

Transition care readiness among patients in a tertiary paediatric department

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ABSTRACT

Introduction: A smooth transition of healthcare for young people with chronic illnesses from paediatric to adult healthcare services is important to ensure optimal outcome. At the moment, there are no standard guidelines to assess a patient's readiness to transfer care.

Methods: A cross-sectional study using a self-administered questionnaire, adapted from UNC (University of North Carolina) TRxANSITION self-assessment tool was conducted to evaluate patients' transition care readiness in paediatric haematology and paediatric diabetes clinic.

Results: A total of 80 patients (37 thalassaemia and 43 diabetes) with the mean age of 21.2 (SD±4.3) years, were recruited during the 3-month study period. Majority of the patients have basic knowledge regarding their medications, and were able to comply with their follow-up. The mean total score obtained by the respondents on this questionnaire was 15.3 (SD±3.59). Self-management skills and knowledge on disease were the two poorly scored section; with mean score of 3.78 (SD±1.38) and 4.28 (SD±1.20) respectively. Overall, only 21 (26.2%) respondents obtained high score (score above 75th percentile). Seventy-five percent of the respondents admitted that they were not ready for transfer to an adult healthcare service yet at the time of the study.

Conclusion: We suggest that patients with high score should be prepared for transition to adult facility whereas those with a low score need to be identified to ensure provision of continuous education.

KEY WORDS:

Transition care, transition readiness, transition scale, adolescent, young adult

INTRODUCTION

Recent advances in treatment, medical technology and health care delivery systems have led to increased survival among children with chronic illness.¹ In 2014, there were nearly five million young people aged between 12 to 24 years old in Malaysia and out of this, 20% were reported to have at least one chronic condition or disability.^{2,3} Therefore, there will be a large number of adolescent patients requiring transition from paediatric to the adult healthcare services in the near future.

Although most paediatricians acknowledge the needs of transition care for their patients, many face a dilemma with regards to the timing and the actual process for the transfer of care.^{4,5}

The paediatric and adult healthcare system differs tremendously. Paediatric care is family-oriented and often includes family members in the management plans, whereas in the adult healthcare setting, patients themselves play an important role in the self-care and decision making.⁶ Therefore, the concept of transition involves a process where gradual change of responsibility from parents to the adolescent must occur before the patient is ready to be transferred to an adult healthcare team. At the moment, there are no standard guidelines to assess a patient's readiness to transfer care and how the transition is best accomplished to ensure a smooth transfer. Most of the literature, consisting of expert opinion and recommendations suggest that the transition planning should be individualized for each patient.^{7,9}

Transition readiness is defined as capacity of the adolescent and his/her support system (family and medical providers) to prepare for, begin, continue and finish the transition process.^{10,11} Consensus by the American Academy of Paediatrics and American College of Physician states that medical practice should choose a readiness assessment tool that may be modified for specific patients' situation.¹² This tool should be able to provide an accurate, point-in time assessment of the individual patient's ability to successful transition. Timing of transfer should be individualized and patients should achieve certain milestones prior to transfer.^{13,14} In an adult healthcare setting, patients are expected to take charge of their own medications and appointments, and be able to discuss their health conditions with their medical providers.¹⁵ Understanding of their disease, medications as well as treatment related side-effect are fundamental, thus, an ideal transition programmes should focus on empowering the adolescent recipients and to help them engage in these behaviours before the transfer of care.

Various transition readiness tools have been described and developed in studies related to transition readiness. Almost all previously developed tools focus on five different health skill areas: (i) knowledge of health condition; (ii) medication and treatment; (iii) taking charge of health condition, medication and treatment; (iv) taking charge at the doctor's

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office; and (v) daily living skills and thinking about the future.¹⁶

In this study, we focused on assessing our patients' readiness for transition by using a locally adapted questionnaire.

MATERIALS AND METHODS

A cross-sectional study was conducted in the Paediatric Haematology clinic and Paediatric Diabetes clinic, Universiti Kebangsaan Malaysia Medical Centre. The objective was to primarily evaluate patients' perception and readiness on the continuation of their healthcare needs from a paediatric clinic to the respective adult clinic. The specific objectives were to (i) determine the patients' level of knowledge on own disease, medication and long-term care; (ii) determine patients' self-reported experience on adherence and compliance, self-management skill; and (iii) to determine patient readiness for long term care and planning. Convenient sampling was used. The study was approved by our institutional research ethics committee.

All patients with thalassaemia and diabetes, between 14 to 30 years old were recruited during the 3-month study period from the respective clinics. These patients were diagnosed with thalassaemia or diabetes mellitus during childhood and were still under the paediatricians' care during the time of recruitment. Written informed consent was taken for all respondents. Exclusion criteria were refusal of consent, inability to understand Malay or English language, and patients with special needs (e.g. mentally challenge or attending special education). A self-administered questionnaire which included questions adapted from UNC TRxANSITION self-assessment tools was used.¹⁷ All patients aged 18 years and above answered the questionnaire independently whilst patients aged less than 18 years old answered the questions in the presence of their parents. The correct answers on disease and medications were re-confirmed by going through the patients' medical records, e.g.: questions on type of disease and medications. Scoring was based on scoring guide which was adapted from TRxANSITION Scale Answer Guide for Kidney Patient.¹⁸

Research Instrument

The questionnaire used in this study was adapted with permission from UNC TRxANSITIONTM Scale, which was developed by a group of researchers at the University of North Carolina (UNC) in 2012 (A Clinical Tool to Measure the Component of Health Care Transition from Paediatric to Adult Care: The UNC TRxANSITION).^{17,18} It is a non-disease specific tool; the development of items were based on two theoretical model, available literature, expert opinion interview and feedback from youth with chronic illness and their parents. The original questionnaire consists of 33 questions on 10 conceptual domains: Type of illness, Rx (medication), Adherence, Nutrition, Self-management, Issues of reproduction, Trade and school, Insurance, Ongoing support and New health providers.^{17,18} The questionnaire was expanded further to 69 questions to suit our local cohort of patients; all original questions and scoring methods remain unchanged. The questionnaire was translated to the Malay language and piloted to test the suitability and assess the content validity and finalized following a focus group discussion of experts in relevant subspecialties.

Table I: Demographic data of 80 respondents

Characteristic	Total (N=80)
Age, n (%)	
<18 years old	23 (28.7)
18-25 years old	43 (53.8)
>25 years old	14 (17.5)
Race, n (%)	
Malay	47 (58.7)
Chinese	24 (30.0)
Indian	8 (10.0)
Others	1 (1.3)
Patient's education level, n (%)	
Primary	1 (1.3)
Secondary	54 (67.5)
Tertiary	25 (31.2)
Father's education level, n (%)	
Primary	4 (5.0)
Secondary	45 (56.2)
Tertiary	31 (38.8)
Mother's education level, n (%)	
Primary	8 (10.0)
Secondary	51 (63.8)
Tertiary	21 (26.2)
Monthly family income, n (%)	
<RM1000	6 (7.5)
RM1000-3000	48 (60.0)
>RM3000	26 (32.5)

n-number; RM-Ringgit Malaysia

Data analysis

Data was entered and analysed using SPSS version 22.0. Frequency and percentage were calculated for categorical variables; mean and standard deviation were calculated for continuous variables. Chi-square test was used to compare categorical data, while continuous data were analysed using student t-test. Significance level was set at a p value of <0.05.

RESULTS

A total of 80 patients were recruited into the study (Figure 1). The mean age for all respondents was 21.2 (SD±4.28) years, with the range from 14.0 years to 30.0 years. The demographic profiles of the respondents are shown in Table I.

Majority of the patients were able to tell his/her diagnosis and list down the medications they were taking. However, most do not know about the impact of the disease on themselves in the future (Table II). Further questioning revealed only 60% of them was actively seeking knowledge regarding their medical condition with majority of them using internet as their source of information. Half of the patients admitted they missed a full day of their medicine in a typical week, citing busy work or school schedule as their main reason (Figure 2). Surprisingly, only 13 (16%) patients are a member of a local support group. Eighty percent of the respondents admitted that they do not have the resources to assist them in seeking care with an adult physician by themselves when the time has come for them to be transitioned to the adult healthcare. Three quarter (75%) of the respondents admitted that they were not ready for transfer to an adult healthcare service yet at the time of the study, with majority of them estimating that they will only be ready by 24 years of age (answers ranged between 17 years to 40 years old).

Table II: Patients' knowledge on their disease and treatment

Items	Respondent's answer, n (%)	Clinician's assessment, n (%)
Able to tell his/her diagnosis		
Yes	79 (98.8)	76 (95.0)
No	1 (1.2)	4 (5.0)
Able to list down physical symptoms of the disease		
Yes	64 (80.0)	54 (67.5)
No	16 (20.0)	26 (32.5)
Knows how the disease will affect their future		
Yes	50 (62.5)	16 (20.0)
No	30 (37.5)	64 (80.0)
Knows which food to take/avoid		
Yes	56 (70.0)	41 (51.2)
No	24 (30.0)	39 (48.8)
Able to list down all their medications		
Yes	71 (88.8)	69 (86.2)
No	9 (11.2)	11 (13.8)
Able to tell the timing/frequency of each medications		
Yes	67 (83.7)	62 (77.5)
No	13 (16.3)	18 (22.5)
Knows the indication of the medications		
Yes	62 (77.5)	55 (68.7)
No	18 (22.5)	25 (31.3)

n-number

Table III: Factors influencing the respondent's score

Patient's characteristic	Total score		p value
	Low score n=59 (73.8%)	High score n=21 (26.2%)	
Age group in years, n (%)			0.009
12-14.9	2 (100.0)	0 (0.0)	
15-19.9	32 (88.9)	4 (11.1)	
>20	25 (59.5)	17 (40.5)	
Disease, n (%)			0.004
Diabetes	26 (60.5)	17 (39.5)	
Thalassaemia	33 (89.2)	4 (10.8)	
Race, n (%)			0.057
Malay	34 (72.3)	13 (27.7)	
Chinese	21 (87.5)	3 (12.5)	
Indian	4 (50.0)	4 (50.0)	
Others	0 (0.0)	1 (100.0)	
Patient's education level, n (%) (for patients >18 years only)¥			0.005
Primary	1 (100.0)	0 (0.0)	
Secondary	26 (83.9)	5 (16.1)	
Tertiary	11 (44.0)	14 (56.0)	
Father's education level, n (%)			0.335
Primary	4 (100.0)	0 (0.0)	
Secondary	31 (68.9)	14 (31.1)	
Tertiary	24 (77.4)	7 (22.6)	
Mother's education level, n (%)			0.361
Primary	7 (87.5)	1 (12.5)	
Secondary	35 (68.6)	16 (31.4)	
Tertiary	17 (81.0)	4 (19.0)	
Monthly family income, n (%)			0.457
< RM1000	5 (83.3)	1 (16.7)	
RM1000-3000	33 (68.7)	15 (31.3)	
> RM3000	21 (80.8)	5 (19.2)	

n-number; RM-Ringgit Malaysia

*Chi-square test used; significant level $p < 0.05$ ¥for 57 patients only (all patients ≤ 18 years old were still in secondary school)

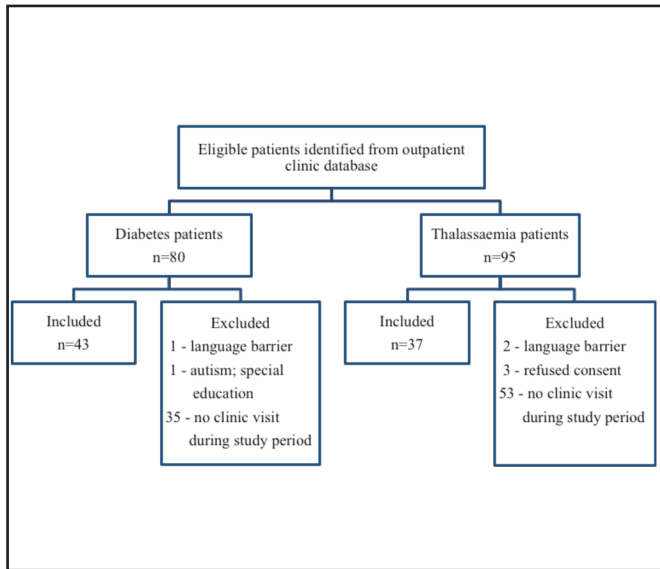


Fig. 1: Flow chart of recruitment process.

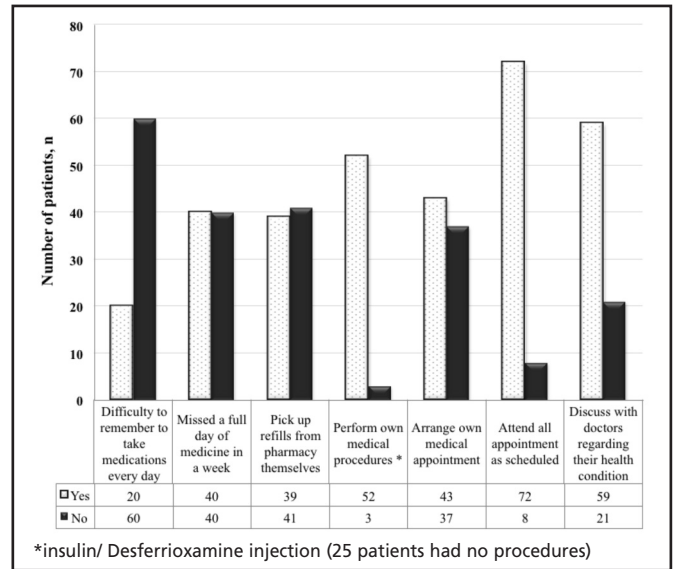


Fig. 2: Patients' compliance and self-management skills.

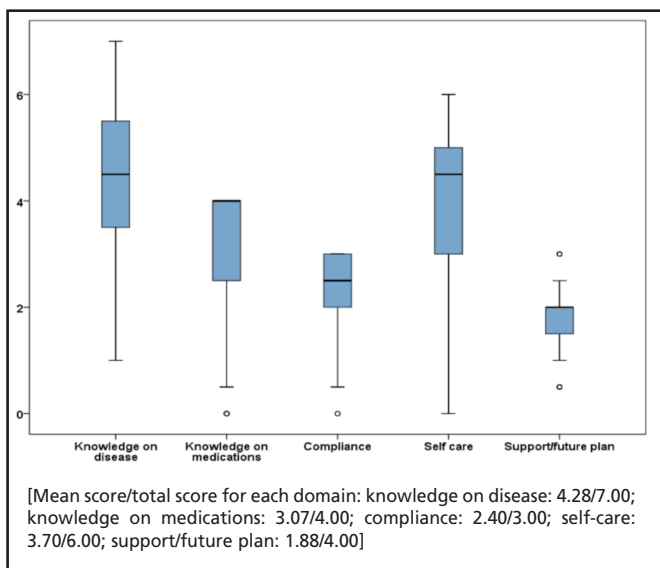


Fig. 3: Scores of five main domains assessed.

The mean score obtained by the respondents on this adapted questionnaire based on the UNC TRxANSITION scale was 15.33 (SD±3.59), with a wide range of score from 4 to 21; maximum score for the questionnaire was 24. As there was no pre-determined passing mark for the scale used, the scores were distributed to a normal curve and the quartiles were determined. Hence, the score of 13.0 was equal to 25th percentile while the score of 16.0 and 18.5 was equal to the 50th and 75th percentile respectively. For the purpose of analysis, we defined a score of 18.5 and above as high score and score less than 18.5 as low score. However, having a high score in this study does not indicate a patient's readiness for transition. Overall, 21 (26.2%) respondents scored above the 75th percentile. Looking at each section individually, knowledge on their disease and self-care were the two poorly scored sections by the respondents (Figure 3).

Majority of the patients who achieved high score were those above 20 years old and had tertiary education level (Table III). Mean total score increases significantly with age; mean total score was 16.15 (SD±3.57) and 14.42 (SD±3.43) for those age ≥20 years old and <20 years old respectively, t-test (78)= -2.207, p=0.030. Most of the thalassaemia patients had low score with mean total score of 13.69 (SD±3.80), whereas 40% of the diabetes patients had high score, mean total score of 16.74 (SD±2.74) with t-test (78)=4.17, p<0.001.

DISCUSSION

Transition care is an arising issue in managing adolescents and young adults with chronic illness. The terms adolescent and young adult were used interchangeably and there are no universal definition. UNESCO defines youth as a person aged between 15 to 24 years, whereas the African Youth Charter defines youth as between 15 to 35 years. Transition care is a continuous process rather than a one-point assessment. Many studies have described assessment of readiness and developed programmes to facilitate the transition process.^{5,7,19} Providers need to individually define their patient's readiness based on their continuous assessment of the patient. This study describes the readiness of health-care transition in our cohort of adolescents and young adults with two different chronic illnesses using an interview-based questionnaire adapted from the UNC TRxANSITION.¹⁷ The original questionnaire was expanded from 33 questions to 69 questions; the additional questions were in an open-ended format to help elaborate on selected items that required further clarification. However, the ten domains involved in the original questionnaire remains the same.¹⁷

In Malaysia, traditionally, patients aged 12 years and above were managed by the adult physicians. However, in 2012, Ministry of Health Malaysia developed an operational policy where the paediatric healthcare services encompasses children from birth to 18 years of age, after which they should be prepared for transfer of care to the adult services.²⁰

Although it was proposed that a transition clinic, jointly managed by adolescent physician or paediatrician and adult physician, should be set up to prepare patients aged 16-18 years old for the transition care, this has not transpired yet. Due to the lack of transition guidelines and standardised assessment tools, some paediatricians opt to continue the care of their patients who were above 18 years old themselves. Others practised mandatory transfer to the adult healthcare services when their patients reached the age requirement without proper evaluation on their readiness for the transition. In our centre, thalassaemia and diabetes patients who were between 18 to 30 years old remained under the paediatricians' care. These patients were included in the study to determine whether chronological age factor itself will influence patients' readiness for transfer. Based on our results, the total score improved with increasing respondents' age with those ≥ 20 years old achieving higher total score than those < 20 years old. Although high scores alone do not guarantee a successful transition, low scores indicate needs of continuous education and support in deficient areas for the respondents during their clinic visits. Follow-up assessments using the same questionnaire at different time points may then be done to assess the effectiveness of continuous education and later, their readiness for transition.

In this study, although the patients know the name of their medical condition, they did not seem to know the details of their disease which includes physical symptoms and its effect on their future, including their reproductive ability. Bearing in mind that they are approaching adulthood and are supposedly thinking of having their own family, they are presumed to know and be able to discuss with their doctor with regards to their ability to have children in order to avoid unexpected pregnancies and optimising their care for better outcome of pregnancies.²¹ For thalassaemia patients, they also need to be aware of the chance of their offspring inheriting the disease and availability of partner screening and prenatal diagnosis.

Our patients were able to name their medication but the knowledge on details of each medication was inadequate. Patients with diabetes appear to know their own medications better as compared to patients with thalassaemia. This may be the result of concerted efforts in organising regular diabetic education programmes, such as the annual diabetic camp, with the involvement of a dedicated diabetic educator and dietician. Many studies agree that continuous education and programme improves patient self-care and adherence.²¹⁻²³

Non-adherence to medication was not a major issue as reported by our respondents. However, we did not explore further on specific evidence of medication adherence such as HbA1c and serum ferritin level for diabetic and thalassaemia patients respectively. Non-adherence to medications is associated with poor medical outcomes in adolescent transplant recipients.⁴ A study of 74 adolescents with IBD reported that the most common barriers to oral medications were "lack of time, forgetting, being away from home, and interference with an activity".²⁴ Our respondents cited similar reasons.

Self-management skills promote autonomy and responsibility for own health care, hence the skill is crucial in assessment of readiness for transfer. The low score of self-management skills in our respondents reflects the patients' dependence on their parents, although 75% of these patients were above 18 years old. Hence, intervention is required during follow up by emphasizing the need to perform their own health related procedures such as making their own appointment, collecting their own medication and ability to discuss their health-related issues with the attending doctor. A study by paediatric and adult liver transplant coordinators identified patients' knowledge of medications, independence and responsibility for medications, and adherence as important components of transition.²⁵

Most of our respondents admitted that they were not ready for transfer; the most commonly cited reason was that they were unaware of the procedure they will have to go through in an adult clinic. They were also concerned of the possible number of medical leave days they would have to take and the cost of treatment as majority of these patients do not have health insurance. These concerns need to be addressed individually to alleviate their anxiety during preparation for transition care.

There are several limitations to this study. Firstly, convenience sampling was employed which involved only patients who attended the paediatric clinic during the study period. In the ideal situation, all patients attending our paediatric clinic should be included; hence data collection should be a continuous process. Second, a multi-language questionnaire which includes Chinese and Tamil, should be made available so as to allow inclusion of all ethnic groups. Third, all respondents aged 18 years and below answered the questionnaire in the presence of their parents which may influence the respondents' answer. However, this may be considered as a continuous medical education process for both respondents and parent(s) as they go through the questionnaire and recapitulate on the relevant information.

Our analysis is also based on reported behaviour rather than observed behaviour, hence there may be bias in the respondents' report due to certain social expectations. Severity of disease was also not evaluated in our study; this may well have influenced a patient's readiness for transfer as a patient with a more severe or poorly controlled disease may have lower self-esteem and confidence in managing their own disease.

CONCLUSION

We propose that transfer of care to adult facility may be initiated for patients with a high score, although further study needs to be conducted to address the consistency of factors which influence a successful transfer. Respondents with a low score should be identified and continuous education and support in specific deficient areas should be provided during each clinic visit. Repeated and sequential assessments with a similar set of questionnaires may be beneficial to assess the effectiveness of continuous education.

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