

RESEARCH ARTICLE

EXPECTATIONS FOR LIFE AMONG GREEK TEENAGE THALASSAEMICS

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Abstract

Objective: To investigate expectations for life of today's Greek teenagers with thalassaemia, a hereditary disease, in association with their characteristics. **Material and methods:** A total of 74 thalassaemic teenagers participated in the study. Data collection was conducted using the "Multidimensional Expectations Questionnaire for Thalassaemia Major Patients" version for thalassaemic children and a questionnaire on teenage thalassaemic patients' characteristics (socio-demographic; health condition management). Descriptive and multiple regression analysis were performed; semi-partial coefficient-squared (sr^2) was used to explore the importance of possible contributors to thalassaemic teenagers' life expectations. **Results:** Thalassaemic teenagers had high overall expectation score (3.10) and family-creating/everyday-life expectation score (3.15) positively correlated with better knowledge of advanced therapies ($sr^2=0.12$; $sr^2=0.15$, respectively). Likewise, their friend-networking expectation was high ($sr^2=0.07$) interpreted by oral chelation administration ($sr^2=0.07$). Their professional-perspective expectation average score was 2.68; it was positively correlated ($sr^2=0.10$) with their close relations with caring nursing staff. **Conclusions:** Greek teenage thalassaemics had great expectations for their life and they anticipated to have a network of friends as they can participate in social gatherings due to the freedom of movement offered them by oral chelation. Their good knowledge on advanced therapies helped them to project their desire for family and everyday life to the future, while their close proximity to nurses helped them to decide their career they may pursue in the future.

Keywords: expectations for life, thalassaemia, teenagers

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Introduction

Expectation can be considered to be one's anticipation for desired events regarding one's own goals to happen in the future. It is the anticipation of possible future outcome that is simultaneously related to hope or fear. Despite not thoroughly understood, the concept of expectation is considered to be acquired while being formed depending on past one's own experiences gained from everyday life. As for patients, their expectations for future health outcome are formed based on their previous experiences and current health status.¹

Expectation is defined as the possibility of a certain behaviour or situation leading to the enhancement of a certain outcome. It is a mechanism changing, albeit not automatically, one's own behaviour.^{2,3} Expectations, beliefs and thoughts, considered to be internal factors of behaviour, are part of an interactive system influencing behaviour when combined with external factors such as rewarding and punishment.⁴ Positive expectations of self-efficacy (positive esteem of one's own competence) can motivate one to make a greater effort in order to achieve one's own goal or solve a problem.^{1,2} Low expectations regarding self-efficacy may make one experience despair, passiveness or weakness. Humans learn to have expectations and not behaviour. Expectation is prediction of a future goal and has internal dynamics that can motivate behaviour and lead to individual's achievement of a pursued goal.^{1,2}

It is important that expectations can be divided into general and specific expectations. General expectation is the outcome of similar one's own experiences, while

specific expectation is associated with a certain situation.^{1,2} Given that motivation can diversify human behaviour, positive expectations enhance motivation for better performance, as opposed to negative expectations that can deconstruct or prevent any action or effort to improve individual's performance.²

For patients, expectation is a complex dynamic concept relating to their predictions for health. Patients' expectations depend on past experience regarding their own health in general, their own attitudes and needs towards health outcome, and their direct and indirect communication with powerful others, such as health providers.⁵ It is important to measure the number and range of patients' features because expectations have important clinical consequences. For health professionals, understanding and assessing patients' expectations is considered to be an important task. It has been argued that raising health professionals' awareness of unfulfilled patients' expectations would enable them to gain a deeper understanding of patients' needs, in order to improve communication.⁶ Patients' characteristics such as age affect their realistic expectations. Older people, who experience inferior health state, may have lower expectations and simply be grateful for what they receive. By contrast, younger people, whose life experiences have been formed by the consumer revolution and instant satisfaction, may become more demanding. For this reason, it is advised to take into account doctors' perceptions and patients' expectations regarding desired patients' health outcome.⁷

Individuals tend to behave according to the expectations of those who have authority, prestige, and power.⁸ Health professionals are considered to be powerful others influencing behaviour and expectations of their patients. The greater one's expectations the better one's performance it is; and vice versa. Likewise, expectations of a positive environment have a beneficial effect on the patients in terms of behavioural modification leading to adherence to therapeutic guidelines.^{1,2}

An Italian study, conducted 20 years ago,⁹ evaluated the impact of thalassaemia on social behaviour of Italian thalassaemic adolescents. Study results showed that thalassaemic adolescents had coping strategies, self-esteem, and normal psychological progress. In addition, they positively considered their future, highly appraised professional career and eagerly looked for a suitable life-partner. Three years later, in 1998, the Italian research team¹⁰ investigated the impact of thalassaemia on psycho-social adaptation of thalassaemic adolescents. It was also found that thalassaemic adolescents continued to have coping strategies, self-esteem, and normal psychological progress. In addition, they had strong ties with their family. Researchers concluded that thalassaemics, who adhered to their therapy, could achieve coping with difficulties in life as teenagers.

The aim of the present study was to investigate expectations for life of today's thalassaemic teenagers in Greece. The objective of the study was to assess whether the characteristics (socio-demographic, health condition management) of teenage thalassaemics were related to their life expectations.

Material-Method

Research team distributed the "Multidimensional Expectation Questionnaire for Thalassaemia Major Patients" version for thalassaemic children and adolescents¹¹ consisting of three dimensions (expectations for family creating and everyday life; for friend networking; for professional perspective) to teenage thalassaemics participating in the study to complete. In addition, study's thalassaemic teenagers were invited to fill in an ad hoc questionnaire regarding their features such as socio-demographic characteristics and health condition management. Descriptive analysis was performed. Mean score and standard deviation for each of the three dimensions was calculated.

Multiple regression analysis was also carried out in order to explore the impact of their features on teenage thalassaemic overall expectations and expectation dimensions. The decision for applying multiple regression analysis was tested. The decision was deemed right as long as residuals were normal. Residuals, considered to be independent with Durbin-Watson statistic values approaching 2, had a constant variance. Inexistence of (multi)collinearity was necessary in order for independent variables (teenage thalassaemic features) to be uncorrelated. Tolerance existed only if variance inflation of an independent value, explained by the remaining independent variables, was small. Collinearity was calculated using tolerance factor and variation inflation factor VIF. Collinearity was evident when tolerance factor values were less than 0.4 and VIF values were more than 2.5, while being considered to be possible when VIF value was more than 5. Collinearity was possible or severe

when condition index values were greater than 15 or greater than 30, respectively. The coefficient of determination R^2 represented the proportion of the variance in the dependent variable that is predictable from the independent variable percentage. An R^2 of 1 indicated that the regression line perfectly fitted the data. The F -test of overall significance indicated whether a selected regression model provided a better fit than a model that contained no independent variables. Stepwise multiple regression was applied to select the subset of independent variables (thalassaemic teenager features) that could be useful for explaining each of dependent variables (overall expectations, expectation dimensions). The number of observations (teenage thalassaemic participants) needed to excel the number of independent variables by at least 50. After the initial ad hoc grouping of thalassaemic teenager features, stepwise regression was used to rank order the theoretical importance of the variable to the model step-by-step. Contribution of independent variables to each model was explored using standardised regression coefficient Beta. Comparison of each model variables was also made by testing semi-partial correlations of the variables. Results were presented as standardised regression coefficients Beta according to the equation:

$$y = \text{Beta}_1 * x_1 + \text{Beta}_2 * x_2 + \dots + \text{Beta}_k * x_k \quad \text{[Equation 1]}$$

where y is each of the dependent variables (expectations), $x_{1,k}$ is the independent variable (feature), $\text{Beta}_{1,k}$ is the standardised regression coefficient, in order for the interpretations to be based on the standard deviations of the variables. Each coefficient Beta showed that the number of standard

deviations may change the dependent variable to be interpreted when standard deviation of corresponding interpreting variable also changed by one unit given that the other interpreting variables remained unchanged. In each model, sensitivity of remaining coefficients Beta was tested by adding and removing the remaining independent variables using the rule of thumb which was that difference greater than 20% possibly implying interpretational confounding of variables.^{410,411}

The importance of impact for each independent x was tested by removing its impact in order for its contribution on interpreted-to-be dependent variable y to be found beyond the remaining independent variables by partialling out their impact.⁴¹² Regression of each independent variable x was carried out on the remaining independent variables. Then, residual of x was correlated to y and semi-partial coefficient (sr) was computed. The coefficient sr indicated the variance of each dependent variable y that could be explained by the given independent variable x . Thus, sr indicated the impact of x on y that is additional to the impact of the remaining independent variables on y . The percentage of the impact of x (teenage thalassaemics' feature) on y (teenage thalassaemics' expectation for life) was expressed as the square of semi-partial coefficient (sr^2). Statistical analyses were performed using SPSS version 21. The p -values less than 0.05 were considered to be significant.

Approval for conducting the present research study was given by hospital authorities that monitored the research throughout the research period. Participation was on voluntary basis and participants could opt out any time they wished without any

discriminatory consequence that may be negative for them. Questionnaire was distributed on an impersonalised basis and its anonymity ensured confidentiality and protection of personal data. The afore-mentioned process did not allow the possibility of participants' identification in the future by using valid methods of generalisation in less specific categories and of linear transformation. Consent on the part of thalassaemic teenagers and assent on the part of their parents were taken for granted as teenage thalassaemic participants voluntarily responded the questionnaire and gave it back without outside intervention.

Results

In total, 74 teenage thalassaemics participated in the study on their expectations for life and corresponded to 30% of the estimated number of today's thalassaemic teenagers in Greece.¹² Their number exceeded that of the distributed life expectations' questionnaire items by 60. The 33 (45%) were boys and the 41 (55%) were girls. Their median age was 14 years old. All of them were pupils with 31 (74%) attending high school. Most (62/74; 84%) of them lived in two-parent households. Their health condition management is demonstrated in Table 1.

Mean scores for the questionnaire's dimensions are presented in Table 2.

For the interpretation of overall expectations for life of thalassaemic teenagers, the selected model was statistically significant ($F=8.95$; $p=0.004$) and interpreted 12.4% ($R^2=0.12$) of the overall expectations

(Overall expectations) = 0.35*(Knowledge of advanced therapies) [Equation 2]

Better knowledge of advanced therapies was positively correlated ($sr^2=0.12$) to greater overall expectations.

For the interpretation of expectations for family creating and everyday life of teenage thalassaemics, the selected model

(Family-creating/everyday-life expectations) = 0.38*(Knowledge of advanced therapies) [Equation 3] was statistically significant ($F=10.7$; $p=0.002$) and interpreted 14.6% ($R^2=0.15$) of the expectations for family creating and everyday life. Better information on advanced therapies was positively correlated ($sr^2=0.15$) to greater expectations for family creating and everyday life.

For expectations for friend networking of thalassaemic teenagers, the selected model was statistically significant ($F=8.15$; $p=0.001$) and interpreted 18.9% ($R^2=0.19$) of variance of the aforementioned expectations

(Friend-networking expectations)=0.26*(Oral chelation) [Equation 4]

Oral chelation, combined or exclusive, interpreted 6.5% ($sr^2=0.06$) of thalassaemic teenagers' expectations for friend-networking in a positive way.

Regarding professional perspective of teenage thalassaemics, the selected model was statistically significant ($F=8.23$; $p=0.005$) and interpreted 10.3% ($R^2=0.10$) of their professional expectations

(Professional perspective)=0.32*(Relations with nursing staff) [Equation 5]

Close relations of teenage thalassaemics with nurses at thalassaemia expertise units positively correlated with their having professional expectations.

Table 1. Distribution of study's 74 children and adolescents with thalassaemia by their health condition management.

Thalassaemia self-management	Categories	N	(%)
Self-care	Always	13	(17.57)
	Often	16	(21.62)
	Sometimes	20	(27.03)
	Rarely	11	(14.86)
	Not at all	14	(18.92)
Information on thalassaemia	A lot of	16	(21.63)
	Enough	45	(60.81)
	Some	11	(14.86)
Knowledge about transplantation/gene therapy possibility	No	2	(2.70)
	A lot of	7	(10.77)
	Enough	11	(16.92)
	Some	35	(53.85)
Intension to submit to transplant / new treatments	No	12	(18.46)
	A lot of	12	(16.44)
	Enough	10	(13.69)
	Some	26	(35.62)
	No	25	(34.25)
Considerations for thalassaemia management	Categories	N	(%)
Difficulties in blood provision	Always	0	(0.00)
	Often	1	(1.35)
	Sometimes	3	(4.05)
	Rarely	17	(22.98)
	Not at all	53	(71.62)
Adoption of blood donors	Rarely	33	(45.21)
	Often	1	(1.37)
	Sometimes	7	(9.58)
Concerns for blood transfusion	Not at all	32	(43.84)
	Always	0	(0.00)
	Often	1	(1.35)
	Sometimes	3	(4.05)
Preferred chelation methods	Rarely	17	(22.98)
	Not at all	53	(71.62)
	Subcutaneous	12	(16.44)
	Combined	26	(35.61)
	Oral	35	(47.95)

Table 2. Mean scores for the three dimensions of the "Multidimensional Expectation Questionnaire for Thalassaemia Major Patients" version for thalassaemic children and adolescents completed by study's 74 children and adolescents with thalassaemia

Dimensions	Expectations	
	Mean score	Standard deviation
Expectations for family creating and everyday life	3.15	0.72
Friend networking	3.22	0.58
Professional perspective	2.68	0.95
Total score	3.10	0.51

Discussion

To our knowledge, this is the first study conducted in Greece regarding life expectations among teenage patients with thalassaemia. From the literature, adolescents are considered to be capable of developing abstract thinking, even though they are more impulsive than adults due to lack of experience and knowledge in addition to their biological growth and development.¹³ In early adolescent stage of growth (less than 13 years of age), they do not care about future, while in late adolescent stage (16-18 years of age) they do not feel threatened by future. Mid-adolescents (13-15 years old) entirely focus the future on the present.¹⁴ In this study, though, it is of interest that teenage thalassaemia participants believed very much in that they are going to live a healthy life as they felt healthy, as opposed to the trend shown among their counterparts, who did not make any future plans in life 25 years ago.¹⁵

Greek thalassaemic teenagers of our study did not seem to be afraid of future as country's thalassaemia expertise units offered adequate health care¹⁶, as opposed to the existing situation of thalassaemics in developing countries such as India¹⁷ where nearly 90% of thalassaemic children die without being diagnosed as having thalassaemia and 60% of diagnosed cases with thalassaemia either received mistaken or no treatment or had narrow or no access to chelation treatment.¹⁸

Nowadays, transplantation is widely offered and breakthrough seems to be underway for gene therapy that would be the ultimate therapy. In Greece, 115 transplantations have been conducted with a success

rate of 85% since 1994.¹⁹ However, most (70%) Greek teenage patients with thalassaemia participating in our quantitative study did not consider transplantation or gene therapy as an option. This finding was compatible with that of a qualitative study conducted in Greece in 2012²⁰ showing that thalassaemics had no intention of undergoing stem cell transplantation. Despite their young age, more than 50% (55%) of study's thalassaemic teenagers were aware that they could undergo transplantation or receive advanced therapeutic treatments in the future. Further to this, the more they were aware of this, the more they believed that a brighter future awaits them as they would eventually become healthy.

Thalassaemic teenagers participating in the present study felt ready to engage in the responsibilities of adulthood when they grow up by raising their own family and coping with everyday life as long as they have the possibility to become as much aware as possible of having the options to undergo transplantation and receive novel therapies. Greek teenage thalassaemics were also found to have a notion about what is a family, in accordance to the stereotypic model of nuclear family, which is typical of today's Greek society,²¹ as most of them came from traditional, two-parent families discouraging divorces. Similar results were reported by previous studies showing that thalassaemic teenagers could consider keeping a normal family lifestyle.¹⁰ Study's teenage thalassaemics strongly expected to create a family as their age-mates would do when they grow up. In the present study, 49 (66%) teenage thalassaemics

reported that they would be able to take care of themselves up to a certain extent as long as they behave healthily within their family, as opposed to the past when thalassaemic children and adolescents could not gain their freedom from overprotective parents due to their vulnerable health state.²² As a result, today's thalassaemic teenagers were capable of involving themselves in controlling their own health outcome²³ and thus, they could be proactive and participate in their daily healthcare. This is possibly why the vast majority (70/74; 95%) of our teenage thalassaemics was not particularly bothered about their routine blood transfusion.

It is of interest that most of study's thalassaemic teenagers (66/74; 90%) had no complications at all. That 61 (82%) responded that they had good or very good information on their own health condition²⁴ was in favour of their effort to self manage their own health condition. By contrast, in developing countries, most of thalassaemic children had mistaken information about their illness and thus, they were in need of be offered a training programme.²⁵

From study results, Greek teenagers with thalassaemia anticipated to have a network of friends. It seems as though they had no difficulties in their integration into the groups of their age-mates, as opposed to the situation in the past when young thalassaemic patients could not be integrated into the groups of their classmates.²⁶ By contrast, in developing countries,²⁶ relations between thalassaemic children and their age-mates continue to be difficult because they are (self-)considered different from their friends and classmates even today. Diversity of thalassaemic children is enhanced in case of subcutaneous chelator

administration due to limited mobility and time caused by chelation therapy machines leading to limited opportunities for social gatherings in comparison with their healthy age-mates. Oral administration of iron chelators seems to ease their lifestyle as they are allowed to move and not be bound to chelation machines.²⁷ Study findings showed that the majority of the Greek thalassaemic teenagers (61/74; 84%) opted for at least combined chelation therapy. Such a therapy facilitated Greek teenage thalassaemics to a great extent and permitted their age-mates to consider them visually healthy. Therefore, they hoped that in the future they would keep on being integrated into the groups of their peers as they expected, in contrast to exclusive use of chelation machines that made their social mixing with others a rather difficult process. Oral administration was also preferred by 14 thalassaemic adolescents participating in a previous study from Greece.²⁸ A recent study conducted at a Greek hospital's thalassaemia expertise unit in 2013²⁹ showed that deferiprone is well tolerated per os. Combined chelation therapy is more and more supported as it is considered beneficial for reducing iron overload. That is also confirmed by similar studies that found that combined chelation therapy reduced cardiac and hepatic iron overload in thalassaemic patients.³⁰

In addition, more than 50% (56%) of study's teenage thalassaemics have been adopted by volunteer blood donors resulting in seamless blood provision, with only 32/74 (28%) rarely experiencing difficulties in finding blood for their transfusion.³¹ By contrast, in developing countries where there is no organised thalassaemia expertise units thalassaemics very often face

difficulties in blood provision necessary for their routine transfusion.

As they were very young,³² study's thalassaemic teenagers did not make any future plan for their professional career. However, their becoming familiar with the work of nurses at thalassaemia expertise units³³ was positively related to their professional orientation making them consider being a nurse when they grow up. The security offered by their close relation to the nurses who were taking care of them corresponded to a professional profile compatible with emotional proximity.³⁴ Thus, nurses can become humanistic role models for teenage thalassaemics in terms of professional orientation.³⁵ An earlier Greek study conducted almost 15 years ago showed that 6.2% of thalassaemics had chosen to work as nurses.³⁶ Another possible explanation for the results of the present study regarding professional perspective might be that the caring nurse who is very close to the thalassaemic teenager can communicate and talk to the young thalassaemic patient³⁷ who shares her or his professional dreams with the carer.

The investigation of expectations for life of teenage thalassaemics was conducted with a wide distribution of the questionnaire copies in a particular time period. Therefore, it is not possible to make any generalisation, even though it made it possible to provide a conceptual frame for further investigation of teenage thalassaemics' future outlook.³⁸ Multiple linear regression was chosen as a generalised approach in order for simultaneous evaluation of relations between independent variables corresponding to thalassaemic teenager features such as socio-demographic characteristics and health condition management and

each of the dependent variables (overall expectations; expectations for family creating and everyday life; friend- networking; professional perspective).^{39,40} That R^2 values were less than 50% did not allow us to make any prevention model; this is fully compatible with unpredictable human behaviour. Hence, the present research interpreted only the impact that study's teenage thalassaemic features may potentially have on their expectations for life. Regression was decided to be performed in order to eliminate the effects of confounders. However, exploration of possible interactions is encouraged,⁴⁰ perhaps, by repetition of similar studies in different time periods. The questionnaire expectations for life, applied to teenage thalassaemics, allowed yielding the impact of their features on their future perspective for living.

Conclusions

The present study allowed us for the first time to extract the following conclusions regarding factors that may have an impact on today's teenage thalassaemics life expectations in Greece. As they had great expectations for their life, thalassaemic teenagers anticipated to have friends and participate in social gatherings. Good knowledge about advanced therapies helped teenage thalassaemics to project their desire for family and everyday life to the future. In addition, close proximity to nurses may be useful for them to make up their mind about what career they may pursue in the future. Differences in the profile between today's teenage thalassaemics and those in the past were important as they reflected hope on the part of thalassaemic teenagers attributed to biotechnological

advancement. Today's thalassaemic teenagers are experiencing their own health condition as part of a healthy everyday life and also they are capable of participating in their age-mates' activities on equal terms with their peers. Further studies are needed in order to discover possible associations between life

expectations of teenagers with a hereditary disease other than thalassaemia and their own characteristics.

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