Integrating Medical and Psychological Health Care for Children with Atopic Dermatitis

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Objective To present descriptive data from a hospital-based interdisciplinary program that provides integrated medical and psychological health-care for children with atopic dermatitis (AD).

Methods Clinical records were reviewed for 69 children seen in our program to examine parent-reported AD-related presenting concerns, as well as common problems and interventions addressed during family visits with the program psychologist. Results The most common presenting concerns included child itching and scratching and associated sleep problems. Parent initial request for a meeting with the program psychologist was not related to child disease severity, but was associated with child sleep problems and parent emotional and practical challenges in managing the child’s condition. Conclusions Results support the need for, acceptance of, and feasibility of providing integrated care for children with AD and their families. Changes to our clinical model based on study findings are discussed.

Key words atopic dermatitis; integrated health care; psychological intervention; children.

Atopic dermatitis (AD) is a chronic, relapsing skin disease characterized by dry, inflamed skin with severe pruritis, or itching. One of the most common childhood skin conditions, AD, affects up to 20% of children (Schultz-Larsen & Hanifin, 2002), with onset typically occurring in the first year of life (Wieland, 1998). Factors associated with skin flares include allergens, irritants, and psychological stressors (Raimer, 2000). There is no cure for AD. Disease management involves skin hydration through daily baths and intensive emollient therapy, avoidance of allergens, and in some cases, use of anti-histamines to alleviate pruritis. Acute flare-ups may be treated with topical corticosteroids or topical calcineurin inhibitors (Leung et al., 2004; Raimer, 2000).

Children with AD and their parents report itching and scratching and associated sleep disruption to be the most problematic aspects of the condition (Chamlin, Frieden, Williams, & Chren, 2004). Discomfort due to itching is often so intense that children scratch until they bleed. A vicious cycle can develop between itching and scratching, as scratching can promote or exacerbate skin inflammation. Compared with healthy children, children with AD have increased rates of difficulty falling asleep, nighttime awakenings, difficulty waking in the morning, and tiredness and irritability during the day (Dahl, Bernhisel-Broadbent, Scanlong-Holdford, Sampson, & Lupo, 1995).

Parents report increased rates of irritability, anxiety, and behavior problems in children with AD (Absolon, Cottrell, Eldridge, & Glover, 1997; Chamlin et al., 2004; Daud, Garralda, & David, 1993). Children report self-consciousness related to the appearance of their skin (Lewis-Jones & Finlay, 1995; Paller, McAlister, Doyle, & Jackson, 2002). Adherence to the skin care regimen is also a challenge for many families. Frequent baths and emollient therapy are time consuming and children often find topical medications and ointments “messy” or “greasy” (Paller et al., 2002).

There is some evidence for the usefulness of psychological interventions in the management of AD. Staab and...
colleagues (2002) describe a structured parent-training group focused on stress management, relaxation, management of sleep disturbances, dealing with itching and scratching, and adherence to the skin care routine, which may promote active coping among parents of children with AD. In adult patients, cognitive–behavioral interventions have led to improved skin condition and reduction in steroid use (Ehlers, Stangier, & Gieler, 1995).

Given the psychosocial challenges facing children with AD and their families, as well as the potential for psychological interventions to improve disease management and quality of life, there is a clear rationale for the integration of medical and psychological health care in the treatment of AD. Integrated health care has been defined as “a continuum of the extent to which mental health services are interwoven in the medical management of a child’s chronic illness” (Walders & Drotar, 1999, p. 119).

Within a highly integrated system, medical and psychological services are delivered to the child and family within the same setting, at the same time (Walders & Drotar, 1999). A key goal of integrated care is to facilitate the communication and collaboration among professionals that is necessary to provide optimal care, recognizing the interplay between psychological factors and physical functioning (Drotar, 1995; Walders & Drotar, 1999).

Naar-King and colleagues (Naar-King, Siegel, Smyth, & Simpson, 2003) highlight several advantages to this model, in which a psychologist functions directly as a member of the treatment team. Specifically, integrated health care supports early identification of concerns, alleviation of subclinical concerns through brief interventions, and increased access to mental health services (Naar-King et al., 2003). Models of integrated health and mental health care for children with other chronic health conditions have been described in the literature (Anderson, Loughlin, Goldberg, & Laffel, 2001; Kazak, 2001; Naar-King et al., 2003). There is evidence that children who receive integrated health care services demonstrate fewer behavioral problems and better school functioning than children who receive more traditional care (Naar-King et al., 2003).

The goal of this study is to provide support for the feasibility of integrating medical and psychological health care for children with AD. We describe our hospital-based interdisciplinary program for children with AD and examine presenting psychosocial concerns using a parent-report measure collected prior to initial visits to our center. We also present data illustrating the scope of problems addressed and interventions introduced during sessions with the program psychologist.

Method
Program Description

The Atopic Dermatitis Center at Children’s Hospital, Boston is an interdisciplinary outpatient program for children with AD. The AD Center was established in 2000 in response to clinical findings that despite effective medication therapies for patients with AD, a sizable fraction (roughly 15%) of children with AD have severe disease that resists conventional treatment alone. The mission for this program was to enhance care and quality of life for children with AD and their families through an interdisciplinary approach to disease management. By providing families with access to psychological services within the context of regularly scheduled clinic visits, we hoped to increase family access to and acceptance of such services.

The AD Center currently has over 135 new patient visits and 350 follow-up visits annually. Generally, children with severe AD are followed monthly or more frequently, children with mild to moderate AD every three months, and children with well-controlled AD semi-annually or annually. Primary referral sources to the AD Center include pediatricians, parents, and allergists and dermatologists in the community.

Prior to scheduling an initial appointment, parents are asked to complete a set of questionnaires assessing the child’s AD symptoms and course, treatment history, and impact of AD on child and family functioning and quality of life. Referrals are screened by the program’s nurse practitioner, based upon information in the questionnaires and the child’s medical record. Although there are no strict inclusion/exclusion criteria for admission to the AD Center, indications of the appropriateness of cases include: (a) a history of moderate to severe AD that has not adequately responded to care from other providers; and (b) significant impact of AD on child and family functioning and quality of life. Because mild cases of AD are typically managed well by pediatricians, referrals to the clinic are generally appropriate; <5% of cases are screened out each year.

Children and families presenting to the AD Center meet with the following members of our interdisciplinary team: a pediatric allergist, a pediatric nurse practitioner, a pediatric psychologist (or a psychology fellow), and a registered dietitian. The goal of the interdisciplinary approach is to ensure the collaboration necessary to provide each family with a comprehensive skin management plan that addresses their specific medical and psychosocial needs.

Team rounds are conducted before each AD Center clinic to review patient history. Members of the treatment
team convene briefly after each provider’s meeting with a family to discuss medical and psychosocial factors impacting the child’s disease and issues of particular concern to be addressed by each provider. Team members collaborate to formulate the child’s skin care plan, and the family is provided with written skin care and behavioral management plans at the conclusion of the initial visit. A letter from the allergist or nurse practitioner detailing the child’s skin care plan is sent to the pediatrician. This letter includes a summary of psychological interventions provided.

Families’ initial and follow-up visits with the AD Center psychologist take place within the context of regularly scheduled clinic appointments. Information regarding problems addressed and interventions provided during these visits is presented in the results section of this manuscript. For children with emotional or behavioral problems requiring more intensive mental health services (e.g., the child has symptoms of severe depression, assessment for a learning disability is warranted), the psychologist plays an active role in facilitating referrals to appropriate programs within the Department of Psychiatry in the hospital or to mental health resources in the community. Many families travel a significant distance to be seen in our center, and for such families, referrals to mental health service providers in the community are particularly important. Families who receive referrals to other mental health providers also continue to meet with the AD Center psychologist during clinic visits, and care is coordinated as appropriate.

Currently, families are not billed for services provided by the psychologist in our program. At the time the AD Center was established, there were significant concerns about third party reimbursement for psychological services provided within a medical clinic, given limitations associated with mental health carve outs and the fact that the majority of children seen in the program did not carry a mental health diagnosis. Therefore, funding for the psychologist’s salary has been provided through grants from private foundations. To ensure the sustainability of our program, we are currently investigating third party reimbursement policies for services billed using the health and behavior current procedural terminology (CPT) service codes.

Participants
Medical records were reviewed for all initial visits to the Atopic Dermatitis Center at Children’s Hospital, Boston between July 2001 and December 2002, resulting in an initial sample of 92 children and their parents. Of the 92 patients identified, 75 (81.5%) had complete parent-report measures (measures of behavioral concerns collected before the initial clinic visit) and were retained for the study sample. Six cases were identified as outliers related to time between completion of parent-report measures and the first clinic visit (nine months or greater) and were removed from the sample, resulting in an average of five weeks between completion of measures and initial visit ($M = 38.2$ days, $SD = 35.0$ days). The final sample consisted of 69 children and their parents.

Children in the sample ranged in age from 2 months to 15 years ($M = 3.8$ years, $SD = 3.5$). Child age was positively skewed (median 2.7 years), with the majority of children preschool age or younger. There was a nearly equal number of boys and girls in the sample (34 girls, 35 boys). By parent-report, approximately two-thirds (66.7%) of the children were White, 8.7% Asian, 4.3% Hispanic, 1.4% Indian, 8.6% “Other” (not specified), and for 10.1% of the sample, information on ethnic background was not completed. Mothers completed the self-report forms in the majority (93.2%) of cases, and fathers in the remaining cases. Parents were highly educated, with 41.8% of mothers having obtained a college degree and an additional 36.4% a postgraduate degree. Similarly, 43.4% of fathers had a college degree and 30.2% a postgraduate degree. The majority (82.1%) of children lived in a household with married parents. Most (87.0%) of the children in the sample were diagnosed with food allergies in addition to AD.

Procedure
The study was approved by the hospital Committee on Clinical Investigation. Clinical medical records were reviewed for demographic information, medical information at the time of the child’s initial visit to the AD Center, and a parent self-report measure of AD-related concerns collected prior to the initial visit. Consistent with the standard practice of the clinic during the study period, parent self-report measures were mailed to families upon scheduling the initial appointment (generally 1 month before the appointment), to be returned prior to the appointment. For families in the study sample, chart notes documenting initial and follow-up sessions with the psychologist were also reviewed for the content of problems introduced and interventions provided.

Measures
Demographic and Medical Characteristics
Demographic and medical characteristics of participants were obtained by retrospective chart review. Child age,
sex, and history of food allergies were obtained from the medical record. Child ethnicity and parent education and marital status were obtained from a questionnaire completed by parents prior to the child’s initial visit.

AD Severity
AD severity at the time of the initial visit was obtained by clinical ratings of: (a) global severity and (b) body area involved. Global severity was rated as mild, moderate, or severe by two of the authors (K.G.T., a pediatric nurse practitioner and L.C.S., a pediatric allergist), based upon: extent of body involvement, type and location of lesions, and intensity/disease course. Body area involvement was dichotomously scored as present or absent on the face and extremities (hands and feet).

AD-related Concerns
Prior to the initial visit, parents completed the Survey of Behavioral Concerns in Children with Atopic Dermatitis. This tool was developed for clinical use in our program based upon the experience of members of the AD Center team to assess common AD-related parental concerns (e.g., concerns about the child’s behavior and functioning as well as parental concerns about managing the child’s disease). Parents are asked to rate the frequency of each concern on a 7-point Likert scale from never to always, with lower scores indicating a lower frequency of concerns. Items related to child behavior and functioning include: (a) itches and scratches; (b) picks at skin; (c) difficulty sleeping; (d) is uncooperative with treatment routine; (e) has difficulty complying with parents’ requests/rules; (f) worries about his/her medical condition; and (g) has negative feelings about him/herself. Items related to parental management of the child’s AD include: (a) difficulty following treatment recommendations for the child; (b) stress of managing the child’s condition/feeling overwhelmed; and (c) concerns or worries about the effects of the medical treatment prescribed for the child. Additionally, parents are asked to indicate whether or not they would like to request a meeting with the psychologist during their visit to the clinic. There is no total score obtained from this measure. Rather, responses to individual items are examined to guide the treatment provided to families within the program.

Problems and Interventions Addressed during Psychology Sessions
To better understand the types of psychosocial problems introduced and psychological interventions provided during families’ visits with the AD Center psychologist, we reviewed all chart notes documenting initial and follow-up sessions with the psychologist for each participant during the study period. Of the full sample, 48 participants (69.6%) were seen by the psychologist during visits to the AD Center. The number of psychology sessions per family ranged from 1 to 10 (M = 2.4, SD = 1.9).

Two of the study authors (A.L. and S.D.K., clinical psychologists) developed coding categories for problems and interventions based upon clinical experience and a review of the clinical records of a subset of the study sample (n = 10). Categories included Child behaviors/concerns specific to AD, Child behaviors/concerns not specific to AD, Parental stressors, and Interventions, each with a variety of subcategories. Very-low-frequency behaviors and interventions were combined into “Other” categories. For each chart note, a dichotomous rating was made as to whether or not each of the subcategories of problems/interventions was documented for that visit. Next, for each child, ratings for multiple visits across the study time period were collapsed, to provide one overall rating for each subcategory of problem/intervention over study period. The same two authors coded each chart note. The majority of kappas were above .60, indicating good to excellent agreement among the raters (Cicchetti & Sparrow, 1981), although some categories fell below 0.60, in the fair (n = 3, 0.40–0.59) to poor (n = 3, below 0.40) ranges. Discrepancies between the raters were dealt with by discussion to reach consensus. See Table I for a list of the problems and interventions included in analyses and statistics on inter-rater reliability.

Data Analyses
Study analyses were conducted in three steps. First, parental responses to the measure of AD-related behavioral concerns were examined to describe presenting psychosocial concerns. Second, bivariate correlations were conducted to examine relationships between child AD severity, parent-report of AD-related concerns, and request for a meeting with the AD Center psychologist at the time of referral. Third, content ratings of psychology chart notes for initial and follow-up visits were examined.

Results
Prescreening Data
Prior to analysis, all data were screened for missing values, outliers, and normality of distribution. Comparisons were conducted to determine whether there were any differences in demographic or disease...
characteristics between those children and parents included in the study and those excluded due to incomplete parent-report measures, as well as between those children and parents seen by the AD Center psychologist and included in the content analysis, and those who were not seen by the psychologist. No significant differences were detected between those families who were included or excluded from the study, or between those families who saw the AD Center psychologist and those who did not see the psychologist, based on demographic characteristics (child age, child gender, child ethnicity, parent education level) or disease characteristics (global severity, facial involvement, presence of food allergies).

### Descriptive Analyses

On the global rating of disease severity, over half of the children (55.2%) were assessed to have severe AD, over a third (34.3%) to have moderate AD, and few (10.4%) to have mild AD. Approximately two-thirds (67.2%) of the children were observed to have facial involvement of AD and almost all (94.0%) to have involvement of one or more extremities. The extremity involvement variable was removed from further analyses due to the significantly non-normal distribution.

Table II presents a summary of mean scores for the sample on the Survey of Behavioral Concerns in Children with Atopic Dermatitis. Data screening analyses indicated that three of the child behavior variables included in this measure had rates of missing data over 20% (difficulty complying with parents’ rules/requests, worries about the medical condition, negative feelings about self), with missing values significantly associated with younger child age. Therefore, Table II presents mean scores on the Survey of Behavioral Concerns separately for subgroups of our sample based on child age (<2 years, N = 28; 2–4 years, N = 22; and 5+ years, N = 19), as well as for the total sample. Given the high rates and non-random pattern of missing data for these three variables, they were excluded from further (correlational) analyses.

### Table I. Problems and Interventions Addressed during Psychology Sessions

<table>
<thead>
<tr>
<th>Problem/intervention</th>
<th>n</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child behaviors specific to AD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nighttime scratching and associated sleep problems</td>
<td>.75</td>
<td>21</td>
</tr>
<tr>
<td>Daytime scratching</td>
<td>.78</td>
<td>20</td>
</tr>
<tr>
<td>Noncompliance/distress with medical regimen</td>
<td>.70</td>
<td>16</td>
</tr>
<tr>
<td><strong>Other concerns specific to AD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e.g., self-image)</td>
<td>.26</td>
<td>6</td>
</tr>
<tr>
<td><strong>Child behaviors/concerns not specific to AD</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General developmental issues (e.g., toileting, socialization)</td>
<td>.66</td>
<td>23</td>
</tr>
<tr>
<td>Emotional distress (e.g., anxiety, depression)</td>
<td>.64</td>
<td>6</td>
</tr>
<tr>
<td><strong>Parent stress/distress</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stressors related to AD</td>
<td>.46</td>
<td>15</td>
</tr>
<tr>
<td>Other parent stressors</td>
<td>.63</td>
<td>5</td>
</tr>
<tr>
<td><strong>Interventions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral interventions for scratching and/or adherence</td>
<td>.65</td>
<td>38</td>
</tr>
<tr>
<td>Sleep-specific interventions</td>
<td>.87</td>
<td>29</td>
</tr>
<tr>
<td>Referrals (e.g., mental health services, support programs)</td>
<td>.79</td>
<td>21</td>
</tr>
<tr>
<td>Parent psychoeducation</td>
<td>.26</td>
<td>21</td>
</tr>
<tr>
<td>Other interventions (e.g., toilet training, picky eating)</td>
<td>.12</td>
<td>9</td>
</tr>
</tbody>
</table>

*Total N = 48.

### Table II. Parent Responses to the Survey of Behavioral Concerns in Children with Atopic Dermatitis Based on Child Age

<table>
<thead>
<tr>
<th>Survey Item Mean* (SD)</th>
<th>Total sample</th>
<th>&lt;2 years</th>
<th>2–4 years</th>
<th>5+ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>Child itches and scratches (N = 67)</td>
<td>6.2 (1.1)</td>
<td>6.2 (0.9)</td>
<td>6.3 (0.9)</td>
<td>5.9 (1.4)</td>
</tr>
<tr>
<td>Child difficulty sleeping (N = 68)</td>
<td>4.9 (1.8)</td>
<td>4.6 (1.6)</td>
<td>5.1 (1.9)</td>
<td>5.2 (2.0)</td>
</tr>
<tr>
<td>Child picks at skin (N = 64)</td>
<td>4.6 (2.1)</td>
<td>3.8 (2.4)</td>
<td>5.6 (1.4)</td>
<td>4.3 (2.1)</td>
</tr>
<tr>
<td>Child uncooperative with treatment routine (N = 63)</td>
<td>3.3 (1.7)</td>
<td>3.0 (1.6)</td>
<td>3.7 (2.0)</td>
<td>3.3 (1.6)</td>
</tr>
<tr>
<td>Child difficulty complying with parents’ requests/rules (N = 54)</td>
<td>3.1 (1.6)</td>
<td>1.5 (0.9)</td>
<td>3.8 (1.4)</td>
<td>3.4 (1.5)</td>
</tr>
<tr>
<td>Child worries about medical condition (N = 54)</td>
<td>2.7 (2.0)</td>
<td>1.5 (1.3)</td>
<td>2.5 (1.3)</td>
<td>4.0 (2.2)</td>
</tr>
<tr>
<td>Child negative feelings about self (N = 50)</td>
<td>2.1 (1.6)</td>
<td>1.0 (0.0)</td>
<td>1.6 (1.0)</td>
<td>3.3 (1.9)</td>
</tr>
<tr>
<td>Parent worries about effects of prescribed medical treatment (N = 67)</td>
<td>4.8 (1.8)</td>
<td>4.8 (1.7)</td>
<td>4.4 (1.9)</td>
<td>5.2 (1.7)</td>
</tr>
<tr>
<td>Parent overwhelmed by managing child’s condition (N = 69)</td>
<td>3.7 (1.6)</td>
<td>3.6 (1.5)</td>
<td>4.0 (1.6)</td>
<td>3.7 (1.8)</td>
</tr>
<tr>
<td>Parent difficulty following treatment recommendations (N = 66)</td>
<td>3.3 (1.7)</td>
<td>3.0 (1.8)</td>
<td>3.4 (1.5)</td>
<td>3.5 (1.9)</td>
</tr>
</tbody>
</table>

*On 1–7 scale indicating frequency of behavior/concern (higher scores indicate greater frequency).
As can be seen in Table II, on average, parents rated the child’s itching and scratching as often a problem, and difficulty sleeping and picking at skin as “sometimes” to “often” a problem. Parents rated the child’s being cooperative with the treatment routine, difficulty complying with parents’ rules/requests, worries about the medical condition, and negative feelings about the self as “almost never” to “seldom” a problem. When the three variables with high rates of missing data are considered based on child age, it can be seen that for children 5 years of age and older, parents rated the child’s difficulty complying with parents’ requests, worries about the medical condition, and negative feelings about the self as slightly more problematic (“seldom” to “sometimes” a problem).

Mean scores for parent-report of their own concerns about managing the child’s AD ranged from “sometimes” to “often” feeling worried about the effects of prescribed medical treatments, to seldom feeling overwhelmed with managing their child’s condition or finding it difficult to follow treatment recommendations. Almost two-thirds of parents (N= 59, 62.7%) used the Survey of Behavioral Concerns in Children with Atopic Dermatitis to make a specific request for a meeting with the psychologist.

**Associations among AD Severity, AD-related Concerns, and Request for Meeting with the Psychologist**

We conducted bivariate correlations to examine relationships between child AD severity, parent-reported concerns on the Survey of Behavioral Concerns in Children with Atopic Dermatitis, and parent initial request for a meeting with the AD Center psychologist. Given the ordinal nature of the data, two-tailed nonparametric Spearman’s correlation coefficients (rs) were used for analyses. To correct for multiple significance testing, the false discovery rate (FDR) was used. The FDR is a new approach that controls the proportion of significant results that are Type I errors, instead of using the more traditional approach (i.e., Bonferroni) of controlling the chance of making a Type I error (Benjamini & Hochberg, 1995). As can be seen in Table III, after correcting for multiple comparisons using the FDR method, there were no significant relationships between child AD severity and parent-reported concerns on the Survey of Behavioral Concerns, nor between AD severity and parent initial request for a meeting with the AD Center psychologist. Using an FDR of .0125 (1/4 × .05), request for a meeting with the psychologist remained significantly associated with parent report of the child’s difficulty sleeping (p < .001). Two parent concerns were significantly correlated with a request for meeting with the psychologist using an FDR of .033 (2/3 × .05): the parent feeling overwhelmed with managing the child’s AD (p < .001), and the parent finding it difficult to follow treatment recommendations (p = .011).

We also examined the relationship between demographic characteristics (child age, child gender, child ethnicity, parent education level) and parent-reported concerns on the Survey of Behavioral Concerns and initial request for a meeting with the AD Center psychologist. No correlations were significant after corrections using the FDR method.

**Content Analyses of Problems and Interventions Addressed during Psychology Sessions**

As can be seen in Table I presented previously, the child behaviors and concerns related to AD most commonly documented during sessions with the psychologist included: (a) nighttime scratching and associated sleep problems (e.g., delayed sleep onset, frequent nighttime awakenings, scratching during sleep); (b) daytime
scratching; and (c) noncompliance or distress associated with the skin care regimen. Common parental stressors included difficulty understanding and following the treatment regimen and worries about the impact of AD on the child’s current and future functioning.

For almost two-thirds (62.5%) of the families who were seen by the psychologist, child behaviors that were not specific to AD were also addressed during sessions. Nearly half of the sample used sessions with the psychologist to address general developmental concerns (e.g., toileting, socialization, school adjustment), while smaller numbers of families discussed problems such as anxiety, depressive symptoms, and tantrums.

A variety of interventions were introduced during sessions with the AD Center psychologist. The most common interventions (prescribed for nearly 80% of families seen by the psychologist) were behavioral strategies to reduce scratching and improve medical adherence. Examples of behavioral strategies included distraction and redirection to hands-on activities to reduce scratching, reducing negative attention to scratching, development of medication schedules, and positive reinforcement and incentives to improve adherence to the skin care regimen. Sleep-specific interventions were introduced to over half of the families, and included behavioral plans to address difficulty falling asleep and nighttime awakenings and suggestions for covering children’s hands at night to reduce scratching. Parent psychoeducation was provided around normative developmental patterns, parent–child interactions, and disease and treatment information. Less commonly, guidance was provided around other developmental issues, such as toilet training, picky eating, and disruptive behaviors.

Referrals to other mental health and support programs were also provided during sessions with the psychologist, as appropriate. One-quarter of the families received a mental health referral, including referrals to providers in the community, a hospital-based clinic for families coping with medical stressors, and early intervention programs. Referrals addressed both illness-specific needs requiring more intensive intervention as well as more general mental health needs. One-third of the families seen by the psychologist received referrals to a hospital-based parent-to-parent support program.

Discussion

This study represents the first description of the integration of medical and psychological services in the routine care of children with AD. At the time of referral to our hospital-based interdisciplinary program, parents of children with AD reported child itching and scratching and associated sleep difficulties to be frequent problems for their children. Notably, there was no association between child disease severity and request for a meeting with the AD Center psychologist at the time of referral. Appropriately, however, parents were more likely to request a meeting with the psychologist if their child had difficulty sleeping, if they felt overwhelmed with the management of the child’s AD, or if they found it difficult to follow treatment recommendations. These findings underscore the importance of routinely screening children and parents for disease-related problems and distress, rather than basing decisions about the need for psychological support solely upon the severity of the child’s illness.

Consistent with parent-report at the time of referral, the content analysis of chart notes from sessions with the AD Center psychologist indicated that itching and scratching, associated sleep problems, difficulties with adherence to the skin care routine, and parental stress related to AD were the most common issues presented by families during sessions with the psychologist. In turn, the nature of interventions introduced during sessions with the psychologist most commonly included sleep-specific interventions and behavioral strategies to reduce scratching and improve adherence.

It is notable that over 60% of families seen by the AD Center psychologist also used sessions to address pediatric issues not clearly related to AD, including general developmental concerns and concerns about behavioral and emotional problems. Parents’ use of sessions to discuss problems outside of the scope of AD suggests that access to psychological services within an integrated care setting may increase the acceptability of such services. Indeed, others have suggested that integration of mental health professionals into medical settings may be less threatening for families and allow for the development of rapport (Edwards, Mullins, Johnson, & Bernardy, 1994). Moreover, for one quarter of the families in our sample, contact with the AD Center psychologist served as an initial point of access to other mental health services. Although we do not have formal data regarding the proportion of families who accepted these recommendations, an important role of the psychologist in our program has been to follow-up with families to assist in the event of any barriers to obtaining services.

Study results have been useful in guiding decisions about how to best serve our patient population and have led to changes in the AD Center model. For example, although all families in our sample were offered the
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opportunity to meet with the AD Center psychologist during initial and follow-up visits, 30% of families did not take advantage of this service. Since the time period during which data for this study was collected, we have changed to a model in which all families are routinely seen by the psychologist during their initial visit. Our experience suggests that this change has been well received by families and improved the level of care provided to all families.

Additionally, nearly 20% of records reviewed for this study revealed incomplete parent-report forms, leading to exclusion from the research. Subsequent to this finding, clinic procedures were modified to improve collection of information about the psychological and behavioral impact of AD. The Survey of Behavioral Concerns in Children with Atopic Dermatitis and other measures assessing the impact of AD on quality of life are now included in the packet of questionnaires that must be completed by parents prior to scheduling an initial appointment in our program.

We have also made changes to the parent-report forms used in our program, based on study findings. Several items on the Survey of Behavioral Concerns were frequently left blank by parents of younger children in this sample, presumably because the items were not applicable to the experience of infants and toddlers. We continue to examine responses to individual items on this measure for purposes of clinical screening. However, we have also begun using two validated age-specific measures of the impact of skin disease on quality of life: the Infants’ Dermatitis Quality of Life Index (for children under 4 years; Lewis-Jones, Finlay, & Dykes, 2001), and the Children’s Dermatology Life Quality Index (for children aged 4–16 years; Lewis-Jones & Finlay, 1995). These measures are completed at each clinic visit, allowing us to track changes in quality of life.

Limitations of the study should also be addressed. There was a high rate of missing data on the parent-report measure of AD-related concerns. Notably, there were no differences in demographic or disease characteristics between those families who completed the parent-report measure and those who did not complete the measure. Additionally, three coding categories in the content analysis of sessions with the psychologist achieved poor levels of inter-rater reliability. Given the preliminary nature of this study, these categories were retained in study analyses in an effort to present data on the full range of concerns and interventions addressed. However, information from these categories should be interpreted with caution and all of the coding categories should be validated in another sample of children with AD prior to use in further research.

Several factors may limit the generalizability of study findings to other populations of children with AD. Nearly 90% of children in this sample were rated to have moderate-to-severe AD, while community and primary care samples estimate the prevalence of moderate-to-severe AD to range from ~25% to 35% (Ben-Gashir, Seed, & Hay; Dotterud, Kvammen, Lund, & Falk, 1995). Given that disease severity was not associated with parents’ AD-related concerns, however, it is unlikely that this bias significantly affected the generalizability of study results. Further, this study included infants, toddlers, and school-aged children. Since the time of data collection, our program has followed more adolescents with AD. For these teens, AD often impacts self-esteem, ability to concentrate on schoolwork, and ability to participate in athletic activities. Clinical experience indicates that for adolescents with AD, cognitive–behavioral approaches, such as relaxation and stress management techniques may also be useful in helping to stop the stress–scratch–itch cycle.

Findings from our hospital-based interdisciplinary program provide initial support for the need for, acceptance of, and feasibility of providing integrated care to children with AD and their families. In order to ensure the sustainability of our program, we are investigating multi-faceted models of financing psychological services for this population. We plan to continue to seek grant funding for our program, and in the near future will begin piloting billing for psychological services using health and behavior CPT codes. A primary concern is ensuring that all families seen through the AD Center have access to integrated care. A critical next step in providing comprehensive, high-quality integrated health care for children with AD will be the development of outcomes-based research demonstrating empirical support for the impact of psychological interventions on symptom reduction, adherence, and quality of life in this population.

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