

EXAMINING MEANING IN LIFE AMONG PATIENTS WITH THALASSEMIA: A CROSS SECTIONAL STUDY

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ABSTRACT

Objectives: The study was conducted with the aim of examining meaning in life among patients with thalassemia, the knowledge of which is essential in developing more suitable clinical, counseling, and social support programs to improve treatment outcomes of these patients.

Design of the Study: A comparative research design

Place and Duration of Study: Different Universities of Karachi from January 2022-January 2023

Sample and method: The study sample consisted of 45 thalassemia patients (ages 11 to 50 years) who were selected randomly, who completed the Meaning in life Questionnaire (Steger et al., 2006) comprising 10 items to determine the presence and search for meaning.

Results and Conclusion: Results showed that minor thalassemia patients had higher meaning in life than major thalassemia patients ($P < .05$). Results regarding gender and age were inconclusive. It may be concluded that higher meanings in life in patients with Thalassemia minor not only reduces distress but also contribute in better adjustment with the disease.

Keywords: Meaning in life (Search for meaning; Presence of meaning); Thalassemia; Major; Minor

INTRODUCTION

Human beings have been asking about the meaning in life and they strive to make their lives more meaningful since the beginning of their existence. Generally, the meaning in life helps individuals to align their interest, passions and motivations that empowering individuals to live a more purpose-driven life. Meaning in life is a broad concept, which can be broken down into two dimensions, namely presence of meaning and search of meaning. *Presence of meaning* refers to “the degree to which people experience their lives as comprehensible and significant and feel a sense of purpose or mission in their lives that transcends the mundane concerns of daily life”, whereas *search for meaning* concerns “the dynamic, active effort people expend trying to establish and augment their comprehension of the meaning, significance, and purpose of their lives” (Li et al., 2019).

Meaning in life is an important aspect and is highly significant to an individuals’ life. Subsequent studies conducted over the past decades to find importance of meaning in life are yet to examine that meaning in life act as a buffer against negative consequences (Pearson & Sheffeld, 1989), and decreases their vulnerability to acquiring mental health issues (Debats, 1999). On the other hand, having a clear life meaning is essential for fostering emotional well-being (O’Connor & Chamberlain, 1996; Zika & Chamberlain, 1992) and enhances the quality of living (Fitzpatrick, 1983). Furthermore, findings demonstrated that if an individual does not find meaning he/she becomes existentially frustrated, which may lead to psychopathology (Crumbaugh & Maholick, 1964).

Moreover, Vail and Routledge (2020) identified meaning in life as a basic human need which affects not only physical but also psychological well-being and such people live not only a longer life but also a happier one and the people who faced mental health challenges but have meaning in life are more likely to show compliance to treatment regimen and more responsive to psychotherapy (Park, 2010; Debats, 1996). A significant amount of empirical data supports the notion that life meaning serves as a vital protective factor against stress and also fostering physical, psychological and mental well-being.

Although studies examining meaning in life on different types of people such as smoking cessation patients, cancer patients, older persons, university students (Hupkens et al., 2018; Khan et al., 2015; Steger et al., 2009; Jim et al., 2006) but the topic has not been explored with relevance to thalassemia.

However, examining meaning in life among different groups is important but in thalassemia patients is essential because this can have a positive impact on their management of disease. Thalassemia is a genetically inherited condition when the body fails to produce sufficient hemoglobin, leading to abnormal red blood cells. A person with a trait or minor form may not have symptoms or only mild one that may not need treatment. Someone with a major form will need medical treatment (Galanello & Origa, 2010).

Diagnoses with Thalassemia, which is extremely stressful and traumatic that disturbs the person's life. It is a very common disease all over the world as about 3% of the global population carries a major Thalassemia gene, leading to around 60,000 newborns being diagnosed with thalassemia annually worldwide (Asif & Hassan, 2016). In Pakistan, the carrier rate of thalassemia is 5-7% and every year around 5000 thalassemia major children are born (Khaliq, 2022).

However, evaluating life meaning is particularly crucial for individual with thalassemia. As mentioned above, meaning in life is an important aspect of an individual life. So, it is very important to examine meaning in life among thalassemia because they are dealing with their disease even from the first day of their life, they are fighting with this disease throughout their lives. No doubt people with thalassemia survive into adulthood due to advanced medical treatment but this disease renders them fragile. This situation makes it imperative to explore their meaning in life. It's essential to find what is the purpose of their lives or are they still searching for meaning in their lives. This study helps in developing more appropriate clinical, counseling, and social support programs to alleviate treatment outcomes of thalassemia patients.

The existing literature found that all of the above-mentioned researches on meaning in life play an important role in the lives of individuals. However, it has been noted that research till now does not exhibit thalassemia. Although the number of studies that examine meaning in life among different types of people is not huge with regards to thalassemia patients, this issue is still comparatively studied less in the literature, which makes it imperative to study this concept at length.

The objective of the study was to find meaning in life between major and minor thalassemia patients as well as to recognize differences in gender and age cohort. To get objective findings that could be standardized or generalized over the thalassemia patients for which following hypotheses to be considered.

- I. There would be a significant difference in meaning in life between major and minor thalassemia patients.
- II. There would be gender differences between thalassemia patients on the scores of meaning in life.
- III. There would be cohort differences in the mean scores of meaning in life.

METHOD

Participants

The sample size of 45 was selected through G*power software (Version 3.1.9.4) with an effect size of 0.70, α error 0.05 with power of 0.95 (Abbas et al., 2021). Out of 45 patients, 20 were with thalassemia minor and 25 were with thalassemia major condition, conveniently selected from a Thalassemia hospital of Karachi Furthermore, the age of the patients was divided into two groups 11-30 & 31 -50 years.

Inclusion criteria

Only those patients were included in the sample, who were willing to participate and cooperate in the study. Secondly, those whose age ranges between 11 to 50 years. Finally, thalassemia patients were the third inclusion criteria of the present study.

Exclusion criteria

Only those patients were excluded in the sample, who were not willing to participate and those whose age were below 11 were excluded. Further, Non-thalassemia patients were also excluded.

Measures

Demographics Information Sheet:

A demographic questionnaire was used to gather basic demographic information about the patients. Its aim was to capture patients' self-identified gender identity, current age, thalassemia center name, family system, qualification, diagnoses (early or chronic), thalassemia major or thalassemia minor.

Meaning in Life Questionnaire (Steger et al., 2006):

The MLQ was developed by Steger et al. (2006). Meaning in life is defined as “the sense made of and significance felt regarding the nature of one’s being and existence”. The MLQ contains 10 items, with 5 items assessing presence of meaning and another 5 items assessing search for meaning, and reversed scoring was done for item no 9, “my life has no clear purpose”. The scores for each subscale range from 5 to 35. The scale demonstrates strong internal consistency, with coefficient alpha values falling within the .80 range, for the presence of meaning in life subscale it is in mid .80s and for the search of meaning subscale it is in .90s. A higher score indicates presence of meaningfulness in their lives or actively seeking meaning in their lives (Steger et al., 2006).

Procedure

After seeking permission from hospital authorities, the researcher conducted in-person meetings with patients to clearly explain the study’s goal and rationale. After establishing rapport with the patient, the consent was sought and requested them to participate voluntarily and cooperate fully during the data collection process. Participants were informed that their responses would remain confidential and would be used solely for research purposes. They were also assured that they can withdraw at any point if they wish so. The patients were asked to read the consent form, after reading the consent form and filling the demographic sheet, they were also requested not skip any personal information question. The instructions were read very carefully given on the top of each scale, asked to fill the meaning in the life scale. Each patient took almost 20 minutes to answer the questionnaire.

Quantitative research design with comparative approach was used in this research. Descriptive statistics, including mean, standard deviation, and frequency, while to make the inference independent t-test was calculated to find the difference between thalassemia major and minor patients using SPSS; V-22. The data was tabulated very carefully for analyzing the data so that the results can be interpreted and communicated in a comprehensive manner.

All the steps outlined in the procedure followed ethical steps including informed consent, confidentiality, right to withdraw and anonymity of data.

RESULTS

Table 1
Sociodemographic Characteristics of Patients at Meaning in Life

Characteristics	Major Patients		Minor Patients		Full n	Sample %
	N	%	N	%		
Gender						
Male	12	48.0	12	60.0	21	46.7
Female	13	52.0	8	40.0	24	53.3
Age						
11 - 30	24	96.0	13	65.0	37	82.2
31 - 50	1	4.0	7	35.0	8	17.8
Family system						
Joint	6	24.0	3	15.0	9	20.0
Nuclear	19	76.0	17	85.0	36	80.0
Qualification						
Grade 0	8	32.0	5	25.0	13	28.9
Grade 10	13	52.0	4	20.0	17	37.8
Grade 12	2	8.0	3	15.0	5	11.1
Grade 16	2	8.0	8	40.0	10	22.2
Diagnoses						
Early	23	92.0		20.0	27	60.0
Chronic	2	8.0	4	80.0	18	40.0

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Note. (n=45)

Table 1 present the frequency distribution and the percentages of all the demographic variables that were considered in this study.

Table 2
Psychometric Properties for MLQ Scale

Scale	<i>M</i>	<i>SD</i>	Range	α
Meaning in life total scores	36.06	9.90	15 – 55	0.636

Note. Cronbach's α is the reliable for this scale

Table 2 shows psychometric properties for the scale used in present study. The Cronbach's α value for Meaning in life Questionnaire was .636 (<.70) which indicated low internal consistency.

Table 3
*Difference Between Major Thalassemia Patients & Minor Thalassemia Patients
 On Meaning In Life Questionnaire (N = 45)*

	Major		Minor		<i>t</i>	<i>P</i>	Cohen's d
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
MILQ	31.40	9.03	42.25	6.95	-4.419	.000	-1.11

Note. *** $p < .001$, Mean parameter values of the analysis are shown for the major patients (n=25) and minor patients (n=20), as well as the results of t-test (assuming unequal variance) comparing the parameter estimation between major and minor patients.

Table 3 illustrated significant mean differences in meaning in life with t (43) = -4.419, $p <.05$. Findings showed that minor patients exhibited higher scores on Meaning in life ($M=42.25$, $SD= 6.95$) compared to the major patients ($M=31.40$, $SD = 9.03$). The value of Cohen's d was -1.11 which indicated a large effect size.

Table 4

Difference Between Male & Female Thalassemia Patients on Meaning in life Questionnaire

	Male		Female		<i>t</i>	<i>P</i>	Cohen's d
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
MILQ	35.29	11.53	37.29	7.36	-.68	.50	-.204

Note. Mean parameter values of the analysis are shown for the male patients (n=24) and female patients (n=21), as well as the results of t-test (assuming equal variance) comparing the parameter estimation between male and female thalassemia patients.

Table 4 illustrates that there are no significant mean differences in meaning in life with *p* value is .50 which is higher than standard value 0.05. The value of Cohen's *d* was -.20 which indicated small effect size.

Table 5

Independent t Test Between Age Cohorts (11-30) (31-50) on Meaning in life Questionnaire

	Age		Age		t	p	Cohen's d
	11 to 30	31 to 50	M	SD			
Meaning in life Questionnaire	35.54 1.008	10.45 .31	39.38	4.68			-.39

Note. p<0.05; This table showed that there is no significant difference between both age groups regarding meaning in life questionnaires.

Table 5 illustrates that there is no age cohort between (11-30) & (31-50) groups regarding meaning in life so our null hypothesis has been accepted. P value is .31 greater than standard value 0.05 The value of Cohen's d was -.39 which indicated small effect.

DISCUSSION

The present study examines meaning in life among thalassemia major and minor patients in Karachi, Pakistan. Table 1 shows the descriptive statistics for the demographic characteristics of the sample. Table 2 shows the psychometric properties of scale, the Cronbach alpha is reported to be .636. Researchers have hypothesized that there would be a significant difference between major and minor thalassemia patients' meaning in life. Table 3 illustrated significant mean differences in meaning in life with results showed that minor patients scored higher on Meaning in life compared to the major patients. The value of Cohen's d was -1.11 which indicated a large effect size. Stavrova and Luhmann (2016) stated that meaning in life predicted connection with community, family, friends and partner. A meta-analytic review by Almeida et al. (2022) showed high levels of meaning in life are associated with high levels of posttraumatic growth in cancer patients. Since there is a dearth of studies on thalassemia patients, studies on other kinds of patients. When people have

meaning in life, it allows them to have a positive experience of their lives that is why better health outcomes are seen as outcome variables.

This finding confirmed the research hypothesis. Hence, present study gave evidence that that minor thalassemia patients would have higher meaning in life than major thalassemia patients. One of the reasons for this finding is that major thalassemia patients are more concerned about their physical health, because they are diagnosed with this from their early childhood, So, disease weakened them from inside day by day. Meanwhile minor patients live normal lives and do not know about their disease until they have routine tests. They don't know that they have minor thalassemia and have the strength and motivation of achieving their life goals, and even searching for meaning actively.

Further, gender differences were also explored between thalassemia major and minor patients. Table 4 illustrates that there are no significant mean differences in meaning in life with p value is .500 which is higher than standard value 0.05. The value of Cohen's d was -.204 which indicated small effect size. It means both the genders react similarly to the disease and have more or less similar in the perception of meaning in life. Whereas, Xi et al. (2018) found that women scored higher on meaning in life while studying the mediating role of altruism, in which women engaged more. In another study Dhanjal (2019) reported that male scored higher on meaning in life.

Last attempt was made to explore the cohort differences, again no significant difference was found with regards to meaning in life, but the senior group scored greater mean scores as compared to younger group, this might be due to survival over the years which motivate them to find meaning in life. Table 5 illustrates that there is no age cohort between (11-30) & (31-50) groups regarding meaning in life so our null hypothesis has been accepted. P value is .319 greater than standard value 0.05 The value of Cohen's d was -.393 which indicated small effect size. Krause and Rainville (2020) while studying age differences in meaning in life found a nonlinear relationship between age and meaning in life, exploring the mediating role of social support.

In the absence of existing literature of this variable with regard to thalassemia patients, this study would prove pivotal in the area.

Conclusion

Researchers strongly suggested that thalassemia patients (minor and major) perceive meaning in life differently. Hence the purpose of the study was to examine the meaning in life among minor and major thalassemia patients differently. It proved that minor thalassemia patients have higher meaning in life than major thalassemia patients. Meaning in life reduces not only distress about disease but also predicts better adjustment to the disease.

Limitations and Recommendations

Limitations of the present study include the use of convenient sampling technique & data were collected from one thalassemia center of Karachi, Pakistan so it prevents generalizability of the result. Further, the sample size needs to be increased because small sample size could affect the accuracy of the result. Hence the data collected from 11 to 50 years old patients but due to the small sample size could not separately assess, so the future research needs to assess equal age range & also gender specific patients with respect to minor and major. The future research should expand its goal in identifying meaning in life in the areas of other palliative care.

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