

*Need and Feasibility of a Transition Clinic
for Adolescents with Chronic Illness: A
Qualitative Study*

**Janaki Menon, Anu Marie Peter, Lathika
Nayar & Anugraha Kannankulangara**

The Indian Journal of Pediatrics

ISSN 0019-5456

Indian J Pediatr

DOI 10.1007/s12098-020-03189-z



Your article is protected by copyright and all rights are held exclusively by Dr. K C Chaudhuri Foundation. This e-offprint is for personal use only and shall not be self-archived in electronic repositories. If you wish to self-archive your article, please use the accepted manuscript version for posting on your own website. You may further deposit the accepted manuscript version in any repository, provided it is only made publicly available 12 months after official publication or later and provided acknowledgement is given to the original source of publication and a link is inserted to the published article on Springer's website. The link must be accompanied by the following text: "The final publication is available at link.springer.com".



Need and Feasibility of a Transition Clinic for Adolescents with Chronic Illness: A Qualitative Study

Janaki Menon¹ · Anu Marie Peter¹ · Lathika Nayar¹ · Anugraha Kannankulangara¹

Received: 27 June 2019 / Accepted: 8 January 2020
© Dr. K C Chaudhuri Foundation 2020

Abstract

Objective To assess the need and feasibility of a Transition Clinic in the care of adolescents with chronic illness.

Methods A qualitative study, piloted by a questionnaire-based survey, followed by Focus Group Discussions was conducted in the Department of Pediatrics in a government teaching hospital in Kerala. The participants were adolescents with chronic disease, *viz.*, renal disease, diabetes, HIV/AIDS, cancer survivors with Hepatitis B, parents of renal patients, pediatricians and adult specialists. Twenty patients were administered a structured, rated, 18-item questionnaire regarding their attitude and preparedness for transfer to adult departments. The need and feasibility of a Transition Clinic was discussed by 7 focus groups *viz.*, pediatricians, adult physicians, 4 patient groups and 1 parent group. Thematic analysis of data was done.

Results Except among pediatricians, awareness of the concept of Transition Clinic was low. All participants agreed that abrupt transfer of care hinders treatment and that there is a definite need for a Transition Clinic. Pediatricians discussed the complex needs of adolescents and limitations of their care. Adult specialist physicians described their inadequacy to handle adolescent problems and difficulties posed by large volumes of patients. The adolescents and young adults with chronic illness discussed their reluctance to shift to the adult departments. Parents voiced their concerns about the future of their children. All groups gave constructive suggestions for conduct of the clinic and smooth transition.

Conclusions There is a definite need for a Transition Clinic in the management of adolescents with chronic illness to ensure smooth transfer of care. Introducing such clinics in the existing health framework is feasible using a multidisciplinary approach.

Keywords Adolescent · Transition clinic · Chronic illness · Focus group discussion

Introduction

Comprehensive specialized healthcare in India has resulted in longer survival of children with chronic illnesses. As they enter adolescence, there is a need to transition them to the respective adult departments. Successful transition begins with assessment of the knowledge and preparedness of the young patient. This is followed by educating the patient and family, after which he or she will attend a 'transition clinic' before the final shift to adult care. Poor execution of transfer of care can lead to inappropriate utilization of healthcare facilities and non-adherence to medical treatment [1]. The consequences of poorly planned transition include increase in

hospitalization and secondary disabilities [2]. When transition and transfer are well organised, benefits include improved self-management and empowerment [1].

This need was recognized in the 1980s in the West, but the concept is yet to take hold in our country. Adolescent healthcare needs have been studied extensively in India, but there are no reports of organised attempts to streamline transition of care. The authors explored the perspectives of adolescent patients with chronic illness, and of their caregivers and physicians, in relation to the concept of a Transition Clinic and the feasibility of introducing such a service in the setting of a large general teaching hospital.

Material and Methods

This was a qualitative study, piloted by a questionnaire-based survey of 20 adolescents with chronic illness, followed by focus group discussions.

✉ Janaki Menon
janakimenon@hotmail.com

¹ Department of Pediatrics, Government Medical College, Thrissur, Kerala, India

In the pilot study, 20 patients were administered a structured, Likert-rated, 18-item questionnaire regarding their attitude and preparedness for transfer to adult departments. The questions dealt with knowledge about disease and its treatment, self-management skills including travelling alone to hospital, getting lab tests done, clearing doubts with their doctor, adherence to lifestyle changes and making treatment decisions. It also addressed their attitude to transfer of care, *viz.* awareness of possibility of transfer, need for transfer, anxiety regarding the same, whether they had ever thought about it and the need for gradual transition. The questionnaire was prepared in the vernacular language (Malayalam). Content validity was established by 2 independent experts and face validity was confirmed.

The patients were aged between 11 & 19 y and were attending pediatric Nephrology, HIV and Endocrine Clinics in authors' hospital, with follow-up of at least one year. The majority were 14 y and older; 6 were boys. Nine had been under regular follow-up for more than 10 y. All of them were attending school regularly; two were in college; one girl was married. Eight were from nuclear families; all had a stable family background. The mother was the primary caregiver in the majority. The questionnaire was randomly administered when these patients came to the General Pediatrics Out Patient Department (OPD) for minor ailments.

The need and feasibility of a Transition Clinic was discussed by 7 focus groups *viz.*, pediatricians, adult physicians, 4 patient groups and 1 parent group. Adolescents aged above 14 y and young adults, on regular follow-up of at least 2 y in the pediatric specialty clinics, formed 4 groups based on specified chronic illnesses (renal disease, Type 1 Diabetes mellitus, leukemia survivors who were Hepatitis B positive, and adolescents living with HIV/AIDS). Parents of the patients with renal disease were included. Each group consisted of 6–10 members. Sample size was decided as per standard guidelines for the design and conduct of focus group research [3].

The patient and parent participants included in the groups were identified by the pediatrician in-charge of their

respective speciality clinics as being communicative and likely to contribute to discussions. As the primary investigator runs the Pediatric Nephrology clinic, she knew the caregivers well, hence this parent group was chosen. Tables 1 and 2 show the background characteristics of participants.

The doctors who participated included pediatricians and adult specialist physicians who had been involved with the care of these patients at some point of time. Their ages ranged from 30 to 60 y. All had been working in the authors' institution for at least one year. They were identified by the primary investigator based on their willingness to participate in discussions.

As per the protocol advised by the Institutional Ethics Committee, informed consent was taken from each participant, and from both parent and patient, if he/she was below 18 y of age.

The chief concerns to be discussed were determined based on the conclusions of the pilot study. They were listed and introduced by the facilitator. An information sheet (discussion guide) introducing the concept of 'transition' was provided to all participants at the beginning of each discussion. The discussions were continued till thematic saturation was obtained. All conversations were audio recorded. A transcript was prepared and line listing was done. Main themes were identified independently by two of the investigators. Thematic analysis was done.

Results

The pilot study showed that adolescents had inadequate knowledge of their disease and treatment, despite prolonged follow-up. Older individuals had better self-management skills. Awareness about need for transfer was low. There was a feeling of insecurity when told about the eventual necessity of transfer to adult care. There was good acceptance of the concept of Transition Clinic.

The issues discussed by the focus groups are delineated in Table 3. The results are summarised below.

Table 1 Background characteristics of patient groups

	Renal disease (n = 7)	Diabetes (n = 8)	PLWHA (n = 7)	ALL survivors with HBsAg (n = 10)
Age range in years (mean)	14–21 (17)	14–20 (17)	16–20 (18)	16–24 (19)
Male: Female	4:3	1:3	3:4	4:1
Mean duration of disease (in years)	10.7	9.5	15.5	13.9
Students	6	8	7	3
Employed	1	None	None	7
Education of mother	Secondary school and above	Secondary school and above	Secondary school and above	Secondary school and above

ALL Acute lymphoblastic leukemia; PLWHA Patients living with HIV/AIDS

Table 2 Background characteristics of caregiver group (mothers of children with renal disease)

S. No	Age (years)	Residence	Occupation	Education	Education of spouse	Kuppuswamy class
1	53	Rural	Unemployed	7th	10th	Upper lower
2	38	Rural	Labourer, part time	10th	10th	Lower middle
3	38	Urban	Unemployed	10th	4th	Upper lower
4	44	Rural	Teacher	MA, B. Ed	AIME	Upper middle
5	39	Rural	Unemployed	10th	9th	Upper lower
6	59	Urban	Unemployed	7th	8th	Upper lower
7	44	Urban	Unemployed	8th	10th	Lower middle

The pediatrician group was the most emphatic about the need for a Transition Clinic. They felt that patients followed-up in the pediatrics OPD tended to remain dependent. They cited the complex emotional needs of adolescents with a chronic illness, their inability to navigate the various hospital departments alone or to articulate their needs to the adult doctor, resulting in the likelihood of dropout and non-compliance. They recommended entry to the Transition Clinic at 12–14 y, and transfer to the adult OPD at 18 y of age.

Interestingly, none of the adult specialist doctors were aware of the concept of a ‘transition clinic’. They felt inadequate to handle the emotional needs of young people, and were unable to give them adequate time during consultations. They felt that their busy schedules would prevent them from running yet another clinic and suggested that the adolescents attend the adult OPD accompanied by a social worker.

Adolescents with renal disease had experienced the adult departments during consultations and were apprehensive of going there alone. A few had been transferred to adult services, but had negative experiences such as stopping medication, dropping out from follow-up, and witnessing disturbing events like death.

Adolescents with Diabetes mellitus had hardly any exposure to adult departments, and found the idea rather alarming.

The young adult survivors of childhood leukemia who were currently Hepatitis B positive were all attending the adult specialty OPD, yet they relied on their pediatrician to clear their doubts and to discuss treatment options and lifestyle changes.

Adolescents and young adults living with HIV/AIDS attended adult and pediatric clinics in tandem as their parents too needed treatment, and were accustomed to the adult OPD. Yet, they continued to rely on their pediatrician for emotional support and decisions regarding treatment. They wanted the

Table 3 Issues discussed by the focus groups

Focus group	Issues discussed
Pediatricians	Ideal timing for transition Current issues with transfer Need, feasibility and conduct of a Transition Clinic.
Adult specialists	Ideal age of transfer Problems faced while dealing with young patients The novel concept of a transition clinic Feasibility in a large government hospital
Parents	Need for a transition clinic Problems of direct transfer Timing of initiation of transition Suggestions as to how the clinic should be conducted
Patients (4 groups)	Perception of the nature of illness Probable duration of follow-up Ability to manage various aspects of their illness and care Concept of transition clinic Need, frequency of visits Members of a Transition Clinic

transition clinic to be held on Saturdays so that their studies and work would be uninterrupted and their confidentiality would be maintained.

Although the younger adolescents (below 16 y) were less articulate during the discussions, their older counterparts were frank and eloquent.

The caregivers of adolescents with renal disease were emphatically against abrupt transfer. They agreed that sensitizing the child to the need for prolonged care should start at 10 y, with entry to the transition clinic at 14 y and final transfer at 20 y. They thought that poor drug compliance, discomfort with body image, and lifestyle were issues that would be best addressed by such a clinic, as very busy adult OPDs inhibited them from voicing their concerns to the doctor. They all felt that their children were knowledgeable about managing lab tests and moving around the hospital, but preferred to accompany them on their visits. They suggested that the presence of a friend during the transition visits would be helpful to their child.

Table 4 gives quotes from the transcripts of the conversation.

Except for a few of the pediatricians, no participant was aware of the concept of a Transition Clinic; the discussions helped to create awareness of the same. All agreed that an abrupt transfer to the adult department would have a negative impact on treatment and that there is a definite need for a Transition Clinic. The pediatricians realised that there was scope for continued care for their older patients. The adult physicians realised that a patient's past too has a bearing on his treatment outcome.

The adolescents and young adults with chronic illness were induced to think realistically about their future. Parents were able to voice their very real concerns about the future of their children.

All the groups gave constructive suggestions for conduct of the clinic and smooth transition of care; the key points are summarized. The suggested frequency was once a month, preferably on a Saturday, during the morning hours. The clinic could be conducted by the pediatrician along with the adult specialist, social worker and a psychologist, and attended by the patient in the company of his/her caregiver or a close friend. The age of enrolment suggested was 14 y and age of transfer to adult clinics was 18 y. Patient education using audio-visual aids, group therapy and individual counseling were considered favourably.

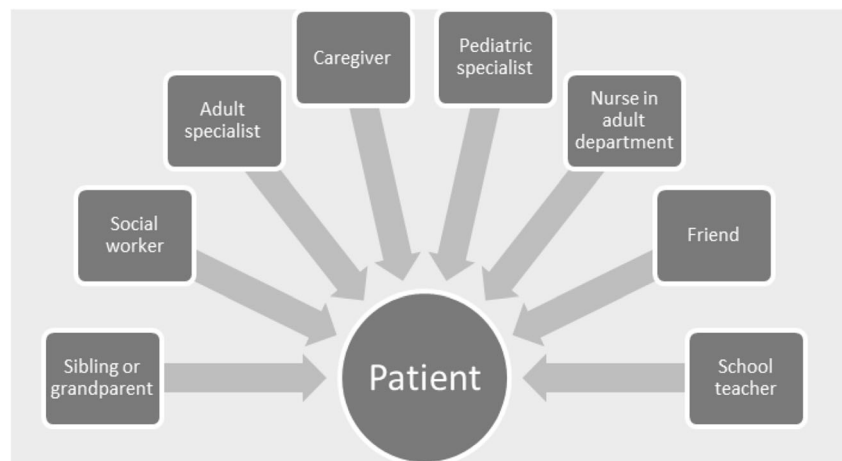
Discussion

The Society for Adolescent Health and Medicine (SAHM) calls transition "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems" [4]. Both the American Academy of Pediatrics (AAP) and the SAHM have provided general guidelines for the conduct of transition [5, 6]. The International Society of Nephrology (ISN) and International Pediatric Nephrology Association (IPNA) published a consensus statement in 2011 regarding transition from pediatric to adult renal services for children with chronic renal illness [7].

Table 4 Quotes from different groups

Group	Quote
Pediatricians	"A well-run adolescent clinic can be used as a venue for transition." "Adolescents with HIV have been attending the adult clinic with their parents right from the first, so it's not an unfamiliar place". "In India, as compared to the West, we become financially independent of our parents at a late age. Even I, as a resident, am not totally independent. That is a hurdle to smooth transition."
Adult specialists	"When adolescents on long-term follow-up in pediatrics come to us, we talk to the patient and expect responses and decisions from the patient. We often do not have time for a detailed explanation and they are unsatisfied. We are helpless due to huge patient load".
Caregivers	"We are so used to the special care taken by Dr. X, we do not want to be seen by any other doctor. We would like to continue under her care." "I don't mind my son being treated by the adult specialist, but we would prefer to be in the children's ward".
Renal disease	"Adult OPD is so busy, it's bewildering and I am scared to ask any doubts to the doctor as I am not familiar with him. I needed admission in adult ward for a renal biopsy; I saw deaths almost every day. It was a very uncomfortable experience."
Type 1 diabetes	"Won't Dr. D be looking after me anymore?" (in tears)
ALL survivors with Hepatitis B	"The gastroenterologist talks to me at length with detailed instructions, but I would never interrupt with a question nor voice my doubts." Moderator: "So who is your counselor?" Reply: "You are".
PLWA	"I am confident to come to the hospital by myself and consult the doctor, but my parents are anxious and they don't let me".

Fig. 1 Conceptual diagram of Transition Clinic



The adolescent is usually enrolled in the transition clinic at around 13 y and transferred to the adult clinic by 18 to 21 y of age [8]. The transition team consists of the Pediatrician to provide continuity of care, the Adult Physician for consultation, nurses from both departments, a clinical psychologist for age and disease-appropriate counseling, a Medical Social Worker, a data entry operator, and the patient's family. Figure 1 shows the conceptual diagram of a Transition clinic.

The recommendations based on the findings of present study are similar to the Western guidelines, even though authors could address feasibility only in a general and superficial fashion. The most comprehensive guideline for transition is that provided jointly by the ISN and IPNA [7]. No marked differences were brought out, the challenges faced appear to be similar.

Studies from other countries indicate that the shift to adult care is stressful to adolescents, who are already experiencing major physical and emotional changes [8]. The adult physician feels ill-equipped to deal with them. Many adolescents return to their pediatrician; a good number are lost to follow-up, or default treatment and develop complications. Early sensitization to transition, opportunities to meet new healthcare teams and visits to adult-oriented venues might ease the transition process [9]. Kakkar et al., in Canada, found that HIV-infected adolescents had difficulty assuming responsibility for their own care, were unable to connect with the adult care-provider and were dissatisfied with the rapidity of appointments [10]. Nakhla et al. reported that Diabetes-related hospitalization increased in the two years following abrupt transfer to adult care, although it may have been attenuated in youths for whom there was physician continuity [11]. Prestidge et al. showed that patients with chronic renal disease who had benefited from a Transition Clinic had improved allograft and patient survival following renal transplant and that such clinics are economically feasible [12].

In India, one of the results of improvement in healthcare is that there is an increasing number of survivors of diseases such as cancer, renal disease, diabetes, HIV, cerebral palsy,

congenital heart disease and others. The system is ill-prepared to tackle the very complex needs of this population [13]. Although there is prolific literature on the varied problems faced by adolescents, there is a dearth of studies dealing with the process of transition. A small study from Bangalore emphasised the need for a separate dedicated space when managing adolescents with cancer [14].

The present study provided a platform for adolescents and their caregivers to voice their hitherto unaddressed needs.

The young people who had already undergone transfer pointed out the defects and pitfalls of abrupt shift of care. The problems faced by their healthcare workers and the limitations in the current services provided by them were also revealed. All the participants, *viz.* patients, caregivers and doctors were open to the idea of a transition clinic.

One of the objectives of the Rashtriya Kishor Swasthya Karyakram is the establishment of Adolescent Friendly Clinics and providing help through peer educators [15]. The Transition Clinic could be envisaged as a part of the adolescent healthcare promotion initiative with peer educators acting as local support.

Detailed feasibility studies, such as in-depth interviews of individuals at administrative level, with wider experience of the healthcare facility in our country may have lent more depth to this study and are envisaged in the future.

Conclusions

There is a need for planned transfer of care from the pediatrician to the adult specialist; a Transition Clinic may be the means to bridge the gap. Introducing such clinics in the existing health framework is feasible using a multidisciplinary approach.

The present study had certain limitations. The younger adolescents were less articulate during the discussions, unlike their older counterparts who were frank and eloquent; As the present patient and caregiver participants were attending the

same government hospital, their background characteristics were fairly similar, participants from varied backgrounds could have enriched the discussions further; Gender-related issues were not discussed, the nuances of gender inequality in smooth transition could be an area for further exploration, particularly in developing countries; Feasibility was not discussed at length, as authors were unable to get a focus group of persons working in administration, for logistic reasons.

Acknowledgements The authors express their deep gratitude to the patients, their parents and the doctors who gave their valuable time and made the effort to participate in the discussions.

Authors' Contribution JM was involved with concept and design of the study, conduct of the pilot study and the focus group discussion (FGD), with drafting the manuscript, critical revision and final approval and will act as guarantor; AMP was involved with concept and design of the study, conduct of the FGD, data collection, drafting and revising the manuscript; LN was involved with the design of the pilot study, data collection and revising and editing the manuscript; AK was involved with concept and design of the study, data collection, assisted in conduct of the pilot study and FGD.

Compliance with Ethical Standards

Conflict of Interest None.

References

- White PH. Access to health care: health insurance considerations for young adults with special health care needs/disabilities. *Pediatrics*. 2002;110:1328–35.
- Gurvitz M, Inkelas M, Lee M, Stout K, Escarce J, Chang R. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J Am Coll Cardiol*. 2007;49:875–82.
- Hennink MM. Designing and conducting focus group research. *Focus Group Discussions (Understanding Qualitative Research)*. New York: Oxford University Press. 2014. p. 35–95.
- Blum RW, Garell D, Hodgman CH. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14:570–6.
- American Academy of Pediatrics. American Association of Family Physicians, American College of Physicians: a consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002;110:1304–6.
- Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 2003;33:309–11.
- Watson AR, Harden P, Ferris M, Kerr PG, Mahan J, Ramzy MF. Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). *Pediatr Nephrol*. 2011;26:1753–7.
- Viner R. Transition from pediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child*. 1999;81:271–5.
- Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child Care Health Dev*. 2008;34:557–63.
- Kakkar F, Van der Linden D, Valois S, et al. Health outcomes and the transition experience of HIV-infected adolescents after transfer to adult care in Québec, Canada. *BMC Pediatr*. 2016;16:109.
- Nakhla M, Daneman D, To T, Paradis G, Guttman A. Transition to adult care for youths with diabetes mellitus: findings from a universal health care system. *Pediatrics*. 2009;124:e1134–41.
- Prestidge C, Romann A, Djurdjev O, Matsuda-Abedini M. Utility and cost of a renal transplant transition clinic. *Pediatr Nephrol*. 2012;27:295–302.
- Ramadass S, Gupta SK, Nongkynrih B. Adolescent health in urban India. *J Family Med Prim Care*. 2017;6:468–76.
- Salins NS, Vallath N, Varkey P, Ranganath K, Nayak MG. Clinical audit on “evaluation of special issues in adolescents with cancer treated in an adult cancer setting”. An Indian experience. *Indian J Palliat Care*. 2012;18:196–201.
- Rashtriya Kishor Swasthya Karyakram (RKSK) | National Health Portal of India. Available at: http://www.nhp.gov.in/rashtriya-kishor-swasthya-karyakram-rksk_pg. Accessed 18 June 2019.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.