

Transition Programs in Cystic Fibrosis Centers: Perceptions of Team Members

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Summary. We previously surveyed cystic fibrosis (CF) center directors and adult patients with CF to assess their perceptions regarding transition from a pediatric to an adult setting. An important finding in those studies was a lack of standard programs for transfer of young adults with CF from pediatric to adult care settings. Patients with CF typically receive care from clinics utilizing a multidisciplinary approach, suggesting that every member of the CF team can impact the transition process. Our purpose in this study was to gain an appreciation for various team members' perspectives on transition. An Internet survey was offered to all CF centers across the country to be completed by team members, excluding physicians. We received 291 completed surveys, nearly half completed by nurses, but our respondents included social workers, nutritionists, respiratory therapists, and a few team members with other training. Nearly half of the respondents work for both pediatric and adult teams. The majority of respondents (71.8%) reported that their adult patients receive care from an internist in a separate adult program, but nearly 20% reported that a pediatrician follows their adult patients. A minority thought that age (37.4% of respondents), marriage (16.2%), and pregnancy (27.1%) were criteria for transfer, though most (86.2%) suggested that patients should be transferred by age 21 years. Criteria precluding transfer included patient/family resistance (45%), disease severity (34%), and developmental delay (31.3%). It was uncommon (11.4%) for an introduction to the concept of transition at the time of diagnosis. Over one-half of patients did not meet the adult team until time of transfer. Team members' perceptions of patients' concerns were similar to what we had previously measured in physicians, again far greater than what we have measured in patients themselves. In many ways, what we have measured here in team members reflects what we have reported by physicians, demonstrating slow development of standard transition programs and an overestimate of patients' concerns regarding transition. These differences may impede the successful transition of patients into an adult program. It is clear from this study that team members have an interest in and opinions on transition, and are likely play a vital role in the transition process. Standard programs of transition should be developed, and team members should be engaged in that process. **Pediatr Pulmonol.** 2004; 37:4–7. © 2004 Wiley-Liss, Inc.

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INTRODUCTION

In concert with the growing population of adults with cystic fibrosis (CF), there is now recognition of the need for adult CF programs. It is accepted that it is appropriate to transition patients to adult programs.¹ Recent research has focused on optimal methods for transferring these patients to adult programs. In our surveys of CF center physicians (both pediatricians and internists)² and CF patients³ regarding their perceptions about transfer and transition, we found a lack of standard programs for transfer of young adults with CF from pediatric to adult care settings. Physicians, especially pediatricians, perceived that CF patients had moderate to high concerns about transfer, a finding not reported by patients themselves. Importantly, physicians and patients reported a desire for a transition process prior to a transfer to adult programs.

Numerous investigations exploring transition issues among chronically ill pediatric populations²⁻⁵ were applied to patients, families, and physicians, presuming these to be the primary parties of interest. However, patients with CF have historically received their care from pediatric clinics utilizing a multidisciplinary approach. The traditional multidisciplinary approach to CF care suggests that every member of the CF team can impact the transition process. It is possible that other team members' perspectives diverge from those of physicians, either supporting or opposing transition and transfer. We felt that it was imperative to gain an appreciation for various team members' perspectives on the transition process. The purpose of this study was to obtain CF team members' unique perspectives regarding transition, and to compare these perspectives to those obtained from physicians and patients previously assessed using a similar methodology.

METHODS

For the purpose of this investigation, transition was defined as a purposeful, planned preparation of patients, families, and caregivers for transfer of the patient to an adult program. Transfer is defined as the actual responsibility of patient care being moved from a pediatric to an adult care setting. The Institutional Review Board for the Protection of Human Rights at the Medical University of South Carolina approved all aspects of this investigation.

ABBREVIATIONS

CF	Cystic fibrosis
ITP	Individualized transition plans
IEP	Individualized education program
IDEA	Individuals with Disabilities Education Act
MANOVA	Multiple analyses of variance
SD	Standard deviation

The CF Transition Survey: Team Member Version is similar to surveys previously completed by CF physicians and patients with CF.^{2,3} The survey was offered over the Internet, and all CF centers across the country were asked to have their team members, excluding physicians, complete and submit the survey electronically. Respondents were asked about information across three domains: 1) organization of CF care and team structure; 2) respondent's role on the CF team; and 3) issues related to transfer of care, including respondent's perceptions about patient's transition and success of established transition programs. Questions and available responses were identical to those posed in previous investigations of physician and patient perceptions of transition, and utilized a Likert scale (range, 0–3; 0, no concerns; 3, serious concerns). Results are reported as means (\pm standard deviation).

RESULTS

We received 291 completed surveys. It is unknown how many potential respondents were available, so no response rate can be calculated. Respondents were as follows: 135 nurses (46.4%), 49 social workers (16.8%), 46 nutritionists (15.8%), 34 respiratory therapists (11.7%), and 27 (9.3%) team members who were classified as "other" (e.g., physical therapist, psychologist, or genetic counselor). The mean age was 41.2 (\pm 8 years), and the majority of respondents were female (90%). Years of service involved with CF care were 7.8 (\pm 6.1 years), and with the current CF team were 6.8 (\pm 5.6 years), with a range of 1–27 years. The majority (79.1%) of respondents reported working at a center with a separate adult program.

The survey asked respondents to describe the professional composition of the multidisciplinary team providing clinical services to adult CF patients. The typical team consisted of a nurse (99.3%), a nutritionist (97.6%), a social worker (95.9%), a pulmonologist (93.8%), and a respiratory therapist (85.6%). Less common members were a psychologist (37.1%), physical and/or occupational therapist (36.4%), and a genetic counselor (26.1%). Almost half of respondents (46%) provided services to both pediatric and adult teams, while 34% served on the pediatric team only, and 20% on the adult team only.

Team members reported three types of CF care for adults. Most reported an internist working within a separate adult program ($n = 196$; 71.8% of those who answered this question). Less common was an internist attending the pediatric CF clinic ($n = 29$; 10.6%). There were many ($n = 48$; 17.5%) who reported no internist involvement, such that adult CF patients continue to be followed by a pediatric CF physician in the pediatric setting.

Team members were asked to identify criteria leading to transfer of CF patients from the pediatric to the adult

clinic. Age of the patient was the most commonly cited criterion automatically leading to patient transfer (37.4%), followed by pregnancy of the CF patient (27.1%), and marriage (16.2%). The majority of team members (86.2%) endorsed CF patients being transitioned by the time they reach age 21 years. Team members reported that patient and family resistance to transfer (45.0%), medical severity of disease (34%), and developmental delay (31.3%) were the most common factors that would prevent transfer of patients to the adult clinic.

Team members were also asked specific questions regarding the introduction of patient and family members to the transition process. The majority of team members (55.4%) indicated that patients are introduced to transfer prior to age 18 years, while 11.4% indicated that transfer is introduced at time of diagnosis. Respondents identified a mean age of 15.8 years as the age when patients should be introduced to transfer (range, 10–21 years). Responses did not differ whether the individual worked with the adult team only, pediatric team only, or both teams.

Using the format of questionnaires previously administered to physicians and CF patients,^{2,3} we surveyed team members' perceptions of patient concerns regarding transfer of care, and we compared these perceptions across team member roles. Overall, team members rated perceived patient concerns about transfer as "mild" to "moderate." Comparison of group means (team member role \times perceived patient concern) suggests that team members' perceived patient concerns are not clinically different from each other (Table 1). The physical therapists rated the least perceived concerns, but this was not statistically significant. In addition, team members were asked to rate how receptive each of the groups was to the concept of transfer. Ratings indicated that overall receptivity was moderate (ranging from mildly receptive to moderately receptive, according to group). When team members were asked to rate the success of their transition program, the majority of respondents reported feeling that their transition program was moderately successful, and this finding was not dependent on team role.

Finally, we conducted a multivariate analysis of variance (MANOVA) comparing the results of how team members perceived patients' concerns regarding transition to those rated by patients themselves and those of pediatric and adult CF program directors, as reported in prior studies.^{2,3} We felt that such a comparison was legitimate, as the questions and response choices were identical. Follow-up a priori, pairwise comparisons were conducted using the Bonferroni technique. We previously showed that pediatricians and internists differed with regard to their perceptions of transition difficulties for patients.² Specifically, pediatricians consistently described patients as having greater concerns with transition than did internists who completed this survey. In this analysis, team members endorsed concerns regarding transition most similar to those of internists. These are greater than those concerns endorsed by patients themselves.³

DISCUSSION

The team concept has long been valued in CF; it has been said that "the best care is that done in a multidisciplinary approach."¹ As such, CF team members can play vital roles in promoting or inhibiting the transition of patients from a pediatric to an adult care setting. Some centers advocate a team approach to transition, including the evaluations of ward nurses, clinic nurses, dieticians, physiotherapists, and physicians to determine the appropriate time to transfer each patient.⁶ The purpose of this survey was to assess the opinions of team members with respect to transition. The large number of responses that we received suggests that transition is an important issue to team members. Though we cannot know how many surveys could have been completed or how many centers are represented in this study group, we had 291 responses, which is an average of 2.65 per center (based on 110 centers in the CF Foundation network). This group represents considerable experience in CF care, meaning that there is plenty time for most to develop an opinion about the issue of transition.

Systematic approaches to transition have positive benefits.⁷ For example, a structured program for adolescents

TABLE 1—Comparison of Team Members' Perceptions of Patient Concerns Regarding Transition¹

	Nurse (n = 86)	SW (n = 33)	Nutritionist (n = 30)	RT (n = 21)	PT (n = 5)	Other (n = 6)
Unfamiliarity with adult staff	1.43 \pm 0.80	1.09 \pm 0.63	1.47 \pm 0.82	1.33 \pm 0.91	0.60 \pm 0.55	1.00 \pm 0.63
Strong relations with pediatric staff	1.88 \pm 0.87	1.58 \pm 0.75	1.87 \pm 0.86	1.81 \pm 0.81	0.80 \pm 0.84	1.50 \pm 1.05
Adult staff meeting medical needs	1.08 \pm 0.83	1.09 \pm 0.72	1.07 \pm 0.94	1.29 \pm 0.96	0.40 \pm 0.55	1.00 \pm 1.10
Adult staff meeting emotional needs	1.15 \pm 0.80	1.18 \pm 0.77	1.00 \pm 0.98	1.14 \pm 0.96	0.60 \pm 0.55	1.00 \pm 0.89
Reluctance to leave pediatric setting	1.55 \pm 0.93	1.36 \pm 0.74	1.53 \pm 1.04	1.57 \pm 1.03	1.00 \pm 1.00	1.50 \pm 1.05
Difficulty in assuming control	1.31 \pm 0.74	1.42 \pm 0.75	1.30 \pm 0.65	1.10 \pm 0.62	0.80 \pm 0.45	1.17 \pm 0.41

¹SW, social workers; RT, respiratory therapists; PT, physical therapists; Other, psychologists and genetic counselors. Values reported are mean \pm SD based on Likert scale, range 0–3, with 0 = no concerns and 3 = serious concerns; no differences were statistically significant.

was associated with overall satisfaction.⁸ Features that suggest a successful transition program include defined criteria for transfer, integration of transition with specific developmental milestones, and transfer of all (or nearly all) adult patients to the adult care setting. Our findings, with respect to these features, suggest that the state of transition programs across the CF network is still not well-developed.

As a group, the CF team strongly believes in the general concept of transition, but there is great variability in the criteria used for transfer. Although age is a frequently cited criterion for transfer, and the most common identified here, it was chosen as a criterion by less than 40% of respondents, and too many (nearly 15%) suggested that transfer could occur beyond age 21 years. There also appears to be disagreement among team members regarding criteria that either mandate or preclude transfer of patient care from the pediatric to the adult setting (e.g., age of patient, severity of illness, marital status, or pregnancy). Instead of selecting rigid criteria for transfer, many provided comments as to how they decide when to transfer patients. They included: "patients should be transitioned when they are developmentally ready," "readiness to transfer should be specific to each patient and how prepared they are," and "transfer should depend on emotional development." How this time is determined and by whom was not offered in any comments.

Blum⁹ suggested that there are three critical times at which we can facilitate the transition process: at time of diagnosis, during puberty, and at time of transfer to an adult program. Betz⁷ stated, "Ideally the transition process is approached from a lifespan perspective, which means it begins early in childhood." Yet very few of our respondents (14%) reported their transition programs as starting very early (i.e., at time of diagnosis). When the concept of transition was introduced to patients and their parents varied greatly across settings and team members. Only about half began the transition process by age 18 years, and the majority (52%) did not meet the adult team staff until time of transfer.

The final feature of a structured transition program is the measure of how many adult patients have made the transfer to an adult program. Disturbingly, nearly 20% of team members reported that adult patients still receive care in a pediatric setting, even though there is an existing adult program.

We asked team members to rate the perceived concerns of patients, parents, and both pediatric and adult teams

regarding transition. In general, perceptions of team members regarding transition are closely aligned to those held by treating physicians, especially internists, in CF centers.² It is impossible to tell if team members' opinions conflict with those of the M.D.s from their respective centers.

The Individuals with Disabilities Education Act (IDEA) specifies that individualized transition plans (ITP), as part of an individualized education program (IEP), be developed for adolescents with disabilities between ages 14–16 years. In order to achieve this goal, members of a transition team convene and plan and develop the ITP.⁷ Similarly, transition programs in CF centers should include evaluations by team members, including nurses, dietitians, social workers, respiratory therapists, physical therapists, and psychologists. It is clear from this study that these team members have an interest in and opinions on transition. There is a need to develop standard programs of transition and transfer, and incorporate the team members in the process. Other programs reported success when team members other than physicians, such as nurses,^{7,8,10} coordinate the transition process.

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