

Psychological Vulnerability and Resilience in Children and Adolescents with Thalassaemia Major

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Abstract

Objectives: Chronic childhood illness may be a risk factor for psychosocial or psychiatric disturbances. Yet, children with chronic illnesses may also show resilience and active coping with varying degrees of success or failure. The present study aims to outline the patterns of coping and adjustment of patients with thalassaemia major, and identify specific developmental issues associated with living with the chronic illness. **Method:** Seventy-three patients receiving treatments at Queen Mary Hospital were assessed with a set of semi-structured interview and questionnaires instruments covering the children's perceptions of their quality of life, illness and treatment. Their psychological adjustment was assessed through measures on life satisfaction, the extent and nature to which they felt they had been adversely affected by the illness and treatment, and their views of the future and of themselves. **Results:** The patients had multiple concerns and dissatisfactions with their illness, treatments, and health status, but many of their concerns were also commonly noted in normal healthy children. Resilience is demonstrated in a proportion of patients. There were clear developmental trends showing that patients had changing concerns over different stages of their development. Older patients had more adverse impact as chronicity and mental exhaustion in coping with the illness seemed to be an important factor affecting adjustment. **Conclusions:** The results indicate the need for psychosocial interventions, especially for the older patients with thalassaemia major.

Key words

Adjustment; Coping; Developmental patterns; Resilience; Thalassaemia major

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Introduction

Children living an extended life with a chronic physical illness have to face up a lifetime of medical treatments and daily reminders of vulnerability and dependency.¹ A child's reactions to the treatment demands often vary depending on his/her stage of cognitive, emotional and social maturity. Diminished quality of life, uncertainties over the entire lifespan, and disruptions to the family system associated with chronic illnesses are legitimate areas of professional concern.²

Thalassaemia major or Cooley's anaemia is an inherited disorder characterised by absent or decreased production of one of the normal globin chains of haemoglobin in the red blood cells. Three point four and five percent of the Hong Kong population are carriers of beta-thalassaemias

and alpha-thalassaemias respectively.³ It is estimated that 400 patients suffer from thalassaemia major in Hong Kong.

Developmental Implications of Having Thalassaemia

An infant with thalassaemia major appears normal at birth. Signs of the disease develop a few months afterwards and become progressively severe. Pallor, irritability, poor appetite, and failure to thrive are generally noted at the end of the first year. Subnormal growth rates for height, weight, and skeletal maturation are common especially in adolescence. Disorders of puberty are common in both males and females but normal pubertal development is possible in optimally treated children.⁴

With improved treatment and extended life expectancy, the stresses and hardships involved in surviving thalassaemia are increasingly recognised. Adolescent and adult patients face difficulties which early sufferers of the illness did not have as the latter may have perished with previous less advanced medical interventions. Difficulties involving education and career development, heterosexual relationships, and forming one's own family have to be dealt with. Hilgartner et al⁵ studied 72 thalassaemia subjects and their families and reported that these adolescent and young adults expressed great concerns over their uncertain prognosis, the genetic transmission, fertility, and body image. Low self-esteem and fear of dependency were also common.⁵

The tasks of health care providers are different from that of two or three decades ago. A multifactorial developmental framework is advocated⁶⁻⁸ as the impact of chronic illness on children and their families are not uniform and not necessarily adverse, and a complex array of factors are often involved in determining the final outcomes. Children are developing and have different needs and capacities depending on the stage of their development. The level of cognitive and emotional development, comprehension of illness and medical procedures, stress and coping capacities, parent-child relationships, family homeostasis, and the meanings attached to the illness may all have an impact on the ultimate adjustment of the child patient concerned.^{9,10}

Developmental Issues

The nature and extent of psychological and emotional difficulties precipitated by the illness often varies depending on the age and developmental level of the afflicted child.¹¹ During infancy and pre-school years, the child patient may not be able to understand the seriousness of the illness, or to anticipate the long-term implications of the illness and treatment. Treatment issues are often handled by the parents.

A common difficulty at this stage involves ensuring the child's compliance and increasing his/her tolerance to the distressing procedures. Confrontations between parent and child over day to day care-taking tasks are common. In thalassaemia patients, the cumbersome daily subcutaneous chelation may pose a particular problem. During early and middle school years, academic performance and peer influence become prominent. Hospitalisations disrupt school attendance and lead to poor academic achievement, social estrangement, and strained peer relationships. During school age, given comparisons with peers, sick children may be forced to acknowledge differences between themselves and others, sometimes with deleterious consequences on their self-esteem and personality development. As poorly controlled thalassaemia often distorts facial appearance and brings about stunted growth, it is not uncommon for these children to be singled out. The adolescent patient gradually takes on more responsibility for his/her self-care so that parents need only provide occasional surveillance and reminders. Adolescents and young adults have to slowly yet painfully come to terms with real and imagined restrictions in work or social opportunities, reduced fertility and a limited life-expectancy. Further frustrations await the maturing adult as he/she has to face squarely with thwarted aspirations and demands, against a background of compromised physical ability and limited life opportunities.

Family Influences

The influence of the family may be critical across all stages of the illness. A major illness in a child precipitates a crisis in the family.⁶ The chronic illness may disrupt the entire fabric of a family,¹² as pre-existing hopes and aspirations have to be relinquished, in place of which are uncertainties, painful anticipations of restrictions and reduced potential for the child, as well as adaptations to multiple changes in routine and habits.¹³ Given the often unpredictable and fluctuating course of thalassaemia, family members may be driven into a state of constant apprehension. Some families harbor a pronounced though covert expectation that things may get worse as time goes by. It has also been reported that some families may become socially isolated as a result of the child's illness.¹⁴⁻¹⁶

Yet, a chronic illness may strengthen family unity and adaptation. Pless and Satterwhite¹⁷ noted that parents of chronically ill children felt that the illness served as a unifying force in the family so much so that sensitivity of family members to each other was enhanced. Markova et al¹⁸ noted in their study of parents of haemophilic

children that half of the parents felt that the illness had promoted the family's solidarity. It appears that the family's capacity to perceive meaning in the chronic illness experience may be an important mediator of the child's mental and physical health.

Aims of the Study

While a developmental understanding of the differing needs of the chronically ill child has been documented to a certain extent, there is a dearth of systematic information available on the developmental needs of patients with thalassaemia from their childhood to young adulthood years. The present study aimed to map out patterns of coping and adjustment to thalassaemia, and identify specific developmental issues faced by these patients. The results obtained may be clinically useful in informing and improving service provisions in the long-term care of the patients. The aims of the study were:

1. To identify the developmental changes in needs, perceptions, and challenges faced by patients with thalassaemia;
2. To identify the nature of the coping processes engaged by patients with thalassaemia at different stages of their development.

Patients and Method

Our study was designed to look into the developmental issues confronted by the entire population of thalassaemia patients who were being followed-up at Queen Mary Hospital, a university teaching hospital in the southern part of Hong Kong. The hospital is by far the most established general hospital on Hong Kong Island, and treats the majority of patients with thalassaemia who resides in Hong Kong. A comprehensive assessment of the patients' psychosocial and family functioning was included.

Subjects

Patients with thalassaemia major receiving treatment at Queen Mary Hospital were included. The subjects were managed by the Department of Paediatrics and Adolescent Medicine and the Department of Medicine. A total of 73 subjects were included. Consent was obtained from both the parents and the subjects themselves, who were briefed on the aims of the study, and were provided with time and opportunity to ask questions about the study. No subject or

parent refused to participate. The study was approved by the Ethics Committee of the Faculty of Medicine, the University of Hong Kong. All subjects were assessed on a standard set of semi-structured interview and questionnaire instruments. The subjects were assessed when they were admitted to the hospital for monthly blood transfusions.

Measures

Instead of adopting a simple questionnaire measure approach, the authors adopted an in-depth interview approach so that relevant issues could be adequately covered and collection of quality data better assured through establishing a trusting rapport with all the subjects. A semi-structured interview schedule as well as a set of standard questionnaires were used in the study and administered through a clinical assessment interview. Both patients and their parents were interviewed but assessed separately. The present paper involves only the use of the semi-structured interview schedule on the patients. The assessment schedule may be obtained from the first author.

The semi-structured interview schedule was designed to obtain both qualitative and quantitative data, and assess a number of areas pertinent to the subjects' perceived quality of life and psychological adjustment. Assessments covered the subjects' current concerns, views of their illness and treatment, self-perceptions and their wishes for the future.

The interview format included the use of a consistent number of open ended prompts. An initial free response was allowed on most questions, and subjects were encouraged to express their ideas and thoughts freely in relation to the specific areas assessed. Standard probes into specific areas were administered subsequently, and subjects were asked to rate their responses on a 3-point scale indicating "mild" through "moderate" to "very much so". When appropriate, a 4-point scale was used with "not at all/not applicable" added as a possible response.

Each subject was also administered two selected verbal subtests of an intelligence test commonly used locally (the Wechsler scales) to obtain a prorated verbal IQ as a quick indicator of their intelligence. The assessment with each subject took about an hour.

Data Analyses

To arrive at an understanding of the developmental patterns in the subjects' adjustment, the subjects were divided into four groups. These are: the preschool group (aged under 6 years and not yet admitted in primary school); the primary school group (aged between 6 and 12 years

and attending primary school); the secondary school group (aged between 12 to 18 years and receiving secondary school education); and the young adult group (over 18 years old and working). As the preschool group was unable to respond meaningfully to the interview schedule, their parents were interviewed separately. For the purpose of this paper, only the results obtained by the last three groups of patients and only descriptive, qualitative data were analysed and reported here.

On questions where subjects were asked to make ratings (e.g. their levels of concern about and the degree to which they feel stressed by the illness stresses; their level of toleration of treatment etc.), the averages of those rated as 2 or above were reported and discussed. The socioeconomic status of the family was classified according to the method devised by Lee et al¹⁹ in their study on the development of a language screening scale for Hong Kong Chinese children. This was done by summing the separate scores assigned to mother's education and father's occupation.

Results

I. Subject Characteristics

The subject sample consists of 42 females and 31 males. The mean age of the subjects was 15.42 years (SD: 7.4 years, range: 30 months to 35 years old). Nine subjects were aged below 6 and attending kindergarten, 14 were in primary school and 23 were in secondary schools. Two subjects had completed secondary school and were

receiving vocational training. Twenty-five young adult subjects were included who were either working or seeking employment. The average number of years of school attendance was 8.42. One subject was married. Most of the working subjects were engaged in clerical jobs. The average monthly income is \$5,300 with a standard deviation of \$3,671. The mean age of diagnosis of the illness was 6.18 months (SD: 4.23). The average prorated verbal IQ was 92.32 (SD: 17.44), which is not very different from the IQ scores obtained among children and young adult with thalassaemias in studies done elsewhere.^{20,21}

II. Developmental Patterns

A. Concerns

The patterns of self-volunteered and prompted concerns were analysed. Subjects in the primary school group volunteered more worries relating to issues of immediate concerns, such as school work, health and treatment. Subjects in the secondary school group had more concerns about health and school, while those in the young adult group expressed more concerns related to the future, health and family-related affairs. Consistently, both self-volunteered and prompted concerns were most frequently related to the illness condition (Figure 1).

The patients also indicated being most concerned with physical deterioration and such treatment procedures as blood transfusion and chelation. In particular, the young adult subjects expressed more concerns over treatment, their physical vulnerability, and possibility of their impending mortality (Figure 2).

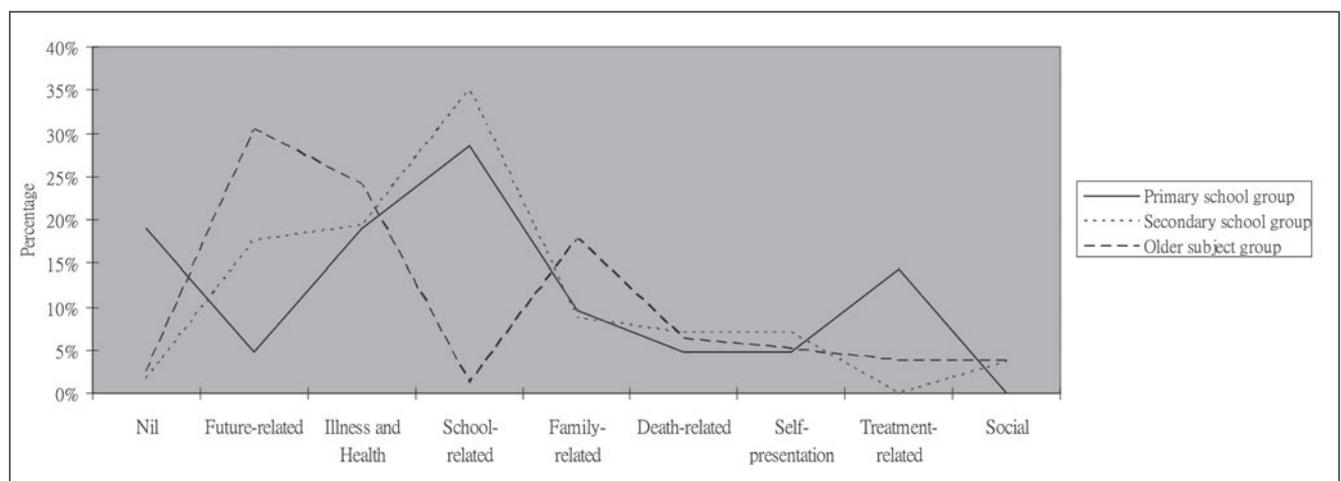


Figure 1 Self-volunteered current concerns.

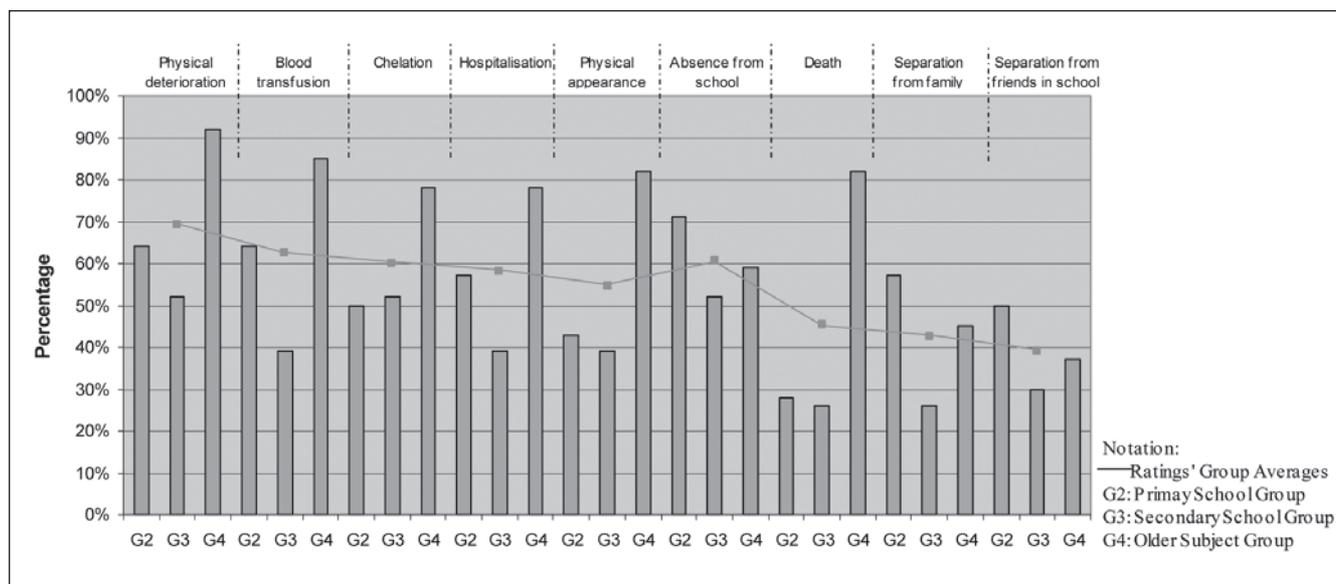


Figure 2 Prompted current concerns.

B. Illness Related Stresses

Subjects' self-volunteered illness stresses include treatment covering chelation, hospitalisation and complications as well as concerns over own health and the health of significant others (Figure 3). When prompted, the subjects reported being most stressed by pain, boredom and general fatigue (Figure 4). When asked to rate their toleration of such treatment procedures as chelation, venipuncture, hospitalisation, and blood transfusion, the results indicated that regardless of age groups, chelation was regarded as most intolerable. Similar findings have been reported in a study involving patients in the United Kingdom and Cyprus and nearly 50% of the patients reported that they disliked chelation.²² Toleration of various aspects of the treatment also deteriorated with age (Figure 5). The younger subjects regarded chelation as bothersome primarily because of its accompanying discomfort. The older subjects, however, rejected chelation mostly because of its effects on limiting their life activities.

Most subjects indicated that their academic and work performance had been adversely affected by thalassaemia. In addition, their leisure activities, mobility, self-care, and relationships with others were also reported to be hindered. Disrupted school performance, difficulty in seeking a job in the future, being a burden to the family, and inability to enjoy good physical health and good personal development in the future were also common issues mentioned. A clear

developmental trend was noted in that the older the subjects, the more handicaps and hindrances were reported (Figures 6 & 7).

C. Positive Aspects of the Illness

Not all subjects were totally negative about their illness. The majority of the subjects somehow managed to report some positive aspects about their illness. The younger subjects valued having more secondary gains (e.g. of being loved and attended to, being more easily allowed to have their way at home, being treated more nicely etc.) and having increased chances for knowing friends who were co-patients. Interestingly, the older subjects valued having better medical knowledge as a result of the illness and also learning to see things in a wider perspective and being more appreciative of others' points of view (Figure 8).

D. Self-perceptions and Views Towards the Future

An average of 10% and 12% of the subjects could not think of any personal strengths and weaknesses respectively. Most of those who could do so consider their strengths as being their social skills, their personality characteristics (e.g. being more caring) and their achievement (e.g. having good school results, being good at a particular skill like drawing, sports, etc.), while their weaknesses relate to their emotional characteristics (e.g. not cheerful, moody), personality (e.g. being passive and introverted, diffident,

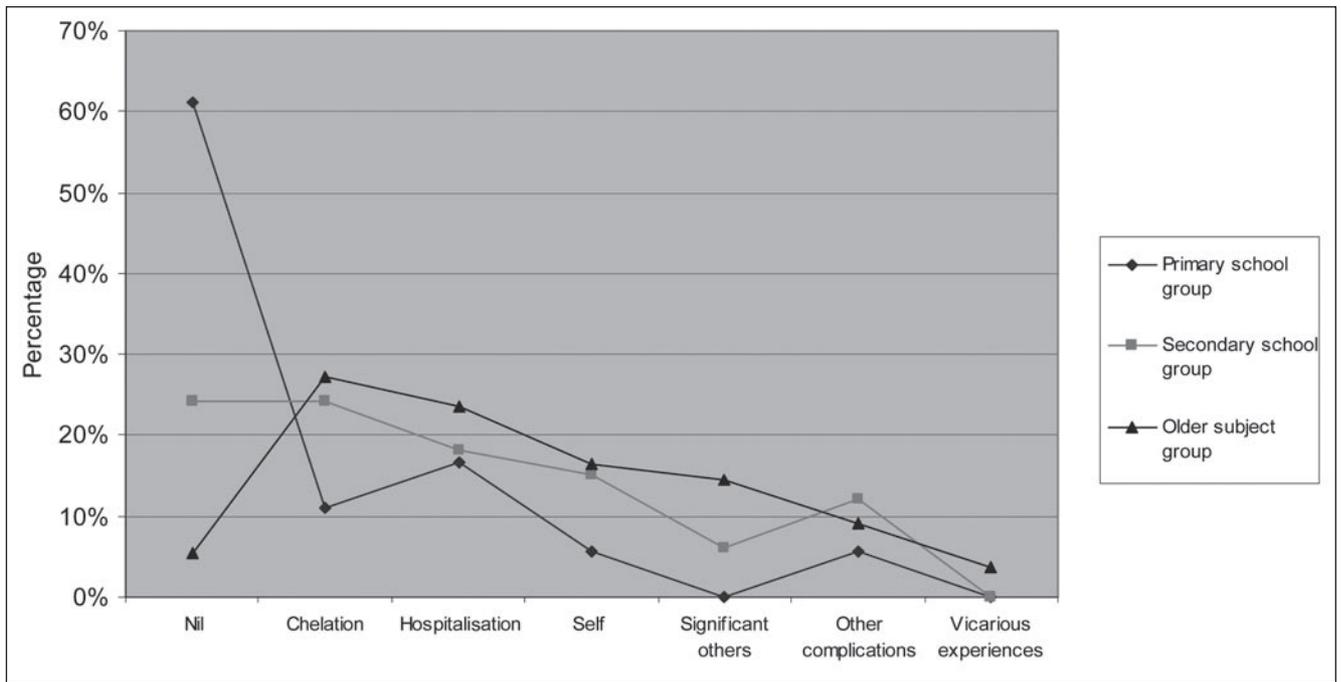


Figure 3 Self-volunteered illness stress.

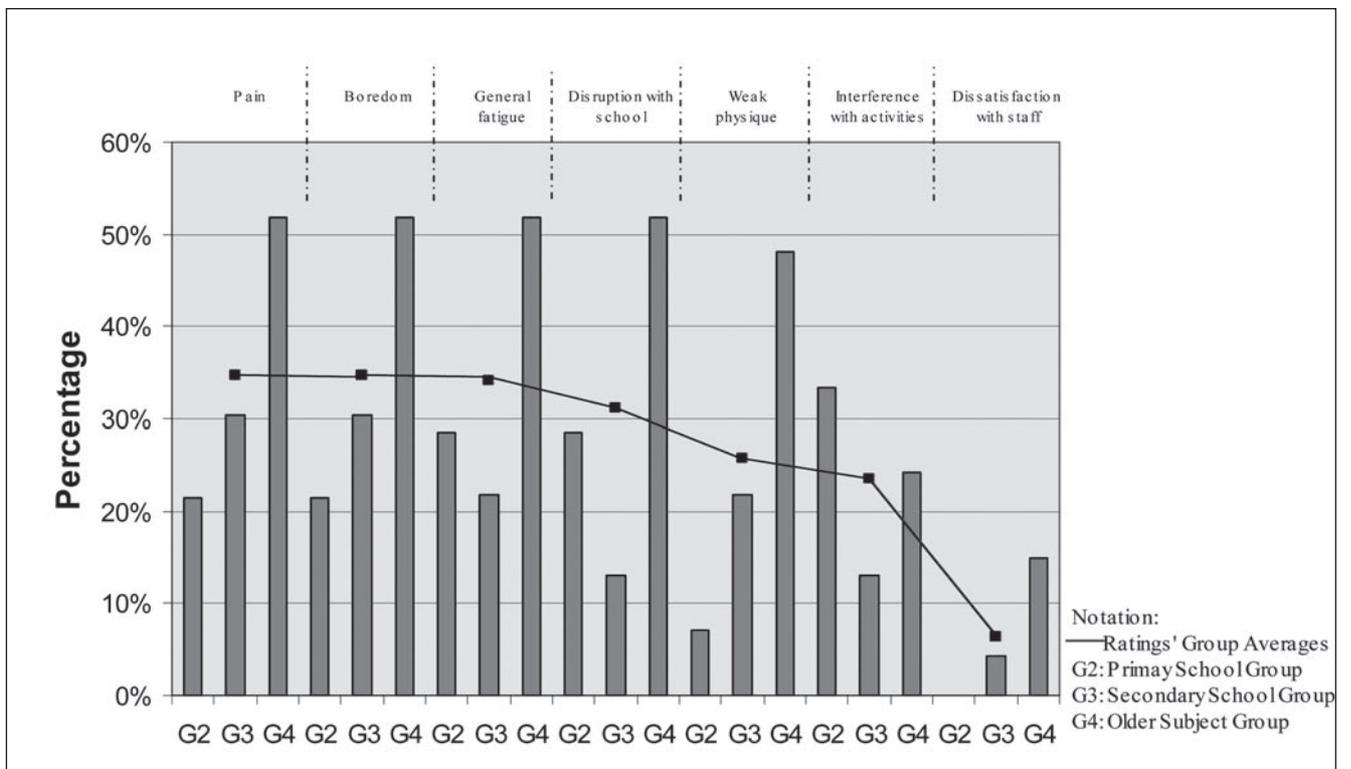


Figure 4 Prompted illness stress.

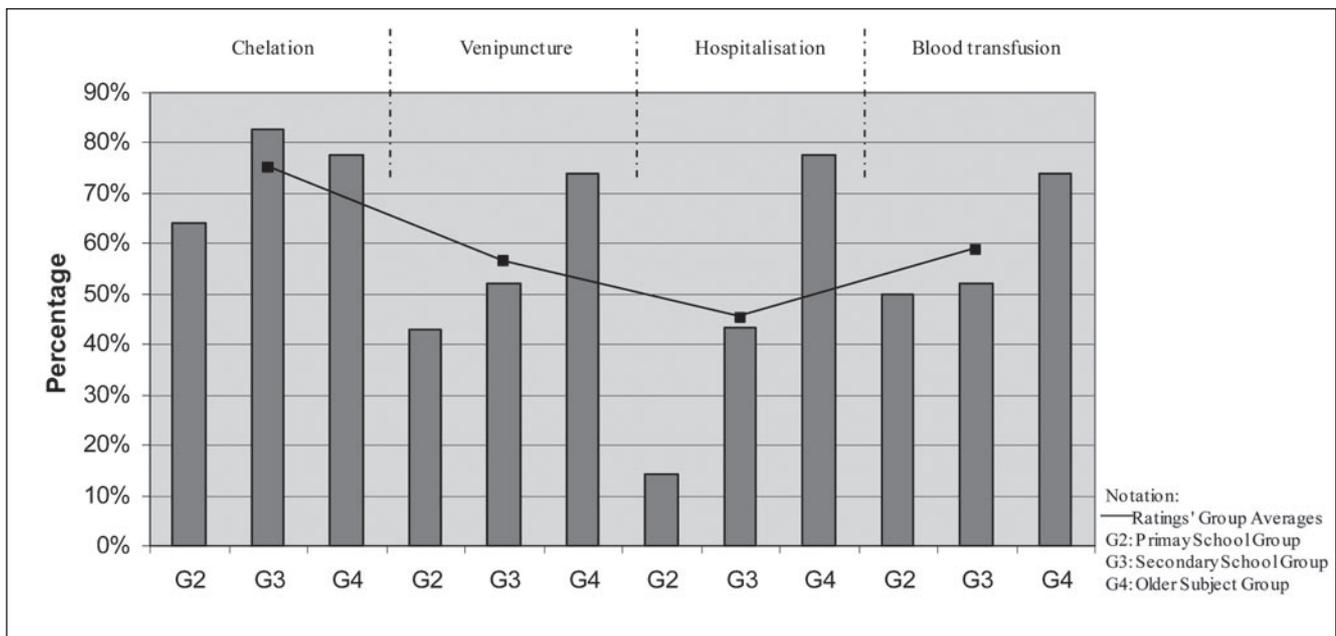


Figure 5 Degree of toleration of different aspects of treatment.

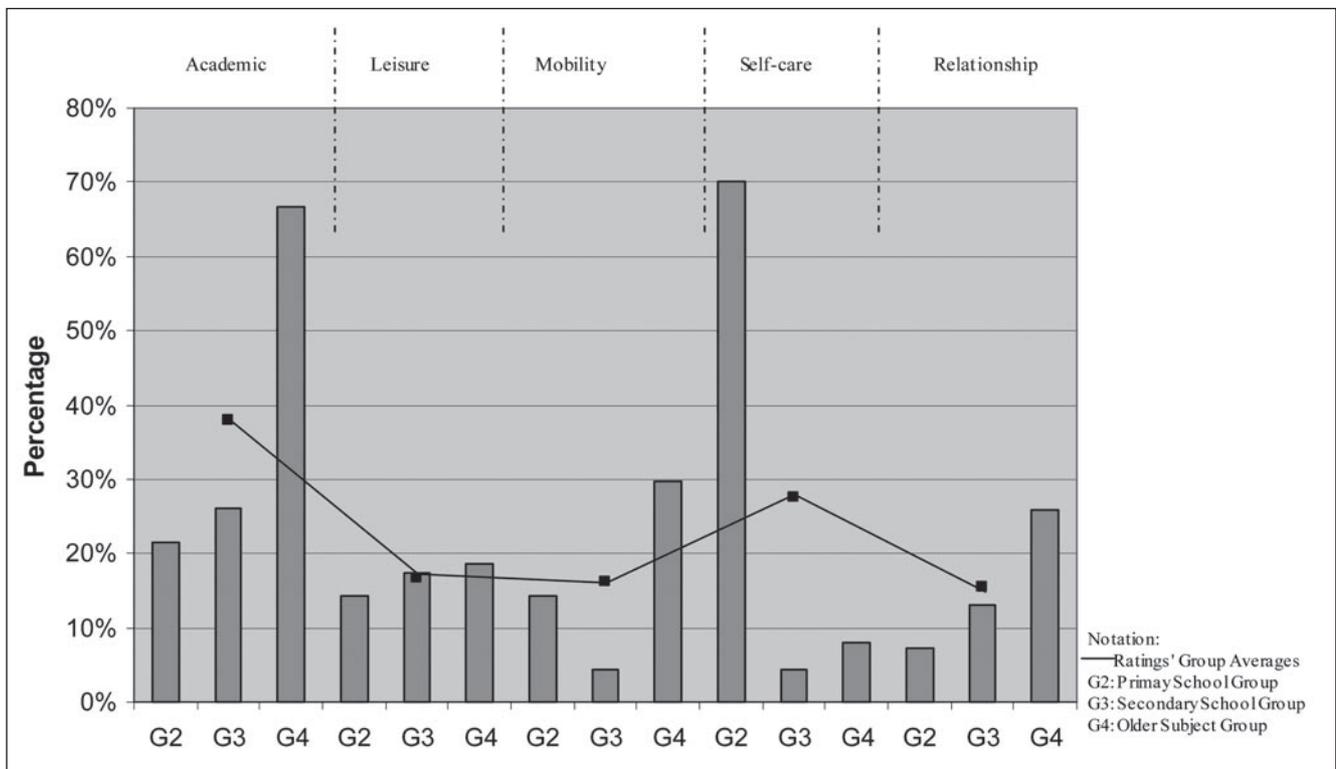


Figure 6 Handicaps.

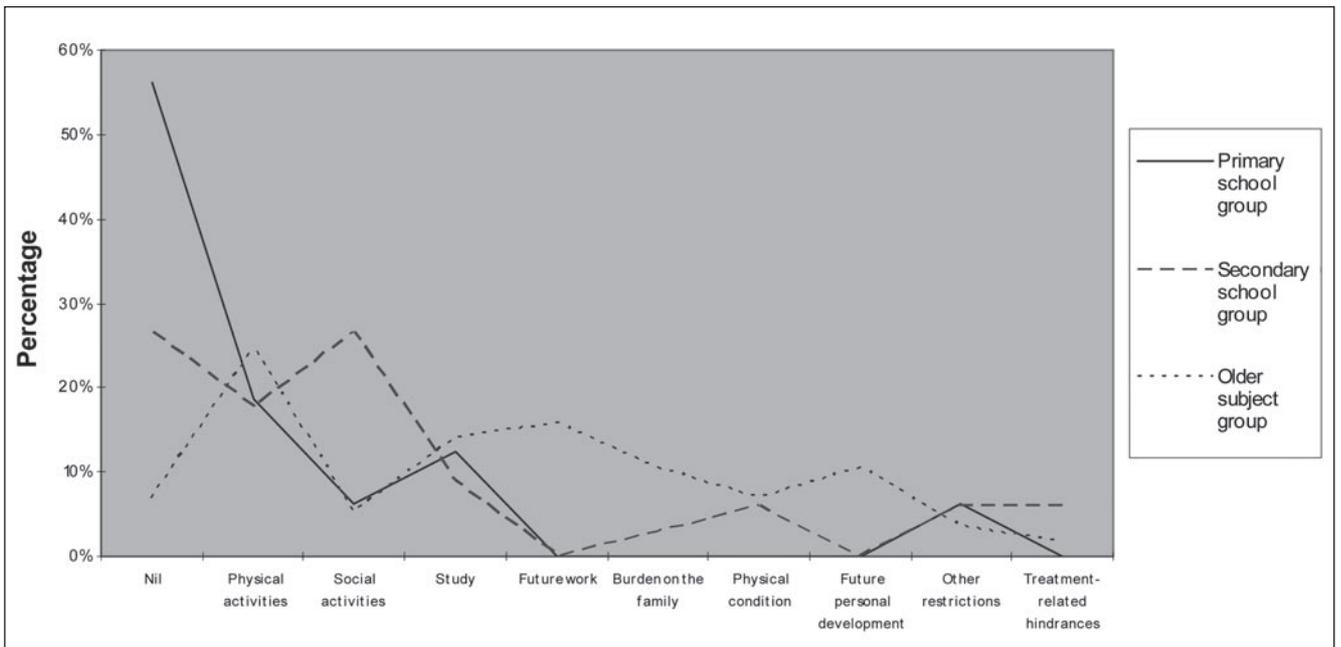


Figure 7 Handrances.

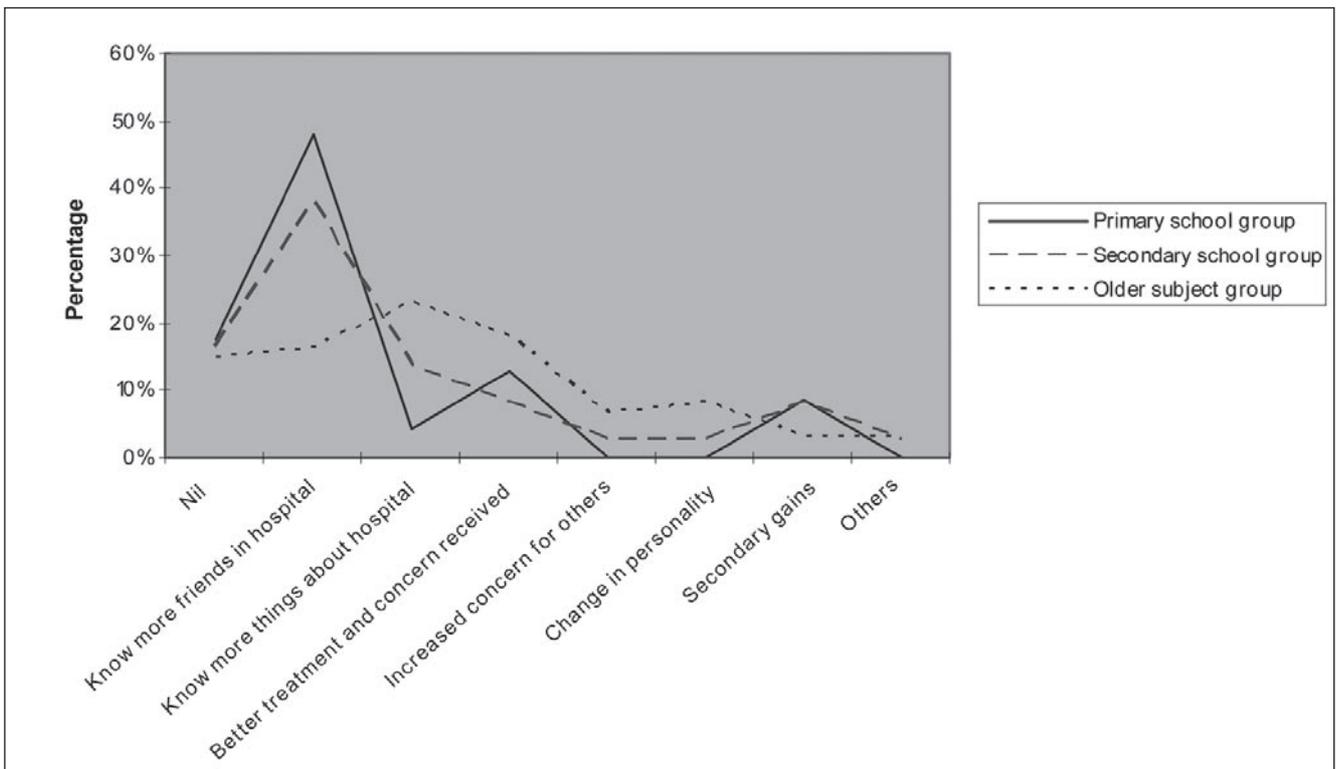


Figure 8 Positive things about the illness.

impatient etc.), their having an illness and their social interactions. In a way, the patterns and strengths noted also indicate the important areas of life concerns of the subjects, being social acceptance, personal character, as well as personal resources for ensuring a better life. It is noted that younger subjects emphasized their strengths and weaknesses in terms of achievements, while older subjects placed more emphasis on personality characteristics and social relationships (Figures 9 & 10).

Regarding subjects' wishes and aspirations, the results indicated that most subjects expressed wishes with themes related to their own illness and their family members' well-being. While younger subjects expressed wishes for better school performance and achievement, the older subject groups expressed more wishes related to future development and career opportunities. Younger subjects aspired more towards idealistic goals. Older subjects, on the other hand, were clearly more down to earth, with their aspirations being more practical and real life oriented (Figures 11 & 12).

E. Coping

The coping strategies used by the subjects were categorised according to the conceptual scales of coping

described by Carver, Scheier and Weintraub.²³ The most commonly used strategies were active coping, mental disengagement, acceptance and positive reinterpretation. Developmentally, the younger subjects preferred more active forms of coping and a stronger reliance on social support. Older subjects tended to use more cognitive strategies, e.g. positive thinking and mental disengagement (Figure 13).

Discussion

Differences in needs, perceptions and coping patterns of subjects with thalassaemia across their developmental stages were evidenced. Younger subjects gave fewer spontaneous responses. Understandably, they were less able to express their concerns, as their self-reflective abilities are less developed than their older counterparts. With growing maturity, there was a distinct shift of concerns from a focus on the immediate environment and oneself to the future and the larger social environment. The ability to de-center, become less egocentric, and think in abstract terms develops with maturity.²⁴ As subjects grow older, it is

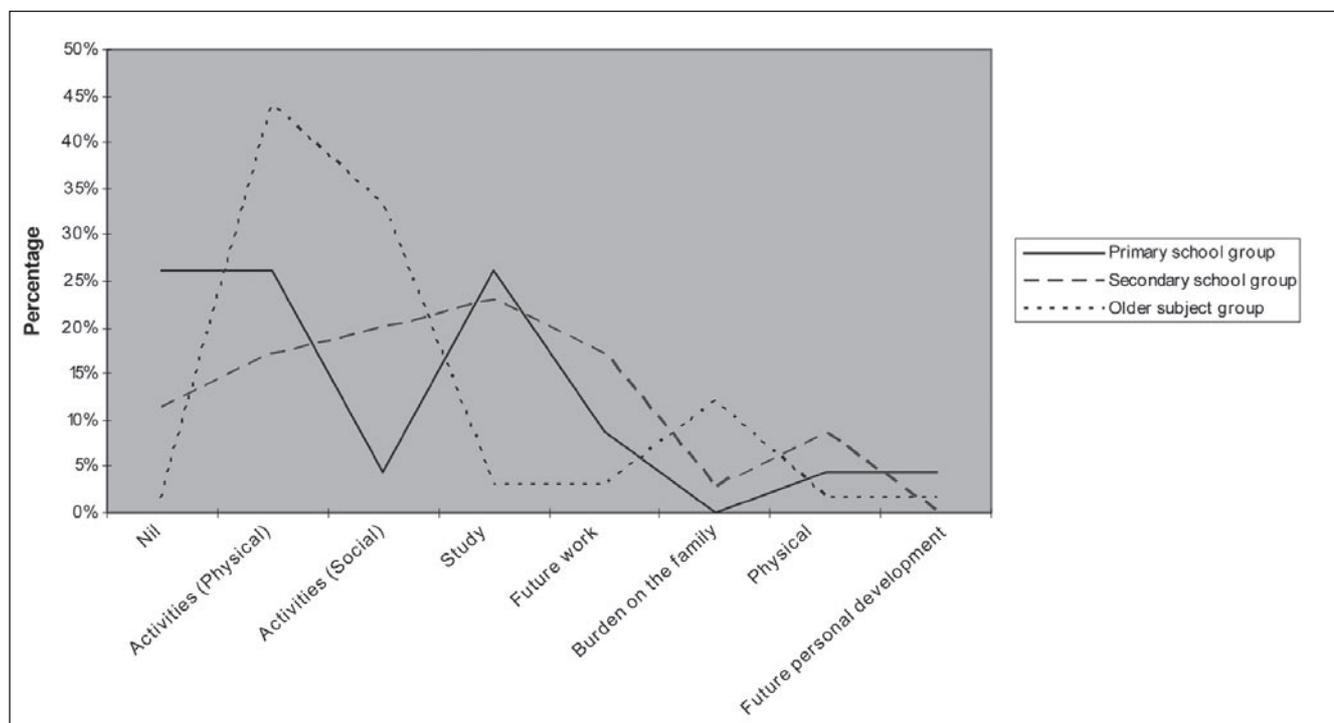


Figure 9 Self-perception of strengths.

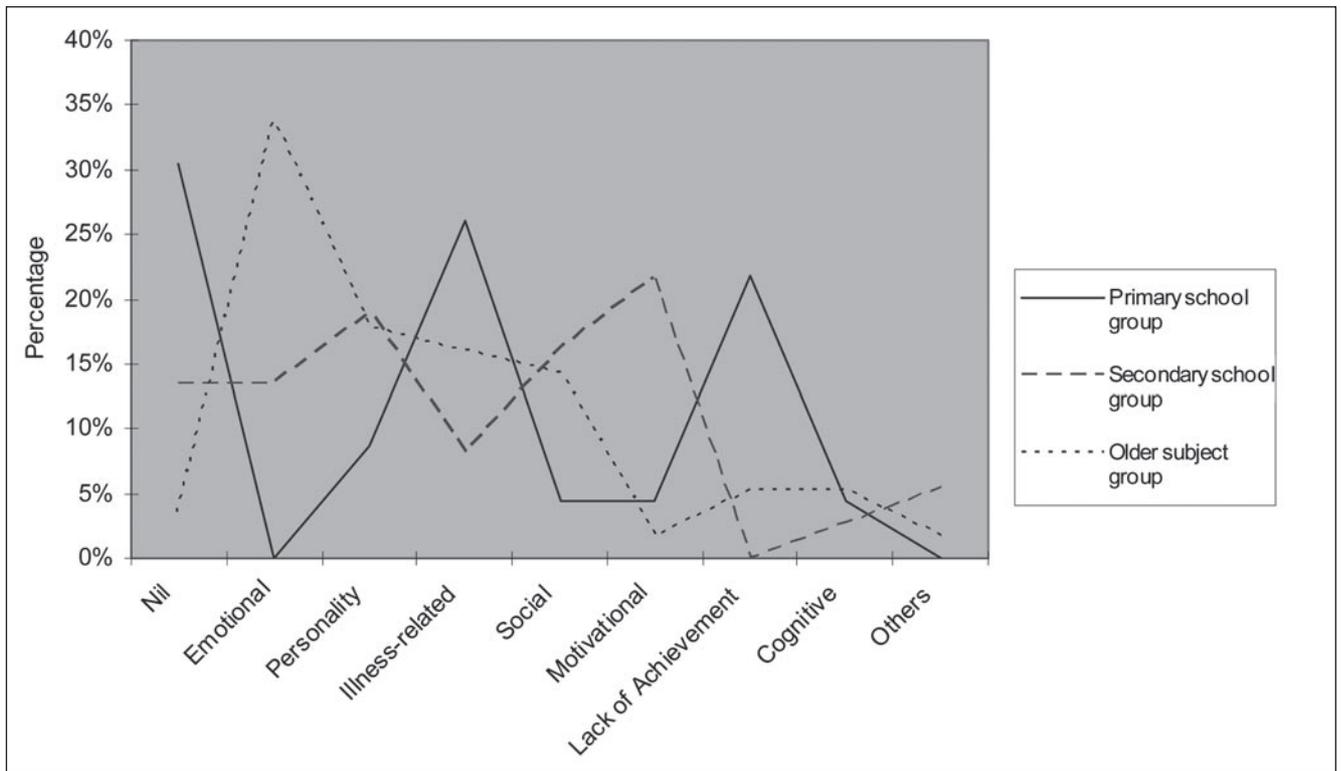


Figure 10 Self-perception of weaknesses.

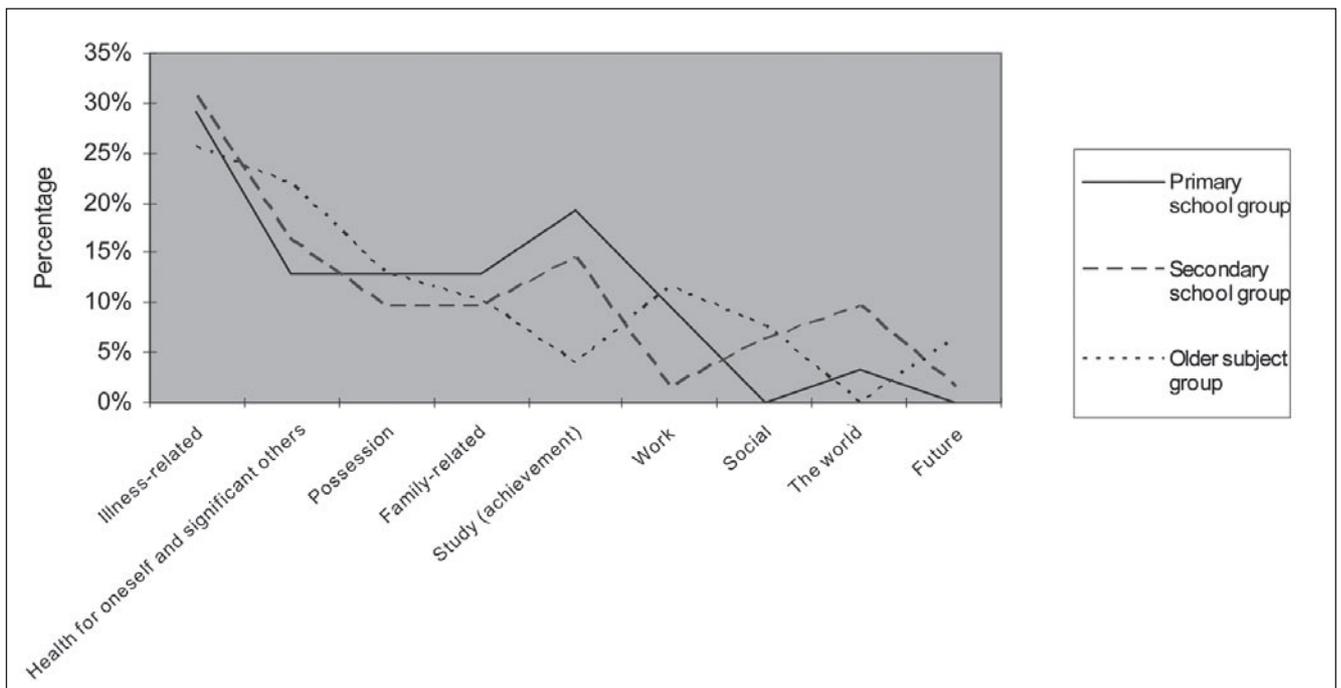


Figure 11 Three wishes.

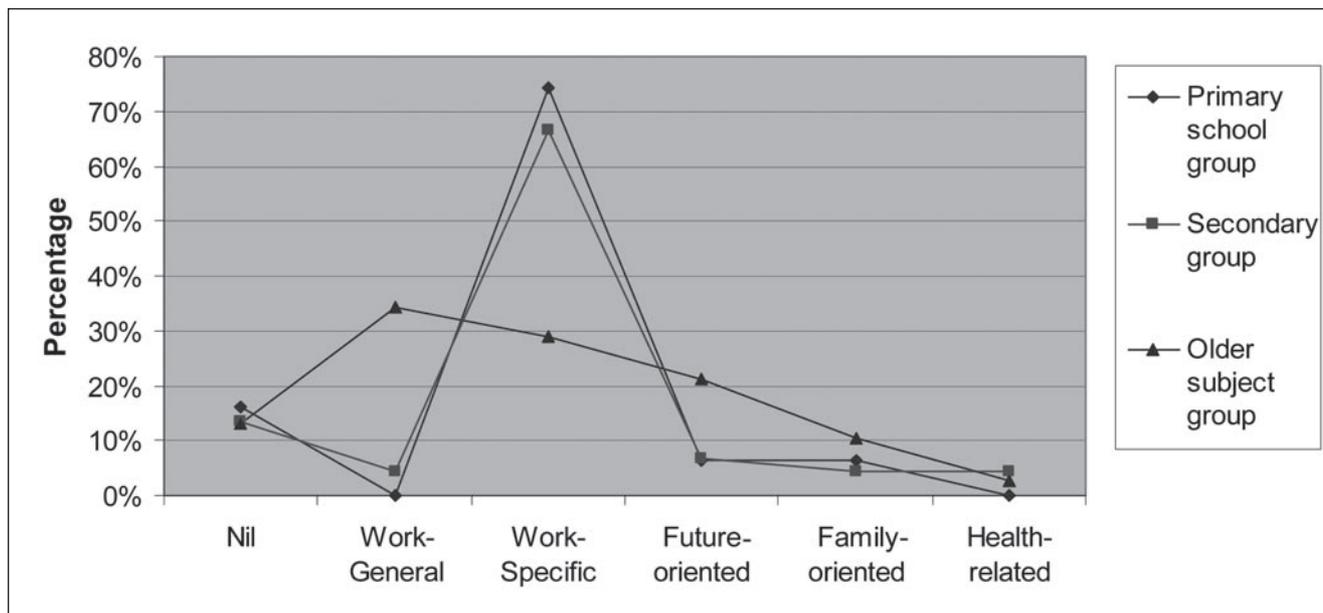


Figure 12 Aspirations.

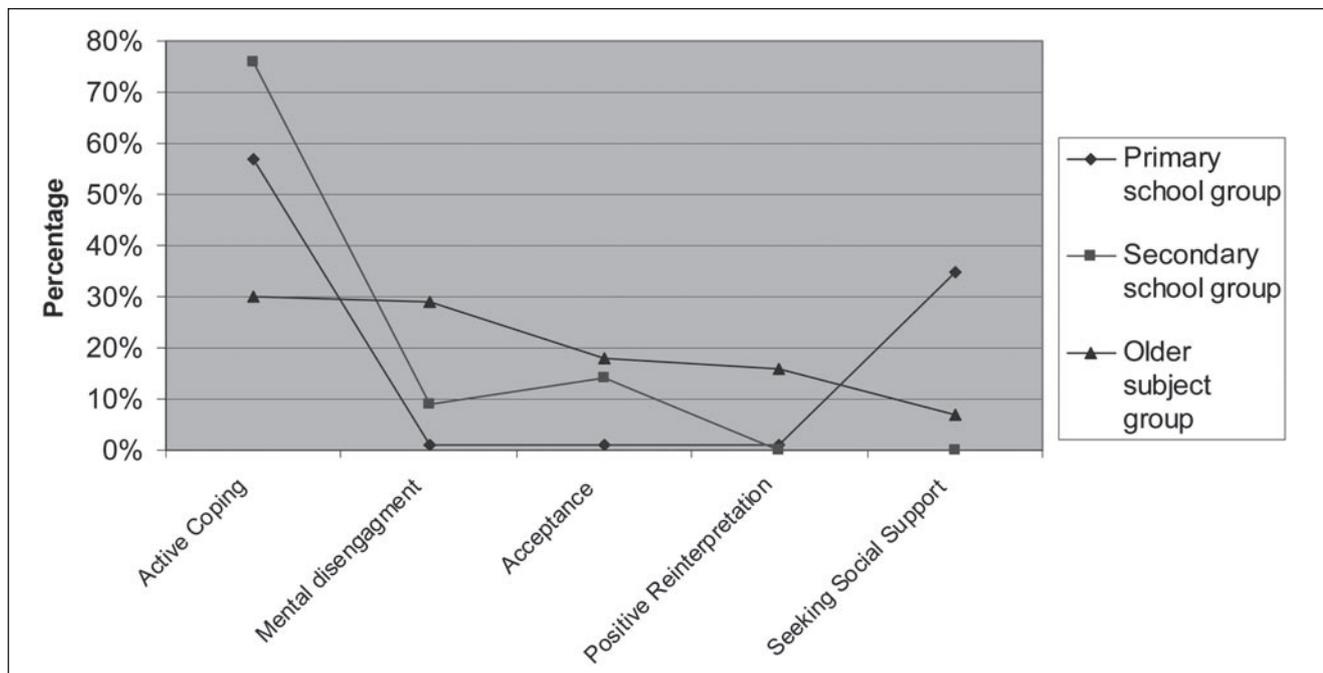


Figure 13 Coping strategies.

inevitable that they should become more in touch with reality issues such as their own personal development, social acceptance, financial independence and well-being, and what might hold for them in the future.

Illness related concerns relating to reduced life expectancy, anticipated illness complications, and lack of cure, were obvious in all subject groups but were more prominent with increasing age. Illness and physical vulnerability concerns also extended to worries for family members and friends. Older subjects, probably as a result of prolonged adverse personal and vicarious experiences with chronicity, consistently reported being more stressed and strained by their illness, and showed the least tolerance for various medical treatments. Older subjects were also more conscious of others' views and discriminations. They were also more self-conscious of their adversely affected physical appearance, and expressed frustrations towards their limited job opportunities which they attributed to their outward appearance. They also considered that the illness had negatively affected their academic performance and their heterosexual relationships. They were highly diffident relating to the opposite sex because of their delayed sexual development, awkward physical appearance and the hereditary nature of the illness. Older subjects were also clearly noted to be more concerned about being a burden to the family. They were more vigilant of their illness progression as well as potential health hazards that their illness and treatment may bring. The growing awareness of death also emerged as a key issue with increasing age.

Differences in cognitive abilities, knowledge about medical procedures and social maturity may account for some of the developmental differences. The older subjects' increased understanding and awareness of health and illness-related issues may be attributable to increased sensitization and a heightened sense of vulnerability developing through the long years of having thalassaemia. Reality constraints, as well as the subjects' notable differences from their "normal" peers also prompted a sense of inferiority and self-consciousness. In addition, chronicity per se would have exerted more stress and strain on anyone forced to bear with thalassaemia simply as a function of number of years of having the illness burden. In this respect, older subjects were clearly worst off than their younger counterparts. With advancing time, there seemed to be less differentiation in terms of what is more or less acceptable to the patients. Anything illness-related seemed to have acquired a conditioned aversive impact. It may also be true that fewer of the older subjects may have benefited from the more advanced and less aversive treatment regimens

available nowadays.

Therefore, with better treatment, less stress and strain from the illness, and a less matured cognitive development, younger subjects apparently harboured a more optimistic attitude towards their illness and its treatment. The advent of hypertransfusion regime, continuous improvements in the efficacy of filters during blood transfusion, and promise of bone marrow transplantation may together have brought about more positive and enhanced tolerance of the various treatment procedures in the younger populations as well as their parents. The younger subjects showed higher aspirations, more robust self-confidence, and a less tarnished self-esteem compared to their older counterparts. With the advent of oral chelators, the burden of illness on the overall functioning of the subjects is expected to be further modulated or reduced in the years to come.

The findings highlighted a more intense need for supportive psychosocial interventions with the older group of subjects with thalassaemia, as over time, they would have shouldered the bulk of adverse influences from their illness compared to younger subjects. To ensure that they continue to comply with treatment as they grow older, better psychosocial support not only from their natural social circles but also from the treatment team is important.²²

It is interesting to note that hospitalisation was not particularly rejected by the majority of subjects in the two school age groups. A possible interpretation may be that school age subjects took hospitalisation as a readily available, temporary refuge from the pressures of school work and peer pressure. In contrast, being more in touch with reality issues, older subjects resented routine hospitalisation because of its disruptive effects on their work. Routine hospitalisation also exposed subjects to higher risk of having to reveal their health status to colleagues and employers. The potential bias and discrimination towards chronically ill individuals unfortunately may still be rampant in the real world in which our subjects find themselves.

Our findings also indicate that the developmental themes noted in our subjects seem to echo those of normal teenagers. The same struggles with developing a sense of identity, self-esteem, as well as the ambivalence towards dependency issues were obvious. Consistent trends associated with the subjects' developmental level were evident in the wishes volunteered. Younger subjects wished for better school performance and to have more possessions. Adolescent subjects, on the other hand, expressed wishes related to the social realm, their family, friends, and the outside world. They were also more concerned with their

future development, health, job prospects, heterosexual relationships and potential for having their own families. While their concerns were in line with the usual tasks commonly seen in adolescents, our subjects seemed to feel such issues as being more pressurising because of the hindrances brought about by the illness. Thalassaemia, apart from its adverse influences on physical status and functioning, clearly exerted additional burdens on young patients in their process of negotiating their own developmental hurdles.

Confronted with a life long illness, the subjects' adjustment and coping strategies varied with different developmental stages. Younger subjects were more action oriented with a stronger reliance on seeking help from others. However, older subjects, burdened with years of treatment related hassles as well as being more aware of the longer-term implications of thalassaemia, seemed to find positive actions no longer appropriate in most circumstances. Instead, they tried to cope with their negative mood by adopting more positive thinking. They also actively tried to avoid thinking about unresolved issues, or of the negative but unavoidable hardships associated with the illness. These differing emphases in coping strategies may reflect differences in the nature of problems encountered across different age groups. As problems associated with increasing age become less likely to be amenable to total resolution – more cognitive and emotional coping tactics are necessary and evidenced. This finding is consistent with findings in the literature concerning change of coping strategies associated with age. As active coping may predominate when constructive actions are possible, emotion-focused coping takes precedent when stressors had to be endured instead of gotten rid of.²⁵ Thus, when the realistic implications of a chronic illness sink in over time, the subjects may gradually adopt emotion-focused coping strategies in place of more direct, active coping methods.

It was also noteworthy to mention that despite the long-term care required, there were few complaints or dissatisfaction expressed towards members of the health care team. This may be due to the highly personalised services provided. Subjects were routinely given 'preferential' treatments in that they were admitted into the same ward with familiar and friendly ward staff. Prior arrangements were also routinely made for patients of similar age to be admitted on the same day so that they could establish a better social network and comradeship with fellow patients. Flexible arrangements for admissions also helped subjects cater better to their school and work constraints on the patients. Given the finding that patients'

level of satisfaction with medical care is important in affecting ultimate adjustment,^{22,26-30} such flexibility and considerations in service provisions are clearly worth emulating.

Likewise, despite the long-term dependency on family members, it was reassuring to note the relatively few complaints against family members. In fact, much of the wishes of the subjects were for the well-being of their own family members. Despite that a major illness in a child may precipitate a crisis in the family⁶ and disrupt the very fabric of a family,¹² it was apparent from our data that a chronic illness like thalassaemia may, on the contrary, strengthen family unity and adaptation. Pless and Satterwhite¹⁷ noted that parents of chronically ill children reported that their illness served as a unifying force in the family such that family members' sensitivity to each other was enhanced. It appeared that the family's capacity to perceive meaning in the chronic illness experience may also be an important mediator of the child's mental and physical health. Our subjects' responses were clearly evident of their sense of gratitude and well wishes towards family members.

Summary and Conclusions

The findings indicated that all subjects assessed expressed varying concerns and dissatisfactions towards their illness, health and treatment. Nevertheless, the adverse impact of the illness was not all encompassing, and most subjects had a life and focus outside of their illness regardless of age. It was also noted that most subjects shared similar concerns as their healthy counterparts of the same age.

Clear developmental trends were noted in that older subjects had a greater range of concerns which encompassed physical appearance, emotional well-being, and issues related to work and heterosexual relationships. They were also more socially-oriented and less egocentric with more concern for others, and also more concerns about how others view or evaluate them. They had worries about their illness, and were less tolerant of their illness and treatments. They harboured the most intense resentment towards their illness as they regarded themselves as having suffered adverse consequences not only in the physical but also psychosocial realms. They felt that their competitiveness in choice of jobs, career development and heterosexual relationships were hampered by their physical development and scholastic achievement. The prospect of having a family of their own was regarded as poor because

of insecurity feelings towards their own physical and financial well-being. They therefore regarded their future as being bleak.

Yet, against the harsh realities of current and future threats, most subjects' view of themselves, the illness, and their future were not uniformly negative. The adaptiveness in learning to see things with a more balanced perspective, with negative as well as positive foci was evident in some subjects, who demonstrated that resilience amidst a lifelong illness was not unreachable.

Admittedly, the study has its limitations, one of which stems from the fact that only patients with thalassaemia major seen in one hospital were included. While there is the inevitable concern about the generalisability of the data obtained from a single center study to the entire group of patients in the territory, the findings of the study are at least useful as a guide for future study and development of psychosocial interventions for patients with thalassaemia across the different age groups. The focus of psychosocial interventions clearly needs to be flexible, child-centred, and in line with the specific developmental issues and concerns of the children. Adolescent patients seem to have a greater need for psychosocial interventions given their more intense reactions towards the illness, the chronicity of their afflictions, and the need to struggle for a better sense of independence and security.

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