

Transition for Youth With Chronic Conditions: Primary Care Physicians' Approaches

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ABSTRACT. Since the US Surgeon General's conference on health care transitions in 1989, transition from pediatric to adult-oriented health care for youth with chronic conditions continues to develop as an important issue among youth, parents, and health professionals. Key professional organizations, public agencies, and disease-specific organizations have promoted research on transition and the development of transition services. Although there is evidence of the advancement of the science and practice of transition in the context of subspecialty medical care, the same may not be true for transition in the context of primary care practice. Little has been written about the role of the primary care provider in facilitating transition, and little is published in the medical literature about how transition occurs in primary care settings. *Pediatrics* 2002;110:1315-1321; transition, chronic conditions, primary care.

ABBREVIATION. GAPS, *Guidelines for Adolescent Preventive Services*.

INTRODUCTION

Transition, as defined in a position paper from the Society for Adolescent Medicine, is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system." That paper goes on to promote transition as an important component of high-quality health care.¹ Similarly, the American Academy of Pediatrics' policy statement on transition of care recommends that pediatricians become active participants in the transition process.² Recently, the Maternal and Child Health Bureau identified transition as 1 of 6 core outcomes that, when achieved, will indicate successful progress toward the goal of a community-based system of services for children with special health care needs.³

Transition has emerged as an important issue as the epidemiology of childhood chronic conditions and expectations for and among these youth have changed. Chronic conditions that may have been uniformly lethal a decade ago in childhood are now associated with survival into adulthood.² Furthermore, there is a shift in the understanding of what

constitutes chronic conditions, and a broader definition is now used to reflect this awareness. Most recently, the Maternal and Child Health Bureau has defined children with special health care needs as "... those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."⁴

Newacheck et al⁵ used data from the 1994 *National Health Interview Survey and Disability Supplement* to estimate the prevalence of special health care needs. Their analysis was limited only to those had or were presumed to have had a chronic physical, developmental, behavioral, or emotional condition and did not include those difficult to identify youth "at risk." The results indicated that 18% of these children younger than 18 years met the criteria for having special health care needs. Twelve percent of the children were using services beyond those used by the others, and 6% were presumed to have a need for services but were not using them at the time of the survey. Those who had special health care needs, compared with those who did not, experienced significantly more days in bed because of illness, more days absent from school, and more physician contacts and days spent in the hospital; were less satisfied with their care; and had a greater proportion of unmet health needs. In comparison, other studies have estimated the prevalence of chronic conditions to range from 31% when the broadest criteria were applied⁶ to 6.5% when more restrictive functional impairment criteria were used.⁷

Supporting the need for transition services is the presumption that transition in health care, as in other domains, is more complex for youth with chronic conditions than it is for others.⁸ Yet, the findings from 2 large population-based studies suggest that many young adults with chronic conditions appear to make the transition into adulthood without serious ill effects. Gortmaker reported on the well-being of 221 young adults with chronic conditions and found them to be only at a slightly higher risk for problems than were young adults without chronic conditions in a comparison group.⁹ Notably, the few young adults with the most severe conditions were reported to experience marked limitations in their functioning and achievements. Bussing¹⁰ reported similar success in transition to adulthood in a sample of 423 young adults. Comparisons between those with and without chronic conditions identified few

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differences in measures of psychosocial well-being, educational status, social development, and behavioral threats to health. For 53 young adults with the most serious conditions, there was a significantly increased level of emotional distress and a lower rate of marriage. Both studies are limited by the small sample size, which may not capture the experience of individuals with rare conditions. Although chronic conditions in childhood may be quite common, the developmental tasks of adolescence appear to be most significantly impacted for youth with the most involved chronic conditions.¹¹ What is not poorly understood is how those who have successfully navigated adolescence and the transition process actually did so. The characteristics of individuals, families, communities and health care systems that facilitate transition are not entirely understood.

Models of health care transition services have been proposed,¹ and programs representative of these models have been highlighted elsewhere.^{11,12} One such model focuses on adolescents with one particular condition, such as cystic fibrosis. The potential advantages of such a model include that the patients have in common a condition with a more homogeneous experience and, thus, a common set of needs, work with a consistent pediatric care team and, presumably have an identified care team of adult providers. A variation on this model could be to orient services around a subspecialty service, such as pulmonology, and thus, the transition services would be available to youth with a variety of pulmonary conditions. In a second model, an adolescent health team focuses on an approach to coordinating care and advancing the transition process within the context of adolescent health services. Here, the adolescent team has an approach to care that is broad in scope, addressing physical, emotional, developmental, and social issues. In a third model, a primary care model is hypothesized to utilize the primary care provider (pediatrician, nurse practitioner, or family physician) to assess and coordinate the health needs of the adolescent and family.

In 1995, 126 interdisciplinary transition programs from across the country were identified and surveyed to describe common processes and themes and identify models of service.¹³ Of the responses, 62% of the programs were condition specific (eg, spina bifida, cystic fibrosis) or subspecialty specific (eg, pulmonology, gastroenterology), and 38% of programs served youth with a range of conditions. Few programs based their services on a primary care model. When the models were compared, there were no differences found among them in the services provided. Most services appeared to be problem oriented and centered around a clinic visit; few were based on the concepts of health promotion. These data provide little support for a framework of distinct models based on services provided. That is not to say that different models do not or should not exist, but simply that they were not identified (see the article by Reiss and Gibson in this supplement).

Although the literature addressing transition provides program descriptions and frameworks for program development, an alternative approach may be

emerging simultaneously in the literature and in practice under what may be described as enhanced primary care and preventive services. Palfrey¹⁴ described these emerging models as "an explosion of experimentation" of comprehensive child health. These approaches, as well as the Maternal and Child Health Bureau's *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*¹⁵ and the American Medical Association's *Guidelines for Adolescent Preventive Services (GAPS)*,¹⁶ seek to bring a more comprehensive perspective of the needs youth and their families into primary care health promotion and supervision. Although these guidelines have not been developed specifically to focus on the needs of youth with chronic conditions, the issues they address are very much the same for youth with and without chronic conditions. However, one model of enhanced primary care specifically tailored to the needs of youth with chronic conditions and their families is the medical home model (see the article by Kelly et al in this supplement). Its overall goal is ensure that children with special needs have access to care that is family centered, continuous, comprehensive, coordinated, compassionate, and culturally competent.

As the importance of transition and primary care issues for adolescents with chronic conditions becomes more apparent and the lack of knowledge regarding the state of transition services in the primary care setting is recognized, the rationale for developing an understanding of the current state of services becomes more compelling. In spring 2001, we set out to describe the range of approaches that represent transition services as they are undertaken in the offices of primary care physicians and to understand them in the context of the current proposed models.

SURVEY OF PRIMARY CARE EFFORTS IN TRANSITION

Nomination Technique

Nominations were sought of primary care providers (described as pediatricians, family physicians, internists, nurse practitioners, or others) who facilitate the transition of medical care from the pediatric to the adult health care system. This nomination request included an opportunity for respondents to comment on the activities of the nominee who facilitated transition. Resource groups for families of and persons with chronic conditions as well as parents of adolescents in the Minnesota Children With Special Health Needs program were contacted for nominations. *Exceptional Parent Magazine* compiles and maintains a resource list of organizations and individuals with an interest in the care of persons with chronic conditions. The organizations in this resource guide include those that are disease specific (eg, the CHARGE Syndrome Foundation, the Cystic Fibrosis Foundation, the Epilepsy Foundation of America), parent-to-parent programs, Family Voices contacts, and parent training and information centers. An e-mail letter describing this project and seeking the nomination of primary health care providers

was sent to these organizations and individuals asking that the recipient respond or forward it to constituents. Additionally, the nomination survey was posted on the Health Care Transition for Youth Digest electronic mailing list developed by the Institute for Child Health Policy. Because many of the originally contacted organizations distributed the survey to their constituents, the total number of nomination surveys is not known but likely exceeds the 6400 individuals and organizations that received the original nomination request.

A total of 36 nominations, representing 35 unique health care providers, were received. Each of the nominees received an in-depth survey via mail; non-responders received 2 reminder phone calls and a second survey by fax. Completed surveys were received by 13 (37%) of the nominated health care providers.

The Survey Instrument

On the basis of the literature specifically addressing transition, theories of physician behavior (social cognitive theory), and factors influencing health care systems change, a questionnaire was developed with 53 forced-response and 8 open-ended items to better understand and describe the practices of the nominated health care providers. Additional questions derived from the critical incident technique^{17,18} were used to explore the reasons for the respondents' behavior regarding transition. The main themes of the questionnaire included the structure and functioning of the program, barriers to transitioning, and the respondents' attitudes regarding perceived importance and self-efficacy to address a broad range of issues for youth in the transition process. Demographic and practice information was also collected. Before distribution, the survey was reviewed by 6 faculty members with experience in research and in the care of adolescents with chronic conditions and was revised to reflect their comments.

Analysis

Written responses to the initial nomination survey were reviewed for themes, consistency with the literature on transition, and novel topical areas not previously reported. For the provider survey, responses to the forced-response questions were summarized as proportions and standard deviations. Open-ended questions were reviewed for themes (comments common to 2 or more respondents) and for insight into successful strategies to transition, including overcoming barriers.

RESULTS

Themes among the responses to the nomination request included the following:

1. Many more responses to the nomination request contained expressions of interest in the research and its findings or comments on transition than a nomination of a particular primary care provider. Typical of the frustration is the comment of 1 parent respondent: "We have received no assistance in the transition. . . Everything we have set

up has been parent initiated. . . ." Another parent reported, "There must be an easier way to get an 18-year-old diabetic patient out of pediatric care. . . At our last visit, the pediatrician failed miserably at handling our questions and concerns! . . . and that was what drove me to seek 'adult care' for my son." Still another parent commented, "It appears that we are being dumped by the pediatricians who brought us this far."

2. Fear and ambivalence characterizes health care transitions. A second theme expressed by respondents was one of ambivalence and reluctance to move toward transition, with 1 parent expressing: "I do not want to make the transition. . . I am very afraid. . . "
3. Transition is a process, not an event. Respondents suggested that it is important to recognize that transition is a process in contrast to an event, a theme represented by this parent's comment: "She always included some discussion of what my daughter will need to do for herself as she gets older. I see more and more of the conversations regarding her health being directed to her [my daughter]."
4. Providers need to orient to the future. An important element to think about is the provider's attitude and orientation to the future. Recognition of the provider's hopefulness and orientation to the future was reflected in 1 parent's nominations: ". . . two exceptional physicians who really care about our daughter's wellness, technology needs, and future within [the] community."
5. Family physicians see transition as integral to their practice. Two parents who nominated family physicians commented on the way that transition is an integral component of care by family physicians: "When the whole family is considered from the start, transition is not a developmental crisis and becomes a moot point" and "I guess I didn't realize we had gone through a transition period!"

Respondent Demographics

Of the 13 completed responses, 3 were excluded from the analysis because the nature of their practice was not primary care. The remaining 10 responses are the focus of this preliminary report. Eight reported training in pediatrics, 1 in family medicine, and 1 in medicine/pediatrics. Data are presented to highlight themes for consideration and not with any attempt to draw statistical significance. All reported that a majority of their work is done in an outpatient clinic setting. Most respondents' perceptions were that they see "about as many" youth with chronic conditions as their colleagues see, several indicated that they see "many more," and 1 reported seeing "fewer." Overall, most of the group was somewhat or very satisfied with their transition efforts, 2 were somewhat dissatisfied, and 1 was neutral.

Early Experiences With Transition

A clinical experience was the way most respondents first became aware of the need to address transition issues, and parent or patient request was the point of entry or awareness for 2 respondents.

Notably, no respondent reported becoming aware of the need as a result of an institutional policy, clinical guidelines, or requests for referrals from adult-oriented providers. To the open-ended question exploring these responses, 1 physician replied: "As a [pediatric] resident I once took care of a 30-some year-old man with Down syndrome who had heart disease, it was clear that our expertise was not in his best interest any longer." There was considerable variability in where the respondents sought guidance on developing an approach to transition. When asked to whom or from where they received guidance on transition issues, most indicated colleagues in medicine or those in other health fields (eg, education, social work, psychology). Almost no one indicated using published guidelines or continuing education programs.

Views on the Important Issues in Transition

Of the 14 transition-related issues explored, those rated as most important by respondents are representative of the medical, behavioral, and social domains of transition (Table 1). All respondents endorsed as very important 2 issues: 1) that adolescents should be able to describe the signs and symptoms requiring urgent medical attention; and 2) that adolescents understand the implications of their condition and treatments on their sexuality and reproductive health. Second-order priorities included: 1) the importance of young adults addressing access to insurance; 2) ensuring adolescents' awareness of condition-specific supporting organizations; and 3) the ability of adolescents to describe the roles of primary care providers and subspecialists. Differences between the reported importance and effectiveness were explored to identify areas in which linkages to community resources or additional training for providers might be important. Overall, the largest gap between importance and effectiveness was in the

area of sexuality and reproductive health. Among the 2 issues reported as the most important, the gap between importance and effectiveness was greatest for understanding the impact of health-promoting behaviors. Narrow differences were noted when the focus of the issue was on the more cognitive functions of understanding the medical aspects of the condition, and the gaps were greatest when the nature of the issue was psychosocial or behavioral.

The Transition Process

Key to the transition process, primary care providers suggest, is individualized care for their patients rather than a uniform protocol. One response was brief: "no typical process." Others detailed the factors influencing the process: "the factors include the specific problem, my comfort level with the problem, availability and interest of other physicians, and patient/family attitude." Another suggested: "this varies greatly on the child, his/her condition, and the family." Additional comments indicated that the individualized effort of the physician is integrated into other services, represented by the comment: "We're alert for transition issues at each clinic visit." Two efforts were described as a specific transition effort. No response provided sufficient detail to allow for a summary of the entire approach and process to be provided here.

Barriers to Transition

Among 8 potential barriers to transition, respondents acknowledged 4 as most significant: 1) difficulty identifying adult primary care providers; 2) adolescent resistance; 3) family resistance; and 4) lack of institutional support (Table 2). Most respondents suggested that they were able to overcome adolescent and family resistance.

In addition, difficulty finding an adult provider is acknowledged as one of the most challenging issues.

TABLE 1. Role Perceptions: Respondent's Perceived Importance of and Personal Effectiveness at Facilitating Accomplishment of These Transition Issues

Adolescents Should Be Able to:	Importance	Effectiveness	Difference
Describe their current condition and treatments	2.78	2.38	.40
Describe the long-term complications of their condition	2.56	2.33	.22
Describe a plan for maintaining and utilizing health insurance benefits	2.11	1.67	.44
Monitor treatments and health parameters	2.78	2.22	.56
Discuss symptoms and treatment plans with their health care provider	2.78	2.56	.22
Describe the role of the primary care providers and subspecialists	2.20	2.00	.20
Describe signs and symptoms that require urgent medical attention	3.00	2.60	.40
Identify emergency health services	2.67	2.56	.11
Understand the impact of their condition and treatments on their sexuality and reproductive health options	2.70	1.90	.80
Be aware of and involved in condition-specific organizations for support and information	2.33	2.22	.11
Be aware of the impact of drug and alcohol use	2.78	2.56	.22
Understand the impact of healthy behaviors (exercise, appropriate nutrition, and rest)	3.00	2.44	.56
Have a substantial connection to caring adults	2.67	2.33	.33
Have a family that supports the transition process	2.80	2.40	.40

TABLE 2. Rank Order of Potential Barriers to Achieving Successful Health Care Transitions

Potential Barriers
1. Difficulty identifying adult primary care providers
2. Adolescent's resistance to transition to an adult provider
3. Family resistance to transition to an adult provider
4. Lack of institutional support (time for planning, resources, personnel)
5. Lack of time to address important transition issues
6. Lack of reimbursement for time spent
7. Difficulty communicating with adult providers
8. Difficulty identifying adult subspecialists

Lack of time for the provider to address issues, lack of support staff, lack of institutional support, and lack of funding to support time spent were also listed as among the significant, though not as critical as other, issues noted above.

Although there was consistency among respondents in identifying the lack of adult primary care providers as a key barrier, there was no common response when asked how they identify adult providers. Among the range of answers, the pessimistic response "luck" may summarize the predominant approach.

Responses to the request for suggestions to assist other clinicians to address transition in their practice are reported in Table 3.

DISCUSSION

The survey describes approaches to transition services as reported by a limited number of primary care physicians, physicians nominated because of their approach to facilitating transition. These respondents indicated that it is equally important to address the medical, behavioral, and social issues in transition care, and they clearly see transition as more than transfer of care. Individualization of services is the single consistent approach employed by these physicians. Consistent with the individualized approach is the considerable variability in the importance of most barriers except the systems barriers. Although the objective of this research was not to quantify the extent to which primary care physicians are involved in transition issues, it is noteworthy that few nominations were received despite a broadly transmitted nomination approach.

Are the low rate of nominations and low response rate to the survey indicative of the state of primary care transition services across the United States? The response to our search for interdisciplinary transition programs in 1995 yielded many more programs than we had anticipated, yet for this current search for primary care physicians, just the opposite is true. Perhaps e-mail has not yet become a viable means of

TABLE 3. Respondent's Suggestions for Successful Transitions

• View transition as a continuum.
• Start early.
• Work as a team.
• Emphasize to all the importance of having an adult health care provider.
• Use common sense.

accessing parents and youth with chronic conditions. Perhaps seeking distribution of the nomination requests through the parent and condition-specific advocacy organizations was not successful at reaching those parents and youth with the information we sought. It is notable that few primary care physicians were nominated when the nomination request was sent by US mail to parents of adolescents in the Minnesota Children With Special Health Needs program. One state policy planner commented on the low response rate: "Why the low response rate? I strongly suspect that primary care physicians are doing little in this area." Although no conclusions can be made from this data regarding the frequency of which primary care physicians are providing transition services, there appears to be a mismatch between the need for service and the level of services provided.

Individualization of services, an approach taken by many of the respondents, fits with our knowledge of the needs of youth and families and the experience of practitioners. From an epidemiologic perspective, a significant proportion children and adolescents may be classified as having a chronic condition. Yet, the prevalence of most chronic conditions in childhood is low enough that any individual primary care provider is unlikely to care for more than a handful of youth with any 1 significantly disabling condition. From a family and youth perspective, there is a clear need to feel that services should be fit to their own needs.¹⁹ Whether by design or as an adaptation to circumstances and experiences, tailoring the set of services and the approach to meet the need of each individual fits the context of primary care.

The obstacles to successful transitioning, from the perspective of these primary care physicians, are representative of the multiple stakeholders involved in the health of youth and young adults with chronic conditions. The youth themselves, their families, and the system of care itself are perceived to be significant barriers. Systems issues appear to be the most difficult to overcome. This survey explored the potential barriers described by Schidlow and Fiel²⁰ more than a decade ago. As was found among a study of interdisciplinary transition programs, youth and family resistance was not as important a barrier as might have been anticipated by discussions in the literature. That most physicians suggested they are able to overcome youth and family resistance is quite hopeful. Unfortunately, responses to this survey do not elucidate what exactly leads to reduced resistance.

The gap that was identified between the importance that the physician respondents attributed to an issue and their perceptions of their own effectiveness at addressing the issue is suggestive of the need for additional training. Specifically, issues of behavior and behavior change and sexuality and reproduction are identified as areas that these respondents felt least effective at addressing. Training may be needed to facilitate the development of skills and competencies or to identify and link to alternative community-based resources. Several surveys have identified the need for training for pediatricians in the area of

chronic conditions²¹ and specifically for transition services.^{22,23} Yet, the recent report on the education of general pediatricians,²⁴ which acknowledges the need for physicians to address the issue of transition, makes no recommendations on how that may best be accomplished.

Limitations of This Survey

The sample of health care providers was collected by means of nomination by families who felt their providers worked to facilitate transition. They are in no way representative of physicians in North America. This sample does not allow for generalization to all physicians and was not collected with such an expectation. The nominations were accessed primarily through organizations that support individuals with chronic conditions and their families, and only individuals connected with these organizations were available to respond. It is likely that many people do not seek the support or belong to these organizations and, as such, represent an untapped group with a different perspective. Additionally, e-mail was used as the means of contacting the organizations; many of these organizations in turn distributed the nomination survey via e-mail to their constituents. The extent of the reach of the e-mails is unknown. As discussed previously, the limited response rate and very small sample size, although important findings themselves, make conclusions based on this data only speculative and worth exploring with a larger sample of physicians.

The small sample size of this survey means that still little is known about the ways that transition occurs in primary care settings. Given the importance of the issue, additional study is suggested regarding the way that models of enhanced primary care and preventive, such as *GAPS*, *Bright Futures*, and the medical home model, can and are appropriately addressing transition.

Implications

Over the past 2 decades, the issue of transition from child-oriented to adult-oriented health care settings has generated increasing interest among parents and policy makers, but it is not clear that the issues have been embraced by primary care physicians. The literature on transition together with the results from this survey identify 2 key issues that must be addressed to advance the state of services for adolescents with chronic conditions and their families. First, training for physicians must be developed for those who have traditionally cared for these adolescents as well as for those who will be increasingly called on to care for adults with childhood chronic conditions. Training in adolescent health should include specific issues in transition for youth with and without chronic conditions. And likewise, training in developmental and behavioral pediatrics should include training in adolescent issues. Specifically, special attention should be paid to developing competencies in addressing psychosocial and behavioral issues; this is probably true for working with youth who have chronic conditions as well as youth who are otherwise healthy. Training for physicians

in internal medicine and family medicine will need to include topics such as addressing the medical, emotional, and developmental issues involved in the care of young adults with what were once strictly “pediatric” conditions. The tenets of the medical home model, that care should be accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective, provide a useful framework for ensuring awareness among physicians and those responsible for their training of the components high-quality care.

Particular attention to the role of the family in the transition process may be especially important. For many adolescents transitioning to adult-oriented care, the role of the family may be diminished over time or even be perceived as being noncontributory, and for many others, especially those young adults with the most significant and disabling conditions, the role of the family changes but remains vital. Training for pediatric residents through programs, such as the Parents-as-Teachers initiative, is helping to move care to a more family-centered system.²⁵ These programs offer future pediatricians an opportunity to gain meaningful insights into the vital role of families in the lives of youth with chronic conditions. Furthermore, they may open the door to establishing partnerships between parents and physicians, partnerships that, if sustained, are likely to facilitate transition. The Parents-as-Teachers program at the University of Minnesota now includes a component that brings trainees and parents together to discuss transition issues. The next step in such programming may be to do the same in a “Youth-as-Teachers” program in which the adolescents themselves, together with the trainees, engage in open and frank discussions regarding transition outside the constraints of a clinical encounter.

Second, a framework for developing institutional support should be created, because lack of institutional support is a major barrier to providing transition services. Physicians need the support of, and need to support in return, nurses and administrators in addressing this issue. Clearly, the development of transition services is a complex task; there is no single change that will alter the entire process, but success is likely to be achieved by a sustained, multidimensional effort on the part of all those involved working together.

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