Psychological Impact of Sickle Cell Anemia in Children on their Mothers

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Abstract

Sickle cell anemia (SCA) is well known chronic disease in the kingdom of Saudi Arabia and Parenting children with this chronic diseases is highly demanding and has practical and emotional consequences on the family particularly the mother. So it is important to address the caregivers’ well-being and to identify needs for additional support. The aim of the present study was to address the well-being of mothers who care for a child with sickle cell disease (SCD) measured with the Adult Quality of Life questionnaire, versus mothers of healthy children of the same socioeconomic standard.

Methods: 58 mothers of children with sickle cell anemia considered as (experimental group) and 37 mothers of healthy children with the same socio-economic status labeled as (control group). We tried to minimize the age difference between both groups which was around 35 years old, diagnosis of SCA was confirmed clinically and by confirmatory investigations, the age at first diagnosis and duration of the disease were considered both groups were subjected to Adult Quality of Life questionnaire, The results of questionnaires were analyzed.

Results: Mothers of patients with sickle cell disease had a significantly lower quality of life on most subscales Compared to the control group of the same socio-economic status, the subscales depressive moods, daily activities and vitality were found to be most aspects affected.

Conclusion: Proper control of SCA might lessen the psychological burden on the family and psychotherapist advise may be needed.

Key Words: Children – Sickle cell anemia – Psychological impact – Mothers.

Introduction

SCD is a chronic anemia characterized by recurrent acute painful vaso-occlusive crises, which occur unpredictably and require immediate management. Many patients eventually develop irreversible organ damage such as a cerebral vascular accident or end-stage renal disease. The unpredictable course of this disease in combination with the lower socio-economic status (SES) of most caregivers places a heavy strain on the caregivers of these children.

Parenting children with chronic diseases is highly demanding and has practical and emotional consequences [1,2]. Young children with a chronic condition are dependent on their caregivers for additional care and monitoring of their health. The quality of care they receive may be affected by the caregivers’ well-being. It is important to address the caregivers’ well-being and to identify needs for additional support, for both the health and well-being of the caregiver and the child [3,4].

Sales described The challenge of parenting a child with SCD as a burden [5]. This burden can be classified as objective and subjective. The objective burden includes day-to-day management of the illness, the effect on other aspects of life and financial consequences. Caregivers of children with SCD have to administer medication daily (e.g. antibiotic prophylaxis and folic acid), promote behavior that minimizes pain episodes and act appropriately when symptoms arise by giving scheduled analgesics and plenty of fluids in the case of a painful crisis [6,7]. Vaso-occlusive crises and hospital visits interfere with work commitments and planned (leisure) activities of caregivers and other family members. Financial consequences may arise as a result of travel expenses for trips to the hospital [8] and a poor health status of a child has been associated with reduced maternal or paternal employment [9]. The emotional distress caregivers experience when dealing with their ill child can be classified as a subjective burden. Confronting the pain of their child during vaso-occlusive crises is emotionally upsetting for parents [6]: Caregivers may have difficulty accepting the child’s diagnosis and prognosis and may experience
anxiety about the child’s future well-being, both in the short and long term.

Several studies found that 30-40% of the caregivers had symptoms of psychological distress [10-13], lower SES is associated with more stress and psychological problems, [14-17] so matching for SES is a prerequisite.

QoL is a multidimensional concept that includes social, physical, psychological and emotional aspects. Studies in caregivers of children with various chronic illnesses have shown that such caregivers report an impaired QoL compared to that of caregivers of healthy children [18-22].

**Aim of the work:**

The aim of the present study was to address the well-being of mothers who care for a child with sickle cell disease (SCD) measured with the Adult Quality of Life questionnaire, versus mothers of healthy children of the same socioeconomic status. We hypothesized that mothers of children with SCD have a lower QoL compared to mothers of healthy children with the same socioeconomic status (SES).

**Subjects and Methods**

**Participants:**

Inclusion criteria: 58 saudian mothers giving care to children with SCA who visited the outpatient clinic and/or inpatient department in King Abdullah University Hospital in the period from January 2008 to August 2008 were invited to participate in this study taking in consideration maternal age around 35 years old and first diagnosis of SCA was at least 3 years before. We included only female caregivers because QoL data are gender-specific and most patients are cared for by their mothers. The following exclusion criteria were applied: The inability of mothers to read and write in Arabic, children who had been diagnosed less than 3 year previously, since the impact of having a chronically ill child on parents is not yet clear for newly diagnosed patients. Mothers who had a chronic disease themselves were also excluded, as this may influence their QoL. Mothers of healthy children (SES control group) visiting the outpatient clinic for minor acute problems of their children and who donot have chronic problems by themselves were included as control group in the study.

**Questionnaire:**

The original Dutch questionnaire, which was translated into English by a professional translator according to scientific standards (translated into Arabic by the researcher for our Arabian mothers), contains four different sections. The first section consists of 68 questions regarding demographics, family relations, rearing children, additional burden in the family (e.g. chronic illness of parents) and use of health care services; the second section contains 15 questions about satisfaction in daily life; the third section contains 87 specific questions about social and financial consequences of taking care of a child with a chronic illness and the last section is a quality of life questionnaire, the Adult Quality of Life questionnaire (AQoL).

**Instruments:**

We used the AQoL questionnaire developed by the Dutch Institute of Prevention and Health and the Leiden University Hospital [23]. This validated questionnaire is a generic Dutch instrument that measures health status problems or limitations weighted by the impact of these problems on well-being. The items are clustered into 12 multi-item scales: Gross motor functioning (e.g. difficulty with walking), fine motor functioning (e.g. difficulty with opening a can), cognitive functioning (e.g. difficulty with memory and attention), sleep (e.g. sleeping restless), pain (e.g. pain in neck-shoulders), social functioning (e.g. the possibility to talk to others; visit friends), limitations of daily activities (e.g. difficulties with work), sexual functioning (e.g. had less sex), vitality (e.g. feeling energetic or tired), happiness (e.g. feeling joyful), depressive moods (e.g. feeling sad or worried) and aggressiveness (e.g. feeling angry). All the scales consist of four questions, except for the scales concerning sexual functioning (two questions) and aggressiveness (three questions). The scale scores are obtained by adding item scores within scales and transforming raw scale scores to a 0-100 scale, with higher scores indicating a higher QoL. It takes approximately 10 minutes to fill in the AQoL questionnaire.

The Care-questionnaire was given to all mothers of the study with an accompanying information letter and they were asked to return the completed questionnaire together with an informed consent form after 2 weeks.

**Statistics:**

The Statistical Package for Social Sciences (SPSS), Windows version 12.0, was used for the analysis. Normally distributed data (age of caregiver) were tested with the independent t-test. Data that were not normally distributed were tested with the Mann-Whitney U test. Differences between the groups were considered statistically significant if the p value was <0.05. Because the
Mann-Whitney U test does not yield an effect size, the median differences and 95% confidence intervals between data from the SCD mothers and the SES control group were also calculated using the computer program Confidence Interval Analysis© version 2.0.0 according to the method described by Altman et al. [24].

**Results**

Of the 95 mothers who were asked to participate, 58 mothers taking care of children with SCD and 37 healthy mothers taking care of healthy children. The median duration of illness of the children with SCA was 5.0 years (range 3-7 years). The demographic characteristics of the experimental group and control group were shown in Table (1) where No statistically significant difference was found between the mothers of children with SCD and the SES control group for age (p = 0.105), marital status (p = 0.492) and educational level (p = 0.843). The SCD group was well matched to the control group regarding income which was found to be low and insufficient.

The experimental group had a lower QoL on the subscales depressive moods, daily activities, vitality, sleeping, happiness which was statistically significant (p < 0.05) when tested by the Mann-Whitney U test (Table 2).

**Discussion**

Several studies have addressed the psychological effects of parenting children with SCD and found that 30-40% of the caregivers had symptoms of psychological distress [10-13]. These studies were descriptive and did not compare caregivers of SCD patients to a control group of parents with healthy children. In order to conclude that psychological distress is related to caring for children with SCD, a well-matched control group is essential.

Two studies using a well-matched SES control group yielded conflicting results. The increase in depressive symptoms of SCD caregivers compared to caregivers of healthy controls found in one study [7] was not confirmed by the other [3]. These differences could be explained by differences in study design and instruments used to evaluate depressive symptoms.

In our study it was found that mothers of children with SCD Compared to the control group matched for SES, have significantly lower QoL.

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**Table (1):** Demographic characteristics of both groups.

<table>
<thead>
<tr>
<th></th>
<th>SCA mothers</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>58</td>
<td>37</td>
</tr>
<tr>
<td>Age, mean±SD (years)</td>
<td>35.1±2.8</td>
<td>34.8±3.5</td>
</tr>
<tr>
<td>Income, mean±SD (reyal)</td>
<td>3200±750</td>
<td>4100±350</td>
</tr>
</tbody>
</table>

**Marital state:**

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>45</td>
<td>77.58</td>
<td>31</td>
<td>83.78</td>
</tr>
<tr>
<td>Divorced</td>
<td>9</td>
<td>15.51</td>
<td>4</td>
<td>10.81</td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>6.89</td>
<td>2</td>
<td>5.40</td>
</tr>
</tbody>
</table>

**Education level:**

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>%</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower</td>
<td>36</td>
<td>62.06</td>
<td>25</td>
<td>67.56</td>
</tr>
<tr>
<td>Intermediate</td>
<td>18</td>
<td>31.03</td>
<td>8</td>
<td>21.62</td>
</tr>
<tr>
<td>Higher</td>
<td>4</td>
<td>6.89</td>
<td>2</td>
<td>5.40</td>
</tr>
</tbody>
</table>

**Table (2): Differences between mothers of SCA patients and the SES control group on the subscale of the TAAQOL.**

<table>
<thead>
<tr>
<th></th>
<th>SCA</th>
<th>SES control group</th>
<th>SCA group to SES control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>IQR</td>
<td>Median</td>
</tr>
<tr>
<td>Depression</td>
<td>42</td>
<td>33-66</td>
<td>60</td>
</tr>
<tr>
<td>Daily activity</td>
<td>68</td>
<td>49-87</td>
<td>87</td>
</tr>
<tr>
<td>Vitality</td>
<td>46</td>
<td>31-58</td>
<td>58</td>
</tr>
<tr>
<td>Sleeping</td>
<td>56</td>
<td>25-69</td>
<td>76</td>
</tr>
<tr>
<td>Happiness</td>
<td>49</td>
<td>33-67</td>
<td>58</td>
</tr>
<tr>
<td>Cognitive function</td>
<td>72</td>
<td>41-100</td>
<td>91</td>
</tr>
<tr>
<td>Fine motor</td>
<td>91</td>
<td>70-100</td>
<td>94</td>
</tr>
<tr>
<td>Sexual function</td>
<td>75</td>
<td>50-100</td>
<td>88</td>
</tr>
<tr>
<td>Pain</td>
<td>53</td>
<td>38-88</td>
<td>73</td>
</tr>
<tr>
<td>Aggressiveness</td>
<td>78</td>
<td>56-100</td>
<td>89</td>
</tr>
<tr>
<td>Gross motor</td>
<td>70</td>
<td>39-100</td>
<td>81</td>
</tr>
<tr>
<td>Social function</td>
<td>75</td>
<td>63-88</td>
<td>67</td>
</tr>
</tbody>
</table>

IQR : Interquartile range.
SES : Is control group, high score means quality of life (score from 0-100).
scores on the subscales depressive moods, daily activities and vitality. Sleeping, happiness and cognitive functioning were negatively affected as well. These differences can probably be attributed to caring for a child with SCD. The effect of carership for sickle cell disease in mothers could contribute to lower scores on depressive moods and happiness. Feelings of guilt about the illness of their child and the risk of having another child with sickle cell disease could have a negative effect on mood. Which was consistent to a lot of similar studies as In a recent American study half of the caregivers of children with SCD were at risk of clinical depression, compared to 1% of the control group, as measured by the Center for Epidemiologic Studies-Depression scale (CES-D) [7]. The psychological adaptation of caregivers of children with SCD is not influenced by the severity of the child’s disease [12,25]. Mood disturbances may result from lack of sleep due to nighttime caregiving duties and worries related to the child’s health [26]. Sleep deprivation is also associated with limited daytime functioning, decreased cognitive performance and decreased motor function [27,28]. This could contribute to lower vitality and happiness scores in caregivers of children with SCD. Similar problems have also been described in caregivers of children with other chronic diseases, e.g. leukemia and cerebral palsy [21,29].

Limitations in daily activities (e.g. working or studying) could be caused by frequent hospital visits, acute painful crises and all other tasks associated with the responsibility of caring for a chronically ill child.

Apparent limitations of the current study should be taken into account. The population of SCD caregivers that we studied has a low SES. This could be different in other countries, which limits the generalization of the results of this study to SCD caregivers in other parts of the world.

Recommendations:

Studying QoL in caregivers of chronically ill children is extremely important, since adequate functioning of the mother is important for the social, emotional and cognitive functioning of a child [31]. In order to deliver appropriate care, help from various health care providers is essential. Promoting good health of caregivers, stress management and a social support network are important [38]. As disrupted sleep patterns have an influence on mood, motor and cognitive functioning, improving sleep quality in caregivers of sickle cell patients is a potentially useful intervention. The effectiveness of behavioral sleep intervention has been demonstrated in caregivers of people with cancer [34].

References


