Result of Video-Education on "Genetic Transmission in Thalassemia" to Thalassemic Patients and Their Parents

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Objective: *To determine the degree of knowledge improvement and retention after a single viewing of a video CD presentation on the genetic transmission of thalassemia among patients with thalassemia and their parents.*
Material and Method: *The present research was approved by Khon Kaen University Ethics Review Board. A video CD on the genetic transmission of thalassemia was created as an educational tool for improving knowledge and retention. The validity and the informative usefulness of the video CD was evaluated, adapted and approved by a thalassemia expert. Between November 1, 2002 and September 30, 2005, 61 subjects (thalassemic patients and their parents, both groups were in reproductively active ages) at the Pediatric Outpatient Unit, Srinagarind Hospital, Khon Kaen, consented to participate. Their ages ranged between 17 and 50 years (mean $\pm$ SD = 36.5 $\pm$ 9.4; median = 38.0) and 44.3% completed elementary while 26.2% completed secondary school. Their occupations varied. Mothers, fathers, and thalassemic patients comprised 68.9%, 21.3%, and 9.8% of participants, respectively. In a quiet room in the Unit, each subject watched a single viewing of the video. A validated questionnaire (Cronbach's alpha coefficient = 0.79) with 40 true/false items was used to evaluate baseline knowledge on the genetic transmission of thalassemia. Knowledge was re-tested four times: immediately after the viewing, then at the 4^{th}, 12^{th}, and 24^{th} week. The scores for each test were skewed toward high scores; therefore, non-parametric tests were used for the statistical evaluation.*
Results: *The running time for the video CD was 20 minutes. The baseline knowledge on genetic transmission was high. Immediately after a single viewing of the video, the knowledge level increased significantly (p = 0.000, 95%CI = 4.0-7.0) and was maintained up to the 12^{th} week, after which (at the 24^{th} week) there was a significant drop (p = 0.020, 95%CI = -2.0 to 0) compared to the immediate post-test.*
Conclusion: *The authors' video CD presentation effectively provided knowledge on the genetic transmission of thalassemia to patients with thalassemia and their parents. Post-viewing knowledge increased significantly and was retained for at least 12 weeks. Thereafter, a refresher should be taken.*

Keywords: *Education, Genetic transmission, Knowledge retention, Thalassemia, Video education*

J Med Assoc Thai 2006; 89 (11): 1909-14
Full text. e-Journal: *http://www.medassocthai.org/journal*

Thalassemia is a growing global public health problem [1]. The life expectancy of patients with thalassemia major, as reported by several groups in different countries, has significantly increased in recent years. However, complications of the disease are still frequent, affecting the quality of life. Fifty percent of patients die before age 35 with heart disease being responsible for more than half of the deaths[2].

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Thalassemia represents a major public health problem in Thailand[3] with about 1% of the Thai population being affected. Annually, ~50,000 pregnancies are at risk of having an affected fetus; one-fourth of which result in thalassemic newborns[4]. Thus, the prevalence of thalassemia in Thailand is not decreasing; evidently, due to a lack of awareness of this disease and its genetic transmission in the Thai population, there is the implication that genetic counseling has failed[3].

A model for prevention of thalassemia by combining four strategies (education, carrier screen-

ing, genetic counseling, and prenatal diagnosis) was developed by the *Thai Thalassemia Task Force*[5]. With inequalities of access to genetic services, particularly for rural people who already have an increased risk of thalassemia, genetic education must spread beyond the narrow confines of a specialist genetic service[6]. In order to meet public health care needs, nurses - even non-geneticist clinicians - should be able to provide patients and their relatives with education on the genetic transmission of thalassemia[7]. In this regard, a recent article documented that with good knowledge in genetics, persons affected by thalassemia make decisions not to give birth to a fetus with severe thalassemic disease[8]. Therefore, the authors' aim was to assess the amount and retention of genetic knowledge patients and their parents would result after a single viewing of a video CD on this subject.

Material and Method

The present research was done between November 1, 2002 and September 30, 2005. The protocol was approved by the university's *Ethics Review Board*. Thalassemic patients and/or their parents who attended the *Pediatric Thalassemia Clinic* during the study period were asked to participate. Participants had to be literate and without any audiovisual deficit. Explanation about the details of the present study and informed consent before enrolment were given.

The authors created a video CD on the general knowledge of thalassemia (*viz.*, burden of the disease, epidemiology, causes, clinical manifestations, treatment, and prevention) and on basic genetic transmission (*viz.*, thalassemic status of offspring of thalassemic carrier parents, importance of genetic counseling and antenatal diagnosis).

Two examples of genetic knowledge were: 1) The best way to avoid severe thalassemia is to avoid giving birth to a homozygous -thalassemic fetus or one with severe compound Hb E -thalassemia. 2) A quarter of the offspring of the thalassemic carrier parents were homozygous or compound heterozygous thalassemic patients, half were thalassemic carriers and a quarter were normal.

In order to test the subjects' knowledge, the authors created a 40-item true/false test about thalassemia and its genetic transmission. Two examples of the items were: 1) "The clinical manifestation of homozygous -thalassemia began during intra-uterine life, true or false?" and, 2) "Prenatal diagnosis can usually be made by DNA analysis of amniotic fluid cells, true or false?"

First, the subjects were examined immediately before viewing the video CD to assess their baseline knowledge, and then they watched the video CD in a quiet room in our Unit. The first author answered any contingent questions until the participants achieved a clear understanding on the subject. Every subject was re-tested for knowledge immediately after viewing the video, and again at the 4^{th}, 12^{th} and 24^{th} week. Scores on each test for all of the subjects were computed and compared to determine any improvement of knowledge and the length of time it could be memorized and retained.

The video CD was approved by a thalassemia expert as a valid and reliable tool for providing an overview of thalassemia and its genetic transmission. The narration and pictures in the video CD were informative and easily understood by Thais with at least 6 years of education. The running time was 20 minutes. An expert in thalassemia assessed and agreed that the 40-item true/false test had good validity (Cronbach's alpha coefficient = 0.79). A sample of the video CD (playable on most DVD machines) and the test can be requested from the corresponding author.

Statistical evaluation

The authors set two hypotheses in the present study; namely, 1) Educating thalassemic patients and their parents on the genetic transmission of thalassemia via video CD immediately increases the level of knowledge on the topic; and, 2) The subjects will retain this knowledge for at least 24 weeks. Descriptive statistics: Mean $\pm$ standard deviation, 95%CI, median and range were applied to present the result. Shapiro-Wilk test was used to test for normal distribution.

Due to skewness to high scores on every testing, non-parametric statistics were used to evaluate the results (*i.e.*, Friedman Test and Wilcoxon Signed Ranks Test). A p-value of less than 0.05 was consi-dered statistically significant.

Results

The present study had 61 subjects ranging between 17 and 50 years of age (mean $\pm$ SD = 36.5 $\pm$ 9.4; median = 38.0. Forty (42.6%) subjects were $\leq$ 40 years of age and 41 (67.2%) were married and living with their spouse. Nearly half of the subjects (27/61; 44.3%) had completed an elementary education, 16 (26.2%) a secondary level and 6 (9.8%) a bachelor level.

Regarding occupation, 13 (21.3%) were housewives, 12 (19.7%) governmental officers, 11 (18%)

farmers, 9 (14.8%) employees, 6 (9.8%) merchants and 10 (16.4%) other occupations. Vis- -vis relationship with thalassemic patients, 42 (68.9%), 13 (21.3%) and 6 (9.8%) were the mothers, fathers of thalassemic patients and thalassemic cases themselves.

Participants who indicated not having any knowledge of thalassemia was 36 (59.0%). Respective to the number of children, 29 (47.5%), 18 (29.5%) and 7 (11.5%) of the subjects had 2, 1 and 0 children. Twenty-two (36.1%) of the subjects intended having more children.

Individual case's scores at the various testing can be checked in Table 1. Before viewing the video, baseline knowledge averaged 31.0 (SD = 5.5, median = 32.0, minima = 15.0, maxima = 39.0). The respective mean knowledge score immediately after the viewing, then at the 4th, 12th and 24th week was 37.4 (SD = 1.9, median = 38.0, minima = 32.0, maxima = 40.0), 38.1

Table1. Individual case's scores of knowledge at various tests in relation to time of receiving education

Cases / Scores	Case Number														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Pretest	37	29	33	30	36	32	29	36	31	37	31	34	27	29	29
Posttest															
Immediately	37	33	35	38	38	39	39	40	39	40	39	37	39	35	35
4th week	39	38	38	38	39	36	37	39	37	38	37	34	37	39	37
12th week	40	37	37	38	40	35	36	38	36	35	35	33	35	38	37
24th week	39	36	33	32	40	33	36	38	35	35	35	33	34	38	35

Cases / Scores	Case Number (continued)														
	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Pretest	34	25	31	37	37	36	31	35	31	29	34	15	37	34	28
Posttest															
Immediately	38	38	39	39	38	39	40	39	35	38	39	40	38	40	40
4th week	37	38	39	38	40	36	36	37	37	36	38	34	38	40	38
12th week	36	38	39	38	39	35	37	36	35	32	38	30	39	40	37
24th week	34	37	36	37	36	35	36	37	33	31	37	31	40	40	37

Cases / Scores	Case Number (continued)														
	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45
Pretest	22	31	34	31	31	20	24	36	36	26	16	26	34	25	36
Posttest															
Immediately	40	37	37	38	35	37	38	37	35	38	33	36	38	38	37
4th week	39	38	36	39	40	38	37	39	38	40	38	38	40	39	38
12th week	38	38	36	37	40	35	37	40	39	39	33	38	40	39	38
24th week	36	37	35	35	39	36	33	40	37	39	35	35	39	39	37

Cases / Scores	Case Number (continued)															
	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61
Pretest	38	34	30	32	33	35	28	18	36	32	32	32	36	36	39	20
Posttest																
Immediately	39	37	37	38	38	35	36	38	37	34	32	36	37	38	39	34
4th week	40	37	37	39	39	37	40	40	38	38	40	38	40	40	40	39
12th week	39	35	38	39	39	34	40	37	37	37	39	33	40	39	40	37
24th week	39	36	37	37	40	34	40	36	35	35	38	39	39	40	40	36

(SD = 1.4, median = 38.0, minima = 34.0, maxima = 40.0), 37.2 (SD = 2.2, median = 38.0, minima = 30.0, maxima = 40.0), 36.4 (SD = 2.4, median = 36.0, minima = 31.0, maxima = 40.0) (Table 2).

The scores for each test did not have a normal distribution (Table 2), so the authors had to compare the scores among tests using non-parametric statistics (*i.e.*, the Friedman Test), which revealed that the median scores of at least a pair of the tests were significantly different (n = 61, ^{2} = 127.873, df = 4 and p = 0.000).

Comparing the scores of the tests pair-by-pair using the Wilcoxon Signed Ranks Test (Table 3) revealed that immediately after the viewing the test scores were statistically higher than at baseline (Z = -6.538, p = 0.000, 95%CI = 4.0-7.0). Among post-tests, the authors found that the scores of the 4th and 12th weeks were not statistically different from the immediate post-test. However, the knowledge scores at the 24th week were significantly lower than the immediate post-test (Z = -2.320, p = 0.020, 95%CI = -2.0 to 0).

Discussion

The authors asked 61 subjects to participate in the present study and all obliged. Most of the samples had less than 12 years of education, were married and all were in the active reproductive life period. The mean score for genetic knowledge at baseline was 31/40 and only 23% of participants had scores below 70%, suggesting that before viewing the video CD the group had some knowledge of genetic transmission of thalassemia. There were some chronic cases of thalassemia, so the involved persons might have had some other education about thalassemia from their doctor(s) and/or nurse(s).

After viewing the video CD on genetic transmission, despite the content's being difficult conceptually[9], they could understand and remember and showed an improvement in knowledge. The mean score

Table 2. Summary of scores of knowledge on genetic transmission of thalassemia at different times

Test situation vis-a-vis learning from video	N	Summary of scores				Test for normal distribution by Shapiro-Wilk test*			Skewness±SE
		Mean±SD	Median	Minima	Maxima	Statistic	df	p value*	
1. Pretest	61	31.0±5.5	32.0	15.0	39.0	0.903	61	0.000	-1.13±0.31
2. Posttest (week)									
2.1 Immediately	61	37.4±1.9	38.0	32.0	40.0	0.915	61	0.000	-0.83±0.31
2.2 4th	61	38.1±1.4	38.0	34.0	40.0	0.911	61	0.000	-0.63±0.31
2.3 12th	61	37.2±2.2	38.0	30.0	40.0	0.918	61	0.001	-0.91±0.31
2.4 24th	61	36.4±2.4	36.0	31.0	40.0	0.950	61	0.014	-0.21±0.31

* Significance < 0.05 means data not normally distributed

Table 3. Wilcoxon Signed Ranks Test for testing the significance of the difference between the medians of paired samples

Statistical value	Testing in pair			
	Immediate post-test vs pretest	4th week after vs immediate post-test	12th week after vs immediate post-test	24th week after vs immediate post-test
Median difference	6.0	0	0	-2.0
Z	-6.538a	-1.950a	-0.459b	-2.320 b
p. (2-tailed)*	0.000	0.051	0.646	0.020
95% Confidence Interval	4.0 to 7.0	0 to 2.0	-1.0 to 1.0	-2.0 to 1.0

a. based on positive ranks
b. based on negative ranks
* p ≤ 0.05 means the medians of the paired samples had significant difference

at the immediate post-test was 37.4, which had increased about 16% from baseline. The group could keep the mean scores consistently high even 24 weeks after watching the video.

Audiovisual programs can effectively increase patient-understanding of their disease[10]. However, the mean score at the 24th week after educating was statistically significantly less than the immediate post-test; indicating that there was a tendency for a decline in knowledge over time. Therefore, a regular refresher should be given. During the observation period, no one in the sample became pregnant.

Providing education on genetic transmission of this common genetic disorder can begin to address the issues of collaboration and improvement for care[11]. In this vein, the authors' research strongly supports the integration of genetic education into nursing practice. Thalassemia patients and their parents were at-risk of transmitting thalassemia. Thus, the clinical picture and genetics of the disease must be included when providing education to assist the viewer to reach a decision to control the disease in their family[5]. The real benefit of any education program would be an increased rate in pre-marital counseling, early attendance to ante- natal care, antenatal diagnosis of the fetus in utero, and a consequent decreased rate in giving birth to children with severe thalassemia.

Thus, audio-visual education could be one part of the outreach for control of this disease in the community[12], however, the result of the present study indicates that a regular refresher should be given every 12 weeks in order to maintain a high level of awareness. Apart from delivering genetic education on thalassemia, nurses should also be prepared to give genetic counseling to help control this healthcare challenge[7].

Conclusion

Teaching the genetic transmission of thalassemia via video CD to thalassemic patients and their parents is an effective and convenient way to convey the information and should be integrated as a widespread nursing measure to help control this disease. A refresher should be done every 12 weeks to maintain a high level of knowledge.

Acknowledgments

The authors wish to thank the Khon Kaen University, Thailand, for its support and Mr. Bryan Roderick Hamman for his assistance with the English-language presentation of the manuscript.

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ผลของการให้ความรู้ด้วยซีดีวีดิทัศน์เรื่องการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียแก่ผู้ป่วยโรคธาลัสซีเมีย และบิดามารดา

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วัตถุประสงค์: *เพื่อศึกษาว่าภายหลังการให้ผู้ป่วยโรคธาลัสซีเมียและบิดามารดาดูซีดีวีดิทัศน์เรื่องการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมีย 1 ครั้ง ผู้ได้รับความรู้สามารถเพิ่มระดับความรู้ได้เท่าไร และสามารถเก็บความรู้ที่เพิ่มขึ้นได้นานเท่าไร*

วัสดุและวิธีการ: *การวิจัยนี้ได้รับความเห็นชอบจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์ของ มหาวิทยาลัยขอนแก่นแล้ว ผู้วิจัยได้สร้างซีดีวีดิทัศน์เรื่องการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมีย และตั้งสมมติฐานว่าการให้ความรู้เรื่องนี้ด้วยการให้ผู้ป่วยโรคนี้และบิดามารดาชมและฟังซีดีวีดิทัศน์ 1 ครั้งเป็นวิธีที่ทำให้มีความรู้เกี่ยวกับเรื่องนี้เพิ่มขึ้น และเก็บความรู้นี้ได้เป็นเวลานาน ทั้งผู้ป่วยและบิดามารดากำลังอยู่ในวัยเจริญพันธุ์ ความตรงและประโยชน์ของเนื้อหาของซีดีวีดิทัศน์ได้รับการตรวจสอบ และแก้ไขจนกระทั่งได้รับการยอมรับจากผู้เชี่ยวชาญโรคธาลัสซีเมีย การวิจัยได้กระทำระหว่างวันที่ 1 พฤศจิกายน พ.ศ. 2545 ถึงวันที่ 30 กันยายน พ.ศ. 2548 ณ หน่วยผู้ป่วยนอกกุมารเวช โรงพยาบาลศรีนครินทร์ คณะแพทยศาสตร์ มหาวิทยาลัยขอนแก่น ผู้แสดงความยินยอมเข้าร่วมกับ โครงการวิจัยมี 61 คน กลุ่มตัวอย่างมีอายุระหว่าง 17-50 ปี ค่าเฉลี่ย $\pm$ ค่าเบี่ยงเบนมาตรฐานคือ 36.5 $\pm$ 9.4 อายุมัธยฐานคือ 38.0 ปี ร้อยละ 44.3 และร้อยละ 26.2 ของกลุ่มตัวอย่างจบประถมศึกษาและมัธยมศึกษาตามลำดับ อาชีพของกลุ่มตัวอย่างมีหลายชนิด ร้อยละ 68.9, 21.3 และ 9.8 ของกลุ่มตัวอย่างเป็นมารดา บิดาและตัวผู้ป่วยตามลำดับ แต่ละคนจะชมและฟังซีดีวีดิทัศน์ เรื่องการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียในห้องเงียบสงบในหน่วยบริการข้างต้นเพียงครั้งเดียว กลุ่มตัวอย่างจะถูกวัดระดับความรู้เรื่องข้างต้นด้วยแบบทดสอบที่ถูกสร้างขึ้นมา แบบทดสอบนี้ประกอบด้วยคำถาม ให้ตอบว่าถูกหรือผิด 40 ข้อ แบบทดสอบนี้ได้รับการตรวจสอบและได้รับการยอมรับว่ามีเนื้อหาตรงเรื่องและมีค่า Cronbach's alpha coefficient 0.79 ทดสอบ 5 ครั้งคือก่อนจะให้ความรู้ หลังจากให้ความรู้แล้วทันที และหลังจากนี้ 4, 12 และ 24 สัปดาห์ เนื่องจากคะแนนของการวัดแต่ละครั้งมีการกระจายแบบไม่ปกติ ทุกครั้งคะแนนจะเบี่ยงไปทางคะแนนสูง การเปรียบเทียบคะแนนระหว่างการทดสอบแต่ละครั้งจึงใช้สถิติชนิด non-parametric*

ผลการศึกษา: *ซีดีวีดิทัศน์มีเนื้อหาเกี่ยวกับการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียความยาว 20 นาที ผู้ดูที่สำเร็จการศึกษาเพียงประถมศึกษาก็สามารถเข้าใจเนื้อหาได้ กลุ่มตัวอย่างมีความรู้พื้นฐานเกี่ยวกับการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียค่อนข้างดี ภายหลังการให้ความรู้ผ่านซีดีวีดิทัศน์ระดับความรู้ได้เพิ่มขึ้นทันทีอย่างมีนัยสำคัญทางสถิติ (p = 0.000, 95% confidence interval = 4.0-7.0) กลุ่มตัวอย่างสามารถคงระดับ ความรู้ได้นานถึง 12 สัปดาห์ ระดับความรู้ภายหลังการดูและชมซีดีวีดิทัศน์ไปแล้ว 24 สัปดาห์ลดลงจากภายหลังการดูและชมทันทีอย่างมีนัยสำคัญทางสถิติ (p = 0.020, 95%CI = -2.0 to 0)*

สรุป: *ซีดีวีดิทัศน์เรื่องการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียที่ใช้ในการวิจัยครั้งนี้เป็นเครื่องมือที่สามารถถ่ายทอดความรู้เกี่ยวกับการถ่ายทอดทางพันธุกรรมของโรคธาลัสซีเมียให้แก่ผู้ป่วยและบิดามารดาได้อย่างมีประสิทธิภาพ ระดับความรู้เพิ่มขึ้นอย่างมีนัยสำคัญทางสถิติ ผู้ป่วยและบิดามารดาสามารถเก็บความรู้ได้นานถึง 12 สัปดาห์ หลังจากนี้ควรจะให้ความรู้ซ้ำเป็นระยะ ๆ*