



Allocation of food allergy responsibilities and its correlates for children and adolescents

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Abstract

This study examined the degree to which children and adolescents with food allergy accept responsibility for their own care, and the extent to which greater self-management is associated with past history of a life-threatening allergic reaction or anxiety. For children ($n = 190$), caregiver and patient report of self-management was consistent, but agreement was poor for adolescent dyads ($n = 59$). History of a life-threatening allergic reaction was associated with greater self-management for children only, while among adolescents, it was associated with greater anxiety. Given that shifting to self-management may be challenging, discussion and preparation about this process is warranted.

Keywords

allocation of responsibility, anxiety, food allergy, self-management, transition

Introduction

Up to 8percent of children have food allergy, and its successful management requires skills that include allergen avoidance and recognition and treatment of reactions (Gupta et al., 2011; Sicherer and Sampson, 2014). Providers and families who care for children with special health-care needs such as food allergies must work together to promote a gradual, developmentally appropriate shift in health-care management skills (Annunziato et al., 2011), often called allocation of responsibilities. At some point in childhood, health-care responsibilities are transitioned from caregivers to the patient who ultimately assumes self-management (SM). Evidence across different illnesses including asthma, cystic fibrosis, diabetes, and liver disease suggests that specific responsibilities, such

as adherence to a medication regimen, may not be fully executed when patients shift to self-managed care, typically during adolescence (Bartholomew et al., 1997; Buston and Wood, 2000; Ianotti et al., 2006; Miloh and Annunziato, 2010).

Successful health-care management of food allergies is complex and, consequently, hard to master. It entails substantial lifestyle changes

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and vigilance as caregivers and patients must monitor the ingredients of packaged foods, meals at home, and food served elsewhere such as at schools, restaurants, and friends' homes (Boyce et al., 2010). In this context, ensuring that patients make the right decisions about ingesting or avoiding foods is very important; failure to master the required decisions may engender a life-threatening reaction. Since the vast majority of near fatal or fatal food-allergic reactions occur among teenagers and young adults outside the home away from caregivers (Bock et al., 2007; Gupta, 2014), SM skills are especially critical in staving off adverse events.

Given the importance of allocating responsibilities, it is surprising that little is known about this process for children with food allergy. In other pediatric medical disorders, allocation of responsibilities has been associated with non-adherence (Fredericks et al., 2010; McQuaid et al., 2003). For example, among pediatric liver transplant recipients, adolescents' report of accepting a higher responsibility for their own care was correlated with non-adherence to medications (Fredericks et al., 2010). Older children with asthma reported more responsibility for, and knowledge of, illness management but were less adherent than their younger peers (McQuaid et al., 2003). Knowing more about allocation of responsibilities and its correlates could inform clinicians who wish to help families facing the transition to self-care and may be a first step in ensuring that such transitions occur safely.

This study aimed to examine SM from the perspective of caregivers and patients. We hypothesized that caregivers and patients would report differences in their perception of who is responsible for ensuring that certain SM tasks are met. First, we focused on responsibilities for identification and seeking treatment for allergic reactions, notifying others about allergies, and following dietary restrictions. Second, we explored possible correlates of SM in order to inform discussions with families about this process. Specifically, we investigated whether families may allocate responsibilities differently if their child has experienced

a life-threatening allergic reaction in the past and whether there is an association between anxiety and SM.

Method

Participants and procedures

The study included families attending the Jaffe Food Allergy Institute at Mount Sinai in New York. To ensure complete representation of the clinic's population, investigators consecutively approached all families with a child who met the inclusion criteria (age 8–17 years, established diagnosis of food allergy, parent or guardian available to consent) with a goal of obtaining data on 250 consenting families. The diagnosis of food allergy was confirmed by an allergist prior to consent. All procedures were approved by the Icahn School of Medicine's Institutional Review Board and involved a full written caregiver informed consent process with child assent.

Measures

Demographic and allergy characteristics. Caregivers indicated their child's age, gender, race/ethnicity; their family income level; their child's specific food allergies; and whether their child has ever experienced a life-threatening allergic reaction defined as breathing trouble or reduced consciousness.

SM assessment. Measures that assess the allocation of responsibility for health-care tasks among family members have been developed for other chronic illnesses such as diabetes, asthma, and HIV (Anderson et al., 1990; McQuaid et al., 2001; Naar-King et al., 2009), but there are no established measures of SM for use among food-allergic children. To evaluate SM, two methods were developed. Using the original allocation of responsibility measure for diabetes (Anderson et al., 1990), as was done for asthma and HIV, five items consistent with these iterations were revised to substitute allergy-related management. Face validity was

achieved by reviewing these items with physicians in the food allergy service. For example, clinicians identified two items utilized in previous surveys, those regarding calling the team and remembering appointments, as not being relevant to this population. Therefore, the final behaviors included were identifying and informing others about allergic reactions, ensuring that food restrictions are followed, and explaining the allergy to others. In this study, carrying/using self-injectable epinephrine was not included due to the wide age range of participants, differences in local school regulations, and rarity of need to use the medication; we included behaviors that could apply to all patients.

As in the original instrument which was geared toward diabetics (Anderson et al., 1990), caregivers and children independently indicated who is responsible for each task, with the choices of 1=adults (parents/caregiver/someone else at home) is/are fully responsible, 2=youth and adult share responsibility, 3=youth is fully responsible, 4=someone else in the home, or 5=nobody does this. Overall, less than 2 percent of respondents indicated that someone else or nobody completed the survey tasks, and therefore, only the first three options were included in subsequent analyses, as was done in prior research (Naar-King et al., 2009). As was the case in other studies using this measurement strategy, for each item, response categories were compared between informants.

For the second SM measurement strategy, two continuously scored questions were created to capture key tasks that food-allergic children must master in order to prevent or minimize life-threatening adverse events (Bock et al., 2007). Using a 4-point Likert-like scale (0=never, 1=sometimes, 2=most of the time, or 3=always), families indicated the patient's ability to identify an allergic reaction and who is responsible for ensuring adherence to dietary restrictions.

Multidimensional Anxiety Scale for Children—10 items. The Multidimensional Anxiety Scale for Children—10 items (MASC-10), a short

version of the MASC, with strong psychometric properties (March et al., 1999), was used to assess the major dimensions of anxiety in adolescents and children (age 8–19 years). The MASC-10 uses a 4-point response scale, ranging from 0 (never true about me) to 3 (often true about me). Higher scores indicate higher levels of anxiety symptoms. Raw scores range from 0 to 30 and are converted into standard *T*-scores ($M=50$; standard deviation (SD)=10) (March et al., 1997). Children and adolescents are considered at risk for anxiety (i.e. above average anxiety levels) if they have a *T*-score of 61 or greater. *T*-scores in the range of 40–60 are considered average and scores below 39 are below average.

Statistical analyses

All analyses were conducted using IBM SPSS Statistics package, 19th edition. A *p* value of 0.05 or less, two-tailed, was chosen as the level of statistical significance. As noted generally (McQuaid et al., 2001), and in this specific population (Simons et al., 2012), the extent of SM should differ between children and adolescents. The process of transition, like the process of child development in general, is not smoothly continuous but rather progresses stepwise following the attainment of certain milestones (Fischer and Silvern, 1985). Therefore, the general consensus in “transition of care” literature was followed, and the age of patient-responders was analyzed in two groups (Annunziato et al., 2011), “children” (age 8–12 years), who are more likely to have shared responsibility for health-care management, and “adolescents” (age 13–17 years), who are more likely closer to self-managed care. Below, “patients” refers to the entire sample, while references to “children” and “adolescents” are specific to the stated age ranges.

To explore the validity of the SM assessment, a principal component analysis (PCA) without a rotation was performed for the allocation of responsibility and the two continuous SM items. To determine the number of principal components, we included only components

Table 1. Characteristics of the sample by age group.

	Children (<i>n</i> = 190)	Adolescents (<i>n</i> = 59)	<i>t</i> or χ^2	<i>p</i>
Age	10.04 (SD = 1.41)	14.65 (SD = 1.31)		
Gender (% female)	36.8	44.1	0.99	0.32
Ethnicity			0.84	0.36
Non-Hispanic	93.4	96.6		
Hispanic	6.6	3.4		
Race*				
White	87.3	84.7	N/A	N/A
Black	2.1	1.7		
Asian	12.7	11.9		
Other	0.5	3.4		
Family income			1.44	0.23
100,000 or less	13.3	20.4		
>100,000	86.7	79.6		
Number of allergies			6.39	0.01
1–2	34.2	52.5		
>2	65.8	47.5		
Life-threatening reaction (% yes)	56.6	37.7	5.85	0.02

SD: standard deviation; N/A: not applicable.

*Sums to over 100 percent because respondents could report more than one category. Therefore, statistical comparisons are not presented.

whose eigenvalues were equal to or larger than 1.00 for interpretation.

Chi-square tests were performed to evaluate differences in the response categories reported by child and adolescent patients. Correlations between the report of caregivers and patients were examined for children and adolescents separately. For the allocation of responsibility items, Spearman's rho correlations were used, while Pearson's correlations were used for the two continuous SM items. Independent samples *t*-tests were used to determine whether there was a difference in SM score between those who had versus had not indicated having experienced a life-threatening reaction. Pearson's correlations were used to examine associations between SM score and patient anxiety.

Results

Table 1 shows the characteristics of the sample. Participants included 257 patients and their caregivers, and of these, 251 completed the survey (six families requested to mail the survey after consenting but did not do so). Two families did

not report child age and were excluded from the analyses; therefore, the final sample size for these analyses was *n* = 249. For some SM items, there was one missing value (no participant was missing more than one response). Pairwise-deletions were used in these instances.

Scale analyses

Factor analyses were conducted to examine the validity of the SM items. For both parent and child report, all five items were included. In both cases, all items loaded strongly on the first component (loadings were all higher than 0.45). Table 2 depicts these findings.

SM assessment

Caregiver and patient report on the allocation of responsibility items are displayed in Table 3. According to both caregivers and patients, adolescents have more responsibility for all tasks than children. Table 4 shows the results of the primary study hypothesis, which was to determine whether caregivers and patients

Table 2. Factor loadings of the self-management assessment items.

	Caregivers	Patients
Notifies allergic reactions	0.76	0.77
Follows dietary restrictions	0.74	0.74
Explains food allergy to others	0.69	0.69
Child is able to tell an adult when he/she is having an allergic reaction	0.59	0.42
Child can be trusted to follow dietary restrictions	0.62	0.50
Eigenvalue	2.33	2.04
%	47	41

% = explained variance.

agree on their report of SM. Overall, for children, there was agreement, whereas for adolescents, caregiver and patient report differed on all items. For adolescents, there was poor agreement (e.g. insignificant correlations between parent and child report) on noticing allergic reactions, Spearman's $\rho=0.24$, $p=0.07$ (patients stated that they were doing this more than their caregiver said they were), following dietary restrictions, Spearman's $\rho=0.16$, $p=0.22$ (patients allocated more responsibility to caregivers than their caregivers reported), and explaining requirements of the allergy, Spearman's $\rho=0.21$, $p=0.12$ (patients stated that they were doing this more than their caregiver said they were). When asked about related items on a continuous scale, "my child is able to tell an adult when he/she is having all allergic reaction," $r=0.02$, $p=0.88$, and "my child can be trusted to follow dietary restrictions," $r=0.17$, $p=0.20$, caregivers and adolescent patients did not agree over the extent to which patients are responsible for these tasks.

SM and past life-threatening allergic reactions

Parents of children who had an allergic reaction were more likely to report that they trust their children to follow dietary restrictions, as compared with those who did not, mean score for

those who did, 2.55 (SD=0.62), versus for those who did not, 2.31 (SD=0.78), experience an episode, 95 percent confidence interval (CI)=0.04–0.44, $t(178)=-2.31$, $p=0.02$. Similarly, *parent* report about the allocation of responsibility over following dietary restrictions was significantly associated with having ever experienced an episode, $\chi^2=7.02$, $p=0.03$. In total, 30 percent of children whose parents reported that they (the parents) are fully responsible ($n=101$) for following dietary restrictions reported a previous episode compared with 59 percent who described sharing responsibilities. Lifetime history of an allergic episode was not associated with any differences in SM among adolescent patients.

SM and anxiety

MASC *T*-scores were 44.96 (SD=9.52) for children and 46.31 (SD=11.94) for adolescents; this difference was not significant, $t=-0.89$, $p=0.38$, and both scores correspond to an average level of anxiety. However, when using the categorical groupings designated by the MASC, adolescents were significantly more likely than children to report "above average" levels of anxiety (22% of adolescents vs 12% of children, $\chi^2=7.14$, $p=0.03$).

Adolescents reported more anxiety when they endorsed more responsibility over their own care. The correlation between MASC *T*-score groups and the SM item for "I am able to tell an adult when I am having an allergic reaction" was $r=0.31$, $p=0.02$ and for "I can be trusted to follow dietary restrictions," $r=0.34$, $p=0.01$. There were no similar significant findings for children.

Discussion

This study sought to learn how responsibilities for food allergy management are allocated, from the perspective of both patients and their caregivers, and possible correlates relating to distribution/perception of responsibility. Similar to other chronic medical problems, both caregivers and patients reported more responsibilities for adolescents compared to younger

Table 3. Caregiver and patient report of allocation of responsibility by age group.

	Parent report		χ^2	Patient report		χ^2
	Children	Adolescents		Children	Adolescents	
Notices allergic reactions			21.02*			19.58*
Patient fully responsible	2.6	18.6		13.7	37.3	
Adult fully responsible	16.3	6.8		14.2	1.7	
Shared responsibility	80.5	74.6		70.0	61.0	
Follows dietary restrictions	0.5	8.5	12.68*	13.7	30.5	16.38*
Patient fully responsible	10.5	6.8		15.8	0	
Adult fully responsible	88.4	83.1		68.9	69.5	
Shared responsibility						
Explains allergy to others			7.56*			15.74*
Patient fully responsible	0.5	5.1		8.9	25.4	
Adult fully responsible	24.2	15.3		23.2	6.8	
Shared responsibility	74.7	78.0		65.8	66.1	

Columns sum to below 100 percent due to missing values.

*Significant at $p < 0.05$.

Table 4. Spearman's rho or Pearson's correlations between caregiver and patient report of responsibility by age group.

	Children–Parents	Adolescents–Parents
Notices allergic reactions	0.39*	0.24
Follows dietary restrictions	0.30*	0.16
Explains food allergy to others	0.42*	0.21
Child is able to tell an adult when he/she is having an allergic reaction	0.32*	0.02
Child can be trusted to follow dietary restrictions	0.37*	0.17

*Significant at $p < 0.05$.

children. Allergy management for children with food allergy is predominantly overseen by caregivers. Interestingly, children who had experienced a life-threatening allergic reaction were given greater responsibility. The cross-sectional study design could not determine whether reaction severity influences allocation of SM, or vice versa, but this is an important topic for further investigation.

Discordance in the perception of SM responsibility was greater for adolescents. This result suggests that caregivers may be unaware of gaps in their adolescents' health-care management. These findings are consistent with a prior study showing that food-allergic adolescents want

their peers to be educated about food allergy, but they themselves do not want to provide this education (Sampson et al., 2006). Adolescents with food allergies are also known to take risks (Sampson et al., 2006). A recent study of college students with food allergy found that only 40 percent followed dietary restrictions and even fewer carried epinephrine (Greenhawt et al., 2009). These indices of poor SM were attributed to the relatively high rates of food allergy fatalities on college campuses. It may be that lapses in SM begin earlier when caregivers presume that adolescents are beginning to take on more responsibility; this could offer an opportunity to intervene while caregivers can still more easily

assist in the process. Understanding how SM evolves over time in this population and others will be an important task to address in future longitudinal studies.

As patient anxiety is common in food-allergic children (Avery et al., 2003; LeBovidge et al., 2009), we examined whether it was associated with SM. Adolescents experienced more anxiety, as measured by the MASC-10, when reporting greater SM. This finding must be interpreted with caution given the study design, but it may be that assumption of more responsibility is related to anxiety or heightens anxiety. This result perhaps supports prior findings that young adults with food allergy may experience greater anxiety as they become more aware of and responsible for their health-care management (Lyons and Forde, 2004). It may be helpful to ask patients about their comfort with increased responsibility. Increased anxiety can compromise quality of life in food-allergic children (Shemesh et al., 2013) and can even lead to avoidance of health management behaviors (Katon et al., 2004), therefore, it is important to identify and address such symptoms.

To our knowledge, this is the first study to directly investigate the issue of transition to self-care over the life of children and adolescents with food allergy. To date, there are no validated measures of SM in this population. Therefore, we adopted a measure of allocation of responsibilities for health care that was developed for other common pediatric presentations, namely, diabetes and asthma that require SM. Face validity was enhanced by expert feedback, and care was taken to address construct validity using items similar to those that have been incorporated in other related measures (Anderson et al., 1990; McQuaid et al., 2001; Naar-King et al., 2009). In addition, our finding of consistent differences between child and adolescent SM also enhances construct validity, as SM is in fact expected to differ between these two developmental periods, and validity was evidenced by factor analysis as well.

There are several limitations to consider in addition to the use of a novel measure of SM.

The study utilized a cross-sectional design, which makes it difficult to ascertain the direction of causality in the findings. Additionally, all outcome measures were based on self-report. With regard to sample characteristics, while this is a representative sample of our food allergy referral clinic, the respondents' demographic composition is somewhat homogeneous and may overall represent a more severe medical presentation and/or greater ability to seek medical attention. Finally, as is also germane to the particular clinic population, the adolescent cohort was a relatively small sample size.

Clinical significance and future directions

As children grow up, they must assume an increasing degree of responsibility over their own care, including allergen avoidance and other aspects of management. If this gradual process of assuming more responsibility is not achieved smoothly, it could result in preventable adverse reactions. We found that caregiver report of the degree to which their child is able to achieve SM was consistent with the child's understanding, but that this consistency disappeared when adolescents answered the same questions. Although it may be consistent with adolescent development for there to be disagreement between caregivers and their children, in this context, it could be concerning if no one is actually overseeing SM or if there is little gain in adolescent mastery of SM. Our results seem to bolster recent recommendations (Gupta, 2014) that it is advisable for clinicians who care for food-allergic adolescents to inquire about the family's expectations of SM in order to ensure that they are consistent. Taking this a step further, it may be helpful to plan and practice shifting allocation of responsibilities with families in clinic (Annunziato et al., 2008).

Finally, we found that adolescents, who reported greater responsibility over their care, also described feeling more anxious. Although limited by a cross-sectional design, taken

together, these results suggest that currently, SM skills are not acquired in a seamless way among families that have children with food allergy as has been discovered in other pediatric populations (Fredericks et al., 2010; McQuaid et al., 2003). Pediatric food allergy can be very emotionally taxing for families (Annunziato et al., 2013) and shifting to SM may exacerbate this state of affairs. Longitudinal research is necessary to uncover reasons or situations which prompt patients to adopt greater SM as perhaps there are contextual issues triggering SM shifts as well as anxiety. More focused efforts are warranted to assess the factors underlying successful allocation of responsibilities and to identify means to ensure a smooth transition over the child's life span.

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