



Awareness and Expectations Surrounding Family Planning and Pregnancy Among Danish Patients with Chronic Inflammatory Disease of the Skin or Joints: Results from an Online Survey

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ABSTRACT

Background: Patients with chronic inflammatory diseases (CIDs) may encounter challenges in their family planning journey. Here, we report on the access to family planning and

pregnancy (FPP) information and the concerns among patients in Denmark with CIDs.

Methods: Patients aged 18–50 years with CIDs participated in an online survey. Patients were recruited through patient advocacy groups and were asked to report information on their diagnosis, concerns related to FPP and perceptions of access to FPP information. Descriptive statistics were applied.

Results: Of the eligible respondents, 368 had rheumatological diagnoses (rheumatoid arthritis, psoriatic arthritis, juvenile idiopathic arthritis or axial spondyloarthritis; mean age 40 years; 83% women, 17% men) and 95 had dermatological diagnoses (psoriasis or psoriatic arthritis; mean age 38 years; 67% women, 33% men). Approximately 70% of all patients reported seeking FPP information from patient advocacy groups; 57% of both cohorts used the internet as information sources; and 73% and 42% of rheumatological and dermatological cohorts used their hospital and specialist doctor, respectively. Despite this, 58% and 67% of patients with rheumatological and dermatological diagnoses reported limited or no access to FPP information, with > 70% of dermatological patients of early/mid-reproductive age reporting a lack of access to this information. Overall, 68% of patients with rheumatological and 73% with dermatological diagnoses had biological children, amongst whom 24% and 18%, respectively, indicated their disease affected the number of children they ultimately

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decided to have. The most frequent FPP concerns among patients who did not want any/more biological children were disease worsening, heredity and taking care of the child.

Conclusions: Despite awareness of available sources of FPP information, patients expressed experiencing a feeling of limited access to information and having concerns that affect key decisions regarding FPP. The results of this survey highlight a need for improved and more standardised FPP information for patients with CIDs in Denmark.

Keywords: Pregnancy; Family planning; Chronic inflammatory disease; Online survey

Key Summary Points

Patients with chronic inflammatory diseases may encounter challenges in their family planning journey.

This survey assessed the awareness of, and access to, family planning and pregnancy information among Danish patients with chronic inflammatory diseases.

Respondents reported limited access to information, as well as concerns which affect their family planning journey.

The results of this survey provide insight on an unmet need in Denmark and the areas where healthcare providers may need to provide more standardised and accessible information.

INTRODUCTION

Chronic inflammatory diseases (CIDs) of the skin or joints, such as axial spondyloarthritis (axSpA; including non-radiographic [nr-] axSpA and ankylosing spondylitis [AS]), juvenile idiopathic arthritis (JIA), psoriatic arthritis (PsA), psoriasis (PsO) and rheumatoid arthritis (RA), can impact patients' attempts to start a family.

CIDs have been associated with adverse pregnancy outcomes, such as preterm birth, intrauterine growth restriction and low birth weight [1, 2]. In addition, evidence suggests that patients with CID may experience a lower likelihood of pregnancy and a lower rate of live births compared to their healthy counterparts and that disease activity, comorbidities and medication use may impact the likelihood of women becoming pregnant [3–9].

Reports on the level of disease activity during pregnancy are mixed in patients with rheumatological and dermatological diseases [10–13]. Whilst some patients have reported stabilisation or improvements in symptoms during pregnancy [12], others have reported an exacerbation of disease activity, highlighting the variation in experiences at the patient level [14–16]. The concern of foetal or infant exposure to medication, justified or not, is deeply embedded among patients and physicians [9, 17, 18].

The clinical dilemma between the need for continuous treatment of these chronic diseases and the patient's wish to conceive calls for careful consideration, professional counselling and planning to enable patients to make informed decisions [18]. Currently, a number of guidelines provide recommendations for patients with rheumatological diseases who are of reproductive age [19–22]. Similar formal clinical guidelines for the treatment of patients with dermatological diagnoses, whilst available, are less prevalent [11, 23].

Real-world data collected from patient advocacy groups may help to inform the local implementation of available recommendations and the awareness of these among healthcare providers. The results of a multinational survey of 969 patients treated by rheumatologists and gastroenterologists in Europe and the USA showed that most patients' concerns regarding family planning and pregnancy (FPP) were inadequately or inconsistently addressed [24]. Similar findings have also been shown in patients diagnosed with PsO (including PsA) [25].

The objective of this study was to investigate the level of FPP information received by and the potential FPP concerns among Danish patients with CIDs.

METHODS

Survey Distribution and Patient Eligibility

An online survey was conducted from 19 September to 15 October 2019 by an independent third-party vendor (Incentive Denmark, Holte, Denmark). Patients were recruited from Danish patient advocacy groups (The Arthritis Association, The Association for Spinal Arthritis and Bechterew's Disease, and The Psoriasis Association) who provided their members with a link to the survey on their websites and emails.

Patients aged 18–50 years with a self-reported diagnosis of CID were eligible for participation. Patients not meeting the age criteria and those who did not indicate their gender or disease were excluded. Patients who only partially completed the survey or did not agree to participate were also ineligible for inclusion in the analysis.

As the survey requested rheumatology- and dermatology-specific responses for some questions, links for two different versions of the survey were sent to the rheumatology versus the dermatology patient advocacy groups. PsA was represented as a diagnosis in both the rheumatological group and dermatological group in order to avoid patients' self-exclusion. These patients were therefore allocated to a cohort based on the advocacy group through which they accessed the link.

Patients completed the survey voluntarily and did not receive payment for participation.

Survey Design

The survey was designed in collaboration with specialists in dermatology and rheumatology and consisted of 34 closed-ended questions. Respondents were informed that the survey would take 10–15 min to complete and were provided with a statement explaining that the appropriate ethical guidelines had been followed, the answers were anonymous and the data were to be handled and organised according to Danish legislation and the General Data Protection Regulation (EU) 2016/679 (GDPR).

Patients were required to actively indicate that they agreed to these terms and conditions and could withdraw from the survey at any time. Ethics approval was not required for this study as questionnaire surveys not involving human biological material are exempt from the obligation to notify the scientific ethics committee (Sect. 14 (2) of the Committee Act).

The survey included questions regarding:

- Patient demographics and disease characteristics;
- Level of patient knowledge and feelings of access to FPP information;
- Sources of information about disease course and treatment in relation to pregnancy;
- Patients' family planning concerns;
- In women who had biological children, their disease status during and after previous pregnancies;
- Treatment(s) taken for managing the patient's disease.

As the survey was closed-ended, except for providing a numeric response for their age, patients could only provide answers that were selected from a distinct set of pre-defined responses. The full survey and possible answers are shown in Electronic Supplementary Material Table S1.

Statistical Analysis

The sampling strategy was aimed at receiving responses from 1000 patients aged 18–50 years. Descriptive statistics were applied. Data are reported as proportions of patients answering each question. Questions not applicable to patients were not provided for their completion (e.g. questions on pregnancy experience were not presented to male respondents). For some questions respondents could select "do not know", which led to variable denominators being applied.

RESULTS

Patient Characteristics

Demographics

A total of 976 patients with rheumatological diagnoses and 136 patients with dermatological diagnoses responded to the survey. Of these patients, 368 with rheumatological diagnoses and 95 with dermatological diagnoses met the eligibility criteria and completed the survey. Approximately 83% of rheumatological respondents and 67% of dermatological respondents were women, and the mean (standard deviation [SD]) age of the rheumatological and dermatological groups overall was 40.0 (7.4) years and 38.3 (8.2) years, respectively. Mean (SD) age at diagnosis and patient characteristics and demographics are shown in Table 1.

Prior Experience with Starting a Family

A slightly higher proportion of men reported having biological children compared with women: in the group with rheumatological diagnoses, 80% of men (51/64) versus 65% of women (198/304); in those with dermatological diagnoses, 81% (25/31) of men versus 69% (44/64) of women. The mean (SD) number of children patients had relative to their diagnosis was 1.4 (1.1) children prior to, and 0.6 (0.9) children after, diagnosis for those with rheumatological diagnoses, whilst for those with the dermatological diagnoses, an inverse trend was observed, as this was reported to be 0.3 (0.7) and 1.8 (1.0) children, respectively (ESM Table S2).

Prior Experience with Disease Activity Changes During/After Recent Pregnancy (Women)

Overall, 16% (32/198) of women with rheumatological diagnoses reported disease worsening during their most recent pregnancy; this proportion was greatest amongst women with 'several types of arthritis' (33%; 5/15) and axSpA only (29%; 15/51). Disease improvement during pregnancy was reported by 31% (61/198) of women overall. In contrast, 34% (67/198) reported disease worsening post-partum, and

6% (12/198) reported improvement (ESM Fig. S1a).

In women with dermatological diagnoses, disease worsening during pregnancy was reported by 20% (9/44), while twice this proportion (41%; 18/44) reported experiencing disease improvement. After pregnancy, 59% (26/44) of women reported experiencing disease worsening versus just 2% (1/44) who reported improvement. Overall, disease change was more pronounced in the PsO cohort both during and after pregnancy compared with the combined PsO and PsA cohort (ESM Fig. S1b).

Access to FPP Information

When asked "To what extent do you feel that you have had access to pregnancy and family planning information?", of all patients ($N = 463$), 60% reported that their access was "to a lesser degree" or "not at all". This lack of access was reported by 58% (214/368) and 67% (64/95) of patients with rheumatological and dermatological diagnoses, respectively. When stratified by gender, reports of a lesser degree or complete lack of access were greatest in women with dermatological disease, with significantly more women (45%; 29/64) reporting their access as "not at all" compared with men (29%; 9/31). When stratified by age, lack of access to information was reported the most by those in the early- and mid-reproductive age groups for all patients (male and female) with dermatological disease (73%; $n = 41$) and by those in the mid- and late-reproductive age groups for patients with rheumatological disease (59%; $n = 329$) (Fig. 1a, b).

Across diagnoses, more women than men reported seeking information from family and friends, social media and the internet relative to other information sources. In the rheumatological cohort, 13% (39/304) of women versus 5% (3/64) of men reported consulting their family and friends, 35% (105/304) versus 20% (13/64) opted for social media and 58% (177/304) versus 48% (31/64) sought information from the internet. In the dermatological cohort, 17% (11/64) of women versus 3% (1/31) of men reported using their family and friends as

Table 1 Patient characteristics and demographics

| Respondents with a rheumatological diagnosis | | | | Respondents with a dermatological diagnosis | | | |
|---|------------------|--------------------|-----------------|---|-----------------|-------------------|-----------------|
| Characteristics | All (N = 368) | Women (N = 304) | Men (N = 64) | Characteristics | All (N = 95) | Women (N = 64) | Men (N = 31) |
| Mean age, years (SD) | 40.0 (7.4) | 39.7 (7.5) | 41.5 (6.5) | Mean age, years (SD) | 38.3 (8.2) | 36.6 (8.6) | 41.7 (6.3) |
| Diagnosis, n (%) | | | | Diagnosis, n (%) | | | |
| Rheumatoid arthritis | 130 (35.3) | 119 (39.1) | 11 (17.2) | Psoriasis ^a | 94 (98.9) | 64 (100.0) | 30 (96.8) |
| Axial spondyloarthritis | 113 (30.7) | 76 (25.0) | 37 (57.8) | Psoriatic arthritis ^b | 28 (29.5) | 17 (26.6) | 11 (35.5) |
| Psoriatic arthritis | 81 (22.0) | 70 (23.0) | 11 (17.2) | | | | |
| Juvenile idiopathic arthritis | 18 (4.9) | 18 (5.9) | 0 (0.0) | | | | |
| Several types of arthritis | 26 (7.1) | 21 (6.9) | 5 (7.8) | | | | |
| Mean age at diagnosis, years (SD) | | | | Mean age at diagnosis, years (SD) | | | |
| One arthritic diagnosis | 30.2 (10.6) | 29.9 (11.0) | 31.6 (8.2) | Psoriasis | 18.3 (9.0) | 17.8 (9.8) | 19.4 (7.0) |
| Several types of arthritis | 29.5 (11.5) | 27.9 (11.8) | 36.4 (7.4) | Psoriatic arthritis | 28.5 (9.0) | 28.9 (10.6) | 27.9 (6.0) |
| Mean time since diagnosis, years (SD) | | | | Mean time since diagnosis, years (SD) | | | |
| Rheumatoid arthritis | 10.3 (9.4) | 10.7 (9.6) | 5.7 (5.8) | Psoriasis | 19.9 (9.9) | 18.8 (10.3) | 22.2 (8.6) |
| Axial spondyloarthritis | 7.4 (6.6) | 5.8 (4.1) | 10.7 (9.2) | Psoriatic arthritis | 12.2 (6.9) | 9.9 (6.5) | 15.8 (5.9) |
| Psoriatic arthritis | 8.7 (6.9) | 8.4 (6.9) | 10.7 (6.8) | | | | |
| Juvenile idiopathic arthritis | 24.4 (11.8) | 24.4 (11.8) | – | | | | |
| Several types of arthritis | 11.2 (10.3) | 12.4 (11.1) | 6.4 (4.0) | | | | |
| Mean time since first symptoms, years (SD) | | | | Mean time since first symptoms, years (SD) | | | |
| Rheumatoid arthritis | 12.7 (9.9) | 13.2 (10.1) | 7.1 (6.5) | Psoriasis | 22.6 (9.7) | 21.2 (10.4) | 25.4 (7.4) |
| Axial spondyloarthritis | 15.5 (8.8) | 14.5 (9.1) | 17.6 (10.3) | Psoriatic arthritis | 16.0 (8.2) | 15.2 (8.8) | 17.2 (7.5) |
| Psoriatic arthritis | 14.1 (7.4) | 13.8 (7.4) | 16.2 (7.9) | | | | |
| Juvenile idiopathic arthritis | 25.6 (11.5) | 25.6 (11.5) | – | | | | |
| Several types of arthritis | 20.7 (12.1) | 23.1 (12.2) | 10.6 (4.3) | | | | |

Table 1 continued

| Respondents with a rheumatological diagnosis | | | Respondents with a dermatological diagnosis | | | |
|---|---------------|-----------------|---|--------------|----------------|--------------|
| Characteristics | All (N = 368) | Women (N = 304) | Men (N = 64) | All (N = 95) | Women (N = 64) | Men (N = 31) |
| Highest level of education, n (%) | | | | | | |
| Primary school | 20 (5.4) | 15 (4.9) | 5 (7.8) | 3 (3.2) | 3 (4.7) | 0 (0.0) |
| High school | 23 (6.3) | 22 (7.2) | 1 (1.6) | 6 (6.3) | 4 (6.3) | 2 (6.5) |
| Vocational education | 74 (20.1) | 57 (18.8) | 17 (26.6) | 21 (22.1) | 11 (17.2) | 10 (32.3) |
| Short/medium higher education | 165 (44.8) | 143 (47.0) | 22 (34.4) | 47 (49.5) | 32 (50.0) | 15 (48.4) |
| Higher education | 86 (23.4) | 67 (22.0) | 19 (29.7) | 18 (19.0) | 14 (21.9) | 4 (12.9) |
| Rheumatological diagnoses All (N = 368) Women (N = 304) Men (N = 64) Dermatological diagnoses All (N = 95) Women (N = 64) Men (N = 31) | | | | | | |
| Employment status, n (%) | | | | | | |
| Working full time | 163 (44.3) | 123 (40.5) | 40 (62.5) | 60 (63.2) | 36 (56.3) | 24 (77.4) |
| Working part time | 41 (11.1) | 41 (13.5) | 0 (0.0) | 8 (8.4) | 8 (12.5) | 0 (0.0) |
| Working flexible hours | 69 (18.8) | 58 (19.1) | 11 (17.2) | 7 (7.4) | 4 (6.3) | 3 (9.7) |
| Unemployed | 19 (5.2) | 16 (5.3) | 3 (4.7) | 4 (4.2) | 4 (6.3) | 0 (0.0) |
| Training | 13 (3.5) | 13 (4.3) | 0 (0.0) | 12 (12.6) | 10 (15.6) | 2 (6.5) |
| Early retired | 30 (8.2) | 27 (8.9) | 3 (4.7) | 3 (3.2) | 1 (1.6) | 2 (6.5) |
| Retired | 2 (0.5) | 1 (0.3) | 1 (1.6) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| None of the above | 28 (7.6) | 22 (7.2) | 6 (9.4) | 1 (1.1) | 1 (1.6) | 0 (0.0) |
| Do not want to disclose | 3 (0.8) | 3 (1.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |

PsA was represented as a diagnosis in both the rheumatological group and dermatological group to avoid patients' self-exclusion. Patients were allocated to a cohort based on the patient advocacy group through which they accessed the link to the survey

PsA/ Psoriatic arthritis, PSO psoriasis, SD standard deviation

^a Psoriasis alone and PSO + PsA

^b PsA alone and PSO + PsA

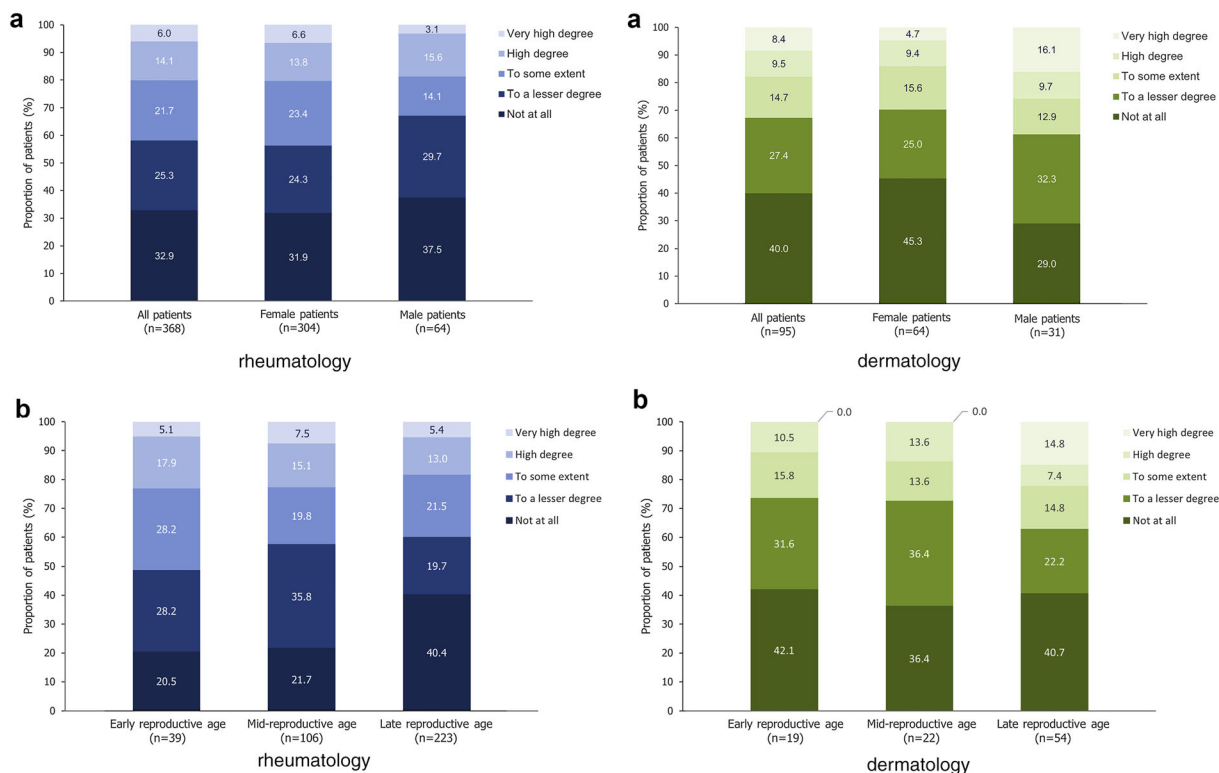


Fig.1 Access to family planning and pregnancy information. “To what extent do you feel that you have had access to pregnancy and family planning information?” a Proportions of patients reporting levels of access to pregnancy and family planning information—overall and by gender (rheumatological patients, dermatological patients).

b Proportions of patients reporting levels of access to pregnancy and family planning information—by reproductive age group (rheumatological patients, dermatological patients) (early reproductive age [18–29 years]; mid-reproductive age [30–39 years]; late reproductive age [40–50 years])

information source, 30% (19/64) versus 13% (4/31) opted for social media and 64% (41/64) versus 42% (13/31) reported using the internet. However, in the dermatological cohort a greater proportion of men (42%; 13/31) compared with women (25%; 16/64) also commonly sought information from their hospital doctor. Overall, the most used sources of information on disease and treatment among patients with rheumatological diagnoses were patient advocacy groups (74%; 274/368), their hospital doctor (73%; 267/368) and the internet (57%; 208/368). Amongst patients with dermatological diagnoses the most used sources were patient advocacy groups (69%; 66/95), the internet (57%; 54/95) and their doctor in specialist practice (42%; 40/95) (Fig. 2).

Family Planning and Pregnancy Concerns

Past and Current Family Planning and Pregnancy

Across diagnoses, both genders indicated to a similar level that their disease affected their ability to become a parent; for those with rheumatological diagnoses this was 23% (84/368) overall (women 23% [71/304]; men 20% [13/64]), and for those with dermatological diagnoses this was 8% (8/95) overall (women 8% [5/64]; men 10% [3/31]).

When women were asked whether they had concerns before or during their most recent pregnancy due to their medical treatment, large proportions in both patient populations reported that they did not, with approximately 75% (n = 203) of women with rheumatological

disease and 80% ($n = 44$) of women with dermatological disease reporting that they were not worried.

Future Family Planning and Pregnancy

When asked whether their illness has affected how many biological children they have chosen to have, 24% (89/368) of rheumatological patients agreed that they have chosen to have fewer or more children (women 25% [75/304]; men 22% [14/64]). Similar but reduced proportions of dermatological patients reported making the same decision (18% [17/95]; women 19% [12/64]; men: 16% [5/31]).

In rheumatological patients, 67% (248/368) did not want biological children or did not want to have more biological children than they already had (women 67% [203/304]; men 70% [45/64]). For those without biological children who did not plan on having them ($n = 51$), 33% (women 36% [16/44]; men 14% [1/7]) stated that they had never wanted to have children, and 34% (15/44) of women cited the potential physical impact of a pregnancy. A high

Fig. 3 The most frequent family planning and pregnancy concerns. **a** Rheumatological patients with no biological children—“What is the reason you do not want biological children?” **b** Rheumatological patients with biological children—“What is the reason you do not want more biological children?” **c** Dermatological patients with biological children—“What is the reason you do not want more biological children?”

proportion also gave reasons related to their disease for not wanting children, including worries of not being able to take care of the child due to their disease burden (39%; women 39% [17/44]; men 43% [3/7]), heredity (inheritance of the disease by the child: 35%; women 32% [14/44]; men 57% [4/7]) and concerns that their disease will get worse (31%; women 27% [12/44]; men 57% [4/7]) (Fig. 3a). These concerns were raised to a lesser extent by patients who already had biological children but did not plan to have more, as the majority (72%; 142/197) stated they already had the children they wanted to have (Fig. 3b).

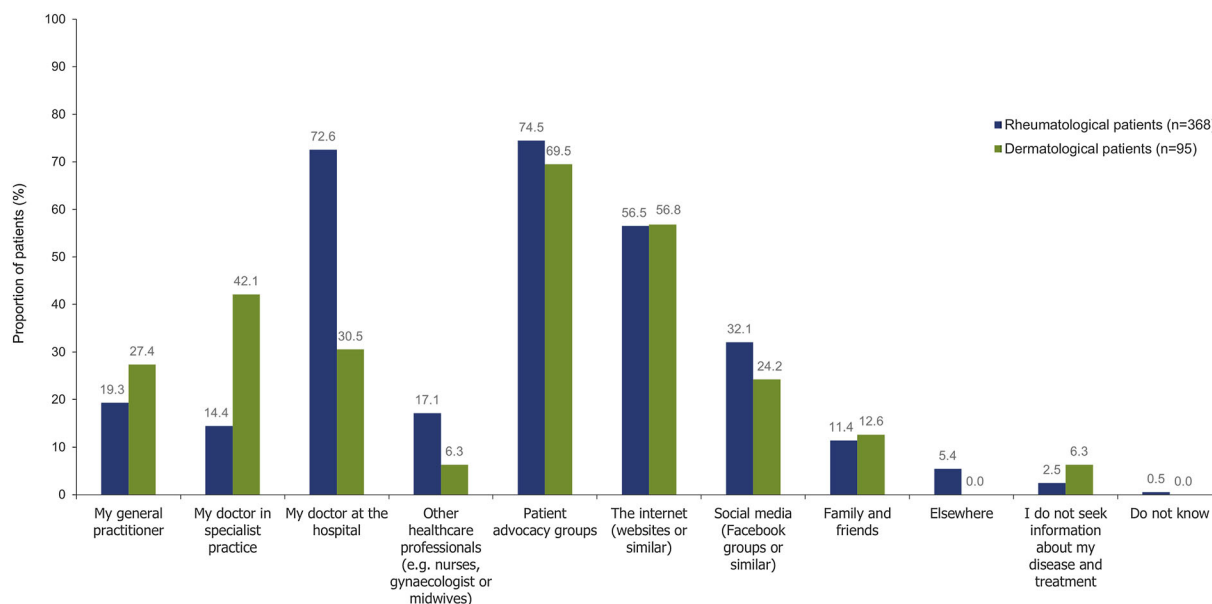
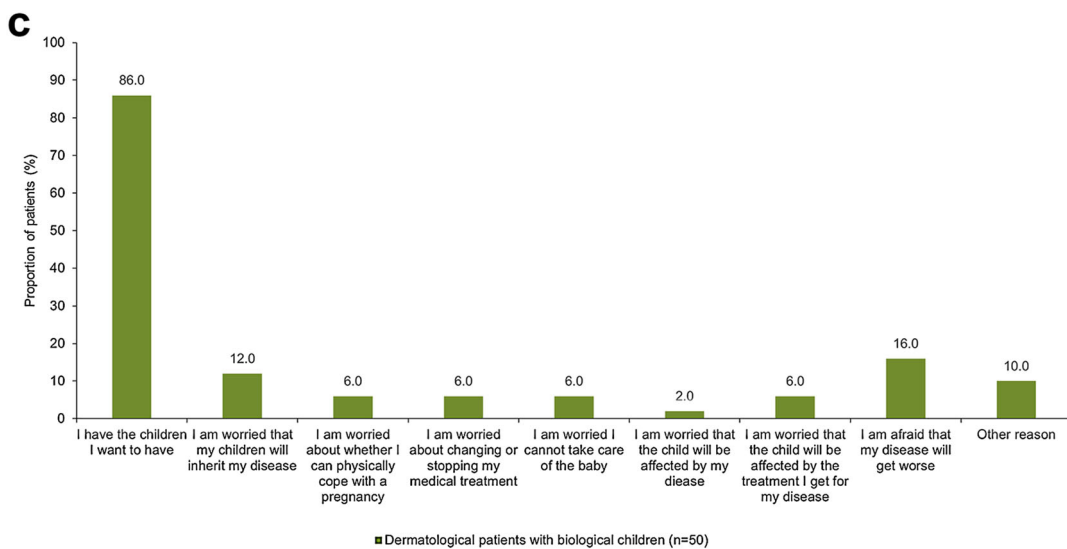
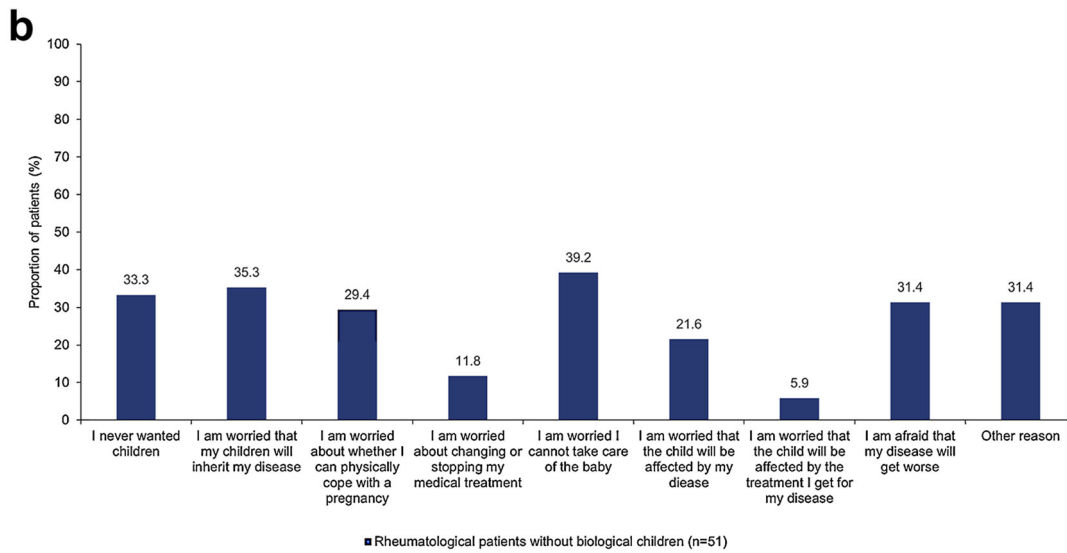
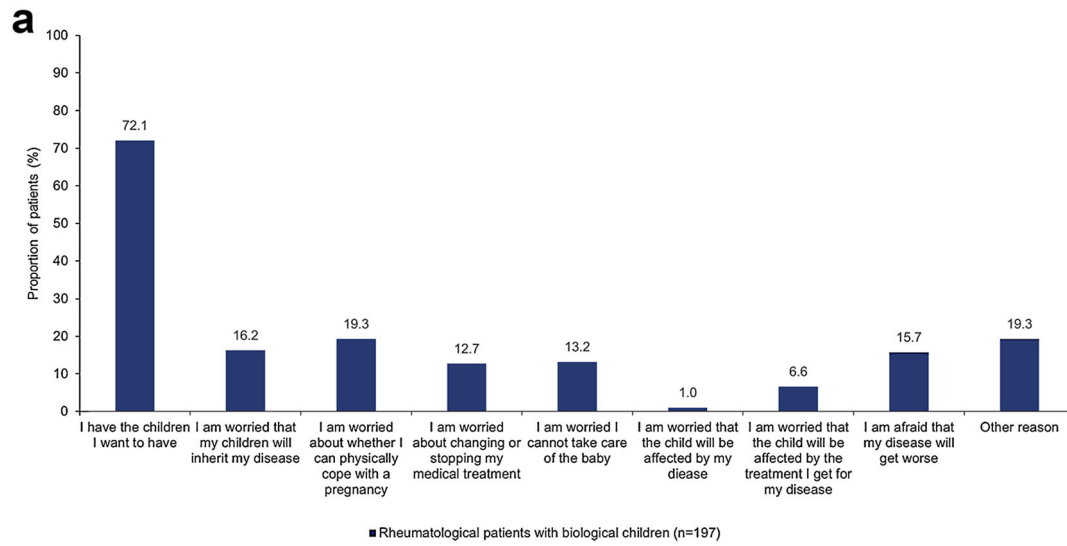


Fig. 2 Sources of information on disease and treatment. “Where do you generally find information about your illness and treatment? (you may tick off more than one)”. The options for patient advocacy groups included The Arthritis Association (Gigtforeningen), The Association

for Spinal Arthritis and Bechterew’s Disease (Foreningen for Rygsøjleligt og Morbus Bechterew), The Psoriasis Association (Psoriasisforeningen), and ‘other’ patient associations



In dermatological patients, low numbers of patients did not have biological children and did not plan on having them ($n = 6$); therefore limited conclusions can be drawn regarding FPP concerns in this subpopulation. Among dermatological patients with biological children who did not want more ($n = 50$), fears that their disease would get worse (16%; women 21% [7/33]; men 6% [1/17]) and heredity (12%; women 3% [1/33]; men 29% [5/17]) were the most frequent FPP concerns (Fig. 3c).

DISCUSSION

This survey found that Danish patients of reproductive age with a CID—especially those with dermatological diagnoses in the early- and mid-reproductive age groups—have concerns which can impact their FPP decisions. Patients also reported a feeling of limited access to FPP information, pointing out an unmet information need, particularly from healthcare providers. This expands upon the knowledge of previous studies [26, 27].

Stratified by reproductive age, the rheumatological and dermatological patients showed a nearly inverse relationship between reproductive age and reported access to FPP information. This might be reflective of an increasing focus on FPP in the Danish rheumatological guidelines in recent years—and the lack thereof in the Danish dermatological guidelines [28, 29].

In the dermatological cohort the lack of access to FPP information was largest among those in the early- and mid-reproductive age groups, i.e. the age groups with the most people about to start a family. This result is highly indicative of the need for structured dermatological FPP guidelines. Inadequate provision of FPP information to this group has previously been reported by Lebwohl et al., wherein > 75% of the patients with PsA and PsO had to initiate discussions around family planning with their healthcare provider themselves [30]. This finding was supported by the National Psoriasis Foundation survey in which only 7% of patients stated that their healthcare provider initiated the family planning conversation [25].

Patients reported concerns related to their CID that had impacted family planning decisions, such as their decision to have biological children. We found that rheumatological patients often had their children prior to their diagnosis, which contrasts with the patients with dermatological diagnoses who often had children after their diagnosis. This may reflect an earlier onset of dermatological disease in these patients or the possibility that they do not experience the same diagnostic challenges as patients with rheumatological diagnoses [31]. Patients with dermatological diseases may also be more likely to have diagnoses earlier on in their reproductive years due to the detection of associated immune-mediated inflammatory diseases prior to their diagnosis [32].

The lack of concern about pregnancy due to medical treatment reported in a large proportion of female patients in the rheumatological cohort may be due to more of these women having had their children prior to diagnosis and treatment, or to a feeling of more reassurance with disease management within the hospital setting. Overall, the reasons for this should be explored further. For those with dermatological diagnoses, this lack of concern could reflect less severe disease, or to the influence of factors such as familial experience and a difficulty in obtaining a referral to a specialist, which may discourage health-seeking behaviours—albeit this may differ across various healthcare systems [33].

Patients reported extensive use of patient advocacy groups as sources of information, although this use is reflective of the way the patients were recruited and may differ significantly from the general population. Hospital doctors were commonly consulted and, to a greater extent for dermatological patients, their general practitioner and doctor in specialist practice. Considering the seemingly available contact with key healthcare professionals, barriers may still exist here to cause the patients in this survey to report a lack of access to FPP information. Examples of these barriers could include a lack of evidence-based resources for physicians to guide reproductive decision-making, competing priorities during clinic visits and physician unawareness of FPP as being a part of

their clinical responsibilities [34–36]. Across diagnoses, the internet and social media were commonly reported as sources of information. However, it must be noted that online sources of information may be inadequate to address patients' educational needs as these sources may be outdated and/or provide misinformation or the information may not cover all essential topics related to their disease and FPP [37]. With patients increasingly embracing technology to access information, and their treating physicians perhaps being unaware of this, it is important that all physicians (in primary and secondary care) are aware of the available content patients may access in order to guide them appropriately [38].

In this survey, women across diagnoses reported stabilisation, worsening and improvements in disease during pregnancy. The results described here reflect that some CIDs (RA, PsA, JIA, and PsO) remain stable or tend to improve during pregnancy, in contrast to axSpA which is often aggravated during pregnancy [10–16, 39]. However, these data are self-reported by patients, so it must be noted that a symptom associated with pregnancy, such as mechanical back pain, could have been perceived as disease worsening, potentially confounding findings in the axSpA population. Post-partum flares were reported by both groups of patients and were more prominent amongst women with PsO, also confirming previous findings [10–12, 15]. However, this must be interpreted with caution, as this survey was not designed to account for whether the reported flares were in fact a return to the patients' baseline psoriatic body surface area, a phenomenon observed by Murase et al. [12]

There are several limitations to this study. As enrolment was conducted through online links on the websites of patient advocacy groups, patients who were not members of an advocacy group were unlikely to be represented in this study, and thus represent selection bias. Furthermore, patients who are members of patient advocacy groups could be more likely to be engaged and to seek out information, so the extent to which the sample is representative of the general population with CID remains unknown, also representing selection bias. As

the study data did not capture disease activity, interpretations of how disease severity may have affected patients' FPP concerns cannot be accurately drawn. Additionally, these results are subject to recall bias, as no medical records were reviewed and the survey relied on self-reported data.

CONCLUSIONS

In conclusion, Danish patients of reproductive age with CIDs have concerns related to their disease which affect decisions throughout the family planning journey. The present study highlights an unmet need for healthcare professionals in Denmark to proactively provide standardised, accessible family planning information in line with international recommendations, as well as in which patient populations these might be most required.

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Compliance with Ethics Guidelines. Ethics approval was not required for this study. Under Danish legislation, questionnaire survey projects not involving human biological material are exempt from the obligation to notify the scientific ethics committee (Section 14 (2) of the Committee Act). Respondents were provided information on the conduct of the survey and had to provide consent before participating. Respondents were informed that the knowledge collected in the survey would be published and had to provide consent before participating.

Data Availability. Data from non-clinical studies is outside of UCB's data-sharing policy.

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