



Family Matters

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Patient- and Family-Centered Transitions From Pediatric to Adult Care

Juliette Schlucter

*"Pick me, choose me, love me."
— Meredith Grey, "Grey's Anatomy"*

This fall, we sent our third child off to college. With one last check around her dorm room, we said our goodbyes. I left emotional and teary-eyed, but feeling confident that our daughter was ready—ready for one of the biggest changes in her life. As her parents, we were ready as well.

In large part, our positive experience with this major life transition was due to the investments made by both the high school our daughter was leaving and the university that was welcoming her. A full two years before her graduation, our daughter's high school anticipated the stress, anxiety, and need for being prepared. They shared checklists and recommended websites; they gave us numerous handouts, brochures, and DVDs. We heard testimonials from families about the road ahead. Parents and students demystified the transition process by sharing their personal experiences, good and bad alike. Ultimately, this information and these informal mentors gave us the peace of mind we needed, and letting go became just a little bit easier.

At the same time, the university search, while daunting, introduced us to one university after another that was

This article is the second in a series addressing the critical issue of the transition from pediatric to adult care for young adults with complex chronic conditions. Using the analogy of her daughter's recent transition from high school to college, the author highlights some of the needs of young adults and their families in a transition process. Then, drawing upon her years of experience in the field, she explains why the core principles of patient- and family-centered care are foundational to successful transitioning from pediatric to adult health care.

showcasing how ready they were for our daughter. We did tours and attended orientations. Our daughter's email box was full of updates and timelines, suggestions, and recommendations. We had maps and parking grids. We studied campus protocols and read endless FAQs. When she had finally chosen the school of her dreams, they had already anticipated almost every step of her transition from a high school senior into a successful freshman. *Pick us, choose us, love us! We're ready for you...*

I am the mother of two chronically ill young adults who are living with cystic fibrosis (one of whom is this new college student) and an advocate for patient and family-centered models of care. In these roles, I notice that this high school-to-college transition experience parallels the other huge transition our family is anticipating: the transition from pediatric to adult health care.

Leaving my daughter's university and heading home, I spent the long car ride thinking about how much the health care system could borrow from this well-planned and resource-rich high school-to-college transition process, a process that included the perspectives, choices, and needs of the young adults and families on the journey.

The topic of transition to adult care has been addressed elsewhere in terms of documented gaps in adult clinical programs for what have been traditionally pediatric illnesses as well as best practices for the care coordination and the care management aspects of transition (American Academy of Pediatrics; American Academy of Family Physicians; American Society of Internal Medicine, 2002). This article focuses instead on incorporating the perspectives of patients and families as the foundation for the design of patient and family-centered transition programs.

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Acknowledgment: The author would like to acknowledge the editing contributions of Susan K. Stathakes, M.Ed., health care writer and developmental editor.

Note: The author acknowledges that terms such as "parents" and "families" are broadly defined in a patient- and family-centered care environment. For the purposes of this article, the word "parent(s)" signifies whomever the patient and family define as having a primary role of caring for the pediatric patient.

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Elizabeth Ahmann, ScD, RN; Series Editor, or Deborah Dokken, MPA, Series Editor; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

Understanding the Perspectives Of Patients and Families

Years of family-centered care assessments, focus groups, and research in many pediatric settings have provided valuable information from the unique perspectives of families and patients transitioning their health care to adult providers. Here are recommendations patients and their families have consistently shared:

- Start talking early about transitioning to adult health care. Families are typically thinking about this process long before anyone on their clinical team(s) raise the topic.
- Help anticipate needs and challenges by providing easy access to information.
- Remove the mystery of when, how, and who will be involved. Build a level of transparency about the process. This helps ease apprehension and empowers all in their new roles.
- Provide options and choices, and be able to modify the approach, if possible, for the unique needs of every patient and family.
- Encourage young adult patients to be proactively involved in the decision-making process; involve them in deciding on the best timing for the transition.
- Help adult care providers understand that many former pediatric patients and their parents bring with them a wealth of knowledge about their illness; in fact, many have been managing and coping with their conditions for all or most of their lives.
- Make sure all parties – all health care providers as well as the young adult and family – are on the same page and have access to the same information, especially other pediatric specialists and the adult team to whom the patient is transitioning.
- Recognize that for some individuals, transitions can mean loss – loss of relationships with the pediatric team, loss of control, and loss of a comfortable context and a known history of how decisions about clinical health and care management have been made.

Not surprisingly, expertise shared by patients and families can serve as a template for the design of a well-coordinated, open, respectful, and compassionate patient- and family-centered process for transition to adult care.

Patient- and family-centered care places emphasis on mutually beneficial partnerships between patients, families, and health care professionals. It acknowledges that families, however they are defined, are essential to patients' health and well-being, and are allies for quality and safety within the health care system (Brewer, McPherson, Magrab, & Hutchins, 1989; Institute for Patient- and Family-Centered Care, [IPFCC], 2010). Table 1 provides key features of transition programs that are well aligned with the core concepts of patient- and family-centered care.

Benefits of a Patient- and Family-Centered Transition Program

The Institute of Medicine's (IOM) six aims for health care in the 21st century include care that is safe, effective, patient-centered, timely, and equitable (IOM, 2001). Developing and implementing transition programs in partnership with the patients and families involved in the transition from pediatric to adult care supports these aims and provides a number of benefits including:

- Improved patient and family satisfaction when needs are anticipated and supported.

- A culturally sensitive approach that meets the needs of diverse patient populations.
- Engaged and empowered patients prepared to manage their own health care in adult settings.
- Improved staff efficiencies when transition resources are shared and communicated across disciplines and settings.
- Improved safety and quality with well-coordinated handoffs of medical history and clinical information from pediatric to adult care.
- Improved management of hospital resources, such as duplicate tests and clinical studies when transitions are well managed and information is transferred proactively.

Emotional Aspects of Transitioning To Adult Care

"I want to avoid transitioning to adult care for as long as possible. I trust my pediatric pulmonologist with my life. He and his team know exactly how to partner with me to manage my cystic fibrosis. I can't imagine starting over."

—Julia Schlucter, Age 22

Although health care checklists have proven effective to ensure high reliability of processes and systems, they do not capture the important emotional aspects of a transition from pediatric to adult care. The pediatric health care team, the patient, and the family typically have a rich and significant history together, so ending these relationships can be challenging for everyone involved.

When I interviewed my own young adult son and daughter for this article, it was this aspect of transitioning that they spoke most about. Though they feel ready to manage appointments, prescriptions, and insurance, their overwhelming preference is to not have to leave the physician and health care team that know them best and have cared for them all of their lives. Many young adult patients share this sentiment. Over years of care, not only has an enormous knowledge base been built that is unique to this patient – but there is also the concept of "being known" and all of the emotional components associated with positive healing relationships.

Within a good framework of therapeutic relationships (McKlindon & Barnsteiner, 1999; McKlindon & Schlucter, 2004), it is important to give attention to and create the opportunity for saying goodbye. It may be helpful to set aside time on the last clinic visit for therapeutic closure for everyone, as well as to share how the patient and family can reconnect if needed and/or how to update the pediatric team about how the young adult is doing.

Summary

Universities know that when everyone is invested in a smooth transition process, they gain capable and prepared incoming freshman. The parallels are obvious: when young adults and families are included in the health care transition process, they are more successful at managing it.

But unlike the high school to college transition, health care transitions do not happen for an entire "Class of 2014." They happen on a case-by-case basis with goals, timetables, and complexities unique to each young adult and family.

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Table 1.
Key Features of Transition Programs Well Aligned with the Core Concepts of Patient- and Family-Centered Care

IPFCC Patient and Family-Centered Care Core Concept	Transition Program Elements
<p>Dignity and Respect: Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural background are incorporated into the planning and delivery of care.</p>	<ul style="list-style-type: none"> • Through formal and informal assessments, provide ample time for patients and families to share their perspectives, hopes, and concerns about the transition process. • Tailor resources to the unique needs shared by adolescents and their families. • Provide transition information in the primary languages the health care system serves. • Seek to understand from the perspectives of the adolescent and family, the cultural influences, values, and beliefs about childhood, the teen years, and young adulthood. • Acknowledge early on that stress or anxiety can be a normal part of any transition. Provide access to resources, such as Child Life, Social Work, Behavioral Health, and Peer-to-Peer programs, to support the unique psychosocial needs of adolescents transitioning to adult care. • Use principles of anticipatory guidance to partner with adolescents and their families. Be clear about what aspects of the transition to adult care will be flexible and open to discussion, such as goals for when to transition to adult care and choices of adult care programs.
<p>Information Sharing and Communication: Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.</p>	<ul style="list-style-type: none"> • Support adolescent and family member needs for clear communication, expectations, and estimated timelines. Families and patients need to be able to anticipate next steps and plan accordingly. • Provide information to adolescents and their families about the inherent differences between pediatric and adult care. • Be open and clear about the challenges and limitations in managing all the aspects of a transition. • Provide easy access to resources and information about transition from your own organization and offer varied national and community-based resources, such as www.gottransition.org • Identify one point of contact from the health care team with whom the patient and family can communicate to coordinate the transition process. • Maximize existing technology, such as the electronic health record and patient portal to everyone's advantage to support the sharing of information between the adolescent and family and the pediatric and adult health care teams. • Capture each adolescent's unique experience with his or her illness, as well as care management preferences, and ensure those are part of the patient history communicated and transferred to the adult health care team.
<p>Participation: Patients and families are encouraged and supported to participate in care and decision-making at the level they choose.</p>	<ul style="list-style-type: none"> • Depending on the developmental needs of the adolescent, encourage active participation in all of the decision-making aspects of the transition, including a determination of the best time for the transition to adult care, a review of potential providers, and touring new care locations. • Provide a transition resource (e.g., binder, folder, booklet) that supports active participation and engagement in the process. Include checklists to ensure the adolescent, family, and health care team are on track with the transfer of needed skills and information. • Host informational meetings and workshops so youth can share ideas, successes, and challenges with one another. Include teens and families who have transitioned to adult care as leaders of these meetings and/or to share their experiences and lessons learned.
<p>Collaboration: Patients and families are included as partners at the system-level. Health care professionals collaborate with patients and families in policy and program development, implementation, and evaluation.</p>	<ul style="list-style-type: none"> • Bring resources and transition program concepts and design ideas early to your hospital's Family and Youth Advisory Council for their review and input. • Consider creating a Transition Committee that includes adolescents, young adults, and families. Have the committee assess the needs across the health care system to ensure a consistent and well-coordinated approach across all diagnosis. • Utilize technology (e.g., Skype and WebEx) so all stakeholders, including adult and pediatric clinicians, adolescents, and family members, have an opportunity to collaborate, share information, establish goals, and effectively coordinate the transition. • Have young adults, their family members, and the health care team evaluate and provide feedback about the transition process to support a continuous improvement model.

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Challenges in implementing supportive patient- and family-centered transitions typically do not arise from a lack of will or intent on behalf of pediatric teams, but instead, from a lack of resources and genuine limitations on time as patient care loads increase.

Healing relationships grounded in mutually beneficial partnerships are the foundation of effective transitions programs. When transitions are mutually respectful, inclusive of the perspectives of all the stakeholders, accompanied by thorough and transparent communication, and effectively timed and well-coordinated, and when attention is paid to the emotional transition involved, everyone wins: patients, families, and pediatric and adult health care professionals.

The next article in this series will highlight a number of exemplary programs and resources for transitioning young adults. ■

References

- American Academy of Pediatrics, American Academy of Family Physicians, & American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*(6, Pt. 2), 1304-1306. Retrieved from http://pediatrics.aappublications.org/content/110/Supplement_3/1304.long
- Brewer, E.J., McPherson, M., Magrab, P.R., & Hutchins, V.L. (1989). Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*, *83*(6), 1055-1060.
- Institute of Medicine (IOM). (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.
- Institute for Patient- and Family-Centered Care (IPFCC). (2010). *What are the core concepts of patient- and family-centered care?* Retrieved from <http://www.ipfcc.org/faq.html>
- McKlindon, D., & Barnsteiner, J.H. (1999). Therapeutic relationships: Evolution of the Children's Hospital of Philadelphia model. *American Journal of Maternal Child Nursing*, *24*(5), 237-243.
- McKlindon, D., & Schlucter, J. (2004). Parent and nurse partnership model for teaching therapeutic relationships. *Pediatric Nursing*, *30*, 418-420.