Leena Nahata*, Sonja I. Ziniel, Katharine C. Garvey, Richard N. Yu and Laurie E. Cohen

Fertility and sexual function: a gap in training in pediatric endocrinology

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Abstract

Background: Infertility and sexual dysfunction result from many different pediatric conditions and treatments and can profoundly impact quality of life. The American Academy of Pediatrics (AAP) has recommended consulting "fertility specialists" for counseling, but it remains unclear who these specialists are. Our objective was to assess whether pediatric subspecialists who manage hypogonadism and/or genitourinary conditions feel adequately trained to provide fertility and sexual function counseling.

Methods: An online survey was distributed to members of Pediatric Endocrine Society (PES), Society for Pediatric Urology (SPU), and North American Society for Pediatric and Adolescent Gynecology (NASPAG). Providers' comfort in counseling various age groups about fertility and sexual function was assessed via a five-point Likert scale. Providers reported whether they felt adequately trained in these areas.

Results: Two hundred and eighty-four surveys were completed by endocrinologists, 124 surveys by urologists, and 41 surveys by gynecologists. Respondents (44% male, 86% Caucasian) represented 39 states and Canada. Seventy-nine percent were at academic centers. Thirty-four percent of providers had been practicing for >20 years. Comfort level was variable and lowest in young males. Ninety-one percent of pediatric endocrinologists reported routinely seeing patients at risk for infertility, but only 36% felt adequately trained in fertility, and 25% felt adequately trained in sexual function.

Conclusions: Infertility and sexual dysfunction are often overlooked in pediatric care. Our results suggest that pediatric endocrinologists, who frequently manage male and female hypogonadism, should also receive formal training in these areas. Optimizing counseling would help prevent missed opportunities for fertility preservation and alleviate distress among patients and families.

Keywords: counseling; fertility; pediatric endocrinology; sexual function.

Introduction

Infertility has a significant and often devastating impact on young men and women who are trying to expand their families [1]. Though infertility and sexual dysfunction have not historically been viewed as pediatric problems, it has become increasingly apparent that many children and adolescents are affected by medical conditions and therapies which may later impair their sexual and reproductive health, including oncologic, hematologic, rheumatologic, gastrointestinal, and renal diseases requiring gonadotoxic therapy, some disorders of sex development, metabolic conditions, and transgender patients receiving cross-sex hormones [2–7]. Due to recent changes in guidelines, there are now established options available for fertility preservation for pubertal males (sperm cryopreservation) and post-menarchal females (oocyte and embryo preservation) [5, 8], but many barriers exist and these methods remain underutilized [9, 10]. When asked, patients and families have ranked fertility as an important life goal and have expressed regret about missed opportunities for preservation due to inadequate counseling [11, 12].

The majority of data with regards to fertility in pediatrics are currently found in the cancer population. Despite increasing awareness about infertility and numerous sets of recommendations, fertility counseling practices among oncologists remain inconsistent [13–16]. Thus, in an effort to standardize counseling and increase the utilization of fertility preservation, the American Society

***Corresponding author: Leena Nahata,** MD, Division of Endocrinology, Nationwide Children's Hospital, 700 Children's Dr. Columbus, OH 43205, USA, Phone: +614-722-4425, Fax: +614-722-4440, E-mail: leena.nahata@nationwidechildrens.org
Sonja I. Ziniel: Center for Patient Safety and Quality Research, Program for Patient Safety and Quality, Boston Children's Hospital, Boston, MA, USA; and Division of Adolescent and Young Adult Medicine, Boston Children's Hospital, Boston, MA, USA
Katharine C. Garvey and Laurie E. Cohen: Division of Endocrinology, Boston Children's Hospital, Boston, MA, USA
Richard N. Yu: Department of Urology, Boston Children's Hospital, Boston, MA, USA

for Reproductive Medicine (ASRM), American Society for Clinical Oncology (ASCO), and the American Academy of Pediatrics (AAP) have recommended referring pediatric patients to a "fertility specialist" for counseling [17, 18]. However, while adults are typically referred to reproductive endocrinologists and/or urologists for fertility evaluations, the term "fertility specialist" remains ill-defined in pediatrics, and recent data show that these referrals rarely occur [15, 19–21].

The goal of this study was to assess comfort level and adequacy of training with counseling children and adolescents about fertility and sexual function in a group of pediatric subspecialists who routinely manage hypogonadism and/or genitourinary disorders and may thus be expected to have expertise in these areas. We chose to survey pediatric endocrinologists, urologists, and gynecologists based on the nature of their training and/or clinical practice. We hypothesized that a significant number of providers would be challenged when counseling young patients about fertility and sexual function and would report inadequate training in these areas.

Materials and methods

Survey instrument and administration

We developed a survey to assess comfort level and adequacy of training among pediatric endocrinologists, urologists, and gynecologists, with counseling patients and families about fertility and sexual function (Supplemental Material). A review of other large survey studies, as well as current literature in fertility, guided development of the survey [21–23]. A survey methodologist reviewed and edited the instrument, and prior to distribution, the survey was tested in cognitive interviews among five pediatric subspecialists (two pediatric endocrinologists, two pediatric urologists, and one pediatric gynecologist) to ensure that questions were understood as intended. Estimated time to complete the survey was 5–10 min. This study was exempt by the Boston Children's Hospital Institutional Review Board (IRB-P00013287).

The first survey question addressed the frequency with which the providers see patients at risk for infertility. Respondents that marked "never" were excluded from the study. The survey was then divided into three major sections. The first section included two vignettes, with one clinical case of a female adolescent with evidence of gonadal dysfunction and one clinical case of a male adolescent with evidence of gonadal dysfunction. Each case was followed by a series of questions about comfort level with counseling male and female patients and parents about fertility and sexual function in different age groups (<13 years, 13–17 years, 18 years and older); providers were given a five-point Likert scale ranging from "very comfortable" to "very uncomfortable". The second section included statements about training ("I have received adequate training about how to discuss fertility with patients and families" and "I would like more guidance about how to discuss fertility with patients and families") and the perceived role of the provider as the "expert" on the topic versus the primary care physician (PCP) or another subspecialist (e.g. "The primary responsibility of counseling pediatric patients and families about fertility and sexual function should be that of the pediatric endocrinologist"), with another five-point Likert scale ranging from "strongly agree" to "strongly disagree". The third section consisted of provider demographics.

The online survey was distributed from August 2014 to February 2015 via email to the listserv (active members) of three national organizations – Pediatric Endocrine Society (PES), Society for Pediatric Urology (SPU), and North American Society for Pediatric and Adolescent Gynecology (NASPAG). A brief description of the survey was included in the invitation email, along with a link to the web survey. No incentive was provided for completion. Based on the standard policies of each organization with regards to provider surveys, one or two email reminders were sent out. Responses were collected anonymously in an effort to maximize response rate.

Statistical analysis

Data analyses were performed using Stata (12.1; StataCorp. LP, College Station, TX, USA). The five-point Likert response scales describing comfort and agreement were dichotomized using the two most positive answer categories as indication of comfort or agreement. The remaining three response categories were seen as indication of discomfort or disagreement. The conclusion of the statistical analyses did not change due to the collapsing of the response categories (analyses not shown). Percentages were used as descriptive statistics to display variable distributions within disciplines. Fisher's exact tests were used to assess differences of responses across disciplines and associations among any other categorical variables.

Results

Sample characteristics

Two hundred and eighty-four surveys were completed by endocrinologists, 124 surveys by urologists, and 41 surveys by gynecologists (response rates 22%, 21%, and 22%, respectively). Respondents represented 39 states in the United States, in addition to Canada. The majority of urologists were male, and most endocrinologists and gynecologists were female. Most of the respondents from PES and SPU reported seeing adults routinely, whereas that was not the case in the NASPAG cohort. A significantly higher percentage of pediatric endocrinologists reported seeing patients at risk for infertility compared to the other two groups. Practice type and race also differed between the provider groups. The remaining characteristics were similar across groups (see Table 1). Approximately one-third of the group as a whole had been practicing for >20

Table 1: Provider characteristics.

Characteristic	Endocrinology, n (%)	Gynecology, n (%)	Urology, n (%)	p-Value
Gender (n = 364)				<0.001
Male	81 (35.7)	4 (10.0)	75 (77.3)	
Female	146 (64.3)	36 (90.0)	22 (22.7)	
Age (n = 364)				0.415
<35 years	34 (15.0)	4 (10.0)	12 (12.4)	
35–45 years	78 (34.4)	19 (47.5)	31 (32.0)	
46–55 years	43 (18.9)	4 (10.0)	24 (24.7)	
56–65 years	38 (16.7)	9 (22.5)	20 (20.6)	
>65 years	34 (15.0)	4 (10.0)	10 (10.3)	
Race (n = 358)				0.018
White, Caucasian	186 (83.0)	38 (95.0)	76 (80.9)	
Black, African American	4 (1.8)	2 (5.0)	1 (1.1)	
Asian and Pacific Islander	28 (12.5)	0 (0.0)	10 (10.6)	
Native American	0 (0.0)	0 (0.0)	0 (0.0)	
Other	6 (2.7)	0 (0.0)	7 (7.4)	
Hispanic ethnicity (n = 363)				0.894
No	214 (94.3)	38 (95.0)	89 (92.7)	
Yes	13 (5.7)	2 (5.0)	7 (7.3)	
Census region of medical practice (n = 323)				0.953
Northeast	27 (12.6)	2 (6.9)	12 (15.2)	
South	47 (21.9)	7 (24.1)	15 (19.0)	
Midwest	82 (38.1)	12 (41.4)	32 (40.5)	
West	59 (27.4)	8 (27.6)	20 (25.3)	
Medical practice type (n = 362)				0.024
Academic medical center	184 (81.1)	30 (75.0)	73 (76.8)	
Community hospital	13 (5.7)	3 (7.5)	2 (2.1)	
Large group practice (six or more physicians)	18 (7.9)	2 (5.0)	11 (11.6)	
Small group practice (five or less physicians)	3 (1.3)	2 (5.0)	8 (8.4)	
Solo practice	6 (2.6)	1 (2.5)	1 (1.1)	
Other	3 (1.3)	2 (5.0)	0 (0.0)	
Practice setting (n = 359)				0.392
Urban	163 (73.1)	35 (87.5)	72 (75.0)	
Suburban	52 (23.3)	4 (10.0)	21 (21.9)	
Rural	8 (3.6)	1 (2.5)	3 (3.1)	
Length medical practice in subspeciality (n = 362)				0.133
<1 year	32 (14.2)	3 (7.5)	10 (10.4)	
1–3 years	28 (12.4)	6 (15.0)	9 (9.4)	
4–6 years	26 (11.1)	2 (5.0)	9 (9.4)	
7–10 years	23 (10.2)	5 (12.5)	16 (16.7)	
11–15 years	24 (10.6)	10 (25.0)	10 (10.4)	
16–20 years	16 (7.1)	0 (0.0)	11 (11.5)	
>20 years	78 (34.5)	14 (35.0)	31 (32.3)	
Fertility program for adolescents/young adults at institution/in clinic (n = 361)				0.093
No	150 (66.7)	25 (62.5)	72 (75.0)	
Yes	44 (19.6)	10 (25.0)	20 (20.8)	
Do not know	31 (13.8)	5 (12.5)	4 (4.2)	
Care routinely provided to patients over 23 years of age (n = 361)				<0.001
No	29 (12.8)	25 (62.5)	22 (23.2)	
Yes	197 (87.2)	15 (37.5)	73 (76.8)	
Frequency of care provided to patients at risk for infertility (n = 374)				<0.001
Never	0 (0.0)	0 (0.0)	0 (0.0)	
Rarely	18 (7.6)	8 (20.0)	19 (19.4)	
Sometimes	133 (56.4)	19 (47.5)	44 (44.9)	
Usually	83 (35.2)	10 (25.0)	28 (28.6)	
Always	2 (0.9)	3 (7.5)	7 (7.1)	

years, one-third had been practicing for 7–20 years, and one-third had completed training <7 years ago.

Factors associated with comfort with counseling

Comfort level with counseling patients and families about fertility and sexual function was lowest in young males across all subspecialties (Table 2). Overall, comfort level was lower with counseling about sexual function than fertility, particularly in the younger age groups. Gynecologists were more comfortable counseling females about both topics than the other providers, and much less comfortable counseling males.

As the breakdown of years of clinical experience was similar in all three provider groups, the association between years of experience and comfort level was examined in the cohort as a whole. Providers who had been in practice for >20 years were significantly more comfortable than the other two groups (those practicing 7–20 years and <7 years) with providing counseling to boys and girls 13–17 years and 18+ years about fertility and sexual function ($p < 0.05$). There was no association found between other demographics such as practice type (e.g. academic versus community center) or routinely seeing patients >23 years of age, and comfort level with counseling. The perception of having received adequate training was positively associated with comfort with counseling in each age group of boys and girls about fertility, as well as sexual function ($p < 0.001$).

Adequacy of training

As shown in Table 3, less than half of pediatric endocrinologists and urologists in this sample felt that they had adequate training to counsel patients about fertility, and all three groups felt inadequately trained to discuss sexual function; the majority of providers in all three groups wanted additional guidance in both areas. Pediatric endocrinologists and urologists felt significantly less trained

Table 2: Providers' comfort with counseling for fertility and sexual function.

	Comfortable or very comfortable with counseling, n (%)			p-Value
	Endocrinology	Urology	Gynecology	
Fertility				
Boys <13 years	136 (57.6)	53 (54.1)	7 (19.4)	<0.001
Boys 13–17 years	178 (75.7)	70 (71.4)	8 (22.2)	<0.001
Boys 18+ years	173 (74.6)	75 (76.5)	10 (27.8)	<0.001
Girls <13 years	154 (66.4)	63 (64.3)	31 (77.5)	0.311
Girls 13–17 years	185 (79.7)	69 (70.4)	34 (85.0)	0.095
Girls 18+ years	184 (79.7)	74 (75.5)	36 (90.0)	0.158
Sexual function				
Boys <13 years	86 (36.6)	43 (44.3)	8 (22.2)	0.063
Boys 13–17 years	137 (58.3)	60 (61.2)	9 (25.0)	<0.001
Boys 18+ years	161 (68.8)	71 (72.5)	8 (22.9)	<0.001
Girls <13 years	93 (41.0)	49 (50.0)	24 (61.5)	0.035
Girls 13–17 years	148 (64.6)	59 (60.2)	33 (82.5)	0.035
Girls 18+ years	168 (73.0)	74 (75.5)	35 (87.5)	0.143

Table 3: Providers' report of training adequacy.

	Agree or strongly agree, n (%)			p-Value
	Endocrinology	Urology	Gynecology	
Fertility counseling				
I have adequate training	83 (35.9)	43 (43.9)	28 (70.0)	<0.001
I need more guidance	173 (74.9)	66 (67.4)	27 (67.5)	0.285
Sexual function counseling				
I have adequate training	57 (24.7)	46 (46.9)	20 (50.0)	<0.001
I need more guidance	172 (74.8)	61 (62.2)	29 (72.5)	0.075

than the gynecologists with regards to fertility counseling, and endocrinologists felt significantly less trained than both urologists and gynecologists with regards to sexual function counseling. In terms of perceived primary responsibility to provide this counseling, responses from the three provider groups were similar, thus the cohort was examined as a whole. Almost half of the respondents thought that the primary responsibility for counseling was that of another pediatric subspecialist or the primary care provider (PCP), as shown in Figure 1.

Discussion

Infertility and sexual dysfunction affect many young men and women worldwide and have a significant impact on quality of life and overall happiness [24–26]. In some cases, these problems result from diseases and treatments experienced in childhood and could potentially be prevented or more optimally addressed. However, topics related to fertility and sexual function are often overlooked or viewed as "private" or "sensitive" and are thus omitted from patient-provider discussions even in the care of otherwise healthy adolescents [27]; additional barriers exist in patients with underlying medical problems [10, 28, 29].

The majority of studies with regards to fertility in pediatrics have been done in the cancer population, with emerging literature in other conditions such as disorders of sex development and rheumatologic/renal diseases. Fertility counseling has been recommended to occur at initial cancer diagnosis [8, 17, 30, 31], and in survivorship to decrease psychological distress and to prevent unintentional pregnancies (in cases where infertility is incorrectly assumed) [32, 33]; however, patients and families consistently report inadequate counseling on this topic [13, 34, 35]. Results of surveys and semi-structured interviews have shown that pediatric oncologists recognize fertility loss as an important topic but may lack knowledge about fertility preservation options and local storage facilities [14, 19], resulting in underutilization of fertility preservation [16, 19, 36]. Similarly, according to a recent national survey, many pediatric nephrologists believe that their patients should be offered a fertility referral, but almost half do not refer due to inadequate training and lack of referral networks [29]. Fewer studies have been done to assess providers' knowledge, attitudes, and behavior with regards to sexual function counseling; a high incidence of sexual dysfunction and dissatisfaction has been shown among childhood cancer survivors, as well as in patients with disorders of sex development [6, 7, 37], and according to one 2009 survey of a group of internists, the majority "never/rarely" addressed sexual function in routine visits with cancer survivors [38]. In 2007, Schover et al. published promising results of a pilot intervention to address reproductive health in adolescents and young adults with cancer, but neither this nor any other intervention has been widely accepted into clinical care [39].

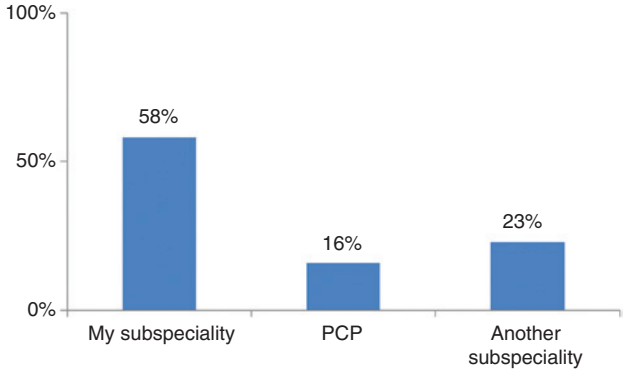

Figure 1: Primary responsibility for counseling.

Recognizing the impact of infertility on quality of life, several organizations such as the AAP have recommended involving a "fertility specialist" for counseling [17]. However, adult urologists and reproductive endocrinologists are not always easily accessible to pediatric providers, prompting us to design this study to assess comfort and training among three groups of pediatric subspecialists who manage hypogonadism and/or genitourinary disorders. Since the majority of respondents in all three provider groups felt that they needed more guidance in both areas, they are unlikely to perceive themselves as experts at this point. Pediatric gynecologists in our study generally felt comfortable discussing these topics with females, but none of the providers felt as comfortable or as well-trained to counsel males, particularly in the younger age groups. In fact, urologists did not report higher comfort levels with counseling males than females. This may, in part, explain why sperm banking rates remain low, despite the fact that it is typically straightforward and non-invasive [35]. Additionally, many centers do not have pediatric gynecologists on staff, which may limit counseling opportunities for females as well.

At this point, multidisciplinary fertility programs at pediatric centers rarely include pediatric endocrinologists. However, pediatric endocrinologists are frequently referred both males and females to manage hypogonadism and routinely prescribe testosterone and estrogen replacement therapies. The scope of their clinical practice is broad, including survivors of cancer and bone marrow

transplantation for a wide range of conditions, as well as patients with gender dysphoria, disorders of sex development, and other genetic or autoimmune causes of hypogonadism. Discussing fertility and sexual function should be an integral component of managing these conditions. Additionally, infertility may even result from treatment prescribed by pediatric endocrinologists, such as cross-sex hormones in transgender patients, necessitating a discussion about risks/benefits. In this study, a significantly higher percentage of the pediatric endocrinologists reported caring for patients at risk for infertility in comparison to the other two provider groups. In fact, almost all of the pediatric endocrinologists who responded to this survey reported "sometimes" or "usually" caring for patients at risk for infertility. It is thus notable that only one-third of pediatric endocrinologists felt adequately trained in fertility (significantly less than the gynecologists), and only one-fourth felt adequately trained to discuss sexual function (significantly less than both of the other provider groups).

This study had several limitations. Twenty-two percent is a relatively low response rate, though not atypical of physician web-based surveys, particularly when there is no incentive [13, 40–42]. We cannot shed light on non-response bias since we did not have access to non-respondent demographics. Additionally, the survey was only distributed to providers that were active members of PES, SPU, and NASPAG, which may limit generalizability of our findings. Further, we did not determine if the pediatric gynecologists who expressed a higher comfort level with these discussions also provided primary care for adolescents, including males, which may have affected responses. One important limitation in the survey itself was that we did not assess the reasons for lack of comfort. For instance, problems could include lack of knowledge and/or discomfort with the sensitive nature of the discussions. This is an area that needs further investigation.

Despite these limitations, we now have a substantial number of responses from providers showing that the term "fertility specialist" in the AAP and other practice guidelines is vague and needs to be better defined, and that formal education and training in these areas are needed. To our knowledge, this is the first study to explore comfort level with fertility and sexual function counseling among pediatric endocrinologists, urologists, and gynecologists. Since inadequate training was noted by the majority of providers overall, it is not surprising that more senior providers (practicing for >20 years) in all three specialties felt more comfortable with counseling on both topics. Currently, pediatric subspecialists may only learn about these topics if they choose to attend related lectures at national conferences or if they repeatedly encounter patients at risk and have an interest and access to more information. Notably, almost half of the practitioners in this study thought that the primary responsibility for providing this counseling may be that of another provider group, such as another subspecialist or the PCP, indicating that at this point, there is no pediatric expert in these areas. Further research is needed to assess comfort with this counseling among general pediatricians and adolescent medicine specialists, as well other types of health care providers such as nurses and social workers, as there may be a role for these groups to become more involved in the initial education of patients about these topics. Additionally, studies should be done in larger provider groups to assess the impact of other demographics (such as religiosity) on comfort with counseling on these topics.

Since awareness about the prevalence and impact of infertility among pediatric disease survivors is increasing, and pediatric endocrinologists are in a unique position to manage both males and females with several different types of conditions that result in infertility, studies should be designed to determine the major gaps in knowledge among pediatric endocrinologists. Additionally, formal education and training about fertility, including conditions that lead to fertility loss, risk assessment, methods of evaluation, and preservation options, as well as management of sexual dysfunction, should be incorporated into pediatric endocrinology fellowship curricula. These topics should be included in pediatric endocrinology textbooks and in creation of educational tools for maintenance of certification and board review. Given that pediatric endocrinologists may not be as familiar with recommendations published by the AAP, ASRM, and ASCO, groups such as PES could consider developing their own guidelines about fertility counseling and preservation; further, the Endocrine Society guidelines for management of transgender youth should include details about fertility counseling [43]. Pediatric endocrinologists should familiarize themselves with local resources, such as storage facilities for oocytes and sperm, as well as local or regional options for experimental procedures such as ovarian and testicular tissue preservation for prepubertal patients or those who cannot undergo oocyte/sperm cryopreservation for other reasons. With this knowledge, pediatric endocrinologists could begin to establish structured fertility programs in many centers where they do not yet exist, and could start functioning as "fertility experts" in pediatric care.

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