



# Psychosocial Problems in Children with Thalassemia and Their Siblings†

ORAWAN LOUTHRENOO, M.D.\*,  
SOMJAI SITTIPREECHACHARN, B.Sc.\*

PATTRATR THANARATTANAKORN, M.D.\*,  
TORPONG SANGUANSERMSRI, M.D.\*

## Abstract

Beta-thalassemia is a chronic illness causing serious symptoms to children and a burden to families. The purpose of this study was to evaluate psychosocial problems in children with thalassemia and their siblings by using a semi-structured interview and the Pediatric Symptom Checklist (PSC). The study sample included 82 children with thalassemia, 20 siblings, and 50 control children without a chronic illness. With children and families demographically controlled, psychosocial problems were significantly more common in children with thalassemia than in those without chronic illness, 28.05 per cent vs 4 per cent ( $p=0.001$ ), but there was no difference between siblings and the controls, 5 per cent vs 4 per cent ( $p=0.64$ ). The mean PSC score in children with thalassemia was higher than that in the sibling and control group (18.34 vs 10.95 and 10.28, respectively;  $p<0.001$ ). These findings suggest an increased risk of psychosocial problems in children with thalassemia that psychosocial intervention may be required to prevent major psychiatric disorders.

**Key word :** Psychosocial, Thalassemia

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SITTIPREECHACHARN S, SANGUANSERMSRI T  
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Beta-thalassemia is one of the major health problems in Thailand and Southeast Asia. The high prevalence of thalassemia in Thailand has been documented<sup>(1)</sup>. This severe and progressive hemolytic

anemia occurs during the first year of life, which requires regular blood transfusions to prevent profound weakness and cardiac decompensation. Iron-chelating agent administration is needed to decrease

\* Department of Pediatrics, Faculty of Medicine, Chiang Mai University, Chiang Mai 50200, Thailand.

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hemosiderosis, which is a consequence of prolonged transfusion therapy. Therefore, it causes serious symptoms to the children and a considerable burden to their families. Even the milder form, thalassemia intermedia, has been shown to have psychosocial burden<sup>(2)</sup>. While methods of prevention have been improving, there are still many children suffering from this disease. Similar to children with other chronic illnesses<sup>(3-5)</sup>, those with thalassemia are at increased risk of developmental and behavioral problems, which may persist into adult life<sup>(4)</sup>.

Although thalassemia is prevalent in Thailand, the authors were not aware of a study of the psychosocial aspect in these children. The purpose of this study was to determine whether children with thalassemia and their siblings have more psychosocial problems than those without chronic illness.

## MATERIAL AND METHOD

### Subjects

Children with thalassemia in the Pediatric Hematology Clinic at Chiang Mai University Hospital aged from 4-15 years were enrolled into the study. The inclusion criteria included families who had a father whose age ranged from 24 to 50 years and a mother whose age ranged from 23 to 45 years, were eligible for an interview, and willing to participate. The controls were from similar families located in the same area who had no children with chronic illness. For the purpose of this study, chronic illness was defined as a medical condition that required either repeated visits to the doctor, repeated hospitalization, or restriction of the child's daily activities. Siblings of thalassemia were also evaluated. Demographic and medical history data were obtained through an interview. The semi-structured interview and a psycho-

social screening questionnaire were administered by the investigators. Ethical approval was obtained from the Ethics Committee of the Faculty of Medicine, Chiang Mai University.

Psychosocial screening was assessed using the Pediatric Symptom Checklist (PSC)<sup>(6)</sup>, which consists of 35 items on a 3-point scale (not true, somewhat or sometimes true, and very or often true). This questionnaire has been used reliably and accurately for psychosocial screening in pediatric primary care<sup>(7)</sup>.

Data were collected for statistical analysis using the SPSS program version 10.0. Analysis of variance was used to compare 3 groups of continuous variables. A p-value of  $< 0.05$  was considered as statistically significant.

## RESULTS

Eighty-two children with thalassemia and 50 cases in the control group met the inclusion criteria. There were also 20 siblings of thalassemia included in this study. The mean age of the child, father, and mother in the three groups were not significantly different. The most common marital status was married and living with their spouse. The other variables (child gender, parents' education, marital status, and parents' occupation) were not different among the three groups, as shown in Table 1.

After the semi-structured interview, there were more parent-reported psychosocial problems found in children with thalassemia than in the sibling and control groups which were 28.05 per cent vs 5 per cent and 4 per cent respectively ( $p=0.001$ ). The mean PSC scores were  $18.34 \pm 8.25$  in thalassemia,  $10.95 \pm 4.37$  in siblings, and  $10.28 \pm 6.20$  in controls ( $p<0.001$ ). The PSC score was significantly higher in

Table 1. Sociodemographic factors.

	Thalassemia (n=82)	Siblings (n=20)	Controls (n=50)	P-value
Age, yr	$9.05 \pm 2.97$	$9.60 \pm 3.80$	$8.70 \pm 2.65$	0.52
Gender, % male	36.59	55.00	46.00	0.26
Duration of disease, yr	$7.94 \pm 3.15$			
Father age, yr	$37.55 \pm 5.18$	$38.21 \pm 4.55$	$36.49 \pm 5.38$	0.38
Mother age, yr	$34.99 \pm 4.64$	$36.05 \pm 4.02$	$33.32 \pm 5.22$	0.05
Father education, yr	$7.06 \pm 3.61$	$8.68 \pm 4.12$	$8.08 \pm 3.95$	0.15
Mother education, yr	$6.96 \pm 3.80$	$9.10 \pm 4.28$	$7.00 \pm 3.65$	0.07
Marital status, % married	89.02	90.00	88.00	0.97
Occupation, % workers	58.54	45.00	66.00	0.52

children with thalassemia. The siblings did not differ from the controls in terms of both percentage of psychosocial problems and PSC score ( $p$ -value=0.64 and 0.66 respectively).

The age and gender of the child, age of father, age of mother, parental education, marital status, and duration of the disease were no different to that of children with thalassemia, who had and did not have parent-reported psychosocial problems. The PSC score was the only variable that differed significantly, as shown in Table 2.

## DISCUSSION

Most families in the thalassemia group in northern Thailand were of low to middle socioeconomic status with an educational level of elementary school and they could only afford standard treatment of regular transfusions and iron chelating agent infusion. The disease was a burden to the child regarding his/her quality of life such as frequent absence from school, discomfort at the time of transfusion, physical limitation, and complications of the illness itself. The families also felt impacts on their economic status, occupation, time for parenting, and general family functioning; therefore, most of them decided to have only 1 child. As many of the siblings were at an age not in the range of the inclusion criteria, only 20 cases of siblings were obtained in the study.

In this study, the mean age of children with thalassemia was  $9.05 \pm 2.97$  years and the mean duration of the disease was  $7.94 \pm 3.15$  years, which indicated that the child had suffered from the illness almost all of his/her life. In many chronic diseases, the risk of adjustment problems is increased, but good psychosocial adjustment is also possible if the

appropriate intervention is provided. More parent-reported psychosocial problems were found in children with thalassemia than those in the controls (28% vs 4%) of this study. These findings were consistent with other studies of children with thalassemia<sup>(8,9)</sup> and other chronic illnesses<sup>(4,5)</sup>. Although there were reports that siblings of children with thalassemia had more problems than controls, especially when they were older than 10 years old<sup>(10)</sup>, these findings were not documented in this study. This might be because of the small number of samples in the sibling group. However, the siblings of chronically ill children were reported to have behavioral problems that fell in the range of those in the general population, and older siblings adapted well<sup>(11,12)</sup>.

The PSC score was certainly higher in children with psychosocial problems. The good correlation of the PSC score and parent-reported psychosocial problems may assure their purpose as a tool for psychosocial screening.

There were some limitations when using the PSC in this present study. Firstly, the cut-point score of the PSC was considered whether appropriate or not for this study, as it was not known if this sample would represent the same norms as that in the development of the PSC score<sup>(7)</sup>. Another limitation was no reassessment of the parent-reported psychosocial problems for a psychiatric diagnosis. Furthermore, a larger number and variety of samples would establish the correlation of the PSC score and psychosocial problems better.

Primary pediatricians may use the PSC for psychosocial screening in children who are prone to psychosocial problems that take a short period of time to identify the problems. Although most of the

Table 2. Characteristics of children with thalassemia and psychosocial problems.

	Reported psychosocial problems (n=23)	No psychosocial problems (n=59)	P-value
Age, yr	$8.70 \pm 3.02$	$9.19 \pm 2.97$	0.50*
Gender, % male	39.13	35.59	0.77
Duration of disease, yr	$7.61 \pm 3.17$	$8.07 \pm 3.16$	0.56*
Psychosocial score	$25.70 \pm 8.27$	$15.47 \pm 6.27$	<0.001*
Father age, yr	$38.32 \pm 5.29$	$37.24 \pm 5.16$	0.41*
Mother age, yr	$36.13 \pm 5.79$	$34.54 \pm 4.08$	0.24*
Father education, yr	$6.86 \pm 3.55$	$7.15 \pm 3.66$	0.76*
Mother education, yr	$7.09 \pm 3.62$	$6.92 \pm 3.90$	0.85*
Marital status, % married	95.65	86.44	0.43

\* t-test (2-tailed)

children with thalassemia can cope well, the PSC may help to identify those who may need special psychological support. There are many factors associated with the psychosocial adjustment of children with thalassemia or other chronic illnesses. Parents of children with a chronic disease are described as excessively worried, overprotective, and unable to discipline effectively. Family characteristics, parent-child relationship, and family functioning, as well as support from the community may be involved with the adjustment of and coping with children and their families. Further study is needed to identify and

explore those factors. However, psychosocial intervention<sup>(13)</sup> may be appropriate in providing children and their families with preventative measures against major psychosocial disorders in the future.

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## ปัญหาจิตสังคมในผู้ป่วยเด็กโรคโลหิตจางธาลัสซีเมียและในพี่น้องของผู้ป่วย†

อรวรรณ เลาห์เรณู พ.บ.\*, ภัทรา มนวัฒนากร พ.บ.\*,  
สมใจ สิกขิบุรีชาชานุ วท.บ.\* , ต่อพงศ์ สงวนเสริมศรี พ.บ.\*

โรคโลหิตจางธาลัสซีเมียนิดเบต้า เป็นโรคเรื้อรังที่ก่อให้เกิดอาการรุนแรงต่อเด็กและมีผลกระทบต่อครอบครัว วัดดู-ประเมินปัญหาจิตสังคมของเด็กที่เป็นโรคโลหิตจางธาลัสซีเมียและพี่น้องของเด็กที่เป็นโรคนี้ โดยใช้ การสัมภาษณ์กึ่งระบบตามหัวข้อและแบบประเมินพดติกรรม Pediatric Symptom Checklist (PSC) กลุ่มตัวอย่างที่ศึกษา ประกอบด้วยผู้ป่วยเด็กที่เป็นโรคโลหิตจางธาลัสซีเมียนิดเบต้า 82 คน พี่น้องของผู้ป่วย 20 คน และเด็กที่ไม่มีโรคเรื้อรังซึ่ง เป็นกลุ่มควบคุม 50 คน ที่มาบันทึกษาที่โรงพยาบาลราชวิถีเชียงใหม่ โดยมีอายุ เพศ และลักษณะทางครอบครัว ไม่แตกต่างกัน พบร่วกกลุ่มเด็กที่เป็นโรคโลหิตจางธาลัสซีเมียมีปัญหาจิตสังคมมากกว่ากลุ่มควบคุมอย่างมีนัยสำคัญ (ร้อยละ 28.05 เปรียบเทียบกับร้อยละ 4;  $p=0.001$ ) ส่วนในกลุ่มพี่น้องผู้ป่วยไม่แตกต่างจากกลุ่มควบคุม (ร้อยละ 5 เปรียบเทียบกับ ร้อยละ 4;  $p=0.64$ ) คะแนน PSC เฉลี่ยในกลุ่มเด็กที่เป็นโรคสูงกว่าของกลุ่มพี่น้องและกลุ่มควบคุม (18.34 เปรียบเทียบกับ 10.95 และ 10.28 ตามลำดับ;  $p<0.001$ ) การศึกษานี้พบว่าเด็กที่เป็นโรคโลหิตจางธาลัสซีเมียมีโอกาสเสี่ยงสูงต่อการเกิด ปัญหาจิตสังคม การให้การช่วยเหลืออาจจำเป็นในเด็กกลุ่มนี้เพื่อป้องกันการเกิดโรคจิตเวชที่รุนแรงตามมา

คำสำคัญ : ปัญหาจิตสังคม, ธาลัสซีเมีย

อรวรรณ เลาห์เรณู, ภัทรา มนวัฒนากร,  
สมใจ สิกขิบุรีชาชานุ, ต่อพงศ์ สงวนเสริมศรี  
จตุหมายเหตุทางแพทย์ ฯ 2545; 85: 881-885

\* ภาควิชาภูมิเวชศาสตร์, คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่, เชียงใหม่ 50200