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Readiness for Transition to Adult Care: Pediatric Kidney Transplant Patients

Clinical Question

| | |
|------------------------|---|
| P (population/problem) | In children with kidney transplants |
| I (intervention) | what are key barriers and facilitators during childhood |
| O (outcome) | that, if addressed systematically, ensure successful graft function after transition from pediatric to adult health services? |

Target Population Adolescents who have had a kidney transplant at any age

Recommendations (See Table of Recommendation Strengths following references)

Note: There are no published studies that evaluate the effectiveness of a transition program for transplant patients. The following recommendations are based on considered judgment from a consensus process that incorporated critically appraised evidence, clinical experience, patient views and preferences, and other dimensions (see Table of Recommendation Strength following references).

1. It is recommended that readiness for transition to adult care be assessed:
 - at least annually beginning in early adolescence (*Forbes 2001 [1b], Reiss 2005 [2a]*)
 - by both self- and health care provider-administered surveys (*Cappelli 1989 [2b]*)(*Cappelli 1989 [2b], McLaughlin 2008 [4b], Betz 2003 [5], Rettig 1991 [5], Local Consensus [5]*). See Appendix 1 and Appendix 2 for survey instruments.
2. It is recommended that the results of the readiness assessment be used to:
 - identify areas for education, intervention, discussion, and other targeted efforts, and
 - develop and implement written action plans that include timelines for review(*Betz 2004 [1b], Forbes 2001 [1b], Hauser 1999 [2a], Cappelli 1989 [2b], Por 2004 [4b], Betz 2003 [5], Rettig 1991 [5], Local Consensus [5]*).
3. It is recommended that pediatric healthcare providers
 - track progress toward complete readiness and achievement of transition using standardized assessment,
 - review progress with the patient's action plan, and revise as appropriate, at least annually and more frequently as needed until individualized transition readiness goals are achieved(*Hauser 1999 [2a], Flume 2004 [4b], Rettig 1991 [5], Local Consensus [5]*). See Appendix 3 for transition checklist tools for the following three age ranges: 12 to 14 years, 14 to 16 years, and 16 to 21 years.

Discussion/summary of evidence

A review of the literature on key barriers and facilitators for successful transition from pediatric to adult care for chronic conditions identified an extensive list of surveys and reviews, and several program descriptions, but few studies of program effectiveness, and few articles using patients with kidney transplants as participants (*Betz 2004 [1b], Hauser 1999 [2a], Brunfield 2004 [2b], Craig 2007 [4a], Scal 2005 [4a], Reid 2004 [4a], Remorino 2006 [4b], Betz 2003 [5], American Academy of 2002 [5], Baldassano 2002 [5]*). A retrospective study of 20 patients transferred from pediatric to adult care was unable to show a direct association between non-compliance and loss of graft, although an unanticipated graft loss of 35% within 36 months of transfer was observed (*Watson 2000 [4b]*).

Consequently, an affinity consensus process was conducted with members of the pediatric kidney transplant team in order to prioritize efforts in the initial stage of development of a transition program (*Balanced Scorecard Institute [5]*). From this process, transition readiness assessment and written action plan were identified as the first priority for implementation.

A search on "readiness" within the broad body of literature on key barriers and facilitators for successful transition identified a number of relevant articles. See Table. Appraisal of the qualitative studies and one systematic review

revealed that readiness, as an important facilitator for successful transition, is supported by high grade of evidence (*While 2004 [1b], Reiss 2005 [2a], Hauser 1999 [2a], McCurdy 2006 [2b]*).

Although age is frequently cited as a criterion for transfer to adult care, an arbitrary chronological age alone is not adequate to determine the complexity of the adolescent's development and one's readiness for transition (*While 2004 [1b], Forbes 2001 [1b], Reiss 2005 [2a], Flume 2004 [4b], Por 2004 [4b]*). Qualitative evidence from focus groups and interviews with patients, families, and healthcare providers supports transition based upon individual assessment of readiness regarding emotional, physical, developmental, and financial dimensions (*Forbes 2001 [1b], Flume 2004 [4b]*). Transition readiness assessment explores needs, concerns, and expectations and allows development of a plan with specific mutual goals (*Betz 2004 [1b], Forbes 2001 [1b]*).

Evidence supports that transition goals are achieved when the adolescent can practice life skills to manage his or her own care, is knowledgeable of his or her own disease and condition, and can adopt and demonstrate behaviors that are favorable to their health (*Hauser 1999 [2a]*).

Health Benefits, Side Effects and Risks


There is a theoretical reduction in the risk of rejection and poor post-transition outcomes among adolescents who are prepared for transition to adult care (*Annunziato 2007 [4b], Watson 2000 [4b]*). Implementing transition readiness assessments and written action plans is an approach more responsive to the adolescent's needs during transition than a transition plan based on patient age (*Hauser 1999 [2a]*).

Nevertheless, there may be a discrepancy between what is believed to be offered and taught to and planned for patients and what is perceived by the patient (*Remorino 2006 [4b]*). Organizational barriers to implementing transition readiness assessment and intervention include the need for coordination and administration of the process, both within the clinic flow and within the individual patient's office visit.

Table: Articles which Address Readiness for Transition to Adult Care (in alphabetical order by 1st author)

| Citation | Study Design | Study Description / Purpose | Patient Population Condition |
|---------------------------------|--|---|--|
| (<i>Betz 2003 [5]</i>) | descriptive | <ul style="list-style-type: none"> program description | special health care needs |
| (<i>Betz 2004 [1b]</i>) | systematic review of literature | <ul style="list-style-type: none"> analysis | special health care needs |
| (<i>Cappelli 1989 [2b]</i>) | psychometric | <ul style="list-style-type: none"> development and validation of readiness questionnaire for cystic fibrosis patients | cystic fibrosis |
| (<i>Flume 2004 [4b]</i>) | descriptive | <ul style="list-style-type: none"> survey of non-physician healthcare team members | cystic fibrosis |
| (<i>Forbes 2001 [1b]</i>) | systematic review of literature | <ul style="list-style-type: none"> development of framework | chronic illness or disability |
| (<i>Hauser 1999 [2a]</i>) | qualitative | <ul style="list-style-type: none"> survey of focus groups of patients, parents and health care providers development of framework for transitioning | sickle cell |
| (<i>McCurdy 2006 [2b]</i>) | qualitative | <ul style="list-style-type: none"> focus group of young adults who have transitioned to adult care | solid organ transplant |
| (<i>McLaughlin 2008 [4b]</i>) | descriptive | <ul style="list-style-type: none"> survey of care team members | cystic fibrosis |
| (<i>Por 2004 [4b]</i>) | descriptive | <ul style="list-style-type: none"> survey of health care professionals | chronic illness |
| (<i>Reiss 2005 [2a]</i>) | qualitative | <ul style="list-style-type: none"> focus groups and interviews patients, family members, health care providers | disabilities and special health care needs |
| (<i>Rettig 1991 [5]</i>) | descriptive | <ul style="list-style-type: none"> program description | rheumatic diseases |
| (<i>While 2004 [1b]</i>) | systematic review of literature (see Forbes above) | <ul style="list-style-type: none"> identify good practices | chronic illness or disability |
| (<i>Wiener 2007 [4b]</i>) | longitudinal | <ul style="list-style-type: none"> scored questionnaire to systematically examine transition readiness | HIV |

References (evidence grade in []; see *Table of Evidence Levels following references*)

Note: When using the electronic version of this document,  indicates a hyperlink to the PubMed abstract. A hyperlink following this symbol goes to the article PDF when the user is within the CCHMC network.

1. **American Academy of P.; American Academy of Family, P.; and American College of Physicians-American Society of Internal, M.:** A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110(6 Pt 2): 1304-6, 2002, [5] [_____](#) .
2. **Annunziato, R. A.; Emre, S.; Shneider, B.; Barton, C.; Dugan, C. A.; and Shemesh, E.:** Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services.[see comment]. *Pediatric Transplantation*, 11(6): 608-14, 2007, [4b] [_____](#) .
3. **Balanced Scorecard Institute:** Affinity Diagram, Module 4, in Basic Tools for Process Improvement. Accessed June 11, 2008 from <http://www.balancedscorecard.org/Portals/0/PDF/affinity.pdf>  [5].
4. **Baldassano, R.; Ferry, G.; Griffiths, A.; Mack, D.; Markowitz, J.; and Winter, H.:** Transition of the patient with inflammatory bowel disease from pediatric to adult care: recommendations of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. *Journal of Pediatric Gastroenterology & Nutrition*, 34(3): 245-8, 2002, [5] [_____](#) .
5. **Betz, C. L.:** Transition of adolescents with special health care needs: review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27(3): 179-241, 2004, [1b] [_____](#) .
6. **Betz, C. L., and Redcay, G.:** Creating Healthy Futures: an innovative nurse-managed transition clinic for adolescents and young adults with special health care needs. *Pediatric Nursing*, 29(1): 25-30, 2003, [5] [_____](#) .
7. **Brumfield, K., and Lansbury, G.:** Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation*, 26(4): 223-34, 2004, [2b] [_____](#) .
8. **Cappelli, M.; MacDonald, N. E.; and McGrath, P. J.:** Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. *Child Health Care*, 18(4): 218-24, 1989, [2b] [_____](#) .
9. **Craig, S. L.; Towns, S.; and Bibby, H.:** Moving on from paediatric to adult health care: an initial evaluation of a transition program for young people with cystic fibrosis. *International Journal of Adolescent Medicine & Health*, 19(3): 333-43, 2007, [4a] [_____](#) .
10. **Flume, P. A.; Taylor, L. A.; Anderson, D. L.; Gray, S.; and Turner, D.:** Transition programs in cystic fibrosis centers: perceptions of team members.[see comment]. *Pediatric Pulmonology*, 37(1): 4-7, 2004, [4b] [_____](#) .
11. **Forbes, A.:** A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. Report for *National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)*: 1-137, 2001, [1b] [_____](#) .
12. **Hauser, E. S., and Dorn, L.:** Transitioning adolescents with sickle cell disease to adult-centered care. *Pediatric Nursing*, 25(5): 479-88, 496-7, 1999, [2a] [_____](#) .
13. **Local Consensus:** During BESt development timeframe. [5].
14. **McCurdy, C.; DiCenso, A.; Boblin, S.; Ludwin, D.; Bryant-Lukosius, D.; and Bosompra, K.:** There to here: young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Progress in Transplantation*, 16(4): 309-16, 2006, [2b] [_____](#) .
15. **McLaughlin, S. E.; Diener-West, M.; Indurkha, A.; Rubin, H.; Heckmann, R.; and Boyle, M. P.:** Improving transition from pediatric to adult cystic fibrosis care: lessons from a national survey of current practices. *Pediatrics*, 121(5): e1160-6., 2008, [4b] [_____](#) .
16. **Por, J.; Golberg, B.; Lennox, V.; Burr, P.; Barrow, J.; and Dennard, L.:** Transition of care: health care professionals' view. *Journal of Nursing Management*, 12(5): 354-61, 2004, [4b] [_____](#) .
17. **Reid, G. J.; Irvine, M. J.; McCrindle, B. W.; Sananes, R.; Ritvo, P. G.; Siu, S. C.; and Webb, G. D.:** Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics*, 113(3 Part 1): Supplement: e197-205, 2004, [4a] [_____](#) .
18. **Reiss, J. G.; Gibson, R. W.; and Walker, L. R.:** Health care transition: youth, family, and provider perspectives. *Pediatrics*, 115(1): 112-20, 2005, [2a] [_____](#) .
19. **Remorino, R., and Taylor, J.:** Smoothing things over: the transition from pediatric to adult care for kidney transplant recipients. *Progress in Transplantation*, 16(4): 303-8, 2006, [4b] [_____](#) .
20. **Rettig, P., and Athreya, B. H.:** Adolescents with chronic disease. Transition to adult health care. *Arthritis Care Res*, 4(4): 174-80, 1991, [5] [_____](#) .

21. **Scal, P., and Ireland, M.:** Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, 115(6): 1607-12, 2005, [4a] _____

22. **The UNC Transition Team:** UNC Kidney Center, Tools for Transition, 2008. Accessed 6/18/08 from <http://www.unckidneycenter.org/hcprofessionals/toolsfortransition.html> [5].

23. **Watson, A. R.:** Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric Nephrology*, 14(6): 469-72, 2000, [4b] _____

24. **While, A.; Forbes, A.; Ullman, R.; Lewis, S.; Mathes, L.; and Griffiths, P.:** Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development*, 30(5): 439-52, 2004, [1b] _____

25. **Wiener, L. S.; Zobel, M.; Battles, H.; and Ryder, C.:** Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: assessing transition readiness. *Social Work in Health Care*, 46(1): 1-19, 2007, [4b] _____

Note: Full tables of evidence grading system available in separate document:

- Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality (abbreviated table below)
- Grading a Body of Evidence to Answer a Clinical Question
- Judging the Strength of a Recommendation (abbreviated table below)

Table of Evidence Levels (see note above)

| <i>Quality level</i> | <i>Definition</i> |
|----------------------|--|
| 1a† or 1b† | Systematic review, meta-analysis, or meta-synthesis of multiple studies |
| 2a or 2b | Best study design for domain |
| 3a or 3b | Fair study design for domain |
| 4a or 4b | Weak study design for domain |
| 5 | Other: General review, expert opinion, case report, consensus report, or guideline |

†a = good quality study; b = lesser quality study

Table of Recommendation Strength (see note above)

| <i>Strength</i> | <i>Definition</i> |
|------------------------|---|
| “Strongly recommended” | There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations). |
| “Recommended” | There is consensus that benefits are closely balanced with risks and burdens. |
| No recommendation made | There is insufficient evidence and lack of consensus to direct development of a recommendation. |

Dimensions: In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.

1. Grade of the Body of Evidence (see note above)
2. Safety / Harm
3. Health benefit to patient (*direct benefit*)
4. Burden to patient of adherence to recommendation (*cost, hassle, discomfort, pain, motivation, ability to adhere, time*)
5. Cost-effectiveness to healthcare system (*balance of cost / savings of resources, staff time, and supplies based on published studies or onsite analysis*)
6. Directness (*the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome]*)
7. Impact on morbidity/mortality or quality of life

Appendix 1: Transition Score Assessment - A health-provider administered survey that takes no more than 10 minutes to complete. It is designed to help providers identify which area(s) of transition require education and also to track each patient's progress.

Name: _____ Date: _____

Overall UNC T.R_x.A.N.S.I.T.I.O.N. Score™: _____ out of _____ (# of questions asked*) times 100 = _____%

*denominator will vary because some questions are conditional or are gender specific

UNC T.R_x.A.N.S.I.T.I.O.N. Score™ for Adolescents and Young Adults:

Type of chronic health condition

| <i>Can you...</i> | Yes | Non-specific | No |
|--|-----|--------------|----|
| 1. tell me the name of your health condition? | 1 | 0.5 | 0 |
| 2. describe symptoms of your health condition? | 1 | 0.5 | 0 |
| 3. tell me how this condition may affect you in the future (e.g., interfere with activities you want to participate in, affect daily life, etc)? | 1 | 0.5 | 0 |

Subtotal T₁:

R_x = Medications

| <i>Can you tell me...</i> | Yes | Some | No |
|--|-----|------|----|
| 4. the name of your medicines? | 1 | 0.5 | 0 |
| 5. when you take your medicines? | 1 | 0.5 | 0 |
| 6. why you are taking each of your medicines? | 1 | 0.5 | 0 |
| 7. what would happen if you stopped taking them? | 1 | 0.5 | 0 |

Subtotal R:

Adherence

| <i>Do you...</i> | Yes | Sometimes | No |
|--|-----|--------------------|----|
| 8. miss a full day of medicine during the week, either because you forgot to take it or didn't want to take it? (If sometimes or yes): How many days per week does this happen? | 0 | 0.5 | 1 |
| | | <1 2 to 3 >3 | |
| 9. have difficulty remembering to take your medicines every day? | 0 | 0.5 | 1 |
| 10. attend your medical appointments when they are scheduled? | 1 | 0.5 | 0 |

Subtotal A:

Nutrition

| <i>Do you know...</i> | Yes | Some | No |
|---|-----|------|----|
| 11. if there is anything you are not supposed to eat/drink, or not supposed to eat/drink a lot of? (if no dietary restrictions, skip to question 13) | 1 | 0.5 | 0 |
| 12. specific examples of these food/drinks? | 1 | 0.5 | 0 |
| 13. how to read nutrition labels on food or drinks to see if they are OK for you to eat or drink? | 1 | 0.5 | 0 |

Subtotal N₁:

UNC T.R.,A.N.S.I.T.I.O.N. Score™ for Adolescents and Young Adults, page 2

Self-management skills

| | Yes | Sometimes | No |
|--|------------|------------------|-----------|
| 14. Do you remember to take your medications on your own? | 1 | 0.5 | 0 |
| 15. Does someone have to remind you to take your medications? | 0 | 0.5 | 1 |
| <i>Do you...</i> | | | |
| 16. call in prescription refills? | 1 | 0.5 | 0 |
| 17. pick-up refills from the pharmacy? <i>If no driver's license: Do you go with your parents, walk up to the counter, and tell the pharmacist what you are picking up?</i> | 1 | 0.5 | 0 |
| 18. call your doctor when you have a question or don't feel good? | 1 | 0.5 | 0 |
| 19. make your own doctor appointments? | 1 | 0.5 | 0 |
| 20. <i>(if applicable)</i> perform your medical procedures yourself, such as catheterization, insulin shots, etc? | 1 | 0.5 | 0 |

| |
|--------------------|
| Subtotal S: |
|--------------------|

Informed about reproductive health issues

| | Yes | Has an idea | No |
|---|------------|--------------------|-----------|
| <i>Can you tell me...</i> | | | |
| 21. if your health condition will affect your ability to get pregnant or get someone else pregnant in the future? | 1 | 0.5 | 0 |
| 22. <i>(female only)</i> if your health condition will affect you during pregnancy? | 1 | 0.5 | 0 |
| 23. <i>(female only)</i> if your medications will affect an unborn baby? | 1 | 0.5 | 0 |
| 24. methods of protection against an unwanted pregnancy or STDs? | 1 | 0.5 | 0 |

| |
|---------------------|
| Subtotal I1: |
|---------------------|

Trade/School

| | Yes | Has an idea | No |
|---|------------|--------------------|-----------|
| 25. What are your future plans in regards to school and/or a job? | 1 | 0.5 | 0 |
| 26. If you do not remain a full-time student after you graduate from high school (i.e., go to college), can you tell me what will happen to your current health insurance coverage? | 1 | 0.5 | 0 |

| |
|---------------------|
| Subtotal T2: |
|---------------------|

UNC T.R_x.A.N.S.I.T.I.O.N. Score™ for Adolescents and Young Adults, page 3

Insurance

| <i>Can you tell me...</i> | Yes | Has an idea | No |
|---|------------|--------------------|-----------|
| 27. why it is important to have health insurance? | 1 | 0.5 | 0 |
| 28. what is the name of your current health insurance provider? | 1 | 0.5 | 0 |
| 29. how your insurance will change when you become an adult? | 1 | 0.5 | 0 |
| 30. how you will get health insurance for yourself when you are an adult? | 1 | 0.5 | 0 |

| |
|---------------------|
| Subtotal I2: |
|---------------------|

Ongoing support

| <i>When you are an adult, who will help you...</i> | Self | Parents/friends | No idea |
|---|-------------|------------------------|----------------|
| 31. manage your health condition (e.g., remind you to take your medicine, call in prescription refills & pick them up from the pharmacy, make your doctor appointments & keep track of them?) | 1 | 0.5 | 0 |

| |
|--------------------|
| Subtotal O: |
|--------------------|

New health care providers

| <i>Can you tell me how you...</i> | Yes | Has an idea | No |
|---|------------|--------------------|-----------|
| 32. would find a doctor if you needed one (for example, if you moved to a new town, who would you ask, where would you look)? | 1 | 0.5 | 0 |
| 33. get your medical records transferred from one doctor to another? | 1 | 0.5 | 0 |

| |
|---------------------|
| Subtotal N2: |
|---------------------|

| |
|---|
| <p>Overall UNC T.R_x.A.N.S.I.T.I.O.N. Score™:</p> <p>_____ out of _____ (# of questions asked*) times 100 = _____%</p> |
|---|

*denominator will vary because some questions are conditional or are gender specific

adapted from (The UNC Transition Team 2008 [5])

Appendix 2: [Transition Readiness Survey](#) - A self-administered instrument that takes 10 minutes to complete. It is designed to help track and determine the transition status of patients in regards to their readiness to move from pediatric to adult care.

Name: _____

Date: _____

STARx Questionnaire

Patients with kidney disease have special skills and tasks they must do. Some patients know a lot about their health, and some patients don't. Some patients find it easy or hard to do certain things. Help us better understand what describes you.

If you do not understand a question, please ask for help. We're here to help you.

How often? Please circle the numbers that describe you best.

| In the PAST 3 MONTHS... | Never | Almost Never | Sometimes | Almost Always | Always |
|---|-------|--------------|-----------|---------------|--------|
| 1. How often did you make an effort to understand what your doctor told you? | 0 | 1 | 2 | 3 | 4 |
| 2. How often did you take your medicines on your own? | 0 | 1 | 2 | 3 | 4 |
| 3. How often did you ask your doctor or nurse questions about your illness, medicines, or medical care? | 0 | 1 | 2 | 3 | 4 |
| 4. How often did you make your own medical appointments? | 0 | 1 | 2 | 3 | 4 |
| 5. How often did you need someone to remind you to take your medicines? | 0 | 1 | 2 | 3 | 4 |
| 6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to? | 0 | 1 | 2 | 3 | 4 |
| 7. How often did you use the internet, books, or other guides to find out more about your illness? | 0 | 1 | 2 | 3 | 4 |
| 8. How often did you forget to take your medicines? | 0 | 1 | 2 | 3 | 4 |
| 9. How often did you work with your doctor to take care of new health problems that came up? | 0 | 1 | 2 | 3 | 4 |
| How Often Subtotal | | | | | |

How much do you know? Please circle the numbers that describe you best.

| | Not Much | A Little | Some | A Lot |
|---|----------|----------|------|-------|
| 10. How much do you know about your illness? | 0 | 1 | 2 | 3 |
| 11. How much do you know about taking care of your illness? | 0 | 1 | 2 | 3 |
| 12. How much do you know about what will happen if you don't take your medicines? | 0 | 1 | 2 | 3 |
| How Often Subtotal | | | | |

How easy or hard is it to do?

| | Very Hard | Somewhat Hard | Somewhat Easy | Very Easy |
|---|-----------|---------------|---------------|-----------|
| 13. How easy or hard is it to talk to your doctor? | 0 | 1 | 2 | 3 |
| 14. How easy or hard is it to make a plan with your doctor to care for your health? | 0 | 1 | 2 | 3 |
| 15. How easy or hard is it to see your doctor by yourself? | 0 | 1 | 2 | 3 |
| 16. How easy or hard is it to take your medicines like you are supposed to? | 0 | 1 | 2 | 3 |
| 17. How easy or hard is it to take care of yourself? | 0 | 1 | 2 | 3 |
| 18. How easy or hard do you think it will be to move from pediatric to adult care? | 0 | 1 | 2 | 3 |
| How Often Subtotal | | | | |

Thank You for Sharing Your Thoughts with Us!

| |
|---|
| <p>Overall STARx Questionnaire Score</p> <p>_____ out of 54 points times 100 = _____ %</p> |
|---|

adapted from (*The UNC Transition Team 2008 [5]*)

Appendix 3: Transition Checklist Tool - It is designed to help track progress with patient's action plan for transition readiness to move from pediatric to adult care.

Name: _____ Date: _____



EARLY TRANSITION (12 to 14 years)

| Page 1 | Youth and family | Reviewed (date/initial) | Met (date/initial) |
|--|---|-------------------------|--------------------|
| SELF ADVOCACY | Learn about transition process | _____ | _____ |
| | Describe chronic health condition | _____ | _____ |
| | Asks health-related questions | _____ | _____ |
| | Describes plan for who to call when not feeling well | _____ | _____ |
| INDEPENDENT BEHAVIORS | Names medications, doses & schedules | _____ | _____ |
| | Choose method to record/remember to take medications | _____ | _____ |
| | Discuss renal illness treatment plan | _____ | _____ |
| SEXUAL HEALTH | Discuss body image; changes in appearance due to puberty or meds | _____ | _____ |
| | Identifies concerns about menstruation | _____ | _____ |
| | Learns about impact of puberty on health condition and/or condition on puberty | _____ | _____ |
| | Describes what is being taught in school – review any questions related to condition | _____ | _____ |
| SOCIAL SUPPORTS | Describe people in family / at home | _____ | _____ |
| | Discuss family role in transition planning / feelings about youths growing older – ability to take on more responsibility | _____ | _____ |
| | Discuss importance of feelings | _____ | _____ |
| | Describes ways to make / have friends | _____ | _____ |
| EDUCATIONAL / VOCATIONAL / FINANCIAL PLANNING | Discusses school – attendance, strengths, goals and concerns | _____ | _____ |
| | Identify youths' responsibilities at home / chores | _____ | _____ |



| Early, Page 2 | Youth and family | Reviewed (date/initial) | Met (date/initial) |
|-------------------------------|--|-------------------------|--------------------|
| HEALTH & LIFESTYLE | Discuss treatment therapies (i.e. IUC; dialysis) | | |
| | Discuss exercise – gym, teams, activities | | |
| | Aware of limitations / restrictions | | |
| | Discusses knowledge of peer use of tobacco – review risks of smoking | | |
| | Describes a health diet plan | | |

| INT. | SIGNATURE | INT. | SIGNATURE | INT. | SIGNATURE |
|------|-----------|------|-----------|------|-----------|
| | | | | | |
| | | | | | |

Name: _____

Date: _____



MIDDLE TRANSITION (14 to 16 years)

| Page 1 | Youth (with assistance of family as needed) | Reviewed (date/initial) | Met (date/initial) |
|--|--|--|--|
| SELF ADVOCACY | Describe condition in own words Describes personal care needs to others Names family physician or pediatrician Names and describes the role of those involved in his/her health care Learns about rights and responsibilities | _____ _____ _____ _____ _____ | _____ _____ _____ _____ _____ |
| INDEPENDENT BEHAVIORS | Reviews treatment plan – confirms adherence Describes tests and reasons for them Describes medications & reasons for them Adheres to medication regimen – describes concerns re: side effects Brings med list to clinic appointments Describes reasons to call MD (i.e. fever, cloudy dialysate, etc) | _____ _____ _____ _____ _____ _____ | _____ _____ _____ _____ _____ _____ |
| SEXUAL HEALTH | Review body image issues – relation to compliance to medications Names persons / places for reliable, accurate information about sexual health questions Discuss safe relationships and dating Identifies sexual health concerns / questions | _____ _____ _____ _____ | _____ _____ _____ _____ |
| SOCIAL SUPPORTS | Discuss family health (history & present) Refer to materials that offer family support and ideas for youth living with a chronic condition Discuss ways to benefit from peer support Discuss family needs for support Describes who to talk to during difficult times | _____ _____ _____ _____ _____ | _____ _____ _____ _____ _____ |
| EDUCATIONAL / VOCATIONAL / FINANCIAL PLANNING | Discuss (real or perceived) restrictions to educational or work opportunities Identify school issues, strengths and concerns Meets with school counselor to discuss options | _____ _____ _____ | _____ _____ _____ |



| Middle - Pg 2 | Youth (with assistance of family as needed) | Reviewed (date/initial) | Met (date/initial) |
|-------------------------------|--|-------------------------|--------------------|
| HEALTH & LIFESTYLE | Describes ways of coping with stress | _____ | _____ |
| | Lists ways used to relax and feel good about self | _____ | _____ |
| | Learns about the use of drugs, alcohol and smoking when mixed with medications | _____ | _____ |

| INT. | SIGNATURE | INT. | SIGNATURE | INT. | SIGNATURE |
|------|-----------|------|-----------|------|-----------|
| | | | | | |
| | | | | | |

Name: _____ Date: _____



LATE TRANSITION (16 to 21 years)

| Page 1 | Youth independently or with Family / Guardian | Reviewed (date/initial) | Met (date/initial) |
|------------------------------|---|--|--|
| SELF ADVOCACY | Understands the importance of preparing for environment / expectations of adult care Review successful changes achieved in life Understands who will need to be involved in providing adult health care Review condition / ways to stay informed Learn about health care advocate / need to identify | _____ _____ _____ _____ _____ | _____ _____ _____ _____ _____ |
| INDEPENDENT BEHAVIORS | Reviews personal care needs Describes renal illness / impact on life Learns about transportation services & benefits Demonstrates knowledge of medications, refilling prescriptions, booking appointments Identifies a family physician and adult specialist (i.e. Nephrologist, Gyn, etc) to meet ongoing health care needs – has M.D. phone number(s) Tours / visits adult clinic and locates important facilities Understands differences between pediatric (family-centered) & adult health care Schedules and prepares for appointment with adult specialist prior to last pediatric visit – schedule tx evaluation with adult program, if applicable. Meets independently with caregiver. Describes when and how to call caregiver to report problems or concerns about health | _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ | _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ |
| SEXUAL HEALTH | Aware of sexual capability, ability to make and have children (to be dealt with as ready) Can identify health care providers / family to discuss sexual health, contraception and family planning Understands risks of sexual behaviors on condition; contraception, STD's and pregnancy. Aware of medications that cause birth defects. | _____ _____ _____ _____ | _____ _____ _____ _____ |



| Late - Pg 2 | Youth independently or with Family / Guardian | Reviewed (date/initial) | Met (date/initial) |
|--|--|---|---|
| SOCIAL SUPPORTS | Aware of condition-specific associations and organizations for support and information. Discuss (real or perceived) concerns around gaining independence – changing roles in family Identifies source of support & a person he / she could contact if feeling lonely, sad or depressed | <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/> |
| EDUCATIONAL / VOCATIONAL / FINANCIAL PLANNING | Describes strengths in school – discuss any patterns that are emerging – careers or interest, limitations Aware of opportunities to job shadow / volunteer Discuss importance of giving information about condition to potential employers or college programs Discuss resources available for education career assistance, counseling and job placement Review plans for future medical insurance benefits Discuss future plans for living | <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> |
| HEALTH & LIFESTYLE | Describe exercise / activity routine Describes health diet and /or any diet restrictions Reviews smoking, drugs or alcohol impact on condition and general health Discuss importance of planning ahead for trips / being away from home | <hr/> <hr/> <hr/> <hr/> <hr/> | <hr/> <hr/> <hr/> <hr/> <hr/> |

| INT. | SIGNATURE | INT. | SIGNATURE | INT. | SIGNATURE |
|------|-----------|------|-----------|------|-----------|
| | | | | | |
| | | | | | |

Supporting information

Group/team members

Jens Goebel, MD, Pediatric Nephrology
 Bradley Dixon, MD, Pediatric Nephrology
 Denise McAdams, RN, Pediatric Nephrology
 Debra Schoborg, RN, Pediatric Nephrology
 Juliann Ross, RN, Pediatric Nephrology
 Ahna Pai, PhD, Center for the Promotion of Adherence and Self-Management

Clinical Effectiveness Support
 Jennifer Russell, Facilitator
 Eloise Clark, MPH, MBA, Evidence Facilitator
 Karen Vonderhaar, MS, RN, Methodologist
 Elizabeth Ricksecker, MA, Outcomes Manager
 Danette Stanko-Lopp, MA, MPH, Epidemiologist
 Barbarie Hill, MLS, Pratt Library

Search strategy

1. Original Search

OID Databases

Medline, CINAHL, and the Cochrane Database for Systematic Reviews (CDSR)

OID FILTERS

| | |
|------------------|--|
| Publication Date | 2001 to present |
| Limits | Humans and English Language |
| Study Type | highest quality evidence |
| Publication Type | Guidelines, Systematic Reviews, and Meta-Analyses |
| Age Limits | Children [All child (0 to 18 years) or "newborn infant (birth to 1 month)" or "infant (1 to 23 months)" or "preschool child (2 to 5 years)" or "child (6 to 12 years)" or "adolescent (13 to 18 years)"] |

OID SEARCH TERMS & MeSH TERMS

Intervention/Exposure: Kidney Transplant\$ or Kidney Transplantation
 transition readiness, transition to adulthood, transition\$ and (adolescen\$ or adult\$)

Within the above search results, a refined search was also conducted for "readiness"

2. Additional articles – identified from reference lists, systematic reviews, and clinicians

Applicability issues

Outcomes that are planned to be measured include:

Average UNC T.R_x.A.N.S.I.T.I.O.N.TM and STARx Questionnaire scores

Copies of this Best Evidence Statement (BESt) are available online and may be distributed by any organization for the global purpose of improving child health outcomes. Website address: <http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/default.htm>

Examples of approved uses of the BESt include the following:

- copies may be provided to anyone involved in the organization's process for developing and implementing evidence based care;
- hyperlinks to the CCHMC website may be placed on the organization's website;
- the BESt may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and
- copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at HPCEInfo@cchmc.org for any BESt adopted, adapted, implemented or hyperlinked by the organization is appreciated.

Additionally for more information about CCHMC Best Evidence Statements and the development process, contact the Health Policy & Clinical Effectiveness office at: 513-636-2501 or HPCEInfo@chmcc.org.

Note

This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.

Reviewed by: Clinical Effectiveness