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Caregiver views on virtual management of food allergy: a mixed-methods study

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1 Conflicts of interest

ESC has received research support from DBV Technologies; has been a member of advisory boards for Pfizer, Pediapharm, Leo Pharma, Kaleo, DBV, AllerGenis, Sanofi Genzyme, Bausch Health, Avir Pharma; is a member of the healthcare advisory board for Food Allergy Canada; was an expert panel and coordinating committee member of the National Institute of Allergy and Infectious Diseases (NIAID)-sponsored Guidelines for Peanut Allergy Prevention; and was co-lead of the CSACI oral immunotherapy guidelines.

SJ has been on speaker's bureaus for Aralez, Novartis, Astra Zeneca, and Sanofi, and on the advisory board for Sanofi.

MH has provided speaker services for Pfizer, Pediapharm, and has been part of an advisory board for ALK and provides privately funded OIT.

VC has been a participant on advisory boards for Sanofi Genzyme, Bausch Health, and ALK, speaker services for Aralez Pharmaceuticals and CSL Behring.

DM has provided consultation and speaker services for Pfizer, Aimmune, Kaleo, Merck, Covis and Pediapharm, and has been part of an advisory board for Pfizer and Bausch Health. He sits on the editorial board for the Journal of Food Allergy.

EA Section Head of Anaphylaxis/Food Allergy for the Canadian Society of Allergy and Clinical Immunology; sits on steering committee for Canada's National Food Allergy Action Plan; moderator/speaker fees from Novartis, GSK, Sanofi, AstraZeneca.

LS None

TW speaking engagements for Pfizer and Stallergenes Greer, Advisory Board member for ALK and Leo Pharma

JP is the Section Head of Allied Health for the Canadian Society of Allergy and Clinical Immunology; and sits on the steering committee for Canada's National Food Allergy Action Plan

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3 Keywords

Allergy; COVID-19; hybrid care; mixed-methods; virtual care

Abstract not required per the instruction for authors.

4 Main text starts on next page

To the Editor:

During the first months of the COVID-19 pandemic, healthcare acutely switched almost exclusively to virtual delivery (1, 2), with little precedent, and even less knowledge about caregivers’ comfort with such delivery. It is unlikely that we will ever return to exclusively in-person care (3, 4). Thus, there is a critical, but currently unstudied, need to understand caregivers’ attitudes toward virtual food allergy management. To address this knowledge gap, we performed a mixed-methods study in which we sought to examine caregivers’ views on virtual food allergy care.

In this embedded mixed-methods study (5), quantitative and qualitative data were concurrently collected from English-speaking caregivers of children <18 years being followed by an allergist for food allergy in Canada. Between October-December 2020, caregivers were contacted via email distribution lists from regional and national patient organizations; and through social media.

Basic demographics and caregiver experiences with virtual care (see Table E1 for definitions) were queried and collected in SurveyMonkey®. Data were described (n/N, %, mean (standard deviation [SD]) and compared (chi2, t-tests), using Stata® 15.1 (College Station, TX), with p<0.05. Open-ended responses were analyzed thematically (6). Quantitative and qualitative findings were mixed in the interpretation. This study was approved by the University of Manitoba Health Research Ethics Board (HS24207(H2020:384)).

Overall, 66 caregivers completed the survey, which represents 85.7% (66/77) who started the survey. Approximately half of caregivers had graduate/professional degrees (30/64; 46.9%). Half of children were age [?]5 years (33/65; 50.8%) with slightly more boys than girls included (59.1% vs. 40.9%; Table 1). The three most frequently reported food allergies were peanut (42/66; 63.6%), tree nuts (30/66; 45.5%) and egg (29/66; 43.9%). Nearly all families lived within 50 km of their allergist.

The most frequently reported type of allergy-related care was routine follow-up (50/66; 75.8%; Table 2). Overall caregiver-reported satisfaction (virtual + in-person combined) was comparable between routine follow-up and initial assessments, oral food challenges (OFC) and oral immunotherapy (OIT). A corresponding comparison to early food introduction was not performed due to a low number of these visits reported (3/66; 4.5%). Satisfaction with virtual versus in-person care was comparable. For example, mean satisfaction scores for initial assessments for virtual and in-person care were 66.5+8.0 and 81.1+5.3, respectively (p=0.21).

Qualitatively, caregivers described virtual allergy-related care as having “the benefit without the burdens” (Figure 1). This theme reflects caregivers’ descriptions of being able to access care for their child’s allergy, without concerns for childcare for other children in the family; losing several hours for travel and wait times; or, about being exposed to the COVID-19 virus. As one caregiver described, virtual allergy care could be done “*from home or work, [with] no childcare issues, no commute time, no exposure to covid (sic).*” Another caregiver noted additional benefits including “*saving money (parking and lunch fees at hospital), don’t need to pull kids from school for appointment, home setting is comfortable [so] child not nervous.*”

Caregivers also perceived disadvantages. The single word theme, “Isolation,” captures the isolation felt by parents of children with food allergy. As a caregiver, whose child’s in-person appointment for routine allergy-testing had been moved to virtual care, commented that virtual care contributed to feelings of isolation

[We are] feeling even more isolated as an allergy family. We already feel we live on the periphery of society as we watch our son's friends have birthday parties while he sits far away from everyone to ensure his safety.

Isolation was also described by parents of children requiring diagnostic testing, those who were newly diagnosed, and those who were receiving OIT. Similarly, caregivers noted the amplification of social isolation that existed prior to the pandemic. A small minority reported “*no advantages*” to virtual allergy care, noting that there are “*just disadvantage(s) ‘cause no skin testing was available.*” This lack of access to testing exacerbated the perception of isolation. Likewise, isolation was described by caregivers whose children were receiving higher risk treatment. Caregivers expressed concern that there was no medical professional physically present to assist if their child were to have a reaction subsequent to testing. As noted by parents whose child had received virtual OIT expressed that, “*I am the only one here to help him .*” Another caregiver, whose child’s in-person appointment for routine allergy-testing had been moved to virtual care, commented that virtual care for food allergy further contributed to feelings of isolation:

In this first mixed-methods study of caregivers’ experiences with food allergy care during the COVID-19 pandemic, there were no significant differences in caregiver satisfaction by type of care, or by type of delivery, based on quantitative data. Qualitatively, caregivers detailed benefits and limitations of virtual care, including amplified social isolation.

In keeping with the theme of isolation identified herein, we identified a similar theme in a qualitative exploration performed prior to the COVID-19 pandemic (7). In the previous study, parents reported “*anxiety and isolation*” and existed tenuously with allergy, which had become their normal (7). Importantly, caregivers described that this isolation was further exacerbated when they lacked support from extended family and/or close friends. In the present study, caregivers similarly described isolation, but did not speak to support from family or friends. This may be partly attributable to the wider isolation as a result of COVID-19-related physical distancing measures, well beyond that experienced in virtual care. But, taken collectively, these findings point toward a likely gap in support structures during the pandemic, which must be addressed or otherwise places caregivers and their children at further risk of isolation, including downstream effects thereof.

Our mixed-methods study provided insights into specific disadvantages that could not be captured through a quantitative survey. The COVID-19 pandemic has propelled virtual healthcare forward in ways that would have otherwise taken generations. This type of healthcare delivery may be a practical option even after the pandemic, particularly in rural and remote regions, providing that there is reliable telephone and/or internet access. We acknowledge that participants in the current study were economically advantaged. Additional work exploring the satisfaction of, and access to virtual care amongst economically-disadvantaged caregivers is warranted. Shared decision making is an increasingly important paradigm in allergy, and one which mandates a strong physician-patient relationship (8). The findings presented herein reinforce the need for caregivers to have a voice, particularly those in lower socioeconomic groups, to promote high quality care. This cannot be overstated if virtual care is to be successfully continued post-COVID-19.

Whereas access to testing that requires in-person contact is logistically challenging during a virtual appointment, we suggest that this may be amendable to a hybrid model. Systems navigation is a documented way of reducing the fragmentation and gaps in care, tailored to address the needs and characteristics of a given patient population (9). In an allergy context, this model may involve testing patients in rural and remote regions with regional/local healthcare partners, after which the results are sent to the allergist for interpretation. Future research is warranted to explore this potential, and the related cost-effectiveness.

In conclusion, caregivers were satisfied, yet felt socially isolated, as a result of virtual care and more generally, food allergy. This study provides the necessary first steps in guiding the sustainability efforts of allergy care in this new virtual medicine era.

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Table E1. List of terms and definitions

Term	Definition
Types of food allergy-related care	Initial assessment (initial assessment or consultation), routine follow-up appointments, and hybrid delivery of care
Hybrid delivery of care	A combination of both virtual and in-person practice, without consideration of the proportion of each
Levels of parent satisfaction	Queried on a scale of 0-100, representing lowest to highest possible satisfaction, respectively
Virtual care	Allergy care received over the phone and/or internet, not in-person

Abbreviations: *OFC* Oral food challenge; *OIT* oral immunotherapy

Table 1. Participating family demographics (N=66)		
Variable	n	%
Child's age group (years)		
1-2	15	23.1
3-5	18	27.7
6-10	21	32.3
11-18	11	16.9
Child's Gender		
Boys	39	59.1
Girls	27	40.9
Parental highest level of education (N=64)		
High school, college, trade school or undergraduate	34	53.1
Graduate school or professional degree	30	46.9
Pre-pandemic income (N=59)		
< \$100,000	16	27.1
\$101,000 -\$200,000	29	49.2
> \$201,000	14	23.7
Pandemic income (N=58)		
< \$100,000	18	31.1
\$101,000 -\$200,000	26	44.8
> \$201,000	14	24.1
Allergy characteristics		
Child's food allergies*		
Peanut	42	63.6
Tree nuts	30	45.5
Sesame	14	21.2
Milk	24	36.4
Egg	29	43.9

Table 1. Participating family demographics (N=66)

Fish	6	9.1
Crustaceans and molluscs	6	9.1
Soy	4	6.1
Wheat	4	6.1
Mustard	2	3.0
Legumes other than soy	7	10.7
Seeds other than sesame or mustard	1	1.5
Other	11	16.7
Age at diagnosis		
<12 months	42	63.6
1-2 years	15	22.7
3+ years	9	13.7
Do not see allergist in own province	2	3.2
Distance travelled to visit allergist		
< 20km	37	56.1
21-50km	18	27.3
51-100 km	6	9.1
100-250km	5	7.5
Not mutually exclusive		

Table 2. Participating caregivers' (N=66) access to allergy-related care, including type of delivery, during the COVID-19 pandemic

Type of care	n	%
A. Allergy-related care*		
Initial assessment	22	33.3
Follow-up	50	75.8
Early introduction	3	4.5
Oral food challenge	18	27.3
Oral immunotherapy	14	21.2
B. Allergy-related care by type of delivery		
Initial assessment		
Virtual	12	54.5
In-person	7	31.9
Both	3	13.6
Follow-up		
Virtual	35	70.0
In-person	14	28.0
Both	1	2.0
Early introduction		
Virtual	3	100.0
In-person	0	0.0
Both	0	0.0
Oral food challenge		
Virtual	16	88.9
In-person	0	0.0
Both	2	11.1
Oral immunotherapy		

Virtual	8	57.1
In-person	0	0.0
Both	6	42.9
Not mutually exclusive		
Abbreviation: <i>SD</i> Standard deviation	Abbreviation: <i>SD</i> Standard deviation	Abbreviation: <i>SD</i> S

9 Figure Legend

Figure 1. Qualitative perceptions of virtual allergy care

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Figure1_FINAL.pdf available at <https://authorea.com/users/400819/articles/513087-caregiver-views-on-virtual-management-of-food-allergy-a-mixed-methods-study>