Considerations for Transition in Sickle Cell Disease

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Thank You

- **Organizers and Attendees of the New England Pediatric SCD Consortium Conference**

- **Adolescents and Young Adults with Sickle Cell Disease**

- **Aleksandra Babic for assistance with slides.**

Context (1)

- **Children and youth with sickle cell disease (SCD) are now living longer and experience better HRQOL than they had before, much like other children and youth with special health care needs (CYSHCN)**

- **We must consider:**
  - **What the current means of transitional care are**
  - **How clients view care**
  - **How physicians view care**
  - **Social and Cultural similarities and differences of the experience of transitional care**
  - **What must be done to improve the system for care**
  - **What the recommendations are toward improved quality of care as a result**

Context (2) – Key Issues

- **The issue of transition to adult care and life has received increased attention over the last 10 years**
  - **Much of this focus has been on school-to-work or medical (transfer) <u>only</u>**
- **There <u>has been an inadequate</u> focus on adolescent HRQOL or a more wholistic approach**
- **Focusing on lessons learned, what others are doing, have accomplished or plan to do and *evidence from empirical studies* is critically important in developing a comprehensive program of transition**

Context (3) - Definition

"**Transition is** a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health transition facilitates transition in other areas as well (e.g., work, community, and the school).

Transition proceeds at different rates for different individuals and families (*and programs*)"

- J. Adolescent Health 1993;14:570-576.

History (1)

- **McPherson, Thaniel and Minniti (2009) found that**
  - **Adolescents reported an inadequate level of preparation for transition to adult care**
  - **Young and older adults felt more prepared and had higher levels of knowledge and interest in learning about transition (readiness)**
  - **Attitudes toward transition, such as interest in learning about the process and anticipated difficulty improved with age but were negatively affected by disease severity**

History (2)

- **Telfair, Alexander, Loosier, Alleman-Velez, and Simmons (2004) found that most providers agree- a transition program is necessary**
  - **Only a few providers did anything to demonstrate their involvement in the transition process, while a significant portion of adult-only providers did not expect the patient to be seen with their parent or primary caretaker**
  - **Minority providers were more likely, than their Caucasian counterparts, to expect more from the adolescent moving to adult health care**

History (3)

- **Most children and adolescents with SCD (94%) and nearly all children with milder forms of SCD (98%) in western countries now live to become adults > 18 years**

- **Quinn, Rogers, McCavit, and Buchanan (2010) found that the incidence of death and mortality changed over the duration of recent (since 1990) cohort**

  - **Sepsis is no longer the leading cause of death, and all the recent deaths in the cohort occurred in patients 18 years and older—most, shortly after transition to adult care**

Where we are Now (1)

- **The quality of care has improved over time but young adults still need the high-quality medical care and systemic follow-up that has been available to children to continue to improve the life expectancy of people with SCD**

- **Prior to the implementation of SCD-focused interventions, Anie, Telfair, and the Sickle Cell Disease Transition Study Working Group (2005) emphasize that demographic variables and the frequency of symptoms experienced by adolescents ought to be considered in the development of any intervention program**

Individuals living with SCD (1)

- **In recent studies (Anie & Telfair, et al) the most common concerns about transition to adult care were:**
  - **Fear of leaving the healthcare provider with whom they were already familiar**
  - **Fear that adult care providers might not understand their needs**
  - **Fear of being treated as adults**
  - **Concerns about payment for the cost of care**

Individuals living with SCD (2)

- **Specific to Social and Cultural Issues (1):**
  - **Lack of an adolescent/young adult orientation - Major focus on pediatric period because this is where support is**
  - **Myths about acquisition of disease and complication, especially social and spiritual**
  - **Not clear if SCD is an infectious disease**
  - **For persons with SCD, life – meaning beyond the pediatric period is questioned – told not to expect.**
  - **Parents told the same thing regarding lifespan**
  - **For many, despite government support, and others paying for care is a challenge - burden on parent, not clear what the burden on the adult is**

Individuals living with SCD (3)

- **Specific to Social and Cultural Issues (2):**
  - **Keeping SCD secret is common, as in the US/UK– only limited, trusted persons are told in general. Not the case for all**
  - **Experience with SCD or persons with SCD allows for better understanding**
  - **Death is a very real concern, religious (faith) beliefs +/- genetic dis, early death**
  - **Cultural influence – meaning of having chronic dis**
  - **Recognition that despite challenges young people are living longer, so the need to plan and educate for all in the medical ecology of the adolescent.**

Recommendations Toward Successful Transition Care (1)

- **Transition should be a gradual process with a flexible timeline of goals and for the patient to fulfill with the help of their medical team**
- **Successful transition requires:**
  - **View of transition as process w/beginning and end**
  - **a baseline and ongoing individual assessment of client's, caregiver's and provider's needs and level of readiness to transition or 'let go'**
  - **Client and caregiver education about their disease and navigating the medical system**
  - **an open invitation to address clients', caregivers' and providers' concerns or questions regarding the process**

Recommendations Toward Successful Transition Care (2)

- **Successful transition requires:**
  - **Clear, thoughtful and informed attention to social and cultural realties of client, caregiver and provider**
  - **At a minimum, take a comprehensive approach that is more than one or two "hand-off" visits to adult providers, and this program must be built into the overall care plan for the young person that begins when he or she is a young adolescent**

Effective Medical Care (1)

- **Medical care with an adolescent/young adult requires a physician and nurse/ physician assistant at a minimum—if possible, a social worker and/or case manager should be added to the team**

- **The program must be the usual source of care for the young person and be designed to provide health care maintenance to address his or her acute and chronic illness needs (or be linked to such a program, preferably one that respects local traditions and concerns)**

Effective Medical Care (2)

- **The design for care should include ongoing explanations to the client, caregiver and the discussions of how the young person's condition affects him or her, and why**

- **Must be good working relationships and communication between pediatric, adolescent and adult providers**

Education (1)

- **Education and training must be designed to assist the adolescent and his or her caregiver to achieve competence in areas of independence, systems navigation and self-care**

- **Education of the client, caregiver, other providers, and community members must emphasize outcomes that demonstrate knowledge and skills obtained**

Education (2)

- **Education and training must be based on a clear understanding of adolescent and young adult developmental, social and cultural issues**

- **Education and training must be designed to provide Initial and ongoing multi-disciplinary provider education and training**

Support Services (1)

- **Multidisciplinary clinical support should include:**
  - **Being supportive of the developmental process in an effort to appropriately integrate the client into the decision-making process**
  - **Focus on building *life sklls* and not just health care skills**
  - **Assisting clients in the decision-making process**

Support Services (2)

- **Multidisciplinary clinical support should include:**
  - **Assisting the clients' caregivers so that they can support the adolescent/young adult, and increase provider education so that the gap between pediatric and adult medicine can be bridged**
  - **Provision of ongoing, developmentally appropriate information regarding client specific disease history, self-care, treatments and what independence means for them, includes addressing myths and related messages about inheritance, life and death**

Support Services (3)

- **Multidisciplinary clinical support should include:**
  - **Creating and implementing means by which adolescents and young adults can and do participate more in their health care decisions**
  - **Creating and facilitating development and use of groups or forum where clients can share ideas, learn about navigation of the systems of care and community environments, as well as support one another**

Solutions - *Program and Community*

- **Use of** in-house/on-site, cross-site and community multi-disciplinary transition teams and individual providers and educators

- **Provide** mechanisms for coordination and accountability at and between levels of care and education

- **Identify and develop** interventions to counter barriers to access and utilization of transition care programs

Solutions - *Program and Community*

- **Assess** the strengths and weaknesses of monitoring program Re: Quality of Monitoring Systems and Cultural and Social Accountability/Sensitivity

- **Encourage, support and provide** a means to conduct evidence-based research and evaluation

Solutions - *Program and Provider*

- **Develop and Use** creative financing of transition care and adult life preparation – e.g., advocate CMS modification, billing codes adjustments

- **Develop** centralized roles for providers and other professionals within the system of the transition of care and preparation for adult life

Solutions - *Program and Community*

- **Integrate** the roles of multi-disciplinary providers within the family, significant other and community-based care and education networks of the adolescents health care and adult life preparation needs

- **Create, support and provide** assistance to multi-disciplinary providers in the study and development of an understanding of the transition process as one of moving on to adult care and life

Solutions - *Client*

- **Identify and utilize** peer, family networks and social support networks/groups and community services

- **Create, support and provide** assistance to adolescent in the actualization of empowerment and enhance self-efficacy at their own pace

- **Create, support and provide** assistance to multi-disciplinary providers in the **study and development** of an understanding of the critical role independent decision-making by the client plays in assuring success of the transition process

Solutions - *Client*

- **Create, support and provide** assistance to multi-disciplinary providers in the study and development of an understanding of the critical role played by families and significant others in the transition process

Solutions - *Other*

- (Where available) *Create, support and provide* assistance for peer education outreach programs and peer-led instruction since these hold great promise, as approaches that are adolescent-centered and adolescent-delivered

- Understand that

  - *Through their own* social networks, young people can reach out to parts of the population that are difficult for older people to reach

Solutions - *Other*

- **Understand that**
  - *Training peers* in schools, in community health settings and in other '*natural environments*' empowers young people by placing them in leadership roles
  - *Providing leadership opportunities* for young people builds their self-esteem and advances self-efficacy enhancement and empowerment efforts among young people

In Conclusion

- **Transition Program – *Independent of location* – must:**
  - **Have an orientation that is future focused and flexible.**
  - **Anticipate change and develop a flexible plan for the future that takes into account social, cultural, environmental and historical issues and concerns**
  - **Foster personal and medical independence and creative problem solving**
  - **Anticipate future needs by developing individual life plans that includes their definition of independence**
  - **Celebrate rights of passage that are appropriate for the social and cultural environment in which the client lives and receives care**

- **Modified from Reiss, Gibson and others recommendations (2002)**

?QUESTIONS?

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