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Transition From a Pediatric HIV Intramural Clinical Research Program to Adolescent and Adult Community-Based Care Services: Assessing Transition Readiness

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Abstract

As treatment options have improved, there has been a significant increase in the life expectancy of HIV-infected children and adolescents. For most adolescents, the time comes when it is appropriate to transition from pediatric care to an adult or community based provider. In response to a program closure, a transition readiness scale was developed. Thirty-nine caregivers of HIV-infected youth (ages 10–18) and twelve youth over the age of 18 years were interviewed at two time points. Barriers associated with transition were identified and addressed between visits. Transition readiness improved and state anxiety decreased significantly from the first time point to the last visit (approximately 7 months later). Not having a home social worker was the most reported concern/ need identified. Barriers to transition and interventions utilized to assist with transitioning care are discussed.

Keywords

Transition readiness; pediatric; adolescent; HIV; chronic illness

Background

As the treatment options for HIV/AIDS have improved, many HIV-infected children who were not expected to survive childhood are entering adolescence and young adulthood. Medical advances in the prevention of mother-to-child transmission have been particularly encouraging. Fewer than 300 children annually are born infected with HIV in the United States while >8500 previously infected children and youth <19 years old living with HIV/AIDS continue to age up in the health care system (CDC, 2004). For most adolescents in pediatric HIV programs, the time comes when it is appropriate to transition from pediatric-based care to an adult provider.

In December of 2004, the staff of an 18 year-old pediatric HIV/AIDS clinical research program received notification that their funding would be reallocated in approximately one year, and the clinical program would close. Consequently, all of the patients needed to transition to community based medical providers for their primary HIV care. The following study was designed to systematically examine transition readiness, state anxiety and potential barriers to successful transition. With 15 as the mean age of the patients and many at an age where

transition to an adult provider was appropriate, this study allowed us to document concerns and barriers associated with transitioning to adult and/or community based health care.

Transition Literature Review

The medical community has responded to the devastating effects of childhood disease by researching and developing new treatment options that prolong and enhance a young person's life. These advances have resulted in a unique set of concerns that include the adult medical community's ability to manage the complexities of childhood onset diseases and the challenge of preparing adolescents for the transition from pediatric to adult centered medical care. Transition from child-centered to adult-oriented health care is a process every young adult must navigate; some do so in an uninterrupted manner and some drop out and do not return to the doctor until much later in life when a medical problem arises.

Adolescents with chronic illnesses are known to engage in many of the same risk behaviors as their unaffected peers, but with outcomes that can significantly increase morbidity and mortality (Tercyak et al., 2005; Valencia & Cromer, 2000; Suris & Parera, 2005; Suris, 2002; White, 2002). Studies in the US and Europe show chronically ill youth engage in alcohol & tobacco use and sexual activity at rates comparable to healthy peers, but generally have poorer knowledge and prevention strategies to cope with negative outcomes (Maiuton et al., 2003; Suris & Parera, 2005; Valencia & Cromer, 2000). In addition, those who drop out of care without transition and lose insurance benefits become users of more episodic and high cost health care over time, putting undue burden on the health care infrastructure (Johnson & Rimza, 2004; White, 2002). For the 500,000 adolescents with special health care needs who turn 18 each year, there is a sense of urgency for the transition to adult-oriented care to be smooth and uninterrupted in order to ensure positive health outcomes (Lotstein et al., 2005). Since there is no literature available on transitioning adolescent patients to community care when a program closes, we will review what is known about transitioning care in general and transitioning to adult care in particular.

In the Society for Adolescent Medicine (SAM) initial position paper on health care transition the authors identify several key characteristics of the transition process: it is multifaceted and impacts not only the medical care but the psychosocial and educational needs of the adolescent; the timing of the transition is different for each family and is dependent on factors such as the developmental readiness of the teen, the health care concerns, and the family dynamics; and finally, it can be more challenging for those adolescents with complex medical conditions (Blum et al., 1993). The authors call for research on the topic of successful transitions and pose a series of research questions to be answered by the larger medical community including studying the efficacy of the different transition program models as well as examining the medical, emotional, and psychosocial outcomes of the adolescents who transition utilizing a formal program.

However, 13 years after the original (SAM) position paper on transitioning adolescents with chronic health conditions and more than 2 decades after Surgeon General C. Everett Koop hosted the first national conference focusing on the needs of older adolescents with chronic and disabling conditions (Blum, 2002), negligible research has been conducted and minimal progress has been made delivering comprehensive services to this uniquely vulnerable population. Recognizing the priority of this issue, in 2001, a consensus conference was held in conjunction with the American Academy of Pediatrics, the American Academy of Family Physicians, and The American College of Physicians-American Society of Internal Medicine with the purpose of crafting a policy statement for adolescent transition that would have wide spread support. It specifically outlined "critical first steps" to ensuring successful transition to adult-oriented care, followed by specific recommendations to provide clarity for efforts to

implement programs and reduce barriers to successful health care transition (Rosen, 2003). The steps included: 1) identifying health care providers for young people with special needs who will assume broad responsibility for the coordination and planning of transition; 2) identifying core competencies needed by health care providers to render appropriate health care for special needs youth and make sure those skills are integrated into medical education and certification requirements; 3) development of a portable and accessible health care record; 4) development of detailed transition plans by provider, patient and family; 5) ensure the same standards for primary care and prevention services for special needs youth as for the general population; 6) ensure affordable continuous, comprehensive health insurance coverage.

Awareness of the importance of adolescent to adult medical transitions for chronically ill adolescents and the frequently poor success rate begs the question of why such transitions are so challenging. A recent survey conducted by The National Center for Health Statistics designed to help develop a baseline for the 2010 Healthy People goals indicated that the majority of adolescents nearing adulthood have not had even preliminary dialog with their health care providers about how their medical care will change when they become an adult (Scal & Ireland, 2005). In response, the Maternal and Child Health Bureau (MCHB) incorporated transition planning into the Healthy People 2010 objectives (Lotstein et al., 2005). Moreover, because of increasingly restrictive policies by hospitals, third party payers, and other entities that impede progress, the transition process has become more complex and daunting for patients, families and providers (Reiss et al., 2005; White, 2002; Bennett et al., 2005; Scal et al., 1998).

Hauser and Dorn (1999) conducted focus groups with adolescents living with a chronic condition and their caregivers to understand their perspective of the transition process. They found adolescents have three major concerns about transitioning to adult care providers: 1) leaving people they are familiar and comfortable with; 2) seeing a doctor who is unfamiliar with their medical condition; and 3) fears that their parent/caregiver would not let them grow up. The caregivers identified similar concerns including: 1) leaving a familiar place with staff they trust; 2) losing their own support system; 3) anticipating their own role change; 4) concerns the adolescent won't advocate for themselves; and 5) the adolescent seeing a doctor who is unfamiliar with the disease/condition. The authors emphasized caregiver reluctance to relinquish control over managing a child's treatment as an important barrier to transition. These concerns were repeated in focus groups conducted by Reiss in 2005 with families and both pediatric and adult health care providers.

Transition is a complex process incorporating all aspects of the adolescent's life (Scal, 2002; Miles, Edwards, & Clapson, 2004; Pinzon, Jacobson, & Reiss, 2004; Rettig & Athreya, 1991; Por, et. al, 2004; and Reiss, Gibson, & Walker, 2005). Shifting from a primary care pediatric medical provider to adult centered care often signifies a change in life stage for the family; one that involves allowing a child to mature and become more independent of the parents (Betz, 1998). A chronic illness often makes this transition more difficult and can increase resistance to the process on the part of the adolescent and/or the caregiver. This is attributed to several factors: the families and their perceptions of the adult medical care venue; difficulty accessing necessary support services outside the pediatric venue; the perceived loss incurred with leaving the place where children have been cared for (sometimes since birth); and the need to terminate close, trusting relationships that have been formed with medical and support staff. In addition, adult medical providers are frequently not receptive to the time and involvement required to provide care to medically complex adolescents that do not fit the adult paradigm (Reiss, 2005; McDonagh, 2005). This is especially true when the adolescent is resistant to the medical advice given and can be further complicated by the need for strict adherence to a medical regimen to avoid potentially life threatening consequences associated with non-adherence. The adolescent may not have played an active role in their care up to this

point and the physical, psychological and social demands of making medical appointments, completing insurance claims, and obtaining prescription medications can overwhelm them. The transition process can also overwhelm the parent, as they may be reluctant to relinquish control of day-to-day access to their child's records and treatment plans. Each of these factors can become barriers to successful transition.

While age, developmental readiness, and resistance predominate the concerns of earlier studies on transitioning chronically ill youth to appropriate adult care, more recent investigations have emphasized the increasingly difficult barriers of inadequate systemic and infrastructure support. Inability to access prescription coverage, medical insurance, user-friendly clinic facilities for youth, consult services for co-morbidities, and ancillary support services such as social work and counseling are significant threats to transition, even when developmental readiness criteria have been met.

Research on what constitutes successful transition is limited and varies by geography, resources, and lack of outcome/follow-up studies related to suggested models for transition. Available literature on transitioning out of pediatric care stems from chronic diseases such as cystic fibrosis, diabetes, rheumatology, cardiology, sickle-cell anemia, and transplant medicine, where young patients are increasingly surviving childhood. There is a paucity of information relating to transitioning pediatric HIV patients, who have an illness that carries the extra burden of social stigma and transmissibility. In an early report on adolescents living with a chronic illness, Betz (1998) identified important areas to assess prior to the start of the transition process including: 1) readiness to assume responsibility for treatment management; 2) previous involvement in managing his or her treatment regimen; 3) demonstration of independent and responsible judgment; 4) relationship with pediatric provider; and 5) extent to which developmental issues have been addressed. These elements are not exhaustive. While they do not address the infrastructure deficits, they are clinically and developmentally focused and provide a valuable framework within which to review available research and to illustrate what is needed for a successful transition to occur.

Generalizable tools to assess transition readiness are limited and most models are disease specific, and do not propose measurable criteria for successful transition. Cappelli, MacDonald, and McGrath (1989) published a study documenting the use of an assessment tool used to assess for readiness to transition in cystic fibrosis clinics. This study focused primarily on disease management knowledge to the exclusion of specific psychosocial and external support factors relating to transition, including developmental readiness. Rettig and Athreya (1991) discuss the use of a questionnaire to assess readiness in a pediatric rheumatic disease clinic. The authors point out that transition readiness encompasses much more than chronological age and ability to state one's diagnosis. They assessed a range of skills necessary to manage complex treatment regimens including behavioral, vocational, psychosocial and financial knowledge/readiness and accordingly, identified potential barriers.

Our study was initiated in response to the closure of an 18 year old pediatric HIV/AIDS clinical research program. A questionnaire was developed that encompasses the readiness criteria identified in the review of the literature. The scale provides a readiness score and identifies barriers to successful transition both to community-based programs as well as to adult providers. We sought to examine whether an association existed between transition readiness, specific barriers to transition, and level of state anxiety. We hypothesized that poor readiness scores would be directly associated with increased state anxiety levels and advanced disease status, greater number of years enrolled in the current treatment program, and lack of confidence in a home provider. An intervention was conducted for each transition barrier identified and we further hypothesized that readiness scores would increase and state anxiety scores would decrease between 2 time points as a result of the intervention conducted.

Methods

Sixty-five HIV-infected children/adolescents at the National Institutes of Health (NIH), National Cancer Institute (NCI) and their caregivers were actively involved in clinical research when the program closure announcement was made. Of these, 14 families returned for one visit only, having what they considered to be good care in their home communities. The remaining 51 families (39 parent-caregiver dyads and 12 adolescents/young adults ≥ 18) participated in the transition readiness program. Each completed two sets of identical interviews, an average of 6.8 months apart (median = 6.1 months, interquartile range = 3.7 months) resulting in a response rate of 68%. Table 1 summarizes the demographic characteristics of the sample. At Time 1 (T1) participants had been in the clinical research program an average of 10.4 years. The mean age was 15.8 years (range: 9 – 25 years). Forty-four percent ($n = 24$) of participants were female, 44% ($n = 24$) were white, 39% ($n = 21$) were Black/African American, 7% ($n = 4$) were Hispanic, 8% ($n = 5$) were “other”; 89% ($n = 48$) acquired HIV perinatally and 11% ($n = 6$) through a transfusion¹. At T1, 14% of participants had absolute CD4 counts below 200 and at T2, 10% had CD4 counts below 200, a level of immune suppression not unexpected given the duration of the study population’s HIV disease. All study participants were receiving antiretroviral therapy and of these, 98% ($n = 50$) were receiving HAART. There were no significant differences between the 51 families who participated in the study and the 14 who did not for race, mode of transmission, child age, child gender, CD4 count or viral load.

Procedure

The study was exempt from IRB review and approved by the NIH Office of Human Subjects Research. Eligibility criteria included: 1) documented HIV infection, 2) enrollment in an active treatment protocol at the NIH, and 3) having at least 2 clinic appointments during the study period to assess transition readiness. The Principal Investigator (PI) approached families during the first clinic appointment after the program closure was announced and offered participation in the study. They were informed that their social worker and medical care provider would work with them to help address the barriers that they identified in order to secure a successful transition. At this clinic appointment and at the last clinic visit prior to the program closing, the caregivers and adolescents ≥ 18 were administered the Transition Readiness Scale and the State portion of the State/Trait Anxiety Inventory for Adults (STAI; Spielberger, 1983). The principal investigator scored completed questionnaires on the day of the clinic visit. Participant transition needs were noted (see Table 3) and both the social worker assigned to the family and the medical provider were provided copies of the scored questionnaire. Together they decided who would address each issue with the family. In most cases, the medical provider made contact with local physicians on behalf of those needing a home medical center in addition to addressing the HIV related knowledge deficits identified for each patient. The social worker generally worked to help secure insurance, pharmacy, transportation, and out-of-pocket expense needs along with addressing anxiety and other identified concerns. All identifying information was stripped from the database prior to analysis.

Measures

State/Trait Anxiety Inventory for Adults

(STAI; Spielberger, 1983) The state anxiety subscale measures a transitory emotional response to a stressful situation and consists of 20 phrases with responses on a 4-point Likert scale. The

¹Adolescents with transfusion associated HIV acquired their infection prior to implementation of standard HIV screening of the blood supply.

total score is the weighted sum of the 20 responses. Caregivers or patients ≥ 18 completed the questionnaire independently at 2 time points.

Transition Readiness Questionnaire

This questionnaire was designed by the investigators to obtain information on factors identified in the literature as obstacles to successful transition (Betz, 1998; Hauser & Dorn, 1999; Rettig & Athreya, 1991). Six variables were assessed: 1) whether a local health care provider had been identified and, if so, a) whether the participant had made an appointment with this provider, b) who made the appointment, c) how comfortable the participant felt calling the provider for advice or turning to this provider for medical care (8 items); 2) if the participant had medical insurance and whether they a) would need to pay out of pocket for medications and b) have the financial ability to cover these costs (4 items); 3) whether the participant had transportation for medical appointments (1 item); 4) whether a pharmacy had been identified and if the participant had obtained medications and/or refills through this pharmacy (2 items); 5) knowledge of disease status, medication regimens and dosages (5 items); and 6) if they had or knew of a social worker who would be available for assistance with obtaining support and/or services (1 item). The scale yields one global readiness score, which summarizes ratings in the categories described above. All categories were weighted equally except for knowledge of antiretroviral medication and HIV disease status, which were given 2 points for completely correct responses on items related to medication, dosages, and specific lab values (CD4 and HIV-1 RNA levels) and 1 point for partially correct responses.

Chart Abstraction

CD4 T-lymphocyte subset values and HIV-1 RNA levels (Roche Amplicor®, lower limits of detection 50 copies/ml) were abstracted from the medical chart for the dates the questionnaire was administered.

Data Analysis

Paired sample t-tests were conducted to compare readiness and state anxiety scores between T1 and T2. A change score was calculated for each respondent based on their readiness and state anxiety scores at T1 and T2. Independent samples t-tests were conducted to see if any of the summary need variables at T1 were related to the amount of change between T1 and T2 for both readiness and state anxiety.

Results

Just over one third of participants had “poor” or “moderate” scores for transition readiness at T1, while none scored in those ranges at T2 (Table 2). At T1, approximately one quarter of participants scored in the “excellent” range for readiness and at T2, over half scored in this range. Thirty percent ($n = 15$) of participants at T1 scored above the clinical cutoff for state anxiety, while only 20% ($n = 10$) scored in the clinical range at T2. Overall, between T1 and T2, mean transition readiness scores increased significantly ($t = 7.5$, $df = 50$, $p < .001$) and state anxiety decreased significantly ($t = 2.5$, $df = 49$, $p < .05$). At T1, readiness was negatively correlated with state anxiety (those who were less ready to transition were more anxious; $r = -.35$, $p < .05$), while at T2, this relationship was no longer significant. There were no significant differences in levels of readiness or state anxiety in patients who were dually transitioning i.e. not only to local medical care, but to an adult medical provider.

The variables describing specific barriers to transitioning health care are summarized in Table 3. While participants reported improvements in all areas between T1 and T2, the most notable

were significant decreases in need for home physicians, social workers and inadequate knowledge about disease status, names of prescribed medication and dosages.

Participants had been receiving treatment at the NIH for an average of 10.5 years (at Time 1; range 1 – 17 years). At Time 1, before patients participated in the readiness program, readiness scores were negatively correlated with numbers of years at NIH (those who had been coming to the NIH for a greater number of years had lower readiness scores than those who had been coming to the NIH for a shorter period of time; $r = -.32, p < .01$). At Time 2, after participating in the transition study, this relationship was no longer significant. No significant association was found between the number of years treated at NIH and state anxiety.

There was no significant relationship between readiness scores and disease status (CD4 or viral load) at either T1 or T2. Those who lacked confidence in their home provider had significantly lower readiness scores at both T1 ($t = 4.1, df = 49, p < .001$) and T2 ($t = 3.4, df = 49, p = .001$) than those who did not lack confidence.

We examined the change in readiness scores between those indicating specific barriers to transition (compared to those who did not report such barriers) in order to determine if the targeted transition intervention had an effect on readiness. Those indicating that they did not have a home physician ($t = 6.5, df = 49, p < .001$), or a social worker outside of our facility to contact ($t = 2.8, df = 49, p < .01$) at T1 had a significantly greater increase in readiness between T1 and T2 than those indicating they already had these providers in their home community. Additionally, those who reported lacking confidence in their home/community-based physician at T1 had a significantly greater increase in readiness between T1 and T2 than those indicating that they already had a provider in whom they were confident ($t = 2.9, df = 49, p < .005$). Those who indicated a need for funding to cover medical expenses at T1, had a significantly greater reduction in state anxiety than those who did not have this need at T1 ($t = 2.7, df = 48, p < .01$).

Participants were given a space at the end of the questionnaire to describe additional concerns or comments about transitioning to home-based care that may not have been addressed. Eighty percent of the respondents wrote comments in this space reflecting distress about the impending program closure, using recurring words/phrases such as "loss", "upset", "frightened about future", "feel abandoned", "concerned about receiving lower level of care", "lack of HIV knowledge elsewhere", and "lack of monitoring of total HIV care at home".

Discussion

As hypothesized, poor readiness scores were associated with increased state anxiety levels, greater number of years enrolled in the current treatment program and lack of confidence in a home provider. Contrary to our hypothesis, readiness or anxiety was not associated with disease severity. This may reflect transitioning from a center where a strong emotional attachment is a stronger predictor for poor readiness scores than anxiety associated with advanced disease status. Participants had been receiving treatment at the NIH for an average of 10.5 years. Most were well known to the staff from either their school-age years through adolescence or adolescence through young adulthood. The emotional attachment to clinic staff may also be associated with the fact that, due to the nature of the disease, many children had lost at least one parent to HIV while receiving care at NIH and we were a link to that parent and time in their life when their parent was alive. This may explain, in part, why those who had been coming to the NIH for a greater number of years had significantly lower readiness scores than those who had been coming to the NIH for a shorter period of time.

At the time the program closure was announced, over one third of the participants had "poor" or "moderate" scores for transition readiness. Along with confidence in the long-term

relationship with the research clinic structure and providers, many families did not live close to medical centers where treatment for HIV-infected children was being provided. Some did not have adequate health care insurance, especially those who were aging out of pediatric Medicaid coverage. Because the pediatric HIV/AIDS program had been in existence since the early years of the HIV epidemic, many children had lost friends who died from complications of HIV and attribute their own survival, at least in part, to the skills of the NIH treatment team. Having to pay for medications out of pocket, lack of insurance coverage, paucity of pediatric community based providers or the need to transition out of pediatric care, and lack of a social worker to provide advocacy and support in the community resulted in a high degree of discomfort among the families comparable to the issues previously described by Hauser and Dorn (1999).

While this study identified a number of barriers to transition readiness, simply identifying barriers is of limited utility to health care practitioners and families without addressing each obstacle directly. We were fortunate to have approximately seven months to help families prepare for the transition providing us with the opportunity to intervene by helping families obtain a home physician, social worker, and to improve knowledge about disease status, names of prescribed medications, and dosages. By the time transition occurred, all participants scored in the good to excellent range of readiness. Along with a significant increase in mean transition readiness scores from T1 to T2, a significant reduction in state anxiety also followed. Confidence or self-efficacy in self care might explain the association between reduced needs and lower anxiety scores at the time of transition especially if increased self-efficacy to manage health care needs can result in uninterrupted care and/or positive health care outcomes. In a 3 year follow up study of youth transitioned to adult medical care Wojciechowski, Hurtig, & Dorn (2002) reported self-efficacy in illness management as a predictor of whether the individual remained in care after transition.

The success of our interventions speaks to the urgent need for formal transition readiness programs that strive to identify early on, potential barriers to a successful transition. The identification of such barriers can then guide the development of an individualized transition plan for each family. The findings from this study suggest that interventions will need to focus on equipping the young adult with the skills and knowledge to understand their disease and medications, in addition to the warning signs of illness/infection, how to access a pharmacy and refills, medical insurance coverage, resources that help cover out of pocket-expenses, and complete tasks involved with managing their healthcare (Hauser & Dorn, 1999; Betz, 1998; Lewis-Gary, 2001). In other words, in addition to a safe and efficient transition of medical care, an approach is needed that addresses an individual's developmental needs and can be viewed in the context of personal growth and the future goal of self management of health care (While et al., 2004).

Several transitional models have been described by While and colleagues (2004) that support and address the need for developmental growth to go hand in hand with the transition process. In a *direct transitional model*, the focus is primarily on good communication between services with continuity of information sharing and team continuity among health care providers. This model works well when the young person's role in their care is unlikely to change significantly, such as with the person with more extreme disabilities or cognitive limitations. A *sequential transition model* recognizes that a person's needs are changing and new services are an extension of the child's current care. In this model, longitudinal continuity is important as the young person is able to rehearse and prepare for adult based care and is given the time to become skilled in understanding their condition. By being afforded increased autonomy in decision making about their care, this model also allows the young person to accept a more independent role in their family. Finally, in a *developmental transitional model*, the family's role in care provision is redefined along with the young person's. The premise is that the young person will

need some help in acquiring the skills and support system necessary to use or experience adult care effectively. Each model focuses on personal growth and development and developmental continuity. Considering the positive change documented in our study from T1 to T2 in obtaining knowledge about HIV disease and treatment medications, it appears that a model that incorporates personal growth and allows sequential transitioning within an environment that respects developmental needs is the most appropriate model for transitioning adolescents.

The findings reported in this paper should be considered in the context of several general limitations. First, we do not have follow-up data on whether the study participants effectively utilized the medical care in their new clinical centers. Randomized studies involving well-established transition models with successful outcomes measured by continued follow-up and engagement in care are needed. Additionally, there is still much to be understood in relation to what helps young people adjust to change in medical care. Future research should longitudinally investigate the young person's perspective on what is important for a successful transition to occur. Second, this report is limited by the use of a transition scale that was designed specifically for this study and reliability and validity data is needed. Furthermore, this study was conducted during a period of major change when families were distressed about the closure of the research program and it is unknown whether this emotional climate during the transition period may have affected the readiness scores and/or our results. While there were no significant demographic or medical differences between the participants who returned for the Time 2 visit and those who did not, the 14 who did not return were those most ready to be transitioned, and therefore the results may be skewed towards those less ready for transitioning. Finally, while a caregiver's loss of control over the child's illness and treatment has been identified as a consistent barrier to transition (Cappelli, MacDonald, & McGrath, 1989) a provider's reluctance to remove themselves from the care provider role can feed into the young person's resistance and give mixed messages as to whether transition is really in their best interest (Reiss, Gibson, & Walker, 2005; Fox, 2002). As the program closure affected both patients and providers alike, this issue could not be evaluated in this study and deserves further attention and investigation.

This is the first report to describe a transition readiness process created to address a program closing. While no articles were identified in the literature that addressed transitioning patients to new care when a program closes, present climate of change in health care financing and mergers between medical centers suggests that this issue will most likely present itself again. The closing of the program allowed us to identify and address barriers to transition in a uniquely stressful situation. Future models for transitioning adolescent care must be done with both a healthy respect for the young person's psychosocial development and in the context of his or her psychosocial needs. Along with facilitating a change of relationship between care providers, transition allows the provider the opportunity to promote growth by helping each chronically ill adolescent learn problem solving skills, accept new life roles, learn to manage their illness independently, and access resources needed to navigate the adult health care community.

Conclusion

Transition can be a complicated and emotionally charged topic for many families who have been working closely with pediatric care providers for extended periods of time. Forced transitions due to either age of patient (transitioning from adolescent to adult programs) or financial cutbacks in programs can raise a plethora of barriers, questions, anxieties and emotions each of which need to be addressed in order to help the client and family have a successful transition. To not address these questions and concerns is to jeopardize the health of the child/adolescent. The challenge for professionals is to engage clients in assessing individual barriers and to identify appropriate medical care and support services to ensure

positive health and psychosocial outcomes. Transition in general, and for children in particular, is a difficult process that has not been thoroughly researched. Developing interventions to help adolescent clients and their families transition to adult centered care is the current call to action by the pediatric medical community. The assessment of psychosocial needs, emotional barriers, and parental and/or provider resistance, resource acquisition, and the promotion of developmental growth are skills social workers are uniquely qualified to provide.

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Table 1

Demographic Information (n=51)

Demographic Variable	% (n)
Gender	55% (28)
Male	45% (23)
Female	
Race	45% (23)
White/Caucasian	37% (19)
Black/African American	8% (4)
Hispanic/Latino	10% (5)
Other	
Mode of Acquisition	86% (44)
Vertical/Perinatal	12% (6)
Transfusion/Hemophilia	2% (1)
Unknown	
	Mean (range)
Age (years)	15.8 (9 – 25)
Severity of Illness	623 (0 – 2,258)
CD4 Cell Count T1 (cells/mm ³)	662 (0 – 2,449)
CD4 Cell Count T2 (cells/mm ³)	51,199 (49 – 634,000)
HIV-1 RNA levelsT1 (copies/ml)	52,206 (49 – 985,000)
HIV-1 RNA levelsT2 (copies/ml)	
Geographic Location:	17 states, 1 Territory 1 District of Columbia

Table 2

Transition Readiness

Transition Readiness	Time 1	Time 2
	% (n)	% (n)
Poor	6% (3)	0.0% (0)
Moderate	31% (15)	0.0% (0)
Good	38% (19)	47% (24)
Excellent	25% (13)	53% (27)

Table 3

Specific Participant Transition Barriers

Needed Interventions	T1	T2	p-value
Needs a physician in home community	31.4% (16)	2.0% (1)	p < .001
Lacks confidence in home physician	47.1% (24)	35.3% (18)	NS
Needs health insurance	21.6% (11)	11.8% (6)	NS
Lacks funds to cover out-of-pocket expenses	25.5% (13)	13.7% (7)	NS
Needs social worker in home community	54.9% (28)	35.3% (18)	p < .01
Needs pharmacy in home community	13.7% (7)	7.8% (4)	NS
Lacks knowledge of disease/medications	47.1% (24)	15.7% (8)	p < .001