



TRANSITION OF ADOLESCENTS WITH CHRONIC ILLNESS TO ADULT CARE-A PILOT STUDY

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ABSTRACT A planned shift from pediatric care to adult care is required for children with chronic illnesses, as the two systems are considerably different. The study was done on adolescent patients with chronic illnesses to understand their knowledge and ability to handle the disease, assess their preparedness and sensitise them for the shift. Twenty patients, aged 11-19 years, with a follow up of at least one year from different departments were included. Clinical and demographic data were collected. A structured questionnaire was administered and data analysed. All participants had stable family with a consistent primary caregiver. A total of 55%, were well aware about the disease and treatment. Self-management skills were more in older children. Only 35% were aware of the need for transfer to adult care. Concern shared by most was about getting proper treatment, but all agreed that the process should be gradual with caregiver and paediatricians help.

KEYWORDS : Transition Clinic, Pediatric Care, Adult Care, Adolescence

Introduction

Over the past few decades, the life expectancy of children with chronic illnesses has increased considerably, and most of these children are surviving beyond adolescence (Newacheck et al., 1998; Gortmaker, & Sappenfield, 1984). Comprehensive and specialized health care in our country has resulted in longer survival of children with many chronic illnesses, kidney disease, Type 1 diabetes and HIV infection. As these children reach adulthood, there is a need for transition to their respective adult departments. One of the challenges for the transition to adult care for these children is the shift from child-centred to adult-centred care. In most of the cases this transition is poorly organized and often do not follow without a structured and coordinated services for transition care (Scal, Evans, Blozis, Okinow, & Blum, 1999). The communication between the caregiver centred childcare and patient centred adult care system is very poor and many patients do not get enough care until a complication/problem arises (O'Connell, Bailey, & Pearce, 2003).

Any program for successful transition to adult system will be based on the needs of the patient, caregiver, and the healthcare providers. Many studies have focused on these specific needs and concerns for transition worldwide (Peter, Forke, Ginsburg, & Schwarz, 2009; Cappelli, MacDonald, & McGrath, 1989). There is paucity of data on transition-related activities, concerns, and attitudes of the patients from India. We have been providing pediatric speciality services in Nephrology, Endocrine, HIV and Disability clinics at our hospital for the last 15 years. Many of these patients are in their adolescence or early adulthood and need a planned transition. This pilot study was proposed to fill the gap in transition-related data on children with chronic illnesses who are moving towards adult care.

The main objectives of this pilot study are:

- To assess the knowledge of adolescents about their disease and treatment
- To observe their attitude towards and preparedness for shift to adult care
- To ascertain their ability to handle their disease on their own
- To sensitize the adolescent patient to the concept of Transition Clinic

Methodology

This descriptive (Knowledge-Attitude-Practice study), cross-sectional study was conducted at Pediatric Nephrology, HIV and Endocrine Clinics at Govt. Medical College, Thrissur. Study subjects included patients in the age group of 11-19 years attending the clinic with follow-up of at least one year. The study was conducted for a period of six months in 2017. Legal permission was obtained from the institutional review board and a written consent was obtained from all participants. Patient demographics and clinical data were collected. The subjects were administered a structured, rated questionnaire of 18 items. The information thus obtained were compiled, tabulated and analysed statistically to draw out observations and meaningful conclusions.

Results

Patient characteristics

In this pilot study a total of 20 patients were included, of which

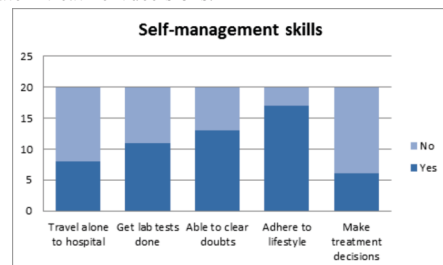
majority were > 14 years. Six of the participants were boys (30%) and the remaining girls (70%). Nine (45%) of the participants had been under regular follow-up for more than 10 years. All participants were attending school regularly, and two were in college. One among the girl participants was married. Eight (40%) were from nuclear families with a stable family background. Mother was the primary caregiver in majority of the cases.

Knowledge

Eleven (55%) adolescents were confident in their knowledge of their disease and its treatment. They were all over the age of 14. This had no relation to duration of illness.

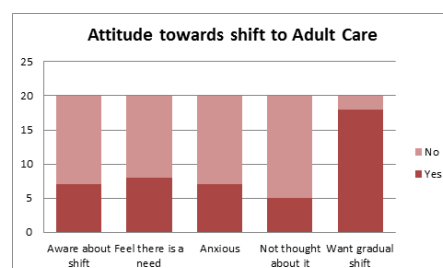
Self-management Skills

Only 8 patients (40%) were able to travel to hospital alone, but 11 were ready to get their tests done in the lab once they reached hospital. All these participants were over 14 years. Thirteen (65%) of them felt free to clear their doubts with the paediatrician. Only three participants needed persuasion by their parents to adhere to lifestyle modifications required for disease management. Six patients (30%) were ready to participate in treatment decisions.



Attitude

Only 7(35%) were aware that they would have to shift to adult care, realizing that this was inevitable. Twelve (60%) felt there was no need to shift, and 7 were anxious about this. Five (25%) had not thought about it at all; they were all below 14 years. The commonest concern was of receiving the right treatment. Except for two children, all felt the shift should be gradual and appreciated the idea of a transition clinic. All felt the support of their caregiver would be needed during transfer. Majority wanted the help of the paediatrician as well; only one thought that the help of the adult physician would be needed.



Discussion:

The shift to adult care is stressful to the adolescent who is already experiencing major physical and emotional changes. The stark difference between family-oriented pediatric care and patient-oriented adult care creates confusion among patients, caregivers and doctors, often resulting in patient drop-out (Wallis, 2007). In most of the countries children up to the age of 18 years are cared for by the paediatrician, while in India the pediatric care is extended only up to around 12 years. So there is lack of care and expertise for taking care of adolescents with chronic conditions in our country. Appropriate and timely promotion of good practices and attitude in transition are important, particularly in India where the disease burden is high. This is a pilot study to understand the knowledge, practice and attitude levels among adolescents about transition clinic, based on which the transition process can be planned. The current study gains importance as there are very few studies dealing with transition care among children from India (Sugunraj, Thabah, & Gupta, 2009).

Careful planning and thoughtful implantation are key to this transition so as not to jeopardise what has been achieved in the early years. Successful transition begins with assessment of the knowledge and preparedness of the young patient, followed by educating the patient and family, after which he or she will attend a transition clinic and finally shifting to adult care (Eluri et al., 2017). This need was recognised in the 1980s in the West, but the concept is yet to take hold in our country. There is no consensus about the time to initiate this process. The process often begins after 12 years; the shift to adult care being complete by 18-21 years (Moreno, 2013). The attitude and practice patterns of health care providers the pediatric residents in this regard is also of importance as lack of experience and knowledge of guidelines may form a barrier in providing successful transitional care (Hart, Deussen, & Gonzaga, 2017).

Our pilot study indicates that adolescent patients have inadequate knowledge of their disease and treatment (55%), despite prolonged follow-up. This knowledge is a key component of achieving the transition goal of self-care, and healthcare decision-making for these children as they move to adult care (Betz, 2004). It is also important as some of the conditions worsen in adolescence (Davies, & Rupp, 2005). Although older children seem to have better self-management skills awareness about the need to transfer to adult care is low (35%). This may form one of the main barriers in successful transition as preparation for transition should ideally begin well before the actual time of transition to discuss the treatment rationale, recognizing symptoms of deterioration and, above all, how to seek help from healthcare practitioner when needed (Viner, 1999).

A systematic review of patient's attitudes and experiences in pediatric rheumatology shows that many patients feel abandoned, insecure, and depersonalized about the transition process (Kelly et al, 2017). This pilot study also indicates feeling of insecurity among the patients when told about the eventual necessity of transfer to adult care. Most of them wanted the shift to be a gradual one with help from caregivers and their paediatrician. Developing a well-planned transition protocol which helps the patient to have a sense of belonging and trust may eventually help in accomplishing a successful transition from pediatric to adult care.

Although there is good acceptance of the concept of transition clinic among the patients, lack of standardized procedures and co-ordination among the different departments may act as major barriers in the implementation of transition clinic in our country (The Joint Commission, 2012). Educating the children about their medical condition and their plan of care, and including them in decision-making process can remove the patient barriers in successful transition. Education is also needed for pediatric residents who need to discuss the details of transition with patient family at the appropriate time.

Conclusions:

This study shows that adolescents with long-standing illness are ill-prepared for shift of care to adult departments. A multi-disciplinary Transition Clinic would ease this shift, by helping the adolescent to learn about his/her disease and treatment and by enhancing capability to cope with hospital routines and treatment decisions.

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