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Please Be Careful with Me: Discrepancies between Adolescent Expectations and Clinician Perspectives on the Management of Pelvic Inflammatory Disease

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Abstract

Study Objective: To compare clinician perspectives for the treatment of pelvic inflammatory disease (PID) with those of adolescent patients and parents.

Design: Cross-sectional study.

Setting: Urban academic pediatric and adolescent medicine practices and school-based health clinics in a large urban community with a high prevalence of sexually transmitted infections (STI) and a national sample of adolescent-serving clinicians.

Participants: Female patients aged 12–19, parents raising an adolescent over the age of 12 in the urban community, and clinicians who serve adolescents collected from regional and national listservs.

Interventions: None.

Main Outcome Measures: Visual analog scale (VAS) scores on a scale of 0 to 10 corresponding to preferences on patient disposition in 17 clinical scenarios for a hypothetical patient with PID.

Results: Compared to adolescents, clinicians were significantly more likely to endorse hospitalizations when patients presented with severe or complicated illness (0.9, SE 0.22, p<0.001), possible surgical emergency (0.83, SE 0.2, p<0.001), concurrent pregnancy (0.59, SE

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0.3, p=0.046), or failure of outpatient treatment (0.58, SE 0.29, p=0.045). Compared to clinicians, adolescents were significantly more likely to endorse hospitalizations when patients presented at a young age (1.36, SE 0.38, p<0.001), were homeless (0.88, SE 0.32, p=0.007), were afraid to inform a partner (1.66, SE 0.40, p<0.001), or had unaware parents (2.86, SE 0.39, p<0.001).

Conclusion: Clinicians were more likely to recommend hospitalization when doing so adhered to national guidelines on PID treatment. Adolescents opted for hospitalization more often than clinicians in scenarios where patients exhibited social vulnerability. Clinicians should engage with adolescents in shared disposition planning and use a more nuanced approach to PID management for adolescents who may not be able to tolerate an outpatient regimen.

Keywords

adolescent behavior; attitudes of health personnel; pelvic inflammatory disease; health care surveys; sexually transmitted diseases

Introduction

Pelvic inflammatory disease (PID) continues to be the most common gynecologic cause of emergency department visits in the US, and is responsible for significant long-term complications and morbidity, including tubal factor infertility, ectopic pregnancy, and chronic pelvic pain.^{1–3} Young age is a significant risk factor for the development of PID. Adolescents are the most vulnerable population with over 70,000 annual emergency department visits and a 10-fold increased risk versus a 24-year-old woman. This increased vulnerability is likely secondary to both biologic and behavioral vulnerabilities, including an immature cervix with a larger surface area of columnar epithelium as well as higher rates of unprotected sex and multiple sex partners.^{4–5} In addition, adolescents with PID are more likely to receive suboptimal treatment⁶, have poor adherence to outpatient treatment regimens, and are at high risk for recurrence of PID.^{6–8}

Despite these troubling characteristics of PID in adolescent populations, the current Centers for Disease Control and Prevention (CDC) guidelines on treatment of PID indicate that adolescents, similar to older women with mild to moderate disease, utilize outpatient treatment.⁹ The rationale for these guidelines are based in part on the Pelvic Inflammatory Disease Evaluation and Clinical Health (PEACH) trial, which demonstrated no significant difference between outpatient and inpatient treatment for the endpoints of PID recurrence, chronic pelvic pain, and ectopic pregnancy.¹⁰ The PEACH trial and other similar trials ultimately led to an overall clinician trend toward declining hospitalization for PID over the past few decades in recognition of the cost effectiveness of oral antibiotic regimens.^{6,11} Nevertheless, the PEACH trial had significant participant refusal rates and was not reflective of adolescent outcomes given that the mean age of the adolescent participants less than 20 years of age was 18 (\pm 1.0). Social supports that are often provided to improve adherence among adolescents—such as behavioral interventions, PID-focused education, risk reduction counseling, and peer and family support groups-were also not applied to the inpatient management group. Further, both the outpatient and inpatient arms of the study demonstrated unacceptable long-term outcomes for participants, including recurrence (12.4% vs. 16.6%), chronic pelvic pain (33.7% vs. 29.8%), and infertility (18.4% vs.

17.9%).^{10,11} As such, the current guidelines for PID treatment in adolescents suffer from a dearth of research specific to adolescent populations.

Providers treating adolescents enjoy significant latitude in determining the disposition of PID treatment based on patients' perceived ability to adhere to outpatient treatment.⁹ We have previously shown that providers treating adolescents with PID act largely in accordance with the CDC guidelines; however, we also demonstrated significant variation in clinician perspectives that reflects major inconsistency in both the way adolescents are treated nationally and the manner in which clinicians determine what factors prognosticate poor outpatient treatment adherence.¹² In particular, clinicians appear to struggle over disposition when social factors complicate a patient's ability to adhere to a treatment regimen.¹² In such situations, more explicit guidelines and clinician training catered toward navigating social complications in adolescent-serving pediatric and adult care settings would be valuable, especially if informed by the perspectives of adolescents and parents of adolescents. PID treatment guidelines informed by patient perspectives could help mitigate the currently poor adherence rates that alter the course of disease and therefore likely contribute to the unacceptably high rate of recurrence and complications.¹³ The purpose of this study is to identify discrepancies between clinician perspectives and patient and parent perspectives on the appropriate disposition for adolescents with PID in a variety of social and clinical contexts.

Methods

The methods of this study have been described previously but will be briefly detailed in this section.^{11,12,14} This study was approved by the Johns Hopkins Medicine Institutional Review Board (IRB# NA_00019203). Three groups of participants were recruited in parallel for this study—adolescents, parents of adolescents, and clinicians who treat adolescents between May 6, 2009 and March 15, 2010. Adolescents and parents of adolescents were recruited by trained research assistants from an academic pediatric and adolescent medicine clinic and five school-based health clinics, all of which were situated in an East Coast urban center with significant socioeconomic disparity and a high sexually transmitted infection (STI) prevalence. Participants were excluded from the study if they were unable to speak English or had a cognitive impairment that would interfere with completion of the online survey instrument. Female patients aged 12–19 years were included in the adolescent group. The parent group was broadly defined to include anyone who had raised or was currently raising an adolescent over the age of 12, including biological parents, foster parents, legal guardians, and family members informally involved in parenting (e.g., aunts and uncles). For the clinician group, physicians, nurse practitioners, and physician assistants who serve adolescents were recruited both locally and at national levels via listservs for members of the Society for Adolescent Health and Medicine and the North American Society for Pediatric and Adolescent Gynecology in order to increase the sample size, given the national workforce disparities for adolescent-serving clinicians. All participants were consented prior to accessing the study. Participants received a \$5 remuneration for completing the survey.

A web-based platform built and run on secure server for data management was used to administer a survey with the assistance of research staff to patients and parents in the clinical

settings where they were recruited. Interested clinicians who met the criteria were able to participate by clicking into the study website and completing the survey. Participants in the study initially completed a demographic survey. They also completed a contingent valuation survey with time trade-offs to establish health utilities for the five health states related to PID and willingness to pay for different types of follow-up care. The data from these sections was used in other studies. Participants were then presented with this prompt related to treatment options:

"Now we are going to ask your opinions on the treatment options for pelvic inflammatory disease (PID). Patients who are treated in the hospital usually stay for antibiotics by vein (through an IV) for 24–48 hours. After she goes home she will take antibiotics by mouth at home for the remaining 2 weeks. Patients treated at home receive antibiotics by mouth for 14 days and are asked to return to the doctor's office within 72 hours for reevaluation. There are many reasons why a doctor may suggest treatment in the hospital instead of being treated at home. There are also many reasons why patients may want or need to be treated in the hospital or at home. Please indicate how strongly you feel [you/your daughter/your patient] should be admitted in the following situations:"

Participants were then asked to indicate their preferences on patient disposition for a variety of different clinical factors that could potentially affect adolescent adherence to selfmanagement recommendations by clicking and dragging a visual analog scale (VAS) from 0 (definitely treat at home) to 10 (definitely admit to the hospital). The 17 clinical factors were divided into five categories: adherence to CDC guidelines (severe or complicated illness, possible surgical emergency, concurrent pregnancy, failure of outpatient treatment); vulnerability (age less than 15 years, developmental delay); personal barriers (fear of informing partner, unwillingness to take prescribed medications); practical barriers (lack of transportation, inability to follow up in 72 hours, lack of insurance, homelessness); and risk status (recent surgical procedure, previous PID, increased risk of pregnancy, increased risk of STIs, unaware parents). This analysis focuses on the differences in treatment options related to PID across participant types. The mean scores for each scenario were ranked and plotted according to participant group, and the p-value for the differences in group means for each scenario was calculated using one-way analysis of variance (ANOVA). Pairwise linear regression analyses were then used to compare perspectives between adolescents, parents of adolescents, and adolescent-serving clinicians.

Results

The study team enrolled 134 adolescents, 121 parents, and 108 clinicians (Table 1). The adolescents were majority non-white (87.1%) and had a mean age of 16 years old (\pm SD 1.74). A minority of the adolescents were Hispanic (4.5%), employed (23.1%) or had children of their own (8.2%). The majority of the parents included in the study were female (89%), non-white (72.3%), and employed (76%) with a median income of \$45,000. A minority of parents were Hispanic (3.3%). The majority of clinicians included in the study were female (83.3%), white (71%), and had children (71%). Eighty-four percent of the clinicians were physicians and 82% had pediatric training (e.g., pediatric residency training,

pediatric and adolescent gynecology training, or pediatric nurse practitioner certification) (Table 1). There was statistically significant variance in 12 of the 17 scenarios between the group means of the adolescents, parents, and clinicians (Table 2). Of the 12 scenarios with statistically significant variance, in 6 scenarios the group means for adolescents and clinicians fell on opposite sides of the halfway point (mean VAS = 5); those scenarios included when patients were afraid to inform their partner, lacked transportation, lacked insurance, were at increased risk of pregnancy, were at increased risk of UTIs, or had unaware parents (Table 2).

Of the three pairings (adolescent-clinician, adolescent-parent, parent-clinician), parents and clinicians were most in agreement on appropriate disposition, with statistically significant differences in 5 of the 17 described scenarios (Table 3). Clinicians more strongly endorsed inpatient care than parents for pregnant patients (β =-0.88, p=0.01) and patients failing to improve (β =-0.60, p=0.043). Parents were more likely to opt for inpatient treatment than clinicians in situations where the patient was afraid to tell her partner (β =1.13, p=0.007), was likely to develop another STI (β =1.93, p<0.001), or had not informed her parents (β =2.01, p<0.001).

Adolescents and parents differed in management in 8 of the 17 scenarios. Adolescents were more likely than parents to endorse inpatient care for patients who declined medication (β =1.14, p<0.001) or were likely to get another STI (β =1.90, p<0.001). Parents, on the other hand, were more likely to endorse inpatient management in cases where the patient had a possible surgical emergency (β =-0.59, p=0.003), was unable to follow up in 72 hours (β =-1.64, p<0.001), had a severe illness (β =-0.57, p=0.019), was uninsured (β =-1.62, p<0.001), had a developmental delay (β =-0.81, p=0.033), or had no transportation (β =-1.79, p<0.001). (Table 3)

Perspectives between adolescents and clinicians were the most misaligned of the three pairings, with statistically significant differences in 15 of the 17 scenarios. Clinicians were more likely to opt for inpatient care in settings where the patient presented as a possible surgical emergency (β =-0.83, p<0.001), was concurrently pregnant (β =-0.59, p=0.046), was not improving (β =-0.58, p=0.045), was unable to follow up in 72 hours (β =-2.02, p<0.001), had severe illness (β =-0.90, p<0.001), was uninsured (β =-1.19, p=0.006), or lacked transportation (β =-2.02, p<0.001). Conversely, adolescents were more likely to endorse inpatient treatment than clinicians in scenarios where the patient was under the age of 15 (β =1.36, p<0.001), was previously diagnosed with PID (β =0.91, p=0.019), was likely to get pregnant (β =0.64, p=0.025), was afraid to tell her partner (β =1.66, p<0.001), was likely to develop another STI (β =3.84, p<0.001), was homeless (β =0.88, p=0.007), or had not informed her parents (β =2.85, p<0.001).

Discussion

Our findings demonstrate that while clinicians and parents had relatively well aligned perspectives on hospitalization, a striking divide existed between the perspectives of adolescents and clinicians. While all three groups were likely to recommend hospitalization in scenarios where doing so complied with CDC guidelines, the scenarios in which the

group means of adolescents and clinicians fell on opposite sides of the halfway point involved social issues complicating care, indicating that clinicians and adolescents on balance disagreed on how to handle those patient scenarios. In a previous study, we noted that clinician perspectives on the role of hospitalization for adolescents with PID largely aligned with CDC guidelines on treatment, with overall higher VAS scores assigned to those scenarios versus declining VAS scores assigned to social factors that might complicate outpatient treatment, suggesting lack of consensus on how to manage disposition in those situations.¹² That trend seemed to hold true throughout our pairings, with clinicians demonstrating a greater inclination to hospitalize patients in scenarios in accordance with CDC guidelines when compared with both parents and adolescents. Notably, clinicians were more likely than adolescents to push for hospitalization in the majority of scenarios that posed concrete, practical barriers to follow up, such as lack of insurance or transportation.

Conversely, the situations in which parents or adolescents were more likely to support hospitalization than clinicians universally involved social factors that did not necessarily constitute a concrete barrier to outpatient treatment but which increased the overall vulnerability or risk status of the patient in question. The observed differences may have resulted from the increased understanding of PID that resulted from the exercises that a general population of adolescents and parents who were naive to PID as a common diagnosis engaged in before completing the VAS for disposition. It is unlikely that concerns about confidentiality were driving adolescents' to desire for more cautious care, but rather a focus on ensuring optimal outcomes after PID. Clinicians may have been less affected by any knowledge gains from the exercises with strict adherence to the CDC guidelines regardless of the complex social issues presented in the VAS scenarios. Evidently, potential consumers of PID treatment seem to favor increased clinical support of patients in vulnerable situations via hospitalization, especially in situations where social isolation or high-risk behavior complicate a patient's ability or willingness to seek out treatment.

To our knowledge, this study is the first to compare perspectives of clinicians and potential consumers of PID treatment on the appropriate setting for adolescent care. The current rates of complications and recurrence of PID are unacceptably high.^{15,16} This study identified a discordance between provider and consumer perspectives on whether or not to hospitalize patients with social factors complicating their ability to seek out care; that discrepancy may play a significant role in why current outpatient treatment regimens are not optimized to prevent sequelae of PID. While hospitalizing every patient with PID for treatment is simply not a cost-effective paradigm, nor is a short hospitalization a panacea for the myriad of social factors that would interfere with long-term adherence, it is evident from our results that clinicians should work with patients and parents during disposition planning in a model of shared decision-making in order to identify adolescents who would be less likely to successfully complete an outpatient regimen.^{17,18} By directly identifying those patients with PID who may feel more vulnerable (i.e., those who desire hospitalization), we will be able to develop clearer guidelines surrounding treatment of adolescents with PID. It may also facilitate development of novel, targeted interventions designed to bolster treatment completion in the outpatient setting and reduce the incidence of long-term sequelae.

Our findings must be considered in light of several general limitations. First, its generalizability is limited because adolescent and parent participants were collected from a single urban center between 2009 and 2010; as such, the results may not be applicable to other settings or representative of current perspectives. Nevertheless, PID disproportionately affects young women in urban centers as well as those with low socioeconomic status and the CDC guidance for treatment has not significantly changed since this time, so our study may be applicable to populations of adolescents with PID who are also historically subject to STI health disparities.^{13,19} Additionally, we had a relatively low survey completion rate from clinicians (51%), who may have been deterred by the extensive nature of the time trade-off aspects of the survey.¹² The clinician population was also collected at both local and national levels to assess clinician perspectives generally, whereas our parent and patient samples were only collected locally, thus limiting regional variation in PID treatment preferences. Furthermore, our study enrolled female adolescents regardless of personal history of PID and is more reflective of the general population of health care utilizers in urban communities. However, because PID is a contractible disorder that is fairly common, the general population has valuable insight as a pool of potential patients. The general population perspective is also preferred over that of strictly individuals affected by the disorder for public policy decisions in similar fields such as health economics, because it more neutrally considers resource utilization in resource-limited environments.²⁰ Finally, the results of the study are based on hypothetical scenarios rather than in the setting of actual clinical decision-making; the adolescent and parent arms will likely have spent less time contemplating PID or issues of disposition than the clinician arm and their predicted preferences may not reflect actual preferences if they were truly found in the above scenarios.

Previous researchers have identified alternative dispositions for treatment that lie between liberalized outpatient therapy and costly inpatient therapy that may prove to be effective and cost-efficient solutions, such as emergency department observation units or community health nurses.^{15,21} Previous research in other contexts has also demonstrated that home interventions improve utilization of health care and the use of text messaging has also shown promising efficacy in improving adherence to medication regimens, particularly in adolescent populations.^{22–24} Useful interventions for improving treatment adherence for PID would likely involve repeat contact with a health care provider in some format beyond the original diagnostic visit. Given the disparate perspectives of clinicians and adolescents in our study, further research is necessary to identify alternative solutions for social complications that worsen long-term outcomes for adolescents with PID, particularly those utilizing cost-effective strategies developed with input from the adolescent communities they intend to benefit.

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Table 1.

Selected Participant Characteristics

	Clinician (N=102)	Parent (N=121)	Adolescent (N=134)	
Mean Age (s.d.)	44.88 (9.96)	42.60 (10.66)	16.16 (1.74)	
Median Age (IQR)	44.0 (16)	42.00 (14)	16.00 (2)	
Gender N (%)				
Female	85 (83.3) 108 (89.3)		134 (100)	
Male	17 (16.7)	13 (10.7)	0 (0)	
Marital Status N (%)				
Single	16 (15.7)	44 (36.4)	131 (97.8)	
Married	78 (76.5)	57 (47.1)	0 (0)	
Divorced	1 (1.0)	9 (7.4)	0 (0)	
Widowed	0 (0)	4 (3.3)	0 (0)	
Separated	1 (1.0)	5 (4.1)	0 (0)	
Partnered/Cohabitating	6 (5.9)	2 (1.7)	3 (2.2)	
Ethnicity N (%)				
Hispanic	1 (1.0)	4 (3.3)	6 (4.5)	
Non-Hispanic	96 (94.1)	102 (84.3)	91 (67.9)	
No Answer	5 (4.9)	15 (12.4)	37 (27.6)	
Race N (%)				
Am Indian/A. Native	0 (0)	1 (0.8)	1 (0.8)	
Asian	3 (2.9)	1 (0.8)	5 (3.7)	
Black	11 (10.8)	81 (66.9)	102 (76.1)	
White	83 (81.4)	33 (27.3)	17 (12.7)	
Mixed Race	1 (1.0)	3 (2.5)	7 (5.2)	
Not available	4 (4.0)	2 (1.7)	2 (1.5)	
Parenting Status				
Are you a Parent (based on parity)?				
Yes N(%)	72 (70.6)	118 (97.5)	11 (8.2)	
No N(%)	30 (29.4)	3 (2.5)	123 (91.8)	
Age of Oldest Child	15.36 (10.21)	20.40 (9.28)	2.22 (1.99)	
Mean (s.d.)				

Table 2.

Mean VAS score and standard deviation by scenario.

Patient Scenario	Clinicians (SD)	Parents (SD)	Adolescents (SD)	p-value*
Severe/complicated illness	9.74 (1.10)	9.40 (1.57)	8.84 (2.24)	<0.001
Possible surgical emergency	9.71 (1.22)	9.46 (1.39)	8.87 (1.79)	<0.001
Concurrent pregnancy	8.86 (1.84)	7.98 (3.14)	8.27 (2.71)	0.046
Outpatient treatment failure	8.89 (1.81)	8.29 (2.61)	8.31 (2.60)	0.112
Age <15 years	6.49 (2.68)	7.25 (3.48)	7.85 (3.07)	0.004
Developmental delay	7.42 (2.23)	7.88 (2.84)	7.07 (3.19)	0.074
Afraid to inform partner	4.07 (2.46)	5.20 (3.74)	5.72 (3.70)	0.001
Unwilling to take medications	8.29 (2.36)	7.79 (3.14)	8.93 (1.87)	0.001
Lacks transportation	6.08 (2.67)	5.85 (3.68)	4.06 (3.96)	<0.001
Unable to follow up in 72 hours	7.13 (2.52)	6.75 (3.37)	5.11 (3.87)	<0.001
Lacks insurance	5.36 (2.87)	5.79 (3.71)	4.17 (3.75)	0.001
Homeless	7.78 (2.48)	8.00 (3.05)	8.66 (2.42)	0.028
Surgical procedure in last 2 weeks	8.18 (1.99)	8.43 (2.50)	7.99 (2.78)	0.36
Previous PID	6.18 (2.48)	6.64 (3.51)	7.08 (3.41)	0.1
Increased risk of pregnancy	4.47 (2.14)	4.93 (3.66)	5.44 (3.43)	0.069
Increased risk of STIs	4.31 (2.41)	6.25 (3.40)	8.15 (2.47)	<0.001
Unaware parents	3.98 (2.49)	5.99 (3.55)	6.83 (3.50)	<0.001

* P-value based on one-way ANOVA.

Table 3.

Pairwise linear regression outcomes for VAS rankings by adolescents, parents, and clinicians.

Patient Scenario	Adolescent-Clinician		Adolescent-Parent		Parent-Clinician	
	Beta(se)	p-value*	Beta(se)	p-value*	Beta(se)	p-value*
Severe/complicated illness	-0.90(0.22)	<0.001	-0.57(0.24)	0.019	-0.33(0.18)	0.066
Possible surgical emergency	-0.83(0.20)	<0.001	-0.59(0.20)	0.003	-0.24(0.17)	0.164
Concurrent pregnancy	-0.59(0.30)	0.046	0.29(0.37)	0.44	-0.88(0.34)	0.01
Outpatient treatment failure	-0.58(0.29)	0.045	0.02(0.33)	0.941	-0.60(0.30)	0.043
Age <15 years	1.36(0.38)	<0.001	0.60(0.41)	0.145	0.76(0.41)	0.067
Developmental delay	-0.35(0.35)	0.327	-0.81(0.38)	0.033	0.46(0.34)	0.174
Afraid to inform partner	1.66(0.40)	<0.001	0.53(0.47)	0.261	1.13(0.42)	0.007
Unwilling to take medications	0.64(0.28)	0.025	1.14(0.33)	<0.001	-0.50(0.37)	0.175
Lacks transportation	-2.02(0.43)	< 0.001	-1.79(0.48)	<0.001	-0.23(0.43)	0.594
Unable to follow up in 72 hours	-2.02(0.42)	<0.001	-1.64(0.45)	<0.001	-0.38(0.40)	0.343
Lacks insurance	-1.19(0.43)	0.006	-1.62(0.47)	<0.001	0.43(0.44)	0.33
Homeless	0.88(0.32)	0.007	0.66(0.35)	0.057	0.22(0.37)	0.56
Surgical procedure in last 2 weeks	-0.19(0.31)	0.538	-0.44(0.33)	0.18	0.25(0.30)	0.401
Previous PID	0.91(0.38)	0.019	0.45(0.43)	0.305	0.46(0.40)	0.254
Increased risk of pregnancy	0.97(0.36)	0.008	0.51(0.45)	0.249	0.46(0.39)	0.25
Increased risk of STIs	3.84(0.32)	<0.001	1.90(0.38)	0.001	1.93(0.39)	<0.001
Unaware parents	2.86(0.39)	<0.001	0.84(0.44)	0.059	2.01(0.41)	<0.001

* Significance determined by p<0.05.