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Abstract

The present study aimed to examine whether caretakers of children with a food allergy experience distress and to determine their family's mental health-care needs and utilization. An anonymous survey was given to a sample of 454 caretakers during conferences hosted by the Food Allergy & Anaphylaxis Network. Overall, 32 percent of caretakers reported above threshold levels of distress while 70 percent stated that mental health support would have been helpful, but only 23 percent sought it. Even when mental health support was desired and available, few received it. Routine discussion of mental health needs with families receiving medical care may help address barriers to utilization.

Keywords

distress, food allergy, help-seeking, mental health, service utilization

Introduction

The treatment of food allergy, a chronic condition that affects approximately 4 percent of the children in the United States (Sicherer, 2011), requires vigilance to avoid the offending food and readiness to treat allergic reactions with medications including injectable epinephrine (Boyce et al., 2010). Successful management requires substantial lifestyle changes. Since children are dependents, having a food allergy affects not only the child but also the entire family whose members must engage in behaviors to minimize the child's risk (King et al., 2009). Caretakers and children need to be concerned about the ingredients of packaged foods,

meals at home and in social settings, and food served at schools and restaurants. Reactions might occur from any error, and this can become a source of anxiety. In fact, data suggest that for food-allergic young adults, having higher levels of awareness of their allergy's requirements and

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health competence are associated with greater anxiety (Lyons and Forde, 2004). Furthermore, a high level of unsafe behaviors have been reported in food-allergic adolescents (Sampson et al., 2006) that can certainly be a source of distress for caretakers.

In general, caretakers of children with special health-care needs may face a significant emotional burden (Kyriacou et al., 2009). Parents of children with a life-threatening medical illness report experiencing a lack of understanding and sense of isolation (Brewer et al., 2008). These themes have been echoed by parents whose child has been diagnosed with a serious mental illness (Ludlow et al., 2012). Parents of children with a mental illness describe several other significant challenges faced including the impact of the diagnosis on their family and judgments from others (Ludlow et al., 2012) that may also be applicable to families with a food-allergic child.

Therefore, some attention has recently been given to the emotional and quality-of-life effects of food allergy on children and their families (LeBovidge et al., 2006, 2009). Indeed, increasingly available data reveal that parents and affected children experience a significant impact on their quality of life (Cummings et al., 2010a, 2010b; Resnick et al., 2010) that may be amenable to interventions (LeBovidge et al., 2008). However, while authors recommended strategies that are meant to alleviate this state of affairs (Klennert and Robinson, 2008), no study to date has evaluated perceived need for and barriers to obtaining mental health (MH) support.

A new initiative at our site seeks to provide MH consultations and treatment to families affected by a child's food allergy. In order to inform the structure of the program, we surveyed a sample of caretakers who participated in four national meetings of the Food Allergy & Anaphylaxis Network (FAAN), a patient advocacy group. FAAN participants attend the 2-day meeting and are able to pay for travel, hotel accommodation, and registration. Thus, they have both an interest in their child's care and

means to pursue strategies related to this care. An unpublished survey of FAAN membership in 2009 firmly put it within the middle-class to upper-middle-class social stratum: 89 percent are college graduates and 59 percent reported an annual income of US\$100,000 or more; 93 percent are Caucasian, 96 percent are married, and the vast majority (96%) are females (mostly mothers of the food-allergic child).

From the perspective of MH services, this sample provides an opportunity to look at the needs of a population segment that is very rarely studied as such. Many would consider those caretakers privileged since they have both the education and the resources to help the child cope with the consequences of the illness. And yet, even in those circumstances, suffering may well be present, and assistance may be desired. The aims of the present study were to assess the self-perceived distress and its correlates of FAAN conference attendees, to determine their family's need for MH support, to evaluate the relationship between caretaker distress and the act of seeking support, and to identify perceived barriers to receiving such care. This information can be used as a starting point to inform the development of programs that are designed to address the MH needs of families with child food allergy and related populations.

Methods

Participants and procedures

During the year 2010, an anonymous survey was administered to an opportunity sample of participants at four national conferences of FAAN located in Baltimore, MD; Las Vegas, NV; Tarrytown, NY; and Oak Brook, IL. FAAN is a US not-for-profit organization dedicated to the needs of families with food allergies. The study was approved by the Mount Sinai School of Medicine's Institutional Review Board. Participants were adult caretakers (mostly, mothers) of children with food allergy. Instructions specified that only one survey was to be completed per household.

Measures

Demographics. Surveys assessed demographic information (child age, child gender, child ethnicity/race, household income, and caretaker education level). Some queries allowed for multiple selections (sum to >100%). Two indices of food allergy severity were included. Caretakers were asked if their child ever required the use of epinephrine to treat an allergic reaction as well as if their child had ever experienced a “serious” reaction defined as breathing trouble or reduced consciousness.

Impact of Events Scale. (Horowitz et al., 1979). The Impact of Events Scale (IES), a 15-item questionnaire, is designed to evaluate current (past week only) posttraumatic stress symptoms and subjective distress that are related to a specific stressor. The IES was previously examined, and repeatedly validated, in numerous clinical and normative settings (O'Connor et al., 2011; Sundin and Horowitz, 2002), including with parents of children with medical illnesses (Colville and Gracey, 2006; Kean et al., 2006; Skredden et al., 2010; Slade et al., 1999). This questionnaire has previously been used to screen parents of children with chronic illnesses (some of whom had food allergy) referred to MH consultations by their pediatricians (Shemesh et al., 2005). Questions can be worded so that they relate to a specific stressor (Shemesh et al., 2000, 2004, 2005), and we cited the child's food allergy as the stressor (e.g. “I tried to remove my child's food allergy from my memory”). The range of potential scores is 0–75. The mean score for a nonreferred sample of college students was reported as 6.9 for males and 12.7 for females (Horowitz et al., 1979). In a prior study with adults suffering from cardiovascular illnesses, a score of 18 or more was correlated with clinically significant morbidity—increased rates of hospital admissions and dysfunctional coping (Shemesh et al., 2005) that was the threshold for a positive screen used in the present study. In addition to its strong psychometric properties and demonstrated use among the target

population of the present study, the IES was chosen because it can be completed quickly (~5 minutes) and therefore minimizes respondent burden.

MH care seeking and needs

Questions about the degree to which MH treatment was sought and perceived barriers to getting such help were included and are displayed in Figure 1.

Statistical analyses

All analyses were conducted using the SPSS 17.0[®] packaged software. Pearson's correlation analyses were performed to examine the associations between demographic variables, illness severity and caregiver distress. Independent sample *t*-tests were used to examine differences in distress scores between respondents who belonged to different groups (i.e. those who did and did not utilize epinephrine). A “*p*” value (alpha level) of 0.05 or less, two-tailed, was chosen as the level of statistical significance. All analyses were predefined before the study commenced.

Results

Baseline characteristics

A total of 760 attendees registered for the meetings, and 454 answered the questionnaire (*N* = 454). Participants were instructed to complete one survey per family. Some attendees belonged to the same family, making an exact determination of participation rate difficult (e.g. the number of eligible respondents might be well below the number of attendees). Given those caveats, the fact that at least 60 percent or, very likely, a substantially higher percentage of eligible attendees, answered the questionnaire, suggests a good response rate for a behavioral/MH questionnaire (Schneider et al., 2012). Respondents' characteristics are presented in Table 1.

Which of the following best describes your situation (**PICK ONE FROM A-D**):

- A) I believe it would be helpful to discuss the emotional impact of my child's allergy on my child or my family with a mental health professional (social worker, psychologist, psychiatrist), but I have not tried to do so.

→ If selected: This is because (CHECK ALL THAT APPLY):

- ☐ 1. I did not think to do so ☐ 2. I was not recommended to do so
☐ 3. Too overwhelmed/busy ☐ 4. Assumed too costly
☐ 5. OTHER _____

OR

- B) I have already discussed the emotional impact of my child's food allergy on my child, myself, or my family with a mental health professional (social worker, psychologist, psychiatrist).

→ If selected. CHECK ALL THAT APPLY

- ☐ 1. Doing so was generally helpful ☐ 2. Doing so was generally not helpful
☐ 3. I saw a psychiatrist ☐ 4. I saw a psychologist
☐ 5. I saw a social worker

OR

- C) I tried but was unable to discuss the emotional impact of my child's food allergy for my child, myself, or my family with a mental health professional (social worker, psychologist, psychiatrist).

→ If selected, I was unable to because (CHECK ALL THAT APPLY)

- ☐ 1. Too costly ☐ 2. Could not find anyone to see
☐ 3. Selection of people to see was problematic (no expertise)
☐ 4. OTHER _____

OR

- D) I do not see a need to discuss the emotional impact of my child's food allergy on my child, myself, or my family with a mental health professional (social worker, psychologist, psychiatrist)

→ If selected, this is because (CHECK ALL THAT APPLY)

- ☐ 1. My pediatrician provided this service ☐ 2. My allergist provided this service
☐ 3. I/we do not think there is a problem
☐ 4. I/we obtain this type of support from support groups
☐ 5. I/we obtain this type of support from family members
☐ 6. I/we obtain this type of support from other sources _____

Figure 1. Questions used to assess the caretaker's perception about the receipt of mental health care.

IES (distress) scores

Overall, 447 caretakers (98% of respondents) completed the IES questionnaire. The mean (*M*) IES score was 14.38 and standard deviation (*SD*) was 8.16. A score at or above the predefined clinically significant threshold score of 18 was reported by 32 percent (*n* = 158) of respondents.

Correlation between baseline characteristics and caretaker distress

There were no significant associations between IES score and any of the included demographic characteristics. IES scores did not significantly differ according to whether the child had ever received epinephrine, but were significantly

Table 1. Baseline characteristics of the sample (N = 454)

Characteristic	%
Responder's role in the family	
Mother	82.5
Father	10.9
Other caretaker	6.7
Age of Child (years)	
0–5	37.8
6–12	46.7
13–18	14.2
19 and above	1.3
Gender of Child	
Male	58.7
Female	41.3
Household income (US\$)	
Less than 50,000 per year	3.8
Less than 100,000 but more than 50,000	23.8
100,000–150,000	25.6
More than 150,000	30.2
Prefer not to specify/left blank	16.6
Ethnicity of the child	
Hispanic	3.6
Non-Hispanic	96.2
No answer	0.2
Race of the child	
White/Caucasian	91.7
Asian	5.8
African-American	1.6
Prefer not to answer	0.9
Education of the responder	
High school	2.9
Some college	7.1
2-year college degree/technical school	6.0
4-year college	40.1
Graduate degree	41.9
Prefer not to specify/left blank	2.0
Characteristics of the child's allergy	
Ever had a severe reaction	56.8
Ever received epinephrine	44.8

higher when the child previously had experienced a serious allergic reaction, $M = 14.93$, $SD = 8.06$ for caretakers whose child had experienced a serious reaction versus $M = 12.83$, $SD = 8.03$ for those whose child had not experienced, $t = -2.60$, $p = 0.01$.

MH care seeking and needs

A large proportion (70%, $n = 317$) of the cohort reported that MH support would have been helpful, but only 23 percent had seen a MH professional. Table 2 summarizes some of the responses regarding help-seeking.

The most frequently cited reason for not having sought support even though it was perceived as potentially helpful was that the caretaker did not think about it (39%), was too overwhelmed/busy (32%), was not recommended to do so (31%), and/or that it was perceived as too costly (27%). Those who sought a MH evaluation reported roughly the same level of distress compared with those who did not ($M = 15.26$, $SD = 7.81$ for help seekers vs $M = 14.12$, $SD = 8.25$ for nonseekers, $t = -1.25$, $p = 0.21$). Among caretakers scoring above the pre-defined "clinically meaningful" threshold on the IES (32% of the cohort, $n = 158$), only 27% sought a MH referral.

Of the caretakers whose family received some form of MH support (23%, $n = 104$), 71 percent reported that it was helpful, 17 percent did not specify whether it was helpful or not, and only 12 percent reported that it was not helpful. Only 3 percent of responders stated that they tried to get MH support but were not able to procure it. The most frequently cited reason for not obtaining MH support when it was desired was an inability to find a provider with the desired expertise, and the second most frequently cited reason was that MH support was too costly.

About a quarter of caretakers reported no need for MH support (27%, $n = 121$). This group had significantly lower distress scores compared to the remainder of the sample, $M = 10.65$, $SD = 7.12$ versus $M = 15.73$, $SD = 8.09$, $t = 6.05$, $p < 0.01$. Yet, only 21 percent (6% of the entire cohort, $n = 26$) stated that this is because they do not need any support. The rest of this group responded that they receive support from other sources. Many (47%) stated that they receive such support from other family members, and other sources were cited such as participation in

Table 2. Responses to questions about seeking mental health (MH) support

Question	Percent endorsing
I think that MH support could be helpful and/but	70
I sought to get it	23
I did not seek it because I did not think to do so	39
I did not seek it because I was too overwhelmed	32
I did not seek it as it was not recommended	31
I did not seek it because I assumed it would be too costly	27
When MH support was received, it was generally helpful	71
I tried but was unable to get MH support	3

support groups (41%), the allergist (31%), and their pediatrician (15%). Additional sources of support were cited by 28 percent, of which the prominent ones were other parents of children with food allergy (23%), and advocacy organizations, in particular FAAN (26%).

Discussion

The present study investigated distress experienced by caretakers of children with food allergy and their associated perceived need and utilization of MH care services. A large majority of this sample (70% of respondents) stated that support from a MH professional would have been helpful. For comparison, consider that a US population-based study found that only 39 percent of parents of children who met criteria for one or more diagnosable MH disorders perceived that there was a MH problem that requires help (Teagle, 2002). Thus, a rate of 70 percent perceiving a need for MH support, in a population in which many children are not expected to be suffering from a diagnosable MH disorder, is very high. This high rate of perceived need for MH services is consistent with the observation that living with food allergy impacts quality of life and increases anxiety/distress (Cummings et al., 2010b).

Nonetheless, only about a third of those who reported that they desired this support actually sought it, and only a minority of those who met our predefined “clinically significant” distress threshold on the screening tool sought

MH help. When MH care was sought, it was mostly perceived as helpful (only 12% of responders said that it was not helpful). Thus, the most striking result from this survey is that a large majority of respondents thought MH support would have been helpful, a large majority thought that it was helpful when received, and yet, only a small minority of respondents actually sought it.

The perception that MH support would have been helpful was consistent with our assessment of caretaker distress as measured by a validated questionnaire (the IES). The average distress score (10.65) for caretakers who did not perceive the need for MH support was very similar to the normative nonreferred score (between 6.9 and 12.7, depending on the gender of the respondent; Horowitz et al., 1979). Conversely, the average score (15.73) of those who did perceive the need was above this range. Taken together, these results suggest that caretakers are aware of their distress status and know when they could use MH support—and yet most of them never receive it.

We reviewed possible correlates for increased distress scores. The only significant association that we identified was the presence of a serious allergic reaction, but even this experience did not elevate distress scores by much (only two points on the IES). While having had a serious reaction was previously reported as being related to distress (Herbert and Dahlquist, 2008), interestingly, having used epinephrine was not associated with higher

levels of distress in the present study. This may be a spurious finding or might be because epinephrine use gives the parent the perception of increased control over the child's illness.

We were particularly interested in identifying barriers to seeking MH support. A major, and consistently reported, barrier in the United States is a lack of access to MH care among children, due to both a lack of availability of providers and prohibitive costs (Kataoka et al., 2002; US Public Health Service, 2000). Not surprisingly, in the present sample, which primarily included middle-class to upper-middle-class respondents, expense and difficulty in finding a MH professional were not the most frequently cited barriers. Only a few caretakers who sought help were not able to receive it (3% of the sample). Perceived costs were cited by 27 percent of those caretakers who thought help was desirable but did not seek it, but this was the least frequently cited reason. The most frequently cited reasons were that the caretaker simply did not think to do so, that the treating physician did not recommend it, and that the caretaker was too busy to think about it. The problem, therefore, was primarily that caretakers were not *seeking* help, even though they believed that they needed it; once they sought help, they generally were able to find it, and thought that it was beneficial. This finding can be seen as a lack of awareness among families and providers that MH support may be available and could be helpful. Another observation is that 32 percent of respondents said that they were overwhelmed or too busy to get this help. But those same respondents were willing and able to make the effort (and financial commitment) to attend a national food allergy conference. Therefore, even these very committed and resourceful caretakers found it overwhelming to look for MH support. The difference between attending a conference and ensuring that a family—or a child—receives MH support could be related to the ease of obtaining information about those tasks. Organizations such as FAAN take special care to advertise their meetings, organize them in advance, and make them

accessible, whereas finding out information about MH resources may be harder and require significantly more research.

Among the minority of caretakers who did not feel the need to seek support from a MH professional, most stated that this is not because they did not see a need for support, but because they received it elsewhere. This finding underscores the potential role of pediatric allergists, pediatricians, and organizations such as FAAN in providing MH support. Those who said they simply do not need such support (only 6% of the sample) indeed had very low IES (distress) scores, in a range that is consistent with scores seen in nonreferred populations. This finding suggests once more that caretakers are well aware of when they need, or do not need, support.

The study has several limitations. The study employed an opportunity sample that may not be representative of the population of food-allergic caregivers as a whole. Participants were skewed toward middle-class and high-middle-class Caucasian mothers, and although this helped hone in on barriers to help-seeking outside of socioeconomic status (SES), our findings should not be generalized to the entire population of families who might need MH support. Another limitation is the reliance on self-reports. The IES is a validated questionnaire, but the other questions were free-standing. It is possible that respondents were not entirely candid in their reply as to the reason for their not seeking MH care (i.e. less likely to admit that they cannot afford it and less likely to admit that they think it will not work). The questionnaires were anonymous, which should reduce the reluctance to report a potentially embarrassing thought or fact. But anonymity cannot guarantee that the respondents were entirely truthful. Finally, this study did not look at the children themselves, and thus, we are unable to substantiate whether the caretaker's distress has any relationship to the child's needs. Prior findings (Shemesh et al., 2005) as well as clinical impressions would suggest that these are related.

Future directions and conclusion

Our findings are consistent with a recent review concluding that "Mental health awareness needs to be integrated into all aspects of health and social policy, health-system planning, and delivery of primary and secondary general health care" (Prince et al., 2007: 870). A majority (70%) of respondents perceived that MH support would be helpful, and a large majority of those who received MH support reported that it was indeed helpful. However, in spite of these reports, only few respondents reported having in fact received MH care, reportedly due to a lack of awareness about MH services and being overwhelmed (presumably by other competing needs). While designing an effective MH support program for this population, one must therefore go beyond simply ensuring that those services are available and affordable, which they likely are, in this high SES sample. Effort should be devoted to educating providers and families about the availability and potential of such care. If MH care is delivered in proximity to medical care, receiving it might be less burdensome, and this allocation of resources would make services accessible to all families irrespective of SES (Annunziato et al., 2008). It is likely that a screening program, tied to programmatic referrals, would be able to address the issue of awareness that turned out to be the major impediment to receiving care in this study.

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