THALASSEMIA IN THE OUTPATIENT DEPARTMENT OF THE YANGON CHILDREN'S HOSPITAL IN MYANMAR : KNOWLEDGE, ATTITUDES AND PRACTICE IN RELATION TO THALASSEMIA

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Abstract. A maternal knowledge, attitudes and practice (KAP) study concerning the nature and prevention of thalassemia was carried out at the Yangon Children's Hospital in Myanmar. The KAP information was collected using a pretested schedule. Only 18 to 28% of the mothers knew at least one of the statements : thalassemia is a genetic disorder; both parents of thalassemic children carry abnormal genes; there is a 25% chance of recurrence in each subsequent pregnancy. Eighty-two per cent of the respondents decided not to have a further pregnancy for fear of recurrence and of these 62% were currently practising contraception. Oral contraception was the most commonly used method (56%). The median scores as well as the percent responses in favor of the three attitude scales relating to limiting thalassemic children, prenatal diagnosis and termination of pregnancy were high. Although there is a need to increase the community awareness of thalassemia in Myanmar, there is a possibility that prenatal diagnosis and pregnancy termination will be accepted for the prevention of thalassemia.

INTRODUCTION

Thalassemia is a chronic genetic disorder which imposes a large burden on both the health services and the patients' families. As it is an incurable disease, its prevention is therefore very important. The effective preventive procedures for thalassemia are carrier detection, family counseling and prenatal diagnosis. Since prenatal diagnosis for thalassemia will probably become available in Myanmar it is essential to find out the knowledge, attitudes and practice (KAP) of the mothers on the nature of disease itself, the prenatal diagnostic procedure and termination of pregnancy. As such we determined the maternal KAP concerning thalassemia as part of the study on thalassemia in the Outpatient Department (OPD) of the Yangon Children's Hospital (YCH) (Khin-Ei-Han *et al,* 1992).

MATERIALS AND METHODS

The KAP information was collected from the mothers of 95 (72%) of 132 patients included in the study. Of the 37 excluded (28%), 5 were siblings with the same mother, in 5 cases the mothers were dead and 27 were not accompanied by their mothers. The study was done at the day care room (DCR) in OPD of YCH during June to November 1990. The details of YCH and its DCR as well as the study population are given elsewhere (Khin-Ei-Han *et al,* 1992).

The pretested KAP schedule was administered by either of two of the authors (KEH, AMH). The attitudinal portion contained 14 statements in Likert format (Oppenheim, 1966) (strongly agree, agree, unsure, disagree, strongly disagree) relating to the respondents' attitudes towards thalassemia. Six statements considered to reflect attitudes towards thalassemic children were : (1) the belief that a mother with a thalassemic child badly misses all the fun and joy of a happy family life("A thalassemic's mother misses fun and joy"); (2) the view that something should be done to prevent having children with thalassemia ("Need to prevent thalassemia"); (3) the notion that if one is to have some more children, one does not mind having some more thalassemic children ("Don't mind

having more thalassemics"); (4) the idea that the thalassemic children are more of a burden than a blessing ("Thalassemics are a burden"); (5) the impression that looking after children with thalassemia demands too much of someone ("Demands too much of me"); (6) the thought that we have no right to prevent having children with thalassemia ("No right to prevent thalassemia").

Four statements were considered to reflect attitudes towards prenatal diagnosis : (1) pertaining to wanting to know if carrying thalassemic child if pregnant ("Want to know if carrying thalassemic baby"); (2) pertaining to the testing for thalassemia during pregnancy if such a test is available ("Will test if test available"); (3) pertaining to not wanting to know if the baby is thalassemic or not ("Don't want to know if baby thalassemic"); (4) pertaining to the usefulness of the tests for thalassemia during pregnancy ("Tests for thalassemia not useful").

Finally, four statements reflecting attitudes towards termination of pregnancy were : (1) the idea that pregnancy termination is killing one's own child knowingly and it ought to be disapproved ("Disapprove pregnancy termination"); (2) the view that a child in you is your own flesh and blood and to prevent it from being born should not be done ("I'll not prevent a thalassemic from being born"); (3) the notion that one will terminate one's pregnancy if one is carrying a thalassemic child ("Will terminate pregnancy if carrying thalassemic child"); (4) the belief that it is better to terminate pregnancy rather than to let the child suffer after he is born ("Better to terminate pregnancy than letting child suffer").

In the analysis, the positive items (items that favor limiting thalassemic children, prenatal diagnosis and termination of pregnancy) were scored as follows : strongly agree = 5, agree = 4, unsure = 3, disagree = 2, strongly disagree = 1. Scoring was reversed (strongly disagree = 5,....., strongly agree = 1) for the negative items.

Questions concerning knowledge about thalassemia (that the disease is a genetic disorder, that both the parents carry abnormal genes and that there is always a 25% chance of bearing a diseased child whenever pregnant) and on the current practice of family planning if one did not intend to have some more children were asked.

RESULTS

Knowledge

Only 18 to 28% of the mothers knew that thalassemia is a genetic disorder, both parents of thalassemic children carry abnormal genes, or thalassemic child's mother has a 25% chance of bearing a diseased child with each pregnancy. Fifty-five per cent did not know all the three statements and only 11% knew all three.

Attitudes

On the scale for attitudes towards limiting thalassemic children the subjects had a median score of 29 (range 18-30, maximum score attainable 30). The scale for attitudes towards prenatal diagnosis had a score range of 8-20, with a median of 20 (maximum 20). Likewise, the termination of pregnancy scale had a median score of 16 (range 4-20, maximum 20).

Scoring of attitudes towards limiting thalassemic children, prenatal diagnosis and termination of pregnancy are shown in Tables 1-3. High scores indicate favorable responses to both the positive and negative statements. Sixty-seven to 99% of time the subjects' responses were in favor of limiting thalassemic children (Table 1). Their responses (81 to 95%) were also supportive of prenatal diagnosis (Table 2). Likewise, despite the fact that they were not so sure about terminating the pregnancy (43%) without reason or preventing a thalassemic child from being born (57%), they nevertheless agreed that they will terminate pregnancy if they were definitely carrying a thalassemic child (70%) and that it is better to terminate pregnancy than to let the child suffer after he is born (73%) (Table 3).

Practice

Most of the respondents (82%) did not intend to have some more children because of fear of recurrence and of these, 62% (48/78) were currently practising contraception. Oral contraception was the most commonly used method (56%) followed by parenteral form (13%), mother sterilization (13%), father sterilation (10%), multiple methods (6%) and intra-uterine contraception device (2%).

Table 1

Scoring of attitudes towards limiting thalassemic children, Yangon Children's Hospital, 1990.

	(%) of subjects scoring						
	1	2	3	4	5	Unknown	Total (n = 95)
(1) A thalassemic's mother misses fun and Joy	6	1	1	14	78	0	100
(2) Need to prevent thalassemia	0	0	0	1	99	0	100
(3) Don't mind having more thalassemics	0	1	0	1	98	0	100
(4) Thalassemics are a burden	6	3	1	5	84	0	100
(5) Demands too much of me	16	2	0	14	67	1	100
(6) No right to prevent thalassemia	6	0	0	6	85	2	100

Table 2

Scoring of attitudes towards prenatal diagnosis, Yangon Children's Hospital, 1990.

	(%) of subjects scoring					
	1	2	3	4	5	Total (n = 95)
(1) Want to know if carrying thalassemic baby	2	1	0	3	94	100
(2) Will test if test available	1	1	0	3	95	100
(3) Don't want to know if baby thalassemic	10	1	3	5	81	100
(4) Test for thalassemia not useful	4	3	1	10	82	100

Table 3

Scoring of attitudes towards termination of pregnancy, Yangon Children's Hospital, 1990.

	(%) of subjects scoring					
	1	2	3	4	5	Total (n = 95)
(1) Disapprove pregnancy termination	47	7	1	1	43	100
(2) I'll not prevent a thalassemic from being born	37	2	2	2	57	100
(3) Will terminate pregnancy if carrying thalassemic children	21	2	3	4	70	100
(4) Better to terminate pregnancy then letting child suffer	18	2	4	3	73	100

DISCUSSION

Unlike the study from Bombay (Sangani *et al,* 1990) where most thalassemia families were well informed about the inherited nature of the disease and the risk of recurrence in future pregnancies, we found that only 18 to 28% of the mothers knew either of the three statements asked concerning thalassemia. With the majority of mothers ignorant about the disease (55%) it is imperative that more should be done to impart knowledge concerning the disease in Myanmar.

Like the study from India (Sangani *et al,* 1990), most of the mothers (82%) did not intend to have further pregnancy and the majority of these were currently on contraception (62%). In this study oral contraception was found to be the most commonly used method (56%) whereas it was female sterilization in Bombay. This may be due to the availability and convenience of the different methods of contraception as well as to the situation concerning family planning programs in each country (no family planning program as yet in Myanmar).

The practice of contraception in the majority to prevent further pregnancy tallied with the high median attitude score (29, maximum 30) towards limiting thalassemic children in most of the mothers. Likewise, most of the mothers were willing to undergo prenatal diagnosis (81-95%) as well as to carry out termination of pregnancy (70-73%). These findings are similar to that of Sangani *et al,* (1990).

Consequently, health education on the knowledge and prevention of thalassemia needs to be implemented on a much larger scale in Myanmar, not only to help the thalassemic families to better understand the disease of their children but also as a prerequisite for the prevention of the disease. From the practice of contraception and from the favorable attitudes in families with thalassemic children, it seems logical to conclude that prenatal diagnosis and termination of pregnancy are likely to be accepted by the people when they are introduced in Myanmar.

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