

Caregiving Time in Sickle Cell Disease: Psychological Effects in Maternal Caregivers

Judith Tedlie Moskowitz, PhD, MPH,^{1*} Ellen Butensky, PhD, PNP,² Paul Harmatz, MD,³ Elliott Vichinsky, MD,⁴ Melvin B. Heyman, MD, MPH,⁵ Michael Acree, PhD,¹ Judith Wrubel, PhD,¹ Leslie Wilson, PhD,^{1,6} and Susan Folkman, PhD¹

Background. Providing home care for a child with a chronic illness can be stressful for the family. The purpose of this paper is to examine patterns of caregiving and the associated psychological impact on maternal caregivers of children with sickle cell disease (SCD). **Procedure.** Fourteen maternal caregivers of children with SCD were interviewed as part of a larger study of maternal caregivers of children with chronic illness. Forty-four caregivers of children with HIV and 36 caregivers of healthy children were included as comparison groups. Interviews included questions regarding amount of time spent providing care for the child (technical care, non-technical care, health care management), hospitalization, emergency room visits, illness stigma, and mental health of the caregiver. **Results.** Children with SCD had significantly lower functional status and significantly more hospitalizations in the previous 3 months than children with HIV. Caregivers of children with SCD were more likely to work full-time and had higher incomes than caregivers of children with HIV. The three caregiving groups did not differ significantly on

amount of total care, although caregivers of children with SCD and caregivers of children with HIV both reported significantly more time spent in technical care than caregivers of healthy children. Despite lower functional status of the children in the SCD group, when group comparisons on caregiving time variables were adjusted for child's functional status, the differences between groups increased. This appeared to be due to the fact that caregivers in the HIV group spent more time in all caregiving categories except skin, crisis, and other care. In terms of caregiver mental health, caregivers of children with HIV and SCD had significantly higher depressive mood scores than caregivers of healthy children but the groups did not differ on caregiving burden. **Conclusions.** The perceived care burden of caregivers of children with SCD may be related to the unpredictable nature of the crisis care they provide. Additional attention is warranted to developing adequate resources for caregivers of children with SCD to mitigate the stress of unexpected crises. *Pediatr Blood Cancer* 2007;48:64–71. © 2006 Wiley-Liss, Inc.

Key words: caregiver; caregiving burden; depression; HIV; informal care; sickle cell disease

INTRODUCTION

Sickle cell disease (SCD) is characterized by intermittent crises, including painful vasoocclusion, splenic sequestration, acute chest syndrome, stroke, priapism, avascular necrosis, and aplastic crisis [1]. These crises occur with varying frequency, severity, and extent of disability in each individual affected by the disease [2]. Crises may also arise at any time and must be managed immediately [3]. Although SCD has variable expression of disease severity, it impacts most systems of the body and can lead to chronic organ damage, growth retardation, and early death [4–6].

Caregivers of children with SCD must perform or manage a variety of potentially stressful caregiving tasks including administration of medication, ensuring the child has adequate nutrition, encouraging behaviors that help to prevent pain episodes (e.g., drinking sufficient water, getting enough rest), managing the pain episodes (providing comfort, analgesics), and helping the child cope with negative feelings about having sickle cell and other social and academic problems [7]. Given these caregiving challenges, it is not surprising that caregivers of children with SCD are at high risk for poor adjustment [8–11].

A number of studies of caregivers of chronically ill children indicate that caregiver distress and depression have an impact on the rest of the family [9,12–14] and are associated with lower levels of family cohesion [15] and increased levels of both internalizing and externalizing behavior in the child [9,16]. Therefore, it is important to

study factors that may affect caregiver well-being. Likely determinants of caregiver well-being include the severity of the child's disease, the amount of care that is required, and the caregiver's perception of how stigmatized the disease is. The relationship between caregiver ratings of functional status of the child and caregiver distress is not clear; some studies find that higher functional status is associated with better mental health [17–19], whereas others find no association [20,21]. The physical manifestations of SCD, such as smaller stature, late maturation, or disfigurements secondary to the disease can lead to feelings of stigma [22], and the caregiver's perceived illness stigma or guilt about passing the illness

¹Department of Medicine, University of California San Francisco, Osher Center for Integrative Medicine, San Francisco, California; ²Pediatric Clinical Research Center, Children's Hospital & Research Center at Oakland, Oakland, California; ³Department of Gastroenterology & Nutrition, Children's Hospital & Research Center at Oakland, Oakland, California; ⁴Department of Hematology/Oncology, Children's Hospital & Research Center at Oakland, Oakland, California; ⁵Department of Pediatrics, University of California San Francisco, San Francisco, California; ⁶Department of Pharmacy, University of California San Francisco, San Francisco, California

Grant sponsor: NIMH/NINR; Grant number: MH58069; Grant sponsor: NIH; Grant numbers: U54HL070583, DK060617.

*Correspondence to: Judith Tedlie Moskowitz, Osher Center for Integrative Medicine, University of California San Francisco, 1701 Divisadero, Suite 150, San Francisco, CA 94115.

E-mail: moskj@ocim.ucsf.edu

Received 22 June 2005; Accepted 10 January 2006

on to the child are likely to influence caregiver well-being [23–25].

Although, as reviewed above, previous work has documented the parenting challenges and increased risk of distress in caregivers of children with SCD, detailed studies of caregiving time in SCD have not been conducted. In previous papers, we have demonstrated that providing care for a child with chronic illness is more time-consuming than caring for a child with HIV [26] but that the time-spent caring for a chronically ill child does not necessarily lead to a corresponding higher level of psychological distress [27]. The goal of the present study was twofold: (1) to document the types and amount of home care provided by maternal caregivers of children with SCD and (2) to examine the associated psychological effects in maternal caregivers of children with SCD. We include two comparison groups: maternal caregivers of children with HIV and maternal caregivers of healthy children. The caregivers of healthy children were included to control for the typical demands and psychological effects of being a parental caregiver. The caregivers of children with HIV were included because HIV shares the characteristics of potential stigmatization and shortened survival, often with a caregiver also having the disease. In addition, caregivers of children with HIV are faced with some of the same caregiving tasks as caregivers of children with SCD including administering medications, and coping with academic and social problems [28,29].

METHODS

Maternal caregivers were enrolled as part of a larger observational cohort study to explore the impact of caring for a child with a chronic illness on the primary maternal caregiver. Given that the majority (82%) of the caregivers of children with SCD were Black, to ensure comparability across groups, we restricted all our analyses to Black caregivers in the three groups.

Maternal caregivers who were the primary caregiver in the home of a child between the ages of 1 and 18 years were recruited from patients followed in the Hematology Department, the Pediatric HIV Programs, and the general pediatric clinics at Children's Hospital & Research Center at Oakland, the University of California San Francisco Children's Hospital, and New York-Presbyterian: Weill Cornell Medical Center, in Manhattan. Following identification of potential participants by the clinic investigators, an interviewer contacted the caregiver, asked for consent to participate, and scheduled a baseline interview.

Caregivers were interviewed on three occasions: at study entry and at 3 and 6 months into the study. Interviews were conducted in English or Spanish by trained interviewers. Interviews lasted between 2 and 3 hr and were conducted at the clinics or in the participants' homes. Participants were given \$50 per interview and childcare and transportation

were provided, when necessary. The study protocol was approved by the Institutional Review Board at each site, and informed consent was obtained from all caregivers prior to enrollment.

Measures

Caregiving time was measured at the entry and 6 months interviews by asking the caregivers to account for all time devoted to providing technical care, non-technical care, or healthcare management for the child each day, on average over the previous 2 weeks. Technical care included time for diagnostic procedures, medication administration, care of indwelling tubes, and skin care. Crisis care (a sudden health event that necessitated an ambulance or trip to the emergency room for immediate care) was considered a form of technical care, but it was assessed over the past 3 months because we expected that it would occur much less frequently than the other types of technical care. Non-technical care included both illness and non-illness-related time for feeding, bathing, skin care (non-technical-related), dressing, grooming, bowel and bladder care, transfer to bed/chair, and toileting. Illness-related non-technical care time included ambulation in the home and outside of the home, laundry, and housecleaning. Health care management included tasks related to arranging care, arranging finances including insurance authorization and coverage, and travel and waiting time, and was measured as the hours per week spent on these activities averaged over the past 3 months. Introductory screening questions were presented at the start of each of the technical care sections (i.e., diagnostic procedures, medication administration, care of indwelling tubes, and skin care and crisis care) to allow the interviewers to go on to the next section if the caregiver had not performed that activity in the past 2 weeks. If necessary, the interviewers provided tools to help the participants make their estimates (e.g., calculators and calendars). We report the time averaged across the two time points for each of these three categories of care.

The child's *functional status* was measured using the Functional Status II Revised (FSIIR) questionnaire [30], which defines child health as the capacity to perform age-appropriate roles and tasks. The FSIIR assesses the child's behavior in several areas (communication, mobility, mood, energy, sleep, eating, and toileting) at home, neighborhood, and school. Each caregiver completed the measure by responding to behavioral statements corresponding to her child's age. Higher scores indicate higher (better) functioning. The scale was developed for use in both chronically ill and well-child populations, and correlations with maternal distress indicate that the mother's report of the child's functional status is not seriously confounded with mother's mood [18,20,31,32].

Hospitalization and Emergency Room Visits were assessed at entry and 6 months by asking caregivers to report

the number of overnight hospital stays and the number of emergency room visits in the past 3 months.

Illness stigma was measured in the two illness groups with a modified version of the Personal Stigma Scale [33,34]. This scale was originally designed to assess HIV stigma and contained 22 statements related to feelings of shame and blame to which participants were asked to rate how strongly they agreed or disagreed, on a 4-point Likert scale (*strongly agree to strongly disagree*). For example: “You feel ashamed that your child has (SCD/HIV)””; “You have been brave in handling your child’s (SCD/HIV)” (reverse coded); “Because of (his/her) illness, you feel your child will be less attractive to those who might want to date (him/her).” Scores ranged from 22 to 88, with higher scores indicating greater stigma.

Depressed mood was measured with the Center for Epidemiologic Studies Depression Scale (CES-D) [35]. This scale contained 20 depressive symptoms rated on a 4-point scale according to how frequently they were experienced in the previous week. Scores ranged from 0 to 60, with values of 16 or greater indicating the respondent was at risk for clinical depression.

Caregiving burden was measured with a 16-item questionnaire, each item having two aspects [36]. For the first part of each item, participants were asked to rate, on a 4-point Likert scale, how much their caregiving activities affected other aspects of their lives. In the second part of each item, participants were asked to rate how bothersome that effect was. For each item, the extent to which the caregiver reported being affected by caregiving and her rating of how bothersome this was for her were multiplied together to calculate the weighted caregiving burden. Higher scores indicate greater perceived caregiving burden.

Demographic assessment included caregiver’s age, education level, ethnicity, and household income; whether the caregiver was the child’s biological, foster, or adoptive mother or other relative; the child’s age; number of other children in the household; and number of other ill children in the household. In addition, caregivers were asked whether they worked outside the home, and, if so, how many hours per week.

Statistical Analyses

Statistical comparisons among the three illness groups on categorical variables were made by Fisher’s exact test. The difference in median income was tested with the Wilcoxon test. Distributions of most caregiving time variables were highly non-normal, with large numbers of zeroes mixed with some very large values. For any given care category, like crisis care or skin care, most cases will have none in a given time interval but a few will have a lot. Accordingly, we tested differences between groups with the bootstrap, using SAS PROC MULTTEST, without centering, with 100,000 resamples. The bootstrap, treating the sample as a population

and repeatedly sampling from it with replacement, is an empirical procedure that makes no distributional assumptions. Similarly, we used a distribution-free randomization test for differences between Pearson correlations with time data. To avoid severe adjustment for a large and quite arbitrary number of variables, we tested variables individually, following the philosophy of interpreting results only when they exhibit a meaningful pattern. Data are presented as mean \pm SD.

RESULTS

The final sample consisted of 14 maternal caregivers of children with SCD, 44 caregivers of children with HIV, and 36 caregivers of healthy children. Of the 14 caregivers of children with SCD, 12 were recruited from Children’s Hospital and Research Center at Oakland, 2 from New York-Presbyterian: Weill Cornell Medical Center. Information on SCD genotype and treatment were available for 12 of the SCD children: 10 were HbSS, 3 received transfusion therapy, and 1 received hydroxyurea but discontinued use during the course of the study. Demographic and illness characteristics for SCD, HIV, and healthy groups are presented in Table I.

Caregivers of children with SCD were more likely to be employed outside the home and had significantly higher income than caregivers of children with HIV (See Table I). In contrast to maternal caregivers of healthy children, a greater proportion of caregivers of children with SCD were biological mothers. Functional status did not differ significantly between children with SCD and HIV. However, the children with SCD had lower functional status than the healthy children. Children with SCD had significantly more hospitalizations in the previous 3 months than children with HIV or healthy children, but did not differ from the other two groups on number of emergency room visits. The caregivers of children with SCD had lower levels of illness stigma than caregivers of children with HIV. The three groups did not differ in the number of other children in the home or in the number of other ill children in the home.

Although maternal caregivers of children with SCD spent fewer total hours providing care than caregivers of children with HIV, this difference was not significant ($P=0.24$; Table II). Not surprisingly, both the caregivers of children with SCD and caregivers of children with HIV spent a significantly higher proportion of time in technical care activities than the caregivers of healthy children.

Given the expected differences in the type of care needed in SCD versus HIV, we examined time spent on the individual technical care activities across the three groups (Table III). Crisis care (93 ± 336 min per week) comprised the greatest proportion of caregiving of children with SCD, and was significantly greater than the time spent in crisis care by the caregivers of healthy children, but not significantly greater than the time spent in crisis care by caregivers of children with HIV. Inspection of each participant’s data on the crisis

TABLE I. Demographic Characteristics of Subject Population (Mean \pm SD)

	SCD (N = 14)	HIV (N = 44)	Healthy (N = 36)
Maternal caregiver characteristics			
Age (years)	37.1 \pm 15.5	42.4 \pm 9.6	39.5 \pm 13.2
Education level (years)	12.0 \pm 1.7	12.6 \pm 2.2	12.5 \pm 3.1
Household income (median)	\$27.5K ^a	\$17.5K ^b	\$20K ^{a,b}
Biologic mother: N (%)	12 (86%) ^a	27 (61%) ^{a,b}	20 (56%) ^b
Caregiver employment (any)	6 (43%)	13 (30%)	21 (58%)
Part-time	0 ^a	9 (69%) ^b	4 (19%) ^a
Full-time	6 (100%) ^a	4 (31%) ^b	17 (81%) ^a
Child characteristics			
Age (years)	8.4 \pm 4.3	8.7 \pm 3.2	7.7 \pm 4.1
Male: N (%)	7 (50%)	19 (43%)	16 (44%)
Functional status	86.9 \pm 15.3 ^a	94.3 \pm 7.7 ^b	95.0 \pm 11.1 ^b
Hospitalizations in past 3 months	0.25 \pm 38 ^a	0.08 \pm 0.21 ^b	0.04 \pm 0.18 ^b
Emergency room visits past 3 months	0.29 \pm 0.32	0.31 \pm 0.57	0.24 \pm 0.44
Illness Stigma	26.4 \pm 5.57 ^a	31.7 \pm 6.62 ^b	—
Number of other children in home	2.07 \pm 0.92	1.48 \pm 1.30	1.44 \pm 1.54
Number of other ill children in home	0.38 \pm 0.96	0.19 \pm 0.47	0.20 \pm 0.41

^{a,b}Values in the same row with different superscripts (e.g., ^a vs. ^b) are significantly different from each other at $P < 0.05$; values in the same row with identical superscripts are not significantly different. The lack of superscripts means that no differences were significant. All tests were conducted pairwise: means by t -tests, percentages by Fisher's exact test, and median income by the Wilcoxon test.

care variable revealed that in the caregivers of children with SCD, one caregiver reported an extreme value of six crises over the course of one 3-month period in which each crisis lasted for a week and the caregiver was involved with the child 13 hr per day. Although our bootstrap procedure is designed to take cases of extreme non-normality of the data into account, given this apparent outlier, we also analyzed the crisis care data in a dichotomous format such that each caregiver was coded as reporting any crisis or not, regardless of the time she spent dealing with the crisis. In the sickle cell group, 28% of the caregivers reported any crisis compared to 16% in the HIV group and none in the healthy group. The chi-square difference between the SCD and HIV groups, however, was not statistically significant ($P = 0.29$).

Group comparisons on caregiving time variables were adjusted for child's functional status to see whether differences remained, on the assumption that lower (poorer) functional status would entail greater caregiving time.

Although children in the HIV group had higher functional status than those in the SCD group (94.3 vs. 86.9, $P < 0.02$), caregivers in the HIV group spent *more* time in all caregiving categories except skin, crisis, and other care. Consequently, adjustment for functional status served to *increase* rather than to remove differences between these groups. In most cases non-significant differences became significant, as the functional-status-adjusted mean times for the HIV group were even higher than the raw means. For the other three variables, where the SCD group spent more time than the HIV, the adjustment was in the expected direction; it removed significant differences on skin and other care, and made the difference on crisis care still more non-significant.

Mean group scores on caregiving burden and depressive mood are presented in Table IV. Caregivers of children with SCD had significantly higher levels of depressive mood than caregivers of healthy children, but did not differ from caregivers of children with HIV. A score of 16 or above on the

TABLE II. Time Spent in Care: Primary Caregivers (Minutes/Week; Mean \pm SD, Percent of Total Care)

	Caregivers of children with SCD	Caregivers of children with HIV	Caregivers of healthy children
Technical care	195 \pm 365 ^a 37.5%	206 \pm 330 ^a 22%	30 \pm 60 ^b 5%
Non-technical care	213 \pm 229 41%	515 \pm 850 55%	477 \pm 499 80%
Health care management	112 \pm 105 21.5%	211 \pm 409 23%	87 \pm 180 15%
Total care	520 \pm 517	932 \pm 1285	594 \pm 517

^{a,b}Values in the same row with different superscripts (e.g., ^a vs. ^b) are significantly different from each other at $P < 0.05$; values in the same row with identical superscripts are not significantly different. The lack of superscripts means that no differences were significant. Means were tested pairwise with bootstrapped t -tests (see text for details).

TABLE III. Time Spent in Technical Care (Primary Caregiver; Minutes/Week; Mean \pm SD, Percent of Total Technical Care)[†]

	Caregivers of children with SCD	Caregivers of children with HIV	Caregivers of healthy children
Diagnostic			
Total time	38 \pm 56	64 \pm 126	23 \pm 53
% of technical care	19%	31%	77%
Medications			
Total time	54 \pm 83 ^a	103 \pm 131 ^a	6 \pm 14 ^b
% of technical care	28%	50%	20%
Crisis care			
Total time	93 \pm 336 ^a	31 \pm 138 ^{a,b}	0 ^b
% of technical care	48%	15%	
Nasogastric tube			
Total time	0	9 \pm 53	0
% of technical care	0	4%	
Skin care			
Total time	2 \pm 7 ^a	0 ^b	0.2 \pm 1 ^{a,b}
% of technical care	1%	0%	0.7%
Other activities			
Total time	8 \pm 28 ^a	0.07 \pm 0.5 ^b	1 \pm 5 ^{a,b}
% of technical care	4%	0.03%	3%

^{a,b}Values in the same row with different superscripts (e.g., ^a vs. ^b) are significantly different from each other at $P < 0.05$; values in the same row with identical superscripts are not significantly different. The lack of superscripts means that no differences were significant. Means were tested pairwise by bootstrapped t -tests (see text for details).

“Other” technical care activities not specifically covered by the questions but offered by the caregivers included giving massages or warm baths, caring for ears, checking for rashes, and administering medication through an inhaler.

[†]No time spent in “IV activities” or “other tubes” in any group.

CES-D is considered at risk for clinical depression [35]. Using this criteria, 50% of the caregivers of children with SCD were at risk for clinical depression compared to 34% of the HIV group and 19% of the healthy group ($\chi^2(2) = 4.8$, $P = 0.09$). The three groups did not differ on caregiving burden.

Given the different types of care required by children with SCD compared to children with HIV, it may be that the determinants of psychological well-being differ between the two illness groups. To address the question of different predictors of psychological response to caregiving, we calculated correlations of the various categories of care and illness and context descriptors (e.g., functional status, number of other children in the home) with CES-D and caregiving burden within the HIV and SCD groups (Table V). As noted in the Methods section, since the care time data are

so extremely non-normal, we used randomization tests for differences between correlations based on 100,000 random partitions of the 58 participants into samples of 14 and 44. By our randomization tests, the difference between the sickle cell and HIV groups in the correlation between number of hospitalizations and depression was significant ($P = 0.0097$, two-tailed), but other significant group differences in correlations with either depression or caregiving burden were not found.

DISCUSSION

This study highlights the extent and impact of caring for children with SCD in maternal caregivers. The care demands of these children are high, about 1.5 hr per day, and the caregiver is generally employed full-time. This burden of care can have an impact on other maternal caregiving responsibilities and needs, including care of well children, management of the household, social activities, and employment [8,37].

Perhaps, the most unexpected finding from this study, however, was that caregivers of children with HIV, despite the significantly better functional status of their children, spent numerically even more time in almost all caregiving categories than did caregivers of children with SCD. Adjusting for functional status made nearly all these differences significant. This result may be due to the fact that caregivers of children with SCD were significantly more likely to work full-time outside the home than caregivers of

TABLE IV. Psychological Measures for Maternal Caregivers

	SCD	HIV	Healthy
CES-D	17.0 \pm 9.26 ^a	14.1 \pm 9.36 ^{a,b}	10.0 \pm 7.04 ^b
Caregiving burden (weighted)	15.38 \pm 18.34	8.69 \pm 11.74	11.20 \pm 14.92

CES-D, center for epidemiologic studies-depression.

^{a,b}Values in the same row with different superscripts (e.g., ^a vs. ^b) are significantly different from each other at $P < 0.05$; values in the same row with identical superscripts are not significantly different. Lack of superscripts means that no differences were significant. Means were tested pairwise by t -tests.

TABLE V. Correlations of Time Spent in Caregiving Activities, Number of Emergency Room Visits, Number of Hospitalizations, and Perceptions of Illness Stigma With Caregiving Burden and CES-D

	Caregiving burden		CES-D	
	SCD	HIV	SCD	HIV
Technical care	0.86	0.54	0.15	0.17
Diagnostic	0.11	0.40	0.26	0.11
Medications	0.37	0.61	0.42	0.08
Crisis care	0.82	0.14	-0.04	0.24
Nasogastric tube	—	0.65	—	-0.03
Skin care	0.22	—	0.29	—
Other activities	-0.14	-0.12	0.51	-0.17
Non-technical care	0.19	0.36	0.16	0.46
Healthcare management	0.20	0.71	0.03	0.04
Emergency room visits	-0.01	-0.07	-0.01	0.19
Hospitalizations	-0.16	0.16	-0.57	0.14
Stigma	0.03	0.41	0.37	0.49
Number of other children in the home	0.09	0.20	-0.46	0.01
Number of other ill children in the home	-0.04	-0.06	-0.40	0.31

Statistically significant correlations ($P < 0.05$) are in bold.

children with HIV. These data thus contain an important warning against naïve assumptions about the relation between caregiving time and illness severity. The time-spent providing care is not simply a function of the child's illness but is multiply determined by additional factors, such as the amount of time the caregiver has available to provide care. The evident explanation in this case is just that caregiving expands (or decreases) to the time available.

Despite spending the same or less time in total care than caregivers of children with HIV, caregivers of children with SCD did score about half a standard deviation higher on care burden. The perceived care burden may be due especially to the unpredictability of crises in SCD and to the pain that it causes. Parents report that coping with pain is the most difficult situation that arises in caring for a child with SCD [7], and that seeing their child in pain is associated with emotional distress and feelings of inadequacy and guilt [8]. In addition to spending much time in providing crisis care, the care of the child with SCD involves a greater proportion of time spent in technical care compared with caring for a child with HIV. This care may cause added burden as it is not part of the expected caregiving required for a healthy child.

Depressive symptom scores were high, overall, for caregivers of children with the two chronic diseases. Depression has not been well studied in caregivers of children with SCD, and our findings suggest that further research is warranted [38,39]. Our data indicate that caregiving burden is associated with amount of crisis care for the caregivers of children with SCD but not for caregivers of children with HIV. Future work should focus on the differential determinants of well-being in the different caregiving groups.

This study has a number of limitations, most notably the small sample size for the SCD group and the reliance on

retrospective self-report measures. The fact that the small group of SCD caregivers was recruited from multiple sites may limit the extent to which the group represents the larger population of SCD caregivers. Although a larger sample size would have given us power to detect smaller differences between the groups, the means we report are valid and can serve as a comparison point for future studies of SCD caregiver time use and its association with psychological well-being. There are certainly drawbacks to using self-report retrospective data, including the likelihood of reporting bias. We are very cognizant of the drawbacks of self-report, retrospective data, and made an effort to maximize the reliability and validity of the data by conducting face-to-face interviews in which the interviewers were trained to help the participant think through their time estimates, providing tools to assist (i.e., calendars and calculators), if necessary. The shorter the time period over which the participants are asked to reflect, the more accurate the data are likely to be. Our time frames of 2 weeks (for technical and non-technical care) and 3 months (for the less frequently occurring healthcare management and crisis care) are actually smaller than other studies of caregivers of children with sickle cell, which typically ask caregivers to report ER visits and pain episodes over the past 9–12 months (e.g., [9,10]). Future research on time use in caregivers may consider using a daily retrospective method that assists participants in more accurately reporting how they used their time on the previous day and how they felt while doing each activity [40].

Crisis care is an important part of the care burden of caregivers of children with SCD. It is difficult to provide support for crises that may occur at any time of the day or night and that are unpredictable. Although a number of

family interventions for SCD have been developed [41–43], the main focus appears to be on outcomes for the child with SCD (e.g., pain, SCD knowledge, psychological adjustment) rather than on support for the caregiver. Further work is necessary to identify areas in which support can be provided in order to decrease the negative impact of SCD on the caregiver. These areas may include improved psychological services to mitigate the effects of care burden and depression, and changes in policies regarding employment, such as allowances for missed days of work due to caring for an ill child at home. Improved support for these caregivers could make a difference, not just in their mental health but also possibly in the physical health of the child.

REFERENCES

- Lane PA. Sickle cell disease. *Pediatr Clin North Am* 1996;43:639–664.
- Shaiova L, Wallenstien D. Outpatient management of sickle cell pain with chronic opioid pharmacotherapy. *J Natl Med Assoc* 2004; 96:984–986.
- Jakubik LD, Thompson M. Care of the child with sickle cell disease: Acute complications. *Pediatr Nurs* 2000;26:373–379.
- Noll RB, McKellop JM, Vannatta K, et al. Child-rearing practices of primary caregivers of children with sickle cell disease: The perspective of professionals and caregivers. *J Pediatr Psychol* 1998; 23:131–140.
- Ris MD, Grueneich R. Sickle Cell Disease. In: Yeates KO, Ris MD, Taylor HG, editors. *Pediatric neuropsychology: Research, theory, and practice*. New York: Guilford; 2000. pp 320–335.
- Platt OS, Brambilla DJ, Rosse WF, et al. Mortality in sickle cell disease: Life expectancy and risk factors for early death. *N Engl J Med* 1994;330:1639–1644.
- Levers-Landis CE, Brown RT, Drotar D, et al. Situational analysis of parenting problems for caregivers of children with sickle cell syndromes. *Dev Behav Pediatr* 2001;22:169–178.
- Melnyk BM, Feinstein NF, Moldenhouer Z, et al. Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatr Nurs* 2001;27:548–558.
- Brown RT, Lambert RG, Devine D, et al. Risk-resistance adaptation model for caregivers and their children with sickle cell syndromes. *Ann Behav Med* 2000;22:158–169.
- Thompson RJ, Gil KM, Burbach DJ, et al. Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *J Pediatr Psychol* 1993;18:549–559.
- Thompson RJ, Gil KM, Gustafson KE, et al. Stability and change in the psychological adjustment of mothers and children and adolescents with cystic fibrosis and sickle cell disease. *J Pediatr Psychol* 1994;19:171–188.
- Beck CT. Maternal depression and child behaviour problems: A meta-analysis. *J Adv Nurs* 1999;29:623–629.
- Casey P, Goolsby MS, Berkowitz C, et al. Maternal depression, changing public assistance, food security, and child health status. *Pediatrics* 2004;113:298–304.
- Williamson GM, Walters AM, Shaffer DR. Caregiver models of self and others, coping, and depression: Predictors of depression in children with chronic pain. *Health Psychol* 2002;21:405–410.
- Murphy DA, Marelich WD, Dello Stritto ME, et al. Mothers living with HIV/AIDS: Mental, physical, and family functioning. *AIDS Care* 2002;14:633–644.
- Bachanas PJ, Kullgren KA, Suzman Schwartz K, et al. Psychological adjustment in caregivers of school-age children infected with HIV: Stress, coping, and family factors. *J Pediatr Psychol* 2001;26: 331–342.
- Lustig JL, Ireys HT, Sills EM, et al. Mental health of mothers of children with juvenile rheumatoid arthritis: Appraisal as a mediator. *J Pediatr Psychol* 1996;21:719–733.
- Silver EJ, Bauman LJ, Ireys HT. Relationships of self-esteem and efficacy to psychological distress in mothers of children with chronic physical illnesses. *Health Psychol* 1995;14:333–340.
- Timko C, Stovel KW, Moos RH. Functioning among mothers and fathers of children with juvenile rheumatic disease: A longitudinal study. *J Pediatr Psychol* 1992;17:705–724.
- Jessop DJ, Riessman CK, Stein REK. Chronic childhood illness and maternal mental health. *Dev Behav Pediatr* 1988;9:147–155.
- Wallander JL, Pitt LC, Mellins CA. Child functional independence and maternal psychosocial stress as risk factors threatening adaptation in mothers of physically or sensorially handicapped children. *J Consult Clin Psychol* 1990;58:818–824.
- Williams I, Earles AN, Pack B. Psychological considerations in sickle cell disease. *Nurs Clin North Am* 1983;18:215–229.
- Wight RG. Precursive depression among HIV infected AIDS caregivers over time. *Soc Sci Med* 2000;51:759–770.
- Mellins CA, Brackis-Cott E, Dolezal C, et al. Patterns of HIV status disclosure to perinatally HIV-infected children and subsequent mental health outcomes. *Clin Child Psychol Psychiatr* 2002;7: 101–114.
- Weiss SJ. Stressors experienced by family caregivers of children with pervasive developmental disorders. *Child Psychiatry Hum Dev* 1991;21:203–216.
- Wilson LS, Moskowitz JT, Acree M, et al. The economic burden of home care for children with HIV and other chronic illnesses. *Soc Sci Med* 2005; 95:1445–1452.
- Heyman MB, Harmatz P, Acree M, et al. Economic and psychological costs for maternal caregivers of gastrostomy-dependent children. *J Pediatr* 2004;145:511–516.
- Havens JF, Mellins CA, Hunter J. Psychiatric aspects of HIV/AIDS in childhood and adolescence. In: Rutter M, Taylor E, editors. *Child and adolescent psychiatry: Modern approaches*. Oxford, UK: Blackwell; 2002. pp 828–841.
- Wrubel J, Moskowitz JT, Richards TA, et al. Pediatric adherence: Perspectives of mothers of children with HIV. *Soc Sci Med* 2005; 61:2423–2433.
- Stein REK, Jessop DJ. Functional Status II(R): A measure of child health status. *Med Care* 1990;28:1041–1055.
- Dadds MR, Stein REK, Silver EJ. The role of maternal psychological adjustment in the measurement of children's functional status. *J Pediatr Psychol* 1995;20:527–544.
- Jessop DJ, Stein REK. Uncertainty and its relation to the psychological and social correlates of chronic illness in children. *Soc Sci Med* 1985;20:993–999.
- Bauman LJ, Camacho S. The relationship between maternal stigma from HIV/AIDS and child mental health. In: Society for developmental and behavioral pediatrics; September; Cleveland, OH; 1998.
- Silver EJ, Bauman LJ, Camacho S, et al. Factors associated with psychological distress in urban mothers with late-stage HIV/AIDS. *AIDS Behav* 2003;7:421–431.
- Radloff LS. The CES-D scale: A self report depression scale for research in the general population. *Appl Psychol Meas* 1977;1: 385–401.
- Gottlieb BH. The dislocations scale. Guelph, Ontario: The University of Guelph; 1988.

37. Williams PD, Lorenzo FD, Borja M. Pediatric chronic illness: Effects on siblings and mothers. *Matern Child Nurs J* 1993;21: 111–120.
38. Hackl KI, Somlai AM, Kelly JA, et al. Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health Soc Work* 1997;22:53–62.
39. Hughes CB, Caliandro G. Effects of social support, stress, and level of illness on caregiving of children with AIDS. *J Pediatr Nurs* 1996; 11:347–358.
40. Kahneman D, Krueger AB, Schkade DA, et al. A survey method for characterizing daily life experience: The Day Reconstruction Method. *Science* 2004;306:1776–1780.
41. Chen E, Cole SW, Kato PM. A review of empirically supported psychosocial interventions for pain and adherence in sickle cell disease. *J Pediatr Psychol* 2004;29:197–209.
42. Chernoff RG, Ireys HT, DeVet KA, et al. A randomized, controlled trial of a community-based support program for families of children with chronic illness: Pediatric outcomes. *Arch Pediatr Adolesc Med* 2002;156:533–539.
43. Kaslow NJ, Collins MH, Loundy MR, et al. Empirically validated family interventions for pediatric psychology: Sickle cell disease as an exemplar. *J Pediatr Psychol* 1997;22:213–227.