Transition Digest 05-09 (Nov 22, 2009)

Colleagues:

I plan to start the Health Care Transition Blog soon after the first of the year. If any of you would like to volunteer to contribute to the blog on a regular or irregular basis, let me know. After the Blog is launched, I still plan to distribute a digest, of items of interest. The Blog site will be the place where you can get additional information.

1. Conferences and Meetings

A. Transitions 5 Conference

The deadline for submission of workshops, papers and posters to the Transitions 5 Conference has been extended to Friday, Nov 27, 2009.

For more information and the proposal submission form, see the enclosed document or go to:

http://www.bloorview.ca/programsandservices/transfertoadultservices/documents/callforpapers.pdf

For more information about the conference, which will be held on May 31 and June 1, 2010 in Toronto Canada, go to:

http://www.bloorview.ca/programsandservices/transfertoadultservices/transitionsconference.php

B. Chronic Illness Initiative Symposium (DePaul University)

Save the date of May 12, 2010 for The Chronic Illness Initiative Symposium. Details will be available at a future date.

If you are interested in submitting a proposal addressing this year's theme (Chronic Illness from the perspective of the Arts), go to:

http://www.snl.depaul.edu/StudentResources/Chronic_Illness/index.asp#Symposium

2. Call for Papers

Special issue on Youth Health Care Transition
International Journal of Child and Adolescent Health 2010;3(4)

This is a call for papers dedicated to the subject of health care transition for youth and young adults that will be published in 2010. We welcome papers from a wide range of professional perspectives and clinical areas. The papers should address some aspect of the process of transition from child-centered health or habilitative systems to adult-centered health or habilitative systems. We particularly seek translational work evaluating the transition process, testing innovative programs to support transition, or assessing transition outcomes for different populations of youth and young adults. We also want to encourage young investigators from

different countries to describe the current state of health care transition experiences around the world.

The articles may focus on the transition experience of populations defined by a particular condition or across conditions. Other populations of interest are youth with developmental disabilities, in the foster care or in the juvenile justice system.

Special issue editors/guest editors for this issue will be
David Wood, University of Florida (E-mail: david.wood@jax.ufl.edu),
John Reiss, University of Florida, (E-mail: jgr@ichp.ufl.edu),
Maria Ferris, University of North Carolina (E-mail: maria_ferris@med.unc.edu) and
Linda Edwards, University of Florida (E-mail: linda.edwards@jax.ufl.edu)

Articles are due April 1, 2010 and should be submitted to professor David Wood, MD, MPH, UF College of Medicine-Jacksonville, Co-Director, Jacksonville Health and Transition Services (JaxHATS) (E-mail: david.wood@jax.ufl.edu) as email attachment (Rtx or doc file). The articles should comply with the requirements of the International Journal of Child and Adolescent Health (Uniform Guidelines for Biomedical Journals-Vancouver style) located in the following web-site:

http://jmerrick50.googlepages.com/IJCAH-Leaflet.pdf

The International Journal of Child and Adolescent Health is a peer-reviewed journal published by Nova Science (New York) aimed at the scientific community interested in the broad area of child health, adolescent health and human development.

Thank you for your collaboration on behalf of the co-editors and editor-in-chief

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3. New HCT articles from the Literature

(or at least they are new to me)

A. Nakahla et al. Translating Transition: A Critical Review of the Diabetes Literature, Journal of Pediatric Endocrinology & Metabolism, 21, 507-516 (2008)
The purpose of this paper is to review the diabetes literature as it pertains to transition including the outcomes, methods and patients' perceptions of the transition period. The results of the studies examined demonstrate a decrease in diabetes care visits following transition and that improvement in clinic attendance may be achieved through: (1) implementing an educational transition program; (2) having a transition care coordinator; and (3) having a young adult transition clinic attended by both adult and pediatric physicians.

B. Doulton. From Cradle to Commencement: Transitioning Pediatric Sickle Cell Disease Patients to Adult Providers. Journal of Pediatric Oncology Nursing. OnlineFirst, published on November 6, 2009 (not yet in print)
We have developed a 2-part transition program. We have transitioned 20 of our 18- to 27-year-old patients to adult providers recognizing that early preparation is essential. At the newborn's initial visit or transfer from another clinic the transition program is explained to the family. At age 13 years, all our patients are given a "Preparation for Transition" binder. This binder is reviewed in detail with the patient and parent on a regular basis. At 18 years of age, coordinating with the milestone of graduating from high school and depending on developmental age, the transition is completed.

C. Survey: Transition services lacking for teens with special needs (PDF of article from AAPNews is attached)
(I did get permission from AAPNews to distribute this copyrighted article)
From this article
Pediatricians identified the following as major barriers to transitioning adolescents with SHCN from pediatric to adult health care:
• lack of available family/internal medicine physicians (41% reporting),
• lack of adult specialists to care for older SHCN adolescents (40%),
• the fragmentation of primary and specialty care in adult care (39%),
• lack of knowledge about or linkages to community resources that support older adolescents/young adults (39%),
• lack of insurance reimbursement for transition services (38%),
• insufficient time for staff to provide transition services (36%),
• lack of skills in transition planning (34%), and
• a hard-to-break bond between adolescents/ parents/ pediatricians (32%).

For additional information about the results from this survey are available on the web (http://www.incenterstrategies.org/)

D. Wang, et al. Health Care Transitions Among Youth With Disabilities or Special Health Care Needs: An Ecological Approach. Journal of Pediatric Nursing (2009) (online, but not yet in print)
This literature review of 46 articles uses the ecological model as a framework for organizing concepts and themes related to health care transition among youth with disabilities or special health care needs (SHCN). Transition involves interactions in immediate and distal environmental systems. Important interactions in immediate environments include those with family members, health care providers, and peers. Activities in distal systems include policies at the governmental and health system levels. The ecological model can help researchers and practitioners to design experimental interventions in multiple settings that ensure smooth transitions and support the well-being of youth with disabilities or SHCN.

E. Miller. Parent-Child Collaborative Decision Making for the Management of Chronic Illness: A Qualitative Analysis Families, Systems, & Health 2009, Vol. 27, No. 3, 249–266
Parent–child collaborative decision making (CDM) is a potentially important precursor to full decision-making independence and may be particularly significant for the management of childhood chronic illnesses. The primary aim of this qualitative study was to explore the concept of CDM from the perspective of children and parents. Children (ages 8–19 years) with asthma, type 1 diabetes, or cystic fibrosis and parents of children with these illnesses participated in focus groups and individual interviews. Several factors emerged as potential predictors of CDM, including parent/family factors (e.g., parental time; parent–child conflict), child factors (e.g., maturity; emotional/behavioral functioning), and decision/situation factors (e.g., seriousness of the decision; extent to which the child is experiencing symptoms). These data suggest ways to enhance collaborative decision-making interactions between children with a chronic illness and their parents, as well as several areas for future quantitative research.

4. On the Web
Adolescent and Young Adult Cancer Bill of Rights
http://www.seventyk.org/

I recently discovered this site, which presents and seeks support for the Adolescent and Young Adult Cancer Bill of Rights.

I invite you to visit this site and consider adding your name to the list of supporters. I did.

From the site.

There are approximately 70,000 people aged 15-39 diagnosed with cancer every year. For over two decades there has been little or no improvement in survival for this age group. By signing this bill, you are supporting the Adolescent and Young Adult Cancer Bill of Rights to be established as a standard for care to meet the needs of this underserved population.

The Adolescent and Young Adult Cancer Bill of Rights

We are neither pediatrics nor geriatrics, we have unique needs- medically, socially, and economically.
However, the rights and dignity of adolescent and young adults are equal and vital to all individuals.
We deserve to have our beliefs, privacy, and personal values respected.
Access to care is a right, not a privilege.
Our rights, as we perceive them to be and intend to preserve them, are:

1. The right to be taken seriously when seeking medical attention to avoid late diagnosis or misdiagnosis, and entitlement to separate and confidential discussions regarding our own care.
2. The right to affordable health insurance, as well as early detection tests unhindered by insurance or socioeconomic status.
3. The right to be offered fertility preservation as well as current information and research regarding ongoing and potentially lifelong effects of cancer treatment that would affect our fertility.
4. The right to be informed about available clinical trials and given reasonable access to them.
5. The right to untethered access to adolescent and young adult cancer specialists and, when requested, a second opinion regardless of insurance or geographic location.
6. The right to access a social worker or caseworker who is well-versed in adolescent and young adult cancer specifics.
7. The right to “generationally applicable” psychosocial support.
8. The right to have our insurance and position as a student or employee protected by law while dealing with our cancer in order to minimize discrimination.
9. The right to clear explanations regarding the long-term side effects of our disease and its treatment, and to be offered all available and applicable physical reconstruction and rehabilitation options.
10. The right to have all of our treatment options explained to us in full detail, to have our questions answered, and to receive clarification when requested so that we can be an active part of our own care.

Preserve our potential.

5. Final Words

Please let me know about items that you would like to have included in a future issue of the Transition Digest.
Please feel free to forward the Digest to others, and let them know that they can be added to the Digest distribution list by sending an e-mail to me.
If do not want to receive the digest, please send me an e-mail.
For those of you in the US, Happy Thanksgiving.

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