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Illness Perception in Patients with Thalassemia in Nablus, Palestine: A Pilot study

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Abstract

Thalassemia is a hemoglobinopathy which is results from a gene mutation in Œ± or Œ≤ chain. It has the preeminent prevalence in Mediterranean, tropical areas and regions near the equator. Thalassemia is one of the most prevalent genetic blood disorders in the world. Research pertaining to patient perception of thalassemia is limited in Palestine. Our study is the first one nationwide that aims to assess the perceptions and attitudes toward thalassemia and thalassemia treatment. A cross-sectional, non-interventional, descriptive study design was used. A convenient sample of 113 thalassemic patients attending the specialty clinic at Al-Watani hospital, Nablus, Palestine was included. We used a previously published Brief-Illness Perception Questionnaire (B-IPQ) version to achieve the objectives of the study. A total of 113 thalassemic patients aged 12-70 (average 21.0¬±9.5 years) were recruited, 51.3% were females, and they have been diagnosed since 19.4¬± 7.4 years. A bit less than half (44.2%) had college education; the rest had high school or less level. The largest category (55.8%) live in villages, 57.5% of them had a consanguineous marriage, yet almost all (98.2%) of the participants did not have any other diseases. As for the perception aspects, participants believe their disease as chronic, and that the treatment can control their disease to a significant extent (treatment control) (median = 10 for both). As for personal control, it was high with a median of 8, and the same value was also achieved for understanding the disease. The remaining components of the B-IPQ were found to be 3 indicating a low score Data indicated that the participants perceive their disease as chronic with treatment being able to control. They also believe that they have some control over the disease, and that it has minimal effect on their quality of life. More steps should be taken to focus on the psychological aspects of this disease, and more education is needed to prevent its occurrence, especially those related to consanguineous marriage.

Keywords

Brief-Illness, blood, Palestine;, Perception, Thalassemia;, Questionnaire;

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Illness Perception in Patients with Thalassemia in Nablus, Palestine: A Pilot study

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Abstract

Thalassemia is a hemoglobinopathy which is results from a gene mutation in α or β chain. It has the preeminent prevalence in Mediterranean, tropical areas and regions near the equator. Thalassemia is one of the most prevalent genetic blood disorders in the world. Research pertaining to patient perception of thalassemia is limited in Palestine. Our study is the first one nationwide that aims to assess the perceptions and attitudes toward thalassemia and thalassemia treatment. A cross-sectional, non-interventional, descriptive study design was used. A convenient sample of 113 thalassemic patients attending the specialty clinic at Al-Watani hospital, Nablus, Palestine was included. We used a previously published Brief-Illness Perception Questionnaire (B-IPQ) version to achieve the objectives of the study. A total of 113 thalassemic patients aged 12-70 (average 21.0±9.5 years) were recruited, 51.3% were females, and they have been diagnosed since 19.4± 7.4 years. A bit less than half (44.2%) had college education; the rest had high school or less level. The largest category (55.8%) live in villages, 57.5% of them had a consanguineous marriage, yet almost all (98.2%) of the participants did not have any other diseases. As for the perception aspects, participants believe their disease as chronic, and that the treatment can control their disease to a significant extent (treatment control) (median = 10 for both). As for personal control, it was high with a median of 8, and the same value was also achieved for understanding the disease. The remaining components of the B-IPQ were found to be 3 indicating a low score Data indicated that the participants perceive their disease as chronic with treatment being able to control. They also believe that they have some control over the disease, and that it has minimal effect on their quality of life. More steps should be taken to focus on the psychological aspects of this disease, and more education is needed to prevent its occurrence, especially those related to consanguineous marriage.

Keywords: Thalassemia; Brief-Illness Perception Questionnaire; Palestine; Blood

Background

Thalassemia is a hemoglobinopathy which results from a gene mutation in the α or β chain [1]. It has a preeminent prevalence in the Mediterranean, tropical areas, and the regions near the equator [2]. Thalassemia is one of the most prevalent genetic blood disorders in the world. Thalassemia affects 4.4 of every 10,000 live births. It affects males and females equally because it follows an autosomal pattern of inheritance. Like in many other countries, thalassemia is an important public health problem in Palestine, with approximately 4.3% of the Palestinians are carriers of the mutations for this disease [3].

The chronic nature of the disease, its need for continuous, lengthy and intense treatments affects all aspects of the individuals' life. It has an arduous and substantial impact on physical, emotional and mental health as well as the quality of life of the patients and their families [4]. Diagnosis of the disease and integrating it into the family is considered as a predicament, with different families reacting differently. Most of the families can adapt with the disease, but others may not be as successful in this regard. This may be due to the lack of knowledge about the disease, also the lack of support, expensive treatment, and the resulting mental stress [5].

In the current time, there are many treatment options for thalassemia that can reduce the disease-related mortality, enhance life expectancy, and improve the quality of life of thalassemic patients [6]. In the past twenty years, there has been an increasing interest in upgrading the quality of life of the patients, especially those who suffer from chronic diseases [7]. In contrast with patients who have short-term injuries, people suffering from thalassemia have exceedingly more depressive symptoms and a lower quality of life. This emphasizes the importance and need to have mental, psychiatric and rehabilitation programs with a goal to elevate the quality of life of thalassemic patients. There is a significant incidence of anxiety, depression, aggression and shyness in thalassemic patients than healthy children. Furthermore, another study indicated that anxiety and depression were in 47% of thalassemic patients and this had an immense impact on self-care and quality of life [8]. One of the main intents of treatment is to bolster quality of life by diminishing the psychological effects of the disease [9]. Compelling advances have been achieved in thalassemia front, leading to an improved understanding of genetic control of hemoglobin, the deformity in the different forms, the pathophysiology of the disease, and the advances in treatment [10]. This considerable development in the diagnosis and treatment has not been balanced by progress in psychosocial rehabilitation in thalassemia patients [11]. Additionally, thalassemia has an effect on patients at the physical, emotional and cognitive levels causing a disruption of what is considered "having a normal psychosocial life". Tremendous attention is needed regarding issues related to the illness, enduring complications, the treatment, and the effect on the quality life. It is a burdening topic that needs to be researched.

Patients' perception-related research, in general, and in thalassemia patients, in particular, is comparatively limited in Palestine and elsewhere. Patient perception has been proven to be a very important component in shaping psychological aspects. Our study is the first in Palestine to focus on this group and it aims to determine the perceptions and attitudes toward the disease and its treatment as well as to explore the concerns, beliefs and feelings of patients and their immediate family members

METHODS

Study design

A cross-sectional non-interventional, descriptive study design was used. A convenient sample of patients being treated at the specialty clinic at Al-Wattani Hospital was chosen. This hospital is a governmental medical hospital providing its services to residents of the northern area of Palestine, especially those having a governmental health insurance. Patients were recruited in order to evaluate their perception towards thalassemia. These patients came from different geographical regions including different cities, villages and camps all over north Palestine. Researchers approached eligible patients during their treatment visits and explained the study objectives. Patients who showed interest in participating in the study were asked to complete a questionnaire in Arabic about their perception toward thalassemia. The questionnaire is the well-known Brief-Illness Perception Questionnaire (B-IPQ), was translated to Arabic, and then back translated to English by a certified translator. The later English version was presented to the author of the B-IPQ and his approval was obtained. Overall, there were 5 major sections in the questionnaire regarding personal information, family history, blood groups, other current diseases, and patients' perception. The perception section focused on major aspects such as the consequence of the disease, time line, personal control, treatment control, identity, coherence, emotional representation, and illness concern. The exact questions were: 1- How much does your illness affect your life? 2- how long do you think your illness will continue? 3- how much control do you have over your illness? 4- how much do you think your treatment can help your illness? 5- how much do you experience symptoms from your illness? 6- how concerned are you about your illness? 7-how well do you feel you understand your illness? And 8- how much does your illness affect your emo-

tionally? Finally, question 9 was to list in rank-order the three most important factors that you believe caused your illness.

For items 1, 2, 5, 6, and 8, a higher score reflects a more threatening view of the illness. While a lower score for items 3, 4, and 7 indicates a more pessimistic view.

The research was approved by the Institutional Review Board (IRB) committee of An-Najah National University. Participants' information for this study remained confidential and within the institution.

Sample size calculation

The sample size was calculated based on a response rate of 50% and the online Roasoft online calculator, with a total number of 130 of thalassemia patients attending Al-Wattani clinic. This calculation reported that the minimum required sample size is 98. In order to have a greater assurance in generalizing the findings in Palestine, it was decided to increase the number of surveyed patients to more than that if possible.

Grading the B-IPQ

A scale from 1-10 accompanied the questionnaire to extract information about different sections. The data from the questionnaire were entered into Statistical Package of Social Sciences (SPSS) version 20 software for further analysis. Descriptive statistics using frequencies and percentages were used to identify participants' perception. Chi-square (χ^2) test was performed to examine the relationship among the categorical variables including the relationships between the different characteristics of participants with all questions included in the questionnaire. In all statistical analyses, a p-value ≤ 0.05 was considered statistically significant. Mann-Whitney test was used to compare differences between two independent groups, and was performed on gender, age, and education questions. Kruskal-Wallis is a test that can be used to determine if there are statistically significant differences between two or more groups of an independent variable on a continuous or ordinal dependent variable; it was used for the questions about residency, and parents' relationship.

Results

Demographics

A total of 113 thalassemic patients were included in the study. About half (55; 48.7%) of the patients were males and the other half were females (58; 51.3%). The mean age of the participants was about 21.0±9.5 years old, with an age range of 12-70 years. Patients have been diagnosed since about 19.4± 7.4 years. The majority have college education (50; 44.2%), a lesser group had only elementary school education (36; 31.9%), and the rest had high school education (27; 23.9%). A bit more than half of the participants lived in villages (63; 55.8%), and the rest lived in cities (31; 27.4%), or camps (19; 16.8%). Blood group analysis for the patients showed that (62; 54.9%) had blood group A, (33; 29.2%) had blood group O, and (8; 7.1%) had blood group B, the rest (9; 8%) were AB blood group. Almost all participants were generally healthy and mostly did not have other diseases (111; 98.2%).

Family History

Data analysis pertaining to family history of the patients indicated that a large percentage (65; 57.5%) of the patients' parents had a consanguineous marriage, and about a quarter (25; 22.1%) were second degree relatives before marriage. The remainder had no family relationship between their parents before marriage (22; 19.5%).

Perception

Data from the B-IPQ is generally presented as median and interquartile range. In general, participants reported that they perceive their disease as chronic (timeline) (median of 10, and interquartile range from 10-10). Patients reported that the disease has minimal effect on their quality of life (consequences) (median of 3, and interquartile range of 0.5-3). Results indicate that participants believe that the treatment can control their disease to a significant extent (treatment control) (median of 10, interquartile range from 8-10), and that they can control their disease by themselves (personal control) (median of 8, interquartile range of 7-10). They reported that they mostly did not experience thalassemia-related health effects

(identity) (median of 2, interquartile range 2-3), and that they were not very concerned about their illness (illness concern) (median of 3, interquartile from 1-4). They also had very good understanding of their illness (coherence) (median of 8, interquartile range from 6-9), and that they were not strongly affected emotionally by thalassemia (emotional representation) (median of 3, interquartile range of 1-4), (Table 1). Testing for normality revealed that data is not normally distributed based on Shapiro-Wilk test, thus responses to the eight questions included in the B-IPQ were not normally distributed, so results are presented as median (interquartile range).

Table (1): Descriptive statistics of the eight items of the B-IPQ

Brief IPQ item	Median	Interquartile range
Consequence	3	0.5-3
Time line	10	10-10
Personal control	8	7-10
Treatment control	10	8-10
Identity	2	2-3
Illness concern	3	1-4
Understanding	8	6-9
Emotional representation	3	1-4

Data analysis regarding the effect of gender on perception using Mann -Whitney Test showed that there was a significant effect of gender on knowledge, with females having more knowledge about the time course of the disease (p= 0.041) (Table 2). Females believed that the treatment can control the disease more than men (p=0.02), females were more concerned about the disease compared to males (p=0.013), and females had more understanding the disease compared to males (p=0.032); (Table 2).

Table (2): The effect on illness perception based on gender, age, education, residence, and the number of years since diagnosis

	P value				
Perception item	**Gender***	**Age***	**Education***	**Residence***	**Years since diagnosis***
Consequences	0.052	**0.002**	0.100	0.508	**0.002**
Time line	**0.041**	0.061	0.171	0.271	0.101
Personal control	0.139	0.343	0.440	**0.004**	0.516
Treatment control	**0.020**	0.309	0.865	0.088	0.213
Identity	0.801	**0.000**	**0.010**	0.209	**0.000**
Illness concern	**0.013**	0.051	0.236	**0.009**	0.056
Understanding	**0.032**	**0.000**	**0.000**	**0.027**	**0.000**
Emotional representation	0.148	**0.001**	**0.043**	0.458	**0.001**

* Bold text indicates a statistically significant difference with a p-value less than 0.05

As for the effect of age, results show that it did have an effect on some aspects of perception, and all the significant results were associated with advancing age. For example, age had a high significant effect on both the identity and illness understanding (P values of 0.000 for both). Age also had a significant effect on the consequences and the emotional representation of the disease (P value of 0.002 and 0.001, respectively) (Table 2). Additionally, Kruskal-Wallis test on the effect of education showed that patients with college education had significantly higher understanding of the disease (P= 0.000), while patients with elementary education showed more significant effects regarding the identity and the emotional representation (P = 0.010 and 0.043, respectively) (Table 2). The same test revealed and effect of the place of residence on the perception items. There was a significant effect for the place of residence on how much personal control the patients felt they had (P = 0.004) with city residence believing they have more. Village residents

showed more in terms of illness concern (P= 0.009), and illness understanding (P= .027) (Table 2). Finally, it was found that the longer the time since the patient was diagnosed with thalassemia the more significant effect was found on the consequences (P= 0.002), identity (P= 0.000), understanding (P= 0.000), and emotional representation (P= 0.001) (Table 2).

DISCUSSION

There are many studies in the literature about patients' perception of many diseases in different countries around the world; however, similar studies in a resource-poor country like Palestine do not exist. To our knowledge, this is the first study of its type to assess patient perception of thalassemia in patients affected by this disease, no similar studies were found elsewhere. This study provides a unique opportunity to understand the psychological aspects of this group of patients. Understanding patients' perception of their own condition is a useful way to predict their behavior, especially with chronic illnesses. All the work on illness perception was based on a theory that proposes that individuals' perception of the disease affects coping with it [12, 13].

For the greatest percentage of participants, their parents were relatives before getting married. This is a current practice among the local community. The government is taking strict steps toward decreasing the emergence of new thalassemia cases by requesting a thalassemia test for couples planning to get married.

Illness perception is expected to increase adherence to therapy, improves family relations, and reduces inappropriate service use [14]. In our study, patient did have good knowledge about several aspects of their disease, such as its time course, which may be due to the fact that most of them have had the disease for a long time. Part of the good attitude patients had was because their disease had minimal effect on their life, based on their perception. Also, they had strong trust that their treatment is controlling their symptoms. A false believe they had is their belief that they can control their symptoms, even though it is known that thalassemia symptoms are not under patients control. An explanation for this could be the fact that they did not experience thalassemia-related symptoms to start with.

The various illness perception components depend to a certain degree on the symptoms patients have. In our study, patient suffering from thalassemia do not have several symptoms, thus it did affect their perception. In our study, patients believed that therapy is capable of controlling their symptoms, which is a positive attitude. This is due to the fact that those patients are regular attendants of the specialty clinic at Al-Wattani for their treatment.

The existing literature has shown that patient's illness beliefs affect clinical outcomes [15, 16]. Not only that, but also research among other patient groups have found that the time to death would be shorter in those patients who have negative psychological beliefs [17]. Thus, illness beliefs can predict survival, with special emphasis on the "identity" variable. The good news is that these beliefs are modifiable [16, 18-22], an aspect that should be focused upon by therapists treating thalassemia patients.

LIMITATIONS

This study has some limitations, for example, it used the B-IPQ and not the extended one, which provides answers about perceptions but not as detailed as the long questionnaire. Additionally, this was a pilot study conducted in Nablus, yet, patients in other cities may respond differently to the questions in the questionnaire. Finally, there was no data about patients' medications, particularly if they were taking antidepressants.

CONCLUSIONS

In conclusion, these findings showed that the participants perceive their disease as a chronic (timeline), yet it had minimal effect on their quality of life (consequences). They also believe that the treatment and themselves can control their disease. Incorporating patients' perception of thalassemia in the treatment plan will be worth the effort since it improves adherences to therapy and decreases mortality. Public education about thalassemia and the role of consignment mar-

riage in transferring it to the off spring is very important.

CONFLICT OF INTERESTS

The authors report no conflicts of interest in this manuscript.

REFERENCES

1) Kasper DL, Braunwald E, Fauci AS, Hauser SL, Longo DL, Jameson JL: *Harrisons manual of medicine*: McGraw-Hill Medical Publishing Division; 2016.

2) Vichinsky EP, MacKlin EA, Waye JS, Lorey F, Olivieri NF: Changes in the epidemiology of thalassemia in North America: a new minority disease. *Pediatrics* 2005, 116(6):e818-25.

3) Hamamy HA, Al-Allawi NA: Epidemiological profile of common haemoglobinopathies in Arab countries. *J Community Genet* 2013, 4(2):147-67.

4) 4. Khani H, Majdi MR, Marzabadi EA, Montazeri A, Ghorbani A, Ramezani M: Quality of life of Iranian beta-thalassaemia major patients living on the southern coast of the Caspian Sea. *East Mediterr Health J* 2012, 18(5):539-45.

5) 5. Yazdi K, Sanagoo A, Joybari L: Psychosocial, social and financial problems with coping strategies among families with thalassemic patients. *J Gorgan Univ Med Sci* 2007, 9(2):71-5.

6) 6. Marlow DR, Redding BA: *Textbook of pediatric nursing*: Saunders; 1988.

7) 7. Czajkowski SM: Health-related quality of life outcomes in clinical research: NHLBI policy and perspectives. *Ann Thorac Surg* 1998, 66(4):1486-7.

8) 8. Pakbaz Z, Treadwell M, Yamashita R, Quirolo K, Foote D, Quill L, Singer T, Vichinsky EP: Quality of life in patients with thalassemia intermedia compared to thalassemia major. *Ann N Y Acad Sci* 2005, 1054:457-61.

9) 9. Ghazavi Z, Minooei MS, Abdeyazdan Z, Gheissari A: Effect of family empowerment model on quality of life in children with chronic kidney diseases. *Iran J Nurs Midwifery Res* 2014, 19(4):371-5.

10) 10. Weatherall DJ, Clegg JB: Human Haemoglobin. In *The Thalassaemia Syndromes*. Blackwell Science Ltd; 2008:63-120.

11) 11. Kuo HT, Peng CT, Tsai MY: Pilot study on parental stress and behavioral adjustment to the thalassemia major disease process in children undergoing iron-chelation in western Taiwan. *Hemoglobin* 2006, 30(2):301-9.

12) Leventhal H: Chapter 1, Illness representations: theoretical foundations. In *Perceptions of health and illness: current research and applications*. Edited by Petrie KJ, Weinman JA. London: Routledge; 1997:19-45.

13) Leventhal H, Nerenz DR, Purse J: Illness representations and coping with health threats. In *Handbook of Psychology and Health*. Edited by Baum A, Taylor SE, Singer JE. NJ: Erlbaum; 1984.

14) Kuipers E, Watson P, Onwumere J, Bebbington P, Dunn G, Weinman J, Fowler D, Freeman D, Hardy A, Garety P: Discrepant illness perceptions, affect and expressed emotion in people with psychosis and their carers. *Soc Psychiatry Psychiatr Epidemiol* 2007, 42(4):277-83.

15) Hampson SE, Glasgow RE, Strycker LA: Beliefs versus feelings: A comparison of personal models and depression for predicting multiple outcomes in diabetes. *British Journal of Health Psychology* 2000, 5(1):27-40.

16) Mc Sharry J, Moss-Morris R, Kendrick T: Illness perceptions and glycaemic control in diabetes: a systematic review with meta-analysis. *Diabet Med* 2011, 28(11):1300-10.

17) Crawshaw J, Rimington H, Weinman J, Chilcot J: Illness Perception Profiles and Their Association with 10-Year Survival Following Cardiac Valve Replacement. *Ann Behav Med* 2015, 49(5):769-75.

18) Petrie KJ, Perry K, Broadbent E, Weinman J: A text message programme designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. *Br J Health Psychol* 2012, 17(1):74-84.

19) Broadbent E, Ellis CJ, Thomas J, Gamble G, Petrie KJ: Further development of an illness perception intervention for myocardial infarction patients: a randomized controlled trial. *J Psychosom Res* 2009, 67(1):17-23.

20) Broadbent E, Ellis CJ, Thomas J, Gamble G, Petrie KJ: Can an illness perception intervention reduce illness anxiety in spouses of myocardial infarction patients? A randomized controlled trial. *J Psychosom Res* 2009, 67(1):11-5.

21) Chilcot J, Wellsted D, Farrington K: Illness perceptions predict survival in haemodialysis patients. *Am J Nephrol* 2011, 33(4):358-63.

22) Jones CJ, Smith HE, Llewellyn CD: A systematic review of the effectiveness of interventions using the Common Sense Self-Regulatory Model to improve adherence behaviours. *J Health Psychol* 2015, 21(11):2709-24.