherit the same maternal disease? No.

(MCTD), Primary Sjögren's Syndrome (SS) and Systemic Sclerosis (SSc). The CA group comprised: Rheumatoid Arthritis (RA) and Seronegative Spondyloarthritis (SpA). Moreover, the analysis focused on female patients who had been diagnosed with rheumatic disease (RD) during their reproductive years ($\leq$ 45 years of age). Ultimately, the study proposed in this paper is based on the analysis of 398 patients and their 349 pregnancies. This study focused on all the sections of the questionnaire, except for that one dealing with the follow-up of children born to patients with RD, that will be the object of a separate paper.

Answers from women with CTD and CA were described using absolute numbers and percentages for categorical variables and mean ± standard deviation for continuous variables. For comparisons between the two groups, the Chi^2 test for categorical data (or the Exact Fisher test in case of a limited number of observations) and the Student's *t*-test for continuous data were used (statistical significance set at a *P*-value less or equal to 0.05).

The Disease Knowledge Index (DKI) was created to synthetically assess the global knowledge of patients on the impact of RD on reproductive issues. The index is based on six key-questions (Box 1). For each correct answer, one point was attributed; not given or incorrect answers were scored zero. Finally, the total score was normalized to obtain an indicator with values between 0 and 1, where 0 corresponds to the lack of knowledge and 1 to the highest knowledge.

The statistical analysis was supported by an unrestricted grant by UCB.

3. Results

Answers were collected from 249 CTD (150 SLE and/or APS; 40 SSc; 28 UCTD, 15 SS, 9 MCTD and 7 DM-PM) and 149 CA patients (100 RA and 49 SpA). The mean age of patients at the time of the interview was 39.8 years for CTD and 39.7 for CA. The mean age at diagnosis was 29.9 years and 29.1 years, respectively. Table 1 reports the comparison between the two groups of patients for the main items of the questionnaire.

3.1. Counselling about contraception and pregnancy planning

Regular gynaecological follow-up was performed by 180 (73.5%) CTD and 103 (70.1%) CA patients; 159 (72.9%) and 95 (69.3%) declared to have undergone a gynaecological visit during the previous year. Counselling about contraception was ever received by 153 (63.2%) versus 104 (70.7%) patients. The counselling on contraception was provided only by Gynaecologists in 89 (58.2%) of CTD versus 66 (63.5%) of CA patients, while 10 (6.5%) and 9 (8.7%) had received counselling from both their Rheumatologist and Gynaecologist. Notably, 78 (31.8%) of CTD and 51 (34.5%) of CA patients reported that they had never been asked by their Rheumatologist about the desire to have children. Among patients who had a pregnancy, 92 (64.8%) CTD and 46 (60.5%) CA received counselling before pregnancy; 31 (34.8%) and 18 (40.9%) received it from both Rheumatologist and Gynaecologists, while 13 (14.6%) and 10 (22.7%) received it only from their Rheumatologist. All these differences between CTD and CA groups were statistically nonsignificant.

Looking at the post-diagnosis pregnancies, 28 (20.6%) among CTD patients and 11 (15.7%) among CA patients were unintended. Among these, CTD and CA patients did not receive any preconception counselling respectively in 9 (32.1%) and 2 (18.2%) pregnancies.

3.2. Knowledge about the implications of RD on reproductive issues

The average values of the DKI were 0.57 for patients with CTD and 0.52 for patients with CA. Notably, 18 (7.2%) of CTD patients and 11 (7.4%) of CA patients responded incorrectly to all six questions, while 68 (27.3%) and 30 (20.1%) responded correctly to at least five questions.

Patients from both groups showed proper knowledge about the possibility for RD women to become pregnant and to have healthy children (about 80%) and to breastfeed (about 60%), while a great proportion of patients chose the "do not know" option for the question on the possibility that children could inherit the mother's disease (about 40%). A significant difference in the answers from the two groups was noted at the question on the possibility of worsening of disease during pregnancy: the answer was "yes" for 103 (41.9%) CTD and 35 (23.8%) CA patients ($P < 0.01$).

Counselling was shown to play a role in increasing patients' knowledge, with a statistically significant difference in the group of patients with CA. The average DKI Score for the patients who received counselling was higher than that of patients who did not receive it: 0.61 versus 0.52 for CTD ($p = 0.09$) and 0.55 versus 0.44 for CA ($P = 0.01$).

3.3. Family size and pregnancy desire

Regarding family size, 145 patients (36.4%) declared that RD influenced the number of children they had or wanted to have. Of them, 91 were CTD and 54 were CA patients. Among patients who declared to have been influenced, 51 (35.2%) declared to have not had any children, 33 (36.3%) in CTD and 18 (33.3%) in CA group. Along with this, among patients who declared to been influenced, 52 (59.1%) CTD and 28 (56%) CA patients had a lower number of children then they wanted. Exploring the reasons for a reduced family size among patients who had children, 26 (52%) for CTD versus 20 (62.5%) for CA patients reported the concern that the disease or the medications could harm the baby, or the concern of not being able to care for their children ($n = 26$; 52% for CTD versus $n = 21$, 63.6% for CA). A minority of patients also reported the fear of transmitting the disease to their children ($n = 15$, 30% for CTD versus $n = 8$, 25% for CA).

Among patients who declared they had received counselling before a pregnancy (92 CTD and 46 CA patients), 57 (62%) CTD and 27 (58.7%) CA patients recognized that counselling had a positive effect on family planning.

3.4. Pregnancy outcomes before and after the diagnosis of RD

Overall, 60 (24.7%) CTD and 27 (18.8%) CA patients had experienced at least one miscarriage. Among these patients, 21 (35%) CTD and 5 (18.5%) CA patients had more than one miscarriage.

Focusing on the 349 pregnancies reported by the patients – 231 in CTD and 118 in CA patients – 136 (58.9%) pregnancies in CTD and 70 (59.3%) in CA patients occurred before the diagnosis.

Table 1
Main results for each section of the questionnaire: comparison between patients with Connective Tissue Diseases (CTD) and Chronic Arthritis (CA).

	CTD patients	CA patients
Age at the time of interview (years, mean ± SD)[b]	39.8 ± 9.21	39.7 ± 9.28
Age at diagnosis of RD (years, mean ± SD)[b]	29.9 ± 8.42	29.1 ± 10.50
Regular gynaecological follow-up (YES)[b]	180 (73.5%) [*n* = 245]	103 (70.1%) [*n* = 147]
Gynaecological check during the last year (YES)[b]	159 (72.9%) [*n* = 218]	95 (69.3%) [*n* = 137]
Counselling about contraception (YES)[b]	153 (63.2%) [*n* = 242]	104 (70.7%) [*n* = 147]
Counselling by rheumatologist about the desire to have children (YES)[b]	167 (68.2%) [*n* = 245]	97 (65.5%) [*n* = 148]
Counselling before pregnancy (YES)[c]	92 (64.8%) [*n* = 142]	46 (60.5%) [*n* = 76]
Effect of counselling before pregnancies on family planning[d]		
No effect	17 (21.3%)	14 (33.3%)
Positive effect	59 (73.8%)	27 (64.3%)
Negative effect	4 (5.0%) [*n* = 80]	1 (2.4%) [*n* = 42]
Knowledge of the disease and family planning		
DKI (mean ± SD)[b]	0.57 (± 0.26)	0.52 (± 0.25)
DKI for patients who received counselling (mean ± SD)[b]	0.61 (± 0.24)	0.55 (± 0.24)
Possibility for RD patients to become pregnant[b]		
Yes	219 (88.3%)	129 (87.2%)
No	2 (0.8%)	2 (1.4%)
Do not know	27 (10.9%) [*n* = 248]	17 (11.5%) [*n* = 148]
Possibility for RD patients to have healthy children[b]		
Yes	204 (82.3%)	112 (75.7%)
No	2 (0.8%)	3 (2.0%)
Do not know	42 (16.9%) [*n* = 248]	33 (22.3%) [*n* = 148]
Children can inherit the mother's disease[b]		
Yes	81 (33.1%)	61 (41.2%)
No	66 (26.9%)	27 (18.2%)
Do not know	98 (40.0%) [*n* = 245]	60 (40.5%) [*n* = 148]
Possibility of worsening of disease during pregnancy[a,b]		
Yes	103 (41.9%)	35 (23.8%)
No	67 (27.2%)	69 (46.9%)
Do not know	76 (30.9%) [*n* = 245]	43 (29.3%) [*n* = 147]
Women with RD can breastfeed[b]		
Yes	150 (61%)	90 (60.8%)
No	18 (7.3%)	7 (4.7%)
Do not know	78 (31.7%) [*n* = 245]	51 (34.5%) [*n* = 148]
RD influenced the number of children they had or wanted to have (YES)[b]	91 (37.1%) [*n* = 245]	54 (36.7%) [*n* = 147]
Did not have children (YES)[e]	33 (36.3%) [*n* = 91]	18 (33.3%) [*n* = 54]
The disease reduced my desire to have children (YES)[e]	52 (59.1%) [*n* = 88]	28 (56.0%) [*n* = 50]
I reduced the number of children I wanted, because I was afraid. . .		
. . .of not being able to take care of my children (YES)[f]	26 (52.0%) [*n* = 50]	21 (63.6%) [*n* = 33]
. . .that children could have the same RD (YES)[f]	15 (30.0%) [*n* = 50]	8 (25.0%) [*n* = 32]
. . .that disease or drugs could harm the baby (YES)[f]	26 (52.0%) [*n* = 50]	20 (62.5%) [*n* = 32]
RD did not influence the number of children they had or wanted to have. . .		
. . .I did not want children before and after the diagnosis[g]	13 (13.8%) [*n* = 94]	9 (13.8%) [*n* = 65]
. . .I cannot have children because of infertility[g]	5 (5.3%) [*n* = 94]	2 (3.1%) [*n* = 65]
. . .I cannot have children because of secondary amenorrhea due to treatment with cyclophosphamide[g]	3 (3.2%) [*n* = 94]	2 (3.1%) [*n* = 65]
. . .I had all the children I wanted, independently of disease[h]	59 (79.7%) [*n* = 74]	28 (77.8%) [*n* = 36]
. . .I had all the children before the diagnosis[h]	44 (53.7%) [*n* = 82]	27 (62.8%) [*n* = 43]
One or more miscarriages[b]	60 (24.7%) [*n* = 243]	27 (18.8%) [*n* = 144]
Two or more miscarriages[b]	21 (35%) [*n* = 60]	5 (18.5%) [*n* = 27]
Live births[i]	179 (84.0%) [*n* = 213]	101 (89.4%) [*n* = 113]
before diagnosis[j]	115 (64.2%) [*n* = 179]	65 (64.3%) [*n* = 101]
Premature births[j]	21 (11.7%) [*n* = 179]	11 (10.9%) [*n* = 101]
before diagnosis[k]	6 (28.6%) [*n* = 21]	6 (54.5%) [*n* = 11]

Numbers in square brackets indicate available answers.
Comparisons were performed between CTD and CA patients.

[a] $P < 0.01$ between the answers "yes" and "no"; *P*-values of other items in the table: not significant.

[b] All the patients: 249 CTD patients and 149 CA patients.

[c] Patients who declared at least one pregnancy: 145 CTD patients and 77 CA patients.

[d] Patients who received counselling before pregnancy: 92 CTD patients and 46 CA patients.

[e] Patients who declared that the RD influenced the number of children they had or wanted to have: 91 CTD patients and 54 CA patients.

[f] Patients who had children and declared that the RD influenced the number of children they had or wanted to have: 58 CTD patients and 36 CA patients.

[g] Patients who declared that RD did not influence the number of children they had or wanted to have: 131 CTD patients and 81 CA patients.

[h] Patients who had children and declared that RD did not influence the number of children they had or wanted to have: 101 CTD patients and 49 CA patients.

[i] Number of pregnancies: 231 for CTD and 118 CA patients.

[j] Live births: 179 for CTD and 101 for CA patients.

[k] Premature births: 21 for CTD and 11 for CA patients.

Live births were 179 (84.0%) for CTD and 101 (89.4%) for CA. Within the two groups, the frequency of live births was lower after diagnosis as compared to before diagnosis, although not statistically significant in the CTD group (79.0% versus 87.1%, $P = 0.12$ for CTD patients; 81.8% versus 94.2%, $P = 0.04$ for CA).

Among live births, premature births were recorded in 21 (11.7%) cases in CTD patients and in 11 cases (10.9%) in CA patients ($P = 0.07$). Notably, premature births were significantly more frequent after the diagnosis than before: 92.2% versus 76.6%, among CTD patients ($P < 0.01$); 90.5% versus 77.4%, among CA patients ($P = 0.12$).

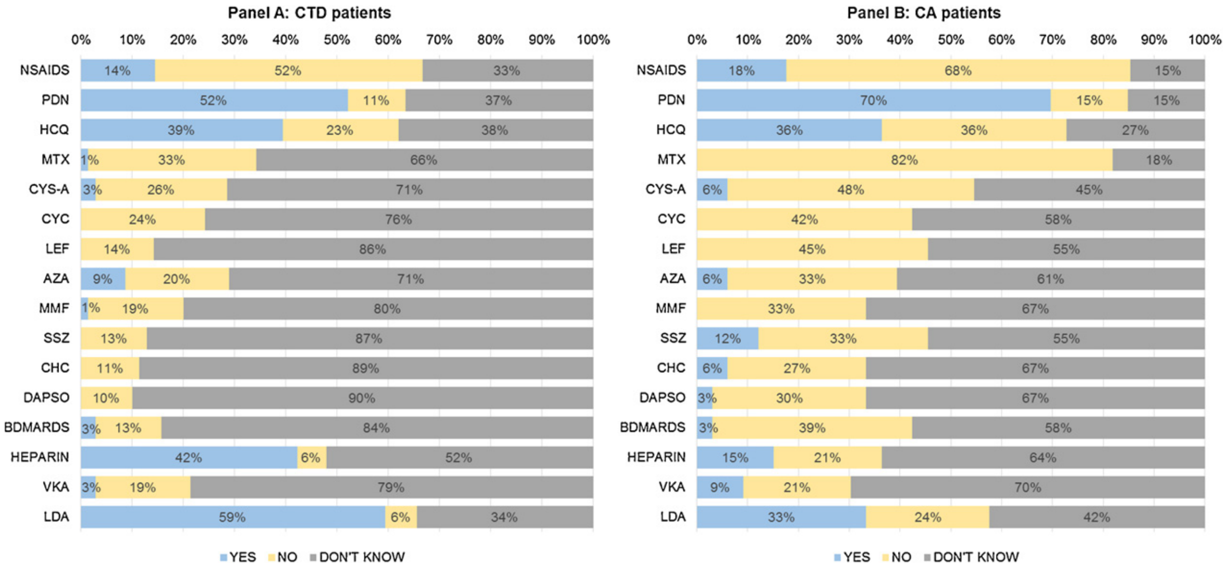

Fig. 1. Patients' knowledge about the compatibility with pregnancy of drugs currently used to treat rheumatic diseases. Panel A: CTD patients; Panel B: CA patients. Abbreviations: AZA: azathioprine; BDMARDs: biologic disease modifying anti-rheumatic drugs; CHC: colchicine; CYC: cyclophosphamide; CYS-A: cyclosporine A; DAPSO: dapsone; HCQ: hydroxychloroquine; LDA: low dose aspirin; LEF: leflunomide; MMF: mycophenolate mofetil; MTX: methotrexate; NSAIDs: non-steroidal anti-inflammatory drugs; PDN: prednisone; SSZ: sulfasalazine; VKA: vitamin K antagonists.

Twenty (8.6%) CTD and 10 (7.3%) CA patients reported at least one voluntary interruption of pregnancy (VIP). VIP occurred after RD diagnosis in 8 (47.1%) CTD and 2 (25%) CA patients. Among the 7 patients who declared the reasons for VIP, 2 patients said it was due to their RD.

3.5. Patients' knowledge about the use of drugs during pregnancy

A section of the questionnaire was specifically dedicated to the patient knowledge about the compatibility with pregnancy of drugs currently used to treat RD. The analysis was restricted to 73 CTD and 34 CA patients who had a pregnancy after the diagnosis of RD. Fig. 1 reports the answers of patients in the two groups according to three options: "yes" (drug can be used during pregnancy), "no" (drug should not be used during pregnancy) and "don't know". Patients with CA correctly identified methotrexate and leflunomide as "not compatible" with pregnancy significantly more often than patients with CTD (82% vs. 33%, $P < 0.01$; 45% vs. 14%, $P < 0.01$, respectively). Conversely, patients with CTD correctly suggested the possible use of heparin and low dose aspirin during pregnancy significantly more often than patients with CA (42% vs. 15%, $P < 0.01$; 59% vs 33%, $P = 0.01$, respectively).

4. Discussion

The gap in communication about reproductive issues has been recognized as an unmet need for women affected by autoimmune RD across countries with different cultural backgrounds, health care systems and degree of socio-economic development [7,8]. For the first time in Italy, a nationwide network was created within the frame of SIR to assure representativeness and adequate sample size to survey the perspectives about reproductive issues of patients of childbearing age with RD. Many of the participating centers are secondary-tertiary level centers harboring a Pregnancy Clinic, in which the multidisciplinary collaboration between Rheumatologists, Gynecologists-Obstetricians, and Neonatologists provide an integrated management of pregnancy and other issues related to "women's health" for patients affected by RD. This can explain why a higher number of CTD patients were enrolled in this study as compared with CA patients. Despite CTD are less prevalent diseases, patients tend to be followed-up in reference centers, and particularly in Pregnancy Clinics, given the more relevant implications of CTD during gestation as compared with CA.

Thanks to the collaboration of patients' representatives, we adapted and extended a questionnaire specifically focused on "women's health" that was proposed by a multinational group from Eastern Europe [6]. The questionnaire was distributed to consecutive patients attending the outpatient clinics in a definite period of time. The Rheumatologist directly proposed the questionnaire, with the advantages of assuring a definite diagnosis for each patient and consistency in answering the questions since the physician was available for requests of clarification. Refusal to compile the questionnaire was negligible (less than 4%) and mostly due to time constrains. This strategy allowed us to overcome a well-known bias of web-based surveys [9], which typically have a low percentage of respondents and tend to collect feedback from either the most motivated or most unsatisfied patients, yielding to non-representative data.

Our study confirms that counselling on reproductive issues is still an unmet need for young patients with RD: nearly one third of both patients with CTD and CA never had a discussion with their Rheumatologist about either the desire for a pregnancy or indication for contraceptive measures. Importantly, most of the women who received counselling about contraception were counselled by the Gynecologists only. The lack of counselling by the Rheumatologist may have a negative impact especially on CTD patients, as Gynecologists may not be aware of particular contraindications with the use of estrogen-containing preparations (e.g. positive antiphospholipid antibodies; high disease activity). We may assume that the lack of counselling reflects a poor attitude of Rheumatologists toward reproductive issues. They may not feel adequately prepared to speak about this topic [5]. Therefore, both physicians and patients should be the recipients of educational strategies in order to improve their communication about reproductive issues.

A smaller family size than desired was declared by nearly 40% of patients with both CTD and CA, similarly to previous reports [10,11]. As infertility or recurrent pregnancy loss may play an important role in reducing the number of children [11], our study highlights the impact of patients' concerns about the health of offspring and parenting capability. These are issues that may be adequately addressed during preconception counselling. In fact, nearly 60% of patients who had received a counselling declared to have received a positive influence from it.

Using a composite set of questions, we created a DKI in order to synthetically assess the degree of patients' knowledge about reproductive issues. A higher DKI was significantly associated with having received counselling, confirming the importance of physician-patient communication. Health care professionals should be promoted as the reference source of information, especially in the era of global and unverified sources that can be preferred by the patients because of easier and immediate access, such as websites and social networks [12]. Women in our cohort displayed moderate to high DKI values, suggesting that preconception counselling (received by nearly two thirds of the patients) was effective, especially within the frame of a Pregnancy Clinic.

Regarding pregnancy outcomes, our patients experienced a higher rate of pregnancy loss (18% in CA patients and 24% in CTD patients) as compared to the general obstetric population in which fetal death has been estimated to be 5% and early miscarriage around 9% [13]. In addition, CTD patients experienced more frequently ≥ 1 pregnancy loss as compared to CA patients (35% vs. 18.5%). A tendency toward a significantly lower live birth rate after diagnosis was found, confirming the role of RD in mediating a poorer obstetric outcome. This was true particularly for CA patients, while it was less evident for CTD patients, as they were more likely to carry autoantibodies with a negative impact on pregnancy before having received the clinical diagnosis or they were diagnosed based on pregnancy failure, as it happens for women with obstetric APS. Similarly, pre-term births occurred more frequently after diagnosis, as a possible consequence of either maternal disease or Obstetrician's choice of avoiding late pregnancy complications by inducing a pre-term birth. In this context, the role of preconception counselling is crucial for risk stratification and implementation of measures that can improve pregnancy outcome [14].

The knowledge about the compatibility of drugs with pregnancy was investigated only in patients who had a pregnancy after the diagnosis of RD, since these patients were supposed to be sensitized on this issue. Consistent answers were given about the use of largely prescribed drugs such as NSAIDs (rated as "not compatible") and prednisone (rated as "compatible"). The majority of CTD patients correctly identified low dose aspirin and hydroxychloroquine as compatible drugs. Most of CA patients declared that methotrexate should not be used during pregnancy. The "do not know" option applied more frequently for other anti-rheumatic drugs (including biologics), especially those of limited use in clinical practice, and for oral anticoagulants, which are indeed not so widely needed in patients with RD. We acknowledge that patients were not supposed to be informed about drugs that they never took, therefore a lack of knowledge reflected by the high frequency of "do not know" option was expected. However, patient perspectives may also reflect the reluctance to seek for information about the compatibility of drugs with pregnancy, as the general belief is that most drugs cannot be used. As a matter of fact, this misconception is not widespread only in the general population, but also among physicians. The perception of teratogenicity of drugs is sub-optimal among general practitioners and specialists in obstetrics/gynecology even for largely prescribed drugs such anti-depressants [15]. Scientific societies have acknowledged the unmet need for both patients and physicians about the management of anti-rheumatic drugs during pregnancy and lactation and put efforts in filling this gap [16–18].

Limitations of this study may include:

- lack of assessment of additional sources of information other than the treating physicians, which could have influenced the decisions about reproductive life;
- length of the questionnaire, which could have negatively influenced the reliability of answers;
- lack of clear definition of infertility and related causes;
- lack of stratification for demographic data such as socio-economic status, level of education, place of living (urban vs rural areas; northern vs. southern Italy);
- lack of sub-analysis for single disease and time-blocks (long-standing disease vs. recently diagnosed disease), which was not feasible because of reduced statistical power due to sub-grouping upon other variables;
- limited generalisability of the results to patients living in other Countries (for instance, lack of universal access to specialised referral centres through the public national health system) and to patients without access to a secondary-tertiary level centre with a Pregnancy Clinic (possible underestimation of the proportion of women who do not receive any counselling).

This study proposes the DKI as an innovative tool to survey few key questions in everyday practice (during visits, in the waiting room, etc.). This index could be validated in larger prospective cohorts (possibly multinational) for evaluating the effectiveness of counselling by means of longitudinal assessment.

In conclusion, this study highlighted the unmet needs of Italian women of childbearing age with RDs and some gaps in communication with physicians. Specialists who are involved in the care of patients with RDs should embrace the discussion about reproductive issues and be able to refer the patients to the correct sources of information and to the best management of pregnancy, as recommended by several international groups working on this topic [6,19,20]. Moreover, the subgroup of patients with CTD, particularly SLE and/or APS, should deserve particular attention, because of a major impact on reproductive life and peculiar implications of pregnancy and contraception on the disease itself [21].

Disclosure of interest

The authors declare that they have no competing interest.

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