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# Transition From Pediatric to Adult Care: Internists' Perspectives

Nadja G. Peter, MD<sup>a,b,c</sup>, Christine M. Forke, MSN, CRNP<sup>a,b</sup>, Kenneth R. Ginsburg, MD, MEd<sup>a,c</sup>, Donald F. Schwarz, MD, MPH<sup>a,c</sup>

<sup>a</sup>Craig-Dalsimer Division of Adolescent Medicine, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; <sup>b</sup>Division of General Internal Medicine and <sup>c</sup>Department of Pediatrics, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania

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## What's Known on This Subject

The transition from pediatric to adult health care for young patients with chronic illnesses is rarely smooth. Several studies have examined the needs of patients and caregivers. One of the greatest difficulties is finding a knowledgeable, willing adult care provider.

## What This Study Adds

This study provides an initial look at internists' concerns regarding care of transitioning, chronically ill young adult patients. This study can help pediatricians better prepare both adult care clinicians and their transitioning patients.

## ABSTRACT

**OBJECTIVE.** The goal was to understand the concerns of adult health care providers regarding transition for young adult patients with childhood-onset conditions.

**METHODS.** Internists from the 2000 American Board of Medical Specialties directory were selected randomly. A 2-stage mail survey was conducted from August 2001 to November 2004. In stage 1, providers stated their concerns regarding accepting care of transitioning young adult patients. In stage 2, providers ranked their concerns.

**RESULTS.** A total of 241 internal medicine providers were selected for participation. In stage 1, 134 of 241 physicians were eligible to participate, and 67 (50%) of 134 completed stage 1 surveys. In stage 2, 112 physicians were eligible, and 65 (58%) of 112 responded. Concerns elicited in stage 1 were clustered into 6 categories: patient maturity, patient psychosocial needs, family involvement, providers' medical competency, transition coordination, and health system issues. In stage 2, concerns rated highest were lack of training in congenital and childhood-onset conditions, lack of family involvement, difficulty meeting patients' psychosocial needs, needing a superspecialist, lack of adolescent training, facing disability/end-of-life issues during youth and early in the relationship, financial pressures limiting visit time, and families' high expectations.

**CONCLUSIONS.** Internists clearly stated the need for better training in congenital and childhood-onset conditions, training of more adult subspecialists, and continued family involvement. They also identified concerns about patients' psychosocial issues and maturity, as well as financial support to care for patients with complex conditions. *Pediatrics* 2009;123:417-423

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Dr Schwarz's current affiliation is the City of Philadelphia, Philadelphia, Pennsylvania.

### Key Words

adolescent health, adult patients, chronic illness/conditions, survey, transition to adulthood

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Address correspondence to Nadja G. Peter, MD, Craig-Dalsimer Division of Adolescent Medicine, Children's Hospital of Philadelphia, 34th Street and Civic Center Boulevard, Philadelphia, PA 19104. E-mail: peter@email.chop.edu

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**A**PPROXIMATELY 18% OF children have a chronic physical, emotional, behavioral, or developmental condition that requires more than routine health services.<sup>1</sup> Over the past 3 decades, the life expectancy of children with chronic illnesses has increased dramatically, with >90% of such children surviving beyond their 20th birthday.<sup>2,3</sup> For example, less than one third of patients with spina bifida survived beyond age 20 in the 1970s and >80% do now.<sup>4</sup> Today, most adolescents with chronic illnesses achieve some degree of independence and live productive adult lives.

The shift from child-centered to adult-centered health care poses one of the greatest challenges in the transition from childhood to adulthood for these young people. The transition from pediatric care to adult care is often poorly organized, and even established transition programs do not always meet the goals of collaborative and coordinated services.<sup>4</sup> Communication between the pediatric system and the adult system is usually poor,<sup>5,6</sup> and many patients receive no care until an adult problem, such as pregnancy, forces them into the adult health care system.<sup>7-10</sup>

A successful transition program must be responsive to the needs of patients, caregivers, and health care providers. Several studies have examined patient, caregiver, and pediatric provider concerns regarding the transition to adult providers.<sup>6,10-24</sup> A recurring concern cited by pediatric providers, patients, and caregivers is the inability to find qualified adult providers to accept transitioning patients.<sup>19,20,25</sup> However, few studies have investigated transition-related activities, attitudes, and concerns of adult providers,<sup>5,6,11,21-23</sup> and fewer still have investigated specific needs, concerns, and expectations of adult providers accepting the care of transitioning, chronically ill, young adults.<sup>5,6,11,21</sup> The objective of this study was to fill this gap by using qualitative and quantitative techniques to elicit the concerns

of adult providers regarding the health care transition process for young adult patients with chronic illnesses. Ultimately, this information can be used for the creation of successful and effective transition programs.

## METHODS

### Participants

Internists were selected randomly from all subspecialties in the 2000 American Board of Medical Specialties directory.<sup>26</sup> A random-number generator was used to select 200 of the 1941 pages from the internist directory and to select 1 name from each of those 200 pages. Because randomization identified few female physicians, additional female physicians were identified by repeating the process for an additional 200 directory pages. Names and addresses were confirmed through the American Medical Association master files, as well as Lycos and AltaVista search engines. For subjects who were not at the location noted in the American Medical Association files, forwarding information was obtained from the listed employer. Participants were excluded when accurate contact information could not be obtained. Because this study was structured to obtain data from physicians actively caring for transitioning patients, physicians who were deceased, retired, practicing primarily in a specialty other than internal medicine, or not seeing young transitioning patients at the time of the survey were excluded. The institutional review board of the Children's Hospital of Philadelphia approved this study.

### Data Collection

The study used a 2-stage Delphi survey to elicit opinions of providers regarding the transition from child-centered to adult-centered care. The Delphi technique allows experts to generate and to refine their ideas through multiple survey iterations, with the goal of obtaining group consensus and ensuring inclusion of topics of key interest to the expert population. The Delphi technique has been used successfully in other health care studies.<sup>27-30</sup> It allows investigators to solicit the opinions of providers in a variety of geographic locations, which ensures that those most affected by the subject of interest can participate.

The 2-stage Delphi survey used open-ended questions to allow participants to generate their own ideas and quantitative survey techniques to allow participants to rate all responses. The stage 1 survey asked respondents, "Please list concerns you have about accepting the care of medically complex patients as they transition from child-centered to adult-centered medical care. As you devise your list, please consider patient, family, clinical, institutional, financial, and psychosocial issues." After receipt of completed surveys, all responses were reviewed, similar items were combined, and items were ranked according to the frequency with which they were mentioned. All unique items from stage 1 were combined into a 45-item survey for stage 2. The stage 2 survey asked providers to rate each of the 45 items on a scale of 1 (does not impact my ability to care for transi-

tioning patients at all) to 4 (impact my ability to care for transitioning patients greatly). At the completion of stage 2, all responses were ranked in order of importance.

Stage 1 and 2 surveys also gathered demographic information on age, race, gender, years in practice, subspecialty, geographic setting (urban, suburban, or rural), and practice type. Stage 2 demographic data were used for subgroup analysis; when stage 2 data were unavailable, stage 1 data were used. To ensure anonymity, surveys did not contain identifiers but were prenumbered and matched to a master list of participants. Reminder telephone calls were made to nonresponders 2 weeks after the original mailing. Up to 5 reminder calls were made to each nonresponder.

### Data Analysis

The 45 stage 2 survey items were ordered according to their mean Likert-scale ratings and then were compared with each other by using the Wilcoxon signed-rank test. A Bonferroni correction was used for multiple-item comparisons, and a *P* value of .002 was used to compare ratings between consecutive items. Consecutive items with no significant difference in their mean ratings received the same ranking; the next ranking was assigned to the first item with a significant difference. The Kruskal-Wallis test was used to compare ratings according to gender, race, specialist versus generalist, private practice versus other settings, and geographic setting. Significance for this analysis was set at *P* = .05, given the smaller size of the individual subgroups. Qualitative analysis was used to categorize stage 2 items into themes. Three authors (Drs Peter and Schwarz and Ms Forke) reviewed and coded each item independently and then compared and discussed categorizations. When coders differed in opinion, the category with the most votes was assigned.

## RESULTS

Initial surveys were sent to 241 internists throughout the United States, in August 2001. A total of 154 male physicians, 69 female physicians, and 18 physicians of unknown gender were selected for participation. Of the 241 stage 1 surveys distributed, 107 were excluded because of death (*n* = 1), retirement (*n* = 12), inability to be located (*n* = 70), or seeing only elderly patients (*n* = 24). Of the 134 eligible physicians, 67 (50%) completed surveys, 16 (12%) declined participation, and 51 (38%) did not respond. Table 1 provides a description of participants for each stage of data collection. In stage 1, 45 unique items were generated. The average number of responses per participant was 1.28, and the number of responses provided by participants ranged from 0 to 5. Only 3 items were cited by >5 participants: difficulty obtaining records (*n* = 13), lack of training in pediatric onset and congenital disorders (*n* = 8), and parents often being reluctant to relinquish responsibility for health care/decision-making to young adult patients (*n* = 6).

Stage 2 surveys were sent to those who completed the survey or did not respond in stage 1 (*N* = 118). Those

**TABLE 1** Description of Participants for Stages I and II

	n(%) <sup>a</sup>	
	Stage 1	Stage 2
Surveys returned	67	65
Male	48 (72)	44 (68)
Race/ethnicity		
White	49 (73)	51 (78)
Asian	8 (12)	3 (5)
Hispanic	3 (4)	3 (5)
Other	4 (6)	4 (6)
Geographic setting		
Urban	30 (45)	30 (46)
Suburban	28 (42)	25 (38)
Rural	6 (9)	7 (11)
Physician type		
Generalist	48 (72)	42 (65)
Specialist	18 (27)	13 (20)
Role <sup>b</sup>		
Private practice	40 (60)	40 (62)
Hospital-based practice	22 (33)	15 (23)
Clinic	13 (19)	12 (18)
Research	10 (15)	4 (6)
Administration	4 (6)	3 (5)
Teaching	2 (3)	1 (2)
Other	3 (4)	4 (6)
Did not answer	3 (4)	3 (5)
In practice >15 y	40 (60)	NA

NA indicates not applicable.

<sup>a</sup> Values may not sum to 100% because of missing information.

<sup>b</sup> Values may exceed 100% because many physicians reported >1 role. Other includes working in a government health maintenance organization, hospital-owned community-based practice, rehabilitation hospital, Indian Health Service, large group practice, employed physician group, or nursing home.

who declined in stage 1 were not contacted again in stage 2. Six participants were excluded in stage 2; 2 denied seeing transitioning patients and 4 had moved without forwarding information. Of the remaining 112 eligible stage 2 participants, 65 (58%) completed surveys and 4 (4%) declined to participate. Survey items are presented in Table 2, with mean Likert ratings, the category classifications generated through qualitative analysis, and the rank order from Wilcoxon signed-rank tests. Six themes or categories emerged during qualitative exploration: family involvement, patient maturity, system issues, providers' medical competency, patient psychosocial needs, and coordination of the transition process. Four items fit into >1 category.

The Kruskal-Wallis test explored differences in Likert ratings according to gender, race, primary versus specialty care, practice type, and geographic setting. Female providers assigned higher Likert scores than did male providers to 3 items: difficulty involving a caring parent to ensure adherence without compromising the young adult patient's growing sense of independence ( $P = .01$ ), potential lack of insurance coverage for young adults with chronic illnesses ( $P = .02$ ), and parents' reluctance to relinquish responsibility for health care and decision-making ( $P = .004$ ). Specialists assigned higher ratings than did generalists to pediatricians' reluctance to "let go" of their patients ( $P = .01$ ). Providers in private

practice assigned lower ratings than did providers in other practice settings to pediatricians' reluctance to let go of their patients and to young adult patients' mistrust of staff members in internists' practices. No significant differences were found among providers from different racial groups.

Several differences in ratings were noted for providers practicing in different geographic settings. Urban providers assigned a higher rating to colleagues' potential unwillingness to care for teenage patients ( $P = .001$ ). Urban and suburban providers seemed more concerned than rural providers about patients' and families' unfamiliarity with the adult health care system ( $P < .05$ ). Suburban providers ranked several items higher than urban or rural providers: difficulty meeting the psychosocial needs of young adults, especially those living with chronic illnesses ( $P = .006$ ), difficulty broadening the doctor-patient relationship to include parents ( $P = .02$ ), young adult patients' ignorance of morbidity/mortality rates and lack of motivation for preventive care ( $P = .003$ ), the common occurrence of young adult patients neglecting to raise issues or to ask questions that their parents previously would have raised or asked ( $P = .02$ ), and parents' reluctance to relinquish responsibility for health care/decision-making to young adult patients ( $P = .02$ ).

## DISCUSSION

It is critical to understand the needs of all participants in the transition process if we are to transfer chronically ill adolescents and young adults from pediatric health care to adult health care successfully. Although previous studies elicited the concerns of patients, their caregivers, and pediatric health care providers,<sup>8,10-24</sup> this is one of the first to examine the broader concerns of adult health care providers. Previous studies included very few adult providers,<sup>6,21</sup> were limited to 1 subspecialty group,<sup>5,11</sup> or addressed very limited aspects of the transition process, such as patients' readiness for transfer.<sup>21-23</sup> Adult health care providers are key stakeholders in the transition process and can offer input critical to the design of effective transition programs.

Several concerns expressed in our study have not been reported previously, including concerns that the family will not stay involved, especially for patients with mental retardation or cerebral palsy, the need for super-specialists (providers with expertise in 1 or a few specific conditions) to care for very complicated medical conditions, such as congenital heart disease, the need to face disability and end-of-life issues at an early age and early in the doctor-patient relationship, time limitations attributable to managed care/financial considerations, and families' high expectations for internists' time.

The issue of family involvement in the health care transition seems to be more complex than thought previously. Several studies indicated that caregivers are concerned about whether young adult patients can responsibly manage their own health,<sup>12,14,17</sup> although young adult patients report being eager to take on this responsibility.<sup>14</sup> Caregivers also often think that adult providers do not want their involvement.<sup>7,31</sup> The inter-

**TABLE 2 Mean Likert Ratings and Wilcoxon Rank Order of Stage 2 Survey Items**

Item	Mean Likert Rating	Category	Wilcoxon Rank <sup>a</sup>
1. Internists may not have the training in congenital and childhood chronic illnesses to prepare them to manage them beyond childhood.	2.86	Medical competency	1
2. It is difficult to care for patients with cerebral palsy or mental retardation if the family does not stay involved.	2.86	Family involvement	1
3. It can be difficult to meet psychosocial needs of young adults, especially those living with chronic illness.	2.77	Psychosocial needs	1
4. Some patients may need a superspecialist to manage complex problems (eg, complex congenital heart disease).	2.77	Medical competency	1
5. Internists often lack training in adolescent medicine, adolescent development, and adolescent behavior.	2.63	Medical competency	1
6. It is often difficult to face disability and end-of-life issues at an early age and early in the doctor-patient relationship.	2.63	Medical competency, psychosocial needs	1
7. Managed care/financial considerations limit the time an internist is able to spend with transitioning young patients.	2.57	System issues	1
8. The families of transitioning patients have high expectations of the amount of time/attention needed for proper care.	2.55	Family involvement	1
9. Because patients with chronic illness are often less mature than their healthy counterparts, they may have increased adherence problems.	2.49	Maturity	2
10. Young patients are not always ready to assume decision-making responsibility.	2.47	Maturity	2
11. While insurance programs may cover sick children, coverage may not exist for young adults.	2.45	System issues	2
12. Internal medicine practices often lack adequate infrastructure and staff training to deal with these patients.	2.45	System issues	2
13. It is often challenging to make sure that the young patient does not get lost to follow-up.	2.44	Maturity, system issues	2
14. Young patients are often ignorant of morbidity/mortality and therefore may lack motivation for preventive care.	2.44	Maturity	2
15. Internists may be unfamiliar with local and regional services for chronically ill, young adult patients.	2.42	Medical competency	2
16. Caring for chronically ill young patients can be potentially very time-consuming.	2.42	System issues	2
17. It is difficult for young adult patients over 18 with chronic illness to obtain insurance because of their preexisting condition.	2.40	System issues	2
18. Parents are often reluctant to relinquish responsibility for health care/decision-making to young adult patients.	2.39	Family involvement	2
19. Young patients with chronic illness often have significant dependency needs.	2.37	Maturity	2
20. It is difficult to meet the expectations of care for chronic incurable problems; often family wants a full evaluation though one has already been completed.	2.37	Family involvement	2
21. The transition from pediatric caregivers is often poorly coordinated.	2.36	Transition coordination	2
22. Young patients often neglect to raise issues or ask questions that their parents previously would have asked.	2.35	Maturity	2
23. Young patients are often closed-minded to different approaches after living with their illness for so long.	2.32	Maturity	2
24. Parents and caregivers can remain excessively protective and may not understand privacy issues.	2.32	Family involvement	2
25. It is often difficult to obtain old records.	2.30	Transition coordination	2
26. Internal medicine practices may not be familiar with reimbursement schedules for patients requiring coordination of services or parental consultation.	2.22	System issues	2
27. It may be difficult to manage adolescent patients with attention-deficit disorder.	2.19	Medical competency	2
28. Internal medicine practices are often less paternalistic than pediatric practices, which can be challenging for transitioning patients (eg, patients may not get called when they miss an appointment).	2.17	Maturity, system issues	2
29. The literature on childhood illnesses is mostly in pediatric journals.	2.17	Medical competency	2
30. It is often difficult to reconcile the different practice styles of pediatric and adult providers.	2.14	Transition coordination	2
31. There is often a large time gap between the last visit with the pediatrician and the first visit with the adult provider.	2.14	Transition coordination	2
32. It is difficult to involve a caring parent to ensure adherence without compromising the patient's growing sense of independence.	2.14	Maturity, family involvement	3
33. It may be difficult to transition ancillary services (eg, radiograph and path) from the pediatric to the adult system; often pediatric services are more experienced with pediatric illnesses.	2.11	Transition coordination	3
34. Patients are often ambivalent about transition: they want an adult doctor but don't want to leave their pediatrician.	2.02	Transition coordination	3
35. Pediatricians are often unsure of whether to refer to an adult specialist or pediatric specialist in this age group.	2.00	Transition coordination	3
36. My colleagues may be unwilling to care for teenage patients.	1.98	Medical competency	3
37. Pediatricians sometimes use different medication doses than those used in adult medicine.	1.98	Medical competency	3
38. Patients/families often don't know how to navigate the adult health care system.	1.98	Transition coordination	3
39. It is often difficult to deal with sexually transmitted infections in adolescent patients.	1.97	Medical competency	3
40. Patients/families often don't know medical history.	1.97	Transition coordination	3
41. It can be difficult to broaden the doctor-patient relationship to include parents.	1.92	Family involvement	3
42. Pediatricians tend to keep compliant patients and transition noncompliant patients.	1.80	Transition coordination	3
43. It is frequently necessary to change the treatment plan because of prior inadequate care.	1.74	Transition coordination	4
44. Young patients frequently distrust staff, often because of logistical issues (eg, procuring referrals).	1.72	Psychosocial needs	4
45. Pediatricians are often reluctant to let go of their patients.	1.68	Transition coordination	4

Item wording is identical to that in the survey.

<sup>a</sup> Rank order was determined by using the Wilcoxon signed-rank test. A Bonferroni correction was used to adjust for multiple comparisons, resulting in a significance level of  $P < .002$ .

nists in our study agreed that patients may not be ready to make decisions independently and were concerned that families would not stay involved when needed. Female providers, in particular, reported that parents often raised important issues that patients did not always voice. Several internists in our study thought that caregivers were reluctant to relinquish responsibility, but this was not one of their highest concerns. The internists seemed to welcome caregiver involvement, especially when the patient was not ready for sole health care decision-making. Our results suggest that pediatricians should encourage families to stay involved during the transition process, while allowing patient autonomy and encouraging increasing self-care.

Several review articles suggested that internists are unwilling to take on time-consuming cases.<sup>7,32</sup> Our informants rated time pressures high on their lists of concerns. Financial pressures often are considerable in internal medicine practices,<sup>33</sup> and internists often are unfamiliar with documentation and coding strategies that could procure more reimbursement for their efforts with time-intensive cases.<sup>32</sup> Educating internists about these strategies would likely lessen the financial disincentive for accepting young adult patients with chronic illnesses. However, the time involved in caring for patients with complex conditions may necessitate changing medical care reimbursement.

There is a paucity of adult-based services for patients with childhood-onset conditions.<sup>7,34</sup> Our participants focused on the lack of adult subspecialists to care for patients with congenital and childhood-onset disorders. These disorders are becoming increasingly common among adult patients, because of increasing life expectancy and survival rates. Opportunities for adult care-trained physicians to acquire education in pediatric subspecialties are limited. For example, there are only 80 genetics fellowship positions nationally, 288 in pediatric cardiology (where training in congenital heart disease usually is acquired), and 9 in neurodevelopmental disabilities. This is in contrast to 2231 positions in adult cardiovascular diseases, 1223 in adult gastroenterology, and 808 in neurosurgery.<sup>35</sup> Although the number of training opportunities may increase as demand for these superspecialists with expertise in 1 or a few specific conditions grows, supply continues to lag demand.

Our participants expressed deep concern about young adult patients facing death and disability early in the doctor-patient relationship. Viner<sup>7</sup> mentioned that patients may view transitioning to adult medicine as being 1 step closer to death and disability; however, adult providers' opinions were not solicited. Previous studies indicated that patients' deaths have strong emotional effects on physicians.<sup>36-38</sup> Because adult providers generally care for an aging population, it may be assumed that they are accustomed to patients' deaths. When the patient is young or the physician identifies more closely with the patient, however, the emotional reaction often is very intense.<sup>38</sup> Adult providers may be reluctant to start seeing patients with high expected mortality risk, and they may think that the patients' previous providers would be better qualified to provide continuing care.

Pediatricians must assess patients' prognoses carefully before transition, because transitioning may be a poor choice if death or significant decompensation is imminent. Improved communication between pediatricians and internists may help internists cope with an unexpected or early death by allowing providers to share their grief. Another solution would involve developing resources to assist providers in dealing with young adult patient loss.

Two concerns elicited in our study are similar to those reported previously: lack of training in childhood-onset and congenital disorders and meeting patients' psychosocial needs.<sup>5,6,11,14,39</sup> Lack of expertise and experience with patients with complex health needs and intellectual disabilities were the primary concerns expressed by general practitioners interviewed by O'Connell et al.<sup>6</sup> Although their study was limited by a very small sample ( $N = 2$ ), our larger sample validates these concerns. In addition, although it did not address training deficits specifically, a survey of adult nephrologists found that only 40% of those surveyed felt comfortable caring for patients with pediatric renal disease.<sup>11</sup>

Patients in previous transition studies echoed concerns about adult providers' ability to meet psychosocial needs.<sup>14,39</sup> Internal medicine practices may lack social workers<sup>11,19,40,41</sup> and case managers, who are common in pediatric practices and are essential in addressing patients' psychosocial and care coordination needs. Internists in this study agreed that meeting patients' psychosocial needs was essential, but they acknowledged barriers to achieving this goal, including insufficient knowledge of social resources, limited training in adolescent medicine, time limitations, and financial considerations.

Among our sample, interesting distinctions were noted when different groups of providers were compared. Specialists were more concerned than generalists about pediatricians not "letting go" of patients. This issue was mentioned in several review articles, although it was not found to be a major issue in existing studies.<sup>5,6</sup> Because general internists are likely accepting care for patients with different levels of medical complexity and involvement with the health care system, compared with specialists, transition issues may be different. Furthermore, chronically ill patients may rarely see their primary care doctors.<sup>42</sup> These patients often form particularly close bonds with their specialists, making the transition to new specialists more challenging.

There are several limitations to this study. First, although a 58% response rate is not unusual for a physician survey,<sup>20,43</sup> it raises concerns regarding selection bias. It is possible that only providers with strong interests or opinions responded. Second, because providers generated all of the responses, items mentioned in other studies, such as "gaining the patient's confidence," were not discussed here. This makes it harder to compare studies. Some important issues might not have been raised by busy providers answering our survey. However, it is likely that the most important issues were at the forefront of providers' minds and thus were included. Third, we did not obtain sufficient information

on experience with transitioning patients, which likely affects the comfort level and the breadth of responses. Fourth, providers who stated that they had no experience with transitioning patients were excluded. Because this was an initial study of internists' concerns, we considered it important to assess first the barriers encountered by experienced providers. Further exploration is needed to examine whether other barriers prevent some internists from accepting young adult patients. Fifth, we obtained limited information concerning specific practice settings (eg, acceptance of insurance, type of hospital affiliation, association with medical school, and availability of subspecialists). Future studies should elicit more-detailed information to clarify these issues. Lastly, this study was not an outcome study. Although we gained insight into potential needs of adult physicians accepting transitioning patients, future work should test whether these ideas affect outcomes positively.

## CONCLUSIONS

Young adult patients with chronic illnesses must have smooth effective transitions from pediatric to adult health care. Otherwise, many may forgo care and suffer serious health consequences, at great personal and societal costs. Although patients' and caregivers' concerns about transition were explored previously, this is the first study to elicit concerns from a broad range of internists about accepting patients with chronic illnesses. Internists identified concerns that clustered into 6 major themes, namely, family involvement, patient maturity, systems issues, providers' medical competency, patient psychosocial needs, and coordination of the transition process. These provider-generated concerns provide pediatricians and program developers with insight into what interventions might enable internists to care more effectively for transitioning young adult patients. They also reaffirm the stakeholders in the transition process, that is, patients, families, pediatric and adult providers, health systems, and payers. To design the most effective, seamless, transition models, future research should engage all key stakeholders in the transition process and enable them to discuss and to plan programs. Ultimately, programs developed to meet the needs of young adult patients, their families, and health care professionals must be pilot-tested, evaluated, and more-broadly implemented until we have developed a health care system that is prepared to care for our young adult patients with chronic diseases into adulthood.

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care providers' needs during patients' transitions from pediatric care.

## REFERENCES

1. Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiologic profile of children with special health care needs. *Pediatrics*. 1998;102(1):117-123
2. Gortmaker SL, Sappenfield W. Chronic childhood disorders: prevalence and impact. *Pediatr Clin North Am*. 1984;31(1):3-18
3. American Academy of Pediatrics, Committee on Children with Disabilities and Committee on Adolescence. Transition of care provided for adolescents with special health care needs. *Pediatrics*. 1996;98(6):1203-1206
4. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health*. 1999;24(4):259-264
5. Crosnier H, Tubiana-Rufi N. Modalities of transition of diabetic adolescents from pediatrics to adult care in the Paris-Ile-de-France region: an appeal to cooperative work for improving quality of care. Paris-Ile-de-France Section of DESG (Diabetics Education Study Group) [in French]. *Arch Pediatr*. 1998;5(12):1327-1333
6. O'Connell B, Bailey S, Pearce J. Straddling the pathway from paediatrician to mainstream health care: transition issues experienced in disability care. *Aust J Rural Health*. 2003;11(2):57-63
7. Viner R. Transition from paediatric to adult care: bridging the gaps or passing the buck? *Arch Dis Child*. 1999;81(3):271-275
8. Dore A, de Guise P, Mercier LA. Transition of care to adult congenital heart centers: what do patients know about their heart condition? *Can J Cardiol*. 2002;18(2):141-146
9. Ford CA, Bearman PS, Moody J. Foregone health care among adolescents. *JAMA*. 1999;282(23):2227-2234
10. Reid GJ, Irvine MJ, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*. 2004;113(3). Available at: [www.pediatrics.org/cgi/content/full/113/3/e197](http://www.pediatrics.org/cgi/content/full/113/3/e197)
11. LoCasale-Crouch J, Johnson B. Transition from pediatric to adult medical care. *Adv Chronic Kidney Dis*. 2005;12(4):412-417
12. Westwood ATR, Henley LD, Willcox P. Transition from paediatric to adult care for persons with cystic fibrosis: patient and parent perspectives. *J Paediatr Child Health*. 1999;35(5):442-445
13. Warnell P. The transition experience of epilepsy patients/families: results of a telephone survey. *Axone*. 1998;20(2):31-33
14. Telfair J, Myers J, Drezner S. Transfer as a component of the transition of adolescents with sickle cell disease to adult care: adolescent, adult, and parent perspectives. *J Adolesc Health*. 1994;15(7):558-565
15. Brumfield K, Lansbury G. Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disabil Rehabil*. 2004;26(4):223-234
16. Anderson DL, Flume PA, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of patients. *Pediatr Pulmonol*. 2002;33(5):327-331
17. Boyle MP, Farukhi Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol*. 2001;32(6):428-436
18. Steinkamp G, Ullrich G, Mueller C, Fabel H, von der Hardt H. Transition of adult patients with cystic fibrosis from paediatric to adult care: the patients' perspective before and after start-up of an adult clinic. *Eur J Med Res*. 2001;6(2):85-92

19. Reiss JG, Gibson RW, Walker LR. Health care transition: youth, family, and provider perspectives. *Pediatrics*. 2005;115(1):112–120
20. Scal P. Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics*. 2002;110(6):1315–1321
21. Cappelli M, MacDonald NE, McGrath PJ. Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. *Child Health Care*. 1989;18(4):218–224
22. Telfair J, Alexander LR, Loosier PS, Alleman-Velez PL, Simmons J. Providers' perspectives and beliefs regarding transition to adult care for adolescents with sickle cell disease. *J Health Care Poor Underserved*. 2004;15(3):443–461
23. Flume PA, Anderson DL, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perception of pediatric and adult program directors. *Pediatr Pulmonol*. 2001;31(6):443–450
24. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *J Adolesc Health*. 2003;32(3):225–233
25. Reiss J, Gibson R. Health care transitions: destinations unknown. *Pediatrics*. 2002;110(6):1307–1314
26. American Board of Medical Specialties. *The Official ABMS Directory of Board-Certified Medical Specialists, 2000*. 32nd ed. New Providence, NJ: Marquis Who's Who; 1999
27. Bowles N. The Delphi technique. *Nurs Stand*. 1999;13(45):32–36
28. Macdonald EB, Ritchie KA, Murray KJ, Gilmour WH. Requirements for occupational medicine training in Europe: a Delphi study. *Occup Environ Med*. 2000;57(2):98–105
29. Stewart J, O'Halloran C, Harrigan P, Spencer JA, Barton JR, Singleton SJ. Identifying appropriate tasks for the preregistration year: modified Delphi technique. *BMJ*. 1999;319(7204):224–229
30. Ginsburg KR, Slap GB, Cnaan A, Forke CM, Balsley CM, Rouselle DM. Adolescents' perceptions of factors affecting their decision to seek health care. *JAMA*. 1995;273(24):1913–1918
31. Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. *J Adolesc Health*. 1995;17(1):10–16
32. Rosen DS. Transition from pediatric to adult-oriented health care for the adolescent with chronic illness or disability. *Adolesc Med*. 1994;5(2):241–248
33. Grumbach K, Osmond D, Vranizan K, Jaffe D, Bindman AB. Primary care physicians' experience of financial incentives in managed-care systems. *N Engl J Med*. 1998;339(21):1516–1521
34. Schidlow DV, Fiel SB. Life beyond pediatrics: transition of chronically ill adolescents from pediatric to adult health care systems. *Med Clin North Am*. 1990;74(5):1113–1120
35. Accreditation Council for Graduate Medical Education. Resident physician populations by specialty. Available at: [www.acgme.org/acwebsite/CMS/CMS\\_index.asp](http://www.acgme.org/acwebsite/CMS/CMS_index.asp). Accessed September 12, 2005
36. Redinbaugh EM, Sullivan AM, Block SD, et al. Doctors' emotional reactions to recent death of a patient: cross-sectional study of hospital doctors. *BMJ*. 2003;327(7408):185
37. Wolpin BM, Chabner BA, Lynch TJ Jr, Penson RT. Learning to cope: how far is too close? *Oncologist*. 2005;10(6):449–456
38. Jackson VA, Sullivan AM, Gadmer NM, et al. "It was haunting.": physicians' descriptions of emotionally powerful patient deaths. *Acad Med*. 2005;80(7):648–656
39. Eiser C, Flynn M, Green E, et al. Coming of age with diabetes: patients' views of a clinic for under-25 year olds. *Diabet Med*. 1993;10(3):285–289
40. Clarke SS, Neuwirth L, Bernstein RH. An expanded social work role in a university hospital-based group practice: service provider, physician educator and organizational consultant. *Soc Work Health Care*. 1986;11(4):1–17
41. Lurie A, Douglas M. Social work in the health field. *Public Health Rev*. 1979;8(1):81–95
42. Carroll G, Massarelli E, Opzoomer A, et al. Adolescents with chronic disease: are they receiving comprehensive health care? *J Adolesc Health Care*. 1983;4(4):261–265
43. Asch DA, Jedrzewski MK, Christakis NA. Response rates to mail surveys published in medical journals. *J Clin Epidemiol*. 1997;50(10):1129–1136

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