

# HIV+ ADOLESCENTS TRANSITIONING TO ADULT CARE: CONFRONTING THE STRUGGLE

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# Disclosure Form

- Harriett Plaskow has no financial interest or relationships to disclose.
- HRSA Education Committee Disclosures  
HRSA Education Committee staff have no financial interest or relationships to disclose.
- CME Staff Disclosures  
Professional Education Services Group staff have no financial interest or relationships to disclose.

# Learning Objectives

1. Participants will be able to identify issues their adolescent patients are facing when thinking about transition and begin to develop strategies to assist them in the process.
2. Presenter's clinic will develop a transition plan using the study data and begin to present it in focus groups to our patients to make it youth friendly and relevant.
3. Attendees of this presentation will learn how to incorporate transitioning adolescents in to the Quality Management plans they have for their clinics.

# Family Center for Special Studies

- Opened in 1985 as a pediatric HIV clinic in an urban out-patient hospital setting
- Staff has changed with the epidemic due to number of patients and funding issues
- Awarded a Ryan White Title IV, Part D adolescent initiative grant in 1998 and have evolved into a primarily adolescent clinic with few + patients under the age of ten
- Have developed a strong youth outreach team (Project KISS) conducting HIV education, counseling and testing in the community
  - also aid + adolescents in issues related to diagnosis disclosure and socialization

# Literature Review

- Barriers to Transition:

- Prompted by age rather than maturity and understanding of the process
- Adolescent resistance to change
- “Starting over” with new providers in a new place
- Adult medicine does not use a psychosocial approach to patient care using a team to understand a patient’s needs
- Leaving providers they have known since childhood

# Creating a Path Towards Transition

- The actual transfer of care to an adult provider will occur when the young person is physically, medically and socially prepared for transition. This is true in all medical settings
- Consider developing a ritual in the clinic for letting go, which will help both the patients and the practitioners by making the process more meaningful
- Make transition a goal with tangible benefits

# Clinic's IRB approved Pre-transition Survey

- Developed by an ID attending and pediatric resident
- Offered to all HIV+ clinic patients between the ages of 17 and 24 (34 patients participated) and still being offered to patients
- First section deals with concerns about the changing of doctor's and being in a new facility
- Second section deals with what is important to them in a new doctor's office

# Pre-transition survey (Cont'd)

- Last section deals with what the patient knows about their diagnosis, e.g., when they were first diagnosed, what medications they are on, and their lab values
- The data showed that less than 24% of those completing the study knew the names of all their medications, their CD4 level, or their viral loads
- All data collected was presented at Annual PAS (Pediatric Academic Society) Meeting, Vancouver, 2010 and will be published soon



# Help! I Need Somebody...

- Communication between patients, caretakers, and medical teams needs to start early (between the ages of 10 and 12) when the patients are cognitively operational and open to new ideas
- On-going discussion of shared experiences and successes the patients have had in the clinic should be an on-going process
- Disclosure of diagnosis is fundamental!!
- Discussion of the medications and lab results of the patients must be done at each appointment to show the importance of taking responsibility for their own care (including learning the names of their medications)

# Easing on Down the Road

- Decide with patient where they want to go for their adult care by providing a list of different settings available
- Set up a tour of the facility where they will be going along with meeting one or two of the staff
- When patient returns to the clinic after the tour, listen to their concerns and worries about the new facility
- Practitioners should prepare a portable, medical summary of patient's care history, list of providers, and medications currently being taken along with those already discontinued

# Being patient with the patients

- Taking control of your own medical care is stressed by clinic staff and in the literature
- Taking care of yourself is part of the growing up process
- Patients have been babied and carried for a long time due to the earlier dire prognosis
- Rewards have been developed for knowing medications and viral status, e.g., points for remembering which lead up to gift card when you reach a certain level

# Remaining Patient with Patients

- Transition is an on-going issue in support groups held in the clinic and we ask patients to bring in their questions and concerns to share with peers who are in the same situation
- Involve group in community activities such as the AIDS Walk, programs about HIV/AIDS that are given in their communities (in such a way that their own status will not be revealed)
- Have clinic patients submit resumes and interview to become part of the clinic's outreach program or other community outreach programs
- Remember, just like disclosure, transition is not a moment in time, but an on-going process

# Additional Plans to Aid in the Transition Process

- Transition protocol was developed by the transition committee comprised of both medical and clinical staff as a continuous QI project
- Focus groups are offered to patients for further suggestions, insights, and clarification of the issues
- Patients who have successfully transitioned are encouraged to return and mentor those who are still in the adolescent clinic

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