Quality of life of female caregivers of children with sickle cell disease: a survey

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ABSTRACT

Caring for a child with sickle cell disease poses extra demands on parents, both practically and psychologically, which may influence their quality of life. Since families of children with sickle cell disease in the Netherlands usually belong to immigrant communities with a low socio-economic status, there may be an additional strain on caregivers. The aim of the present study was to evaluate the quality of life of caregivers of children with sickle cell disease. The quality of life of female caregivers of sickle cell disease patients, measured with the TNO-AZL Adult Quality of Life questionnaire, was compared to the norm data of healthy Dutch females (n=700) and female caregivers of healthy children with the same socio-economic status and ethnic background (socio-economic status control group). Groups were compared by the Mann-Whitney U test. Point estimates and 95% confidence intervals of the median difference are presented. The results of questionnaires of 54 caregivers of children with sickle cell disease and 28 caregivers of a control group of the same socio-economic status were analyzed. Caregivers of patients with sickle cell disease had a significantly lower quality of life on all subscales compared to the Dutch norm population. Compared to the control group of the same socio-economic status, the quality of life of caregivers of patients with sickle cell disease was significantly lower on the subscales depressive moods, daily activities and vitality. In this first study reporting on the quality of life of caregivers of children with sickle cell disease, we demonstrate a reduced quality of life in these caregivers compared to the healthy Dutch female population and caregivers of healthy children with the same socio-economic status.

Key words: sickle cell disease, quality of life, caregivers.

Introduction

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] In this study we address the well-being of caregivers who care for a child with sickle cell disease (SCD).

SCD is characterized by chronic anemia and 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.

The challenge of parenting a child with SCD has been described by Sales 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] as one of the mothers in our cohort stated, "*I cannot ever get used to my child experiencing pain. I feel helpless when I cannot stop the pain*". 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.

Previous studies have addressed the psychological effects of parenting children with SCD. Several studies 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. In the Netherlands, many patients with SCD come from immigrant families who often have a lower SES compared to that of the population with Dutch ancestors.[14,15] As lower SES is associated with more stress and psychological problems,[15-17] matching for SES is a prerequisite. 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.

As the effects of caring for a child with SCD may influence more aspects of life besides mental health, the aim of the present study was to investigate quality of life (QoL) of caregivers of children with SCD. 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] We hypothesized that caregivers of children with SCD have a lower QoL compared to that of the healthy Dutch female population and caregivers of healthy children with the same SES.

Design and Methods

Participants

All mothers or female caregivers of children with SCD who visited the outpatient clinic of the study center at least once a year were invited to participate in this study. The following exclusion criteria were applied: the inability of caregivers to read and write in Dutch or English, children living in foster care and children who had been diagnosed less than 1 year previously, since the impact of having a chronically ill child on parents is not yet clear for newly diagnosed patients. Caregivers who had a chronic disease themselves were also excluded, as this may influence their QoL. We included only female caregivers because QoL data are gender-specific and most patients are cared for by their mothers. Female caregivers of healthy children (SES control group) in two primary schools located in the lower income neighborhoods, where most of the included SCD patients live, were recruited for the control group in the study. Both biological mothers and caregivers (e.g. adoptive parents) of the patients and controls are named caregivers.

Questionnaire

A questionnaire on the social and financial consequences of caring for children with a chronic illness was developed as part of a larger study (Care project), which will be reported separately. The original Dutch questionnaire, which was translated into English by a professional translator according to scientific standards, 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 TNO-AZL Adult Quality of Life questionnaire (TAAQoL). The control group received a shortened version of the questionnaire that did not contain the third section. The burden of filling in the questionnaire was addressed in the invitation letter. Generally it took 1 hour to complete the whole questionnaire. Parents were allowed to take short breaks while completing the questionnaire.

Instruments

We used the TAAQoL questionnaire for people 16 years and older, developed by the Dutch Institute of Prevention and Health and the Leiden University Hospital (TNO-AZL).[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. It offers the respondent the possibility of differentiating between their functioning and

the way they feel about it. 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 restlessly), 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 TAAQoL questionnaire.

The questionnaire has been validated in two samples of the general population.[23] Cronbach's α varies between 0.72 and 0.90 for the different domains, which justifies the use of the TAAQoL for studies on groups of patients. Furthermore the convergent validity was assessed by calculating correlation coefficients with the results from the Dutch versions of the Short Form-36 and with the Psychological complaints-scale of the Hopkins Symptom Checklist. The expected relationships between TAAQoL and Short Form-36/Hopkins Symptom Checklist domains measuring the same concepts (e.g. pain [0.65], daily functioning [0.65], vitality [0.81] and depressiveness [0.70]) were in general higher than other correlations (<0.59), indicating convergent validity. Based on these results it was concluded that the instrument measures health-related QoL on a group level in a reliable and valid way.

Procedures

Data were collected between May and October 2006. The Care-questionnaire was sent to all eligible caregivers of children with SCD with an accompanying information letter and a reminder after 4 weeks. The caregivers were asked to return the completed questionnaire together with an informed consent form by mail (no stamp necessary). In case parents did not have mastery of the Dutch language, they received an English translation of the questionnaire and/or help with completing the questionnaire at the outpatients' clinic. Anonymity of the data was guaranteed. Questionnaires for the SES control group were distributed among school children at two local primary schools. A collective reminder was placed in the school paper after 1 month.

Norm data for the TAAQoL from a Dutch reference population above the age of 15 years (4410 respondents) were available. For this study we selected a sample (n=700) from the reference population of similar gender and age as the caregivers of the children with SCD. In this reference population information on country of birth was limited to "born in the Netherlands", "born in a western country" and "born in a non-western country".

Statistics

QoL results from the study population were compared to those of the Dutch norm population (n=700 females) and a control group matched for SES and ethnicity consisting of 28 caregivers of healthy children.

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 caregivers 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 99 caregivers who were asked to participate, 54 caregivers of 60 children with SCD (49 HbSS/HbS-β⁰-thalassemia, 11 HbSC/HbS-β⁰-thalassemia) returned a completed questionnaire. The median duration of illness of the children was 7.0 years (range 1-17 years). The caregivers in the participants group had been living in the Netherlands for a median of 16 years (range 3.7-32.6 years). Thirty-seven caregivers filled in the questionnaire in Dutch, 17 in English. The demographic characteristics of the participants and non-participants of the SCD group were similar (p>0.05) (Table 1).

The majority of the SCD caregivers originated from non-western countries, were single parents and had a low educational level (Table 2). No statistically significant difference was found between the caregivers 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 SES control group for income and country of birth. As expected, caregivers of patients with SCD differed significantly from the Dutch norm population for marital status and educational level (p<0.01). Data on income were not available for the Dutch norm population.

Caregivers of SCD patients had a lower QoL on the subscales depressive moods, daily activities, vitality, sleeping, happiness and cognitive functioning when the point estimates of the median difference were compared (Table 3). The differences between the scores for SCD caregivers and SES controls on the subscales depressive moods, daily activities and vitality were statistically sig-

nificant ($p<0.05$) when tested by the Mann-Whitney U test (Table 3).

Compared to the Dutch norm population caregivers of SCD patients had lower scores on all QoL subscales ($p<0.05$ on all subscales) (Table 3).

Discussion

This first study reporting on QoL in caregivers of children with SCD demonstrates that such caregivers have, in comparison to the Dutch norm population, a lower QoL on all subscales. These differences may be due to demographic differences, such as a lower SES and more single parents. Compared to the control group matched for SES, caregivers of children with SCD have significantly lower QoL 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 carriership for sickle cell disease in caregivers 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.

This is not the first study demonstrating that depressive moods occur more frequently in caregivers of children with SCD than in caregivers of healthy children. In a recent American study half of the caregivers of children with SCD were at risk of clinical depression, compared to 19% 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 day-time 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

Table 1. Demographic characteristics of the caregivers of SCD children: participants and non-participants.

	Participants N=54		Non-participants N= 45	
Age of caregiver, mean ± SD (years)*	37.3±7.3		37.1±8.2	
Age of child with SCD, mean ± SD (years)*	9.2±4.2		10.2±4.7	
	N	%	N	%
Country of birth *				
Netherlands	5	9	1	2
Surinam	17	32	16	36
Netherlands Antilles	2	4	5	11
West/Central Africa	24	44	21	47
Other	6	11	2	4
Marital status *				
Married/ living together	22	41	21	47
Single	30	55	22	49
Not specified	2	4	2	4
Highest level of education*ᵃ				
Lower	29	54	18	40
Intermediate	20	37	14	31
Higher	5	9	2	5
Not specified			11	24
Paid employment*				
Yes	25	43	14	31
No	27	50	21	47
Not specified	2	7	10	22

ᵃEducation: Lower: elementary education, MAVO (general secondary education-junior level), VBO (lower vocational education); intermediate: HAVO/VWO (general secondary education-senior level) and MBO (vocational education-junior level); higher: HBO (vocational education-senior level) and WO (university education). *p>0.05

Table 2. Demographic characteristics of the caregivers of SCD children, the SES control group and the Dutch normal population.

	SCD caregivers N=54		SES control group N=28		Dutch norm population N=700	
Age, mean±SD (years)	37.4±7.2		40±6.7		35.6±8.7	
Net income, mean±SD (euro)	1341±720		1422±720			
	Number	%	Number	%	Number	%
Country of birth						
Netherlands	5	9	3	11	261	37
Western country	-	-	-	-	5	1
Non-western country	49		23		3	0
Surinam	18	33	13	46	-	-
Netherlands Antilles	2	4	3	11	-	-
West/Central Africa	23	43	5	18	-	-
Other	6	11	2	7	-	-
Not specified	-	-	2	7	431	62
Marital status*						
Married	14	26	8	30	425	61
Living together (not married)	7	13	-	-	127	18
Single	31	57	19	70	129	19
Other	-	-	1	0	17	2
Not specified	2	4	-	-	2	0
Highest level of education*ᵃ						
Lower	29	54	16	57	266	38
Intermediate	20	37	9	32	218	31
Higher	5	9	3	11	188	27
Other	-		-	-	28	4

*p<0.01 caregivers of sickle cell patients compared the Dutch norm population.
ᵃEducation: see legend to Table 1.

Table 3. Differences between caregivers of patients with SCD, the SES control group and the Dutch norm population on the subscales of the TAAQOL.

	SCD group		SES control group population		Dutch norm		SCD group compared to SES control group	
	Median	IQR	Median	IQR	Median	IQR	Point estimate of median difference (95% CI)	p value MW
Depressive moods *	58	33-66	67	50-88	83	75-92	-17 (-25 ; 0)	0.020
Daily activities *	81	43-97	97	75-100	100	88-100	-6 (-25 ; 0)	0.033
Vitality *	42	31-58	58	38-75	75	58-83	-8 (-25 ; 0)	0.043
Sleeping	50	25-69	72	31-88	88	63-100	-13 (-31 ; 0)	0.072
Happiness	54	33-67	58	46-71	67	67-83	-8 (-17 ; 0)	0.090
Cognitive functioning	75	41-100	91	70-100	100	81-100	-6 (-25 ; 0)	0.122
Fine motor	100	100-100	100	100-100	100	100-100	0 (0 ; 0)	0.182
Sexual functioning	75	50-100	88	75-100	100	88-100	0 (-25 ; 0)	0.465
Pain	63	38-88	63	25-81	88	69-97	6 (-13 ; +19)	0.556
Aggressiveness	78	56-100	89	56-100	89	89-100	0 (-11 ; +11)	0.791
Gross motor	75	39-100	81	28-100	100	100-100	0 (-13 ; +13)	0.817
Social functioning	75	63-88	75	53-85	100	81-100	0 (-13 ; +13)	0.969

*Higher scores indicate a higher QOL (scale 0-100). * p<0.05 with the Mann-Whitney U test (MW); SCD group compared to the SES control group. For all subscales p<0.05 with the Mann-Whitney U test; SCD group compared to the Dutch norm population; IQR = interquartile range.*

responsibility of caring for a chronically ill child.

Compared to the Dutch norm population both caregivers of children with SCD and caregivers from the SES control group had lower scores on gross motor function and pain. The higher proportion of single parents and lower educational level in these groups may explain these findings. Both single parenting and a lower educational level are associated with worse subjective health perception. Single parents are more likely to experience stress due to the increased burden of caregiving in comparison to other parents, which can be manifested by, for example, limitations in gross motor function and more limitations in daily activities due to pain.[15] Furthermore, obesity is more common in a population with a low education level (prevalence 66%) than among more highly educated individuals (prevalence 43%)[15] and can also lead to impaired physical functioning and an increased incidence of pain.

Certain 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. Having identified a lower QoL in the group of SCD caregivers, it is important to predict which caregivers are at the highest risk of a low QoL. This group has the potential to benefit most from supportive interventions. Our cross-sectional study design does not allow analysis of such predictors. The measurement of QoL that we employed was validated in a Dutch reference population. In other cultural groups the interpretation of the questions, and the meaning attributed to the words may be influenced by cultural background and difficulties with the Dutch or English language.[30] We addressed the cultural diversity in our sample by including a control group with the same ethnic and socio-economic background.

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. When they were asked about their unmet needs, issues such as financial support and personal guidance about available services were mentioned both by the caregivers in our study and by the caregivers in a study by Chamba et al.[32] In the latter study the need for support was much higher among caregivers of ethnic minority groups of disabled children than among white caregivers. This might be due to, for instance, lower levels of employment, less access to financial benefits and low levels of support from an extended family.[32] A social worker could help parents to gain access to financial benefits and appropriate housing. Furthermore, employers should be encouraged to offer care-related leave of work to stimulate employment of caregivers of chronically ill children.

Promoting good health of caregivers, stress management and a social support network are important.[33] As disrupted sleep patterns have an influence on mood, motor and cognitive functioning,[26] 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]

This first study reporting on the QoL of caregivers of children with SCD demonstrates that caregivers have a significantly worse QoL on the subscales depressive moods, daily activities and vitality, compared to the control group matched for SES. Lower QoL scores were also found on the subscales sleeping, happiness and cognitive functioning. Doctors and other health care workers should be aware of the emotional and functional needs of these caregivers. Better support may be needed to improve the QoL of both children with SCD and their caregivers.

Authorship and Disclosures

XvdT designed the study, acquired, analyzed and interpreted the data and drafted the manuscript; JH analyzed and interpreted the data and revised the manuscript; EE acquired, analyzed and interpreted the data and revised the manuscript; HvdL designed the study, analyzed and interpreted the data, and drafted and revised the manuscript; MP supervised acquisition of the data, and revised the manuscript; KF designed the study, supervised acquisition of the data, analyzed and interpreted the data, drafted and revised the manuscript; MG designed the study, analyzed and interpreted the data and revised the manuscript.

All authors read and approved the final manuscript.

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