

Quality of life of patients with haemoglobinopathies in periods of economic austerity

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Abstract

Introduction

The concept of quality of life (QoL) encompasses a broad spectrum of meaning that is variously influenced by individual, natural and psychological conditions. The chronic diseases deteriorate patients physical health and their health related quality of life.

Aim

Considering the chronicity of hemoglobinopathies (β -thalassaemia and sickle β thalassaemia), the aim of this study was to evaluate the Health Related QoL (HRQoL) in Greek β -thalassemics and SCD patients and to investigate the correlation of HRQoL to demographic and clinical factors related to the disease.

Materials and Methods

The study was conducted involving 221 β -thalassemic transfused patients and 102 SCD patients, from urban, semi-urban and rural regions of Greece. Data were collected by completing the questionnaires SF-36 and EQ-5D, as well as a questionnaire with social demographic and disease related data.

Results

β -thalassaemia patients

According to the data analysis the mean EQ VAS was 74.2 (SD 16.6). Thalassemics presented an decrease in the scales of General Health and Vitality compared to the general population. Gender (women) was negatively correlated to Physical Functioning and Social Functioning,

while age (≥ 35 years) had a negative effect on Physical Health Component scales. Differences in educational level were statistically significant referring to Physical Functioning, Physical Role, Bodily Pain, Emotional Role and Mental Health. Subcutaneous chelation treatment had a negative effect on General Health and Emotional Role scales, while severe hemosiderosis and especially heart hemosiderosis affected negatively the General Health scale.

SCD patients

Patient mean age was 45.15 ± 11.64 yrs, (50,52) and 83,35% of patients suffered from sickle- β Thalassemia. Mean EQ VAS scale was 64,33. Mean values of SF-36 eight dimensions were significant lower compared to these of the general population. Sex (female) was negatively associated with physical functionality only but age negatively affects most of EQ-5D and SF-36 dimension. Educational level affects only the VAS score and the physical functionality (SF-36). Transfusions are related to and influence the dimensions of mobility and stress/depression (EQ-5D), as well as the vitality subscale (SF-36). Iron chelation treatment rate was associated with the perception of pain/discomfort (EQ-5D) while the frequency of painful episodes is significantly associated with and considerably affects almost all dimensions of patients physical and mental RHQL. The frequency of infections is related to the dimensions of pain/ discomfort and stress/depression (EQ-5D) and also influences the VAS score and most of SF-36 subscales negatively postirely. While comorbidity is associated with the daily activities and the pain/discomfort (EQ-5D) and influences the VAS score as well as the total physical and mental scales of patients (SF-36).

Conclusions

HRQoL of Greek hemoglobinopathy patients is lower compared to the general population as it is influenced by multiple social demographic and disease related parameters.

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