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SELF-REPORTED INVOLVEMENT OF FAMILY MEMBERS IN THE CARE OF ADULTS WITH CF

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Abstract

Background—Few empirical studies have examined the role of family caregivers in the lives of adults with CF.

Methods—As part of the Project on Adult Care in CF (PAC-CF), an on-going prospective, longitudinal panel study of adults with CF, 119 family members and friends of adults with CF completed a mail survey in which they reported the frequency of help they provide for their family member with CF during routine care, hospitalization, and home IV treatment.

Results—The 119 caregivers were mainly spouses or unmarried partners (56%) and parents (29%). Fifteen percent of caregivers were children, friends, siblings or roommates. Family caregivers for adults with CF report assisting mainly with communication and social support during routine treatment, although one third provide some clinical care on a regular basis. Family caregivers report an increase in assistance during periods of acute illness, such as during a hospitalization and home IV treatment, especially with clinical care tasks.

Conclusions—The depth of commitment required of families of children with CF has been well documented for decades. Our results suggest that the responsibilities of family members diminish only moderately as those with CF reach adulthood.

INTRODUCTION

Improvements in life expectancy for cystic fibrosis in recent years have resulted in a substantial population of adults with CF. In 2004, over 41 percent of patients in the CF Foundation Registry were 18 years or older, as compared to 30 percent in 1990 [1]. Due to the recent growth in the adult population, there is a greater need for research and care focusing on adults [2].

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At the same time as survival for those with CF has increased, there has been a gradual shift in the location of CF care away from the inpatient setting toward the home. Even for those with mild disease, the daily home regimen of preventive and maintenance care is complex and time consuming. Daily CF treatment regimens can include oral and/or nebulized antibiotics, chest physical therapy, nebulized mucolytic agents, pancreatic enzymes, vitamin supplements, exercise, and close monitoring of diet and nutrition [3]. The treatment regimen becomes more intense as the disease progresses [3,4]. Even complicated and intensive therapies such as multiple intravenous antibiotics are now commonly administered at home. Patients experiencing pulmonary exacerbations (or patients having routine “clean-outs”) were previously hospitalized as a matter of course; current treatment practices commonly include either direct care at home or a combination of a shorter hospital stay, followed by home IV treatment [5].

The simultaneous rise in the complexity of the care regimen and the shift of care to the home means that the burden of care increasingly falls on patients and families; this requires that family caregivers provide direct and complex clinical care that was previously provided by professionals [6,7]. Such a shift in care requires not only greater technical skill on the part of family caregivers, but also a substantial commitment of time and energy.

Parents of children with CF know the demands of the CF regimen well and the work of parents as family caregivers for children with CF is well documented. Research has examined the quality of life of parental caregivers and siblings of children with CF [4,8–10] and the relationship between family function and the health of the child with CF [11–14]. Patterson et al [14] found that the level of burden experienced by parents of children with CF is associated with decreased pulmonary function over time. Coyne et al [9] describe how time-consuming and complex daily care is for children with CF and point to the need to provide support for their parents.

Given the intensity of the clinical regimen, it would not be surprising if adults with CF continued to need substantial support from family caregivers, yet little attention in the medical literature has been paid to the involvement of family caregivers in the clinical care of adults with CF. To our knowledge, only one study has examined the role of family caregivers for adults with CF. [15]. As part of a qualitative interview study in the United Kingdom, thirty-one family caregivers were asked what types of care they provided to adults with CF. The caregivers reported picking up prescriptions, preparing and cleaning nebulizers, performing chest PT, and preparing and administering home IV therapies. Lowton found that parental caregivers provided more support overall to the adults, but spousal caregivers reported an increase in assistance to adults during periods of acute illness, such as during a hospitalization.

Because of our clinical suspicion that the involvement of family in the care of adults is substantial, and because of increasing use of outpatient therapies in the adult CF population, we sought to examine the self-reported role of family caregivers [16].

METHODS

The research reported here is part of a larger study of the care and quality of life of adults with CF in the United States called the Project on Adult Care in Cystic Fibrosis (PAC-CF). The design of the PAC-CF study and assembly of the study cohort have been described elsewhere in detail [17]. In brief, adults with CF 18 years of age or older were recruited from 10 CF Centers in the United States. Clinical characteristics provided anonymously by the CF Center were used to calculate each individual’s predicted probability of 5-year survival [18]. Because the primary focus of PAC-CF was to examine changes in quality of life as CF progressed, all adults with a predicted probability of 5-year survival [18]less than 0.975 and a randomly selected 25% of adults with a predicted probability of 0.975 or higher were asked by a study coordinator at their CF Center to participate in PAC-CF. Recruitment was initiated in 2004 and a total of 333 adults (58% of those approached) were enrolled. The study protocol was approved by the Institutional Review Boards at Education Development Center, Inc. and the ten hospitals in which the participating CF Centers are located.

For the caregiver component of the study, 289 of the PAC-CF participants were asked to provide the name of the family member or friend age 18 or older who was most involved in their care. Recruitment for the family caregiver study began about six months after data collection began with the adults with CF enrolled in the study. At that time, 16 participants had dropped out of the study due to death or receiving a transplant. An additional 28 adults enrolled in the study had not returned the first two surveys and were not asked to nominate a family member or friend. Of the 289 participants who were asked, 131 nominated a family member or friend (41% nomination rate) for recruitment. Of the 131 family caregivers nominated, 119 agreed to participate by completing a mail survey, for a 91% participation rate.

The family caregiver survey included demographic questions and a series of questions related to the type and frequency of assistance the family caregiver provides for their loved one with CF. Lists of the ways in which family caregivers may assist adults with CF were developed by a research team that included a pulmonologist who specializes in CF care and an adult with CF. The types of care included routine clinical care (e.g. “performing chest physical therapy,” “setting up nebulizer treatments,” “reminding to take routine pills”), obtaining and paying for medical care (e.g. “scheduling clinic visits,” “communicating with insurance companies”), care during hospitalizations (e.g. “bringing in outside food,” “meeting with a physician”), and care during home IV treatment (e.g. “taking care of home IV equipment,” “preparing meals”).

For routine care provided during the past four weeks and care provided during hospitalizations and home IV treatments, family caregivers were asked to rate the frequency of help they provide using six categories that included “not at all”, “a few times”, “about once a week”, “2–4 times a week”, “almost daily”, and “once a day or more”. Caregivers were asked to report how frequently they assisted their loved one with CF with activities related to obtaining and paying for routine care during the past 12 months using six categories that included “not at all”, “rarely”, “occasionally”, frequently, “almost always”, and “always”. As will be described in detail in conjunction with reporting of results, some categories were combined to facilitate summary of results.

Clinical data on PAC-CF participants, including maximum FEV1%, weight-for-age z-score, number of pulmonary exacerbations, diabetes, pancreatic sufficiency, and colonization with *Burkholderia cepacia* and *Staphylococcus aureus*, was provided by the participant’s CF Center. Patient age, gender, education, marital, and employment status were reported by the PAC-CF participant in the first PAC-CF mail survey.

Standard descriptive statistics were used to summarize the demographic characteristics of the caregivers and the demographic and clinical characteristics of the adults with CF who nominated the caregivers. T-tests and chi-square tests of independence were used to compare characteristics of adults with CF in PAC-CF who did and did not have a participating caregiver. One-way analysis of variance and chi-square tests of independence were used to compare the characteristics of adults with CF and their caregivers as well as the types of assistance provided by the caregivers by type of caregiver. The delineation of types of caregivers is explained below in the results section. Analyses were completed in SPSS version 14.0 (SPSS, Inc., Chicago, IL.).

RESULTS

We compared the demographic and clinical characteristics of PAC-CF participants with and without a participating family caregiver to determine whether the 119 adults with CF with family caregivers differed systematically from the 214 adults without. The mean age, gender distribution, and clinical characteristics of these two groups did not differ significantly. However, adults with a participating caregiver are more likely to be married (61% vs. 30%, p=.0001), live with family members (82% vs. 53%, p=.0001) and be employed (62% vs. 50%, p=.03).

About two-thirds of the caregivers live with the adult with CF. Just over half of the caregivers are spouses or partners (56%, n=67), about 30% are parents (n=35), and the remainder include siblings (n=8), an adult child (n=1), friends (n=7), and a roommate (n=1). Some parents did not currently live with the adult with CF (n=24) and some parents did (n=11). Nearly all (65 of 67) of the spouses/partners were currently living with the adult with CF while most (15 of 17) of the other caregivers (siblings, adult child, friends, roommate) did not currently live with the adult with CF. Since living with the adult with CF and the relationship of the caregiver to the adult with CF could impact the type of assistance provided, four types of caregivers were delineated by a combination of these two characteristics: 1) Spouse/partner living with the adult with CF (n=65), 2) Parent living with the adult with CF (n=11), 3) Parent not living with the adult with CF (n=24), and 4) Friends/siblings/adult children,(n=15) not living with the adult with CF. The small number of unusual cases, two spouses/partners not currently living with the adult with CF and one roommate and one sibling who did currently live with the adult with CF are excluded from comparisons based on the type of caregiver but included in analyses of the entire sample of caregivers.

Demographics of the Caregivers

Table 1 reports the demographic characteristics of the caregivers by type of caregiver. The age and gender of the family caregivers vary by type of caregiver with parents being older than the other types of caregivers. Most caregivers are women, except for spouses/partners, where only 43% are female. In general, the majority of caregivers are employed (78%) and have a college degree (60%). Most caregivers are also married, though this characteristic varies some by type of caregiver.

Demographics of the adults with CF

Table 2 reports the demographic and clinical characteristics of the adults with CF by type of caregiver. There are significant differences in some demographic characteristics of the adults with CF by type of caregiver. The adults with CF who live with parental caregivers are the youngest (mean age=21.4) and the adults with CF with spouse/partner caregivers are the oldest (mean age=36.4). These age difference may contribute to the lower level of education (only 9% with a college degree), the smaller percentage who are married (0%), and the better clinical status (mean FEV1%=77.6 and mean number of exacerbations=.82) of the adults with CF who live with their parents. Similarly, the increased age of the adults with CF with spouse/partner caregivers may account for the higher level of education (77% with a college degree) and the poorer clinical status (mean FEV1%=59.0 and mean number of exacerbations=1.2) of these adults with CF.

Assistance Provided by Caregivers during Routine Care

Table 3 summarizes the assistance provided by caregivers with twelve tasks related to routine care during the past month. Of 12 types of assistance, only two, reminding to complete treatments and preparing special meals, differed significantly by type of caregiver. Two-thirds of caregivers who lived with the adult with CF reported that they reminded their loved one to complete treatments. Over half of parents who lived with the adult with CF but only one-quarter of spouses/partners reported reminding their loved one more than once a week. In contrast, less than half of caregivers who did not live with the loved one with CF reported reminding their loved one to complete treatments and very few reminded them more than once a week. With preparing special meals, 60% of parents who lived with the adult with CF prepared special meals more than once a week while 73% of siblings/friends never prepared special meals.

The assistance provided with most routine tasks did not differ by type of caregiver. In general, more than half of caregivers did tasks such as reminding the adult with CF to exercise or take pills, though less than one-quarter did these activities more than once a week. Less than one-third of caregivers were involved in more clinical aspects of care such as cleaning nebulizer equipment, performing chest physical therapy, or maintaining oxygen supplies. Very few caregivers reported doing these more clinical activities more than once a week.

Assistance with Obtaining and Paying for Care

Caregivers were asked to report how frequently in the past 12 months they helped the adult with activities related to obtaining and paying for medical care. Table 4 reports the percentage who reported frequently, almost always, or always (versus those who reported not at all, rarely, or occasionally) by type of caregiver. One-third and one-quarter of caregivers reported, respectively, going to clinic visits and communicating with clinic staff during visits though less than 3% of caregivers reported communicating with clinic staff between clinic visits. On these tasks, there were not significant differences between types of caregivers. However, spouse/partners and parents living with adult are significantly more likely to order or pick up prescriptions (p=.006). Parents living with adults are significantly more likely than other types of caregiver to schedule clinic visits (p=.0001), take notes at clinic visits (p=.042), communicate with hospital billing offices (p=.0001), communicate with insurance companies (p=.0001), and complete insurance forms (p=.0001).

Assistance during hospitalization

Table 5 summarizes the assistance provided during the most recent hospitalization by the 81 caregivers who reported that their loved one with CF had been hospitalized in the past 12 months. The assistance provided during hospitalization did not vary by type of caregiver, so the percentage of all caregivers who provided each type of assistance is reported. Caregivers spent considerable time with the adult while hospitalized, with 80% reporting that they spent all day in the hospital at least once, and 34% report spending all night at the hospital at least once. Almost all reported bringing in outside food for the adult with CF. Nearly three-quarters reported meeting with a physician and/or a nurse. Nearly half met with a social worker and accompanied their loved one to testing during the hospitalization. The assistance provided by the caregivers came at the expense of lost time at work. About two-thirds of caregivers reported missing at least one day of work during a recent hospitalization and one-fifth reported missing 3 or more days of work.

Assistance during home IV treatment

Caregivers provide considerable assistance to adults with CF during home IV treatment. As reported in Table 6, routine household maintenance is provided by the overwhelming majority of caregivers during home IV therapy, even by those who do not live with the adults. Caregivers also report assistance with complex clinical tasks directly related to the home IV treatment: 62% take care of the IV equipment, 54% prepare antibiotic doses, and 42% maintain or change dressings on IV lines. Caregivers also report playing a role in managing the professionals who enter the home during IV therapy, as 81% of spouses/partners, 100% of parents living with adults, 39% of sibling/adult child/friends, and even 57% of parents not living with the adult communicate with home nursing staff during home IV treatment.

DISCUSSION

Family caregivers report substantial roles in both the routine and intermittent care of adults with CF. The depth of commitment required of the families of children with CF has been a recurrent theme in the literature on CF for decades; our study strongly suggests that the responsibilities of family members diminishes only moderately as those with CF reach adulthood. These findings should not be surprising, given the burden of self-management which is characteristic of CF; yet we suspect that the depth of involvement of family members reported here will be surprising to some because the care provided outside the walls of medical facilities is often invisible to clinicians. The increasing shift of care away from the institutional setting has it benefits, such as greater autonomy, but these results suggest that moving care into the home has burdens as well. Family members are essential partners in the care of adults with CF, not only as psychosocial support, but as providers of direct clinical care. The 91% response rate among caregivers in this study may be evidence of their commitment to their loved one with CF as well as their eagerness to have their role recognized and understood.

The role of family caregivers in maintaining a treatment regimen should not be underestimated. Family caregivers for adults with CF report assisting mainly with communication and social support during routine treatment, although one third provide some clinical care on a routine basis. One of the most frequently reported forms of assistance provided by family caregivers is to serve as reminders to take pills, complete treatments, and exercise. This simple assistance may be especially helpful to adults, since research on self-management for CF patients suggests that forgetfulness is the most common reason given for omitting treatment [3,19]. Another type of frequently reported assistance provided by family caregivers is to pick up prescriptions. This is consistent with Lowton’s [15] study of family caregivers for adults with CF.

All types of family caregivers reported more direct involvement in providing assistance with care during periods of acute illness. Family caregiver involvement during hospitalization is substantial and led to missed work for two-thirds of the family caregivers for adults with CF. Adults with CF are likely to experience the most disruption of daily life during a pulmonary exacerbation, and family caregivers play an important role in assisting with day-to-day household tasks and providing support such as spending time with them while hospitalized. It is striking that even those family caregivers who do not live with the adults provide assistance such as preparing meals and housecleaning while adults are undergoing home IV treatment.

Parental caregivers living with the CF adult report the highest frequency of assistance with routine care and obtaining and paying for medical care, especially with tasks related to scheduling visits and communicating with CF center staff and insurance companies. This may be because adults still living with parents are younger, may still be included on their parent’s health insurance, and are undergoing the transition from pediatric to adult care. Even with the transition to adult clinical models of care, with the standard that adults be seen as responsible for their own care [2], young adults with CF continue to rely on parents for many aspects of routine care, and the dependence on parents persists even after they marry and no longer live under their parents’ roof.

Aside from the depth of involvement of family members, several aspects of the character of family care giving were notable. Although it was anticipated that most of the family caregivers nominated for participation would be spouses or parents, it was interesting to find that 42% of CF adults with parental caregivers not living with them were married. This suggests that adults with CF who are married may consider their parents, and not their spouses, as primary caregivers with regard to CF. This pattern is supported by Lowton’s finding that partners have less involvement in the care of adults than parents, except when the adult experiences an exacerbation. This finding may point to a different type of transition in care for adults than is typically described. Much of the literature on adults with CF has described the transition that CF patients make as they move from pediatric to adult care and take on greater responsibility for their own care. After transition to adult care, adults may experience a second transition involving a shift in the family caregiver from parents to spouse or partner. The mean age of adults in the sample with parental caregivers not living with them is 28. These adults may be experiencing a second transition involving a shift from parental to spousal/partner caregiver, approximately 7 to 10 years after the initial transition from pediatric to adult care.

Given their depth of involvement in the care of adults with CF, family caregivers may also experience similar burdens as has been reported for family caregivers in other illness [20–22]. However, because of the much higher functional status of most adults with CF, comparison of family caregiver burden to adult children caring for elderly parents may not be informative. A second stage of our research to measure family caregiver burden is underway. Support for family caregivers of adults with CF is a necessary part of the activities of adult CF care. Even though adults with CF should be seen as autonomous individuals, our research suggests that family caregivers are deeply involved in achieving and maintaining the gains in life expectancy seen over the past decades in CF.

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References

1. Cystic Fibrosis Foundation. Patient Registry 2004 Annual Report. Bethesda, Maryland: 2005.
2. Yankaskas JR, Marshall BC, Sufian B, Simon RH, Rodman D. Cystic fibrosis adult care: consensus conference report. Chest 2004 Jan;125:1S–39S. [PubMed: 14734689]
3. Kettler LJ, Sawyer SM, Winefield HR, Greville HW. Determinants of adherence in adults with cystic fibrosis. Thorax 2002;57(5):459–464. [PubMed: 11978927]
4. Foster C, Eiser C, Oades P, Sheldon C, Tripp J, Goldman P, et al. Treatment demands and differential treatment of patients with cystic fibrosis and their siblings: patient, parent and sibling accounts. Child Care Health Dev 2001;27(4):349–364. [PubMed: 11437838]
5. Cottrell J, Burrows E. Community-based care in cystic fibrosis: role of the cystic fibrosis nurse specialist and implications for patients and families. Disabil Rehabil 1998 Jun–Jul;20(6–7):254–261. [PubMed: 9637934]
6. Myaskovsky L, Dew MA, Switzer GE, McNulty ML, DiMartini AF, McCurry KR. Quality of life and coping strategies among lung transplant candidates and their family caregivers. Soc Sci Med 2005 May;60(10):2321–2332. [PubMed: 15748679]
7. Dew MA, Myaskovsky L, DiMartini AF, Switzer GE, Schulberg HC, Kormos RL. Onset, timing and risk for depression and anxiety in family caregivers to heart transplant recipients. Psychol Med 2004 Aug;34(6):1065–1082. [PubMed: 15554577]
8. Eiser C, Zoritch B, Hiller J, Havermans T, Billig S. Routine stresses in caring for a child with cystic fibrosis. J Psychosom Res 1995 Jul;39(5):641–646. [PubMed: 7490699]
9. Coyne IT. Chronic illness: the importance of support for families caring for a child with cystic fibrosis. J Clin Nurs 1997 Mar;6(2):121–129. [PubMed: 9188350]
10. Hodgkinson R, Lester H. Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals. J Adv Nurs 2002;39(4):377–383. [PubMed: 12139650]
11. Bluebond-Langner, M. In the Shadow of Illness: Parents and siblings of the chronically ill child. Princeton: Princeton University Press; 1996.
12. Cowen L, Mok J, Corey M, MacMillan H, Simmons R, Levison H. Psychologic adjustment of the family with a member who has cystic fibrosis. Pediatrics 1986 May;77(5):745–753. [PubMed: 3703640]

13. Walker LS, Ford MB, Donald WD. Cystic fibrosis and family stress: effects of age and severity of illness. Pediatrics 1987 Feb;79(2):239–246. [PubMed: 3808796]
14. Patterson JM, McCubbin HI, Warwick WJ. The impact of family functioning on health changes in children with cystic fibrosis. Soc Sci Med 1990;31(2):159–164. [PubMed: 2389151]
15. Lowton K. Parents and partners: lay carers' perceptions of their role in the treatment and care of adults with cystic fibrosis. J Adv Nurs 2002;39(2):174–181. [PubMed: 12100661]
16. McGuffie, KI.; Sellers, DE.; Sawicki, G.; Robinson, WM. North American Cystic Fibrosis Conference. Denver, CO: 2006. Self-reported Involvement of Family Members in the Care of Adults with CF: A Report from the PAC-CF Study.
17. Sellers, DE.; Dawson, R.; McGuffie, KI.; Sawicki, G.; Robinson, WM. The Relative Contribution of Psychosocial and Clinical Factors to Quality of Life in Adults with CF. Education Development Center, Inc; 2007.
18. Liou TG, Adler FR, FitzSimmons SC, Cahill BC, Hibbs JR, Marshall BC. Predictive 5-year Survivorship Model of Cystic Fibrosis. Am J Epidemiol 2001;153(4):345–352. [PubMed: 11207152]
19. Conway SP, Pond MN, Watson A, Hamnett T. Knowledge of adult patients with cystic fibrosis about their illness. Thorax 1996;51(1):34–38. [PubMed: 8658366]
20. Haley WE, Levine EG, Brown SL, Bartolucci AA. Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. Psychol Aging 1987 Dec;2(4):323–330. [PubMed: 3268224]
21. Helder DI, Kaptein AA, Van Kempen GM, Weinman J, Van Houwelingen JC, Roos RA. Living with Huntington's disease: illness perceptions, coping mechanisms, and spouses' quality of life. International Journal of Behavioral Medicine 2002;9(1):37–52. [PubMed: 12112995]
22. Jacobi CE, van den Berg B, Boshuizen HC, Rupp I, Dinant HJ, van den Bos GA. Dimension-specific burden of caregiving among partners of rheumatoid arthritis patients. Rheumatology (Oxford) 2003 Oct;42(10):1226–1233. [PubMed: 12810934]

Table 1

Demographic Characteristics of Caregivers by Type of Caregiver

	Total (n=119)	Spouses/partners (n=65)	Parents living with adult (n=11)	Parents not living with adult (n=24)	Siblings/adult child/ friends (n=15)	Sig. Diff. [a] p-value
Mean Age	43.7 (12.5)	39.7 (10.6)	52.9 (4.5)	57.3 (6.8)	37.7 (11.2)	.0001
% Female	65	43	91	100	80	.0001
% Married	78	89	82	63	73	.03
% Employed	78	83	82	65	73	.36
% With College Degree	60	70	46	44	53	.09

[a] The p-values reported are from chi-square tests of independence (nominal measures) or one-way analysis of variance (continuous measures) used to assess the association between each characteristic and type of caregiver.

Table 2

Demographic and Clinical Characteristics of Adults with CF by Type of Caregiver

	Total (n=119)	Spouses/ partners (n=65)	Parents living with adult (n=11)	Parents not living with adult (n=24)	Siblings/adult child/ friends (n=15)	Sig. Diff. [a] p-value
Total N	119	65	11	24	15	-
% Female	63	55	64	75	80	.17
Mean age (SD)	32.6 (10.3)	36.7 (9.8)	21.4 (2.9)	27.9 (8.0)	32.2 (10.6)	.0001
% Married	61	91	0	42	27	.0001
% Employed	62	64	56	57	64	.90
% With a College Degree	58	77	9	46	40	.0001
Mean FEV1 (SD)	61.2 (20.4)	58.9 (19.9)	77.6 (23.4)	58.4 (17.4)	62.6 (19.9)	.03
Mean Weight-for-age z-score (SD)	−.31 (1.0)	−.09 (.97)	−.70 (.92)	.36 (1.1)	−.81 (1.1)	.02
% Pancreatic sufficient	13	12	0	13	27	.25
% Diabetes mellitus	17	12	18	21	20	.73
% Staphyloccoccus aureus	37	40	18	46	20	.20
% Burkholderia cepacia	9	10	0	13	7	.65
Mean # of acute exacerbations (SD)	1.5 (1.4)	1.2 (1.3)	.82 (1.3)	1.7 (1.3)	2.4 (1.7)	.01
% Diagnosed as adults	12	15	0	8	13.3	.48

[a] The p-values reported are from chi-square tests of independence (nominal measures) or one-way analysis of variance (continuous measures) used to assess the association between each characteristic and type of caregiver.

Table 3

Involvement of Caregivers during Routine Care in the Past Month

	N*	% Not at all	% A few times to weekly	% More than once per week
Reminding to complete treatments				
Spouse/partner	58	33	40	27
Parent living with adult with CF	11	36	9	55
Parent not living with adult w/ CF	21	57	33	10
Sibling/adult child/friend	12	58	33	8
Preparing special meals				
Spouse/partner	52	42	21	37
Parent living with adult with CF	10	20	20	60
Parent not living with adult w/ CF	19	42	42	16
Sibling/adult child/friend	11	73	27	0
Reminding family member or friend to exercise	111	33	44	23
Reminding to take routine pills	108	33	42	25
Joining in exercise/exercising together	108	43	42	15
Carrying extra food (i.e., diabetes, extra nutrition)	62	56	37	7
Cleaning nebulizer equipment	99	62	29	9
Carrying an extra supply of pills	105	63	19	18
Setting up nebulizer treatments	98	68	25	7
Performing chest physical therapy	83	69	14	17
Maintaining oxygen supplies (e.g. cleaning, ordering supplies)	51	76	20	4
Setting up “the Vest” for treatments	74	85	12	3

[*] Number of caregivers who provided a valid response to the question summarized in that row. If the adult with CF for whom the caregiver provides care does not undertake a particular activity as part of their treatment regimen, the caregiver was instructed to select a “does not apply” response to that item. Caregivers who selected “does not apply” were excluded from the analysis of that particular question.

Table 4

Percent Reporting Assistance with Obtaining and Paying for Medical Care in the Past Year by Type of Caregiver [a]

	Spouses/partners (n=65)	**Parents living with adult (n=11)**	**Parents not living with adult (n=24)**	**Siblings/adult child/ friends (n=15)**	**Sig. Diff [b] (p-value)**
Scheduling clinic visits	3	36	4	0	.002
Going to clinic visits	29	45	38	20	.480
Communicating with CF staff during clinic visits	29	36	13	13	.211
Taking notes at clinic visits	11	36	8	0	.029
Ordering or picking up prescriptions	35	64	13	7	.003
Communicating with CF Center staff between visits	2	9	10	0	.228
Communicating with home health agencies	6	18	8	0	.334
Completing insurance forms	6	55	8	0	.0001
Communicating with insurance companies	8	60	10	0	.0001
Communicating with hospital billing offices	6	55	0	0	.0001

[a] Percent responding ‘frequently’, ‘almost always’, or ‘always’ vs. ‘not at all’, ‘rarely’, or ‘occasionally’.

[b] The p-values reported are from chi-square tests of independence used to assess the association between each type of assistance and type of caregiver.

Table 5

Percent of Caregivers Providing Assistance during the Most Recent Hospitalization

	Percent Providing Assistance (n=81[a])
Bringing outside food in (for the adult with CF)	86
Spending all day in the hospital	80
Meeting with a physician	71
Meeting with a nurse	71
Accompanying to testing within the hospital	48
Meeting with the social worker	45
Spending all night at the hospital	34
Bringing in outside medications (for the adult with CF)	29
Assisting with bathing or showering	21
Providing chest physical therapy	14

[a] 81 caregivers reported that their loved one with CF had been hospitalized during the past 12 months and thus were asked to report on the assistance provided during the most recent hospitalization.

Table 6

Percent of Caregivers Providing Assistance during the Most Recent Home IV Treatment by Type of Caregiver

	Total (n=65)	**Spouses/ partners (n=36)**	**Parents living with adult (n=3)**	**Parents not living with adult (n=15)**	**Siblings/adult child/ friends (n=11)**	**Sig. Diff [a] (p-value)**
Preparing meals	87	97	100	92	46	.0001
Housecleaning	86	97	100	85	50	.0001
Communicating with the home nursing staff	69	81	100	57	39	.02
Taking care of home IV equipment	62	72	67	62	31	.07
Preparing antibiotic doses	54	61	67	54	31	.3
Maintaining/changing dressings on IV lines	42	47	67	33	31	.5
Changing needles on permanent lines (Portacath, Passport)	16	26	0	0	8	.2
Returning home IV equipment	15	15	0	36	0	.09

[a] The p-values reported are from chi-square tests of independence used to assess the association between each type of assistance and type of caregiver.