Transition of Adolescent with Chronic Diseases from Pediatric to Adult Care

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June 2024

Disease Course Differences

- For specific chronic diseases, there are documented variations in **clinical course** and **prognosis** when the disease presents in childhood compared with adulthood.

- Clear differences in diagnostic and therapeutic **IBD** management dependent on **age at diagnosis** with a higher use of exclusive enteral nutrition in children with Crohn's disease and general anesthetic use for endoscopy in children compared with sedation in adults.

- Children presenting with IBD have a **more extensive** disease phenotype and rapid early progression.

Disease Course Differences

- In the field of Ped GI due to the comparatively larger sizes of the patient populations, transition has to date been more frequently undertaken in the IBD and liver disease patient (**Referral Letter**).
- The majority of patients with celiac disease and other common illnesses (constipation, GERD), together with simple functional GI disorders, have been transferred from pediatric to adult care or discharged from pediatric care with the **expectation that the primary care physician will refer** to an appropriate adult consultant if required.

Scope and Purpose

- The risks of poor transition include **delayed and inappropriate transfer** that can result in disengagement with healthcare.
- **Structured transition** care can improve control of chronic diseases and long-term health-related outcomes.
- The aim of the guideline is to provide clinical guidelines based on current available literature for the care of adolescent as they progress from pediatric health services through to adult care.

Headings

1. Patient populations involved in adolescent transition
2. Risks of failing transition or poor transition
3. Models of adolescent transition
4. Patient and parent perspective in adolescent transition
5. Surgical perspective

Patient Populations

- For example in Ped GI, adolescent and young person with:
  - IBD
  - Celiac Disease
  - Chronic Liver Diseases

should be involved in formal transition arrangements

- Adolescent with other chronic GI and liver conditions, including **complex functional disorders**, are likely to benefit from formal transition arrangements and may be incorporated into existing transition services.

Practice Points

Health Care Professionals involved in the management of adolescent with chronic diseases should:

- Aware of the **differences** between classification, diagnostic methods, treatment and natural history of relevant pediatric and adult chronic diseases
- Receive **appropriate training** in transition care such as the pitfalls and benefits of transition and strategies to improve transitional care

Practice Points

- Centers should audit their population of adolescent with chronic diseases to **determine the prevalence** and **service requirements** for transition.
- Adolescent should be transitioned once they have finished or are in the **later stages of puberty**
- Patients with growth issues should be transitioned once the **growth issues are resolved**

Benefits of Successful Transition

There is evidence to support the benefits achieved by successful transition programs in chronic diseases in various disciplines.

- For adolescents with **Diabetes**, successful transition has been shown to result in improved objective measures of **glycemic control**, better engagement with **screening programs**, improved **outpatient attendance** and **engagement with adult providers** in addition to **decreased hospitalization** with diabetic ketoacidosis.

Benefits of Successful Transition

- In **Juvenile Idiopathic Arthritis** and **Congenital Heart Disease**, successful transition was associated with improved **self-knowledge** and improved **disease knowledge** among parents. These were accompanied by **increased satisfaction** with the process and **better quality of life**.
- In **Renal Diseases**, an integrated pediatric-adult clinical transition service was associated with a striking **reduction in the rate of graft loss** among the patients with renal transplants.

Benefits of Successful Transition

- A recent UK study in 72 patients with **IBD** in pediatric care and then transferred to adult care service who either went through a formal transition program versus no formal program has shown that establishment of a transition program resulted in improvements in **drug adherence**, **clinical attendance** and **growth** with a **reduced need for surgical** intervention on retrospective analysis of their medical records.

- Inadequate transition in **IBD** is associated with clinic **non-attendance** and **non-adherence** with medication, **restricted growth** potential and an increased likelihood of **requiring surgery**.

Benefits of Successful Transition

- Following **Solid Organ Transplantation**, inadequate transition has been associated with **worsening adherence**, increased **graft loss** and higher **mortality**.
- In **Celiac Disease**, inadequate transition arrangements are associated with **dietary non-adherence**, **anemia** and **reduced bone density**.

Risk of Failing Transition or Poor Transition

- Transition to adulthood is a **complicated process** for most adolescent and is particularly so where adolescent have chronic illnesses and ongoing health needs.
- Inadequate transition arrangements have been associated with a number of adverse outcomes.
- These consequences include **delayed and inappropriate care**, poor communication with adolescent and their families, as well as **emotional** and often **financial stress** for patients, their families and healthcare systems

Inadequate Transition Arrangements

- As the adolescent grows into adulthood, considerations of further **education** and **employment** become important.
- There is some emerging data on the relevance of a coordinated transition during adolescence in chronic disorders, which may have impact on the future work and employment.

Recommendations

Use of structured transition programs to:

1. Improve control of chronic disease
2. Enhance adherence to medications, clinic attendance and clinical outcomes
3. Increase disease related knowledge in patients and parents
4. Improve psychological outcome and health-related quality of life
5. Reduce adverse outcomes such as hospitalization and surgery

Improvements in Adherence and Compliance

- Adolescents who had moved from pediatric to adult care after liver transplant with the support of a liver **transplant coordinator** had more appropriate tacrolimus levels and enhanced healthcare management parameters compared with a historical comparison group.

Models of Adolescent Transition

An effective transition model may benefit from inclusion of the following elements:

- **Flexible** timing of transition
- A named transition **coordinator** to oversee the process
- **Individualization** of the transition model based on local expertise, staffing, resources and geography
- Assessment of **readiness** for transfer
- **Disease-specific** education program

Models of Adolescent Transition

Combined Care During Transition:

- **Combined Clinic Visits** with input from both pediatric and adult Health Care Professionals are clinically beneficial and endorsed by patients.
- The exact format of transition may be highly variable and may include **Combined Adult/Pediatric Clinics** and/or **Joint Multidisciplinary Clinics** or **‘Virtual’ Transition Clinics**.

Ped/Med

Models of Adolescent Transition

- **Direct Model:** The focus is primarily on **relations between services** and addresses continuity of information between them, rather than focusing on the adolescents' personal growth and development.

- **Sequential Model:** Is **more flexible** and recognizes that the adolescents' needs are changing and that they **require some preparation** if they are to adjust to adult care successfully.

Models of Adolescent Transition

- **Developmental Model:** Starts from the premise that the adolescent will need some help in acquiring the skills and support systems necessary to use or experience adult care effectively, with an **active focus on personal growth and development**.

- **Professional Model:** In contrast to the other models, **focuses on the expertise** from within one service type (adult or pediatric) and **not on the adolescent**.

  - This may be important in conditions with a **short life expectancy** or where expertise is heavily located within one service, for example, cystic fibrosis.

Recommendation

- An **overlap** between pediatric and adult care is a core element of every structured transition service.
- While there are numerous models of transition there is no evidence to support a particular type.

Essential Components of Transition Clinics

It is important to design the transition process to be flexible and dependent on patient factors including:

- Chronological age
- Current disease activity
- Adherence with medical therapies
- Views of adolescent
- View of the parents
- Self-advocacy skills of the patient

Essential Components of Transition Clinics

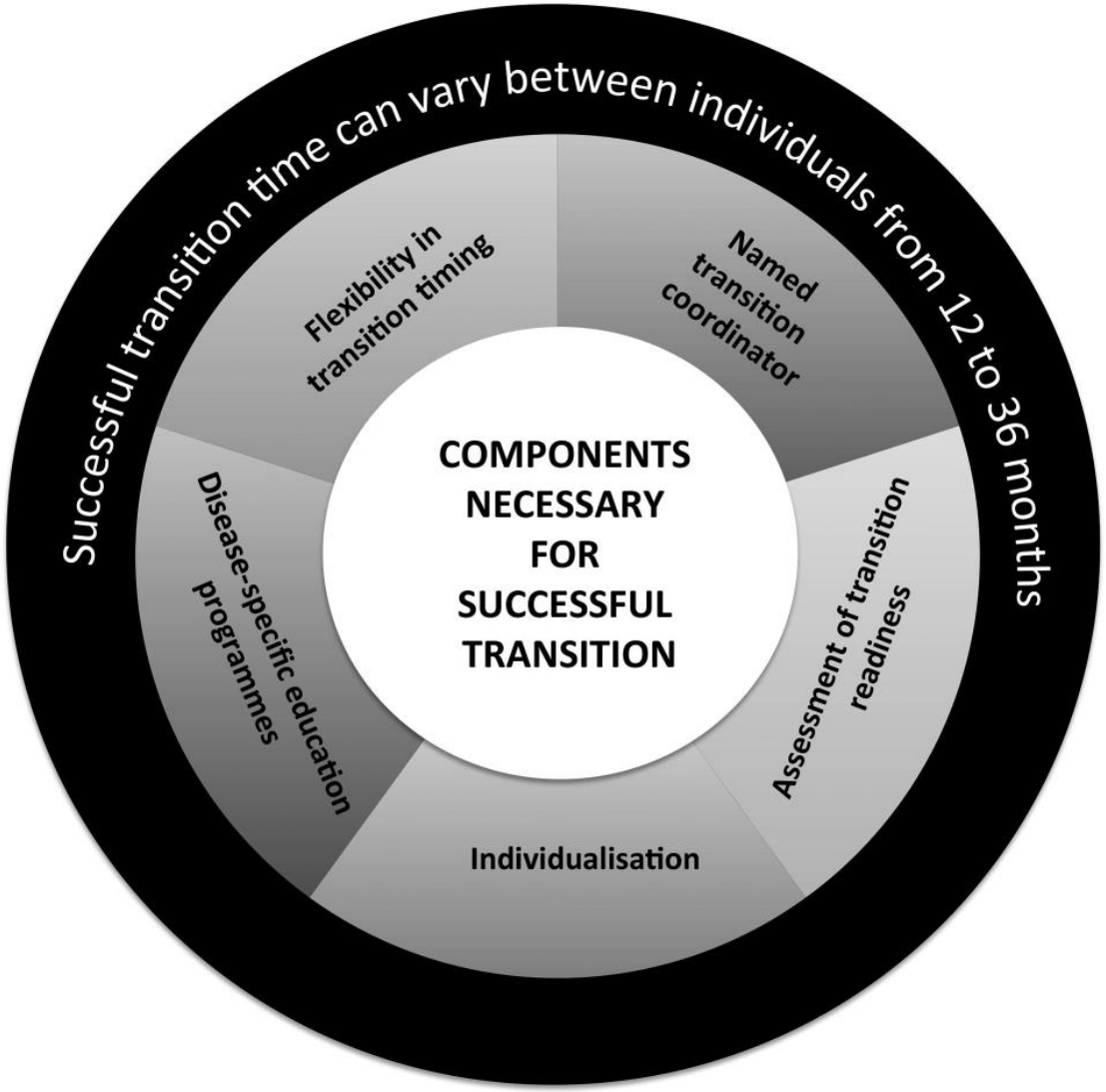
Three core areas that require attention when developing a successful transition service.

- Staffing requirements (transition coordinator)
- Service delivery (separate young adult clinics, out-of-hours telephone support and enhanced F/U)
- Patients (educational programs and skills training)

Adolescent Transition Coordinator

- The adolescent transition coordinator is frequently a **specialist nurse**, often, but not exclusively based within the pediatric service.
- In this model, the transition coordinator continues to work with the patients after transfer to the adult services to help address gaps identified in the patients' healthcare management.

Diagrammatic Illustration



Use of Technology in Transition Programs

Recent studies have highlighted the impact and interest in **web-based** and **mobile** technologies to assist in the transition process.

Such technologies offer several unique advantages including:

- Potential for individualization of the health message being delivered
- Rapid access
- Low cost
- Ability to overcome most geographical barriers

Use of Technology in Transition Programs

- With **wireless technologies** now being ubiquitous and text messaging being one of the main forms of communication by adolescents today.
- Such technology should be incorporated into the design of transition models to enable good, rapid communication with health providers for reporting of symptoms, obtaining essential medications, ensuring appointments are not missed, as well as providing links to educational materials and useful websites and support forums.

Audit of Transition Programs

In view of the inability to recommend one specific transition model for any specific service:

- Regular audit of the transition service in order to improve the service, outcomes and assess key performance indicators.

Patient and Parent Perspective

- Addressing patient and parents readiness during transition
- Prediction of the timing of transition for adolescents has been identified as one of the most important factors for its success.
- Patient and parents uncertainty and behavior during transition
- Failure to connect with an adult healthcare provider post transition has been demonstrated to predict future complications.

Patient and Parent Perspective

- Parents of adolescent undergoing transition may find it difficult to cope with their reduced role in medical care and should be actively included where appropriate.
- Negotiating the appropriate level of protectiveness with parent should be based on the adolescents self-efficacy.

Patient and Parent Perspective

- Adolescents displaying non-adherence may benefit from more frequent appointments, with intensified clinical interventions.
- Disease-specific knowledge is an important part of adolescent transition but information given is not always pertinent to adolescents stage of development, with information more often geared towards the parents rather than adolescent.

Recommendation

- Health Care Professionals consider concerns of adolescent and their parents during transition and identify when additional emotional and psychological support is required.
- Health Care Professionals maintain the goal of empowering the adolescent to become independent while acknowledging the parent perspectives.

Lifestyle, Psychosocial Health and Sexuality

- Studies in transplant recipients demonstrate that adolescents wish to be treated as adults and prefer healthcare professionals to address them instead of their parents.
- These studies have identified that areas that may not be addressed in a pediatric setting such as sexual relationships and recreational drug use are important to adolescents, but they are often reluctant to ask for such information.

Recommendation

- The transition process addresses the adolescent’s lifestyle, future health concerns, educational/employment goals, psychosocial health, sexuality and reproduction.

Surgical Perspective

- There is limited data in relation to transition of adolescent in the field of surgery. There are several groups of patients that may benefit from transition from pediatric to adult care:

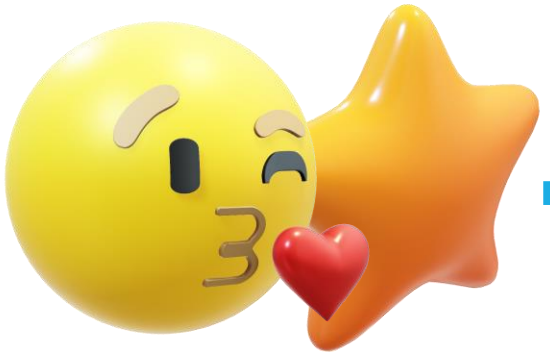
1. Patients who have undergone surgery in a specialist pediatric unit who require long-term follow-up and have reached an age where care in a pediatric setting is no longer inappropriate.

2. Patients who have been receiving ongoing pediatric medical treatment for a condition requiring surgical intervention at an age on the cusp of needing transition to an adult surgical service.

3. Patients with newly diagnosed conditions needing surgical intervention diagnosed at an age where transition to an adult service is indicated.

Practice Point

- Adolescents who require surgical intervention during the transition period have a named adult surgeon in the disciplined concerned involved in their care pre-operatively, peri-operatively and post-operatively, and that surgeon will form part of the multidisciplinary team in transition care.



Thanks