

Virtual Mentor

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Clinical Case Transition of Care

Commentary by Jonathan Spahr, MD, and Don Hayes, Jr, MD

Heather Jorgenson was born with cystic fibrosis (CF) and has been under the care of the pediatric CF team since her diagnosis. As a child, Heather was quite healthy and had few hospitalizations. At age 3 her parents divorced, and her mother remarried shortly thereafter. Heather's father has maintained limited contact with her since that time. Heather moved into an apartment with her mother and stepfather, a smoker, and it was at about that time that she began to need more hospitalizations for CF exacerbations. She has been in charge of her own medications and chest physical therapy since she was 16, when her mother felt she was "old enough to do all that herself." Heather spent so much time in the hospital during 11th grade that she failed her exams and had to repeat the year.

Heather's pediatric CF team consists of Dr Smith, as team leader, and a group of physicians, nurses, nurse practitioners, social workers, respiratory therapists, and nutritionists who closely monitor her care from multiple angles. At each clinic visit she sees several team members who provide information, support, and reinforcement of positive medical treatments.

At 19, Heather has just finished high school and is working part-time as a cashier, while living with her mother and stepfather. On her last visit to the University Pediatric CF unit, Heather talked with her pediatrician, Dr Smith, about her ambition, saying that she would like to become a veterinary assistant in the future, but that she has not yet applied to any colleges or vocational programs. Heather says that she began smoking about 2 years ago and, when Dr Smith asked about alcohol use, she said that she drinks alcohol 2 or 3 times a week. She said she does not use any other drugs and would like to quit smoking. She says she takes her prescribed medications according to directions, but her frequent hospitalizations suggest that she may be slipping in this regard. She has kept approximately half of her scheduled appointments in the CF clinic, often showing up late.

The hospital administration has put pressure on the pediatric CF team and Dr Smith to transfer Heather to the adult team—a transition that usually occurs when the patient is about 18. The hospital has received complaints from parents of patients on the pediatric unit that Heather is too old to be there. Several parents have also expressed concern about the way Heather dresses and the friends that visit her while she is on the unit. One parent claimed to smell cigarette smoke coming from Heather's room.

The pediatric CF team is concerned about Heather: her smoking and suspected noncompliance with her medication worries doctors that she could “slip through the cracks” with the less intensive monitoring that goes along with adult patient care but Dr Smith understands that Heather is no longer a child and must accept the consequences of adult decision making. When Dr Smith asked Heather how she felt about the transition, Heather said, “whatever you guys decide is fine with me.”

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The early stage of cystic fibrosis is a time of mild lung disease, and health care is provided to pediatric patients with no expectations placed on them and no questions asked. As these patients age and the disease progresses, more intensive care is needed. Suddenly, as adolescents, they face a demanding health care regimen, often placed upon them without adequate preparation. It is difficult enough in our society to be a healthy teen let alone one with CF, a condition that requires daily medical care. Therefore, compliance is a seed that must be planted early in the life of a child with CF. A lack of preparation can lead to the problems seen in Heather Jorgenson’s case.

The transition from pediatric to adult cystic fibrosis care is difficult for the patient, the family, and the clinicians involved. Relationships between patients and families with the CF team may have existed for several years. Often, the intensive monitoring and care provided by the health professionals is given with little or no input by patients or families. This hand-holding approach is commonly observed, and without active involvement by patients and families it leads to the type of behavior described in this case. It is only natural that pediatric clinicians develop a nurturing relationship with patients they have known from infancy. Consequently, it is sometimes difficult for pediatricians to place responsibility on their patients as they age, and this may prevent opportunities for the patients to mature in their ability to be responsible for their own care.

Heather is now starting to make adult decisions about smoking and using alcohol, even if they are irresponsible decisions. Her actions demonstrate that she wishes to be treated as an adult and should be transferred to adult care at this time. By keeping her in the pediatric clinic, the staff will enable her to be dependent upon them for her CF care.

Heather’s indifferent response about her own preferences for medical care is quite common among children beginning to move from pediatric to adult care. Health maintenance is low on the priority list for young adults, so it is not unexpected that Heather appears disengaged when it comes to matters of her health. It may be difficult for the pediatric team to let go of long-term patients with confidence that they will continue to receive good care. This phenomenon has been demonstrated in previous studies [1,2].

An Ideal Transition

The ideal method would have been to start Heather's transition years before her 18th birthday so that she would gradually be ready to take on more responsibility. For example, Heather would have been responsible for taking her medications and refilling them, making her own appointments and carrying her insurance card at the beginning of her teen years in order to become the primary party with responsibility for her health care.

As it is, we now lack the luxury of time, and, while it may be uncomfortable, the transition needs to occur for the sake of Heather's maturation process. Furthermore, Heather seems to be languishing in her pediatric clinic; only keeping half of her appointments and needing several hospitalizations in the last year. This will only continue if a change is not made.

Teams Must Meet in a Care Continuum

Another factor in Heather's transition is the relationship between the pediatric and adult CF teams. If the pediatric team has confidence in the adult team, they will feel more comfortable about the transfer. A meeting between them specifically about Heather would be beneficial, so that the pediatric team can voice their concerns and open up a line of communication that should exist throughout the transition. While there should be a specific point in time when the adult team assumes primary responsibility for Heather's CF care, the transition process should be ongoing, a continuum during which the pediatric and adult teams both contribute to the care plan, although all contact with Heather should be through the adult team only, so that she identifies them as her primary caregivers.

Transition without preparation can be a painful experience. It is important for us, as pediatric care professionals, to realize that our patients will be adults one day and that we must promote the transformation from dependent child to self-sufficient adult. Heather's case reminds us that if we allow our patients with chronic diseases to continue their dependence upon us for all aspects of their care, then we have done them a disservice. As pediatricians, we are responsible not only for providing health care to our patients, but also for making sure that they are allowed to mature into adults who can advocate for their own health care.

References

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