

## 研 究

思春期の胆道閉鎖症患児の健康にかかわる  
情報の入手と健康行動, 社会的因子との関連田中 千代<sup>1)</sup>, 奈良間美保<sup>2)</sup>

## 〔論文要旨〕

思春期の胆道閉鎖症患児の健康にかかわる情報の入手と健康行動, ソーシャルサポート, 社会的因子との関係を明らかにするために, 外来通院中の小学5年以上20歳未満の患児24名に質問紙調査を行い, 次のことが見出された。1) 情報を得ている程度と求める程度との間に明らかな関係はみられなかった。2) 移植患児の方が移植していない患児よりも病気の情報を得ていたが, 病気の情報を求める程度には明らかな違いはみられなかった。3) 健康一般の情報を得ている患児または求めている患児ほど健康行動を実施していた。4) ソーシャルサポートが高い患児ほど健康一般の情報を求めている。5) 病気の情報を求める患児ほど学外活動に参加していた。

Key words : 健康にかかわる情報の入手, 胆道閉鎖症, 思春期患児

## I. Introduction

In biliary atresia, critical care and long-term survival have become possible due to the development of radical surgery and liver transplantation. As a result, the number of adolescent patients has been increasing year after year. The disease may present in a variety of medical conditions, and the 10-year survival rate after transplantation is considered to be 81.5%<sup>1)</sup>, although long-term prognosis is unknown. Thus, biliary atresia is an intractable disease characterized by an unforeseeable prognosis. Meanwhile, in daily life, although most patients with the disease usually attend school and live a normal school

life<sup>2)</sup>, problems related to social development and social adaptation have been noted in children with liver transplants<sup>3,4)</sup>. In adolescent patients, previous reports have mentioned problems related to insufficient explanation about the disease<sup>5)</sup>, difficulty in making decision about the need for transplantation<sup>6,7)</sup>, and self-cessation of immunosuppressive drugs<sup>6)</sup>. It is important to provide support in terms of acquisition of information for patients in this age group, so that they can become self-reliant in maintaining good health and participate proactively in therapeutic decisions. According to earlier studies<sup>8)</sup>, adolescent patients' desire to acquire information and actual conditions of information acquisition about

Relationship between the Acquisition of Health-related Information, Health Behaviors, and Social Factors in Adolescent Patients with Biliary Atresia

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Tel : 058-239-3250

[2081]

受付 08.10.24

採用 10. 7. 2

healthy lifestyles are comparable to those of healthy children, but the characteristics and the factors involved in the acquisition of health-related information about their disease and its treatment are, as yet, unclear. The relationship between acquisition of information and health behaviors, as well as the relationship between social factors and the adolescent patients' acquisition of information are particularly important when considering the possibilities of nursing support.

The purpose of this study was to clarify the following: (1) the relationship between acquisition of health-related information (referred to below as "acquisition of health-related information") and health behaviors in adolescent patients with biliary atresia (referred to below as "adolescent patients"); (2) the relationships between adolescent patients' acquisition of health-related information, social support, and participation in activities. This study considered the possibility that information content and methods of provision of information in accordance with the needs of adolescent patients can be explored and used as a support to patients and their families.

The term "acquisition of health-related information" refers to the issues involved in adolescents' own health conditions, including the context, extent, and method of acquisition of knowledge and understanding about issues related to general health at the age of adolescence (referred to below as "general health information") and issues related to the disease (referred to below as "disease information"). The term "acquisition of health-related information" includes the extent of information actually acquired (referred to below as "actual conditions of information acquisition") or the desired extent (the "desire to acquire information").

## II. Methods

### 1. Survey patients

Outpatients with biliary atresia attending Department of Pediatric Surgery, including patients in fifth grade or older but less than 20 years old.

### 2. Survey location

The outpatient service of the Departments of Pediatric Surgery in 3 medical care facilities located in the Tokai region.

### 3. Survey content

We administered a questionnaire survey about patients' acquisition of health-related information, health behaviors, social support, and their participation in intramural and extramural activities.

We used an original tool for the measurement of the acquisition of health-related information. Issues related to general health information and disease information comprised 10 items (Table 1). For each item, the actual situation and the patients' desire were assessed in a 4-stage evaluation process, using a 4-point scale that ranged from "well aware" (4 points) to "not aware at all" (1 point) to evaluate the actual situation, and a 4-point scale that ranged from "I strongly want to know" (4 points) to "I do not want to know at all" (1 point) to evaluate the patients' desire. A high score indicated that the actual degree of acquisition of information or the degree of desire to acquire information was high. The Cronbach's  $\alpha$  for the actual access scores and for the desire scores were 0.85 and 0.72, respectively, for general health; the scores were 0.78 and 0.93, respectively, for the disease.

Health behavior was assessed by 9 items (7 items for elementary school students) (Table 2), using a 3-stage evaluation process, and the answers were scored according where

**Table 1** Items for the measurement of patients' acquisition of health-related information

▶General health information	
· Diet	"What is important in terms of food and eating habits for the sake of one's own health"
· Body type	"A good balance of height and weight"
· Constipation	"The effects of constipation on health, and one's own method for preventing constipation"
· Sleep	"The effects of staying up late on health, and how to sleep well at night"
· Change of puberty	"The mental and physical changes of puberty"
▶Disease information	
· Symptoms	"What kinds of symptoms should one be careful about in order to keep good health"
· Surgery	"The reasons why surgery was performed"
· The laboratory results of blood samples	"The normal values of blood tests which are important to you"
· Oral administration	"The reasons for taking medicines"
· Cold prevention	"The reasons why it is important to prevent the common cold"

**Table 2** Items for the measurement of patients' health behavior

· Regular diet
· Prevention of constipation
· Getting enough sleep
· Hand-washing upon arrival at home
· Avoidance of alcohol*
· Avoidance of smoking*
· Observations for jaundice
· Periodic medical consultation
· Use of internal medicines

\*For elementary school students, "Avoidance of alcohol" and "Avoidance of smoking" were excluded.

the participants felt their behavior fell between "I always do so" (3 points), to 1 point for "I do not always do so." For each item, a high score indicated that the particular health behavior was being undertaken.

The measurement of social support (referred to below as "support") was conducted using the scale of Nakamura et al<sup>9)</sup>. This standard scale measures the degree of feeling individually supported by people close to the patient, with subscales consisting of parents, friends, teachers, and physicians or nurses. Scores from 4-stage evaluation process ranged from 4 points (for "Yes, exactly right") to 1 point (for "No, absolutely not"). High scores indicated that the level of support was high. In this survey, the Cronbach's  $\alpha$  was 0.81-0.90 for the subscales, and 0.95 for

the entire scales.

Regarding demographic variables, and participation in intramural and extramural activities, inquiries were made by using alternative choice questions.

#### 4. Survey procedure

We conducted the survey in the outpatient clinics of the Departments of Pediatric Surgery in health care facilities which agreed to participate. The selection of patients for the survey was performed by consulting with the attending physicians and nurses in each facility. When a consent to participate in the research was obtained from the adolescent patients and their mothers, the questionnaire was distributed and then collected by mail within a submission period of up to 1 month.

#### 5. Analysis methods

The Mann-Whitney U test and the Kruskal-Wallis test were used to compare 2 or more groups of sampled data, and the Bonferroni correction was performed for multiple comparisons. The relationships between factors were confirmed by using Spearman's rank correlation coefficient. Statistical analyses were performed using SPSS ver. 13.0J for Windows.

## 6. Ethical considerations

Oral and written explanations about the purposes of the study were provided to the surveyed adolescent patients and their mothers, and data collection was performed only in cases where consent was obtained. The issues of privacy protection, maintenance of anonymity, and of the voluntary nature of participation were specified in the written explanation. The survey was explained to mothers before being explained to the adolescent patients. After the mothers had gained an understanding of the study and of the explanations to be given to the adolescent patients, the survey was explained to the adolescent patients. This study was conducted after approval was obtained from the Ethics Committee of the institutions involved.

## III. Research findings

### 1. Patients' background

A questionnaire was distributed to 29 adolescent patients, and recovered from 24 patients (response rate : 82.8%). The average age was  $14.5 \pm 3.1$  years old, 8 patients were male, 16 patients were female ; 6 patients were primary school students, 7 were junior high school students, and 11 were high school students or above (including 1 university student and 1 working person). There were 13 patients who were adolescent liver transplant patients, and 6 patients with current symptoms showed evidence of deterioration of liver function, portal hypertension, thrombocytopenia, or renal dysfunction. There were 22 subjects who were being prescribed medicines for internal use, 8 exercised caution in everyday life, including the secure use of medicines for internal use and the avoidance of abdominal contusions. The number of days of absence from school was less than 1 week for 14 (60.9%) patients. There were 21 (91.3%) patients who participated in physical education and festivities at school, and one (4.3%)

did not.

### 2. Characteristics of the acquisition of health-related information by adolescent patients

For general health, the actual acquisition score was  $13.1 \pm 3.2$ , the desire score was  $14.4 \pm 3.1$ , and for the disease, the actual acquisition score was  $15.0 \pm 2.5$  and the desire score was  $14.0 \pm 4.1$ . By comparison of background factors, a significant difference in terms of experience of transplantation was found only in the actual acquisition scores for the disease. For liver transplant in adolescent patients, the actual acquisition scores for the disease were significantly higher ( $p < 0.05$ ) (Table 3).

While there were positive correlations between the actual acquisition scores for general health and disease information and between the desire scores for general health and disease information, there was no significant correlation between the actual acquisition scores and the desire scores for either general health or the disease (Table 4).

### 3. Relationship between the acquisition of health-related information, health behaviors, social support, and participation in activities

Regarding regular diet and prevention of constipation, patients who always practiced these behaviors had significantly higher scores for desire to acquire general health information, in comparison with patients who did not or sometimes do so ( $p < 0.01$ ). Patients who always observe for jaundice had significantly higher scores for desire to general health information, in comparison with patients who did not or sometimes observe for jaundice ( $p < 0.05$ ) (Table 5).

In the relationship with social support, a moderately positive correlation was found between the desire scores for general health information and total support ( $\rho = 0.44$ ,  $p < 0.05$ ) (Table 6).

Table 3 Mean and S. D. of the scores for health-related information

		General health information (score range : 5-20)	Disease information (score range : 5-20)
Actual acquisition scores	▶ Total (n = 24)	13.1 ± 3.2	14.4 ± 3.1
	▶ Background		
	Grade level <sup>a</sup>		
	elementary school (n = 6)	13.2 ± 3.4	13.2 ± 1.9
	junior high school (n = 7)	13.1 ± 3.5	13.7 ± 4.0
	high school (n = 11)	13.0 ± 3.2	15.7 ± 2.7
	Gender <sup>b</sup>		
	male (n = 8)	13.5 ± 3.0	14.8 ± 4.0
	female (n = 16)	12.9 ± 3.4	14.3 ± 2.6
	Transplantation <sup>b</sup>		
received (n = 13)	12.9 ± 2.9	15.8 ± 2.0	
not (n = 11)	13.3 ± 3.6	12.7 ± 3.4	
Precautions in daily life <sup>b</sup>			
required (n = 8)	14.3 ± 3.3	14.6 ± 4.0	
not (n = 15)	12.7 ± 3.0	14.4 ± 2.7	
Desire scores	▶ Total (n = 24)	15.0 ± 2.5	14.0 ± 4.1
	▶ Background		
	Grade level <sup>a</sup>		
	elementary school (n = 6)	13.2 ± 3.4	13.7 ± 5.6
	junior high school (n = 7)	13.1 ± 3.5	14.0 ± 3.2
	high school (n = 11)	13.0 ± 3.2	14.3 ± 4.1
	Gender <sup>b</sup>		
	male (n = 8)	14.9 ± 1.5	15.3 ± 2.9
	female (n = 16)	15.1 ± 2.9	13.4 ± 4.8
	Transplantation <sup>b</sup>		
received (n = 13)	15.6 ± 2.7	14.8 ± 4.1	
not (n = 11)	14.4 ± 2.3	13.1 ± 4.1	
Precautions in daily life <sup>b</sup>			
required (n = 8)	15.8 ± 3.3	14.4 ± 5.4	
not (n = 15)	14.7 ± 2.0	14.1 ± 3.4	

<sup>a</sup> In the three-independent-samples, the Kruskal Wallis test were used.

<sup>b</sup> In the two-independent-samples, the Mann-Whitney U test were used.

Significant at \*p < .05

Table 4 Bivariate correlations of four factors of information acquisition

		Actual acquisition		Desire	
		General health information	Disease information	General health information	Disease information
Actual acquisition	General health information		0.46*	0.38	0.11
	Disease information			0.25	0.26
Desire	General health information				0.64**
	Disease information				

Spearman's correlation coefficients

Significant at \*p < .05 : \*\*p < .01

Patients who participated in extramural activities had significantly higher scores for desire to acquire disease information, in comparison with patients who did not participate

in extramural activities (Table 7).

Table 5 Mean and S. D. of the scores for health-related information by health behaviors

	Regular diet		Prevention of constipation		Getting enough sleep		Hand-washing upon arrival at home		Avoidance of alcohol	
	Always	Sometimes /Not	Always	Sometimes /Not	Always	Sometimes /Not	Always	Sometimes /Not	Always	Sometimes /Not
Actual acquisition										
General health information	(n = 18) 13.6±3.4	(n = 6) 11.5±1.8	(n = 12) 14.5±3.6	(n = 12) 11.7±1.9	(n = 5) 14.2±4.3	(n = 19) 12.8±2.9	(n = 14) 14.2±3.5	(n = 10) 11.5±2.0	(n = 14) 13.4±3.6	(n = 3) 11.3±0.6
Disease information	(n = 17) 14.3±3.1	(n = 6) 14.8±3.3	(n = 11) 15.2±2.8	(n = 12) 13.8±3.3	(n = 5) 15.0±3.3	(n = 18) 14.3±3.1	(n = 14) 14.9±3.1	(n = 9) 13.8±3.0	(n = 13) 15.5±3.2	(n = 3) 12.3±4.0
Desire										
General health information	(n = 17) 15.9±2.3	(n = 6) 12.7±1.4	(n = 11) 16.6±2.5	(n = 12) 13.7±1.6	(n = 4) 15.8±1.5	(n = 18) 14.9±2.7	(n = 13) 15.8±2.5	(n = 10) 14.1±2.3	(n = 14) 15.2±2.2	(n = 3) 13.3±1.2
Disease information	(n = 17) 14.4±4.6	(n = 6) 13.2±2.2	(n = 11) 14.2±5.4	(n = 12) 13.9±2.6	(n = 5) 13.2±5.4	(n = 18) 14.3±3.8	(n = 14) 13.6±4.9	(n = 9) 14.7±2.6	(n = 13) 14.5±3.9	(n = 3) 12.7±3.5
	Avoidance of smoking		Observations for jaundice		The use of internal medicines		Periodic medical consultation			
	Always	Sometimes /Not	Always	Sometimes /Not	Always	Sometimes /Not	Always	Sometimes /Not		
Actual acquisition										
General health information	(n = 15) 13.2±3.5	(n = 2) 11.5±0.7	(n = 4) 16.0±3.2	(n = 20) 12.5±2.9	(n = 13) 13.7±3.4	(n = 9) 12.2±3.1	(n = 24) 13.1±3.2	(n = 0)		
Disease information	(n = 14) 15.5±3.2	(n = 2) 10.5±3.5	(n = 4) 17.3±2.8	(n = 19) 13.8±2.9	(n = 13) 14.9±2.6	(n = 9) 13.7±3.8	(n = 23) 14.4±3.1	(n = 0)		
Desire										
General health information	(n = 15) 15.1±2.2	(n = 2) 13.0±1.4	(n = 4) 15.3±2.1	(n = 19) 15.0±2.6	(n = 12) 15.8±2.6	(n = 9) 13.8±2.2	(n = 22) 15.0±2.5	(n = 0)		
Disease information	(n = 14) 14.6±3.7	(n = 2) 11.0±2.8	(n = 4) 13.5±6.0	(n = 19) 14.2±3.8	(n = 13) 14.1±4.9	(n = 9) 13.8±3.2	(n = 23) 14.0±4.1	(n = 0)		

Mann-Whitney U test  
Significant at \*p < .05 : \*\*p < .01

Table 6 Bivariate correlations between information acquisition and social support

	Social Support				
	Total	Parents	Friends	Teachers	Physicians or Nurses
Actual acquisition					
General health information	0.21	0.09	0.31	-0.02	0.18
Disease information	-0.10	-0.14	-0.03	-0.10	-0.12
Desire					
General health information	0.44*	0.30	0.29	0.26	0.14
Disease information	0.12	0.22	-0.08	0.08	-0.02

Spearman's correlation coefficients  
Significant at \*p < .05

Table 7 Mean and S. D. of the scores for health-related information by participation in activities

	School activities		Extramural activities	
	Participating (n = 20)	Not (n = 3)	Participating (n = 17)	Not (n = 6)
Actual acquisition				
General health information	13.1±3.3	14.0±2.6	13.4±3.4	12.5±2.8
Disease information	14.5±3.3	15.0±1.4	14.4±3.2	14.7±3.3
Desire				
General health information	15.1±2.6	16.0±1.0	15.8±2.3	13.5±2.3
Disease information	14.6±3.8	9.5±6.4	15.0±4.1	11.7±3.7

Mann-Whitney U test  
Significant at \*p < .05

#### IV. Discussion

##### 1. Characteristics of the acquisition of health-related information

Unlike in healthy children<sup>10)</sup>, no gender differences were found among adolescent patients for acquisition of information. However, adolescent liver transplant patients had acquired a lot more disease information than patients without transplant experience. Of the 13 adolescent liver transplant patients being studied, 10 had undergone transplantation in late childhood. These adolescent patients are thought to have experienced the acquisition of information by gaining a further understanding through a gradual accumulation of information about past treatments acquired at the time decisions were made about transplantation, present conditions, and immunosuppressive therapy after transplantation. Another reason for differences in acquisition of disease information is thought to be that it was difficult for adolescent patients without transplant experience to become aware of major changes in their medical condition because they had not had opportunities to gradually receive such information. Even if they received explanations when they had medical examinations, it was difficult for them to feel they had obtained information. Meanwhile, no clear differences in actual access to general health information were found in relation to the

transplant experience. In addition, no clear differences in the desire to acquire general health information or disease information were found in relation to the transplant experience. Furthermore, the purpose of providing information before and after transplantation was to obtain informed consent for the treatment, which did not appear to lead to an increase in adolescent patients' interest in healthy lifestyles and health behaviors.

##### 2. Relationship between the acquisition of health-related information and health behaviors

The actual conditions of general health information acquisition were associated with observation for jaundice. The desire to acquire general health information was associated with regular diet and prevention of constipation. The provision of information about general health and the increase of interest in information are thought to promote behaviors such as good eating, prevention of constipation, and observation of symptoms. On the other hand, friends and family members have a strong influence in terms of avoidance of alcohol and avoidance of smoking<sup>11)</sup>. Because oral medicine behavior is routine and its efficacy difficult to realize, its relationship with adolescent patients' access to information is thought to be weak. Thus, support for a healthy life within the family and support for the adolescent patients' acquisition of life skills are important

for promoting these health behaviors.

Meanwhile, neither the actual conditions of disease information acquisition nor the desire to acquire disease information showed any relationship with health behaviors. In previous studies, adolescent patients with diabetes have been reported to show a therapeutic behavior appropriate to that of people who are aware of the importance of therapeutic behaviors<sup>12)</sup>, and therefore, it was expected that the higher the concern for disease information or for people who have obtained disease information, the better the implementation of health behaviors would be. However, because in the case of hepatic disorders standard therapeutic behaviors are unclear and because the symptoms are vague, they are thought to be difficult to associate with information on disease and treatment or with everyday life behaviors. It is important that feedback be provided. That is, laboratory test results should be placed in context with symptoms and feelings based on the adolescent patients' perception of their physical condition in everyday life and with their health behaviors at the time of changes in their physical condition.

### 3. Relationships between the acquisition of health-related information and social factors

Total scores for social support were positively associated with the desire to acquire general health information, which coincides with results from surveys of healthy children<sup>10)</sup>. Like healthy children, adolescent patients are thought to be motivated to acquire information because of an increase in their interest in having a healthy life, by way of their relationship with other people that they consider important. Furthermore, because patients who participated in extramural activities sought disease information more than patients who did not, it seems that the increase in adolescent patients' need for information about their own disease occurred through

participation in activities that they themselves wanted to do. At the same time, they are thought to have as much interest in social participation as patients who had acquired a realistic understanding of their own health conditions, including their symptoms. It was also suggested that acquisition of health-related information had an influence on social adjustment. Previous reports on children with liver transplants have mentioned the effects of the restriction of their activities with their friends<sup>4)</sup>, the effects of changes in physical appearance on social adaptation<sup>4)</sup>, the excessive consideration by people close to the patient, such as at school<sup>3)</sup>, and the importance of normalcy<sup>13)</sup>. Therefore, it is necessary that adolescent patients' will and desires should be respected, that they be not made an exception, and that support be provided to them, their family members, and their schools in order to allow them to engage in activities that they want to do with their friends.

On the other hand, the desire to acquire disease information was not clearly associated with social support. The reason for this was that the increase in information needs about the disease is thought to be due to an intrinsic motivation rather than to other people's influence. More specifically, even if anxiety is felt during exchanges with the people close to the patient, some factors might cause hesitation to acquire information. Adolescent patients with biliary atresia are said to be exposed to sudden changes, anxiety about an irreversible deterioration, fear of death, and uncertainty about the future<sup>14)</sup>. Because of such anxieties and fears, adolescent patients might want to avoid disease information as much as possible. In addition, there was no clear relationship between actual acquisition to information and social support, and it was shown that the sense of support did not increase at the time of acquisition of health-related information. For adolescent patients, the sources of infor-

mation are mainly adults such as the patients' mother, physician, or teacher<sup>8)</sup>. Particularly with regard to disease, patients' mothers are assumed to be their primary source of information. Meanwhile, it has also been assumed that children with liver transplants recognize that their disease makes their mothers feel sad<sup>13)</sup>. It is conceivable that such patients cannot express their own anxieties and fears, because they do not want to sadden their parents or because they cannot complain to their parents. In terms of relationships with the medical staff, it has also been reported that adolescent patients with biliary atresia rarely take the initiative to speak about their own doubts<sup>5)</sup> or to ask for explanations<sup>15)</sup>. In our study, no clear relationship was found between the actual conditions of information acquisition and the desire to acquire information, and because the adolescent patients' access to information was not due to their own desire but rather done passively, there were few opportunities for adolescent patients to express doubts or negative feelings that occurred upon access to information. This might be related to a low level of support. It is necessary to provide support based on a relationship of mutual trust with adolescent patients, which reassures them and allows them to express their thoughts and anxieties about their disease and their lives and which allows them to think about having a healthy life and about the future. Moreover, although awareness about their own disease can easily be accompanied by negative feelings, such as anxiety and fear, it is important to convey that in order for the adolescent patients to be able to seek information or engage in health behaviors, the medical staff and people close to the patient will carefully keep them close to their hearts, based on the feelings that the adolescent patients themselves carefully keep close to their hearts.

In addition, due to the characteristics of the

disease, the number of adolescent patients surveyed was small, and the group of patients who had undergone transplantation was limited to those who had good clinical outcomes. Therefore, the results may not be generalizable to other populations.

## V. Conclusions

The results of this study revealed the following points regarding the acquisition of health-related information by adolescent patients with biliary atresia, and the association between acquisition of information, health behaviors, and social factors :

- 1) There was no obvious relationship between the extent of acquisition of information and the extent of information-seeking.
- 2) Adolescent transplant patients acquired more disease information than adolescent patients who had not undergone transplantation, but no clear differences were found in the extent of the search for disease information.
- 3) Adolescent patients with biliary atresia adopted health behaviors as much as people who actually acquired or who desired to acquire general health information.
- 4) Adolescent patients with biliary atresia sought general health information as much as patients with high social support did.
- 5) Adolescent patients with biliary atresia who sought disease information participated in extramural activities.

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### [Summary]

The purpose of this study was to clarify the following: (1) the relationship between acquisition of health-related information and health behaviors in adolescent patients with biliary atresia, (2) the relationships between adolescent patients' acquisition of health-related information, social support, and participation in activities. A total of 24 adolescents from the fifth grade of elementary school and below the age of twenty completed a self-report questionnaire. The main results were as follows. 1) There was no obvious relationship between the extent of acquisition of information and the extent of information-seeking. 2) Adolescent transplant patients acquired more disease information than adolescent patients who had not undergone transplantation, but no clear differences were found in the extent of the search for disease information. 3) Adolescent patients with biliary atresia adopted health behaviors as much as people who actually acquired or who desired to acquire general information. 4) Adolescent patients with biliary atresia sought general health information as much as patients with high social support did. 5) Adolescent patients with biliary atresia who sought disease information participated in extramural activities.

### [Key words]

health-related information, biliary atresia, adolescent patient (s)