Comfort of General Internists and General Pediatricians in Providing Care for Young Adults with Chronic Illnesses of Childhood

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BACKGROUND: As an increasing number of patients with chronic conditions of childhood survive to adulthood, experts recommend that young adults with chronic conditions transfer from child-focused to adult-focused primary care. Little, however, is known about how comfortable physicians are caring for this population.

OBJECTIVES: To assess the comfort of general internists and general pediatricians in treating young adult patients with chronic illnesses originating in childhood as well as the factors associated with comfort.

PARTICIPANTS: In a random sample, 1288 of 2434 eligible US general internists and pediatricians completed a mailed survey (response rate = 53%).

METHODS: We measured respondents' comfort level in providing primary care for a patient with sickle cell disease (SCD) or cystic fibrosis (CF). We also measured levels of disease familiarity, training and subspecialty support, as well as individual physician characteristics.

RESULTS: Fifteen percent of general internists reported being comfortable as the primary care provider for adults with CF and 32% reported being comfortable providing primary care for adults with SCD, compared with 38% of pediatricians for CF ($p<.001$) and 35% for SCD ($p>0.05$). Less than half of general internists felt that their specialty should take primary care responsibility for adult patients with CF and SCD.

CONCLUSIONS: A majority of general internists and pediatricians are not comfortable providing primary care for young adults with chronic illnesses of childhood origin, such as CF and SCD. Efforts to increase treatment comfort among providers may help with the transition to adult-focused care for the growing numbers of young adults with complex chronic conditions.

KEY WORDS: transitional care; cystic fibrosis; sickle cell disease; young adults; adolescents; children with special health care needs; primary care; childhood diseases; health care transitions.

Abbreviations

CF	cystic fibrosis
PCP	primary care physician
SCD	sickle cell disease

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BACKGROUND

Advances in medical treatments for patients with chronic conditions previously fatal in early childhood (e.g., cystic fibrosis (CF), sickle cell disease (SCD) and complex congenital heart disease) have extended life expectancies to 30 years and beyond.[1–4] Consequently, the prevalence of chronic illness among young adults is increasing.[5] Approximately 30% of children have a chronic condition and almost one half of these children have significant health care needs requiring higher health care utilization.[6,7] To effectively meet the needs of the growing adult population with chronic conditions of childhood origin, several professional societies have advocated formal "transitioning," defined by Blum as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems."[8] In 2002, the American Academy of Pediatrics, the American College of Physicians—American Society of Internal Medicine, and the American Academy of Family Physicians released a consensus statement stating that "All adults with special health care needs deserve an adult focused primary care physician."[9] This recommendation specifies that the transitioning process should start by age 14.[9]

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Little is known about how prepared and comfortable adult-trained primary care providers are in treating adults with chronic illnesses of childhood origin. The aim of our study was to assess general internists' and general pediatricians' comfort in providing care to adult patients with chronic illnesses of childhood origin and to identify factors associated with treatment comfort.

METHODS

Data Source

Between October 2005 and March 2006, we conducted a national mailed survey of a random sample of internists and pediatricians identified through the American Medical Association Masterfile. We sampled physicians who reported their primary profession as general internal medicine or general pediatrics and reported providing "direct patient care." To minimize sampling those who may be retired, we excluded physicians over 65 years of age. We also excluded physicians affiliated with the Veterans Health Administration or other government-based practices and those who reported a primary research appointment.

A total of 3000 surveys (1500 to internists and 1500 to pediatricians) were sent in the first mailing, together with a $5 cash incentive. We followed with two additional mailings to non-respondents. We also telephoned the offices of persistent non-respondents to verify the information included in the AMA Masterfile. Physicians were randomly assigned to receive one of two survey versions: one with a clinical vignette involving a patient with CF and another with a nearly identical patient with SCD (see Appendix for vignette text). IRB approval was obtained through the University of Michigan Medical School Institutional Review Board for Human Subjects Research.

Conceptual Framework

Items for the survey were developed from previous studies that examined primary care for multiple disease states.[10–15] We utilized a conceptual framework that centered on how comfortable physicians felt treating a specific disease (hereafter referred to as 'physician treatment comfort'). Treatment comfort is a necessary component of readiness and willingness to provide care, as previous studies have shown that provider treatment comfort alters physician treatment and referral patterns.[16–18] We hypothesized that factors such as physician experience (e.g., treating specific conditions during residency and practice), physician characteristics (e.g., board certification, years in practice), practice characteristics (e.g., practice type) and available resources (e.g., access to disease center, services such as social work or nutrition, and subspecialists) would be associated with physician treatment comfort.[19–21] We also hypothesized that internists with higher treatment comfort would be more willing to accept responsibility for primary care delivery of young adults with childhood onset chronic conditions.

Treatment Comfort and Primary Care Physician Delegation

At the beginning of the survey, we provided the Institute of Medicine definition of primary care: "Primary care is the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."[22] To determine the physicians' treatment comfort, we asked physicians to what extent they agreed with the following statement: "I would be comfortable being the PCP for young adult patients (17–25 years of age) with these chronic conditions." Agreement was measured on a 6-point Likert-type response scale ranging from 1 = strongly disagree to 6 = strongly agree. Physicians were also asked to what extent particular barriers (e.g., insufficient training, time during office visits, access to specialists) limited their ability to provide high quality primary care for young adults with chronic illnesses of childhood origin. Degree of limitation was rated on a 6-point scale, from 1 = significant limitation to 6 = no limitation.

We assessed respondents' beliefs regarding the best PCP (primary care delegation) for an 18-year-old patient with CF or SCD. After reading a clinical vignette about a hypothetical patient with CF or SCD, respondents were asked, "Who would be the best primary care provider for this patient?" Response choices included pediatric generalist, pediatric subspecialist (pulmonologist or hematologist), adult generalist, adult subspecialist (pulmonologist or hematologist), or other.

Factors Associated with Treatment Comfort and Primary Care Physician Delegation

To measure experience in treating patients with CF and SCD, physicians were asked the number of patients with these diseases they had treated during residency and in subsequent clinical practice (none, 1–10, >10 patients). We also determined physician years in practice, gender, and patient care hours per week. Questions on practice structural characteristics included practice type (solo/2 person, single specialty, multispecialty, hospital-based, community-based practice). Physicians were asked about access to specific resources often found in specialized disease centers (social work, pain center, occupational/physical therapy, care coordination and mental health), as well as direct access to specialized disease centers for CF and SCD. Resources were measured by asking if a resource was not available, available but not easily accessible, or available and easily accessible. Resources available and easily accessible were then summed to generate a composite resource score ranging from 0 to 6.

ANALYSES

We compared characteristics and views of internists and pediatricians using bivariate statistics. We performed two sets of multivariate logistic regression models which were stratified by specialty to account for the possibility of other unmeasured specialty-specific characteristics that may mediate comfort. In the first set of models (models 1–4), we assessed factors associated with treatment comfort. Our dependent variable was comfort level in providing primary care to patients with CF (models 1 and 2) and with SCD (models 3 and 4). Respondents who agreed or strongly agreed that they would be comfortable providing primary care for these patients were categorized as being comfortable, and all others as not comfortable. We chose this cut point for dichotomization to characterize those respondents who were definitely comfortable. The results from subanalyses using other cut points were similar to those presented. Independent variables included physician age, gender, years in practice, practice type, and level of experience with patients with the relevant chronic conditions in residency and in practice.

In the second set of models, we examined whether treatment comfort was associated with primary care physicians' views on whether an adult-focused generalist provider was best suited to provide care for young adults with either CF or SCD. The dependent variables were belief that an adult-focused generalist physician should provide primary care to a patient with CF or SCD ("primary care delegation"). The main independent variable in each model was treatment comfort for the specific condition (treated as a linear variable). In a sensitivity analysis, we included in models all the physician and practice variables examined in models 1–4. All analyses were performed using STATA 9.1 (Stata Corporation; College Station, TX, USA).

RESULTS

Response Rate

Out of 3000 physicians initially sampled, 421 physicians were determined ineligible (non-working address, died, retired, or not practicing primary care). We were unable to verify eligibility for 470 of the non-respondents. Assuming the proportion of eligible physicians was the same among those we were and were not able to contact,[23] our final eligible sample size was 2434, of which 1288 responded, leading to an overall response rate of 53%. Most questions had approximately 1%–4% missing responses, with 1.7% missing in our main dependent variables. Patient care hours had the largest percentage missing at 7.9%. Any variation in the total n listed in the tables compared to the overall response rate is due to missing values for those particular questions.

Overall, pediatricians had a higher response rate (58%) than internists (42%; p<0.001). There was no difference between years in practice, age, or board certification between respondents and non-respondents among internists (Table 1). Women had a higher response rate than men among internists (48% vs. 41%, p=0.02). Among pediatricians, respondents were slightly younger than non-respondents (mean age 49.1 vs. 50.4 years, p<0.01) and had fewer years out of training (18 vs. 21 years, p<0.001).

Respondent Characteristics

Internist respondents were more likely than pediatrician respondents to be men and to be in solo practice (Table 2). Internists were less likely to report easy access to specialized disease centers for CF and SCD, compared with their pediatric colleagues (Table 2), but more likely to report easy access to subspecialists and a higher mean resource score (3.9 versus 3.2, p<0.001). Internists had less experience with patients with CF and SCD, in both residency training and practice

Comfort and Primary Care Delegation

Internists and pediatricians were similarly comfortable in being the PCP for 17–25 year old patients with SCD, but less comfortable being the PCP for patients with CF and congenital heart disease (Table 3). Both internists and pediatricians were more comfortable treating patients with common diseases, such as asthma and hypertension, than treating patients CF and SCD. Internists were significantly more comfortable than pediatricians treating young adults between the ages of 17–25 with hypertension, diabetes, depression and chronic pain.

About one-half of the general pediatricians reported that a pediatrician (generalist or specialist) should be delegated primary care responsibility for an 18-year-old young adult with CF or SCD (Table 4). Conversely, over 80–90% of internists thought an adult-focused provider (generalist or specialist) should take responsibility for the primary care needs of an 18-year-old young adult with CF or SCD. Internists were equally divided as to whether the primary care functions would be best served by an adult-focused generalist or an adult-focused specialist. (Table 4).

Internists were more likely than pediatricians to report that insufficient training severely or significantly limited their ability to provide care to young adults aged 17–25 with chronic illness (24% vs. 12%, p<0.001). Pediatricians were more likely than internists to report barriers due to insufficient time during office visits (33% vs. 42%, p<0.01), insufficient mental healthcare support (28% vs. 52%, p<0.001) and insufficient social work support (20% vs. 28%, p<0.01). Insufficient availability of specialists was identified as a barrier by few internists (12%) or pediatricians (10%).

Factors Associated with Comfort and Primary Care Delegation

Experience treating a larger number of patients with CF in practice was associated with higher treatment comfort for both internists and pediatricians (models 1 and 2, Table 5). In contrast, experience with CF during residency was not associated with comfort for CF for either group. Similarly, experience treating a higher number of patients with SCD in practice was associated with higher treatment comfort for both internists

Table 1. Respondent Versus Non-respondent Characteristics Based on AMA Masterfile Data

	Internist*			Pediatrician*		
	Respondent N=537	Non-respondent N=724	P value	Respondent N=751	Non-respondent N=584	P value
Mean age in years (SD)	49.5 (8.4)	49.9 (8.3)	0.3	49.1 (8.9)	50.4 (8.8)	0.005
Female n (% female within response category)	163 (30)	178 (25)	0.02	383 (51)	275 (48)	0.2
Board certified n (%)	461 (86)	626 (86)	0.8	706 (94)	516 (88)	<0.001
Years out of training (SD)	18.6 (14.3)	19.8 (14.6)	0.1	18.4 (11.6)	20.7 (15)	0.002

*numbers reported are based on cohort prior to CASRO adjustment[25]

Table 2. Respondent Characteristics Based on Self-report

	Internists* N=515	Pediatrician* N=751	P value
Mean age (SD)	49 (9)	48 (9)	0.3
Female n (%)	156 (31%)	362 (50%)	<0.001
Mean years in practice (SD)	17 (9)	17 (9)	0.5
Mean hours a week worked in practice (SD)	33 (14)	34 (12)	0.3
Board certified n (%)	474 (92%)	719 (96%)	0.006
Practice setting n (%)			
Solo/2 physician	188 (38%)	150 (21%)	<0.001
Group practice (single or multi specialty or HMO)	233 (47%)	473 (66%)	<0.001
Hospital-based	44 (9%)	57 (8%)	0.6
Other	30 (6%)	38 (5%)	0.6
Listed subspecialty board/field	65 (13%)	53 (7%)	<0.001
Proportion having treated CF in residency	78%	96%	<0.001
Proportion having treated SCD in residency	94%	99%	<0.001
Proportion having treated CF in practice	39%	76%	<0.001
Proportion having treated SCD in practice	57%	70%	<0.001
Proportion with CF center easily available	18%	67%	<0.001
Proportion with SCD center easily available	15%	63%	<0.001
Hematologist (available and easily accessible)	89%	87%	0.2
Pulmonologist (available and easily accessible)	90%	82%	<0.001
Mean resource score† (SD)	3.9 (1.7)	3.2 (1.6)	<0.001

*Numbers are based on those who answered these questions on the survey

†Scaled resources were comprised of having available and easily accessible: coordinator for community resources, nutritionist, pain clinic, physical/occupational therapy, mental health services and social work

and pediatricians (models 3 and 4, Table 5). However, experience with a larger number of SCD patients in residency was also associated with increased treatment comfort for internists but not for pediatricians (model 3, Table 5).

Higher treatment comfort among internists was, in turn, significantly associated with delegating to an internist primary care responsibility for patients aged 18 with CF (OR 1.3, 95% CI [1.1, 1.6]) and for those with SCD (OR 1.8 CI [1.5, 2.5]). These results were unchanged after adjusting the models for physician gender, physician age, resources, patient care hours, years in practice, exposure to patients with the disease in question, disease center, subspecialist availability and practice type.

DISCUSSION

Current recommendations from internal medicine, family medicine and pediatric specialty societies encourage the involvement of primary care physicians in the health care of young adults with childhood-onset chronic illness and the transition of young adults to adult-oriented physicians. In this study, 80–90% of internists agreed with national recommendations that primary care should be delivered by an adult-oriented physician.[9] Yet, only 15–32% of internists reported that they themselves were comfortable as the PCP for a young adult patient aged 18 with CF or SCD, respectively. Given this low comfort level, it is perhaps not surprising that about one-

Table 3. Proportion of Physicians Who Report Agreeing or Strongly Agreeing to the Statement, "I Would Be Comfortable Being the Primary Care Provider for Patients with the Following Conditions"†

	Internists* N=509	Pediatricians* N=739	P value
Hypertension	91%	31%	<0.001
Asthma	85%	86%	0.9
Diabetes mellitus, type 1	68%	44%	<0.001
Depression	54%	29%	<0.001
Chronic pain	43%	16%	<0.001
Sickle cell disease	32%	35%	0.3
Complex congenital heart disease	16%	42%	<0.001
Cystic fibrosis	15%	38%	<0.001

*Numbers are based on those who answered these questions on the survey

† Physicians were asked to what extent they agreed with the following statement: "I would be comfortable being the primary care provider for young adult patients (17–25 years of age) with these chronic conditions." Agreement was measured as a 6-point Likert-type response scale ranging from strongly disagree (1) to strongly agree (6)

Table 4. Beliefs Among Internists and Pediatricians Regarding Who Would Be the Best Primary Care Provider for an 18-year-old Patient with Cystic Fibrosis or Sickle Cell Disease

		Internists*	Pediatricians*
		N=308	N=440
Patient with cystic fibrosis†	Pediatric generalist	2%	28%
	Pediatric pulmonologist	12%	24%
	Adult generalist	41%	33%
	Adult pulmonologist	42%	10%
	Other	4%	6%
		N=200	N=301
Patient with sickle cell disease†	Pediatric generalist	3%	25%
	Pediatric hematologist	3%	18%
	Adult generalist	46%	34%
	Adult hematologist	46%	17%
	Other	3%	6%

*Numbers are based on those who answered these questions on each survey. Physicians surveyed were randomized to receive either a scenario about treating a patient with cystic fibrosis or a patient with sickle cell disease

† p<0.001 by chi-square analysis

Table 5. Odds of Treatment Comfort as the Primary Care Physician for Patients with Cystic Fibrosis and Sickle Cell Disease, Among General Internists and General Pediatricians

		Internist OR (95% CI)	Pediatrician OR (95% CI)
		n=429	n=657
		Model 1	Model 2
Cystic fibrosis	Female	1.8 (0.9, 3.5)	0.9 (0.6, 1.2)
	Years in practice	0.9 (0.9, 1.0)	1.0 (1.0, 1.0)
	Hours per week seeing patients	1.0 (1.0, 1.0)	1.0 (1.0, 1.0)
	# CF patients treated in residency†	1.5 (0.7, 3.0)	1.2 (0.9, 1.7)
	# CF patients treated in practice†	6.5 (3.5, 12.0)	2.4 (1.7, 3.4)
	Composite specialized resources	1.1 (0.9, 1.4)	1.2 (1.1, 1.3)
	Cystic fibrosis center easily available	1.4 (0.7, 3.0)	1.2 (0.8, 1.7)
	Pulmonologist easily accessible	0.5 (0.2, 1.4)	1.2 (0.7, 1.7)
	Practice type: group practice*	0.7 (0.3, 1.3)	1.2 (0.7, 1.8)
	Practice type: hospital-based*	0.3 (0.1, 0.9)	0.9 (0.4, 1.9)
	Practice type: other*	0.3 (0.1, 1.6)	0.6 (0.2, 1.4)
		n=425	n=658
		Model 3	Model 4
Sickle cell disease	Female	1.2 (0.8, 2.1)	1.2 (0.8, 1.7)
	Years in practice	1.0 (0.9, 1.0)	1.0 (0.8, 1.8)
	Hours per week seeing patients	1.0 (1.0, 1.0)	1.0 (1.0, 1.0)
	# SCD patients treated in residency†	1.8 (1.2, 2.8)	1.4 (0.9, 2.2)
	# SCD patients treated in practice†	3.5 (2.4, 5.0)	3.1 (2.2, 4.2)
	Composite specialized resources	1.1 (0.9, 1.3)	1.1 (1.0, 1.2)
	SCD center easily accessible	1.7 (0.9, 3.1)	1.0 (0.7, 1.5)
	Hematologist easily accessible	0.7 (0.3, 1.5)	2.3 (1.2, 4.4)
	Practice type: group practice*	0.6 (0.4, 1.1)	0.8 (0.5, 1.3)
	Practice type: hospital-based*	0.3 (0.1, 0.7)	0.7 (0.4, 1.8)
	Practice type: other*	0.1 (0.0, 0.7)	0.5 (0.2. 1.4)

**Reference group is solo/2 person practice*

†Treated as linear variable in model

half of the internists felt that primary care for these patients should be delegated to an adult subspecialist, not a generalist.

These findings highlight that practicing internists and pediatricians differ in their comfort levels caring for young adults with CF and SCD. There are several possible reasons for these findings. Among internists, comfort level was significantly associated with current practice volume of patients with CF and SCD and also with the number of patients with SCD cared for during residency. This pattern underscores the importance of experience in internists' perception of comfort, which appears to outweigh other factors such as access to specialists and to ancillary patient services (social work, care coordination and mental health).

Although many pediatricians were not comfortable providing primary care for patients with CF and SCD, most still felt that primary care for these patients should be delegated to a pediatrician (generalist or specialist). This finding suggests that pediatricians may share the view of many internists in our sample that adult-oriented generalists are not prepared to care for these complex young adult patients. Other treatment barriers may exist as well for treating young adults, as neither internists nor pediatricians were overwhelmingly comfortable in treating even common diseases such as asthma.

LIMITATIONS

This is the largest national survey of which we are aware that has assessed internists' and pediatricians' preparedness to treat young adults with chronic illnesses of childhood origin. Several limitations should be noted. First, we examined opinions of internists and pediatricians and did not assess comfort level of family physicians, nurse practitioners, or specialists. We chose to study internists and pediatricians because they are the group most affected by the need to transfer care to and from another provider, while physicians trained in medicine/pediatrics and family medicine tend to care for patients longitudinally over the lifespan.

The vignettes described patients who are 18 years old, a commonly accepted age for transferring patients to an adult-based provider. The decision to refer to another provider may be dependent on the patient age. We used an age range of 17–25 for general questions related to treatment comfort and clinical resources. We included the upper range of adolescence (age 17) to include pediatricians who may limit their clinical practice to those patients under age 18. Therefore, our results may also have differed had we used an older age range.

Because we did not assess the comfort of internists in treating young adults without chronic conditions, we cannot attribute lack of comfort entirely to treating chronic conditions. However, internists reported being much more comfortable treating a young adult with hypertension, diabetes, chronic pain or depression than one with CF or SCD. These differences in reported comfort across diseases suggest that comfort in treating young adults with CF or SCD is largely driven by the disease rather than the age of the patient.

In addition, treatment comfort, while a factor in physician referral and treatment behavior,[24,25] does not directly determine willingness or adequacy of treatment by internists and pediatricians for this population. Our estimate of treatment comfort could be biased if there were a systematic tendency towards higher or lower treatment comfort among non-respondents. Unfortunately, in order to address this issue, untestable assumptions would have to be made. Although this is not possible to compare all characteristics of respondents and non respondents, we saw no variation in CF or SCD outcome measures between responses to the initial survey and those from later survey rounds. Also, respondents and non-respondents did not differ in age, years in practice and board certification for internists, and our response rate of 53% compares favorably with other national surveys of physicians.[26]

The cross-sectional nature of this study does not allow us to determine if greater experience with patients in practice led to higher treatment comfort, or if physicians who had baseline higher comfort were more likely to accept into their practices patients with childhood-onset chronic illness. In addition, most internists had subspecialty access so the lack of association between ready access to subspecialists and comfort may be due to little variation in this practice domain. Finally, we focused on CF and SCD, and our findings may not be generalizable to other diseases.

CONCLUSIONS

Despite consensus recommendations by professional societies to transition young adults with chronic illnesses of childhood origin to adult-focused providers, our study suggests that many general internists are not comfortable treating this patient population. In addition, over one-half of general internists indicated that a specialist should be delegated the responsibility for primary care delivery to young adults with chronic illnesses. Given gaps in care for young adults with chronic illnesses,[27] generalists serve an important role in ensuring that the primary care needs of patients with relatively rare and complex chronic conditions are met, ideally in active collaboration with sub-specialists.[28,29] Our findings suggest that enhancing internists' experience and training in treating these diseases may be important steps for increasing internists' treatment comfort. Efforts to increase individual providers' treatment comfort, however, need to be linked to broader efforts to establish coordinated systems ensuring high-quality, long-term health care for adult survivors of chronic illnesses of childhood origin.

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APPENDIX

Physicians were randomized to receive a CF or SCD clinical vignette to anchor their answers to the question who would be the best primary care provider to a patient.

Cystic fibrosis clinical vignette:

An 18-year-old woman with cystic fibrosis comes to your office to establish care. Her medical history is significant for multiple pulmonary infections and pancreatic insufficiency. Today she would like to discuss with you her chronic cough, increased sputum production, chronic back pain, dysmenorrhea and cystic fibrosis management.

Sickle cell disease clinical vignette

An 18-year-old woman with sickle cell disease comes to your office to establish care. Her medical history is significant for multiple pain crises, complicated by acute chest syndrome and an intracranial hemorrhage in the past. Today she would like to discuss with you her chronic back pain, dysmenorrhea and sickle cell management.

We then asked the following question:

Who do you feel would be best to provide for the primary care needs for young adults (17–25 years old) with sickle cell disease/cystic fibrosis?

Response choices included pediatric generalist, pediatric pulmonologist or hematologist, adult generalist, adult pulmonologist or hematologist or other depending on vignette.