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114.SICKLE CELL DISEASE, SICKLE CELL TRAIT AND OTHER HEMOGLOBINOPATHIES, EXCLUDING THALASSEMIAS: CLINICAL AND EPIDEMIOLOGICAL

Assessing Aspects of Quality of Life Among Patients with Sickle Cell Disease in Saudi Arabia

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Introduction: Sickle cell disease is a genetic disorder that can significantly alter the patient's quality of life. The disease trajectory can lead to acute and chronic complications, mainly resulting from repeated episodes of vascular occlusion. The patients can experience frequent infections and hospitalizations, chronic pain, fatigue, hand-foot syndrome, delayed growth. Therefore, assessing the quality of life among sickle cell patients in Saudi Arabia is pertinent to the devise of a comprehensive plan of patient care. The quality of life can be determined based on numerous markers, including physical health, psychological health, happiness, and physical activity. We aimed **t**o assess the overall quality of life among Saudi sickle cell disease patients living in different regions of the Kingdom. This an ongoing study with open enrollment target of more than 600 patients. **Methods:** A questionnaire-based survey was conducted among the adult Saudi sickle cell disease population residing in different provinces, who were stable, Saudi nationals and over age of 18 years. The questionnaire assessed the quality of life, including fatigue, general happiness, physical activity, and psychological well-being using standardized questionnaire SF-36 and HADS validated Arabic version. Additional data about blood transfusion and visit to ER were collected The collected data were recorded for each respondent, and the results were statistically analyzed. **Results:** The included participants' (n=166) mean age 33.6 ± 9.2. years, with respondents belonging to eastern region Qatif (n=48; 28.9%), central region Riyadh (n=75; 45.1%), and southern region Jizan (n=43; 25.9), respectively. The study's cohort had varying educational backgrounds, with the highest number holding a bachelor's degree (n=77; 46.4%); followed by secondary education (n=50; 30.1); master's degree (n=8; 4.8); doctoral degree (n=5; 3.0) and other education (n=18; 10). In total, 17.5% of participants reported excellent reviews about health, and only 9% reported badly. However, the overall quality of life compared to the previous year was much lower, with 10.8% responses as worse. Strenuous activities constrained 40.9% of the participants, 14.5% were constrained by work of medium intensity, and 13.2% felt even a lot of constraint while carrying groceries. Almost 40% of respondents answered negatively when asked about feeling energetic compared to psychological health, where more than 50% of responses were positive. More than 52% of participants felt their ability to do activities at work and otherwise was diminished. More than 80% of participants felt pain over the past four weeks that affected their quality of life. The findings have been graphically summarized in **Figure 1.** The patients with blood transfusion assessed their health significantly poor than those without transfusion (p-value = 0.0022). Their health conflicted with their daily routine significantly (p-value=0.003), where they were significantly more tired (p-value=0.04), and felt less assured (p-value=0.02). **Conclusion:** The physical and psychological health-related quality of life is satisfactory among Saudi sickle cell disease patients.. Furthermore, the lack of energy and appropriate physical activity is a serious concern that can negatively impact sickle cell disease patients' overall quality of life. This is a planned

cohort to measure quality of life in sickle cell disease in Saudi Arabia at a large scale with link to demographic representation
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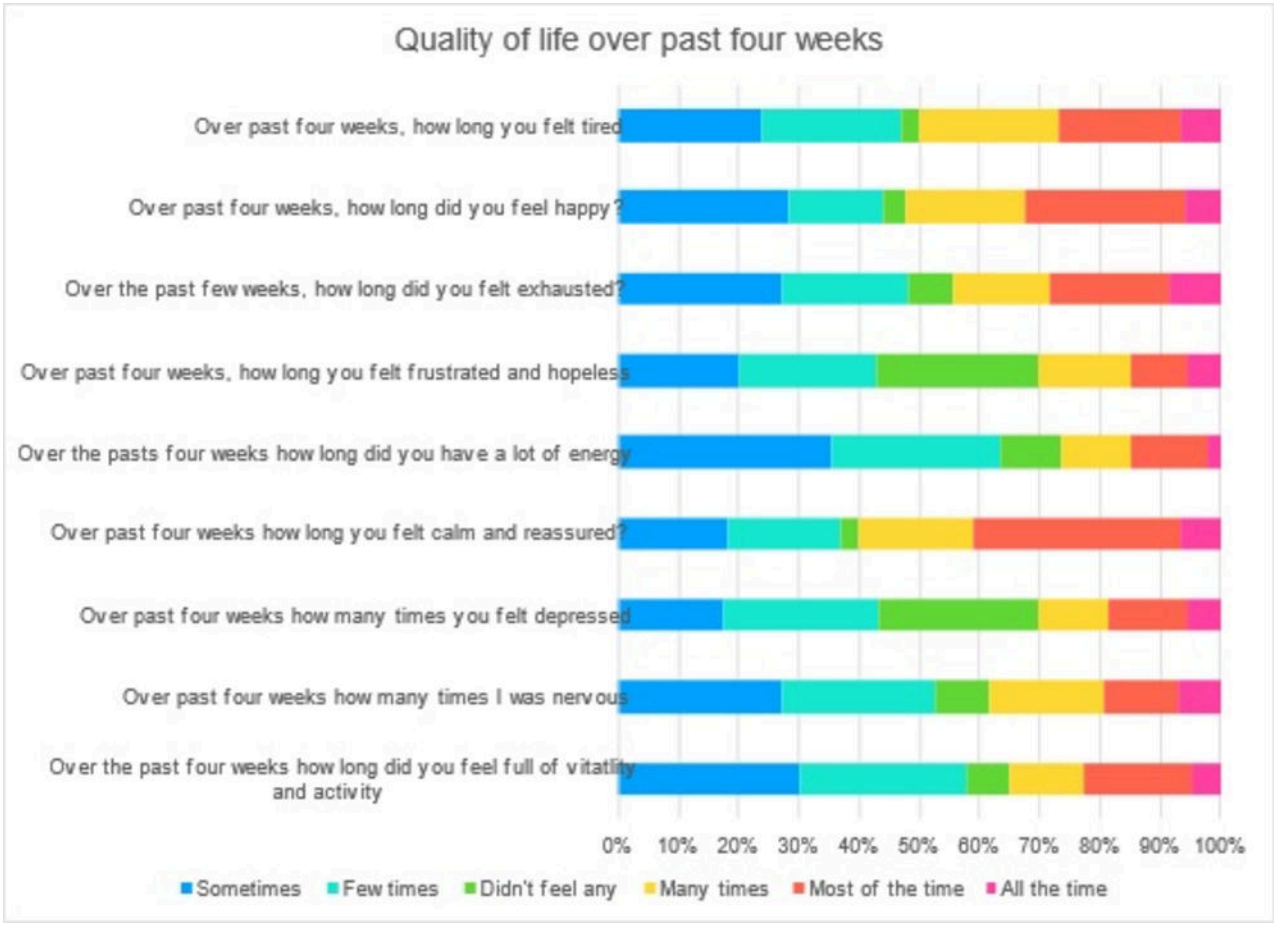

Figure 1

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