Title

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Permalink

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Journal

Journal of palliative medicine, 17(4)

ISSN

1557-7740

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Publication Date

2025-02-26

JOURNAL OF PALLIATIVE MEDICINE
Volume 17, Number 4, 2014

DOI: 10.1089/jpm.2013.0263

Palliative Care Answers the Challenges of Transitioning Serious Illness of Childhood to Adult Medicine

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Abstract

Advances in the field of medicine have improved the overall life expectancy in children. Consequently, many children with previously lethal diseases now live into adulthood. There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. Palliative care, by virtue of its unique skills, is ideally positioned to play a part in this transition. This report will summarize the urgency for proper transition modalities and then introduce palliative care as a proposed solution for current challenges in transition. Along the way, it will touch on financial and workforce obstacles to this solution and will offer a potential funding option.

Introduction

As a result of advances in medicine, many children with previously life-limiting disease now live into adulthood. Thus, there is an increasingly urgent need to develop approaches to assist with the transition of care from pediatrics to adult medicine. This report will summarize the urgency for proper transition modalities and then introduce palliative care as a proposed solution for current challenges in transition. Along the way, it will touch on financial and workforce obstacles to this solution and will offer a potential funding option.

The American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), and American College of Physicians/American Society of Internal Medicine (ACP/ASIM) have endorsed a consensus statement emphasizing the need for greater support of children with chronic health conditions as they transition from pediatrics to adult care.[1] Studies have shown that, while there are increasing numbers of transition clinics for specific diseases, there are still factors impeding the success of these care models.[2–4]

Children with diseases such as cystic fibrosis and sickle cell, who would not have been expected to reach adulthood in the 1970s, are now living into their 40s and 50s.[5,7] Despite these advances in life expectancy, maintaining their quality of life during the transition period remains problematic.[6] Most alarmingly, the highest mortality for these populations occurs during the transition from pediatric to adult medical homes.[8] Quinn and colleagues showed that the majority of deaths occurred after 18 years of age and after transfer to an adult provider (85%) in patients with sickle cell disease. Furthermore, they demonstrated that the mean time to death after transfer to adult provider was 1.8 years.[9]

At the time of transition, patients struggle to form a relationship with members of their new medical home. Meanwhile, care plans and routine surveillance are disrupted by the lack of bridging communication from one medical home to the next. Patients and their families are not well suited to bridge these worlds. A national survey of parents of youth with special health care needs found that only 50% reported any discussion with their primary care provider regarding their child's changing health care needs in adulthood. Among the 50% with whom a discussion occurred, 40% reported that the discussion lacked a plan for addressing those changing needs.[10]

Barriers to a successful transition include developmental considerations of adolescence, limited staff, financial difficulties, and anxiety in both the patients and their providers.[11,12] These barriers are compounded by the complexity of their conditions; changes in their illness trajectory; insufficient knowledge of the resources required for living, educational and vocational pursuits; and lack of a trusting relationship with adult care providers.[21]

Solutions that address transition are needed not only at the patient level, but also at the family and health care system levels. One elegant solution to the barriers on all three levels is pediatric palliative care.

Palliative Care Answer

The primary goal of the multidisciplinary palliative care team is to improve the quality of life for the patient and

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Accepted October 29, 2013.

family through expert management of physical symptoms, care coordination, and psychosocial support. The pediatric palliative care team is experienced in caring for children and young adults with complex medical conditions. In addition to complex symptom management, it is part of the expertise of this team to facilitate communication between multiple caregivers and different medical teams.

Embedding a member of the palliative care team as part of the medical home early in the course of the patient's disease would allow the patient and the family to become familiar with the palliative care team and build the same level of trust as they would have with any member of the medical home. The palliative care team would then work together with members of the primary medical team creating an interdisciplinary team that can follow the patient on an inpatient and outpatient basis. Members of this team then follow their patients into the adult world serving to lower feelings of abandonment that families often have when the topic of transition is broached as well as carrying the care plan through the transition period and reducing the discomfort of the new medical team.

Funding and Workforce Obstacles

As elegant a solution as this might appear on paper, the viability of the plan lies in how it can be financed and staffed.

Adult palliative care teams are able to demonstrate that palliative care consultation fundamentally shifts the course of care away from the usual hospital pathway and, in doing so, significantly reduces costs by preventing expensive, nonbeneficial interventions.[15] Using these cost saving methods, adult palliative care programs have been able to expand much faster than pediatric programs.

Medicaid, as the largest payer for pediatric health care services, is a program that has, historically, operated under fee for service mechanisms that reward volume of service.[18] Therefore, demonstration of a decrease in the utilization of high-cost services is not necessarily as powerful an indicator for pediatric hospitals as it is for hospitals serving primarily adult populations.

As a result of funding realities as well as health system priorities, the pediatric palliative care workforce is underdeveloped and not at present in a position to have an impact on the system at large. The number of board-certified physician specialists in pediatric palliative care is small, and pediatric palliative care services are heterogeneous in makeup and largely limited to the acute care setting.[22,23]

Supporting a Workforce

It is, therefore, imperative that mechanisms be put in place to generate a pediatric palliative care workforce that address these difficult care transitions. One possible answer lies in accountable care organizations (ACOs).

The underlying intent of ACOs is to encourage a health care delivery system that fosters optimal quality of care for patients through greater clinical integration of care across health care settings and greater financial efficiency. Providers within an ACO are still reimbursed on the traditional fee-for-service basis, but they are also eligible to receive shared savings for reducing costs without sacrificing the quality of care provided to the patients served by them.

Because pediatric palliative care providers need to be the leaders in the formation of pediatric ACOs, the U.S. Secretary of Health and Human Services has established a Pediatric Accountable Care Organization Demonstration Project. Providers in participating states will be allowed to form ACOs for the purpose of receiving incentive payments.[19] Providers can vary between professionals in group practice arrangements to partnerships or joint venture arrangements between hospitals and professionals.[20]

Pediatric palliative care providers forming ACOs with medical homes could provide the necessary funding mechanism to establish and embed these teams for transition of children with chronic illnesses. By creating ACOs for children with chronic illness that are inclusive of pediatric palliative care, providers will be incentivized to increase access to palliative care, leading an overall improved quality of care. Joining this demonstration project will not only have the benefit of providing the financial argument necessary for continued growth and evolution of a pediatric palliative care workforce, but could also lead to an overall increase in access to specialty palliative care for children.

Conclusion

Over a decade has passed since the AAP, AAFP, and ACP/ASIM endorsed a consensus statement emphasizing the need for greater support of children with chronic health conditions as they transition from pediatrics to adult care and yet very limited progress in new services has been made.

This report proposes a model for such progress. By embedding the components of the pediatric palliative care team into the primary team early in the course of serious illness, the palliative care team can then serve as the bridge between the existing care model and the future one.

We will never know whether proposed solutions such as the one outlined herein answer the need for better transitional care without clinical trials, health system investment, and measures to increase the pediatric palliative care workforce. Pediatric palliative care is a field that is early in gestation; to viably address transition, we need to seek sustainable avenues of growth into settings that are beyond acute care. There is an enticing funding model in ACOs, but we need specific demonstration projects to further elucidate the best medical home structures. Viable models and sustainable funding structures will also allow for the infrastructure necessary to support more robust research in pediatric palliative care outcomes and quality.

We believe that pediatric palliative care offers a solution to the transition problem, but workforce changes will not occur on their own nor will supporting research manifest itself. It is time to take the next step, as our seriously ill pediatric patients cannot afford another decade of high-mortality transitions to adult medical homes.

Author Disclosure Statement

No competing financial interests exist.

References

1. Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians/American Society of Internal Medicine: A consensus statement on health care transitions for young adults with special health care needs. Pediatrics 2002;110;1304.

2. Gurvitz M, Valente AM, Broberg C, et al.: Prevalence and predictors of gaps in care among adult congenital heart disease patients (The Health Education and Access Research Trial: HEART-ACHD). J Am Coll Cardiol 2013;61:2180–2184.
3. Tuckman, LK, Schwartz LA, et al.: Cystic fibrosis and transition to adult medical care. Pediatrics 2010;125;566
4. Lewis K: All grown up: Moving from pediatric to adult diabetes care. Am J Med Sci 2012;345:278–283.
5. Elborn JS, Shale DJ, Britton JR: Cystic fibrosis: Current survival and population estimates to the year 2000. Thorax 1991;46:881–885. Published correction appears in Thorax 1992;47:139.
6. Bourke SJ, Doe SJ, et al.: An integrated model of provision of palliative care to patients with cystic fibrosis. Palliat Med 2009;23:512–517.
7. Quinn CT, Rogers ZR, Buchanan GR: Survival of children with sickle cell disease. Blood 2004;103:4023–4027.
8. DeBaun MR, Telfair J: Transition and sickle cell disease. Pediatrics 2012;130:926–935.
9. Quinn CT, Rogers ZR, Buchanan GR: Survival of children with sickle cell disease. Blood 2004;103:4023–4027.
10. Scal P: Transitions for youth with chronic conditions: Primary care physicians' approaches. Pediatrics 2002;110:1315.
11. Tuchman LK, Schwartz LA, Sawicki GS, Britto MT: Cystic fibrosis and transition to adult medical care. Pediatrics 2010;125;566–573.
12. Sawicki GS, Lukens-Bull K, Yin X, et al.: Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ-Transition Readiness Assessment Questionnaire. J Pediatr Psychol 2011;36;160–171.
13. Thompson LA, Knapp C, et al.: Pediatricians' perceptions of and preferred timing for pediatric palliative care. Pediatrics 2009;123;e777.
14. Feudtner C, Kang T, et al.: Pediatric palliative care patients: A prospective multicenter cohort study. Pediatrics 2011;127:1094.
15. Morrison RS, Penrod JD, et al.: Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med 2008;168:1783–1790.
16. American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians; Transitions Clinical Report Authoring Group: Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics 2011;128:182.
17. Centers for Medicare & Medicaid Services: *EHR Incentive Programs*. Centers for Medicare & Medicaid Services. http://www.cms.gov/EHRIncentiveprograms/ (last accessed September 10, 2013).
18. George Washington University's Hirsh Health Law and Policy Program and the Robert Wood Johnson Foundation: Medicaid accountable care organization demonstration project. George Washington University's Hirsh Health Law and Policy Program and the Robert Wood Johnson Foundation. www.healthreformgps.org (last accessed September 10, 2013).
19. Medicare Shared Savings Program. Title XVIII of the Social Security Act. (42 U.S.C. 1395 et seq.). Section 3022. 2010.
20. Medicare Shared Savings Program. Title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.). Section 1899. 2010.
21. Cook K, Siden H, Jack S, Thabane L, Browne G: Up against the System: A case study of young adult perspectives transitioning from pediatric palliative care. Nurs Res Pract 2013;2013:286751.
22. Himelstein B, et al.: Pediatric palliative care. N Engl J Med 2004;350:1752–1762.
23. Browning DM, Solomon MZ: The Initiative for Pediatric Palliative Care: An inter- disciplinary educational approach for healthcare professionals. J Pediatr Nurs 2005;20:326–334.

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