

Quality-of-life of patients living with thalassaemia in the West Bank and Gaza

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Abstract

Background: In countries with low resources, the health and quality-of-life of people living with thalassaemia can be severely affected.

Aims: This study examined the health-related quality-of-life of people living with thalassaemia in the West Bank and Gaza, Palestine.

Methods: This was a cross-sectional study of a convenience sample of 104 patients (71 adults and 33 children) who lived with thalassaemia and their families in 2015 in the West Bank and Gaza. Participants were surveyed using the 36-item Short Form Health Survey, version 2 (SF36v2), Pediatric Quality of Life Inventory™ (PedsQL) and PedsQL Family Impact Module to assess their quality-of-life. With the SF36v2, we used normed-based scoring and for the PedsQL and Family Impact Module, we used the 0–100 scoring. Scores are reported as means and standard deviations and $P < 0.05$ considered statistically significant.

Results: Quality-of-life scores were low across all domains, indicating poor quality-of-life. For bodily pain in the SF36v2, a significant difference was observed between the West Bank and Gaza. No significant differences were found between males and females. Data from the PedsQL showed no significant differences between the West Bank and Gaza. With the Family Impact Module, the summary score was higher among adults than among paediatric patients. Compared with other countries, thalassaemia patients in Palestine generally had lower quality-of-life scores in most domains.

Conclusion: The lack of access to healthcare and blood transfusions, and the geopolitical challenges may be responsible for the low quality-of-life scores of patients living with thalassaemia in Palestine.

Keywords: thalassaemia, quality-of-life, cross-sectional study, West Bank, Gaza.

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Introduction

Worldwide, genetic haemoglobinopathies such as thalassaemia are considered serious health burdens. In the United States of America, thalassaemia is rare and considered a disease of migration and it is managed as a chronic illness (1,2). However, in countries with less resources, the health burden of thalassaemia patients, which will also be a family burden, affects health-related quality-of-life (3,4). Thalassaemia is common in the Mediterranean, Middle East and sub-Saharan Africa (5). The prevalence of thalassaemia in Palestine which includes the Occupied West Bank and Gaza, is high; about 4% of the population are carriers (4). The political conflict and often violent conditions in Palestine complicate medical care of patients and their families who need to make regular clinic visits. Blood supply for transfusions is limited and chelation medication treatments are expensive or unavailable. Continuity of care is lacking, social and psychological support services are limited, and there are few healthcare workers with specialized training in the management of thalassaemia. The World Health Organization (WHO) lists Palestine as having

the second-lowest health expenditure as a percentage of the Gross National Product among the Middle Eastern countries (6).

The quality-of-life and outcomes of people with thalassaemia vary depending on clinical care and other circumstances. In Palestine, thalassaemia patient-reported health outcomes are poorly understood, and clinical research data are limited (7–10).

Research that measures quality-of-life can help identify the effect of chronic illness on patients' lives and allows comparison of different groups (11).

This study aimed to identify the quality-of-life of people with thalassaemia in the West Bank and Gaza. In 2009, we conducted a pilot study on the quality-of-life of patients with thalassaemia in Palestine (12). The study was designed to answer the question: could behavioural and social science research data be systematically collected in contested areas classified by WHO as a low-income country? Our study in 2015 is a follow-up to that pilot. During the time of this study, regional conflict was a challenge to conducting this research (13,14). This study also compares Palestinian data with other populations

such as Turkey, Thailand, Italy, Greece and Middle Eastern countries.

Methods

Sample, instruments and data collection

Both the 2009 and 2015 studies were cross-sectional and used convenience samples recruited from regional clinics in Palestine. In 2009, only adults were part of the sample. In 2015 we expanded the sample to include children and their guardians. Data were collected on demographic characteristics of the sample. Three standardized quality-of-life tools were used: the 36-item Short Form Health Survey, version 2 (SF36v2), Pediatric Quality of Life Inventory™ (PedsQL) and PedsQL Family Impact Module (FIM).

Patients with thalassaemia and guardians of patients with thalassaemia who attended a transfusion clinic were approached to participate in the study. If they were interested they were provided with information and an informed consent form to sign. If they chose to participate and signed the consent form, they were given the surveys to complete.

The instruments used in the study measured a patient's quality-of-life and the impact the patient had on their family. The widely used SF36v2 instrument measures quality-of-life for young adults (ages ≥ 16 years) and older patients (15). The 36-item questionnaire measures 8 dimensions of general health-related quality-of-life: physical functioning, role physical (limitation because of physical health problems), bodily pain, general health, vitality, social functioning, role emotional (limitations due to emotional problems), and general mental health. Two summary scores assess physical and mental dimensions of health and well-being: physical component summary score and the mental component summary score. A high score indicates a more favourable health state. The instrument has been used extensively in clinical trials and academic studies, across disease areas, including thalassaemia. Its validity and reliability to measure health-related functional status and well-being have been established (15). It has a high level of consistency across countries and the Arabic translation has been validated (16).

The PedsQL 4.0 generic core scales contain 23 items grouped into four scales: physical functioning, emotional functioning, social functioning and school functioning. It also includes composite scales for a total scale score (23 items) and a psychosocial health summary score which is the sum of emotional, social, and study/work functioning. A high score indicates a more favourable health state (17–19). All paediatric patients and their caregivers were surveyed using the PedsQL.

The FIM survey has 36 items and measures the effect of chronic paediatric health conditions on parents and the family. The survey measured six scales of parent self-reported functioning: physical functioning, emotional functioning, social functioning, cognitive functioning,

communication and worry. It also measures two scales for parent-reported family functioning: daily activities and family relationships (20).

In 2009 we used the SF36v2. In 2015, we assessed paediatric health-related quality-of-life using the PedsQL. Because of the chronic nature of transfusion-dependent thalassaemia, we used the PedsQL FIM to assess the impact the disease had on caregivers.

Statistical analysis

The SF36v2 manual provides a standardized approach for statistically analysing the data. It allows a systematic approach for converting the individual data points into a meaningful component for a scale. The initial step converts the score into a 0–100 range with 0 (worst health) to 100 (best health) results. The SF36v2 designers recognized that the component nature of the scales and what they intended to measure were widely variable; the range between top and bottom scores varied substantially across health domains. Without understanding this, the data could be easily misinterpreted. Therefore, in order to simplify interpretation and make direct comparisons, a norm-based scoring approach can be used with the SF36v2, where each scale has the same average (50) and same standard deviation (SD) (11). This approach makes the health impact of a domain norm-based scoring score clearer and can more accurately reflect the impact of the disease. An individual score of < 45 or a group score of < 47 indicates that quality-of-life is severely affected. Norm-based scoring requires the assessment of a general population, and because SF36v2 was developed in the United States (US), it uses the US population as its norm.

The PedsQL and the FIM were scored using the 0–100 scale. For comparisons across studies, the *P* values were used for all instruments. $P < 0.05$ was considered statistically significant.

Ethics

The study was approved by the Institutional Review Board Committee of the California State University San Marcos and the ethics review and administrative authority of the clinics where the participants were drawn. Support to conduct the study and obtain participants was provided by the Thalassaemia Patients Friends Society. The Thalassaemia Patient's Friends Society is a non-profit Palestinian nongovernmental organization working to build patient capacity to manage their health, economic and social lives to improve their quality-of-life (21,22). All patients who visited clinics at the time of the study were invited to participate voluntarily. Patients were excluded only if they chose not to participate.

Results

Characteristics of the sample

At the time of the 2015 study, there were 750 people with thalassaemia and their families in the West Bank and Gaza. Of these people, 104 participated in the study: 65 from the West Bank and 39 from Gaza. Our sample size

was adequate compared with other published studies on thalassaemia. Seventy-one participants completed the SF36v2, and 33 paediatric participants completed the PedsQL (Table 1). The participants were distributed fairly equally by sex: 51 males and 52 females overall (data on sex were missing for one person). The age range was < 10 years to \geq 30 years; most were between 15 and 24 years. Of the 33 participants who completed the PedsQL, 19 were from Gaza and 14 from the West Bank.

SF36v2 results

In the 2015, 71 participants completed the SF36v2 (Table 2). Most participants were from the West Bank, 46 compared with 25 from Gaza. SF36v2 scores were poor for physical functioning and mental health. The physical health component scores showed a statistically significant difference between Gaza (40.53) and the West Bank (39.49). However, the mental health component scores showed no statistical differences, but Gaza patient scores were lower than those from West Bank. Gaza scored lower in most domains than the West Bank and had the lowest mental health component score (31.45). Male and female scores were low in most areas with females scoring lower for bodily pain (34.52), social function (33.67), mental health (33.29) and mental health component score (32.46). The only significant difference in scores in the various domains was between Gaza and West Bank for bodily pain; no significant difference was seen between the sexes. Male participants in the West Bank scored significantly lower for bodily pain than male and female participants in Gaza. In the analysis by location and sex, the lowest scores were in the mental health component summary.

PedsQL results

Of the 33 participants who completed the PedsQL, 19 were from Gaza and 14 from the West Bank (Table 3). The scores in Gaza were consistently lower than in West Bank

across all domains. However, these differences were not statistically significant. Most (61%) of the participants were female. In the child self-report, females generally scored lower than males, except for school functioning. The lowest score for females was for physical functioning (54.06). The differences between males and females were not significant. The ages were < 10 (27%), 10–14 years (36%) and \geq 15 years (36%). The oldest age group scored the lowest for all domains. Parents scored children 10–14 years the highest, except for school functioning where parents scored both younger and older age groups higher (Table 3).

FIM results

In the Family Impact Module scoring, the 104 participants who completed the survey scored lowest in physical and emotional functioning (Table 4). Overall, males had lower scores than females. Parents perceived that younger children were harder to understand when they communicated on their health care. However, as the children got older, the scores generally increased indicating that overall the families seem to have adapted to thalassaemia healthcare needs.

Discussion

PedsQL comparison

In comparison with studies using the PedsQL in Turkey, among Middle-Eastern patients in Italy and in Thailand, the Palestinian scores were consistently lower across all domains (Table 5) (23–25). The PedsQL scores were significantly higher in Turkey and Thailand in the domains of emotional functioning, social functioning, psychosocial health summary score and overall functioning (23,24). Scores in Thailand were significantly higher for physical functioning (24). The scores in Italy were not significantly different from our Palestinian

Table 1 Demographic characteristics of the sample, by region and questionnaire, Palestine, 2015

Variable	Total, no. (%) (n = 104)	Total, %		PedsQL, %		SF36, %	
		WB (n = 65)	Gaza (n = 39)	WB (n = 19)	Gaza (n = 14)	WB (n = 46)	Gaza (n = 25)
Sex^a							
Male	51 (49)	28	23	7	12	21	11
Female	52 (50)	30	22	6	8	24	14
Child, age in years							
< 10	9 (9)	4	5	4	5	NA	NA
10–14	12 (12)	6	6	6	6	NA	NA
\geq 15	12 (12)	4	8	4	8	NA	NA
Adult, age in years							
< 20	17 (16)	10	7	NA	NA	10	7
20–24	32 (31)	15	17	NA	NA	15	17
25–29	13 (13)	12	1	NA	NA	12	1
\geq 30	9 (9)	9	0	NA	NA	9	0

PedsQL: Pediatric quality-of-life Inventory™; SF36v2: 36-item Short Form Health Survey, version 2; WB: West Bank; NA: not applicable.

^a Information on sex was missing for one person.

Table 2 Scores on the SF36v2 of Palestinians affected by thalassaemia in the West Bank and Gaza, 2015

Variable	No. (%) n = 71	Mean score (SD)									
		PF	RP	BP	GH	Vitality	SF	RE	MH	PCS	MCS
Total		43.99 (9.06)	40.33 (10.09)	35.69 (10.52)	37.38 (5.96)	43.69 (6.65)	35.03 (8.09)	35.62 (12.02)	33.63 (7.77)	40.21 (4.79)	32.35 (7.98)
Region											
Gaza	25 (35)	42.97	38.63	41.49	37.78	42.72	36.78	32.87	34.01	41.53	31.45
West Bank	46 (65)	44.54	41.25	32.54	37.16	44.22	34.08	37.12	33.42	39.49	32.83
P (Gaza vs West Bank)	NA	0.24	0.12	< 0.001*	0.31	0.16	0.08	0.06	0.37	0.040*	0.22
Sex^a											
Male	38 (54)	43.30	39.45	36.54	37.81	43.38	36.61	34.40	34.15	40.08	32.60
Female	32 (46)	45.26	41.78	34.52	36.64	44.38	33.67	37.54	33.29	40.43	32.46
P (male vs female)	0 (45)	0.16	0.13	0.17	0.16	0.23	0.10	0.09	0.39	0.43	0.41
Sex and region											
Gaza male	14 (37)	42.45	36.74	43.40	38.36	41.61	38.15	31.17	33.92	41.70	30.93
West Bank male	24 (63)	43.53	40.22	33.24	37.88	44.03	35.03	35.15	33.82	39.38	32.66
P (Gaza male vs West Bank male)	NA	0.37	0.12	< 0.001*	0.40	0.08	0.13	0.15	0.48	0.08	0.22
Gaza female	11 (34)	43.64	41.05	39.07	37.03	44.14	35.03	35.03	34.14	41.31	32.11
West Bank female	21 (66)	46.11	42.16	32.13	36.43	44.51	32.96	38.85	32.84	39.97	32.65
P (Gaza female vs West Bank female)	NA	0.21	0.37	0.018*	0.37	0.44	0.22	0.16	0.34	0.21	0.43
Age, in years											
< 20	17 (24)	41.83	39.17	38.17	36.36	42.90	36.55	33.85	32.80	39.90	31.81
20-24	32 (45)	44.20	40.50	36.22	37.45	43.73	33.98	35.69	33.75	40.51	32.04
25-29	13 (18)	47.48	40.46	31.56	37.86	43.21	35.03	38.24	34.19	39.90	33.22
≥ 30	9 (13)	40.50	38.31	36.16	36.66	45.40	34.25	34.22	33.11	38.42	32.70

SF36v2: 36-item Short Form Health Survey, version 2; SD: standard deviation; PF: physical functioning; RP: role physical; BP: bodily pain; GH: general health; SF: social functioning; RE: role emotional; MH: mental health; PCS: physical health component score; MCS: mental health component score; NA: not applicable.

^a Information on sex was missing for one person.

*Significant at P < 0.05.

Table 3 Scores on the PedsQL of Palestinians affected by thalassaemia by demographic characteristics, 2015

Variable	No. (%) n = 33	Mean (SD)											
		Child self-report					Parent proxy report						
		Physical functioning	Emotional functioning	Social functioning	School functioning	Psychosocial health summary score	Overall	Physical functioning	Emotional functioning	Social functioning	School functioning	Psychosocial health summary score	Overall
Total		58.24 (30.00)	63.18 (24.96)	77.88 (23.02)	58.33 (24.32)	66.45 (20.88)	63.60 (22.10)	60.16 (0.39)	63.48 (0.48)	78.03 (0.49)	54.39 (0.26)	63.52 (0.28)	63.52 (0.49)
Region													
Gaza	19 (58)	54.77	59.74	77.37	54.21	63.77	60.64	58.06	59.47	78.42	53.16	61.73	61.73
West Bank	14 (42)	62.95	67.86	78.57	63.93	70.09	67.61	63.01	68.93	77.50	56.07	65.94	65.94
P	NA	0.24	0.21	0.45	0.15	0.23	0.22	0.32	0.15	0.46	0.38	0.30	0.30
Sex													
Male	13 (39)	64.66	67.69	84.23	55.77	69.20	67.62	63.94	63.85	84.62	54.23	66.30	66.30
Female	20 (61)	54.06	60.25	73.75	60.00	64.67	60.98	57.70	63.25	73.75	54.50	61.70	61.70
P	NA	0.16	0.19	0.08	0.31	0.26	0.19	0.26	0.47	0.07	0.49	0.25	0.25
Age, in years													
< 10	9 (27)	61.11	63.89	74.44	71.67	69.96	66.88	49.65	63.33	78.33	71.11	63.53	63.53
10–14	12 (36)	60.42	67.08	79.58	55.83	67.50	65.04	71.09	65.42	80.42	42.50	65.67	65.67
≥ 15	12 (36)	53.91	58.75	78.75	50.83	62.78	59.69	57.11	61.67	75.42	53.75	61.35	61.35

PedsQL: Pediatric Quality of Life Inventory/TM; SD standard deviation; NA: not applicable.
*Significant at P < 0.05.

scores (25). These statistically significant lower findings may reflect environmental challenges related to lack of resources. Data collection for our study was during a period of substantial conflict in Palestine.

FIM comparison

The FIM results demonstrate that Palestinian parents are affected similarly compared with studies in other areas (Table 6). Palestinian parents appeared to have poorer quality-of-life on the parental quality-of-life measures than other studies, but the differences were not statistically significant. For the family quality-of-life, Palestinian families appeared to be doing better in the overall domain, although no significant differences were found except in the domain of daily activities (26). The effect on the family of having a child with thalassaemia was similar across studies (Table 6).

SF36v2 comparison

In our statistical analysis comparisons, many Middle Eastern studies that used the SF36v2 only reported their 0–100 results. Most did not report the scale range (bottom to top). While potentially useful for understanding internal differences between patients, the lack of data on a standardized general population limited what these studies in the Middle East could report. Because the research studies we used for comparison only published 0–100 scores and not norm-based scoring, it was difficult to interpret the significance of differences in scoring.

Palestinian SF36v2 scores were generally lower across all domains (Table 7), except when compared with older Italian patients with thalassaemia in a 2008 study in Milan where Palestinian thalassaemia patients scored better for social functioning and role emotional (27). Because the Italian study did not report standard deviations, we do not know whether this difference was statistically significant. Compared with the results of another Italian study in 2008, the only significant difference with our results was for bodily pain, with Palestinian patients having lower scores (28). Compared with the results of a 2021 Italian study, Palestinians in our study had significantly lower scores than Italian patients for lower bodily pain, general health, vitality and social functioning (29). Because these data are not norm-based scores, we do not

Table 4 Scores on the Family Impact Module of Palestinians affected by thalassaemia by demographic characteristics, 2015

Variable	No. (%) n = 104	Parental quality of life				Family quality of life				Overall		
		PF	FF	SF	CF	Communication	Worry	Daily activity	Family relation		Parent	Summary Family
Total		57.29 (24.84)	55.34 (28.03)	67.79 (27.70)	63.37 (25.53)	63.46 (28.26)	54.28 (26.32)	65.06 (28.40)	73.13 (26.23)	60.42 (22.33)	73.13 (24.05)	61.97 (22.13)
Age group												
Child	33 (32)	54.92	61.52	69.32	62.88	56.06	50.00	58.84	66.06	61.44	57.81	59.83
Adult	71 (68)	58.39	52.46	67.08	63.59	66.90	56.27	67.96	76.41	59.95	66.75	62.97
P	NA	<0.001*	0.19	0.42	0.24	0.08	0.06	0.26	0.06	0.49	0.03*	0.24
Region												
Gaza	44 (42)	49.34	52.61	67.19	61.36	58.90	49.55	63.07	68.30	56.73	59.69	58.05
West Bank	60 (58)	63.13	57.33	68.23	64.83	66.81	57.75	66.53	76.67	63.13	67.01	64.85
P	NA	<0.001*	0.19	0.42	0.24	0.08	0.06	0.26	0.06	0.49	0.129	0.29
Sex												
Male	51 (49)	53.51	57.24	62.50	62.24	56.80	52.76	63.60	73.68	58.42	62.09	60.05
Female	52 (50)	60.03	57.97	75.39	65.94	67.45	53.59	64.32	67.66	64.06	62.60	63.41
P	NA	0.31	0.12	0.45	0.07	0.36	0.37	0.25	0.44	0.41	0.30	0.38
Age, in years												
< 10	9 (9)	45.24	50.00	52.68	60.00	36.90	40.71	46.43	52.14	51.61	44.64	48.51
10-14	13 (13)	40.48	55.71	64.29	48.57	45.24	35.71	48.81	42.14	51.07	41.96	47.02
15-19	29 (28)	53.45	55.52	64.44	57.24	62.36	56.90	56.90	71.72	57.11	62.55	59.53
20-24	31 (30)	59.29	43.85	73.08	70.77	69.23	56.54	75.64	75.00	61.06	68.27	64.26
25-29	13 (13)	62.18	53.08	59.13	60.38	69.23	56.54	64.74	81.15	58.85	68.15	62.98
≥ 30	9 (9)	67.13	51.11	79.86	69.44	71.30	51.11	80.56	77.78	66.25	68.75	67.36

SD: standard deviation; PF: physical functioning; FF: emotional functioning; SF: social functioning; CF: communication functioning; NA: not applicable.
*Significant at P < 0.05.

know if any of the scores were clinically significant.

The 2012 European Evaluation of Patients' Iron Chelation (EPIC) trial on the oral chelator deferasirox only reported 0-100 scores for each SF36v2 domain and graphically showed score ranges (15). The study did however report the physical component summary and mental component summary scores (and SDs) which requires norm-based scores for each domain. Both summary scales show that thalassaemia patients in the EPIC study had significantly better overall quality-of-life than patients in Palestine. It is important to note that EPIC patients were generally from high-income countries or from established clinics with access to adequate resources.

It is theoretically possible to convert published 0-100 data to norm-based scoring. However, because we lacked necessary information such as maximum and minimum scores, any such conversion would not accurately reflect the data set and would be strictly theoretical (see the difference in reported and calculated scores for the mental health component and physical health component in the 2012 EPIC trial) (15). This exercise however can give us an “eyeball test” of the clinical effect of thalassaemia on quality-of-life. We used the SF36v2 recommended norm-based scoring score of < 47 as being below average for the general population and suggesting clinical significance. As shown in the theoretical comparisons in Table 7, Palestinian patients had scores < 47 in all domains, suggesting poor quality-of-life of clinical significance. The data also show that even in high-income countries where patients have access to more healthcare resources, the psychosocial health of thalassaemia patients is severely affected (scores < 47 for mental health component, social functioning, role emotional and mental health). With the exception of the 2008 studies in Italy (27,28), thalassaemia also affected the physical health component score, with lower scores for role physical and general health. A 2021 study in Greece shows the effect of new oral chelators on quality-of-life with improved mental health scores (29), while the Italian data (29) show improved social functioning scores.

The SF36v2 norm-based scoring scores suggests that, while Palestinian psychosocial scores are low, they are also

Table 5 Scores on the PedsQL of parents of a child with thalassaemia from Palestine and other countries

Study sample	No.	Parent proxy report, mean (SD)					Overall health summary score
		Physical functioning	Emotional functioning	Social functioning	School functioning	Psychosocial	
Palestinian, 2015		58.24 (30.00)	63.18 (24.96)	77.88 (23.02)	58.33 (24.32)	66.45 (20.88)	63.60 (22.10)
Turkey, 2017 (22)	80	70.7 (18.09)	77.5* (17.5)	83.31* (19.06)	72.25 (16.76)	77.69* (12.83)	75.94* (12.59)
Thailand, 2015 (23)	34	78.80* (14.60)	76.31* (16.82)	86.68* (13.66)	65.69 (19.95)	76.31* (12.94)	76.73* (12.72)
Middle Eastern patients, Italy, 2012 (24)	60	68.4 (27.2)	76.9 (24.6)	76.4 (20.6)	69.4 (21.4)	73.6 (20)	71.9 (206)

PedsQL: Pediatric Quality of Life Inventory™; SD: standard deviation.

*Significantly different from the Palestinian score at $P < 0.05$.

low for thalassaemia patients in other countries. This suggests that the disease's pathophysiology and needed clinical interventions create a level of patient concern that affects their health outcomes. Regarding physical health, the lower physical functioning and higher bodily pain reported by Palestinian patients are troubling. How a patient reports physical functioning could be associated with access to blood transfusions, because higher haemoglobin levels from transfusion have an immediate response. Everywhere, patients with access to healthcare resources report greater physical functioning and less bodily pain. The low bodily pain scores suggest that Palestinian patients are under-transfused. Within the context of conflict areas, restricted access to blood transfusion is not surprising and would lead to lower patient quality-of-life scores in all domains.

Our study has some limitations. We used a convenience sample, time to gather the data was limited and supporting clinical data were lacking. Several barriers were noted such as difficulty for participants to reach clinic sites, and lack of funding. There were challenges associated with gathering paediatric patient data because most quality-of-life assessments are conducted through a parental caregiver proxy. The study instruments used are not specific to thalassaemia which is a potential limitation as particular nuances of the disease could be missed.

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Competing interests: None declared.

Conclusion

Our study shows that research can be conducted in areas experiencing conflict with active collaboration between research groups. The results could help healthcare professionals plan how to support access to care for people with chronic illness and hence improve their quality-of-life.

Our data suggest that the low quality-of-life scores could be associated with patients' haemoglobin levels which were below the international recommendations (4). The low Palestinian quality-of-life physical measures are most likely related to low transfusion levels at clinic visits.

Systematic research to collect quality-of-life as well as clinical data, including patient outcomes, haemoglobin and iron levels, and complications from treatment, is suggested to support our findings. Research on access to healthcare under conflict conditions would be enlightening (31,32).

While the patient physical functioning score and physical component summary score were better in 2015 than 2009, the scores in other domains were worse. This may reflect a decline in the Palestine-Israel situation in 2015 and increased conflict, forcing thalassaemia patients to find alternative means of coping with their disease and limited access to healthcare under occupation.

Table 6 Scores of parents of patients with thalassaemia from Palestine and the United States on the Family Impact Module

Study sample	No.	Parental quality of life				Family quality of life				Summary		
		PF	EF	SF	CF	Communication	Worry	Daily activity	Family relation	Parent	Family	Overall
Palestinian, 2015	104	57.29 (24.84)	55.34 (28.03)	67.79 (27.70)	63.37 (25.53)	63.46 (28.26)	54.28 (26.32)	65.06 (28.40)	73.13 (26.23)	60.42 (22.33)	73.13 (24.05)	63.91 (22.13)
US pilot, outpatients (12)	11	53.03 (22.83)	64.48 (26.59)	61.93 (25.99)	74.09 (18.95)	52.15 (14.67)	56.82* (25.52)	68.81* (24.11)	51.89 (31.48)	62.94* (20.81)	78.95 (27.62)	62.49* (18.51)
US, parental: mother (12)	157	67.3 (23.26)	55.27* (22.73)	75.71 (26.03)	73.53 (24.7)	74.3 (23.91)	46.79 (22.58)	64.11* (28.51)	67.13 (24.76)	67.44 (20.73)	66.1 (23.41)	64.68* (19.54)

SD: standard deviation; PF: physical functioning; EF: emotional functioning; SF: social functioning; CF: communication functioning; US = United States.
*Significantly different from the Palestinian score at P < 0.05.

Table 7 Scores of patients with thalassaemia from Palestine and other countries on the SF36v2, by scoring method

Scoring method	No.	Mean (SD)												
		PF	RP	BP	GH	Vitality	SF	RE	MH	PCS	MCS			
0-100 scoring														
Palestine, 2015	71	69.34 (21.52)	57.83 (25.74)	37.82 (24.88)	44.95 (12.51)	45.92 (13.30)	50.00 (18.54)	56.57 (25.78)	45.92 (13.79)	NR	NR	NR		
Milan, Italy 2008 (26)	136	78.92	68.75	83.03	65.47	52.85	37.32	35.89	66.71	NR	NR	NR		
Italy, 2008 (27)	137	82.80 (16.70)	68.20 (36.50)	69.40* (24.3)	52.60 (22.40)	64.50 (19.10)	74.10 (22.80)	71.70 (39.70)	70.00 (39.70)	47.0 (8.3)	45.0 (8.7)			
Italy, 2022 (28)	167	74.47 (20.67)	63.33 (40.88)	70.47* (38.20)	53.19* (21.11)	67.35* (19.77)	67.38* (26.43)	65.14 (25.85)	41.66 (17.71)	NR	NR			
EPIC, 2021 (14)	50	77.99	71.03	70.53	51.31	59.53	75.29	75.99	68.53	45.64* (9.25)	47.72* (10.63)			
Theoretical normed-based scoring														
Palestine, 2015	71	43.99	40.33	35.69	37.38	43.69	35.03	35.62	33.63	40.21	32.35			
Milan, Italy, 2008 (26)	136	49.65	48.28	55.97	48.30	47.97	30.85	35.46	45.06	52.23	33.29			
Italy, 2008 (27)	137	51.18	48.13	50.29	42.42	53.41	46.30	46.58	46.91	47.05	44.76			
Italy, 2022 (28)	167	47.14	41.38	52.06	43.45	48.84	48.52	41.42	45.56	44.92	42.95			
EPIC, 2021 (14)	50	46.29	42.48	49.64	41.58	54.51	42.62	39.62	31.23	46.37	44.88			
Greece, 2021 (29)														
Any ICT	80	48.11	44.71	51.13	39.30	51.69	45.33	39.41	45.71	41.31	41.31			
Oral ICT	51	49.29	45.18	52.74	40.21	52.99	44.76	46.16	43.19	46.16	43.19			
Deferasirox	17	47.69	41.53	50.16	38.78	49.89	43.24	46.40	35.49	46.40	35.49			

SF36v2: 36-item Short Form Health Survey, version 2; SD: standard deviation; PF: physical functioning; RP: role physical; BP: bodily pain; GH: general health; SF: social functioning; RE: role emotional; MH: mental health; PCS: physical health component score; MCS: mental health component score; EPIC: Evaluation of Patients' Iron Chelation; NR: not reported; ICT: iron chelation therapy.

* Significant at P < 0.05.

Note: Scores < 47 implies clinically significant (shaded fill).

Qualité de vie des patients vivant avec la thalassémie en Cisjordanie et à Gaza

Résumé

Contexte : Dans les pays disposant de faibles ressources, la santé et la qualité de vie des personnes vivant avec la thalassémie peuvent être gravement impactées.

Objectifs : La présente étude examine la qualité de vie liée à la santé des personnes vivant avec la thalassémie en Cisjordanie et à Gaza (Palestine).

Méthodes : Il s'agit d'une étude transversale menée auprès d'un échantillon de commodité composé de 104 patients (71 adultes et 33 enfants) vivant avec la thalassémie et de leur famille, en 2015, en Cisjordanie et à Gaza. Les participants ont été interrogés à l'aide de la version courte du questionnaire sur les problèmes de santé, version 2 (SF36v2) en 36 items, de l'Inventaire systémique de qualité de vie pour enfants™ (PedsQL) et du Module d'impact familial sur la qualité de vie pédiatrique PedsQL afin d'évaluer leur qualité de vie. Pour le questionnaire SF36v2, nous avons utilisé le score normalisé et pour le PedsQL et le Module d'impact familial, nous avons recouru à un score de 0 à 100. Ces scores sont présentés sous forme de moyennes et d'écart-types et un $p < 0,05$ est considéré comme statistiquement significatif.

Résultats : Les scores de qualité de vie étaient faibles dans tous les domaines, témoignant d'une mauvaise qualité de vie. Concernant les douleurs corporelles indiquées dans le questionnaire SF36v2, une différence significative a été observée entre la Cisjordanie et Gaza. Aucune différence significative n'a été observée entre les hommes et les femmes. Les données du PedsQL n'ont montré aucune différence significative entre la Cisjordanie et Gaza. Pour le Module d'impact familial, le score global était plus élevé chez les adultes que chez les patients pédiatriques. Par rapport aux autres pays, les patients thalassémiques en Palestine présentaient généralement des scores de qualité de vie plus faibles dans la plupart des domaines.

Conclusion : Le manque d'accès aux soins de santé et aux transfusions sanguines, ainsi que les défis géopolitiques peuvent être à l'origine de la mauvaise qualité de vie des patients vivant avec la thalassémie en Palestine.

جودة حياة المرضى المتعايشين مع الثلاسيميا في الضفة الغربية وغزة

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الخلاصة

الخلفية: في البلدان ذات الموارد المنخفضة، يمكن أن تتأثر صحة المرضى المتعايشين مع الثلاسيميا وجودة حياتهم تأثيراً شديداً.

الأهداف: هدفت هذه الدراسة إلى تقييم جودة الحياة الصحية للأشخاص المتعايشين مع الثلاسيميا في الضفة الغربية وغزة، فلسطين.

طرق البحث: أجريت هذه الدراسة المقطعية لعينة عشوائية ضمت 104 مرضى (71 بالغاً و33 طفلاً) من المتعايشين مع الثلاسيميا وأسرهم في عام 2015 في الضفة الغربية وغزة. ولتقييم جودة حياة المشاركين، أجريت مقابلات معهم باستخدام الإصدار 2 للمسح الصحي القصير المكوّن من 36 بنداً (SF36v2)، ومقياس جودة حياة الأطفال (PedsQL)، ووحدة تأثير الأسرة. وقد استخدمنا حساب الدرجات المعيّر مع الإصدار 2 للمسح الصحي القصير المكوّن من 36 بنداً، بينما استخدمنا حساب الدرجات على مقياس من 0-100 مع كل من مقياس جودة حياة الأطفال، ووحدة تأثير الأسرة. ووردت الدرجات كمتوسط وانحرافات معيارية، واعتُبرت القيمة الاحتمالية الأقل من 0.05 ذات دلالة إحصائية.

النتائج: كانت درجات جودة الحياة منخفضة في جميع المجالات، وهو ما يدل على تدرّج جودة الحياة. أما الألم الجسدي في الإصدار 2 للمسح الصحي القصير المكوّن من 36 بنداً، فقد لوحظ تباين كبير بين الضفة الغربية وغزة. ولم يلاحظ فرق كبير بين الذكور والإناث. وأظهرت البيانات التي حُصل عليها من مقياس جودة حياة الأطفال عدم وجود فروق كبيرة بين الضفة الغربية وغزة. وأما وحدة تأثير الأسرة، فقد كانت درجة المنخفض أعلى بين البالغين منها بين المرضى من الأطفال. ومقارنةً ببلدان أخرى، حصل مرضى الثلاسيميا في فلسطين بوجه عام على درجات أقل بشأن جودة الحياة في أغلب المجالات.

الاستنتاجات: قد يكون كلٌّ من عدم إمكانية الحصول على الرعاية الصحية ونقل الدم، بالإضافة إلى التحديات الجغرافية السياسية من العوامل المسؤولة عن انخفاض درجات جودة حياة المرضى المتعايشين مع الثلاسيميا في فلسطين.

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