# **Promoting Factors for Transition Readiness of Adolescent Chronic Illnesses: Experiences in Thailand**

Buntham Pakdeeprom MNS\*, Supinya In-iw MD\*\*, Nongluk Chintanadilok DNS\*\*\*, Kaimook Wichiencharoen Ed D\*\*\*, Boonying Manaboriboon MD\*\*

\* Faculty of Graduate Studies, Mahidol University, Bangkok, Thailand \*\* Department of Pediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand \*\*\* Department of Pediatrics, Faculty of Nursing, Mahidol University, Bangkok, Thailand

**Objective:** Health care transition, a unique process of providing continuity of care from pediatrics to adult care system, has succeeded in some countries, particularly in the developed world. In Thailand, transition readiness has been in the forefront to improve health care system. The present study aimed to determine the factors correlated to transition readiness in chronically ill adolescents.

*Material and Method:* Participants aged 14 to 20 years old having varieties of chronic illness, from randomized hospitals in the upper southern part of Thailand, were voluntarily interviewed and completed validated self-administered questionnaires related to studied factors.

**Results:** Transition readiness had statistical significant positive correlation with self-esteem and psychosocial support (r = 0.38, p < 0.01, r = 0.39, p < 0.01, respectively), while anxiety showed strongly negative correlation (r = -0.25, p < 0.05). **Conclusion:** To improve the health care transition system in Thailand, clinicians should focus on the process of preparing the patients. Building patients' self-esteem and providing rich psychosocial rapport as well as training stress management to the adolescent patients is an essential task that builds from the routine education on disease knowledge.

Keywords: Transition readiness, Adolescents chronic illness

J Med Assoc Thai 2012; 95 (8): 1028-34 Full text. e-Journal: http://jmat.mat.or.th

Innovative technology and advanced medical treatment lead to the increasing people life expectancy and to the decreasing in diseases morbidity and mortality rate in pediatric populations. This results in the rising number of chronic illness in adolescent population<sup>(1)</sup>. Adolescence is the stage of life where physical, sexual, and cognitive as well as psychosocial development start. Those are very important for the patient's future well being. Therefore, being sick with chronic diseases during this stage is a risk that development in independency will fail and will increase other developmental difficulties as well as increase psychosocial delay. In order to complete the transition process from pediatric to adult-oriented care, adolescents are unavoidably faced with the feeling of abandonment, unfamiliar health systems, and anxiety for a new system<sup>(2)</sup>. To facilitate the transition process,

Correspondence to:

Manaboriboon B, Department of Pediatrics, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok 10700, Thailand. Phone: 0-2419-5996-7

E-mail: Boonying.man@mahidol.ac.th

health care providers have to take responsibility for coordinating this process, providing the knowledge, and anticipate the guidance prior to the transfer of the patients to the adult care system $^{(3,4)}$ . The key to a successful transfer of care is to achieve transition readiness during adolescence. Conversely, age cut-off policies, limited utility to practitioners and service providers, financial and insurance issues, and attitude of parents and health care providers are transition barriers<sup>(5-7)</sup>. In addition, some studies demonstrated the essential factors in readiness for transition in chronically-ill adolescents were psychological developmental maturity, severity, duration of illness, the preparation of self-management and self-advocacy skills, and good supporting systems<sup>(8-11)</sup>. Never the less, peer-reviewed researches showed that adolescents with chronic diseases had poorer self-esteem and higher level of anxiety even though they perceived their long-term illness and lives as normal as other youths<sup>(9,12-16)</sup>. As a result, psychosocial support to establish independency and adaptation to adultoriented medical systems were needed to be highlighted for chronically ill adolescents. When transferring from pediatric-oriented to adult-oriented care, health care providers should emphasize the factors that facilitate a patients' transition process and lead to a successful transition process to adult continuity of care. Transition readiness is a unique process for each culture and countries. The most successful processes were done in the developed countries. Few studies were done in developing countries. In Thailand, the problems of health system transition were either never reported or under reported. However, now, these transition problems are becoming challenging for the health care providers.

The purpose of the present study was to determine the factors correlated to transition readiness in Thai adolescents who had been defined as having chronic illness. The studied factors included the duration of the disease, participant's self-esteem, and mental health problems focusing on participant's anxiety issues. It also included a self-assessment about the psychosocial support from families, peers, and health care providers.

#### **Material and Method**

Four out of seven provincial hospitals located in the upper part of Southern Thailand were randomized into the present study. The participants were selected from the Outpatient department (OPD). Because the patients were getting treatment in the outpatient setting, we assumed that the chronic diseases were stable enough. Thus, this was done to avoid disease bias, generalize disease severity, and increase validity. One hundred adolescents aged between 14 and 20 with chronic illness and ability to speak, read, and write in Thai languages enrolled between July 1 and September 30, 2009.

#### Instruments

All participants were interviewed privately by the same pediatric clinical nurse and completed self-administered questionnaires, which were validated and approved. There were four questionnaires to fill and each participant spent approximately 30 minutes to fill them.

The self-esteem assessment, a 4-point rating scale, was developed by Kromvongkon<sup>(17)</sup>. There were 10 items inquiring about self-image of adolescents with chronic illnesses. High scores represented high self-esteem.

The trait anxiety assessment, a 4-point rating scale of 20 items questionnaire, was the tool that

assessed the anxiety perception in Thai adolescents. Chanwatana and colleagues developed this tool. The higher score indicated having more anxiety in general<sup>(18)</sup>.

The social support questionnaire, a 4-point rating scale of 20 items, was used to assess the participants' supporting system from peers, family, and service providers. It covered the physical and psychological wellness, as well as the feeling that they could easily have access to medical information or getting knowledgeable medical resources from their medical providers, and felt having social acceptance for themselves<sup>(19)</sup>. The higher scores were interpreted as having higher social support.

The transition readiness assessment, a 4-point rating scale of 25 items questionnaire was initially developed from literature reviews<sup>(8,20-23)</sup>, by Buntham et al. This modified tool was examined by a panel of five experts in the area of treatments and nursing care for adolescents with chronic illnesses for content validity. The reliability of this tool was determined and analyzed by 20 adolescents with chronic illnesses fitting in the same inclusion criteria as the present study population. Internal consistency was calculated by using Cronbach's alpha coefficient. The reliability values of the self-esteem, trait anxiety, social support, and transition readiness assessment questionnaire were 0.80, 0.83, 0.87, and 0.87, respectively.

The authors used this tool for measuring the readiness for transition of the chronic illness patients from pediatric to adult care system. The main issues for assessment included self-management skills, self-advocacy, and health care utilization skills. The outcome of higher score represented the more selfreadiness for transition.

The present study was part of the thesis that was approved by Mahidol University Institutional Review Board and Committee of Ethics for Hospital Settings. The authors obtained consent from parents and assent from participants. The eligible adolescents were interviewed using demographic data and completed all self-administered questionnaires.

#### Data analysis

All analyses were conducted by using SPSS for windows (Version 11.5, SPSS, Inc., and Chicago, IL, USA). Descriptive statistics including frequency, percentage, mean, and standard deviations were used to describe the characteristics of the samples and the study variables. The authors used Kolmogorov-Sminov test to analyze the probability distribution of variables. A Pearson's product-moment correlation coefficient was computed to assess the relationship between transition readiness and duration of chronic illness, self-esteem, trait anxiety, and social support. The normality of the present study variables and linearity

**Table 1.** Characteristics of participants (n = 100)

1 1 1	,
Characteristics	% (n = 100)
Gender	
Male	46
Female	54
Age (years old)	
14-15	67
> 15	33
Duration of illness (years)	
1-5	42
6-10	13
11-15	39
> 15	6
Primary diagnosis	
Thalassemia	28
Congenital heart disease	11
Epilepsy	10
Asthma	9
Other endocrine disorders	8
Cancer	7
Systemic lupus erythematosus	7
Chronic renal disease	6
Rheumatic heart disease	6
Diabetes mellitus	4
HIV infection	4

among independent variables and dependent variables were also examined. A p-value of less than 0.05 was considered statistically significant.

#### Results

Characteristics of the participants were described in Table 1. Two thirds of participants were middle adolescents with up to 50% had been sick for at least 11 years. Participants' scores to questionnaires on their self-esteem, anxieties, psychosocial supports, and transition readiness were shown in Table 2. Overall, self-rating scores for all domains were interpreted as good except anxiety, which possibly meant that participants had moderate degree of anxiety in general. As shown in Table 3 and Fig. 1-3, the authors found that transition readiness of participants was shown to have highly significant positive correlation with their self-esteem and having social support (r = 0.38, p < 0.01, r = 0.39, p < 0.01, respectively),but shown significant negative correlation with anxiety (r = -0.25, p < 0.05). Of these results, it could be implied that having high self-esteem and good psychosocial support, as well as having less anxiety or no anxiety, strongly correlated with more self-readiness to transfer from pediatric to adult medical care. Interestingly, transition readiness had no relationship with duration of illness (r = 0.03, p > 0.05).

# Discussion

In the present study, the tool for assessing transition readiness was developed and analyzed for its validity and reliability. Such a tool, transition readiness assessment questionnaire, was a 4 point self-rating scale with 25 items, mainly focused on participant's knowledge of diseases, self-management, self-efficacy, and health care utilization skill. Assuming

Table 2. Overall self-scoring of studied factors and interpretation (n = 100)

Study factors	Ranged of rating scales	Mean (SD)	Interpretation
Duration of illness (years)	1.00-18.00	8.48 (5.45)	N/A
Self-esteem	2.00-3.60	2.78 (0.29)	Good
Anxiety	1.55-3.05	2.32 (0.30)	Moderate
Social support	2.40-4.00	3.26 (0.36)	Good
Transition readiness	2.12-3.68	2.90 (0.34)	Good
Self-management skills	1.66-4.00	2.98 (0.44)	Good
Self-advocacy skills	1.66-4.00	2.95 (0.47)	Good
Knowledge of disease	1.66-4.00	2.89 (0.48)	Good
Health care utilization skills	1.71-3.85	2.78 (0.41)	Good

Study factors	Correlation coefficient (r)	Coefficient of determination (r <sup>2</sup> )
Duration of illness (years)	0.03	0.09
Self-esteem	0.38**	14.44
Anxiety	-0.25*	6.25
Social support	0.39**	15.21

**Table 3.** Correlation of transition readiness and studied factors (n = 100)

\* p < 0.05, \*\* p < 0.01

that all aspects could highly represent for self-readiness to transfer to adult care, similarly to the study of adolescents with cystic fibrosis that used these focused issues as the predictors for transition achievement<sup>(22)</sup>, overall score for assessing transition readiness in studied population was interpreted as good. However, future longitudinal researches should be done to prove this hypothesis.

For factors related to transition readiness, many studies proposed varieties of them, but they focused on internal factors such as duration of illness, self-esteem, and anxiety, and external factors such as social support.

Self-esteem was the individual's attitudes and perceptions of self-worth that played a key role in young people's behavior. Although, self-esteem increased with age particularly during adolescence, where the stage of changes were developing, chronically-ill youths were also at risk for having risky behaviors and having greater negative health consequences from such behaviors than healthy adolescents<sup>(23)</sup>. Peer-reviewed researches showed that youths with chronic illness had lower self-esteem than their peers, which contributed to the complexity of disease management and having ineffective application of shifting to adult-oriented care<sup>(9,12,14)</sup>. On the other hand, the young people who had higher self-esteem were more likely to be living in more normal lives and be more proficient in coping with stress<sup>(24)</sup>. In the present study, participants also presented the high scores of self-esteem and the authors found that having a high score of esteem was significantly correlated with the successful transition (r = 0.38, p < 0.01).

For anxiety, the present study found that, it had statistical significance associated with transition readiness (r = -0.25, p < 0.05) and participants had some degrees of stress on their health and the transition system. Some reported having distress, being anxious











Fig. 3 Scatter plot between transition readiness and anxiety score, showing negative linear correlation

and having fears, as well as having high expectation to use adult services. However, of those, some might get more stressed when exposed to the new practice leading them to have poorer adjustment and more anxiety. Therefore, to strengthen the transition readiness, anxiety management might be one of the important issues concerned.

For social support, the supporting system from peers, families, health care teams as well as people and environment around participants was shown as being one of the most significant correlation with transition readiness (r = 0.39, p < 0.01). Similarly, many studies also emphasized the important role of social support and the collaboration among health care teams<sup>(25)</sup>, which highly benefited the patients. Health care providers should help maximizing this system by encouraging parents to provide emotional support, act as troubleshooters and protectors, as well as help develop self-confidence, decision-making skills, and disease management to their teenagers. In addition, health care providers must not forget the impact of school and peers, which were indeed very powerful to strengthen the competency of adolescents with chronic conditions<sup>(9)</sup>. Importantly patients, as adolescents need to be informed about their disease, learn how to take care of their health, and learn about their risky behaviors. In addition, counseling and information provided should be available and easily accessed. By enhancing young people' self-confidence, independency, understanding disease knowledge, and promoting family support, the heath care team would help patients successfully go through the transition.

Similar to other study, duration of illness was not considered to be a factor of adolescent readiness for transition<sup>(4,23)</sup>. Therefore, the long duration of illness did not assure that the patients had all the knowledge provided and were ready for the transition.

The present study strongly demonstrated that studied factors such as participants' self-esteem, anxiety, and social support were strongly correlated with the transition readiness. In order to have success in the transition process from Pediatric to Adult care setting, younger patients should be taught on the process of patients' preparation, which include building their self-esteems, providing life skill on stress or anxiety management, and maximizing psychosocial support system, as well as providing patients' disease knowledge and self-care education on a regular basis.

In the light of the present study, although there was a broad eligible criterion of adolescents with chronic illness, the participants did not reflect the large population of the country because the present study setting was located only in the upper southern part of Thailand. Therefore, further researches should be done in different parts of Thailand to compare the results and find other factors related to transition readiness *e.g.*, health coverage systems, severity of diseases, and quality of life.

## Conclusion

The findings of the current study could be provided to health care providers who currently play a role in taking care of adolescents with chronic illnesses. They can get information about some factors to promote transition readiness. Not only did the authors highlight the understanding of the relationship between transition readiness and related factors, but also developed a tool for assessing transition readiness in adolescents with chronic illnesses, which can be used as the screening tool for assessment the readiness for transition in Thai adolescents. In order to achieve a successful transition, the authors suggested health care providers as the multidisciplinary teams, to realize the necessity of the preparation for this process, which meant advocating some time for building the patients' self-esteem, teaching how to relieve their anxiousness, and providing good psychosocial support, in addition to the regular clinic basis.

# Acknowledgement

The authors wish to thank all the participants, their parents, health care providers, and the hospital directors of the studied provincial hospitals for their help and generosity.

## **Potential conflicts of interest**

None.

## References

- LoCasale-Crouch J, Johnson B. Transition from pediatric to adult medical care. Adv Chronic Kidney Dis 2005; 12: 412-7.
- Turkel S, Pao M. Late consequences of chronic pediatric illness. Psychiatr Clin North Am 2007; 30: 819-35.
- Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. 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.
- 4. While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity

during transition from child to adult care: synthesis of the evidence. Child Care Health Dev 2004; 30: 439-52.

- Wiener LS, Zobel M, Battles H, Ryder C. Transition from a pediatric HIV intramural clinical research program to adolescent and adult community-based care services: assessing transition readiness. Soc Work Health Care 2007; 46: 1-19.
- 6. Robertson L. When should young people with chronic rheumatic disease move from paediatric to adult-centred care? Best Pract Res Clin Rheumatol 2006; 20: 387-97.
- McDonagh JE. Growing up and moving on: transition from pediatric to adult care. Pediatr Transplant 2005; 9: 364-72.
- Sawicki GS, Lukens-Bull K, Yin X, Demars N, Huang IC, Livingood W, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ— Transition Readiness Assessment Questionnaire. J Pediatr Psychol 2011; 36: 160-71.
- Vitulano LA. Psychosocial issues for children and adolescents with chronic illness: self-esteem, school functioning and sports participation. Child Adolesc Psychiatr Clin N Am 2003; 12: 585-92.
- Malhi P. Psychosocial issues in the management and treatment of children and adolescents with asthma. Indian J Pediatr 2001; 68(Suppl 4): S48-52.
- Grey M, Boland EA, Yu C, Sullivan-Bolyai S, Tamborlane WV. Personal and family factors associated with quality of life in adolescents with diabetes. Diabetes Care 1998; 21: 909-14.
- Howenstine MS, Eigen H. Medical care of the adolescent with asthma. Adolesc Med 2000; 11: 501-19.
- Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel disease: a comparison with children having other chronic illnesses and with healthy children. J Child Psychol Psychiatry 1992; 33: 563-82.
- 14. Seigel WM, Golden NH, Gough JW, Lashley MS, Sacker IM. Depression, self-esteem, and life

events in adolescents with chronic diseases. J Adolesc Health Care 1990; 11: 501-4.

- Kellerman J, Zeltzer L, Ellenberg L, Dash J, Rigler D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. J Pediatr 1980; 97: 126-31.
- Berntsson L, Berg M, Brydolf M, Hellstrom AL. Adolescents' experiences of well-being when living with a long-term illness or disability. Scand J Caring Sci 2007; 21: 419-25.
- 17. Kromvongkon S. Factors affecting health status among amputee adolescents. Bangkok: Mahidol University; 2002.
- Chanwattana B, Chintanadilok N, Apanakapun P, Chalamkat W, Bennedetti M. Effect of information for release anxiety of mothers who has hospitalized child. Thai J Pediatr Nurs 2001; 1: 26-36.
- Sangsuwan W, Chintanadilok N, Sriassadaporn P, Sitthimomgkol Y. The relationship between sosial support and adaptation in adolescents with chroniic illness. Thai J Pediatr Nurs 2001; 1: 37-45
- Betz CL, Redcay G, Tan S. Self-reported health care self-care needs of transition-age youth: a pilot study. Issues Compr Pediatr Nurs 2003; 26: 159-81.
- Newland JA. Factors influencing independence in adolescents with sickle cell disease. J Child Adolesc Psychiatr Nurs 2008; 21: 177-85.
- 22. Cappelli M, MacDonald NE, McGrath PJ. Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. Child Health Care 1989; 18: 218-24.
- 23. Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: challenges living, challenges treating. Lancet 2007; 369: 1481-9.
- Meijer SA, Sinnema G, Bijstra JO, Mellenbergh GJ, Wolters WH. Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness. Soc Sci Med 2002; 54: 1453-61.
- 25. Bryant R, Walsh T. Transition of the chronically ill youth with hemoglobinopathy to adult health care: an integrative review of the literature. J Pediatr Health Care 2009; 23: 37-48.

# ป้จจัยที่เกี่ยวข้องกับความพร้อมสู่การเปลี่ยนผ่านระบบการรักษาของวัยรุ่นโรคเรื้อรัง: ประสบการณ์ ในประเทศไทย

บุญธรรม ภักดีพรหม, สุภิญญา อินอิว, นงลักษณ์ จินตนาดิลก, ไข่มุกข์ วิเซียรเจริญ, บุญยิ่ง มานะบริบูรณ์

วัตถุประสงค์: เพื่อหาปัจจัยที่มีผลต่อความพร้อมสู่การเปลี่ยนผ่านจากการรักษาแบบเด็กสู่การรักษาแบบผู้ใหญ่ของวัยรุ่นโรคเรื้อรัง ของเด็กไทย โดยปัจจัยที่ศึกษาได้แก่ ระยะเวลาที่เจ็บป่วย การรับรู้คุณค่าในตนเอง ความวิตกกังวล และได้รับการสนับสนุนทางสังคม วัสดุและวิธีการ: สุ่มตัวอย่างจากวัยรุ่นโรคเรื้อรังอายุ 14-20 ปี จำนวน 100 ราย ที่มารับการตรวจดิดตามการรักษาที่คลินิก ของโรงพยาบาลประจำจังหวัดในเขตภาคใต้ตอนบนเพื่อสัมภาษณ์ และตอบแบบประเมินความพร้อมสู่การเปลี่ยนผ่านที่ผ่านการ ตรวจสอบความเที่ยงและความตรงเชิงเนื้อหาแล้ว วิเคราะห์ข้อมูลด้วยสถิติเชิงพรรณนาและหาสัมประสิทธิ์สหสัมพันธ์เพียร์สัน ผลการศึกษา: พบว่า การรับรู้ถึงคุณค่าของตนเองและการได้รับการสนับสนุนทางสังคมมีความสัมพันธ์เชิงบวก (r = 0.38, p < .01, r = 0.39, p < 0.01 ตามลำดับ) ในขณะที่ความวิตกกังวลของอาสาสมัครมีความสัมพันธ์เชิงลบกับความพร้อมสู่การเปลี่ยนผ่าน (r = -0.25, p < 0.05) อย่างมีนัยสำคัญทางสถิติ

สรุป: การเปลี่ยนผ่านจากการรักษาแบบเด็กสู่การรักษาแบบผู้ใหญ่ของวัยรุ่นโรคเรื้อรังในบริบทของคนไทยจะประสบผลสำเร็จได้ นั้นบุคลากรทางการแพทย์จำเป็นต้องเตรียมความพร้อมสู่การเปลี่ยนผ่านการรักษาให้เด็ก โดยการส่งเสริมให้เด็กรับรู้คุณค่าของ ตนเอง สอนให้มีทักษะในการจัดการกับความเครียดและความวิตกกังวลของตน รวมถึงให้การสนับสนุนทางด้านสังคม เป็นปัจจัย ที่สำคัญที่ทำให้การเปลี่ยนผ่านประสบผลสำเร็จ นอกเหนือจากการให้ความรู้เกี่ยวกับโรคที่เด็กเป็นอยู่