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Illustrating Risk: Anaphylaxis Through the Eyes of the Food-Allergic Child

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The risk perception research is widely focused on children as targets of risk. To date, very few studies have consulted with the impacted group to assess the perceptions of risk associated with the exposures of interest. Much less research has investigated the experiences of children at risk for anaphylaxis, their concerns, and the psychosocial stresses associated with risk. The present study explores the perceptions and experiences of Ontario students with anaphylaxis, and their parents regarding school as a safe place in order to inform school policy around risk management and coping. A "child-centered" analytical framework incorporating illustrative techniques within interpretative analysis is outlined. Five prominent themes: (a) social and environmental barriers to safety, (b) coping strategies, (c) emotional burden of responsibility, (d) balance of responsibility (transitions), and (e) redefining "normal" are discussed. Results found that "child-centered" techniques empowered children in a process that is meaningful and relevant to their lives. A preliminary framework for understanding what risk means to children highlighted the differences in how they cope in the public sphere of school.

KEY WORDS: Anaphylaxis; children's illustrations; risk perception; school policy

1. INTRODUCTION

The death of 13-year-old Ontario student, Sabrina Shannon, in her school cafeteria in 2003 brought children at risk of anaphylaxis to the forefront of public policy in Canada. Sabrina's Law (Bill 3) took effect in Ontario in January 2006. This legislation mandated that all publicly funded school boards and their schools put in place measures to safeguard students at risk of anaphylaxis. Recent data indicating substantial differences in prevalence of peanut allergy between Canada and the United States, with rates shown to be much higher in the former, add tremendous uncertainty to the risk associated with these deadly allergies.[1,2] Anaphylaxis is a potentially life-threatening condition affecting people of all ages.[3] Adolescents and young adults particularly appear to be at increased risk of developing severe and fatal anaphylactic reactions due to risk-taking behaviors.[4] Other consistent risk factors for food-induced anaphylaxis fatalities include active asthma, peanut or tree nut allergy, and unavailability or delayed use of adrenaline.[5] The purpose of this research was to explore the perceptions and experiences of Ontario students with severe allergies or

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at risk for anaphylaxis, and their parents regarding school as a safe place in order to inform school policy around risk management and coping. A critical component to this research was the use of children's illustrations as a methodological technique, integrated with more traditional narrative interview data. The result is an analytical framework depicting a "child-centered" approach to understanding risk.

Food allergy affects up to 6% of young children[6,7] and is believed to be a growing health risk in Canada.[8,9] Allergic reactions can be mild, moderate, or severe, sometimes progressing to anaphylactic shock, and death.[10] In the United States, there are an estimated 150–200 fatalities each year;[7,11] Canadian figures are generally scarce for anaphylaxis-related deaths; experts extrapolate from American figures, estimating between 15 and 20 children die annually.[12] Peanut allergy accounts for the majority of severe food-related allergic reactions.[13] Yet, despite current opinion that the prevalence of food allergy is increasing,[14] much of the evidence is inconclusive.[15] However, there is tremendous media attention to the issue,[16] which is causing greater concern and a heightened perception of risk among the general population. Currently, the primary mode of preventing potentially life-threatening reactions is strict avoidance of the implicated food or foods and provision of medications (e.g., epinephrine, antihistamines, and possibly corticosteroids) for symptomatic treatment of reactions.[17] Accidental exposures are common,[18] and occur in homes and in other locations, such as schools, camps, and restaurants.[19] Thus, food-allergic children and their families must learn to cope; otherwise, they may increase the risk of exposure to harm or death.

The article is organized in four sections. Section 2 reviews the methodological literature on the use and usefulness of children's illustrations as "data." Section 3 precedes a detailed discussion of Section 4. Section 5 reflect upon the effectiveness of using illustrations to understand the contextual dimensions and conditions that shape risk perceptions and highlight the differences in risk perception between children and adolescents. Implications for future research as well as policy are also addressed.

2. USE OF CHILDREN'S ILLUSTRATIONS TO UNDERSTAND RISK

Conducting research with children rather than on children represents a recent paradigm shift.[20,21] Traditionally, children's lives have been explored through the views of adults,[21] thereby excluding them from the research process. Involving children as social actors in the research process has meant a revisiting of epistemologies and methodologies,[22,23] shifting the gaze from seeing children as passive recipients to viewing them as active participants in constructing and determining their own experiences.[23] Methodological techniques, such as drawings, are considered effective methods to understand children's experiences and "actively engage" them directly about issues that matter to them.[24,25]

The use of children's illustrations has a long history in psychiatry, psychology, and education[26] and is increasingly being used to explore children's life experiences.[25] These child-centered techniques[27,28] are of benefit in at least three ways:

1. They help children organize their thoughts more effectively, particularly younger children.[29,30]
2. They serve to address any power differences between adult researchers and children.[20]
3. They generate rich descriptions of lived experiences.[23]

A meta-analysis of this literature has shown that asking young children to draw prior to being interviewed (draw-and-tell) is a robust strategy that facilitates memory performance, verbal reports of emotionally laden experiences, and more detailed narratives.[31] It is important to note that the use of drawings is inadequate as a stand-alone method; for drawings to be a useful research method, they are best used in dialogue.[32,33]

In general, research with children's health at risk has predominantly used quantitative, survey, and experimental approaches;[34] however, such techniques by themselves are insufficient to provide a comprehensive picture.[35] Accordingly, there is a growing variety of interpretative methods that provide complementary information in order to enrich our understandings of children's health and illness.[36–40] These qualitative methods are designed to engage children more directly, and include such techniques as individual interviews and group discussions;[41] task-centered activities, such as drawings;[25] photographic techniques,[36] such as photovoice;[40] and video intervention/prevention assessment (VIA).[42] In particular, VIA is an innovative participatory photographic technique that has been used to investigate health issues from a patient's perspective.[37] VIA's primary data consist of visual illness narratives and video diaries made by participants to capture

their experiences living with and managing chronic medical conditions.[43] Visual narratives have been shown to positively affect self-management behaviors in children and adolescents with asthma,[44] and increase awareness of how adolescents with obesity perceived themselves and their condition.[45]

Health-related research with children is increasingly using interpretative methodologies in combination[33,46–48] to explore psychosocial experiences. For example, research on the impact of HIV/AIDS on 48 child "carers" (aged 11–17) used photography and drawing to explore their coping strategies.[48] Video diaries, along with interviews, were useful in exploring children's perspectives of handling serious cancer illness in a parent.[49] Research on asthma among inner-city school-aged children and their families used drawings, along with explanatory models, to explore beliefs about asthma.[50] Illustrations, along with interviews, were also used to explore experiences of childhood chronic illness,[30] stressors of children with cancer,[47] hospitalization of children with pervasive developmental disorder,[39] and pain.[51] Sartain *et al.*[30] used illustrations to explore childhood chronic illness and found that children were competent interpreters of their world.

Research with children's drawings increasingly makes use of a variety of analytic techniques to interpret their experiences.[25,39,52] Mitchell[20] used a critical visual methodology to analyze the content, production, and circulation of children's drawings.[53] An adaptation of this method was used to explore conditions of illness in children.[54] In combination, linguistic narrative analysis along with thematic analysis were used to understand children's experiences of fear,[31] and homeless children's meanings of hope were thematically analyzed.[52] Kostenius and Ohrling[55] employed a three-step phenomenological analytical approach: seeking meaning, theme analysis, and interpretation with reflection to analyze children's illustrations.

The risk perception/risk analysis literature focuses a great deal on children as the targets of risk:[56] (a) the impacts of contaminated breast milk on infant development, (b) the impacts of consuming food products treated with growth hormones on childhood development, and (c) exposure to low level electromagnetic radiation on the health of children are just a very few examples. However, seldom do we consult with the impacted group when it comes to children. Even in the case of a particularly germane childhood exposure issue (i.e., mobile phones) children themselves are not consulted.[57] And while risk researchers expound the virtues of engaging experts in the risk assessment process,[58] infrequently do we inquire directly in the context of childhood risk.[59,60] While children with severe food allergies or at risk for anaphylaxis have been asked to complete surveys regarding their quality of life,[61] very few studies have asked children to share the details of their experiences, their concerns, or their psychosocial stresses (see Ref. 3, for exception). This research attempts to fill this gap by going directly to affected children in order to allow them to describe their experiences, their concerns, and their psychosocial stresses associated with the risk of anaphylaxis. In order to do so, we use illustrative techniques within interpretive analysis. The details of this methodology are described below.

3. RESEARCH DESIGN AND METHODOLOGY

This exploratory study employed a qualitative research design that included in-depth interviews and illustrations to investigate the perceptions and experiences of Ontario students with severe food allergies. Participants were purposefully selected to represent children and adolescents attending Ontario schools. The criteria for selection included: (a) attendance at publicly funded schools in Ontario; (b) clinical diagnosis of life-threatening food allergy; (c) age groups—children (8–12 years) and adolescents (13–18 years); and (d) diversity of gender. The sample was recruited and limited to the registry of a national nonprofit organization that supports families with loved ones at risk for anaphylaxis who have severe food allergies in Canada. Several different recruitment methods were used (e.g., newsletter announcements, direct e-mail, and targeted e-bulletins). A total of 60 participants responded to the initial call; the final sample was determined on the basis of geographic distribution across the province. This study enrolled 10 children and 10 adolescents with equal representation by sex in both age groups. The McMaster University Research Ethics Board approved the study.

After receiving parental consent and child assent, children were asked to draw a picture of "what it was like to live with a severe food allergy" and then explain their illustration. Following this draw-and-tell exercise,[31] children then engaged in an in-depth face-to-face interview independent of parental presence that explored more fully

their perceptions and experiences of living with anaphylaxis at home and at school as well as their feelings about "school" as a safe place. All explanatory narratives and interviews were audio-recorded, transcribed verbatim, and member-checked with participants for their confirmation.[62] Subsequent thematic analysis using NVIVO,[63] a qualitative analysis software package, was used to manage, code, and structure the data. Interviews ranged in length from 60 to 120 minutes.

The integrated analytic framework consisted of three stages of analysis: (a) reflexive analysis, (b) thematic analysis, and (c) depth analysis. Three types of data were used in analyzing the illustrations: (a) illustration, (b) narrative explaining the meaning of illustration, and (c) in-depth interview.

The first stage involved reflexive analysis, defined as: a process whereby researchers examine the ways in which their involvement influences, acts upon, and informs research.[64] This process involved two research team members who critically examined the interview transcripts in order to validate the thematic categories and determine the levels of coding agreement (i.e., interrater reliability).[65] A random selection of interviews was coded independently by two members of the research team who then met to discuss code definitions and inclusion/exclusion criteria, and to reach consensus on scores. A 76% agreement rate was achieved and to ensure validity, only common analyses, those that were in agreement, were coded. The source data were repeatedly examined to validate, enrich, and add dimension to the analyses. For example, the notion of teacher burden (due to dealing with parental concerns of safety) emerged, which expanded the context of emotional burden. Specific strategies were also used to ensure that the illustrations stayed connected to the participant's view of reality. This step initially involved moving between the image and its explanatory narrative, a step that consisted of simultaneously reading the text while listening to the audio recordings in order to stay attuned to children's voices and expressions. Audio expressions, such as whispers, silences, "emphatic speech" tones, and sighs, were tagged to the image and to phrases in the text in order to better understand various meanings. These emotional expressions were deemed critical in detecting potentially unstated assumptions and implicit meanings that may have been embedded within the illustration: these were subsequently explored in more depth in the interview data.

The second stage involved thematic analysis, defined as: an approach that involves the creation and application of "codes" to the data.[62,66] In this study, line-by-line coding of the interview transcripts involved close reading and coding discrete units of text using an intricate coding system developed using both inductive and deductive approaches; that is, it was informed by the objectives of the research as well as the themes that emerged from the interview data. Essentially, there were five overall themes (each divided into several subthemes) that represented (a) environmental barriers and supports to safety, (b) coping strategies, (c) emotional burden of responsibility, (d) adaptation, and (e) redefining "normal."

The third stage involved depth analysis, defined as: an analytic approach to examine the structural conditions that shape situations (context) and the flow of behaviors that occurs in response to situations (process).[67] In this study, coding for context and process involved working with another team member using different techniques (e.g., writing, diagramming, and reflection) to expose the meaning of children's experiences. Depth analysis is similar to thematic analysis; yet, it involved asking questions of the data, such as "why, when, where, and what" in order to understand the actions, interactions, and emotions that emerged in response to particular events or circumstances.[67] This analytic process revealed the connectivity between the themes and further expanded the meaning of the concepts depicted within the illustrations.

The results presented below are organized in two sections: the first presents an interpretative analysis of children's illustrations of risk using one representative case from each age group, and the second presents the thematic analysis of the in-depth interviews.

4. RESULTS

All 20 children who participated in the study attended the local public or separate schools in the community where they lived. The sample was 55% female, and consisted of an age range from 7 to 17 years. Of the 20 children, seven were allergic to a single food (35%) and 13 were allergic to more than one food (65%). Participants were allergic to a range of 1–7 foods: peanut, tree-nuts (e.g., hazelnuts, almonds, brazil nuts, etc.), sesame, egg, shellfish (e.g., shrimp, lobster, clams, etc.), fish, and milk. Most children (>60%) reported food allergy to peanut. The

Fig. 1. Selected children's illustration and narrative with line-by-line coding.

average age at diagnosis was 2.18 years, ranging from 12 months to 4 years. More than 55% of the respondents reported having a food allergic reaction subsequent to diagnosis.

4.1. Reflexive Analysis of Children's Illustrations of Risk

4.1.1. Ashley[7]

Ashley is allergic to peanut and all tree nuts. She was diagnosed at the age of $2\frac{1}{2}$ years and was 9-years-old at the time of the interview. She had never experienced another reaction since her initial one at the time of her diagnosis at 2.5-years old, but she has faced difficult situations involving unsafe food during holiday times and at birthday parties. Ashley admitted that birthday parties would be easier if "people told her (us) where they had gotten the cake from and then they could research it on the web site." When Ashley first started school, kids were scared of her allergy and bugged her about it, which made her feel "not so good." She said it made her feel

> like a baby because it is like people didn't believe that she (I) could handle something, so they would always try and get between me and the nuts—even though they maybe didn't have to because it might be impossible for me to get hurt.

[7] Pseudonyms have been used to protect the confidentiality and anonymity of the respondents.

The highlighted words and phrases represent the line-by-line coding of thematic analysis. Figure 1 depicts and describes an imagined scenario. The early themes that emerged from these data surfaced in ideas about the emotional dimensions of risk (e.g., scared and annoyed) and exposed Ashley's expectations of others and her standards of safe practice (e.g., wash hands, clean surfaces, and removal of unsafe food). In this scenario, Ashley copes by seeking support from her Mom, which was a typical response in this age group. In this particular case, it is important to note that Ashley's imagined scenario was based upon a previous unsafe encounter at school.

Can you tell me about your picture?
These are six people in my class **(classroom scenario)**.
Are they real people?
I just drew random people **(imagined people).** We are sitting at our desks eating lunch and my friend says to me, she is feeling panicked and says **(projecting emotional reaction)** "Matt has Reese's Pieces" **(risky food)** and those have nuts in them. I am feeling annoyed **(feeling annoyed)** and kind of scared **(feeling scared)** because over there is a weird dude.
Is there actually a weird dude in your class?
No **(imaginary person)**.
Okay, you just made it up?

Yes, he is wearing a safety mask, with oxygen in it and he is holding a fire extinguisher and shooting it at Matt and he is saying **(friend combating risk)** "Matt put that stuff a mile away and wash your hands with antibacterial soap" **(rules about being safe)**. Sometimes I feel annoyed **(feeling annoyed)** because people get too crazy about my allergy **(feeling annoyed about other people's reaction to allergy)**.

What does that mean "too crazy?"

I am glad that they do care, but sometimes I feel like they are, I don't know what the word is.

Is this about the person, this guy here or Matt?

Matt does not know **(uninformed kids)** because he is taking it out and he took a bite out of it and he just remembers that I have a nut allergy, but he is still worried **(emotional reaction means caring)** and I like that because he is not super crazy but it is not like he doesn't care.

I see. So Matt still cares that you have a peanut allergy and what would tell you that he still cares?

Because he is in my head, after that he (cares) because he threw it in the garbage at the principal's office, not in our classroom and then went to wash his hands **(caring = fits expectations of safety practices)**.

So he did sort of listen to this right? That weird dude, in your mind, this person who said this is what you need to do and he did do that?

Well, he did listen to him, but he thought of doing that before.

So did that kind of give you the sense that he cared about that? Does this ever happen?

I just imagine this stuff **(imaginary scenario)**.

Is there anything that did happen at school that made you imagine this?

Well, one time in Grade 2, **(actual incident of risk)** my friend Krista had Nutella **(risky food)** at school in a sandwich and I was feeling really scared **(feeling scared)** because she sat in the group beside me **(proximity to risk)** and so I was backing up my chair **(remove herself from risk)**. I went to call my Mom **(seeking support from Mom)** because I was worried **(feeling worried)** and Mr. Burke, the janitor, cleaned her desk off at recess **(safety practice)** and my Mom said that I would be fine **(needs reassurance)** if I didn't feel anything and I didn't feel anything. So when he cleaned the desk, I felt more safe. I could walk around **(feeling less restricted)**.

4.1.2. Richard

Richard is allergic to peanut, all tree nuts, and some shellfish. He was diagnosed with an allergy to peanut and all tree nuts at age three and to some shellfish (shrimp, lobster) at age six. At the interview, Richard was 16-years-old and had never had another reaction since his initial one three months prior to being diagnosed at age three. In the early days, when he was in elementary school, if someone brought peanuts to school, Richard was sent to the hall to eat his lunch. He admitted that he rarely carried an EpiPen at elementary school because he trusted the security of one classroom teacher, consistent routines, and supervised lunches in his homeroom class. Richard remembers a lot of things changing when he started middle school; it was the year he joined the cadets and began to feel more independent. He talked at length about his EpiPen and the dichotomous feelings of fear and safety; feeling fear of needles, in general, while feeling safe in knowing the EpiPen was a "life-line."

This sample illustration in Fig. 2 depicts a cafeteria food fight and Richard describes how he dealt with this particular unsafe experience at school. The early themes that emerged from the data exposed ideas about characteristics of risk (e.g., unexpected and sudden) and the subsequent feelings (frustration) that Richard felt while coping to overcome an unsafe situation (e.g., planned escape and proximity to exit).

Can you tell me about your drawing?

Sure, so there is the cafeteria table along here and so this guy is like, "food fight," right **(unsafe, risky place)**.

Did that really happen?

Oh yea. It happens all the time **(frequency of risky event)** like throwing food and food splattering in places **(risky activity in school)** although this is supposed to be me, although I never do that **(imagined escape)** I always run for the door **(escaping risky place—coping)**. I figured I would be more able to head underneath the table, so there is me, "not again, kind of thing" **(frustration)**.

So how do you feel when that goes on? Does it happen regularly?

This happens usually once every other month **(occurrence of risky event)**.

When it happens, how does that make you feel?

You just kind of get yourself and get out **(coping mechanism—escaping)**. Usually, I am close enough to a door **(coping strategy)**.

Fig. 2. Selected adolescent's illustration and narrative with line-by-line coding.

Do you plan that?
No, it is just where, well in a way kind of **(planned escape)** but that is just where my group of friends sit
Can you tell me what else is in your picture that is important?
A garbage can knocked over **(unsafe food exposed)**.
How are these situations dealt with?
Well, they usually don't **(feeling unsupported)** they try and get in there as soon as possible. They have teachers supervising.
What would the teachers do if that kind of thing happened?
Well, there really isn't anything they can do **(feeling unsupported-excluded)**. Like they can't stop the whole school kind of thing **(feeling in minority-excluded)** so they have to get like the higher, like administration—like the principals.

4.2. Thematic Analysis of In-Depth Interviews

The thematic analysis of the in-depth interviews uncovered five prominent themes, three of which pertain to the younger children (i.e., environmental barriers and supports to safety, coping strategies, and emotional burden of responsibility) and two of which pertained to the adolescents (i.e., balance of responsibility and redefining normal). For the most part, children's perceptions were mentally constructed and their illustrations represented imaginary scenarios of the children's group; adolescents' perceptions of risk were socially constructed and their illustrations represented real life experiences of dealing with unsafe events or circumstances.

4.2.1. Social and Environmental Barriers to Safety

All children (both age groups) identified various environmental and social barriers that left them feeling isolated, excluded, or teased. Social exclusion meant missing out on school activities, being deprived of time with friends, or being singled out. A 16-year-old male stated, "I remember a few years ago when I wanted to go to camp, the same camp as my friends, but they wouldn't let me come because of my allergies" and "I feel left out because I can't have everything, like my friends and the other people in my family." While close friends provided a strong safety net and were described as key supports for all children, the greatest barrier stemmed from uninformed or misinformed people (e.g., school personnel, friends, and other parents). For the most part, all participants viewed elementary schools as safer environments due to four factors: (a) consistent school; (b) consistent school personnel; (c) daily routines (e.g., supervised lunch room, trained school personnel, and communication strategies); and (d) a stronger presence of parents. Conversely, most adolescents described high schools as less protected environments (i.e., "peanut-aware" vs. "peanut-free")

that posed greater potential risk due to structural differences (e.g., semester system, common eating spaces, unsupervised lunch areas, and uninformed school personnel).

> Sometimes I feel safe, sometimes I can't because I can't be sure that people . . . like people bring peanut butter to school, they don't sit with me, but then they come into my classes, and be like, "Oh, I had peanut butter for lunch," but teachers don't monitor what you eat for lunch every day, and high school is just like, do whatever you want. We don't have teacher walking around, looking over our shoulders, "So what do you have for lunch."

> It is not as big of a deal in high school, because there are so many more kids.

> There are some (teachers) that I trust, and some (teachers) that I don't trust. I don't trust my Math teacher. I don't trust my French teacher. I trust my English teacher, and I am pretty sure I trust my Geography teacher, because her daughter has the exact same allergy.

4.2.2. Coping Strategies

The ways that children and adolescents coped in overcoming risk were described differently. For most young children, coping with risk at school involved greater dependence on parents:

> I guess I don't check every single time, because my mom usually does that, when she buys them I have to always read the labels, and it sort of takes longer and then we have to go home. So it takes a lot of time to just read the labels, and then I call my mom to make sure it is safe.

> If somebody offered me a food that I haven't had before, I would just have to ask what was in it, or I would have to ask my mom. Because I am not allowed to have any foods that my mom or dad doesn't say it is okay.

> My mom usually goes in ahead of me and clarifies all that, so every once in a while I will get a question about that from teachers or something. Well (my mom) just kind of like they take care of the situation, way before I even have to get involved.

In less emotionally charged situations, both children and adolescents coped by avoiding risky foods, educating others, or escaping from unsafe places. In contrast to children, adolescents fended for themselves, often alone. In uncertain situations, adolescents described vigilant patterns of coping that were often triggered by fear. Most adolescents described coping to overcome risk in anxious ways, "keenly aware of surroundings," "being alert," and often "being on guard." For a few adolescents, coping meant "giving up and giving in," which was a response to feeling overburdened emotionally. This response occurred when they felt helpless and disempowered—plummeting into an emotional space and isolating him/herself from others. This type of response was usually accompanied by overcompensating coping strategies that consumed energy and attention on a day-to-day basis (i.e., obsessive hand washing).

> Well, like I am constantly washing my hands before like I have any food product, so it is kind of like annoying, because I am kind of like afraid to not wash my hands for once, but that is really about that.

> Well it used to like kind of not be such a big deal, like I was like anyone else, because I wouldn't wash my hands before, and now it has gone to like a lot worse, where I am washing my hands all the time and stuff.

> Well I try to have my pen (EpiPen) on me. I try to watch what I eat, and who is around me, eating what, and making sure that I wash my hands if I think I am near something, or anything.

> So I did lose some weight, though because of it (afraid) and like sometimes when my parents weren't home, I wouldn't eat until they got back, just in case I had something, that would have it, and then I would have no one to drive me to the hospital or anything.

4.2.3. Emotional Burden of Responsibility

Participants were able to easily articulate their feelings about specific times, places, or objects of emotional significance. The emotional burden of responsibility emerged when children and adolescents felt at risk when negotiating situations in their environments that had potential for exposure to allergenic substances, bringing to light the relational nature of emotion that moves in-between people and places rather than the objective view of emotion as statically residing within a person. The emotional burden for younger children appeared to be mediated by protective parents who had internalized their child's allergy and carried a greater burden for managing it. Younger children described feelings of sadness and annoyance, and being scared about their allergy. Interestingly, a few younger children attributed these emotional responses (i.e., annoyed) to feeling disempowered in certain situations, where control was taken from them (either by peers, parents, or school personnel) in managing risk.

> When I go to stores, when I go to reach the door, my dad always butts in because my mom and dad say that there could be peanut butter oil or something like that on the door, so they always butt in, and do all the stuff that I think I should be able to do, and my grandpa and grandma let me do it a lot, and let me to do that, and nothing has happened.

In contrast, adolescents felt they had to fend for themselves in unsafe situations and their emotions were described as intense feelings of anxiety, fear, or embarrassment. All participants described their food allergy as a "big deal" because it was a "life or death" issue:

> Well, the fact that it is life or death that is why it is a big deal.

> I know it is hives, I know you stop breathing, and I know it is like I can't inject myself with the EpiPen, we are pretty sure, because I would be too unconscious and or like trying to breathe, so I find it scary. And also, if I wasn't sure it was my peanut reaction, it was the early part of it, right when you start to get hives, and have a bit of trouble breathing, I wouldn't know for sure to stick the EpiPen in, which scares me because if I didn't stick it in, I could die, and if I did stick it in, it wouldn't help with the other thing that I was having, so that is why I am not sure when to stick the EpiPen in. I know if you are unconscious, someone sticks it in, but how would they know for sure that it was a peanut allergy and not something else.

> Like what I said about the parties, they won't invite me, or they won't hang around me, because they have something, but they are kind of like protecting me, because I won't go near it. I kind of got a bit more anxiety and stuff and I was more careful with everything that I did.

> Well, because I live my life completely cautious. Everything I do is . . . I have a certain cautiousness to what I do, and like every time I want to eat something, I have to double check it, so that if somebody brings in snacks to school or something like that, I am constantly on the look-out for something.

4.2.4. Balance of Responsibility—Transitions

Themes 4 and 5 were unique to adolescents. As adolescents felt more confident and independent in dealing with their allergy, they assumed more responsibility for managing potential risks. A balance of responsibility was reported by adolescents whose experiences in dealing with unsafe situations enabled them to cognitively and emotionally grasp the implications of their condition for safety and their need for avoidance. These experiences enabled adolescents to transition away from parents and adapt more independently with or to their environment (e.g., people and places). Transitioning meant assuming more responsibility for managing their allergy; being more independent, taking more risks, making more independent decisions, and advocating for themselves. In these circumstances, most adolescents attributed choice and control to feeling more empowered and gaining trust in themselves, others, and certain places. Transitional spaces were described in relational terms; between an allergic child and his or her environment, parents, or peers, and often involved a degree of risk taking. Risk-taking meant taking responsibility for negotiating situations in their social environments, asking questions, and self-advocating. Adolescents who admitted to risk-taking behaviors were less encumbered with fear, which enabled them to deal more independently within their social environments. Frequently cited transitional adjustments occurred most often when participants entered high school, became more self-aware of their bodies, and engaged in independent activities:

> But it has also made me take a lot more responsibility, because if I didn't have one (allergic reaction), I wouldn't really think about it, and now I think about stuff, and I am more responsible knowing that I have to bring my EpiPen with me, and read the labels, and everything before I do it.

> Yea, because nobody else can answer the questions like I can, because it is my personal experiences, and take on it. Like my mom will try to explain it to my friends, but nobody was going to try and explain what a reaction is like, just because I have been through it.

> Grade 6, 7, yea. It (taking more responsibility) really started with like Grade 7, because I joined the cadets, and we were traveling for parades everywhere, and what not, and I would have to start relying on myself.

> With high school, when you have four teachers a semester, eight teachers a year, it spreads out. You don't have that home room that you stick with the whole year, all day kind of thing. So where that was helpful in elementary school, my mom doesn't get to meet my teachers before I have them. So it is my responsibility to tell them. So they know. If I am on the floor that is what is going on. This isn't a joke. This is serious.

> It has always been a general thought, that as much as my mom does protect me in that way, it is me. It is my body. I have to take care of myself, and if I don't do that, then it is down the drain, because she can't be there 24 × 7. Eventually I grow up. Eventually she won't be here anymore. I am going to have to take care of myself as an adult. So it is better to adapt now, than to be clinging onto mom's lap.

4.2.5. Redefining Normal

Adolescents talked about redefining their life as "normal." A new normal came more easily for those adolescents who were able to embrace a new social identity with severe food allergies. The independent strategies they deployed involved some form of separation of the self from an old identity and a

subsequent shift to a new sense of self. Developing an altered self-concept of living with anaphylaxis was essential to learn how to redefine life as normal.

> Because in no way does allergies, EpiPens, and Medic-Alert define me as a person. Like sure, I have an allergy. That makes me no different than the person living up the street kind of thing.

> I am to the point now; this is a box of cookies. I won't put it in the cart, before I read through the whole thing, because it is just a train of thought.

> I just have to know I can't eat certain things, or food at all sometimes, but it is not that hard. After a while you just get use to it, or if I am going to something that I am not going to be able to eat any food, I will bring food with me, but it is not that bad now.

> Well, if you have a food allergy, then it sort of can help, because you learn how to like talk to them, like if you do want to make a new friend, you learn how to talk to them, and how to be like you know how to talk to them, and you won't just say, "Hi, what is your name?" You will say like, "Hi, my name is whatever, and I have food allergy." And you will like learn how to say that to people when you do make new friends.

> Well, I let people know that I have problems doing this or that, but it doesn't stop me from playing sports. It doesn't stop me from going out with my friends. I just have to be extra careful when I do. It doesn't stop me from doing anything.

5. DISCUSSION AND CONCLUSIONS

The results of the depth analysis exposed the connectivity between themes to form a social context consisting of three key domains: (a) institutional (place and people), (b) personal (allergic child), and (c) emotional (expressed feelings). In general, the institutional domain consisted of environmental factors (e.g., places, people, food labels, and school structures) that either benefited or hindered safety. For the most part, elementary schools were described as safer environments due to the dominant presence of parents and consistent school structures (e.g., one classroom, one teacher, and separate eating area). For example, Richard, a 16-year-old who is allergic to peanuts, all tree nuts, and some shellfish, speaks to the difference:

> It is to the point in high school, where you are fending for yourself. You don't have one classroom that you sit in and eat your lunch with your class of 30 every day. When that bell rings, you are on your own. You are out on the safari by yourself. You go down to the cafeteria. You listen. That is the biggest thing. You look and listen.

The personal domain reflected individual knowledge based on past experiences that formed individual beliefs about risk (e.g., risk experience, information, and family patterns). For instance, some participants reported that a risky experience (i.e., allergic reaction) helped their ability to cope. Surprisingly, over 55% of the participants had experienced subsequent allergic reactions after their initial diagnosis, which for some participants was seen as beneficial to the development of coping strategies. For example, Michelle, 16-year-old who is allergic to peanut, sesame, and some tree nuts, discussed the benefits of experiencing minor reactions, "the benefit to me is it reminds me that I should be careful . . . and then after I have a reaction, I am reading everything."

The emotional domain reflected individual feelings expressed in response to unsafe situations. Adolescents expressed such feelings as fear, anxiety, and frustration, which were in contrast to younger children who described sadness, annoyance, and unhappiness. The varied emotional responses reflected different coping strategies between younger children and adolescents managing more independently. So too, feelings of achievement emerged for a few adolescents who talked about adapting with or to their environment (i.e., self-advocacy and independence) in creating a new social identity and "life style."

The present research employed child-centered methodologies to explore perceptions and experiences of Ontario students at risk for anaphylaxis regarding school as a safe place in order to inform school policy around risk management and coping. Engaging children and understanding their experiences, concerns, and psychosocial stresses are important for policymakers responsible for the risk management measures in Ontario schools because it can assist in assessing the effectiveness and sustainability of such measures for those directly affected.

First, we found the use of child-centered techniques (i.e., illustrations) provided a window into how children perceived, felt, and coped in unsafe situations. Illustrations enabled children to better articulate their most salient risk factors and, similarly, the perceptions of risk that were embedded within different social and cultural environments. These findings confirm those of Driessnack[29] who used illustrations as a facilitative technique to encourage children to express and organize their thoughts and feelings. In asking children and adolescents to draw, explain, and then dialogue about living with anaphylaxis, the process enabled them to freely speak about their

experiences and expanded their power of expression. Our results, in line with recent results,[23] found that illustrations empowered children in a process that was meaningful and relevant to their lives and encouraged them to openly express their feelings about safe and unsafe places.

Second, these findings showed meaningful differences between children's and adolescents' perceptions and emotional responses to risky situations and how they coped. In such circumstances, younger children described feelings in less intense terms (e.g., feeling scared, annoyed, and unhappy) than adolescents and their illustrations depicted imaginary scenarios or abstract drawings of risk factors (e.g., unsafe food and unsafe events). Younger children coped by seeking parental support, which reflected the dominant role that parents played in allergy management of younger children.[68] Conversely, adolescents described more intense feelings (e.g., anxiety, stress, and fear) and their illustrations depicted real life experiences of them dealing with risk. For the most part, adolescents described their allergy in life and death terms, as being a "big deal," and for the most part were vigilant in managing risk (e.g., reading food labels, avoiding risky places, and preplanned exit strategies). These findings are in contrast to Akeson *et al.*,[3] who found that adolescents viewed anaphylaxis as "no big deal." These authors attributed this attitude to an inability to remember any severe reaction; only one of the 15 could remember having had an anaphylactic reaction, which is in contrast to 5 of the 10 adolescents in this study. In addition, a few adolescents felt overburdened emotionally; a space consuming energy and attention that had detrimental effects on coping strategies. Again, these results are in contrast to a range of studies that conclude that high levels of stress in families with a peanut-allergic child may be constructive and have beneficial effects on coping strategies.[4,61,69] In particular, Mandell *et al.*[69] found when perceptions of risk or inadequate management strategies led to heightened concerns about safety and emergency response, parents and children benefited from access to adequate support and information, which enabled them to develop constructive strategies.

Finally, bringing context into the analysis exposed a broader understanding of risk perception within a number of different domains (institutional, personal, and emotional). Understanding these domains and their underlying emotional factors provided a means to interpret the array of information that influenced the construction of risk. Weick[70] argues that individuals make sense of situations based on how they notice and select information from their environments. Moreover, individuals actively interact with their environment, which relocates risk to health within the self, creating the risky self.[71] These results demonstrate the crucial nature of understanding the specific conditions that shape perceptions of risk, which are embedded within different social environments.[72]

The limitations of this study include those inherent to qualitative study and those related to study sample. While this research may contribute to our understanding of the societal impacts of anaphylaxis in schools, its generalizability across cultural groups is limited given similarity of ethnic and socioeconomic groupings. The sample was relatively small, purposefully selected, and was not representative of the multiracial society in which we live. The sample was chosen from a database of people with life-threatening allergies living in Ontario; so, it is unknown how children from other geographic areas or cultural groups would respond. The sample was highly informed about food allergy as they were chosen from Anaphylaxis Canada—a nonprofit organization that provides information and support to people with anaphylaxis. Future research, therefore, needs to be carried out across cultural groups in order to investigate experiences of anaphylaxis cross-culturally, which would strengthen the validity of the theories and methods used in this study.

The findings have a number of implications for allergic children and risk management in schools. One of the most compelling implications for children and adolescents living with anaphylaxis is finding methods that can empower them in a process that is meaningful and relevant to their lives. The use of participatory research methods not only opens a space for children to freely express both the benefits and barriers of living with anaphylaxis, but also illuminates the commonalities and diversities of childhood as one phenomenon and anaphylaxis as another and how they relate and interact in different contexts and at different stages of life.[30] Moreover, social, emotional, and institutional factors are central to how individual children perceive and manage risk. These results provide a preliminary framework for understanding what risk means to children and highlights the differences in how they cope in the public sphere of school. Understanding these differences may well be the most effective way of informing educational and interventional efforts in responding to risk in schools. Finally, it is anticipated

that this research will advance our understanding of the societal impacts of anaphylaxis in schools and provide insights into how children and adolescents construct risk within their allergic environments.

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