

When to Disclose? The Impact of Anaphylactic Food Allergies on  
Identity and Interpersonal Relationships

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### **Abstract**

This study focuses on the under researched social implications of anaphylactic food allergies in the communication discipline. Research explored how the disclosure of anaphylactic food allergies, identity, and interpersonal relationships impact one another through 10 in-person interviews with individuals diagnosed with anaphylactic food allergies. Drawing from existing scholarship in the realms of food allergies, stigma, communication identity theory (CTI), and the Disclosure Decision Making Model (DD-MM), several key themes emerged. Identity impacts were varied among participants; however, data revealed that identity was fluid and flexible, influenced by context, and changed over time. Relational impacts saw disclosure decisions greatly affected by relevance and proximity factors with specific implications depending on whether relationships were platonic or romantic. In platonic relationships, proximity played a role in who participants disclosed their allergy to with relevance impacting when in relationships an allergy was disclosed. Romantic relationships were found to be more impacted by the disclosure of an anaphylactic allergy with disclosure occurring earlier in relationships due to increased risk and required lifestyle changes by romantic partners. Tensions between disclosure, identity, and interpersonal relationships were also explored in the form of unwanted attention versus awareness and downplaying severity of an allergy versus medical reality. Ultimately, this study contributes new knowledge for understanding the management and negotiation of stigmatized identities in the form of anaphylactic food allergies.

*Keywords:* anaphylactic food allergies, disclosure, identity, interpersonal relationships, stigma, stigmatized identities, CTI, DD-MM

## Chapter 1: Literature Review and Rationale

### Introduction

It is estimated that 5% of adults and 8% of children in the United States are diagnosed with food allergies, which amounts to roughly 30 million Americans, a number that is only continuing to rise (Cannon, 2018). This growing population of individuals face evolving challenges as they navigate their lives through the lens of food. Sometimes the most difficult part about having a food allergy is not food itself, but the social implications of having an allergy. Going out to eat with friends, parties and social events, shared dining areas, catered meals, and even flying in an airplane are all instances where food allergies, especially anaphylactic food allergies, must be considered. Anaphylaxis is an allergic reaction so severe that it can cause death due to respiratory failure and cardiovascular collapse, if not treated with an injection of epinephrine, usually in the form of a prescribed EpiPen (Cianferoni & Muraro, 2012). This potentially fatal outcome makes food allergies an ever-present stressor that is not only a concern during meals but also when those nearby choose to eat, which is often uncontrollable. Because of this, those with food allergies must constantly navigate social interactions surrounding their food allergy and must make difficult decisions about when, where, and how to tell others about their allergy in order to stay safe while maintaining social relationships and positive face.

These dilemmas are something I know all too well. When I was 16 months old, I was diagnosed with an anaphylactic peanut allergy. Due to a faulty immune response with no clear causality, if I eat or even touch peanuts, my throat will close, and I could die if not treated. Because of this risk, I carry around two EpiPens and have trained friends and family on how to administer the injection and what to do if I start having an allergic reaction. Growing up with such a severe allergy, I learned from a young age that I had to advocate for myself and

communicate my allergy to others in order to stay safe. This included going to the nurse when I got hives, not sharing food with classmates, and educating my peers so that they would not accidentally expose me to peanuts, or if I was, they would be able to help me. Because my peanut allergy is so severe, I not only have to manage it through my diet, but I also have to manage the actions and responses of people around me. Having an invisible health issue like a food allergy requires the disclosure of the allergy with certain responses being more desirable than others. I've come to realize that so much of how I think about the world, how I interact with people, and how I view my identity is intertwined with my allergy and how I communicate it.

Prior research on food allergies has mainly focused on medical science (Cianferoni & Muraro, 2012, Cannon, 2018), societal and cultural impacts (Johnson & Woodgate, 2017), and public policy (Dean, Fenton, Shannon, Elliott, & Clarke, 2016), failing to consider implications for the management of interpersonal relationships and identity. This project will fill this gap in research and explore food allergies from a communication standpoint, examining anaphylactic food allergies as a stigmatized identity and exploring disclosure events in order to understand the impact of anaphylactic food allergies on an individual's identity and interpersonal relationships through participant interviews.

### **Concealable Stigmatized Identities and Food Allergies**

An important aspect of anaphylactic allergies to consider as it relates to identity, relationships, and communication is their invisibility or concealability. Anaphylactic food allergies are a concealable stigmatized identity which necessitate disclosure events because they are not inherently visible or knowable by looking at someone. According to Chaudoir and Fisher (2010), concealable stigmatized identities are comprised of socially devalued personal information which is not readily apparent, and which requires the disclosure of information to

others. Stigmatized identities are identities that harbor negative social connotations and can include alcoholism, disabilities, and sexual orientation (Chaudoir & Fisher, 2010). Stigma is a process that can be experienced or felt and may involve labelling, stereotyping, exclusion, discrimination and/or status loss (Dean et al., 2016). I place anaphylactic food allergies in this same arena in order to acknowledge the potential negative social connotations of allergies which can impact how individuals manage their identity and how/when they choose to disclose it (Choi et al., 2016, Greene, Magsamen-Conrad, & Venetis, 2012, Omarzu, 2000, Chaudoir & Fisher, 2010). The decision to disclose an invisible health status is contentious because stigma and health status can be linked. In the case of food allergies, this has mainly been observed in the school setting where a student may be forced and legally obligated to disclose their health status in order to protect their safety (Dean et al., 2016).

The school setting has been an extremely important area of focus for prior research because it not only functions as an institutional organizational setting with implications for policies, but also as a social setting during the formative years of an individual's life (Dean et al., 2016, Fong, Katelaris, & Wainstein, 2017, Johnson & Woodgate, 2017). With food allergies and their severity on the rise, many schools in the United States have had to adjust their policies in order to accommodate severely allergic students; these include the creation of allergen free tables monitored by school staff and the enforcement of allergen-free classrooms to ensure students (especially younger ones) do not accidentally come into contact with their allergen (Dean et al. 2016). The negative result of this, however, can be that students are singled out from their peers and given an "other" status which may result in stigmatization that likely would not have been assigned to them without the forced disclosure of their allergy (Dean et al., 2016). This tension between health and safety versus the potential for stigmatization then complicates the decision to

disclose.

Otherness can also occur due to the responsibility individuals have to take for their health (Johnson & Woodgate, 2017). Johnson and Woodgate (2017) found that teens with anaphylactic allergies are required to be more responsible for their health but are subjected to rules and policies in schools that create a reliance on adults and peers for support. This means that teens with anaphylactic food allergies may feel othered both internally based on their perceptions of the responsibility they have as compared to their peers and externally due to the ways that rules, policies, and adults treat them in the school environment (Johnson & Woodgate, 2017). In these instances where concealing an allergy/health status is not a viable option, individuals may attempt to protect themselves from stigmatization by advertising themselves as an educational tool or downplaying the severity of their health status (Dean et al., 2016). Because school years are formative and act as a training ground for future communication skills related to allergy disclosure, it is important to consider how health status management, disclosure management, and the subsequent outcomes can impact students with food allergies as they learn to manage stigma and how this carries on into adulthood. This examination of the school setting and the broader social interactions and trends taking place within this environment begs the question: How does the management of a stigmatized identity, like anaphylactic food allergies, impact the individual and their personal experiences?

In adults, social situations that involved eating out can be a source of anxiety and embarrassment for individuals with severe food allergies (Leftwich et al., 2010). Despite the increased risk of an allergic reaction posed by eating outside of the home, many participants in the Leftwich et al. (2010) study reported that they often engaged in increased risk taking to avoid the embarrassment of disclosing their allergy in situations where they would be perceived as

“causing a fuss” or “drawing unwanted attention to themselves” (p. 247). Some participants described their willingness to risk an allergic reaction rather than publicly identify themselves as having an allergy in order to avoid such unwanted attention (Leftwich et al., 2010). This demonstrates that physical danger and negative health impacts may be overwritten by the fear of social embarrassment and potential stigma which that continues outside of the school setting and into adulthood; however, disclosure does not always result in an entirely negative response.

Aside from physical health and safety, other positive outcomes can occur. Disclosure events may provide an opportunity to express ideas and emotions, help develop a positive sense of self, and build intimacy in relationships which may help reduce anxiety and fear surrounding the allergy (Chaudoir & Fisher, 2010). Yet the risk of harmful outcomes such as social stratification through othered status, negative perceptions of self, and the general fear of drawing unwanted attention, remains (Fong et al., 2017, Leftwich et al., 2010). This artificial divide between physical and mental health and the potential for stigmatization can create conflict and internal struggle among those living with anaphylactic allergies who must face and manage several tensions connected to their allergy and their identity (Johnson & Woodgate, 2017). These tensions can include physical/medical health vs. mental health, social acceptance vs. stigma, risk management vs. self-isolation, and spontaneity vs. anxiety and fear. The management of these tensions and the stigmatized identity status not only impacts the individual with the anaphylactic food allergy, but also impacts their interpersonal relationships and the ways in which they communicate their allergy.

### **Disability Classification, Stigmatization, and Identity**

The stigmatization of food allergies is particularly contentious in the debate over the classification of allergies as a disability. In 2008, amendments to the Americans with Disabilities

Act (ADA) officially added severe dietary restrictions and food allergies as disabilities under U.S. law (Mustard, 2015). This legal delineation has allowed for the protection and accommodation of those with anaphylactic food allergies, as in the case of beneficial school policies discussed previously. However, it has also brought complicated implications for those that may not have previously considered their health status a disability.

The legal classification and labeling of anaphylactic allergies as a disability can contribute to feelings of marginalization and otherness, and force those who may not have self-identified as having a disability to reassess how this label plays into their identity and other people's perceptions of them (Bandini, 2015). Because the term disability does not have one salient definition, and is in part socially/culturally constructed, medically defined, and legally regulated, it is possible for a person with a disability to not recognize themselves as such and for those with a disability to not be recognized by others (Grue, 2016). In a broader sense, disability is not a label that is associated with a single form of illness or impairment that is physically identifiable, and instead more powerfully denotes the social structures and marginalization associated with disabled individuals (Grue, 2016). For a concealable stigmatized identity like food allergies that already harbors its own stigma, it is understandable that some individuals may not wish to categorize themselves within the broader label of disability which brings its own unique stigma and broader association to a variety of groups (i.e. deaf, blind, mentally handicapped, etc.) (Grue, 2016). With such groups varying widely in their physical and/or mental manifestations, qualifiers, and challenges (i.e. deafness vs. blindness), individuals may choose instead to focus on their illness or impairment-specific category, a common occurrence among those labeled generally as disabled (Grue, 2016). This then leads to the importance of self and group identification as it relates stigma and identity negotiation under the disability label

(Grue, 2016).

Nario-Redmond, Noel, and Fern (2013) found that those with a high degree of group identification with their disability category are more likely to use collective/group coping strategies such as community pride, challenging stigma, and striving for social change to improve the status of the group. Whereas those less identified with their disability are more likely to take steps to minimize or conceal their disability, which are considered individualistic coping strategies (Nario-Redmond et al., 2013). In surveying individuals with both visible and less apparent disabilities, including those with physical, sensory, learning, and psychiatric disabilities, Nario-Redmond et al. (2013) found disability identification to be a strong predictor of collective self-esteem. However, the strategy of “working to overcome one’s difficulties” and “valuing one’s disability experience” also emerged as significant predictors of personal self-esteem (Nario-Redmond et al., 2013, p. 480). In the case of anaphylactic food allergies, group identification may be lower due their non-visible nature, thus resulting in more individualistic coping strategies, i.e. minimizing and concealing, which could predict lowered self-esteem, especially when using the concealing strategy (Nario-Redmond et al., 2013). However, depending on the individual’s use of the “working to overcome one’s difficulties” and “valuing one’s disability experience” strategies, this self-esteem predictor for those with anaphylactic allergies may differ (Nario-Redmond et al., 2013, p. 480).

Overall, when considering how the disability label may factor into the negotiation and enactment of identity within the food allergy community, these predictors of self-esteem as discussed by Nario-Redmond et al. (2013) and the tethering of an individual’s identity to assumptions about the disability label, including stigmatization as discussed by Grue (2016), are valuable to consider. This interplay between identity, disability, stigma, and self-esteem also

leads to further questions on how specifically identity is negotiated through communication and the ways in which such challenging disclosure decisions are made for those with anaphylactic allergies.

### **Allergy Communication, Identity, and CTI**

One such lens that can be used to examine identity negotiation and creation is the communication theory of identity (CTI). Drawing from social identity theory (Hogg, 1993) and identity theory (Schlenker, 1985), CTI conceptualizes identity and communication as a reciprocal process wherein communication helps “build, sustain, and modify one’s identity” (Hecht & Choi, 2012, p. 139). This perspective integrates community, communication, social relationships, and self-concepts into the co-creation and maintenance of identity (Hecht & Choi, 2012). With the concepts of social relationships, self-concepts (i.e. self-esteem and negative perceptions of self), and community (i.e. bullying and/or ingroup/outgroup status) established as key aspects in the discussion of anaphylactic allergies and their communication, this makes CTI a relevant framework for the conceptualization of identity within this study (Hecht & Choi, 2012). Under this framework, identity is continuously negotiated and co-created through the interpenetration of the four layers of identity: personal, enacted, relational, and communal, which can be used to examine different aspects of identity within this study in the context of anaphylactic food allergies (Hecht et al., 2005).

The personal layer of identity refers to feelings or concepts about the self, including self-image, self-cognitions, and self-esteem (Hecht & Choi, 2012). These feelings and concepts of the self can be applied to an individual’s conceptualization of their health status as recommended by Hecht and Choi (2012) and are relevant to understanding how those with anaphylactic allergies view themselves in relation to their allergy. The enacted layer refers to the expression or outward

performance of identity (Hecht & Choi, 2012). In the context of anaphylactic food allergies, the enacted layer is especially relevant to the discussion of disclosure and the ways an allergy is communicated and performed and what impact this has on an individual's identity (i.e. does the communication of an allergy as a minimal issue relate to feelings of the allergy having little bearing on the individual's identity?). In the relational layer, identity is viewed as jointly negotiation and formed in relationships through three aspects: the modification of identity based on views of others, in identifying through/in light of relationships with others, and through social roles as a unit of identity (Hecht & Choi, 2012). The relational layer provides an intriguing overlap between the central themes of this study: identity and interpersonal relationships, helping to tie these two concepts together and providing a conceptual framework to understand how these two themes may be integrated within this communication-based research of anaphylactic food allergies. Lastly, the communal layer of identity that refers to the ways in which group membership and the collective or community to which an individual belongs contributes to identity (Hecht & Choi, 2012). This final layer of identity within the CTI framework joins together the concepts of disability identity negotiation/labeling, stigma, and ingroup/outgroup status related to anaphylactic food allergies as discussed by Grue (2016) and Nario-Redmond et al. (2013), and relates them to identity and the ways group membership may impact interpretations of identity within this study.

Although CTI has previously been used to discuss race, ethnicity, and gender, Hecht et al. (2005) have advocated for the usefulness of applying CTI to illness/health related identity negotiation, making it even more relevant in the discussion of anaphylactic food allergies. Because identity is continuously built, sustained, and modified through communication, the discussion of disclosure events, labeling, stigma, and even interpersonal relationships, involve all

four layers of identity outlined by CTI. Thus, making CTI key to examining the impact of anaphylactic food allergies on identity as well as helping to understand the interplay between identity and relationships as outlined above (Hecht et al., 2005).

### **Allergy Communication and Disclosure**

With an understanding of how identity is negotiated through communication and recognizing the relevance of disclosure events in the study of anaphylactic food allergies, it is pertinent to consider how individuals decide to disclose. Prior health and stigma related research (Choi et al., 2016, Greene, Magsamen-Conrad, & Venetis, 2012, Omarzu, 2000, Chaudoir & Fisher, 2010) has analyzed the complex risk assessments conducted by individuals with a stigmatized identity through the Disclosure Decision Making Model (DD-MM). DD-MM has identified three factors that individuals assess when considering whether they will disclose information to another person (Greene et al., 2012). This includes an assessment of the information they are considering disclosing, aspects about the potential receiver of the information, and the perceived disclosure efficacy (Greene et al., 2012). When assessing the receiver of the information, individuals will weigh their relationship quality (how close and comfortable they are with the other person), the anticipated reaction as it relates to provision of support and relational consequences, and the discloser's confidence that the receiver will respond in the way they anticipated (Greene et al., 2012). Thus, those who perceive the information they may disclose as relevant (i.e. sharing an allergy while at a restaurant), the receiver as someone they are comfortable with and believe will respond in a supportive manner, and who believe that the receiver will understand the information (i.e. the food allergy) are more likely to disclose (Greene et al., 2012).

In the application of DD-MM to stigmatized nonvisible illness disclosure, Choi et al. (2016) conducted two studies expanding on Greene's model of DD-MM to include post-decision consideration of disclosure planning including stigma and intimacy of information. Study 1 comprised of 204 individuals with nonvisible physical and mental health conditions who reported on disclosure of their condition (Choi et al., 2016). Study 2 was comprised of 283 dyads with individuals bringing with them a person that they had previously shared personal information with, equaling 566 individuals (Choi et al., 2016). The dyads were then asked to complete a survey based on a time personal information was shared between them with one partner returning for a second survey (Choi et al., 2016). At the conclusion of the survey, Choi et al. (2016) found that when individuals perceive the disclosure information as more stigmatized, they are less confident in revealing that information. They found that those who feel more confident in revealing the stigmatized information are less likely to plan the disclosure event, and that people predict positive responses from receivers they are close with and are more likely to disclose personal information to people they are close with (Choi et al., 2016). Choi et al. (2016) also found that disclosing stigmatized information related to a nonvisible health status can lead to higher individual risks like identity threats.

Prior research by Greene et al. (2012) that also applied DD-MM to nonvisible illness disclosure as in the case of Choi et al. (2016) and surveyed 183 individuals with serious/significant nonvisible illnesses comparing models for the prediction of decision making based on whether or not the illness had been disclosed. Greene et al. (2012) found that the models were able to be modified with variables specific to health diagnosis disclosure decisions with participants with undisclosed information perceived as more severe and relevant anticipating more negative outcomes. However, higher relational quality positively predicting

confidence in response, anticipated response, and efficacy in the undisclosed model (Greene et al. 2012). A disclosure response with the desired outcome, or disclosure efficacy, also positively predicted the likelihood of future disclosures of the information and those who can more confidently anticipate outcomes are more likely to feel confident in the response of the other person (Greene et al. 2012). These complicated variables relating to health/illness disclosure in the disclosure decision making process provide a framework for understanding how individuals may navigate a nonvisible illness such as anaphylactic allergies, especially when considering the impact of stigma related to identity as aforementioned (Nario-Redmond et al., 2013, Grue, 2016, Chaudoir & Fisher, 2010, Dean et al., 2016). Therefore, DD-MM is not only useful in its understanding of how individuals choose to disclose private information, but it also has direct implications for understanding the interplay between stigma, stigmatized identity disclosure, illness/health status disclosure, identity negotiation, and the maintenance of interpersonal relationships, making it extremely valuable for understanding anaphylactic food allergies in these contexts previously discussed.

### **Rationale**

Based on the review of literature, anaphylactic allergies have been studied in contexts related to medical science, societal implications, and public policy. While some research has touched on more personal issues such as bullying, these studies have focused on the school setting and related more to public policy changes for schools rather than to the individuals with the allergy themselves. In considering anaphylactic allergies as a stigmatized identity, specifically a nonvisible illness or health status, this study has been able to draw upon other areas of research including disability classification/labeling and stigmatization, ingroup vs. outgroup status and predictors for self-esteem, the four aspects of communication identity theory (personal, enacted,

relational, and communal), and the disclosure decision making model in relation to nonvisible illnesses. Prior research has indicated that disclosure outcomes have the potential to be positive and/or negative with a multitude of factors influencing this distribution. These concepts can now be applied directly towards the disclosure of anaphylactic food allergies and their impact on identity and interpersonal relationships, leading to the research questions of this study:

- 1) How do identity and the disclosure of anaphylactic allergies impact one another?
- 2) How do interpersonal relationships and the disclosure of anaphylactic food allergies impact one another?
- 3) How are interpersonal relationships and identity managed during the disclosure of anaphylactic food allergies?

## Chapter 2: Methods

### Participants

Interviews were conducted with 10 adults (18 years and older) with anaphylactic food allergies providing data for this study. Snowball sampling was used as a method for the initial identification of participants and later as an aspect of social media recruitment. Snowball sampling began with individuals in my network that I knew had food allergies whom I asked to participate in the study. Those individuals were then asked to identify other people they knew with food allergies that may be interested in the study, and so on. Four participants were gathered using this method of recruitment and the other six participants were found using social media posts made via Facebook. Posts were made on my personal Facebook page and on the private Facebook page “CU Class of 2020” to which I had access. Snowball sampling also occurred at this juncture, with individuals sharing my original post with friends and family members resulting in two of the six social media participants finding out about the study indirectly and not from my initial posts.

Of the 10 participants, six were female and four were male. Nine of the 10 participants were 18-24 years old who all developed their allergies as children ranging from infancy to approximately eight years old. Of these nine participants, seven were college students, one was an 18-year-old high school student, and one was a young adult approximately 24 years old. The outlying participant was a middle-aged female with adult onset allergies. This skewed demographic distribution was not created by design, but rather due to the individual’s I had access to within my network and the availability of potential study participants. All participants had anaphylactic allergies with nine of the 10 participants anaphylactically allergic to multiple allergens. Tree nuts were the most common allergen with seven of the participants having allergies to one or more tree nut. Six participants were allergic to peanuts. Two participants were

allergic to fish excluding shellfish. Three participants had unique allergies that only they had which included Sulfa drugs, peas, and mangoes. Lastly, six participants had other non-anaphylactic allergies which included environmental allergies, coconuts, carrots, and several other uncommon allergens.

### **Procedure**

Once willing participants were identified, a time and place for a one-on-one interview was scheduled. All interviews were conducted over the period of two months, with participants being interviewed a single time which lasted between 20-60 minutes in length. Interviews were conducted in person by me, with eight taking place in private library study rooms and two taking place at the homes of participants. The interviews were guided by an interview schedule (see Appendix C) with follow up and probing questions asked at appropriate junctures. All interviews were audio-recorded, stored on a password protected laptop, and converted into transcripts for data analysis using a transcription software. Audio recordings and transcripts were deidentified through the removal of participant names and assignment of a participant number in the order interviews were conducted. All identifying information was changed or redacted to protect the privacy of participants.

Prior to each interview, the participants were asked to read through a printed-out IRB approved consent form that I explained verbally to them (see Appendix B). Participants then had time to ask questions and any concerns were addressed. The participants and I then signed and dated the consent form and the interview started. All consent forms were coded using the same method for the transcripts, using numbers in the order the interviews were conducted so that if necessary, the consent form could be linked to the corresponding interview data. The hardcopy consent forms were kept in a locked filing cabinet.

## **Data Analysis**

Upon the completion of the interviews and their subsequent transcription, data analysis began using a phronetic iterative approach or an analysis that alternated “between considering existing theories and research questions ... and emergent qualitative data” (Tracy, 2020, p. 211). Transcripts were printed out and a primary cycle of coding initially examined the data for themes relating to disclosure, relationships, and identity with reoccurring words or phrases being highlighted in the transcript and coded. A code book was created that was edited, expanded on, and synthesized throughout the data analysis process (Tracy, 2020, p. 211).

In the next phase of coding, a secondary cycle of coding was undertaken, new themes emerged and the data was color-coded appropriately, these themes included the general categories of romantic relationships, platonic relationships, disclosure events, identity (including stigma), medical and health references/impacts, adaptability/learning from past experiences, and cultural differences (which included references to travel). Notes were taken on themes that emerged from these coded categories with each transcript containing individually recorded themes and a compilation of general themes/codes that reoccurred among all or a portion of the interviews noted in the codebook. These codes were then considered in relation to CTI and DD-MM along with the research questions of the study, with the most frequent and relevant codes converted into a new set of categories prompting another secondary cycle of coding. The transcript data was then reanalyzed, and coding continued until no new findings were identified and saturation was reached.

This method allowed for the emergence of patterns and themes which related to the overall purpose of this study: examining the impact of anaphylactic allergies on interpersonal

relationships and identity in relation to disclosure events. These patterns and themes that were uncovered will be explored further in the following sections.

## Chapter 3: Findings

### Identity Impacts

This study found that the impact anaphylactic allergies had on identity was complicated and varied across individuals due to a variety of factors. It is important to note that within the context of this study, identifying as a person with an anaphylactic allergy and considering one's allergy as a part of their identity are two different things. All participants in the study identify as individuals with anaphylactic allergies, but not all of them consider their allergy to be a part of their identity. Findings within this section will solely focus on the impact allergies have on the identities of participants rather than their allergy identification.

Within the study, four participants (1, 2, 8 & 9) viewed their anaphylactic allergy as part of their identity with participants 1, 8, and 9 describing it as a small or passive part of their identity that was not always at the forefront. On the other hand, six participants (3, 4, 5, 6, 7, & 10) did not consider their allergy to be part of their identity and instead described its relation to them in varying terms such as: a part of who they are, something they have to deal with, something that effects their actions, or a restriction. These results demonstrate the extremely personal and variable nature of identity, with each participant reporting notably different answers to questions about their allergy as it related to identity and the connection they see to themselves; however, one theme did arise that was similar across all participants, the *fluid and flexible* nature of identity.

**Fluid and Flexible Nature of Identity.** The fluid and flexible nature of identity refers to the way in which identity can ebb and flow, becoming more or less prominent as different facets of identity become more relevant and on display. This means facets of identity are not rigid and can become more or less important over the course of one's life; change over time; and be added

or lost. Within this theme two categories can be used to describe this recurring theme: *context* and *change over time*.

*Context* arose as an important factor in how participants viewed their allergy in relation to identity. A majority of participants discussed the importance of certain situations that can bring their allergy identifier into the forefront of their minds and self-presentation as discussed by Participant 8:

... I don't think it's like the forefront of my identity, I think it does become so right after an allergy attack. Or when there's a lot of food around especially, as soon as there's peanut butter in the room, I'm like, oh, peanuts, I'm allergic. (P8, line 313-316)

For the majority of participants, their allergy and the way it impacts them personally or how they present themselves as an allergic person is neither stagnant nor constant. Instances like an allergic reaction, contact with food, changes in routine (including travel), trying new foods, and even interacting with new people may cause their allergy to become more prominent in relation to their identity or self-presentation in a disclosure scenario. This factor may also play a role in why not all participants viewed their allergy as part of their identity along with the possibility of differing ideas/understandings of identity itself. For example, Participant 4 reported "... my identity is more defined by the values I hold, than my... biology" (P4, lines 218-219) whereas Participant 7 described their identity components as "...something I go around like, projecting and putting on my sleeve" (P7, line 99-100).

*Change over time* was also a significant factor in the fluidity and flexibility of identity with several participants describing the ways in which their allergy had a bigger impact on them as a child in school and/or when they were adjusting to managing their allergy. Participant 10

described this change over time when discussing how he felt more defined by his allergy as a kid and being asked to elaborate on that change:

“As people grow up, I think people care less about something like that. I think in elementary school in particular, like kids become identified pretty quickly... people get identified into these social norms very quickly... I was, at least my first or second year there... the nut allergy kid because everybody was aware of it...” (P10, lines 448-454)

For the nine participants who developed their allergies as children, they all discussed the ways in which their allergy presentation and identification changed as they matured. Describing how being children who were getting used to managing their allergies was very different from dealing with the issue as adults in the present day. A majority of participants described their allergy as being a more prominent identifier as a child and related to the forced or unintentional disclosure of their allergy by the school they were in which occurred in a variety of ways including: having a separate allergen-free lunch table, receiving a different snack than their peers, or having their allergy disclosed to classmates by a teacher. This change over time was also reflected in the one participant with adult-onset allergies, Participant 6 who responded to the question “Do you feel like your food allergy is a part of who you are?” (OC, line 161) with:

It definitely has dictated- now it feels like it doesn't, right, like it's normal routine. I know exactly what to buy. I know exactly what to look for quickly on a label and know how to, but it definitely defined me for a good year and a half, two years of trying to figure out how to maneuver. (P6, line 157-160)

For all participants, the way their allergy impacted their identity, regardless of whether or not they considered their allergy as part of their identity, was fluid and flexible, highly dependent on context, and likely to change over time. These findings for identity and self-presentation then

lead into the ways allergies are disclosed to others and the way this impacts interpersonal relationships.

### **Relational Impacts**

This study found that anaphylactic allergies can have a significant impact on interpersonal relationships but the ways they impact these relationships tends to be dependent on the specific type of relationship. Responses from participants in this study differed depending on whether the relationships in question was platonic or romantic; however, two key factors, relevance and proximity, were identified as significantly impacting disclosure and the role that anaphylactic allergies play in these relationships across both categories.

**Relevance and Proximity Factors.** In the interviews conducted in this study, all participants in varying ways, reported the same two factors which help them determine whether or not to disclose their anaphylactic allergy to someone: *relevance* and *proximity*. In terms of relevance, this is exemplified in the statement by Participant 5 when asked if she tells people about her allergy early on in friendships:

I think more just when it comes up. I don't usually volunteer it. But not, you know, it's just doesn't necessarily seem relevant right away, and when it becomes relevant or comes up, I'll share it..." (P5, line 87-89)

This statement was echoed by all the participants in varying forms with all referencing the presence of food as a key component of relevance. This included situations of eating out, eating at someone's house, eating on a date, going to an event or function where food was present, or being in spaces where other people were eating.

Other components of relevance were related to medical necessity usually again in the context of food, as well as travel and changes in daily routine. Medical necessity was usually

brought up as the potential need for a friend, acquaintance, or romantic partner to intervene in an anaphylactic allergic reaction by either calling 911/alerting the appropriate responders or administering an EpiPen injection in the event the allergic individual was unable to do so themselves.

Potential exposure to an allergen was also a component of medical necessity as it related to physical contact, usually in the context of romantic relationships. Travel was referenced as a condition that would increase the need for disclosure of an anaphylactic allergy due to exposure to new foods, changes in support systems, potential cultural factors (such as the lack of understanding of allergies), and changes in medical infrastructure/emergency services.

Changes in routine were also referenced in a similar context to travel but with a lesser degree of danger and uncertainty usually referring to trying new foods, eating at a new location (including someone's house), and starting a new job or going to a new school where individuals were not aware of the allergy. All of these factors acted as reasons why participants would feel the need to disclose their allergy to someone and were linked to the other disclosure factor of proximity.

For most participants, proximity was brought up as some form of relational closeness as exemplified by the statement from Participant 2 when asked what prompts him to tell someone about his allergy:

I think it more has to do with someone else's proximity to me, relationship wise. So if I'm going to see somebody more often I'm making a friend or somebody in class, I usually just try and slip it into conversation. (Participant 2, line 102-104)

Other participants described similar scenarios where those physically closest and relationally closest to them were guaranteed to know about their allergy due to both necessity

and a desire for increased intimacy. Allergy disclosure was described as being both the cause and effect of relational proximity. As individuals became closer and more intimate in a relationship, there was a greater desire to share their allergy status with the other person or persons. At the same time, increased intimacy was created by the disclosure event itself – which also increased relational proximity. However, this was not true regarding necessity in proximity considerations – in instances where allergy disclosure occurred purely as an effect of necessity. An example of this is the need to disclose an allergy when someone is physically and relationally close to an allergic person. This related to relevance as those individuals whose relational proximity was higher were more likely to be involved in contexts that were relevant for allergy considerations as described above. Thus, relationships deemed proximally close combined with a relevant context saw an increase in the need for disclosure and the need for disclosure earlier on in relationships. This was true in both platonic and romantic relationships, however, some key findings between these two relational groups differed.

**Platonic Relationships.** For platonic relationships, relational proximity was connected to who participants said were aware of the allergy whereas relevance factors were tied to the point at which participants said they disclosed their allergy. All ten participants said that their close friends knew about their anaphylactic allergy and discussed how more casual friends or acquaintances were less likely to know about their allergy unless a relevant scenario that required them to disclose it had occurred. This is illustrated in the statement from Participant 10 when asked if all his friends and close acquaintances knew about his allergy:

Most of them do just because it's come up in casual situations, it's not anything I feel the need to have a sit-down talk with, it's more so, like if we're out to dinner or again, like at an event it's like, "Hey, I can't eat that." And so most of them have picked up on it by

now. I also have a pretty tight knit group. So I have a difference between like my close friends and then my casual friends. I couldn't tell you if my casual friends know they might just from being around me, but like my close-knit circle does. (P10, lines 164-169)

All participants discussed how they usually wait for a relevant situation to occur before telling friends or acquaintances about their allergy so that the disclosure was more organic. A majority of participants also reported that they didn't believe their allergy greatly impacted their platonic relationships but did admit that it could impact social activities like eating out. Despite these statements, several responses from participants did indicate positive relational implications – such as increased feelings of security and safety, increased intimacy, and kinder regard towards friends/acquaintances who were cognizant of their allergy and accommodated it.

Increased feelings of security and safety were largely related to the belief that friends would be competent in an emergency situation and be able to help the allergic person if they were to have an anaphylactic reaction. Participants 2 and 8 also reported a general desire for their friends to know about their allergies in order to limit potential accidental contact with their allergen. In general, platonic relationships were not reported as being negatively impacted by the disclosure of an anaphylactic allergy and initial disclosure events were largely dependent on relevance with proximity factors influencing who was likely to be disclosed to but not necessarily the time of disclosure.

**Romantic Relationships.** Unlike platonic relationships, 7 out of 10 participants reported romantic relationships as being more impacted by their anaphylactic allergy/allergies. These disclosure outcomes were more likely to be negative or detrimental to the relationship because of the increased risk for exposure to an allergen from physical contact with a romantic partner resulting in added stress as in the case of Participant 3:

I had a boyfriend who ate some nuts and I didn't know and I had to use [my EpiPen] I was terrified... It freaked him out and we broke up, most likely because of that. It just probably just, like, traumatized him too much. (P3, line 14-15 and 25-26)

Disclosure of an anaphylactic allergy was also deemed as more necessary earlier on in the romantic relationship than with platonic relationships by 7 of the 10 participants because of the physical component of these relationships (i.e. kissing), the tendency for romantic dates to take place over food, and the overall lifestyle adaptations required to accommodate the health of the allergic individual. The same seven participants specifically discussed the dangers of kissing as an impact anaphylactic allergies can have on romantic relationships citing instances where they themselves experienced a mild to severe allergic reaction(s) due to someone kissing them, having heard stories of people going to the hospital due to a romantic encounter, or were generally warned about the potential for an allergic reaction due to kissing.

Participants also discussed some of the lifestyle adaptations romantic partners must implement which can include changing dietary habits, washing hands more frequently, brushing teeth after meals, potentially limiting physical contact, and generally being more cognizant and aware of what they eat during a given day. In general participants affirmed that their romantic relationships are/can be greatly impacted by their anaphylactic allergy due to added risks and the necessity for romantic partners to implement lifestyle changes represented by the statement from Participant 5:

...that's probably one of the bigger impacts is a romantic relationship. Just because there is that more physical interaction that could be deadly. (P5, line 228-230)

In considering the disclosure event, the same seven participants specifically discussed the need to disclose their allergy earlier on in romantic relationships, with both *relevance* and

*proximity factors* being higher than with platonic relationships. Participants 1 and 3 also discussed how the outcome and reaction of the potential romantic partner to the disclosure of their allergy was a pivotal moment that could determine whether or not to continue pursuing the relationship unlike platonic relationships where no such pivotal moment was identified by any of the participants.

### **Tensions**

The final themes that arose from the analysis of participant interviews were tensions summarized as: *unwanted attention versus awareness* and *downplaying severity versus medical reality* which generally occurred sequentially and combined aspects from both identity and interpersonal relationship findings.

**Unwanted Attention versus Awareness.** A majority of participants brought up the issue of unwanted attention. Participants described a desire to minimize the amount of attention they received because of their allergy, reporting that they didn't want to "draw positive or negative attention" (P1, line 153) or "make a big deal" (P5, line 169) of their allergy which could result in avoiding disclosure of their allergy. However, this desire conflicted with a need for those around them to be aware of their allergy for their safety, creating tension surrounding disclosure situations. In these situations, like going out to eat, riding in an airplane, being served a catered meal, and even meeting new people, participants inadvertently indicated that this tension impacted their disclosure decision making process when asked if they had ever purposely avoided telling someone about their allergy as in the case of Participant 5:

I may have not brought it up in certain situations just because it feels awkward and like not, not comfortable... because then you know, it draws attention to yourself and you have to be accommodated. (P5, line 93-95)

This then connects to the following tension, *downplaying severity versus medical reality* which is another factor for allergic individuals to analyze during their disclosure decision making process.

**Downplaying Severity versus Medical Reality.** This tension was usually reported following or connected to the prior tension. After navigating unwanted attention versus the need for allergy awareness, if the participant decided to go ahead with disclosing their allergy, they then had to contend with the tension between a desire to downplay the severity of their allergy versus the medical reality. In some instances, this may also be seen as a more connected/intertwined (rather than sequential) component to unwanted attention and awareness as disclosure can still occur in instances where an allergic individual attempts to avoid unwanted attention by downplaying the severity of their allergy. Examples of this from participants included limiting the number of people in a situation they disclose to, utilizing humor to diffuse the situation, and describing their allergy as less severe.

When asked about their reactions to specific disclosure scenarios which included talking to new roommates, restaurant staff, or family members who dismissed their allergy, participants expressed their desire to not be seen as a “pain in the butt” (P1, line 109) or “high maintenance” (P6, line 57). To avoid these potentially negative perceptions participants described an inclination to not bother other people with their allergy unless completely necessary which conflicts with their medical reality. All participants described their allergies as being severe and life threatening with eight of the ten able to remember recent anaphylactic allergies that required some form of medical intervention. Despite these recent memories, most participants reported hesitation to initially disclose their allergy with such strong terms. It was often the case for platonic relationships that the full severity of an allergy was not elaborated on unless the initial

disclosure was ineffective and did not produce the desired results, as in the case of Participant 2 and his college roommates:

I told the three guys immediately, one who had already lived with me so he was very aware. And the two, other two who weren't, those two guys for the first couple months were pretty decent about it. But I'd say about halfway through the year either forgot or just stopped caring... But eventually, what happened was, I'm like, "Look guys, I'll be better about my stuff, but this is kind of a life or death situation." And once I said life or death it changed a lot for them. (P2, lines 152-160)

Initially, Participant 2's disclosure and description of his allergy was not effective at modifying the behavior of his roommates which required him to further elaborate on his allergy and remind them of the severity and medical reality of his allergy. Other participants echoed this tension describing similar scenarios in which they were required to elaborate on the severity of their allergy, explaining medical and health details in order for the disclosure outcome to align with their intended purpose and produce the appropriate response. As expected, participant interviews revealed numerous relational and identity implications for the management and disclosure of anaphylactic food allergies.

## Chapter 4: Discussion

### Summary of Findings

In summary, responses to participant interviews attended to the research questions in varying ways. The research questions were as follows:

- 1) How do identity and the disclosure of anaphylactic allergies impact one another?
- 2) How do interpersonal relationships and the disclosure of anaphylactic food allergies impact one another?
- 3) How are interpersonal relationships and identity managed during the disclosure of anaphylactic food allergies?

Research question one was addressed through the discussion of the fluid and flexible nature of identity which included themes of context and change over time. Participants revealed that the way they view and present their identity in terms of their anaphylactic allergies has evolved as they matured and became accustomed to managing their allergies. The role of context was discussed with participants describing how their allergies could be brought to the forefront of their identity or self-presentation in a disclosure event when in situations involving food, following an allergic reaction, and when experiencing changes to their routine (including travel). However, participants had differing opinions on the ways their anaphylactic allergies impact their identity and generally different ideas/understandings of identity as a concept. More research is likely needed to fully understand the relationship between identity and the disclosure of anaphylactic food allergies.

Research question two was more thoroughly attended to as the interconnected nature of interpersonal relationships and the disclosure of anaphylactic food allergies was discussed. The themes of relevance and proximity exemplified the complex connection between the disclosure

of anaphylactic allergies and interpersonal relationships. This study found that these impacts were dependent on whether relationships were platonic or romantic. Platonic relationships saw less of an impact with proximity and relevance as key factors for the likelihood of who the allergy was disclosed to and at what point in the relationship. Romantic relationships saw a greater relational impact from the disclosure of anaphylactic allergies with the disclosure outcome more likely to be negative/play a more important role in relationships compared to platonic relationships, along with a greater need for earlier disclosures.

The final research question was attended to by all three components of the findings: identity impacts (the fluid and flexible nature of identity), relational impacts (proximity and relevance as factors in disclosure), and tensions (unwanted attention versus awareness and downplaying severity versus medical reality). These findings revealed that identity and relationships are constantly being managed through the timing, context, and method of disclosure. The tensions section also explicitly responded to the third research question by describing how identity and interpersonal relationships are managed through the navigation of said tensions. All three research questions were also further addressed in the discussion of tensions, which combined the impacts of both identity and relationship in the disclosure decision making process of participants.

### **Connection to Prior Research**

This study positioned anaphylactic food allergies as a concealable stigmatized identity with participant interviews supporting this initial assertion (Chaudoir & Fisher, 2010; Choi et al., 2016; Dean et al., 2016; Greene et. al., 2012; and Omarzu, 2000). Findings revealed the importance of disclosure to the understanding of anaphylactic food allergies due to their concealable nature. Topics of stigma also arose including bullying (Dean et al., 2016), otherness

(Johnson & Woodgate, 2017), and negative social connotations (Chaudoir & Fisher, 2010) with similar language being used by participants to describe these topics as seen in prior research.

The themes of tension in this study's findings – unwanted attention versus awareness and downplaying severity versus medical reality – directly connected and supported the tensions discussed by Dean et. al. (2016) who initially discussed the behaviors of downplaying the severity of a health status and using one's health status as an educational tool (i.e. discussions of medical reality). Additionally, the findings related to tensions, connected to the research of Leftwich et al. (2010) who discussed risk taking as a behavior to avoid “drawing unwanted attention,” which was supported by the findings of this study that independently identified unwanted attention versus awareness as a recurring tension among participants (p. 247). This study provides further insight into these tensions within the focused context of identity and interpersonal relationships while also supporting preexisting research and behaviors associated with the food allergy community.

Disability status was another concept from prior research that appeared in the interview process. Some participants identified disability status as a label associated with stigma, aligning with findings from Grue (2016) and Nario-Redmond et al. (2013); however, none of these participants identified as being disabled. Participants specifically described how it was beneficial to have allergies as a legally acknowledged/protected disability but did not consider them a socially constructed disability. No further insight regarding disability status or group identification (Nario-Redmond et al., 2013) was gleaned from this study.

One of the major components of this study was identity and identity implications which lead to the discussion of the communication theory of identity (CTI), coined by Hecht et al. (2005). Because an inductive approach was used for the examination of data, identity themes

developed with considerations and an understanding of identity from CTI in mind but did not explicitly use the theory to inform the findings, instead letting themes arise independently. However, several of the four layers from CTI – personal, enacted, relational, and communal – were addressed (Hecht et al., 2005).

Participant discussions of their differing conceptualization of identity and their identity components relates to the personal/internalized layer of identity (Hecht et al., 2005). The enacted layer related to the disclosure of anaphylactic food allergies and the tensions experienced by participants as they managed the communication and performance of their allergy identity component (Hecht et al., 2005). The relational layer was also touched on by considering the role of interpersonal relationships in identity and providing an overlap between the two concepts in the tension discussion (Hecht et al., 2005). Despite a lack of acknowledgement in the findings, the communal layer of identity was also slightly addressed by a few of the participants who mentioned self-identification with other allergic individuals and with other individuals who share dietary restrictions (i.e. vegan and gluten free), but not enough data was collected concerning this layer to draw any conclusions (Hecht et al., 2005). CTI was also generally referenced as framework for understanding the fluid and flexible nature of identity, drawing on CTI's assertion that identity is multifaceted and co-created/maintained (Hecht & Choi, 2012). The findings of this study and the connection to CTI, support the Hecht et al.'s (2005) assertion that CTI would be useful to apply to illness/health related identity negotiation.

Lastly, the Disclosure Decision Making Model (DD-MM) was used to conceptualize disclosure events within this study, but again was not explicitly used to inform the data analysis or subsequent findings (Greene et al., 2012). Prior research by Greene et al. (2012) established decisions to disclose private information involved the assessment of three factors - information,

receiver, and disclosure efficacy - with Choi et al. (2016) expanding on this by including stigma and intimacy factors into the decision-making process. Data from this study, specifically the theme of proximity in the findings of relational impacts, supports the Greene et al. (2012) and Choi et al. (2016) results that individuals are more likely to disclose personal information to people they are close to and predict positive responses to these disclosures. Greene et. al. (2012) also found that the relevance of information played an important role in the likelihood a person will disclose private information which was also supported by the independently arising theme of relevance in this study. Overall, this study supports components of DD-MM and further provides a rationale for the continued application of DD-MM to illness and health status disclosure decisions and to anaphylactic food allergies specifically.

### **Limitations**

Two main limitations in this study were a lack of demographic diversity among participants and a small sample size. Because the methods of recruitment consisted of snowball sampling within my network and social media posts, participants were gathered either from my personal connections and/or came from a similar background as me (i.e. young adults, college educated). Nine of the ten participants are categorized as young adults who were diagnosed with their allergies as children and who were either college students (7 participants), recently graduated (1 participant), or about to attend college (1 participant). Additionally, limitations existed in the number of participants that were interviewed due to the method of recruitment that was used which restricted the pool of individuals who fit the study's criteria, and the time constraints of this project. Because of these factors, the data in this study is not entirely representative of the anaphylactic food allergy community. Future scholarship may choose to expand on these findings by conducting interviews on a larger number of participants with a wider age

distribution and diverse demographic factors in order to capture a broader set of lived experiences.

Another limitation was the participants' differing conceptualizations of identity. As discussed previously, participants had varying ideas and understandings of identity which led to a variety of answers concerning the impact of their anaphylactic food allergy. Interviews were conducted in a semi-structured manner and while follow-up and probing questions were asked in order to ascertain these differences in conceptualization, I had generally not anticipated so much variation and was not able to pivot and solely focus interview questions on the topic of identity. With such a complex topic, it may have been pertinent to ask more focused questions on participants' general conceptualization of identity and then proceeded with more in-depth questions about the impact of their anaphylactic food allergy. This may have been more effectively achieved by conducting two separate interviews for each participant, one focusing on identity and the other on interpersonal relationships.

Lastly, one of the main components of this study was the role that the disclosure of an anaphylactic allergy played in identity and interpersonal relationships; however, because the data collection method was interview based, descriptions of disclosure events were all discussed from memory or as hypothetical situations which are subjective and can be distorted. These descriptions of disclosure events were also one sided and did not consider the perspectives of the other individuals involved in such events. The study may have benefited from interviewing individuals platonically and romantically involved with the participants of this study to further understand the impact of anaphylactic allergies and their disclosure on interpersonal relationships. Future research may benefit from conducting a larger scope of interviews which

include both sides of disclosure events and/or by using a method of data collection that would allow for the witnessing of disclosure events firsthand, such as ethnographic research.

### **Future Research**

In addition to those areas of limitation mentioned above, several other topics arose during the interview process that would warrant further attention. Multiple participants brought up travel and cultural differences as situations that posed unique challenges to the management of their anaphylactic food allergies. Such challenges included having to adapt communication to different languages and/or cultural understandings of allergies as well as differences in cuisine. While travel was a factor discussed in relation to the topics of this project, not enough data was collected to make any additional claims regarding allergy disclosure while traveling internationally nor the impact intercultural communication had on disclosure events. These aspects may prove interesting to explore further.

Interviews also highlighted specific habits and behaviors participants used to cope with their allergy in disclosure situations. These coping mechanisms or specific disclosure strategies were described as allowing allergic individuals to maintain or regain control of their environments in situations filled with uncertainty, reducing the impact their allergy had on others. While these did not align completely with the research questions of this study and were not prevalent enough to draw conclusions from to include in the findings, they are relevant, nonetheless. Future research may consider examining these specific strategies/coping mechanisms and their interaction with disclosure and interpersonal relationships.

Generally, the impact of anaphylactic food allergies on identity and interpersonal relationships warrants further in-depth research outside the realms of medical science, public

policy, and stigma. While these concentrations are important considerations in the study of anaphylactic food allergies, more can be gleaned from continued and expanded research.

### **Conclusion**

In summation, the findings of this study help shed light on the complex nature of anaphylactic food allergies in the context of communication and academic studies. With the number of food allergies continuing to rise, this under researched health status will continue to be a significant and life changing topic that impacts far more than what a person can eat. Overall, this study found that both identity and interpersonal relationships were impacted by the disclosure of anaphylactic food allergies and that disclosure decisions were also impacted by identity and interpersonal relationship factors. For identity, these factors included: the fluid and flexible nature of identity, context, and change over time; whereas factors for interpersonal relationships included: relevance and proximity as applied to platonic and romantic relationships. The tensions of unwanted attention versus awareness and downplaying the severity versus medical reality were also key themes that provide a framework for understanding the multifaceted interaction between the disclosure of anaphylactic food allergies, identity, and interpersonal relationships. I hope this study encourages further research into the complex social issues faced by this community and continues to validate the lived experiences of those with anaphylactic food allergies.

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**Appendix A: IRB Approval****Office of Research Integrity**UNIVERSITY OF COLORADO **BOULDER****INSTITUTIONAL REVIEW BOARD**

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**APPROVAL**

30-Jan-2020

Dear Olivia Cornejo,

On 30-Jan-2020 the IRB reviewed the following protocol:

Type of Submission:	Initial Application
Review Category:	Exempt - Category 2 -
Risk Level:	Minimal
Title:	When to Disclose? The Impact of Anaphylactic Food Allergies on Identity and Interpersonal Relationships
Investigator:	Cornejo, Olivia
Protocol #:	19-0827
Funding:	None
Documents Approved:	19-0827 Consent Form (30Jan20); Interview Script; 19-0827 Protocol (30Jan20);
Documents Reviewed:	CITI Certification; HRP-211: FORM - Initial Application v9;

The IRB confirmed the Exemption of this protocol on **30-Jan-2020**.

You are required to use the IRB Approved versions of study documents to conduct your research. The IRB Approved documents can be found here: [Approved Documents](#)

In conducting this protocol you must follow the requirements listed in the [INVESTIGATOR MANUAL \(HRP-103\)](#).

Sincerely,

Douglas Grafel

IRB Admin Review Coordinator

Institutional Review Board

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within the University of Colorado Boulder's IRB records.

## Appendix B: Consent Form

**Title of research study:** When to Disclose? The Impact of Anaphylactic Food Allergies on Identity and Interpersonal Relationships

**IRB Protocol Number:** 19-0827

**Investigator:** Olivia Cornejo

**Sponsor:** Ruth Hickerson

### **Purpose of the Study**

The purpose of the study is to understand the impact of anaphylactic food allergies on an individual's identity and interpersonal relationships through the collection of personal accounts and experiences through interviews.

Very little research specific to food allergies exists and research that does tend to focus around medical science, societal impacts, and public policy, ignoring implications for disclosure and the management of interpersonal relationships and identity. Research that does directly discuss food allergies and implications for disclosure usually focus on the school setting and bullying as a widespread issue, and/or school policy. Whereas, the health communication field focuses on stigma/stigmatized identities as related to health conditions and disclosure practices but does not currently include research specific to food allergies. This project will go outside the realm of the public and organizational settings, and instead focus on the individual experiences of those with anaphylactic food allergies, the navigation of their identity, and their management of interpersonal relationships, connecting food allergies to the larger topic of health communication and the disclosure of stigmatized identities.

This study will advance knowledge on food allergies and their impact on identity and interpersonal relationships in the communication field, a currently under researched subject.

We expect that you will be in this research study for 30-60 minutes.

We expect about 10 people will be in this research study.

### **Explanation of Procedures**

You been asked to participate at a time and place convenient for you. I will ask you questions about your allergy, your experiences disclosing your allergy to other people, and how your allergy has impacted your identity. The interview will be audio recorded for data collection purposes. There will be no other follow up visits or required participation other than this one-time interview that should take 30-60 minutes.

### **Voluntary Participation and Withdrawal**

Whether or not you take part in this research is your choice. You can leave the research at any time and it will not be held against you. If you decide not to continue with this research all your data will be destroyed.

If you are a CU Boulder student or employee, taking part in this research is not part of your class work or duties. You can refuse to enroll, or withdraw after enrolling at any time, with no effect on your class standing, grades, or job at CU Boulder. You will not be offered or receive any special consideration if you take part in this research.

**Risks and Discomforts**

You may experience psychological or emotional discomfort when talking about experiences disclosing your allergy or instance when you had an allergic reaction. If at any time you feel uncomfortable answering a question you can decline to answer.

**Confidentiality**

Information obtained about you for this study will be kept confidential to the extent allowed by law. Research information that identifies you may be shared with the University of Colorado Boulder Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to research, including people on behalf of the Office for Human Research Protections. The information from this research may be published for scientific purposes; however, your identity will not be given out.

Audio recordings and transcripts of the recordings will be stored on the Principal Investigator's laptop in an encrypted password protected folder. The laptop will be password protected and have automatic log-off enabled. Only the Principal Investigator will know the password and have access to the laptop and raw data; however, raw data may be shared with the Faculty Sponsor. Audio recordings and transcripts of the interviews will be coded using numbers in the order they were conducted and using pseudonyms to protect confidentiality. Consent forms will also be coded using numbers in the order they were collected, so that if necessary, the consent form can be linked to the corresponding interview data. The hardcopy consent forms will be scanned and electronically uploaded onto the Principal Investigator's laptop which will be stored in an encrypted and password protected subfolder separate from the interview transcripts and recordings. The hardcopies of the consent forms will be stored in a locked filing cabinet until the study is complete. Once the study is complete, the hardcopy consent forms will be shredded and destroyed and the electronic copies will be deleted, thus destroying all identifiable data and de-identifying the coded interview recordings and transcripts.

**Payment for Participation**

You will not be paid to be in this study.

**Questions**

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the Principal Investigator at (303)-704-8785 or [olivia.cornejo@colorado.edu](mailto:olivia.cornejo@colorado.edu).

This research has been reviewed and approved by an IRB. You may talk to them at (303) 735-3702 or [irbadmin@colorado.edu](mailto:irbadmin@colorado.edu) if:

Your questions, concerns, or complaints are not being answered by the Principal Investigator.

You cannot reach the Principal Investigator.

You want to talk to someone besides the Principal Investigator.

You have questions about your rights as a research subject.

You want to get information or provide input about this research.

**Signatures**

Your signature documents your permission to take part in this research.

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Signature of subject

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Date

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Printed name of subject

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Signature of person obtaining consent

Date

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Printed name of person obtaining consent

### Appendix C: Interview Schedule

**Title of Research Study:** When to Disclose? The Impact of Anaphylactic Food Allergies on Identity and Interpersonal Relationships

**Investigator:** Olivia Cornejo

**Sponsor:** Ruth Hickerson

#### Interview Questions:

- What are you allergic to?
- When did you first find out you had a food allergy?
- Have you had any notable or recent reactions?
  - What happened?
  - Did that change your perception of your allergy?
  - Did you tell people about this reaction? Who and why?
- What prompts you to tell someone about your allergy?
  - Do you worry about telling people about your allergy? Why or why not?
- Do all your friends and close acquaintances know about your allergy? Why or why not?
  - When did you tell them?
- Can you tell me about a time you decided not to tell someone about your allergy? Why?
- Can you tell me about a time where you told someone about your allergy, but you felt like they blew it off or compared it to something else less severe?
  - How did that make you feel?
  - What did you do after they blew it off? Did you try and correct them and explain it more or move on?
  - How do you think that person, or other people who do this, perceive you?
- When other people think about you, do you think they think about your allergy? Why or why not?
  - When you think about yourself (who you are as a person, who you are to other people), do you think about your allergy?
- When someone asks you to tell them about yourself, do you usually include your allergy? Why or why not?
- Do you feel like your food allergy is a part of who you are? Why or why not?
  - What other ways might you categorize your allergy?
- How much do you think your food allergy impacts your social life and relationships with people?