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A Pilot Study of Reproductive Health Counseling in a Pediatric Rheumatology Clinic

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Abstract

Objective—To assess perception and behavior after reproductive health counseling among adolescent patients in a tertiary care-based pediatric rheumatology clinic.

Methods—Adolescent females seen at Stanford pediatric rheumatology clinic were prospectively enrolled during routine visits. At study start, standard clinic procedures for the following were reviewed with providers: 1) HEADSS (home, education, activities, drugs, sexual activity, and suicide/depression) assessment; 2) reproductive health counseling; and 3) medical record documentation. Patients were enrolled if providers indicated that they performed HEADSS assessment and reproductive health counseling. At enrollment, patients completed a survey to assess perceptions of reproductive health counseling. Chart review confirmed documented discussions. Follow-up survey 3-5 months after enrollment tracked reproductive health information seeking behavior.

Results—Ninety females (ages 17 ± 2 years old) participated. Almost all patients (99%) agreed that reproductive health was discussed. Seventy-one percent reported that pregnancy risks were discussed, 42% had recent concerns about reproductive health, and 33% reported their provider recommended that they seek further reproductive health care. Eighty-four patients completed follow-up phone surveys, with 25% reporting seeking further information on reproductive health concerns but merely 9.5% actually sought further care. Only 18% reported having ever asked their rheumatology provider for guidance regarding reproductive health care concerns.

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Author Contributions

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Ronis had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Study conception and design. Ronis, Frankovich, Yen, Sandborg, Chira.
Acquisition of data. Ronis.
Analysis and interpretation of data. Ronis, Frankovich, Chira.

Conclusion—Routine reproductive health discussion and counseling are necessary in a rheumatology clinic; as in our experience, a substantial number of adolescents have concerns and actively seek reproductive health information. Despite these discussions, teens rarely pursued further reproductive health care. Further work to bridge this gap is needed.

Introduction

Adolescence is a unique period of rapid biological, social, emotional, and intellectual growth[1]. The psychosocial developmental process can be especially challenging for adolescents with chronic rheumatic diseases as they are encouraged to achieve self-care and independence, potentially causing conflict between teens and providers. For instance, adolescents may refuse medications with cosmetic effects despite understanding the benefits of treatment, or parents and providers may be unwilling to relinquish control of care to the adolescent for fear of adverse consequences. During this time many teens exhibit the impulsive decision-making of childhood, while experimenting with risky behaviors and not adhering to therapy[2].

Typical adolescent behaviors can include unsafe sexual practices. The 2011 National Youth Risk Behavior Surveillance of high school students conducted by the Centers for Disease Control showed that 46% of high school females had ever had sex, 46% of sexually active females had not used a condom during their last sexual intercourse, and 78% of sexually active females did not use hormonal contraception before their last sexual intercourse[3]. These behaviors can have negative outcomes such as sexually transmitted infections and unplanned pregnancies, and the United States has the highest teen pregnancy rate of any developed country (estimated 400,000 teens aged 15-19 giving birth annually)[4]. Teen mothers are more likely to receive late or no prenatal care, have a preterm or low birthweight infant, and experience negative social outcomes, including school dropout[4,5]. Pregnancy rate data among adolescent rheumatology patients are lacking but unprotected sexual activity is a recognized clinical problem. Yearly screening of adolescent sexual health is recommended by the American Academy of Pediatrics (AAP) and American Medical Association (AMA) and is a quality measure for optimal care of patients with Juvenile Idiopathic Arthritis (JIA)[6–8].

Pediatric rheumatology patients often take teratogenic or cytotoxic medications (e.g., methotrexate, leflunomide, mycophenolate mofetil, and cyclophosphamide,) contraindicated during pregnancy. Some rheumatic diseases (such as lupus) are reportedly more severe in adolescence with higher frequency of aggressive renal disease, requiring steroids and cytotoxic drugs[9]. Should unplanned pregnancy arise, the teen is typically advised to stop these medications to decrease risks to the developing fetus. Unfortunately, discontinuation of medicines and/or pregnancy itself can cause disease flare. Patients with active disease are more likely to have complications with pregnancy such as spontaneous abortion, intrauterine growth restriction, or preterm delivery[10], compounding the risks of adolescent pregnancy.

Women aged 18-45 felt counseling regarding potential teratogenic risks of medications should occur when the medication is prescribed[11]. Since pediatric rheumatologists often see adolescents more frequently than their primary care physicians and are the prescribers of

these medications, the rheumatology clinic visit represents an important opportunity to effectively screen, counsel, and promote good reproductive health to prevent adverse pregnancy outcomes. Research on reproductive health in pediatric rheumatology patients has been limited with one study demonstrating physician screening practices could be improved with an educational intervention[12].

No study has reported the correlation between adolescents' perception about reproductive health screening and recommendations and physician documentation of this assessment, but literature has shown that physicians and adult patients often give discrepant reports about the events during a clinic visit[13]. Factors leading adolescents to seek further information and care regarding reproductive health have not been evaluated. The quality, effectiveness, and outcomes of reproductive health counseling have been challenging to assess[14].

The goal of this study is to assess adolescent rheumatology patients' perception and behavior after reproductive health counseling in the rheumatology clinic. Our overall objective is to foster positive reproductive health outcomes among adolescents with rheumatic diseases by improving reproductive health counseling in the pediatric rheumatology clinic.

Materials and Methods

Study population

A convenience sample of consecutive patients were invited to participate in the study if they met the following inclusion criteria: female sex, age 13-20 years, English speaking, diagnosis of a rheumatologic condition, >2 rheumatology clinic visits at Lucile Packard Children's Hospital at Stanford, and provider indication that the patient had received the routine reproductive health screening and counseling during the visit on enrollment day. IRB approval was obtained and all patients and at least one parent/guardian assented/consented to participate.

Reproductive health screening and counseling

Prior to study start, all clinic providers were instructed in the use of the HEADSS assessment, counseling tool, and medical record documentation and were encouraged to follow these standard clinic practice guidelines and documentation practices for all pediatric rheumatology patients. HEADSS is a psychosocial risk assessment instrument that has been in clinical use since 1974 and is a mnemonic for home, education, activities, drugs, sexual activity, and suicide/depression. It addresses the major areas of adolescent psychosocial stress and is a practical clinical screening instrument[15]. We developed a standardized clinic counseling tool that addressed topics of confidentiality, pregnancy risk in the context of the rheumatic disease, teratogenic risks of medications, contraception, and referral to reproductive health services (Table 1.) Eligible patients were screened and counseled with a paper HEADSS assessment and counseling tool that was included in the medical record by the rheumatology provider as part of their routine clinic visit.

Data Collection and Presentation

Patients completed a questionnaire in clinic, directly after enrollment, on the day of the reproductive health screening and counseling. The initial questionnaire assessed patient-provider trust, patient's perceptions of whether counseling had occurred, their general knowledge about medications and disease and whether the patient had recent reproductive health concerns. Follow-up phone surveys occurred 3-5 months after the initial enrollment and assessed whether the patient had sought further reproductive health information or care and their perception of talking about reproductive health with the rheumatologist. Charts were reviewed for demographic and medical data as well as for documentation of reproductive health screening. All questionnaires were pilot-tested to ensure that language was appropriate and understandable. Data are presented descriptively.

Results

Ninety patients were enrolled and completed an initial survey (from December 2010 -March 2011.) All 90 participants had a rheumatologic disease, and 15 (17%) had a concurrent pain syndrome. Patient diagnoses, medication use, and demographic data are included in Table 2. Ninety-four percent had documentation of reproductive health counseling in the medical record.

Of the 90 patients enrolled, 23 (26%) had engaged in sexual intercourse and 3 (3%) were considering sexual activity. Eleven (12%) were already followed by another provider for reproductive health care. Almost all patients (99%) agreed reproductive health was discussed and 88 (98%) felt confidentiality was assured. Sixty-four patients (71%) reported that pregnancy risks of medications were discussed. All patients agreed they felt comfortable enough with the provider to ask questions. Eighty-eight patients (98%) understood the need to take medications for disease control. Almost half (38 patients, 42%) had recent concerns about reproductive health (which included pregnancy, sexually transmitted infections, or contraception issues.)

One third of the patients (30 patients, 33%) reported their provider recommended that they seek further reproductive health care. Of those patients who were recommended by their provider to seek further reproductive care, 10 (33%) were already followed by another provider for reproductive health care, 2 (6.7%) said they would definitely go, 12 (40%) planned to go in the future, 5 (17%) were noncommittal and 1 (3%) did not answer. See Figure 1.

Follow-up phone calls were completed in 84 patients (93%) with a median interval of 136 days after the initial survey (range 115-185 days.) Of the 30 patients who initially reported that they were advised by their rheumatologist to seek further reproductive health care in the initial survey, only 3 patients did so at the follow-up call. Of the 84 who completed the follow-up call, 30 (36%) had concerns and questions about reproductive health over the past 3 months. Twenty-one patients (25%) reported seeking further information about sex or reproductive health (since their initial visit) from family, internet, friends, school, other doctors, and the rheumatologist. Thirty-one patients (37%) reported seeking further information about their condition or medications (since their visit) from the internet,

rheumatologist, other doctors, family, and information packets. Fifteen patients (18%) reported having ever asked their rheumatology clinic provider for guidance regarding relationships or sex. Eight patients (10%) reported seeking additional reproductive or sexual health services since their visit at Planned Parenthood clinics, family doctors, gynecologists, and school clinics. Only one patient stated that she sought further care based on a rheumatologist's recommendation. Of the 8 patients who sought further reproductive health care, 7 were currently on high risk medications (OR 3.63, 95% CI 0.4 to 31.0.) See Figure 2 for the distribution of patients who expressed health concerns at follow-up, and who actually sought care.

Discussion

This is the first study investigating patient perception of reproductive health counseling and its potential to effect behavior change in a pediatric rheumatology clinic. Our study indicates that a considerable proportion of teen rheumatology patients (42%) have recent reproductive health concerns but few necessarily follow through with a formal visit with a reproductive health care professional when counseled to do so. While teens do acknowledge counseling about reproductive health occurs during these physician-patient interactions, they may not have the know-how to obtain the necessary reproductive health services and interventions. This highlights the potential need for a different counseling tool, a formal referral process, or an additional intervention such as having a combined clinic with adolescent gynecology. Different settings may also be helpful to introduce the subject which may include having parents (mothers) be a part of the counseling process or a confidential peer session to review the information.

Patients taking high risk medications may require extra guidance compared to those not on high risk medications. For example, a new federal mandate in the United States requires that patients prescribed mycophenolate-containing compounds receive reproductive health counseling; however there are no specific guidelines for adolescent rheumatology patients. Changes in guidelines now recommend that screening by Papanicolau (Pap) test should not be used for women aged <21 years, regardless of initiation of sexual activity[16]. This may lower the barrier for pediatric rheumatologists who are comfortable in doing so to prescribe oral contraception and may reduce the need for more than annual gynecological exams from another provider. Making reproductive health discussion a routine process may help open communication and provide better understanding of patient motivation to seek further care. Training in core competencies of contraception counseling as a requirement in pediatric rheumatology fellowship is one way of implementing provider education, as well as potentially including it as a quality improvement initiative for maintenance of certification for rheumatology boards.

Study limitations

This study was limited by small sample size, its exclusion of males, and only enrolling English speaking families. Male patients do need counseling about reproductive health and may require a different intervention than females. Non-English speaking patients of Hispanic and Asian descent who comprise a significant proportion of patients at Stanford

may have different cultural beliefs than the studied population. Patients attending the clinic at Stanford reflect the demographics of Santa Clara County (which includes the city of San Jose), which has a higher median income and higher percentage of Asian and Hispanic populations than other major US cities. Our data may not be generalizable to other metropolitan centers with different demographics (e.g. more African-Americans or lower median incomes) that may have higher likelihood of sexual activity at a younger age but may also have different reproductive health seeking behaviors and resources. For the purposes of this study, data about sexual history, contraception, and information about fertility and gonadal protection were not collected but may be important variables in future research. Respondents potentially knew the interviewer conducting phone calls which could have influenced results as a way to please the investigator.

This observational study demonstrated the importance of reproductive health counseling in pediatric rheumatology. Future studies could include the development of a more standardized and effective counseling tool and referral process. There may also be a role for partnerships with other community service providers, such as adolescent clinics, to facilitate education and services, as well as trying to create a format to include other people in the conversation such as peers and/or parents to reinforce positive behaviors and follow through.

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Significance and Innovations

- This is the first study investigating patient perception of reproductive health counseling and subsequent follow up in a pediatric rheumatology clinic.
- Teen rheumatology patients are a high risk group for adverse reproductive health outcomes.
- Many teen rheumatology patients have recent reproductive health concerns.
- Few adolescent rheumatology patients follow through with a formal visit with a reproductive health care professional.

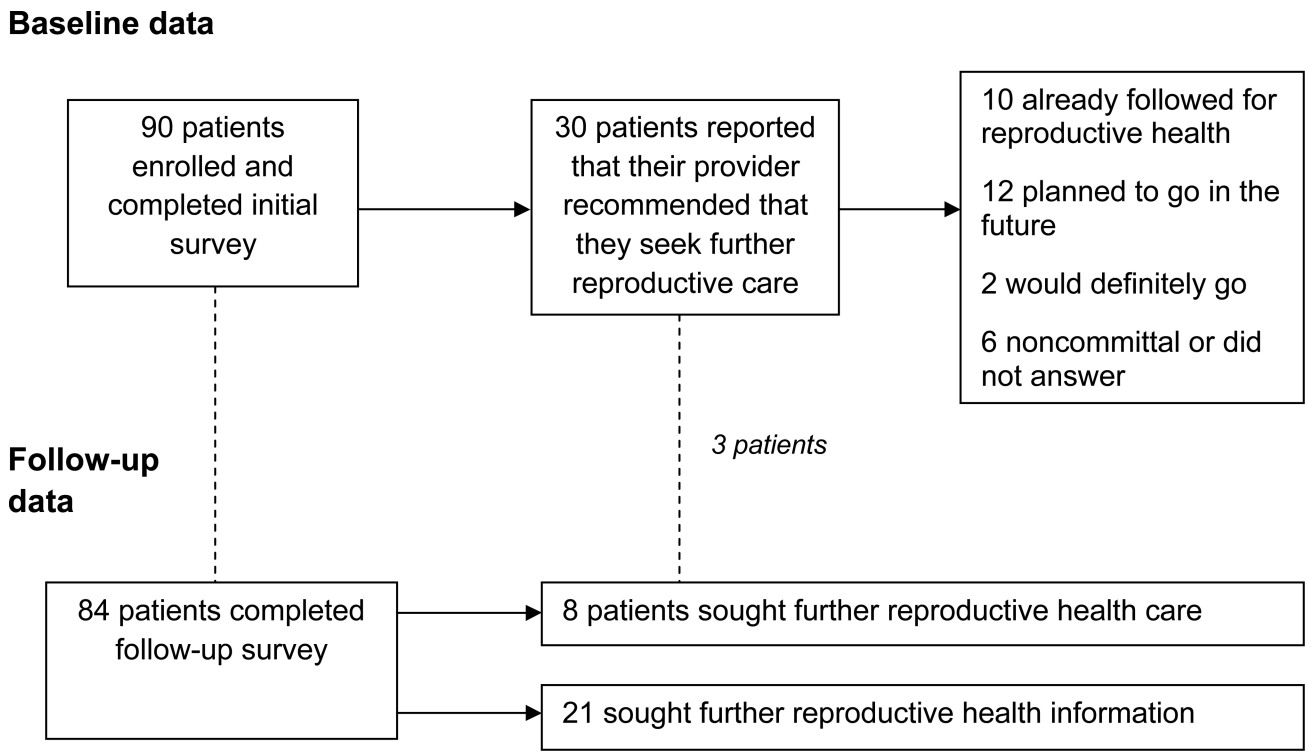

Figure 1. Patient reproductive health seeking

Of the 30 patients who initially reported that they were advised by their rheumatologist to seek further reproductive health care in the initial survey; only 3 patients did so at follow-up. Two of those patients had said that they would plan to go in the future and one had said that they would definitely seek further care.

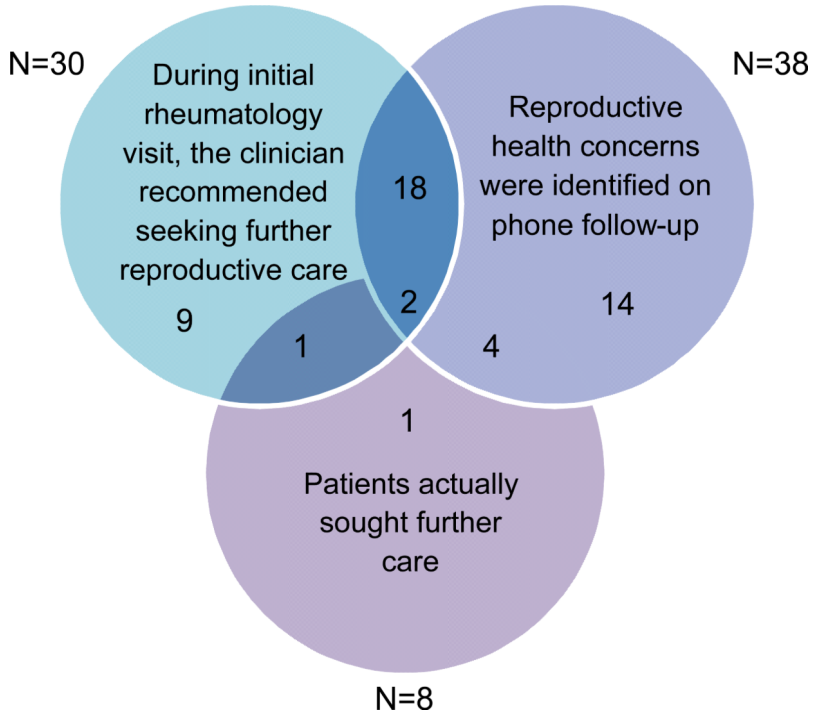

Figure 2. Overlap of patients with reproductive health concerns who sought further care

At the initial visit, 30 patients were recommended to seek further reproductive health care. At follow-up, 3 of these patients actually sought further care while 20 still reported having reproductive health concerns.

Table 1

Reproductive Health Counseling Tool

✓	Discussed need for contraception
✓	Recommended double barrier contraception if sexually active
✓	Discussed adolescents' right to confidential reproductive health care
✓	Risks of pregnancy in context of rheumatic disease
✓	Risks of potentially teratogenic medications:
✓	Need for planning prior to pregnancy in conjunction with medical provider
✓	What to do if worried about being pregnant
✓	Worries about future fertility
✓	Referred: ☐ Adolescent Medicine ☐ gynecologist ☐ PMD ☐ Planned Parenthood

Table 2

Baseline patient characteristics

Patient Characteristics	n	%
Total	90	
Age (SD) (yrs)	17 ± 2	
Diagnosis		
JIA	41	45.6
SLE/MCTD/Sjogren's	36	40
Vasculitis	4	4.4
Juvenile Dermatomyositis	3	3.3
Scleroderma	2	2.2
Other	4	4.4
+ Pain syndrome	15	16.7
Disease duration (SD) (yrs)	5 ± 4	
Race/Ethnicity		
Non-Hispanic white	45	50
Hispanic	22	24.4
Asian/Pacific Islander	18	20
Non-Hispanic black	3	3.3
Unanswered	2	2.2
Insurance status		
Private	70	77.8
Public	20	22.2
Medication use		
Remission off medications	5	5.6
Current high risk medication use	61	67.8
History of high risk medication use	74	82.2
Current high-risk medications		
biologics	21	23.3
mycophenolate	17	18.9
methotrexate	16	17.8
azathioprine	11	12.2
leflunomide	2	2.2
cyclophosphamide	1	1.1
tacrolimus	1	1.1
Development		
Post-menarchal	88	97.8