IMPACT OF CLINICAL AND SOCIAL FACTORS ON QUALITY OF LIFE (QOL) IN PATIENTS (PTS) WITH TRANSFUSION-DEPENDENT (TDT) AND NON-TRANSFUSION-DEPENDENT (NTDT) BETA-THALASSEMIA: A MULTICENTER STUDY

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Abstract: PF691

Type: Poster Presentation

Presentation during EHA23: On Friday, June 15, 2018 from 17:30 - 19:00

Location: Poster area

Background

Life expectancy for pts with β-thalassemia has increased significantly in recent years. Improved survival is accompanied by considerable ongoing healthcare needs related to this chronic condition; therefore, QoL has emerged as a primary focus of comprehensive pt care.

Aims

To use data from a multicenter study to investigate the clinical and social factors that impact the difference in QoL outcomes between pts with TDT and NTDT β-thalassemia in the routine clinical care setting.

Methods

Adult pts with β-thalassemia were prospectively enrolled in an observational study from centers in Italy, Greece, Lebanon, and Thailand. All pts completed Short Form 36 Health Survey version 2 (SF-36v2) and Functional Assessment of Cancer Therapy (FACT)-Anemia (An) questionnaires at baseline, and then once every 3 weeks using a hand-held electronic device; this analysis evaluated QoL in pts with TDT and NTDT at study entry. Transfusion dependence was defined as receiving ≥ 6 red blood cell units in the 24 weeks prior to study entry with no transfusion-free period for ≥ 35 days during that time.

Results

In total, 102 pts were enrolled, of which 52 had TDT and 50 had NTDT. The mean age of pts was 31.2 years and 70 (68.6%) were female. On average, pts with TDT were 3.6 years younger ($P = 0.06$) and had moderately higher hemoglobin levels at baseline (8.8 vs 8.2 g/dL; $P = 0.02$). Of 102 pts enrolled, 65 (64%) were of White ethnicity (39 NTDT, 26 TDT) and 37 (36%) were of Asian ethnicity (11 NTDT, 26 TDT). Older pts (≥ 30 years) and pts with a long diagnosis history (≥ 25 years) had worse QoL versus younger pts and pts with a short diagnosis history ($P < 0.05$). Currently married pts had better QoL ($P < 0.05$). Pts transfused at baseline (100% of TDT pts; 10% of NTDT pts) had better QoL than non-transfused pts. Pts with NTDT reported lower QoL scores on all SF-36v2 domains and summary scores, except for Role-Physical. On average, pts with NTDT experienced lower QoL versus their TDT counterparts on the domains of General Health (39.5 vs 44.0; $P = 0.01$), Vitality (49.3 vs 53.7; $P = 0.01$), and Mental Health (46.8 vs 50.8; $P = 0.01$), and in the Mental Component Summary Score (46.5 vs 50.8; $P = 0.01$). Similarly, pts with NTDT reported lower FACT-An questionnaire QoL scores on all domains; statistically significant differences were observed for Emotional Well-Being (18.5 vs 20.0; $P = 0.02$), Functional Well-Being (20.0 vs 23.2; $P < 0.01$), and FACT-General (82.9 vs 89.4; $P = 0.01$). Pts recruited by the Thai center reported higher QoL scores on the Functional Well-Being (23.11 vs 20.74; $P < 0.05$) and Fatigue Scale domains (41.75 vs 38.27; $P < 0.05$) compared with pts from centers in Italy, Greece, and Lebanon.

Conclusion

In the routine clinical care setting, there are critical unmet medical needs for pts with NTDT as they reported lower QoL scores compared with pts with TDT, as captured by two health questionnaires (SF-36v2 and FACT-An), across all domains except one. There is a need for new interventions to treat pts with NTDT and reduce their burden of disease. Significant differences between pt populations from different geographical locations were identified, suggesting social factors had an impact on difference in QoL between pts with TDT and NTDT. Pts from Thailand reported higher QoL scores for domains on the FACT-An questionnaire versus pts from centers in Italy, Greece, and Lebanon; half of the pts with TDT were from the Thai center.

Session topic: 36. Quality of life, palliative care, ethics and health economics

Keyword(s): Beta thalassemia, Quality of Life, transfusion