



सत्यमेव जयते

Ministry of Health & Family Welfare
Government of India



POLICY ON TRANSITION OF CARE (TOC) FOR YOUTH WITH SPECIAL HEALTH CARE NEEDS (YSHCN)

Transition of Care (ToC) for Youth with Special Health Care
Needs (YSHCN)

Preamble:

Transition of Care (ToC) is a crucial aspect of health care, emerging due to significant improvement in survival into adulthood of patients with chronic diseases with onset in childhood.

It is a common trend, especially in public sector hospitals, to direct the adolescent and young adult patients to the Medical OPD rather than the Pediatric OPD, when they are beyond the cut off age for pediatric services for that particular hospital. This method works well for otherwise healthy people attending the hospital for intercurrent illnesses. For Youth with Special Health Care Needs (YSHCN, defined as **“Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”** by the Maternal and Child Health Bureau (MCHB) of the USA) proper transition (transition of health care) to adult care system is required. In our country, we have no guidance for such a transition and hence, this guideline, which will deal with the process of transitioning care, for patients who have been diagnosed with illnesses in childhood, which are chronic and need adolescent and adult care in the future.

Definition:

Transition of Care (ToC) is defined as **"purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centered to adult orientated healthcare systems"** [1].

In practice, this translates to movement from a child and family-centered environment of pediatrics to a patient-centered adult medicine setting. Transition is often used interchangeably with *transfer of care*; however, the latter is the final outcome, a single event where care is handed over from a pediatric care provider to adult care provider.

Goal of ToC:

The American Academy of Pediatrics states, “The goal of transition in health care for YSHCN* is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood” [2].

With continued good quality health care, the young adult is envisaged to attain full developmental potential and will be a productive member of the society.

Rationale for ToC:

According to the National Survey of Children’s Health, funded by the US Department of Health and Human Services, almost 31% of adolescents have one moderate to severe chronic illness, such as asthma or a mental health condition. Other common chronic illnesses include cancer, cardiac disease, HIV infection, spastic quadriplegia, and developmental disabilities and epilepsy. One in 4 adolescents with chronic illness has at least one unmet health need that may affect physical growth and development, including puberty and overall health status as well as future adult health [3]. Such data from India is not easily available. However, data on certain disease specific prevalence among adolescents highlights the magnitude of the problem in our country. Recently, data from India on 514 patients of transfusion dependent thalassemia (TDT) in north India has been collated. Of these 222 (43%) patients are above the age of 18 years [4]. A large Mumbai centre has 35 % of the TDT patients above the age of 18 years [5]. Prevalence of epilepsy among 15–18-year-old boys and girls has been estimated to be 821 and 625 per 100,000 respectively [6]. According to 2022 estimates, over 8.5 lacs children and adolescents are affected by juvenile diabetes and with annual increase of 6.7%, the figure is likely to be over 17 lacs by the year 2040 [7]. Prevalence of asthma in children with mean age of 12 years is estimated to be 7.9 % [8]. According to ICMR estimates, there are 80,000-100,000 children with severe hemophilia in the country [9].

In the USA and other developed countries, policy statements and guidelines on ToC of YSHCN are in place for over 3-4 decades [3,10]. In India, ToC at present is sporadic.

Need for Proper ToC:

It is stated that ToC is “to affirm that just as children receive optimal primary care in a medical practice experienced in the care of children, so too adults benefit from receiving care from physicians who are trained and experienced in adult medicine” [2].

Additionally, with increased survival in chronic diseases, newer long-term complications and disabilities have emerged which require focused attention. Some examples include: a) patients with transfusion dependent thalassemia (TDT) are now at greater risk of atherosclerotic cardiovascular disease due to prolonged survival and associated impaired glucose metabolism; b) Cystic fibrosis associated diabetes mellitus which occurs in 2% in childhood, increases several folds in adolescence and adulthood; c) large number of survivors of childhood cancer will have other health issues such as obesity, hypertension and hyperlipidemia among the more common ones [11-13].

Another reason for ToC is to ensure ongoing treatment adherence. In the absence of proper ToC, adolescents are likely to have non-adherence to treatment. HIV infected adolescents on anti-retroviral therapy (ART) remain largely asymptomatic. They do not feel need of taking ART anymore, and if left unsupervised are at risk for loss of treatment adherence and relapse of disease [14]. Similarly, poor glycemic control and higher emergency room visits among patients with type 1 diabetes mellitus. Increased risk of loss of follow up resulting in transplant rejection among kidney transplant recipients are described when ToC is not well addressed [15-18]. Better satisfaction among YSHCN is described when ToC is well planned. This facilitates improved adherence/ compliance to therapy [15, 19, 21]. Positive youth development programs associated with ToC have shown better self care and advocacy as well [22, 23].

Barriers to HCT:

Despite perceived need for proper ToC for YSHCN for their attaining full developmental potential, there are several barriers to ToC. These barriers exist at the level of pediatricians, family and patients, physicians, and administrators.

Pediatricians may feel less comfortable referring their patients to an adult provider who is perceived as less familiar with a childhood-onset conditions. There is a fear of missing out/ losing contact with the patients they cared for years. There may be negative “research

consequences” of reduction in patient numbers and a loss in long term follow up. In private set up, there may be issues related to negative financial consequences.

If informed suddenly, patients and families are unable to cope with the transition to adult care and develop anxiety. Patients feel they may lose the comforts of the pediatric care and miss the emotional attachment to pediatric health care providers. They may experience grief and loss when these trusting relationships end. Moving to adult services may be seen as a step closer to disease complications. Adjustments are required for individual rather than family approach of adult physicians. Parents may suddenly feel excluded from all decision making.

Acceptance by the physicians and taking the YSCHN under their care is the most important aspect of ToC. However, physicians may have limited interest in “pediatric” diseases which they do not encounter in their day-to-day practice. It may appear to be an additional responsibility as they may have their own areas of interest. When the ToC services are newly developing, physicians may feel inadequately equipped in care of childhood onset diseases.

Administrators in our country at the present time may be unaware of the concept of ToC and in the absence of a hospital policy, they may be reluctant to provide support in terms of staff and logistics.

Overcoming the barriers:

This policy document describes interventions to overcome these barriers and ensure a smooth ToC in place [24-26].

1. Secure senior leadership support and develop ToC policy (national/ state/ hospital level):

At the state, district and hospital level, appropriate administrative chief (such as medical superintendent of the hospital) should be approached to solicit support. The administrators should be apprised of how investing in ToC will help to retain YSCHN in care and improve patient satisfaction and outcomes. The administrators may be provided with the data on the need for ToC, such as the number of youth who will need transition to adult services over the next 5 years in the system/state/practice or the percentage of youth not receiving ToC services from health care providers in the state/ hospital. Leadership should be made aware of the evidence that population health outcomes are improved with a structured ToC approach.

2. Define Age of Transition:

Opinion remains divided around the optimal age for transition. The US 'Got Transition' recommends initiating transition discussion at 12-14 years of age and complete all steps of transition by 18-23 years [24]. The cut-off ages of 12 years, 13 years and 18 years are suggested by others, based on hospital policy. Some have recommended a flexible approach, taking into account not only chronological age, but also emotional and developmental maturity of the individual [27]. Yet others feel that this may be counterproductive as the adolescents may feel upset while comparing with peers.

Across our country, the cut-offs for transition from pediatric to adult care for general patients are extremely variable across states and hospitals as well as differ in public versus private sector. Increasing the age of transition from pediatric to adult care from 12 years to 18 years, may have following implications:

1. It will increase the number of patients in OPD and indoors on Pediatrics side.
2. It will necessitate different ward arrangements- separately for adolescent boys and girls.
3. Increased patient load may require additional staffing in Pediatrics. Given the economic implications, it may mean reducing the staff on the Medicine side. This staff rearrangement may have implications related to NMC regulations.

As adolescent care falls under Pediatrics in India and in most parts of the world, YSHCN should be managed in Pediatrics services till 18 years age. For the time being, in view of the above implications, the age cut off for ToC of YSHCN may be allowed to remain same as the hospitals have for adolescents without special health care needs. However, in the long run, across the country uniform age cut off of 18 years for ToC of YSHCN should be the goal.

3. Self management/ Self care/ patient empowerment:

Self-care / management is the practice of activities that an individual initiates and performs on his or her own behalf to maintain life, health, and well-being. Self-management is an active operational process driven by the patient.

Education program of self-management for chronic diseases has shifted from the traditional approach to the empowerment model. **Empowerment is defined as helping people to discover**

their innate ability to control their disease and situation. Due to increased number of patients with chronic diseases, it is necessary to pay attention to patient empowerment. However, physical, psychological, and emotional maturity of the patient should be considered while embarking on coaching on self management. In cases where the patient him/ herself is deemed unfit; caregiver should be identified who should receive coaching in self care.

Empowerment on self-care entails the understanding of the disease, the treatment rationale, the source of symptoms, recognizing deterioration-clinical versus laboratory based and taking appropriate action, how to seek help from health professionals and how to operate within the medical system [28]. Psychological empowerment of patients is important for their active participation in self-care. To achieve this, preparation must begin well before the anticipated transfer time—preferably in early adolescence, when a series of educational interventions should discuss ToC.

Various methods suggested for coaching in self care include lecture session, question and answer, presentation of PowerPoint, photo presentation, educational pamphlets, and peer training to which several digital forms of training methods may be added. In addition to the disease related information, the content of sessions should consist of daily activities, fitness and health, nourishment, stress relief, job and home environment, time management and expression and creativity.

4. **Transition initiation and assessment of readiness for ToC:**

It is suggested that the patients and families should be informed well in advance about ToC. Got Transition (USA) suggests initiating the process at 12-14 years, which is 6-8 years before actual transition takes place. However, the process of ToC should be begun at least one year before actual transition as has been suggested by some experts [29].

It is important to periodically assess whether the YSCHN are adequately equipped in self care, health care utilization skills, decision making skills and self advocacy. This assessment allows the care providers and patients/ families to know the gaps and to act upon required areas. Studies on assessment of transition readiness using specific questionnaires addressing different domains have highlighted correlation between transition readiness and outcome. Assessment of transition readiness is also important to understand the needs of the patient and family, so that resources

around health care, education, psychosocial needs can be individualized. There are validated tools available for such screening, such as “Transition Readiness Assessment Questionnaire” (TRAQ)- a tool that is not disease specific, and easy to administer [2,20].

5. Communication with receiving team of physicians:

In developed countries, it is easy to decide about transfer of YSHCN as there are well developed systems in place. In our country, as the system is being initiated now, it is important as a first step to identify a physician who will be entrusted with the task of caring for patients with specific diseases. Currently, there are institutional differences regarding availability of speciality/ sub speciality care. In institutions with specialty services, one or two adult care physicians/ specialists may be identified to take care of young adults of the concerned specialty. In situations where the YSHCN must be transferred to the adult Medicine department, physician who will be interested in looking after the patients with specific diseases, needs to be identified. This may be done with the help of the administration. Communication regarding the need for ToC should be developed with the identified physician(s). They need to be apprised about specific needs of the adolescents and young adults with specific diseases. An ongoing communication needs to be built up with the receiving team and pediatric clinician being available for inputs wherever and whenever needed. The adult physicians may be provided with relevant resource material. Collaborative partnership with physician team is important for process of transition, including organizing joint clinics, transition completion and transition registry. Patients who need ToC usually have a long and often complex medical history. A detailed ToC document should be prepared by the treating pediatrics team and provided to the receiving physician for future reference. This is specially needed if medical records are not automatically being transferred with patient's transition.

6. Process of Transition:

A hospital policy describing in detail the actual process of ToC needs to be available with duties on both ends clearly delineated. Casual agreement is easy to make, but it is less likely to succeed in the long run.

At a minimum, a hospital ToC policy should state i) the age of transition, ii) transition initiation and assessing readiness, iii) nominated care providers- both pediatrician and receiving physician,

iv) joint care clinics, v) care coordinator/ counsellor/ nurse(s). It is important to educate all staff about ToC. For information of patients and families, patient information sheet for ToC should be developed which should be validated.

A. Joint Clinics:

Joint Clinics are the clinics which are attended by both- pediatric and adult care teams. These joint care clinics aim at familiarizing the patients with the staff and environment they are moving to. These should also be attended by care coordinators and nurses as well. It is important to transfer the records and relevant data regarding the patients' illness at the time of actual transfer or before that. Special needs of the patients should be discussed by both the teams and management plan be drawn up in advance. The place where joint clinic is organized should be closer to the adult care department. A visit to the department should be organized. Frequency of such meetings can vary depending upon the number of YSHCN requiring transition.

Transition completion, transition registry and follow up:

A summary of a patient's record should be prepared carrying information about specific health issues, if any, requiring attention. The summary should be handed over to the adult care team at the time of transfer of the patient.

A nurse or a counsellor (transition navigator) needs to be identified for assistance required during transfer. The navigator may be disease specific if the numbers of YSHCN are large enough. In settings with small number of cases requiring transition, only one navigator can be entrusted with the task.

To minimize the chances of loss of follow up, a transition registry needs to be maintained [30]. The registry should be maintained by the transition navigator under the supervision of the pediatric team. The administration should make arrangements for secretarial help required.

A follow up visit 3-6 months after transition is recommended to ascertain if YSHCN is attending the adult care services.

SOP for Implementation of ToC

At the National / State level:

The ToC policy should be circulated from the MoHFW or DGHS to:

- Health Secretary of the State / Union Territory; and
- Directorate of Health Services / Medical Education of the States/ UTs
- Director General, Employee State Insurance Corporation (ESIC), Ministry of Labour and Employment

(MoHFW / DGHS should also share the policy with NMC for including ToC in PG (Pediatrics, Internal Medicine) and Super Specialty curriculum.

- State Health Secretariat/ DHS of the State / DG- ESIC, should share the document with all medical colleges/PG institutions/autonomous institutions such as AIIMS/ District Hospitals/ Missionary Hospitals/ Children Hospitals in public and private sector
- Medical Superintendent/ Principal/ Dean / Director of the Institution/ Hospital should discuss the ToC with HODs of Internal Medicine/ Concerned Specialty and Pediatrician to take necessary steps for implementation (see below)

At the Hospital Level (Medical Colleges / All Autonomous Institutions such as AIIMS / PG Institutions / District Hospitals) :

Step 1: Define Age of ToC (taking into account prevailing age cut off for Pediatrics / adult care in the particular hospital. Refer to the ToC Policy Document)

Step 2: Identify:

- Pediatrician/ Specialist Pediatrician from whom the youth with special health care needs (YSHCN) need to be transitioned (the Pediatrician will be different for different diseases/ systems)
- Physician/ Specialist/ Super-specialist who will be receiving the YSHCN
- Transition coordinator/Navigator (Medical Social Worker/ Counselor/ Nursing Officer)

Step 3: Responsibilities of Pediatrics Team

- Develop a program of transition initiation for YSHCN at least one year before actual transfer of care (written document can be prepared for patients and care givers for need of ToC, and its timing)
- Develop a program of Self Care and Patient Empowerment for self management of the particular disease- written material/ leaflets/ lectures and group discussion etc.
- Assess readiness for transition
- Organise joint clinics for patients to be transitioned with the adult care teams
- Discuss patient management plan with adult care team

- Arrange the complete record / copy of record to be transferred (physical/ digitized)
- Remain available to the adult care team and the transitioned patients (need based)

Step 4: Responsibilities of Adult Care team:

- Participation in the joint Clinics.
- Providing uninterrupted care to YSHCNs.

Step 5: Maintain Disease Specific Transition Registry at the Hospital level (Transition Coordinator/ Navigator should be doing this task).

Step 6: Follow up of transition 3- 6 months after actual transfer of the patients for transition completion and picking up loss of follow up (transition coordinator / navigator should do this task).

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