

Disclosing food allergy status in schools: health-related stigma among school children in Ontario

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What is known about this topic

- Anaphylaxis is an emerging health risk with rising rates in North America.
- The primary management strategy for anaphylaxis is avoidance by modifying or limiting exposure to environments where allergens may be present.
- Previous studies report that people with allergies experience heightened levels of fear and risk in their everyday lives.

What this paper adds

- Sabrina's Law enhanced perceived safety for children, youth and parents vis-à-vis the school setting in Ontario.
- Unique social implications of disclosing allergies in schools suggests Sabrina's Law presents challenges for Ontario students.
- Students who reported their allergies experienced *enacted* (bullying, discrimination, physical threats/harm) and *felt* (feeling different, worrying about fitting in) stigma.

Abstract

In 2006, 3 years after the tragic death of 13-year-old Sabrina Shannon, the Province of Ontario (Canada) passed Sabrina's Law ushering in a new era of focus and concern for severe food allergic children at risk of anaphylaxis. Questions were raised at the time regarding the potential of doing more harm than good with the new legislation. This paper reports the experiences of health-related stigma among food allergic children at risk of anaphylaxis who were required to disclose their health status under this new legislation. In 2008, in-depth interviews were conducted with 20 children and youth and their parents in order to explore the experiences living with a severe food allergy. This particular study explores their experiences of *felt* and *enacted* stigma in the school setting as a result of the disclosure process. Interviews were tape recorded with permission and transcribed for subsequent thematic analysis using NVIVO, a qualitative analysis software package. Results indicate that participants were stigmatised as a result of protective school policies under the law, and that created tension between their physical safety and social well-being. Sabrina's Law also led to a cultural shift in awareness of food allergies that resulted in some participants normalising their health status, offering promising directions for the future.

Keywords: anaphylaxis, food allergy, health-related stigma, qualitative methods, social exclusion, youth

Introduction

Food allergies have been declared a newly emerging health risk (Harrington *et al.* 2011) and a 21st-century epidemic (Waggoner 2013). Those experiencing this *invisible* risk in Ontario, Canada, are required, under Sabrina's Law, to disclose their food allergies in order to mitigate risk in public settings; that is, you will not know how to deal with my (invisible) food allergy unless I disclose to you that I have one. For those with *visible* health conditions, disclosure is a moot point, but for those with a concealable health status (e.g. addiction, epilepsy, HIV/AIDS), the choice to disclose often results in public scrutiny and sometimes stigmatisation (Quinn & Chaudoir 2009, Scambler 2009, Keyes *et al.* 2010). Given recent literature on the rise of food allergies (Prescott & Allen 2011), stigmatisation may be extended to this newly emerging health risk.

While multiple conceptualisations of stigma exist (Elliott *et al.* 1982, Jones *et al.* 1984, Link & Phelan 2001, Weiss *et al.* 2006), the term is most often credited to Goffman (1963). He argues that an individual's social identity enables others to assess one and determine how one fits into the social world. This identity is analysed by the perceiver's assumptions and

expectations, which are both largely reflective of the social norms of the time. When expectations are not met, the identity is negative, problematic or spoiled, and the individual is subsequently stigmatised as abnormal and inferior.

Stigma is a process either enacted (experienced) or anticipated (felt) that involves labelling, stereotyping, exclusion, discrimination and status loss (Link & Phelan 2001, Scambler 2009). Individuals may *internalise* stigma by identifying with the negative labelling or stereotyping, or experience the exclusionary and discriminatory effects of stigma enacted *interpersonally* or *structurally* (Link & Phelan 2006, Stuber *et al.* 2006, Hatzenbuehler 2009). Subsequently, experiences of stigma can shape life chances, such as employment, housing and well-being (Link & Phelan 2001), while others suggest stigma (and associated exclusion) are important determinants of population health (Davey-Smith *et al.* 2001, Reidpath *et al.* 2005).

The link between health status and stigma gained momentum in the 1980s with research on people with epilepsy (Schneider & Conrad 1981, Scambler & Hopkins 1986). In these studies, those with epilepsy were discredited because of their health status and not only experienced overt discrimination (*enacted stigma*) but also reported feelings of shame and fear over being discriminated against (*felt stigma*) (Scambler & Hopkins 1986). Health-related stigma has been reported for various other health outcomes including infectious diseases such as HIV/AIDS (Herek & Glunt 1988, Parker & Aggleton 2003, Nyblade 2006), mental health problems (Link *et al.* 1997, Sayce 2000, Moses 2010), alcoholism (Link *et al.* 1997, Keyes *et al.* 2010) and 'deviant' bodies such as the case with obesity (Gard & Wright 2005, Longhurst 2005, Campos *et al.* 2006, Curtis 2008) or physical disability (Fine & Asch 1988, Dear *et al.* 1997, Wilton 2003).

For individuals with invisible health outcomes, the *decision* to disclose health status is a contentious one. For instance, Schneider and Conrad (1983) found that in order to cope with the negative social implications of their health status, people with epilepsy would: (i) downplay or hide their epilepsy unless absolutely necessary to disclose; (ii) conceal their health status in any possible way to avoid exposing their social unacceptability; and/or (iii) advertise their health status as way to educate others and avoid negative judgement. Similar approaches to concealing health status have been reported for other invisible health outcomes (e.g. HIV/AIDS, mental problems, developmental disabilities) in order to prevent anticipated stigma (Quinn & Chaudoir 2009, Chaudoir *et al.* 2011, Francis 2012). The aim of this paper was to investigate, through this exploratory study, health-related

stigma among food allergic elementary and secondary school children (aged 8–12) and youth (aged 13–18) at risk of anaphylaxis in the Province of Ontario who are subject to Sabrina's Law and therefore have disclosed their health status to authorities in the interests of protecting their physical health.

Living with food allergies

In the US, prevalence of food allergy (e.g. to peanuts, tree nuts, shellfish, sesame) in youth is estimated to be around 6% (Sampson 2004, Branum & Lukacs 2008), and approximately 7% in Canada (Ben-Shoshan *et al.* 2010), yet perceived food allergy rates are considerably higher (Harrington *et al.* 2012). As such, anaphylaxis has been acknowledged as an emerging health risk among research, clinical and lay populations (Yu *et al.* 2006, Sicherer & Sampson 2007, Harrington *et al.* 2011). Waggoner (2013) argued that the alarmist concern over food allergies in the general population combined with the increasing surveillance and diagnoses of food allergies by the medical community have co-produced the food allergy 'epidemic' to its current controversial state.

In this climate of heightened concern, individuals with severe food allergies are considered at risk in public environments (Fenton *et al.* 2011, Stjerna *et al.* 2013) where contact with potential allergens can either directly – or through cross-contamination – be unpredictable. Most allergic individuals cope by avoiding the allergen, often through modification of the local environment (e.g. removing peanuts from the home), or limiting exposure to environments where the allergen may be present (e.g. avoiding certain restaurants, events) (Pitchforth *et al.* 2011, Barnett *et al.* 2013, Fenton *et al.* 2013). Consequently, allergic individuals limit their spatial and social contact in order to protect their physical safety and well-being.

Within the Province of Ontario in Canada, children, youth and families in the school system are certainly familiar with the severity of food allergies and potential management strategies. In 2003, 13-year-old Sabrina Shannon died from cross-contamination of food products in her school cafeteria causing a fatal allergic reaction. Three years later, the first piece of legislation in the world was implemented to safeguard other anaphylactic students in the Province of Ontario. Sabrina's mother, Sara, was a strong advocate for the legislation and continues to be a strong advocate for allergic children and youth at risk of anaphylaxis in the Province of Ontario; she tells her own story of exclusion in Box 1. The signing of Sabrina's Law ensures that schools create appropriate management and emergency plans for food allergic

Box 1 Understanding life with anaphylaxis: a mother's perspective

Social isolation from anaphylaxis can be lonely. We all want to fit in. It is a human need. Yet much of the world, particularly family and social events, revolves around food. One cannot escape food. It is the foci of most gatherings. We need food to live.

My daughter, Sabrina loved people and loved socialising. I used to call her my social butterfly. Even Sabrina however faced social isolation as a child. Looking back, I see parallels between racial segregation in the 1950s and children like Sabrina with anaphylaxis growing up 10–20 years ago. During school meals, Sabrina was instructed to sit alone away from all her classmates at a table well removed from other students. Sabrina was also often excluded from activities and birthday parties because of her food allergies. Despite showing a brave front and positive attitude, I believe that this exclusion at a tender age was hard for her.

The simple good gesture at school of handing out baked goods in a classroom can create a very difficult situation for a food allergic child. Such individuals feel singled out when this happens. They are either explicitly excluded or must choose not to participate in this human gesture of sharing. The only other choice is life-threatening for a food allergic child.

Sabrina had an anaphylactic friend who played on a basketball team. She could not join a big celebratory dinner because the coach would not accommodate her need by selecting a safe restaurant. The team spent the evening celebrating in a restaurant with peanut shells crunching under their feet, while Sabrina's friend, a key member of team, sat home alone watching TV.

Sabrina and I won a trip in the mid-1990s to Disney Land. Even though we both really wanted to go, I decided against it because of the risk. There just was not a way back then to ensure a safe trip. Awareness of anaphylaxis was lacking at the time and I was concerned whether I could ensure it would be a safe trip for her.

Sara Shannon, mother of Sabrina Shannon (1990–2003), personal communication, January 2012.

children of all ages. Specifically, the law requires that all school boards implement an anaphylaxis policy that includes staff training on how to deal with anaphylactic allergic reactions, develop individual plans for students with anaphylactic allergies and designate emergency procedures in the event of a severe allergic reaction.

To date, much of the research into allergies is of a clinical nature focusing on prevalence, aetiology, management and treatments (such as immunotherapy). However, there is a growing body of literature on the lived experiences of food allergies among adults, parents and children, which include explorations of coping strategies (Mandell *et al.* 2005, Akeson *et al.* 2007, Nettleton *et al.* 2009, Pitchforth *et al.* 2011, Fenton *et al.* 2013), experiences of risk (Sampson *et al.* 2006, Gillespie *et al.* 2007, Monks *et al.* 2010, Fenton *et al.* 2011, Stjerna *et al.* 2013) and sociocultural understandings of food allergies (Lauritzen 2004, Rous & Hunt 2004, Nettleton *et al.* 2009, McNicol & Weaver 2013, Waggoner 2013). These studies have found that allergic individuals experience heightened levels of fear and risk in their everyday lives, feel socially isolated from peers and family members, and anticipate anxiety in public spaces and social settings. These studies further highlight that parents play a crucial role in protecting the safety of their children by changing their food purchasing and preparation practices, scrutinising food labels and ingredient lists for food consumed outside the home, limiting exposure to unsafe environments (e.g. birthday parties, airplanes), encouraging presence of emergency epinephrine injectors and ensuring common environments, like schools and extended family members' home are safe (e.g. allergen-free or at least

allergen controlled) (Mandell *et al.* 2005, Barnett *et al.* 2013, Stjerna *et al.* 2013).

Within this literature, it has been found that as they enter adolescence, youth take over many of these responsibilities from their parents but are less vigilant about maintaining allergen-free environments and report greater risk-taking behaviour (Mandell *et al.* 2005, Monks *et al.* 2010, Fenton *et al.* 2013). Further, this literature acknowledges that the effects of individual food allergies have negative implications for parents and other family members (Lauritzen 2004, Mandell *et al.* 2005). Despite these insights into life with a food allergy, there are still gaps in our understanding of the social implications of this health status. Waggoner (2013) calls for more research examining potential stigma faced by the food allergic population given the evolution of the allergy epidemic, particularly in relation to peanuts.

A growing body of literature has noted that exclusionary and discriminatory practices exist for food allergic school children and youth. For instance, in a study of 353 parents of food allergic children and youth in the USA, 24% reported that their children had been bullied due to the allergy (50% of those in grades 7–10) and this occurred in the school setting 82% of the time (Lieberman *et al.* 2010). In the majority of those cases (57%), the bullying was physical with perpetrators touching, waving or throwing the allergen or intentionally contaminating food with the allergen (Lieberman *et al.* 2010). Follow-up studies with children and youth reported that school was still the predominant site for bullying related to food allergies and that this bullying had negatively influenced quality of life and

increased feelings of distress for both children and parents (Shemesh *et al.* 2013).

Only recently have studies begun to examine negative social consequences, including stigma, associated with food allergies (Nettleton *et al.* 2010, Pitchforth *et al.* 2011, McNicol & Weaver 2013). For example, Pitchforth *et al.* (2011) conducted a qualitative study of UK children and parents with a confirmed nut allergy in order to understand the experiences of living with a food allergy for both parties. All participants in their study stated that the food allergy diagnoses in the child resulted in a new less desirable identity. Parents described experiences of *felt stigma* (e.g. feeling shame about delayed diagnosis) and *enacted stigma* (e.g. being called neurotic or 'faddy'; being exposed to negative comments, jokes) as a result of their child's allergy. Children too experienced *enacted stigma* when they could not take part in school activities and were teased for their allergy.

While there is an emerging body of literature that has examined experiences of living with food allergies and the associated negative social consequences (e.g. increased fear, social isolation, bullying), there is little research exploring the experiences of health-related stigma among the food allergic population (see exception – Pitchforth *et al.* 2011). In this exploratory study, we examine the health-related stigma of food allergic children at risk of anaphylaxis who are differentiated from their peers after being required to disclose their food allergy in the school setting.

Methods

This study employed in-depth interviews with food allergic children and youth at risk of anaphylaxis and their parents in an attempt to understand the lived experience of a severe food allergy. Participants were recruited from a national non-profit patient advocacy organisation that supports anaphylactic individuals and families. This organisation has worked with our research team on multiple occasions assisting with recruitment for food allergy studies. Initial contact with potential participants was made by the research team through newsletter announcements, direct e-mails and targeted e-bulletins through the non-profit organisation. Information was provided such that if any families were interested in participating, they would contact the research team directly. Thus, the research team at no time had access to mailing or membership lists. If interested, a parent would contact the research lead and express interest. The research lead would provide more detail and answer any questions. If the parent agreed to participate,

signed letters of consent (parent) and assent (child/youth) were obtained at the time of the interview.

In total, 10 children (aged 8–12) and 10 youth (aged 13–17) who attended school in Ontario, along with their parents, took part in the study. The sampling strategy focused on maximum variation with equal number of male and female participants from various geographical regions across the province (Patton 2002).

In-depth interviews took place in 2008, approximately 2 years after Sabrina's Law was promulgated. This study focuses on the passing of Sabrina's Law in 2006 and the experiences of children and youth at risk for anaphylaxis after the legislation was passed. As such, the relevance of data collected in 2008 is high in relation to the enactment of school-level policies that were initiated by legislation passed 2 years before. Interviews took place in participants' homes and parents and children/youth were interviewed alone ($n = 18$) except in two cases where both parent and child ($n = 1$) and youth ($n = 1$) were interviewed together at their request. In three cases, mothers and fathers took part in a joint interview, while the other parent interviews were with mothers exclusively ($n = 17$). Interviews were semi-structured and questions focused on the initial diagnoses of anaphylaxis, what it is like to live with/have a child with severe food allergies, and experiences of various physical environments (e.g. school, home) in relation to anaphylaxis. In addition to the interview, children and youth were asked to draw a picture of what living with a food allergy was like, which served as a facilitative technique to encourage children to reflect freely upon their experiences (Amsden & VanWynsberghe 2005, Santo *et al.* 2010) and generated important sources of data (for discussion of illustrative results, see Fenton *et al.* 2011, 2013).

The interviews lasted between 60 and 120 minutes and were audio recorded and transcribed verbatim. Analysis was first conducted inductively by identifying key experiences of living with a food allergy using thematic analysis based on grounded theory (Charmaz 2006). Three broad themes emerged from the data, including risk-taking behaviour, and coping strategies, which have been published elsewhere (Fenton *et al.* 2011, 2013). The third theme that emerged from the interviews was social exclusion and stigma; indeed, it was such a major outcome from the interview data, it was decided to focus this paper on this one particular theme, linking it to the emerging literature on health-related stigma. For this theme, all original transcripts were recoded using a codebook based on the health-related stigma and social exclusion literature discussed above through

deductive thematic analysis (Crabtree & Miller 1999). Parent and child/youth interviews were analysed separately and subsequently compared for a comprehensive view of stigma among allergic school-aged children. Due to small sample size and joint interviews, there was no comparative analysis between mothers and fathers. Coding was facilitated using NVIVO, a qualitative software package.

Rigour in this qualitative study was maintained using a range of techniques. All interviews were conducted by a single researcher to enhance reliability and validity. Further, inter- and intra-rater reliability was assessed using a second coder on the qualitative transcripts. Agreement exceeded 75% in both cases. Member checking was used to assess the credibility of the transcript data (Baxter & Eyles 1997). This study was approved by the McMaster University Research Ethics Board.

Findings

Of the 20 interviews conducted, most participants were allergic to multiple foods (65%), while 35% of participants were allergic to only one. Most were allergic to peanuts (>60%) followed by tree nuts (e.g. almonds, hazelnuts, cashews), sesame, shellfish (e.g. crab, lobster shrimp, clams), dairy and fish, and a few had other significant health issues (e.g. blood disorders).

Within the overall theme of health-related stigma, four sub-themes emerged; these are discussed below and accompanied by direct quotes from participants to elucidate key concepts. While these themes will be discussed individually, they intersect and interact with one another to create the daily reality for food allergic children at risk of anaphylaxis, and their parents.

Disclosure

As reported earlier, food allergies are an invisible health status and can be concealed in several arena areas of an individual's life; however, in the case of school-aged children, the disclosure process is a necessary (and legislated) step in order to maintain their safety. The specific practices and policies for implementing Sabrina's Law vary by school board and school, although essential to all is that the affected children declare their health status. Thus, students (predominantly their parents) must reveal the specifics of their allergy so that at-risk students can be identified, planned for and physically protected.

Upon revealing their invisible health status, students were 'outed' and marked as different both on an interpersonal level with their peers and structur-

ally through the implementation of protective policies. The policies and practices included identifying food allergic individuals through posting pictures in the classroom or school bus, 'marking' food allergic students through medical safety devices [e.g. medical-alert bracelet, auto-injector (Epi-pen) with carrying pouch], isolating food allergic students in separate rooms or cafeterias for lunch periods, excluding allergic students from group celebrations or events involving allergic foods, and separating food allergic students from their peers through differential treatment.

All student participants reported that once they were 'outed' as being food allergic, they faced some form of exclusionary or discriminatory treatment which was rationalised as: (i) precautionary – generally when conducted by a teacher or administrator; or (ii) mean-spirited – generally in the case of treatment from peers (other students). In essence, teachers were seen as simply implementing the well-intentioned (although problematic) protective policies on a structural level, while peers used the food allergic student's 'spoiled' identity to ostracise or exclude them on an interpersonal level. Analysis of the interview data revealed that while all participants reported experiencing some form of negative and exclusionary treatment as a result of the disclosure requirement in the school setting, the dominant discourse around those experiences was viewed differently by participants, either as stigmatising or normalising.

Stigmatisation

Many students and parents (75%) reported negative implications resulting from the process of having to disclose their health status. We categorise reports of stigma as either *enacted* (i.e. overt discrimination and differentiation) or *felt* (i.e. internalised feelings of shame, fear or worry about future discrimination).

In terms of *enacted stigma*, previous research shows that food allergic children experience teasing, bullying, discrimination, and physical threats and harm in the school setting as a result of their health status (Lieberman *et al.* 2010, Shemesh *et al.* 2013). Children and youth participants in this study shared similar stories of being threatened with a food allergic substance as a means of exclusion:

They didn't want me to join their group, so they picked on my allergy to get me to go away. They were water sliding down the hill and I asked if I could play, and they said 'No, we put peanut oil on the water slide'. And they told me that I couldn't come over and play and I didn't think that was very funny at all... that was pretty mean. It is

more like ostracising, kids were excluding me. (Morgan – youth)

In my class, they actually had a peanut butter sandwich, and he actually like stuck it in my face, and like the waft of the peanut butter, it was just like up my nose. I guess when you smell that, I just feel nauseous right away because I know like it is so nauseating to me. I think it is gross. (Lauren – youth)

Such examples represent extreme cases of stigma and discrimination. However, it was often the more subtle forms of discrimination that were reported as troublesome to participants. For instance, in separating allergic youth from allergic substances, the former were sent away and isolated from their peers (e.g. eating in separate rooms, leaving the classroom). Participants often interpreted this process as unfair punishment:

Well [students were eating peanuts in class], I felt really unsafe... [the teacher] really didn't care about it, 'Yeah, go sit in the hall'. They are the ones opening the peanut butter, but then I am the one being punished and having to miss class. Sometimes I don't think it is fair. (Ashley – child)

In most cases, especially among younger participants, this physical separation of allergic students from others was initiated by school officials. Yet, among older participants who were attending high school with loosely enforced policies, this was not always the case. Older participants reported leaving the classroom against teachers' wishes because an allergic substance was being consumed in the classroom. Parents felt that if safety could not be guaranteed, their allergic children could not be included in a given activity such as overnight school trips (often not a mandatory requirement for students but an important milestone both developmentally and socially). Such examples were predominantly interpreted by youth as unfair, careless and prioritising the status quo (e.g. the needs of hungry students) over the well-being of those with life-threatening food allergies.

Felt stigma was less commonly reported by youth in this study. Rather, several of the young participants were predominantly concerned about what would physically happen if a reaction were to occur: 'It's really, really painful', 'I won't be able to breathe' and 'I could die'. It was the older participants and parents who expressed concerns over the social implications of their health. In several cases, youth stated that they worried about how their health status would impact their friends and therefore, themselves:

... I kind of stay with my friends so that I can interact and all that. I don't want to go away for like a minute, and

wash my hands and then come back... I have to keep going back and forth [between friends and bathroom to wash hands], and I don't want to keep doing that, because then they are going to be like, 'What are you doing?' (Thomas – child)

Older allergic youth did not want their status to limit their participation in activities or make them appear as different from their peer group. Moreover, they did not want their daily practices for feeling safe (e.g. frequent hand washing to avoid cross-contamination) to be a reminder of their difference.

Parents in this study more frequently discussed fear over how health status would influence their child socially, especially about the potential *felt stigma* their child would face:

[Fitting in and making friends] has also been kind of a fear of ours. It is hard enough with social groups and bullying and all kinds of things at school. You don't really need to give them another piece of ammunition. Here is how she is different. (Angela – parent)

In many cases, parents' anticipation of both enacted and felt stigma was greater than the reports of stigma shared by children in the interview. This was due in large part to the normalisation process discussed by many participants.

Normalisation

There was a shift in perspective between older and younger youth (and their parents) about the meaning of being food allergic. While the older participants more often reported that their health status was a 'big deal' because 'I could die from it', or it limits their day-to-day activities, many of the younger participants were quick to minimise its status, relating it to 'like a diet' or 'a kind of lifestyle'. Younger participants shared that outsiders were very accommodating and that they had other friends in similar circumstances:

There are lots of people on my street [with an allergy]. One of my best friends has a peanut allergy, and in my grade there are probably five people, and there is one in my class. There are three in another class. Well most of them are my friends, so I can always talk to them, and stuff, and if I go to my friend's house, then I always know that everything is safe in there. Well, we both kind of have the same ideas, like whenever we go to a restaurant, we ask the same questions, and we always do the same things. (Leah – child)

Some had normalised their experiences with a food allergy and shared that they felt others (peer group members, teachers, coaches) had also accepted their allergy and made adjustments accordingly. This may be attributed to the growing acceptance and

understanding of food allergies in current society initiated in the schools as one parent highlights:

Sabrina's Law definitely [has made a difference]. More awareness, unfortunately more incidents of it, so that is why there is more awareness... (Suzanne – parent)

It was both the (apparent) growing incidence of food allergies and the increasing awareness of food allergies (via Sabrina's Law) that allowed some participants to feel a sense of belonging and normalcy.

Perhaps the biggest benefit associated with Sabrina's Law is the shift in awareness for a cohort of children and their parents. Awareness is considered an important step to accommodation and acceptance, which in turn may reduce social exclusion. This process was most evident when talking to youth about what it is like to live with a food allergy and noting the difference between the older youth who attended school prior to the passing of the law and those who had grown up in the era of protective food allergic policies.

Tension and disclosure

Prior to Sabrina's Law, the process of disclosing a child's allergy was often the responsibility of parents who would give information to those in direct contact with their children (e.g. teachers, principal). Once Sabrina's Law came into effect, the disclosure process became standardised and multiple others in the school became aware of a child's allergy in order to meet the legislated guidelines.

For parent participants in this research, perspectives on this protective legislation were mixed. A small minority reported that food allergy policies were already in place at the school prior to the passing of Sabrina's Law and thus the law did not change much, but the vast majority felt that the law was crucial for making schools safer spaces for food allergic children:

I think absolutely we need the law. It gives us a push back place as parents of anaphylactic kids. So when you do get the parent who says, 'My kid can eat peanut butter if they want to', it is 'actually they can't'. Full stop... It depersonalises it, so it is not about [us] against the school. It is the law. Just like you don't smoke at my kid's school, you don't eat peanuts. That is the end of the story. (Michelle – parent)

In addition, many parents felt that the policies did not go far enough to protect at-risk youth, citing that high school policies were far more lenient than elementary school, and that children with peanut and nut allergies were more protected through school policies than youth with other food allergies (e.g. dairy, sesame). A handful of participants were unaware of the law, though they stated that more definitive

protective policies in the school setting could put them more at ease in terms of safety of their children. Overwhelmingly, parents expressed positive benefits for the physical well-being of their child.

On a social level, however, the disclosure process did subject some allergic youth to the labelling, isolating, discriminating and excluding effects of stigma. Both parents and youth in this study reported that while they felt school was a safe place to be as a food allergic individual, they wished that they would not receive any extra attention or specialised treatment because of their health status, which would ultimately differentiate them from their peers.

For those younger participants who felt a sense of belonging to the 'food allergic group' of students, this (social) safety-in-numbers is brought on by the apparent normalisation of food allergies in Ontario schools. For many older participants and those who reported both *felt* and *enacted stigma* due to their health status, the disclosure process was fraught with tension. Sharing their health status to the school board under the requirements of Sabrina's Law meant their physical safety was protected at the expense of their social well-being. A better understanding of the individual and contextual factors that fuelled the normalisation process for some participants is a promising step forward to enhancing the physical and social well-being of food allergic children and youth at risk of anaphylaxis.

Discussion and conclusion

The introduction of Sabrina's Law – to physically safeguard students with a serious health condition – was largely achieved according to participants in this study. However, social implications of *how* this law was operationalised in the school setting were far less positive. While the intent of the legislation was to create a safe environment inclusive for allergic youth, the results of this study show that some of the practices and policies implemented to ensure safety (e.g. removing allergic students from the classroom, posting pictures of allergic students) resulted in youth feeling stigmatised. Moreover, it highlighted the tension between balancing physical safety with social well-being in a system that often finds the two mutually exclusive due to the disclosure process.

These findings reiterate the difficulty that disclosure presents to individuals with invisible or concealable health conditions (e.g. HIV) given the risk of stigma via physical harm, isolation, labelling, exclusion and/or discrimination (Ogden & Nyblade 2005, Chadoir *et al.* 2011). While children, youth and their parents described the interpersonal and structural

stigma they faced in school settings as a result of their health status, these were instigated by the requirements of legislative guidelines that depend on this disclosure process.

On the other hand, a major benefit associated with Sabrina's Law is the cultural shift in awareness for a cohort of children and their parents. While Waggoner (2013) argued that food allergy prevalence (and its often cited status as *epidemic*) may be an exaggerated product of research and medical attention combined with increased societal awareness, anaphylaxis is a very real and serious condition for the participants in this study. We argue that the increased awareness via policies like Sabrina's Law can have beneficial effects for the allergic population, including knowledge and awareness among school personnel. This was evidenced when participants reported their health condition to be 'no big deal' and felt a sense of normalcy. Awareness is considered an important step towards accommodation and acceptance, which in turn may reduce further exclusion and stigma of these groups in the future. While this was an exploratory, cross-sectional study, we acknowledge the need for longitudinal and/or pre-post policy studies to validate these findings.

Our findings echo that of other research focusing on stigma for individuals with health conditions, specifically that exclusionary practices and discrimination are experienced in settings with peers, family, teachers and members of society at large (Puhl & Brownell 2006, Moses 2010, Hinton & Kirk 2014). Our study also sheds new light on the experiences of health-related stigma for children and youth with life-threatening food allergies, something that has been well documented in support groups/associations for those directly affected by allergies but not acknowledged in the academic literature. Very little attention has been paid to the issue of stigma among anaphylactic children and youth in the research literature (for an exception, see Pitchforth *et al.* 2011, on nut allergic families in the UK).

Research suggests that social exclusion and stigma can exacerbate existing health issues as well as contribute to other physical ailments with stress being the primary mechanism (Kurzban & Leary 2001, MacDonald & Leary 2005, Link & Phelan 2006, Stuber *et al.* 2006, Hatzenbuehler 2009). Again this is particularly concerning for young people given the rise of teen suicide in Canada and elsewhere, largely from exclusionary practices such as bullying (Kim & Leventhal 2008, Hindujah & Patchin 2010). The consequences of stigma and exclusion are magnified in youth because they are at a psychologically and sociologically formative time in their life (Papalia *et al.* 2004).

During these formative years, health-related stigma and the subsequent social exclusion can be especially problematic because it can deter individuals from engaging in health-seeking behaviour (Reidpath *et al.* 2005, Weiss *et al.* 2006). Indeed, past research has shown that anaphylactic youth are much more likely to put themselves at risk by ignoring food labels that suggest allergens may be present, or entering unsafe spaces without their epinephrine injection in an effort to fit in with their peer group (Gowland 2001, Sampson *et al.* 2006, Fenton *et al.* 2011, 2013). The importance of social connection and interaction for children and youth is well documented (Papalia *et al.* 2004), and is no less significant for allergic youth, although some of the routes they take to be included can put their lives in jeopardy.

This study is not without its limitations; qualitative research – by definition – is characterised by small sample sizes, and there is always the need to go beyond the exploratory work possible under these circumstances. Ongoing work by the research team related to vulnerable populations and the big questions associated with food allergy (What's causing it? Is it increasing? Can we develop a cure?) continues (see <http://www.allergen-nce.ca/>). In the mean time, this research has provided a glimpse of the stigma associated with this growing chronic disease.

Those populations experiencing health-related stigma face double jeopardy; subjected to negative social experiences resulting from their health status, the stigma experienced subsequently puts their health further at risk. Food allergy risk is increasing on a global scale and in order to pave the way for a more accepting policy environment, future research must continue to deconstruct the socio-cultural-political elements of the lived experiences of individuals and families affected by anaphylactic food allergies.

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