

“It’s Too Much On Top of Your Own Food Drama”: Exploring Food Allergy Identity and Experience Through Social Media

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Abstract

This paper provides an in-depth view of people’s experiences with food allergies, focusing on their social media use and its influences on healthy habits and identities. Through 18 interviews, our study examined how information and identity work on social media influences health behaviors, social interactions, self-expression, and navigation of algorithms for those with food allergies. Social media functions as both a source of empowerment and community and a platform for stigma and emotional distress. Our findings highlight how individuals manage their food allergy identity and online visibility on algorithm-driven platforms. The concept of “on-and-off identities” is introduced to capture this complex identity work. Design considerations for HCI include: 1) creating mindful social media experiences that support agency while addressing vulnerability in identity and information work, and 2) reflections on the challenges of evolving health contexts and social media ecologies. We urge HCI researchers and designers to adopt a holistic perspective on identity and information work to better support marginalized populations.

CCS Concepts

• **Human-centered computing** → **Collaborative and Social Computing**; *Empirical studies in collaborative and social computing*.

Keywords

food allergies; social media; health; food; identity work

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1 Introduction

Approximately 33 million people (27 million adults, or 11% of the adult population) in the U.S. have at least one food allergy [47], and 1% of the global population has celiac disease [74]. These rates have been steadily increasing for decades in both children and adults [47, 60, 134]. A food allergy occurs when a person’s immune system identifies a harmless food protein as a threat and overreacts to it

[47]. Mild reactions may present as eczema, diarrhea, or stomach aches, whereas severe reactions can result in anaphylaxis, marked by the rapid onset of life-threatening allergy symptoms shortly after ingestion [136].

Studies show that individuals with food hypersensitivities report reduced quality of life, both for themselves and their families [2, 4, 5, 8, 24, 29, 100]. Food is deeply embedded in cultural practices and social interactions [46, 72], and people with food allergies may face exclusion, stigma, or misunderstandings in both personal and public spaces [100].

The rise in food allergies has also brought attention to their broader social and psychological impacts. For individuals living with food allergies, managing daily life often extends beyond the physical challenges of avoiding allergens—it includes navigating social situations, cultural norms, and identity formation. Such challenges have led people to seek help and support online. For a number of years, online patient forums and Facebook groups dedicated to food allergies served as an important virtual space for exchanging information and offering emotional support during challenging health situations [35, 36, 65]. As algorithmically-driven social media like Instagram and TikTok have gained popularity with young adults (18-to-39-year-olds) [17], these platforms now provide a crucial infrastructure for building a sense of belonging among young people with food allergies. These social media are not only viewed as “fun” and “performative,” but also serve as spaces where individuals with health-related conditions or goals can find community, information, and emotional support [23, 48].

Importantly, HCI research has also shown the risks of social media for young people living with food-related health conditions. Common digital harms include the normalization and promotion of eating disorders as a lifestyle, where casual encounters with pro-eating disorder (pro-ED) material can lead from experimentation with dieting to adopting harmful behaviors without fully understanding their long-term implications [106]. Understanding the online experiences of young people with food allergies then is essential to uncovering how digital spaces can impact health behaviors, either by amplifying stigma and harmful practices or fostering support and positive engagement. This research strove to answer these research questions:

- RQ1. How do individuals with food allergies navigate and use social media content around food and food allergies?
- RQ2. How do they experience and express their food allergies identity on social media?

Reporting on study findings from 18 semi-structured interviews with young adults with food allergies, we explore how people use social media to manage their food allergy conditions, experience social harm or support, and express their identity. Our study shows



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that living with food allergies as a young person involves a wide range of online and offline experiences, from cooking Instagram-inspired recipes to exploring restaurant recommendations on TikTok, to protecting oneself from online trolls. In this way, the lived experience of chronic illness is not merely a medical condition or information problem, but deeply intertwined with the work of identity creation and sense of self. People with food allergies must navigate and reflect on how they present themselves, manage social interactions, and learn how take care of themselves across both physical and digital spaces. In this paper, we draw together the theoretical concepts of “identity work” and “information work” to show how information, algorithms, and personal health intersect for individuals managing chronic health conditions like food allergies.

Our findings reveal four themes in social media experiences for people with food allergies. First, while managing dietary restrictions offline is essential, social media offers endless inspiration and guidance for navigating life with allergies, alongside challenges with information and identity. Second, it provides a platform for social interaction, balancing support and harm both on and offline. Third, it serves as a space for self-expression, where users share stories, advocate for awareness, and reflect on their identities. Finally, social media’s algorithms shape users’ perceptions of self and well-being, prompting participants to curate their digital self and environments for a safer, more supportive experience.

We contribute to the HCI literature by deepening the understanding of how individuals with stigmatized chronic illnesses, such as food allergies, navigate social media. We also examine the fluid identities and varying levels of visibility of identity within this population, providing design implications to foster mindful social media engagement that empowers individuals to exercise agency while balancing vulnerability in both identity work and information management. To this end, we propose the sensitizing concept of “*on-and-off identities*” to capture the complex forms of identity work undertaken by people managing food allergies on social media. Additionally, the paper explores the complexities of designing for health in the context of chronic illness and social media ecologies, underscoring potential intersections between health needs and identity work, as well as the design trade-offs.

2 Background and Related Works

In this section, we provide an overview of the food allergy population and review prior HCI research on health-related stigma. We also examine existing studies that explore how individuals with food allergies engage with social media platforms. Finally, we discuss the construction and experience of self-identity in the context of algorithm-driven social media.

2.1 Food Allergies and Other Health-Related Stigma in HCI Work

Food hypersensitivities, including intolerances, allergies, and celiac disease, are defined by adverse health reactions triggered by specific foods [10, 103, 131]. Dining out can be risky and isolating for individuals with these conditions, significantly impacting their quality of life and their ability to engage in social activities [100].

The social stigma surrounding food allergies often stems from a lack of understanding and awareness among the general public. One in three children with food allergies report being bullied [54], and adults also encounter food allergy-related stigma as these conditions could continue to develop throughout life [51, 67]. People with food allergies are often dismissed as overly cautious or exaggerating their concerns, which can lead to isolation and exclusion. As an “invisible risk” or “invisible disability” [32], food allergies remain unnoticed until disclosed, often resulting in stigmatization in social settings like schools or workplaces [26].

In HCI and CSCW, stigma has increasingly been explored in prior work concerning various health conditions, such as eating disorders [44, 45], mental health [91, 94], polycystic ovary syndrome (POC) [22], HIV [59, 86, 87], and senior health [15]. These studies have examined how stigma affects self-image and individuals’ behavior in seeking online social support. Some research has developed technological interventions to reduce stigma by providing access to social support and healthcare [121], some developed chatbots to reduce the stigmatization of mental illness [28]. Other research has explored designing technologies that help individuals cope with internalized stigma through gamification [88] and self-reflection [16]. Research on food allergies can benefit from these approaches, particularly in understanding how stigma affects identity and online behaviors.

Sharing food has long been a cornerstone of social interactions, influencing inclusion and exclusion [46, 72]. Extensive research on food-related stigma reveals that having different eating habits exposes individuals to stigma, as seen with vegetarians and vegans whose choices challenge societal norms and traditions around animal consumption [85, 89]. Unlike voluntary eating choices, food allergies carry life-threatening risks, intensifying the stigma in social settings where food is prominent, and creating an “allergic identity” that food-allergic individuals are forced to navigate [62]. To avoid such stigma, even those with life-threatening food hypersensitivities sometimes even choose to consume unsafe foods to evade judgment [37, 64].

Food allergies present a unique avenue for research on health-related stigma because they are often seen as “harmless” compared to other health conditions. They are frequently subjects of jokes or humorous portrayals in media and social settings [1, 101], which reinforce stigma and downplay their challenges. Exploring how these individuals engage with social media has the potential to improve their often-overlooked, stigmatized experiences. By investigating these experiences, we aim to uncover the nuanced challenges they face in navigating social interactions and self-presentation in digital spaces.

2.2 Social Media and Health, and How Food Allergy Is Studied

Although the popularity of health content on social media inspires users and raises awareness about health [55, 77, 132], seemingly positive posts about weight and fitness on social media can also negatively affect viewers’ body image and well-being, often intensifying body dissatisfaction [25, 43, 127]. Additionally, various types of food-related digital content, including restaurant reviews, eating broadcasts, and cooking demonstrations, have raised concerns

about their potential to contribute to problematic eating habits and dietary health issues [70, 95, 109]. The use of social media has been recognized as an influence on risky food-related health behaviors, particularly within eating disorder communities. Platforms have been misappropriated to foster harmful interactions, such as engagements with pro-eating disorder communities on Twitter through hashtags like #meanspo or #thinspo, which promote the pursuit of thinner bodies [99, 108].

While existing literature does not explicitly address the encouragement of unhealthy behaviors in food allergy communities, it does highlight challenges related to misinformation when seeking emotional support and practical advice [35]. Unverified information on these platforms can heighten perceptions of risk and uncertainty, exposing them to misinformation about diagnosis (controversial diagnostic methods including IgG testing, pulse test, and kinesiology), food safety, allergen labeling, and dietary advice [36, 53]. People use social media to fulfill various types of food allergy-related goals, like seeking information [63] or social support [53, 123]. Facebook plays a key role in patient education, professional interactions, and information-sharing in allergy and immunology [36]. Meanwhile, short-form video platforms like TikTok foster community and awareness, where users publicly share their diagnoses and experiences despite facing stereotypes [135], enabling personal storytelling [82], expert-driven education, and documentation of daily life with food allergies [13].

Social media provides an outlet for expressing concerns and finding social support, but it also has the potential to exacerbate mental well-being if not used carefully. Prior research on individuals with food allergies is mostly based on content analysis, without a further understanding of *why* users posted certain content, what content they watch, and how that influenced their healthy behaviors. In this light, we aim to understand more in depth of people with food allergies experience using social media and how this use expands to managing health and identity.

2.3 Self Identity in the Age of Algorithmic Social Media

Understanding how people with food allergies use social media to manage their health and identity requires examining not only their behaviors and motivations but also the broader context of identity formation on social media platforms. Building on Goffman [50] and Hogan's [56] theories, research has examined social media affordances [34, 138] and how users selectively craft identities [66, 133] for an "imagined audience" [79, 80]. However, with the rise of algorithms, these tools increasingly shape and constrain how identities are crafted and perceived. This shift from the "networked self" [104] to the "algorithmized self" [19] provides an opportunity to examine how individuals navigate identity in digital spaces.

Unlike traditional identity-building through direct social interactions, the "algorithmized self" [19] highlights a reflexive process where algorithms shape and reinforce identities based on users' past behaviors and self-representations. Algorithms, in turn, create a dynamic feedback loop that co-produces identity ([116], e.g. on Facebook [110]). As users interact with platforms, their behaviors and preferences inform algorithmic outputs, which then influence

the content they see and the ways they perceive and present themselves [12, 69, 116]. For example, on TikTok, individuals engage not only with content curated for them but also with algorithmically inferred versions of themselves, shaped by their prior interactions on the platform [3, 7]. This algorithmic mediation of identity can present a mix of gratifying and disconcerting experiences, as users encounter both idealized and unflattering representations of themselves [75].

Recent research has examined how identity is constructed in algorithmically curated interactions, particularly on platforms like TikTok [7, 69, 71, 117]. However, these platforms may unintentionally reinforce stigma and marginalization by favoring popular content that downplays or overlooks the seriousness of food allergies, reflecting broader societal inequalities and dominant norms [69].

Individuals' perceptions of algorithms are often shaped by their theories about how these systems work, along with their understanding of the technical processes behind personalization [42, 73]. Moreover, some TikTok users believe that the platform's algorithm identifies, categorizes, prioritizes, and marginalizes social identities, reinforcing gender and racial power dynamics already present in society [69]. This implies that TikTok's algorithm does more than simply curate content but also perpetuate existing societal inequalities through users' interactions with it. For individuals managing a stigmatized health condition, algorithms can amplify these challenges by shaping how their condition is represented and perceived, both by themselves and others. This raises critical questions about how algorithmic curation intersects with health behaviors [113] and identity formation [3], particularly for those navigating conditions that require strict dietary vigilance.

In this study, we examine how individuals with food allergies, a highly stigmatized condition, explore the complexities of their experiences on social media. We aim to understand how they shape their identity, social interactions, and health management in digital and physical contexts. We seek to provide insights to how people with illness identities engage with information, connect with others, and present themselves using social media.

3 Theoretical Framing

Living with food allergies, for our participants, involves a wide range of online and offline activities, from cooking Instagram-inspired recipes in the safety of one's kitchen to protecting oneself from online hate to exploring far-flung restaurants discovered in TikTok feeds. Our data, therefore, called for a conceptual framework that captures the complexities of allergy activities and interactions connected to this wider ecology of social media platforms, as well as social worlds. To this end, we draw together two sociological concepts grounded in symbolic interactionism—"identity work" and "information work"—to theoretically unpack the particular ways information, algorithms, as well as a person's health and sense of self becomes entangled for those living with food allergies.

3.1 Identity Work

The concept of "identity work," introduced by sociologists David A. Snow and Leon Anderson in their 1987 study of homelessness, describes the processes individuals undertake to create, present,

and sustain their personal identities, primary through “identity talk,” or storytelling [118, 119]. This includes activities such as: 1) arranging physical environments and items to align with their identity, 2) selecting and joining specific communities, 3) managing their appearances, and 4) constructing and asserting their identities through verbal construction [119].

Identity work has since been taken up in a wide range of fields from organizational studies and medicine, which have theoretically expanded it to include activities around collective identity formation [58, 119, 124]. In HCI/CSCW, the concept of identity work has been used to explore a wide range of design contexts, including social media platforms and online communities. For instance, identity work has been used to investigate the experiences of disability activists participating in a virtual march [76], understand how migrants navigate offline and online environments [78], and study how new college students use social network sites in this transition [93].

Particularly relevant for our interpretation of identity work in this paper are the forms of identity work connected to how marginalized communities interact with social media platforms to navigate issues around race, culture or gender [38, 39] [31]. For example, Simpson and Semaan’s work explores how for LGBTQ+ communities on TikTok, people’s identity is impacted by engagement with algorithmic systems, often negatively [117]. Collectively, this literature articulates a sociotechnical understanding of identity work that is highly situated with respect to particular configurations of data, technologies, and social worlds; as well, it calls attention to identity work as a critical design consideration for supporting vulnerable communities in online contexts. In our study, we identify new forms of identity work connected to the challenges of managing chronic illness (e.g. food allergies) on social media platforms where health needs are often stigmatized.

3.2 Information Work

Our analysis is also informed by sociologist Anselm Strauss and colleagues writings on information activities in various health settings [122]. Strauss et al. argue that the production, transmission, and use of health-related information (e.g. communicating with doctors or the creation of a medical record) is a form of interaction work that requires situating within different social worlds (e.g., home, hospital etc.) [122]. While their analysis predates social media technologies, we argue that today’s health information work should include online activities like engaging with TikTok algorithms or messaging food allergy content creators as these activities reflect how people manage their health within new digital contexts [122].

Importantly, for Strauss et al., information work is deeply intertwined with the social, emotional, and human aspects of the patient experience, aligning closely with the concept of identity work [117]. In our study, then, we conceptualize information work as encompassing all the activities through which individuals with food allergies engage with, organize, and disseminate health-related information to manage their condition and negotiate their identities. This interplay between information work and identity work highlights the critical role of digital platforms in shaping not only the management of health information but also the ways users define and present themselves within their social worlds.

In sum, in our study, the concepts of identity and information work provide a theoretical lens that helps explain the social and emotional significance of how individuals with food allergies engage with social media. Identity work calls attention to the ways individuals present and negotiate their food allergy identities in online spaces, while information work highlights the types of interactions with information, data, and algorithms being used to support identity management on social media. Together, these concepts offer a situated understanding of young people’s online experiences with food allergies, bridging practical health management practices with deeper questions of self-identity and stigma in digital and physical worlds in order to highlight new design opportunities that better support patient well-being and care.

4 Methods

We conducted 18 semi-structured interviews [81] online using Zoom with English-speaking individuals in the United States over the age of 18 who have food allergies and experience using social media. We asked them about their food allergy conditions and their experiences on social media, including the content they view and share across different platforms.

4.1 Participants

We recruited participants by posting on social media (Reddit, Instagram, and TikTok), reaching out to food allergies accounts (or accounts that have mentioned food allergies on their feed on Instagram and TikTok), contacting people who were actively commenting in online spaces, and sharing recruitment emails to mailing lists associated with food allergies through websites like F.A.R.E. (Food Allergy Research & Education), and putting up flyers in universities, restaurants, and local bulletin boards.

We interviewed 18 participants who responded to us on social media or via email. They self-reported using social media, engaging with food or food allergy-related content. All participants provided consent according to our university’s IRB protocol. Detailed participant information can be found in Table 1. We gave an approximate of followers on social media to anonymize the accounts since this information could serve as identifiers within such a niche community. All participants were compensated with a \$20 Amazon gift card for their time.

4.2 Interview Protocol

Our interview protocol consisted of two parts. We first asked participants about their food allergies, health conditions, and eating habits, including what food allergies they have and how they managed them daily. Next, we focused on their social media use, exploring how they engaged with food and allergy-related content. Participants were reminded they could skip questions, withdraw, or take breaks as needed during the interviews. Given the sensitivity of the topic, we avoided initiating potentially distressing topics, such as bullying or health emergencies. Instead, we began with general questions and used open-ended prompts for participants to control the depth and breadth of their sharing. Interviews lasted between 43 to 76 minutes (*Mean*=63.26, *SD*=7.46). All interviews were recorded, anonymized, and transcribed using an online transcription service.

Table 1: Overview of Study Participants

Participant	Age	Gender	Food Allergies Experience	General Social Media Use	Food Allergy-Related Social Media Use
P1	20	Woman	Peanuts and tree nuts; diagnosed at 3 years old	TikTok	Viewer: Viewed food allergies content sometimes on TikTok
P2	20	Woman	Celiac disease; diagnosed at 14 years old	TikTok	Viewer: Viewed food allergy content regularly on TikTok
P3	23	Woman	Peanuts and tree nuts; always had food allergies but grew very severe after 16 years old	Instagram; TikTok; YouTube	Viewer: Viewed food allergy content on TikTok, posted privately on Facebook about food allergy experiences
P4	27	Woman	Severe allergies to all tree nuts, intolerance to dairy and onions; diagnosed at 4 years old	TikTok; Twitter; Reddit; Facebook; Snapchat	Viewer: Viewed food allergy content on all four platforms, posted privately on Snapchat
P5	26	Woman	Over 180 allergies, including gluten, eggs, milk, fish, soybean, potato, etc.; developed at 24 years old	Instagram; Reddit	Viewer: Viewed food allergy content on Instagram and Reddit
P6	23	Man	Nuts, fruits, cheese, soybean; ; diagnosed at 7 years old	TikTok; YouTube	Viewer: Viewed food allergy content on TikTok
P7	20	Man	Nuts; diagnosed at 5 years old	TikTok; Twitter	Viewer: Viewed food allergy content on TikTok
P8	21	Woman	Peanuts, seafood; has had food allergies since birth	TikTok	Viewer: Viewed food allergy content on TikTok
P9	27	Woman	Severe allergies to peanuts, tree nuts, shellfish, soybeans; developed dairy allergies and more in the past year	Instagram; Reddit; Facebook	Content Creator: Owns a dedicated food allergy account on Instagram (with 1K* followers)
P10	25	Woman	Apples, potato, etc., developed at 17	TikTok; Instagram; Facebook	Viewer: Viewed food allergy content on TikTok and Instagram
P11	24	Man	Nuts, mangoes	TikTok	Viewer: Viewed food allergies content on TikTok
P12	18	Woman	Severe allergies to wheat, peanuts, tree nuts, sesame, shrimp, seafood, gluten, fruits, most vegetables, many spices, red dye, some SSRIs	TikTok (deleted); Instagram	Viewer: Viewed food allergy content on Instagram
P13	25	Woman	Nuts, shellfish; developed wheat allergies as a teen	Instagram; TikTok (deleted); YouTube; Facebook	Viewer: Viewed food allergy content on TikTok
P14	28	Woman	Celiac disease with other less severe food hypersensitivities; developed at 18 years old	Instagram; TikTok	Content Creator: Owns a dedicated food allergy account on Instagram (with over 120K* followers) and TikTok
P15	27	Woman	Severe allergies for dairy, onions and garlic, potatoes, tomatoes, citrus, carrots	Instagram; TikTok; YouTube; Reddit	Viewer: Owns a dedicated food allergy account on Instagram, TikTok, and YouTube (with under 1000* followers)
P16	24	Woman	Celiac disease; allergic to oat, wheat, rye, barley, gluten flour and malt	Instagram and TikTok	Content Creator: Owns a dedicated food allergy account on Instagram (with 2K-5K* followers) and TikTok
P17	31	Woman	Wheat, soy, oat, corn, peanuts, tree nuts, sesame, banana, avocado and kiwi; had food allergies since 5, still developing more	Youtube, TikTok, Instagram	Content Creator: Owns a dedicated food allergy account on Youtube, TikTok, and Instagram (with 1K-2K* followers)
P18	24	Woman	Peanuts, tree nuts, sesame, seafood, potatoes; developed food allergies at 4 years old	Instagram, TikTok	Content Creator: Owns a dedicated food allergy account on Instagram (with under 1000* followers) and TikTok

* The precise follower counts were obscured to ensure anonymity. A “dedicated account” refers to an account where the posts primarily, if not exclusively, focus on sharing experiences related to living with food allergies.

4.3 Analysis

We used a mixed inductive and deductive approach to analyze the data. We first uploaded transcripts to an online collaborative whiteboard, breaking them into approximately 1,200 notes, and created an affinity diagram to visualize patterns in participants’ experiences managing food allergies online and offline [57]. Through iterative

analysis, we identified 16 high-level themes, which formed the basis of our codebook for qualitative coding. We then conducted a second round of analysis, refining codes and examining emergent themes in depth. We mapped out themes and connections alongside data collection to help us reflect on the data and iterate on interview directions.

We continued data collection until reaching saturation. The initial themes evolved to be clustered around user motivations and actions on the platforms, such as “viewing food allergies content on algorithms” and “posting and expressing on social media,” and strategies on how they managed food allergies, such as “looking for safe restaurants” and “using safe recipes.” As identity creation and management emerged as central themes, we adopted the theoretical framing of identity work and information work and further re-analyzed the data to refine our focus. While our dataset contained additional interesting examples, we prioritized those that aligned with our theoretical focus, excluding themes that, while relevant, did not directly contribute to our understanding of identity and information practices. We moved around the themes and also made micro-level iterations to align examples better with the information and identity work. This process led us to the four core themes of social media experience presented in this paper.

4.4 Positionality

The authors of this study are HCI and health informatics researchers with experience in technology design for various patient populations, including type 1 diabetes, IBS, HIV, and cancer. A patient-centered perspective informs our broader research agenda and design goals, including addressing stigma for those managing health conditions and harmful or discriminatory content online. These values inform both our empirical and theoretical approach to this study, guiding us to prioritize the voices and experiences of those with food allergies.

Our past experiences also inform our understanding of food allergies. The first author is an avid social media user with a long-standing interest in food-related content, recognizing how food habits are closely intertwined with social media use and engagement. The second author personally experienced the death of a teenage family member with food allergies due to anaphylaxis. And the third author is a domain expert in the area of food, diet and health information, with over a decade of research in this area. Taken together, these experiences shape how we interpret the stories and experiences shared with us by our participants, and give us an awareness of the stakes of food allergy research for not only for HCI, but the wider allergy community.

Finally, we recognize that while technology has the potential to offer support, it is not a panacea for the deep-rooted societal issues (e.g. lack of health access or public health education) that contribute to the stigmatization of many chronic illness experiences, including food allergies. Our ultimate goal is to contribute to the development of technologies and social media platforms that empower individuals with food allergies to live full and safe lives both online and offline, while also advocating for a society where food allergies are better understood and respected.

4.5 Limitations

As an interpretivist study, our work documents the experiences of a specific group—young adults living with food allergies who regularly use social media. Not all people with food allergies will share these types of online experiences. Additionally, the majority of our participants identified as women, which could impact the types of interactions and data we captured in this study. However,

as a highly engaged and casual technology-using group of users, the social media challenges and strategies documented here can potentially provide theoretical and conceptual design insights relevant to other chronic illness communities or stigmatized groups.

5 Findings

Our findings highlight four key themes of social media experiences for young people with food allergies, each representing different types of interaction with information and expression of identity.

First, we detail how people seek out and use information on social media to support their allergy needs and health goals and, in turn, how people’s identities are shaped by interacting with allergy-related content. Participants’ stories show how information work is critical in supporting (and challenging) the formation of a person’s chronic illness identity. Second, we discuss how people with food allergies choose to connect with—or distance themselves from—others on social media, illustrating the power (and drawbacks) of collective allergy identity and its related forms of information work. The third theme centers on self-expression, noting examples of how people create and share their own narratives within the broader ecosystem of food allergy communities and online content (a particular fraught form of identity work mediated by both helpful and harmful online experiences). Finally, the last theme focuses on how young people sought agency in shaping their allergy identities by carefully curating their social media feeds, in short fine-tuning their engagement with online content so that their feeds better reflected the identities that participants *wanted* algorithms to pick up about them.

The four themes we describe here are not meant to be viewed as exhaustive nor mutually exclusive categories; rather, they are deeply interconnected in practice. Analytically separating them, however, allows us to explore the multifaceted identity experiences of young people managing food allergies as well as draw attention to the complex new forms of information and identity work around chronic illness in the digital age.

5.1 Food Allergy Information Work: Shaping Illness Identities

Living with food allergies as a young person is often challenging given the need to carefully manage food restrictions while also exploring life with increased independence. Due to the medical risks of food allergies, many participants in our study had adopted a more conservative attitude towards eating and food-related activities which they found frustrating. Several people, for instance, shared how they often ate the same food every day (P3, P4, P5, P6, P8, P12):

Sometimes you just lose the excitement in eating. I don’t even know what a variety means. [When] I try to make meals, I’ll eat them for the next couple of days too, because with allergies, there’s just not so much variety. (P6)

This constrained relationship with food impacted participants’ lives in a number of ways as experimenting with new recipes and dining out became rare occurrences. This in turn changed the ways young people saw themselves. Some participants described a sense of loss that came from missing out on food experiences centered around cultural diversity or entertainment. P4 shared how she typically

didn't go out for meals except for local restaurants that she carefully studied before visiting. Traveling was also an activity that some participants curtailed due to their food allergies, explaining that they were “scared of going to places” (P2).

These dietary dilemmas reflect the reality of managing a serious health condition, requiring careful deliberation, adaptation, and boundary-setting in daily food activities. To live well, young people must perform ongoing information work to find safe options, adapt recipes, and manage dietary restrictions.

Social media played a key role in participants' information work, with young people using platforms like Instagram and TikTok to shape health goals, habits, and identity. While online content offered strategies for dietary restrictions, it sometimes clashed with self-identity, creating tensions. Despite this, social media empowered them to explore, adapt, and reconstruct their eating habits meaningfully.

5.1.1 Living Better through Engagement with Food Allergy Information. While managing food allergies often requires a cautious and deliberate approach to new experiences, social media can provide young people with a much needed space for illness identity exploration and discovery. In our study, participants engaged in substantial information work through social media, seeking, creating, and incorporating allergy-related content into their lives. These practices were crucial for both navigating food restrictions and reflecting on how they wanted to live their life as someone with allergies.

Many participants, for example, strategically used social media to find information on how to travel safely with food allergies, including searching for Instagram guides created by local people with food allergies or using hashtags (e.g. #glutenfreeBoston). P2 shared how she exclusively used TikTok to find safe dining options when visiting a new city by following food allergy accounts: “I don't have to really worry about look[ing] on Google and trying [to] figure out a restaurant that works for me; I know that if I can find a TikTok, I'll be fine” (P2).

Social media also enabled young people with food allergies to be less fearful of travel. As P14 noted: “Seeing videos of people eating the most amazing gluten-free options on Tiktok in Italy is what made me book a trip to Italy with my boyfriend two years ago.” Traveling and eating-out content helped her “feel braver about eating out, explaining my dietary needs, and asking more specific questions about cross-contact protocols.”

Feeling braver to inhabit the world as a person with allergies—to go to new places, try new foods, and advocate for one's health needs—motivated social media content consumption as well as creation. P14 (who now maintained a dedicated food allergy Instagram account) noted that posting and remaining active on social media encouraged her to explore more and share exciting experiences in life:

[Posting on social media] encourages me to get out, eat out more, and live life more just because if I want my content to be interesting, my life has to be more interesting than just me making chicken and rice every night in my own home. (P14)

These examples illustrate how information work is often tied up with identity work for people with chronic illness. Not only did

young people use social media to help streamline research on food allergies, but sharing/consuming content also encouraged them to expand their understanding of how a person with food allergies could be in the world (e.g. going from a restricted view of eating “chicken and rice” at home to being an empowered world traveler).

Participants commonly used social media to research (and sometimes create) allergy-free versions of recipes. This information work involved actively searching for creative alternatives to traditional recipes and identifying suitable substitutions for allergens. For example, P5 learned from TikTok that avocados could replace eggs in gluten-free pancakes, and P15 found that mangoes could be a substitute for tomatoes. However, finding recipes was often challenging, as searches like “[food] without [allergen]” often showed results containing the ingredients they were trying to avoid instead of excluding the allergen.

Finding ingredient substitutes for food allergies was not a simple process of content consumption or a “one-size-fits-all” solution (P4). Instead, participants had to tailor online information to their specific needs. P17, for example, described the frustration of finding recipes that accommodated her rare allergies:

People will use oats. I'm allergic to oats. Or they'll use corn—I'm allergic to corn. I found a lot of recipes that'll have oat milk, but I can actually have dairy milk. It's hard to find an exact replica of the things that I can eat. (P17)

To overcome these challenges, participants relied on strategic research and creative problem-solving. Those with multiple allergies first filtered recipes to avoid common allergens (e.g., gluten, nuts, seafood) and then adjusted for their specific needs. This often required extensive research and trial-and-error cooking, as few ready-made recipes were available. P15 shared how she experimented with various substitutes (such as using grape juice instead of wine or non-brewed condiments in place of vinegar) due to her allergies. In desperation, she developed a strategy of going to alcoholic recovery sites for recipes without wine: “You look at how to substitute it if you're cooking for somebody who is a recovering alcoholic. That was where I was grabbing guides from, and I was cooking using grape juice.”

5.1.2 Struggling with Food Allergy Information and Identity: Being “Healthy” on Social Media. Food hypersensitivities and allergies often create significant challenges in achieving health and fitness goals, and participants noted that social media at times amplified these difficulties by highlighting the complexities of navigating their goals while managing dietary restrictions. For those wanting to maintain a conventional “fit” body standard, many typical weight-loss or healthy foods (e.g. TikTok salads) featured on social media contain nuts or certain grains that are off-limits. Maintaining a balanced diet is even more challenging when essential nutrients are restricted by food allergies: P12 and P15 struggled to find alternative protein sources, as they were allergic to many health foods promoted on social media.

Participants also faced obstacles in aligning their limited food choices due to allergies with other facets of their identity, such as being an athlete. P11, a cyclist, sought nut-free energy bar recipes on social media to fuel his bike rides, but was disappointed about the fact that many energy-dense foods relied on allergens he couldn't

consume: *“I used to cycle a lot. A lot of those healthy hiker foods [contain nuts]. Nuts are a great source of energy, and I can’t have them”* (P11). Feeling limited in his food choices in turn diminished his motivation to be a cyclist.

Food allergies also created challenges for some participants in aligning with their family’s cultural practices around shared meals and traditional foods. P6 found it difficult to stay vegan like his family members due to allergy and nutritional concerns: *“It’s very hard to be vegan because a lot of the things that I have to eat are on that side. I’m allergic to soybeans, for example, so it’s another protein [that I can’t have]...”* (P6). Social media’s portrayal of veganism as aspirational and accessible, reinforced the gap between P6’s dietary realities and his family’s cultural practices, pushing him to avoid vegan-related content by not actively searching for it, reflection on the limitations of social media in supporting diverse identities and dietary complexities.

Participants’ exposure to food allergy-related content on social media also acted as a starting point for a hyper-focus on health and wellness information. P10 shared that after developing food allergies, she became fixated on organic foods and began obsessively consuming informational content about detox water on social media, trying them out in a desperate attempt to improve her health. This heightened awareness often led participants to seek out more content related to healthy eating, both reinforcing their commitment to maintaining a safe and healthy diet and (at times) leading to anxiety about food safety.

5.2 Being in the Food Allergy Community: Collective Identity Experiences through Content Engagement

The social stigma faced by individuals with food allergies is often overlooked or minimized, yet it profoundly shapes people’s daily experiences with food and sense of self. A number of participants in our study, for instance, shared stigmatizing experiences around being bullied about their food allergies growing up. For example, P3 recounted a distressing experience in university:

A professor threw something that had nuts in it at me because I was refusing to take it after I had said several times that I can’t eat this. (P3)

On social media, participants engaged not only with food allergy information but also with other people navigating similar challenges around stigma and belonging, reinforcing a collective sense of identity. These interactions revealed the motivations behind how individuals with food allergies expressed and negotiated their identities in both public and personal ways. Whether seeking validation, advocating for awareness, or reclaiming control over narratives, participants used social media as a space for identity exploration and connection.

5.2.1 Experiencing the Food Allergy Self Positively through Kins.

Social media served as a space for participants to find and join food allergy communities. While a few of the participants in our study preferred not to talk much about their food allergies with others online (P1, P5, P6, P7, P11), we found that those who developed allergies as young adults or whose food allergies worsened with age sought out supportive communities online. Instead of joining formal

online patient forums, they turned to platforms like Instagram and TikTok as informal spaces for identity exploration and connection, following accounts that reflected their lived experiences.

These online social interactions were all the more important when offline experiences seeking support fell short (P4, P9, P14, P17). As described by P17, friends who didn’t have food allergies often reinforced feelings of isolation:

I had a reaction that prompted me to be more involved in food allergy discussions. I wanted to voice, or find a community, that understood me. It was hard to talk to friends who didn’t understand the fears around eating and figuring out allergies. (P17)

These participants, as young adults managing food allergies, struggled to find support and were upset about assumptions that food allergies were a childhood health issue. Challenges of finding support online resonated with P9’s offline world in her adult life, where *“a lot of people won’t take it as seriously for adults, as opposed to children, which just sucks because it’s still life-threatening, whether you’re a child or an adult...”*

Their sense of community on social media platforms was built on the interactions between viewers and creators. For viewers like P3, engaging with content creators fostered a sense of belonging and affirmed her identity as someone managing severe food allergies. When a creator responded thoughtfully to her direct message about traveling safely, she found the advice invaluable and reassuring. Similarly, P9, a new content creator, appreciated interactions with followers of her food allergy account, sharing, *“It’s nice having people in your corner who appreciate the advice and information you’re giving.”* These connections strengthened her self-perception and provided a sense of purpose on the platform.

While many participants did not feel like they were exactly “part of a community,” they still experienced enough support on social media through simply browsing content. Even lighthearted and casual browsing offered users a way to engage without the burden of excessive seriousness: *“[I haven’t become] friends [with anyone by browsing content on TikTok], but it’s definitely nice. It’s bonding and reassuring whenever I see random people comment about their own peanut allergies because it is such a weird experience.”* (P8)

Extending from online interactions, sharing social media content with close friends and family further strengthened participants’ ability to embrace their food allergy identities. Participants frequently mentioned how loved ones would send them recipes that were safe for them to enjoy. For instance, P2 shared that her friend sent her *“gluten-free cookie recipes that she’s going to make,”* and P3 mentioned exchanging *“[TikTok pasta recipe videos] back and forth”* with friends since pasta was a safe food. Although some participants avoided searching for recipe videos themselves due to the potential emotional impact of certain food content, they appreciated the recipes shared by friends and family. To them, these interactions, food content, and food information on social media were seen as tokens of love and care, offering both practical help and mental support, adding greatly to their positive experience of their identities as individuals with food allergies.

Engaging with social media became a way for people with food allergies to push back against societal narratives that marginalized

their experiences, creating a space to share their realities and validate their identities as adults managing life-threatening conditions. Our findings highlight how social media can serve as a platform for negotiating and affirming food allergy identities, addressing both the stigma and misconceptions people face in their everyday lives.

5.2.2 Experiences of Food Allergy Hate and Harm: The Risks of Embracing Illness Identity amid Social Media Stigma. Being a part of the food allergy community on social media means dealing with stigma, especially for people who have more popular (and visible) accounts dedicated to food allergies. P14, who has more than 120K followers on her food allergies Instagram account, shared an example of hateful comments from strangers on a video where her boyfriend tasted bread to verify if it was gluten-free or not: *“He’ll be like, ‘Yeah, that’s gluten-free. It tastes like cardboard. You’re totally good.’”* Despite explaining in a caption that she was not using this as her primary strategy for food allergy safety, the video received numerous negative comments:

I got so many hate comments like, *“If you’re that sensitive, you don’t even deserve to eat out,”* even though I always explain this is step four of what I do to verify if something is gluten-free. I also [got] a lot of comments about how my partner should leave me; he deserves someone with normal genes... (P14)

Common strategies to avoid online hate, such as filtering harmful comments, proved challenging for food allergy content creators. P14 noted that the word *“weak”* could be used to insult someone for having food allergies, but it could also serve as a way for others with food allergies to express vulnerability about managing their condition. She explained, *“I don’t [filter out words]. There really just aren’t any words that would necessarily always be an insult.”* (P14). Her hesitance to filter words reflected her commitment to protecting the community and supporting others with food allergies.

For content-viewing participants, moments of collective identity were often heightened in the face of online hate. While not everyone directly experienced harmful comments on their posts, witnessing attacks on popular food allergy accounts evoked a shared sense of hurt and frustration: *“The bigger profiles of the people with food allergies, there’ll be trolls that come and say, ‘Oh, it’s all in your head!’ They’ll belittle the person or their experience”* (P18).

Sometimes simply commenting and sharing personal experiences about other people’s food allergy content also exposed participants to hate. P9 recounted the response she got when commenting on a post where a content creator shared about an awkward dining experience with coworkers:

They were being weird about [her refusing food], asking her uncomfortable questions about her food allergies. I [left] a comment about being around different allergens all the time since people are always ordering food in the office I work in. Someone [replied], *“You’re weak because you have allergies!”* (P9)

This example shows how hateful replies shifted the narrative from validating food allergy experiences to attacking the food allergy identity. It was challenging to address such moments, as going on the defense would often attract increased negative attention. For

example, P9 believed increased engagement led to more people seeing the hateful comment rather than focusing on the food-allergy message the original content was conveying:

I’ve made a statement [replying to hateful comments], like, *“Maybe show some empathy,” “That’s not all in their head, that’s their experience. Somebody just died from a peanut allergy. Show some respect.”* People will flock in and start insulting my appearance, or insulting my page, or being like, *“imagine only having your allergies as your personality.”*

The negative attitudes and misconceptions young people encountered online deepened their feelings of marginalization, making it difficult for them to engage openly and confidently in these digital spaces: *“[I] don’t want to have that conversation [e.g. share personal experience with food-allergies]. Maybe that’s an insecurity of me, but I generally just don’t [talk about it]...I don’t like the pity that comes with”* (P6).

Witnessing or experiencing online hate served as a painful reminder of the broader stigma participants encounter, but it also underscored the importance of their collective presence and advocacy. Despite the risk of harm, however, some participants continued to engage in these difficult encounters, defending their community and attempting to shift public narratives on living with food allergies, even as these interactions revealed the emotional labor required to sustain their identity in the face of hostility.

5.3 Food Allergy Identity Talk: Using Social Media as an Expression and Reflection of Self

Participants who created content on social media engaged in ongoing identity work, navigating their digital presence and evolving the type of content they shared over time. Social media served as an exploratory space for participants to shape and reshape their food allergy identities through storytelling and the sharing of information. By crafting content that transformed their food allergies from a limitation into a source of strength and self-expression, participants actively constructed their digital identities.

Though not all participants openly shared their experiences with food allergies on their personal accounts —across all of the participants, including viewers and content creators, only four chose to do so — some found solace in creating separate accounts dedicated to navigating and documenting their relationship with food allergies. Those who owned a dedicated account to food allergies curated their feeds on content ranging from making food (P15), snack reviews (P9, P16), restaurant reviews (P16, P18), traveling with food allergies (P18), general daily experiences of being a person with food allergies (P14, P17), and sharing knowledge about food allergies (P16, P17, P18). In these spaces, they navigated and negotiated their digital identities as individuals with food allergies, finding their voices and expressing themselves within the online community.

Before participants started to create a food allergy presence on social media, observing other food allergy identities on social media was crucial. These observations prompted participants to re-define and negotiate their stances and identities in the online space. P17 found that there are a ton of food allergy accounts with

different focuses. Some focused on “*being a college student with food allergies*,” while others shared undergoing “*treatments such as tolerance induction programs*.” (P17). She navigated and found where her food allergy identity stood out but also fit in:

Not a ton of people on social media have a [chronic illness] ¹ account with allergies. And I’ve got people reach out to me [on social media] saying [they] have that too. [Also,] I’m an adult student—I’m not a younger college-age student. [That’s] what sets me apart from the other accounts. (P17)

This process reflects how participants used information work to explore the landscape of food allergy identities and engaged in identity talk to define their unique position within it.

Other content creators iterated on their sharing goals and adjusted the type of content they shared over time. For example, P14, whose account had gradually grown big on Instagram, shared how her motivation has shifted over time, now being “*to create greater awareness in public, in general, to educate others*” (P14). She incorporated humor and movie clips to make information more digestible, a practice that also encouraged her to reflect on her sometimes challenging experiences with a more cheerful and approachable tone.

For those without dedicated food allergy accounts, social media remained a venue for voicing their stories. P4, while critical of how some food allergy content creators “*portray food allergy experiences as dramatic*,” admitted that she did something similar—she once Snapchatted her friends of herself when she ended up in the ER due to food allergy reaction:

I sent them a snapshot of like, “lol hospital vibes.” And then 45 minutes later, I had gone into anaphylactic shock... they were calling me, terrified. They had not encountered that as the funny content that I thought I was making.

While sharing a humorous snapshot of her experience reflected an attempt to downplay the seriousness of her condition to maintain a sense of normalcy or to cope with the stress of her situation through humor, the reaction from her friends—who perceived her content as alarming rather than amusing—highlighted a disconnect between her intention and the audience’s interpretation. She regretted this action: “*That’s an emergency and I just don’t see the value in sharing it. And I think it’s traumatizing for a lot of people*” (P4).

This example highlights the tension between self-expression and audience perception in food allergy identity work. For P4, social media was a tool to navigate vulnerability, humor, and the realities of her condition. Her experience underscores how individuals with food allergies experiment with presenting their stories, balancing personal coping strategies with the potential impact on others. Even without dedicated accounts, platforms like Snapchat offered a space to negotiate the narratives and complexities of their identities.

P3, who was an avid social media content consumer, did not have a dedicated food allergy account, but occasionally reposted content from FARE (Food Allergy Research & Education) on her Facebook. In one post, she shared her experience of being bullied, noting that “*food allergies are a lifelong thing, and the bullying*

continues throughout life. People make comments to you throughout your life.” (P3). Posting this allowed her to revisit and reflect on her past experiences, release accumulated experiences, and to inform and educate others through an engagement of personal history.

Even without dedicated accounts, individuals leverage social media to share their experiences in informal and personal ways. Together with the curated and intentional content that traditional food allergy creators make, these examples show the various approaches participants take to express and reflect on their identities on social media.

5.4 Allergy Identities Mediated by Algorithms: Information as Visibility of Self on Social Media

The ways people with food allergies engaged with social media algorithms were intricate and layered. Algorithms shaped the experience that both viewers and creators encountered, but their interactions with these systems revealed distinct strategies and experiences to cultivate an online environment that reflects and support their identity, their information needs, and well-being. Participants who primarily viewed food allergy content on social media saw their identities mediated through the automated content shown to them by algorithms. While these algorithms offered participants access to useful information and meaningful allergy-related content, they also unexpectedly exposed people to distressing or anxiety-inducing material about food allergies. Those participants who created food-allergy content, however, sought to leverage algorithms on different platforms to stay visible to the audience.

5.4.1 Viewing Food Allergy Content: The Experience of Being “Known” by an Algorithm. Algorithms on social media played a crucial role in discovering content that was both enjoyable and relevant. Participants shared how, even without intentionally looking for food allergy information, they experienced algorithms showing them allergy-related content on platforms like TikTok and Instagram. This serendipitous discovery can be particularly beneficial when it introduces users to useful information about food allergies (P3, P4, P11), such as new food alternatives (P8, P11), easy allergy-free recipes (P1, P3), and helpful travel tips (P4). As a participant explained: “*I actually didn’t learn that [e.g. how peanuts could be invisible but still exist in Italian cuisine] by looking up: ‘where in Italian dishes are nuts?’ I learned that kind of passively by liking food content that appeared on my explore page.*” (P4).

However, while engaging with content on social media could be surprisingly helpful, stumbling upon certain food content often made people with food allergies feel stressed or anxious. Common life-sharing videos about food, such as “What I Eat in a Day” content on TikTok, often led to problematic comparisons with one’s dietary habits:

There were a lot of videos that were “What I eat in a day”. It would show a variety of what they were eating, and I would compare that to myself. Also, it would be a lot of foods that I couldn’t have. I mostly keep scrolling and just don’t watch it. (P3)

¹We redacted this information to protect the anonymity of the participant.

To avoid discomfort and negative feelings associated with this content, participants often chose to scroll past these videos without engaging.

Participants also expressed a sense of frustration with TikTok showing content about the varied experiences of people attempting to build up a tolerance to allergens. These videos showed some people successfully “desensitizing” themselves by gradually introducing allergens into their diet, while others recounted worsening reactions from doing the same. As one participant explained: *“I am aware that [for] some, their allergies get worse when they keep eating the foods they are allergic to, [but for] some, they build a tolerance. It’s kind of a toss-up. If I’m tired of having allergies, I’m just gonna eat this. I don’t care”* (P8).

This “toss-up” mentality that P8 mentioned reflects the exhaustion and emotional toll that long-term food allergy management can pose to individuals, particularly when social media showcases others’ varied approaches and results on an endless loop.

Participants in our study actively looked for ways to manage their exposure to content. Many people aimed to control or even avoid the frequent, unpredictable appearance of food allergy-related videos. This need for control stemmed from the overwhelming nature of such content, which could exacerbate existing anxieties and mental health struggles. P9 reflected on how becoming too absorbed in food allergy content on social media could negatively impact her mental health:

[On social media] people talk about their anaphylactic reactions and new food allergies. Sometimes you just have to tune it out because it’s too much on top of your own food drama. (P9)

As a result, over time, she adopted a nonchalant approach to scrolling on TikTok, acknowledging that *“[browsing these contents] kind of hypnotized me. I would just keep going without any thought to it.”* (P9) The emotional stress also led other participants to limit social media use or even delete social media apps from their phones (P3, P4, and P12 all reported deleting TikTok at least once in the past).

Many participants were not surprised that social media algorithms could correctly infer that they had food allergies. Several participants, for instance, associated food allergy content appearing on their accounts as algorithms “knowing” due to their past food-allergy information work like *“looking things up”* and posting content (P6, P14, P18). In fact, P2 felt that her For You Page exactly reflected her particular eating habits and dietary restrictions: *“If you don’t have celiac, you’re probably not going to see the type of videos that I see on a daily basis.”*

Other participants puzzled out hypotheses about why certain allergy or food content appeared or did not appear on their For You Page. As a foodie, P8 shared how she often explored a wide range of cooking-related content on TikTok that she could not safely eat herself. Nevertheless, she *“noticed a lot of the food shown on my page is stuff I can eat.”* This left her uncertain about how the TikTok algorithm was able to detect her specific allergens. Participants also noticed that the content they saw on social media changed with the development of their food allergies. P5, who developed severe food allergies only recently, noticed a change in her Instagram algorithm: *“With pastries, it used to be [on my feed a lot] because I liked it a lot. And I like coffee shops. ... I think they’re not promoting any for*

me right now” (P5). She explained that the presence of gluten in pastries and dairy in many coffee shop drinks (both of which she was now allergic to) made it difficult for her to enjoy this content anymore.

On a broader level, P11 reflected on how TikTok’s algorithm felt like a rotating deck of cards, where content—including food allergy-related topics—would appear intermittently. He described a sense of control over this rotation by interacting with preferred content:

[The algorithm] is a deck of cards, and it’s shuffling. Sometimes, if you don’t interact with [food allergies-related content], it’s just permanently out of your deck for the time being. I interact with it, and it stays on my rotation in order to shuffle. (P11)

This sentiment was echoed by several participants, who, being constantly reminded of their food allergies in real life, expressed a desire for greater control over when and how they encounter related content on social media.

Participants shared how they tried to train their algorithm to show them recipes without their allergens:

If I come across one [recipe] that does have my allergy allergen, I keep scrolling. When [a recipe] does not have my allergen, then I’ll send it to my friends... Sometimes I will look up specific things [without my food allergens]. (P3)

This careful curation of their digital environment and personal strategy around ways to interact with content highlighted the ongoing effort participants made to balance the benefits and risks of engaging with food allergy-related content on social media. By selectively interacting with certain types of content, they aimed to create a safer and more supportive online experience.

5.4.2 Creating Food Allergy Content: Navigating Algorithms to Craft Identity. As a content creator, P15 was particularly conscious of how algorithms “pick up” what content was allowed on YouTube and adjusted her language around describing her experience of food allergies accordingly:

You can’t glorify having a disease. So I can’t say my life is better now that I’m allergic, even though health-wise it probably is—I eat fresher foods and I don’t eat out anymore—but I can’t say that. You have to be mindful of what you can and cannot say, because the algorithm can really pick [it] up. (P15)

Navigating such algorithms led P15 to carefully reframe her identity as a person with food allergies and temper the empowering illness narrative she might have presented to her audience.

Creators also actively experimented with algorithms to better curate their desired audience reach. P16 described segmenting content across platforms: she felt that the Instagram algorithm favored her polished gluten-free food posts, while TikTok favored more casual sharing of personal experiences, such as grocery hauls. This platform-specific adaptation enabled creators to target different audience segments effectively.

Algorithms also influenced creators’ posting strategies. P14 observed that Instagram’s fixed audience distribution required spacing out posts to avoid redundancy, whereas TikTok’s broader reach

allowed for more frequent postings without audience fatigue. These observations highlight how creators leveraged algorithmic behaviors to maximize engagement, and also how they perceive the platforms “know” their content and themselves as people with food allergies.

Our findings point to important distinctions between the experiences of food allergy viewers and creators on social media, illustrating the complex interplay between managing a chronic illness and algorithms. While viewers often passively discover content, their food allergy experiences mediated through the algorithms, creators aim to actively navigate algorithms to craft their identities and connect with their audiences. Together, these dynamics underscore the dual role of algorithms as both facilitators of discovery and sources of tension within the digital lives of individuals with food allergies.

6 Discussion

This paper examined the ways people with food allergies navigate living with a chronic health condition using social media. Importantly, we found that people’s food allergy identities (both individual and collective) were impacted by a wide range of sociotechnical factors, including changing health needs (e.g. new allergies, increased severity of conditions), social media infrastructure (e.g. algorithms, platform policies), and social concerns (e.g. stigma, bad actors).

In this section, we discuss the significance of these findings for the HCI community by reflecting on the new types of “identity work” performed by participants to live well while managing chronic health conditions like food allergies in online contexts. We also point to the ways creating, protecting, and expressing identity as a person with food allergies requires taking on additional types of “information work” from developing information-seeking strategies for recipes on TikTok to avoiding harmful content and online trolls to becoming a food-allergy content creators. We consider design opportunities for using technology to support patient-centered identity work. Our paper contributes to discussions in HCI on the relationship of technology to diverse identities in online settings by highlighting complexities around illness identities on social media.

6.1 On-and-Off Food Allergy Identities: Navigating Food Allergy Identity and Information Work

Social media has long served as an opportunity for many groups and communities to experiment with identity in different ways. We found that people with food allergies carefully engaged different parts of their identity to find useful information and support on social media. For participants in our study, these experiences were shaped by both of their information work—learning, deciding, and reflecting on their health and well-being—and identity work—creating and maintaining identities as a person both with and without food allergies.

Here we point to how participants intentionally created distinct identities when using various platforms as a strategy for circumventing algorithms that filtered allergy-related content in overly narrow or problematic ways. We name this type of identity work *on-and-off identities* to highlight how cultivating different levels

of identity visibility, such as *algorithmic* (experiencing identity through social media algorithms) and *expressive* (self-presentation), are vital for understanding how people with food allergies or other chronic health conditions navigate online spaces.

Importantly, the visibility of food allergy identity on social media is shaped not only by users’ actions but also by the platforms’ algorithms, which play a significant role in determining what content is seen and shared. Visibility in algorithmic social media literature [3] refers to how identities are perceived and shaped by both algorithms and other users. In this context, reflected algorithmic visibility [3] captures individuals’ sense of control over how their illness identity appears in their feeds. Participants in our study expressed a range of feelings about how well algorithms “knew” their food allergy identity. Some felt the algorithms failed to capture critical nuances, such as specific allergens like gluten or dairy, while others were unsettled by how accurately algorithms inferred their food allergies despite a limited engagement with allergy-related content. This uncertainty created a sense of unease, as participants experienced a lack of control over how their identity was being reflected on their feeds, leading to concerns about encountering unwanted portrayals of themselves (e.g., as a vulnerable person with restricted choices).

Visibility on social media exists on a spectrum, with participants in our study demonstrating different levels of comfort and control over how their food allergies were perceived by other users on the platform. Those with dedicated accounts (P9, P14, P15, P16, P17, P18) made their food allergies explicit in profiles or content, while others avoided disclosure entirely. While visibility is essential for activism and awareness, content creators with illnesses face additional challenges, such as social stigma, algorithmic suppression, and heightened vulnerability to harassment [114]. Prior research also highlights the risks of visibility, including stigma, harassment, and algorithmic suppression [3, 11, 114]. To this, content-creating participants used indirect strategies, incorporating their allergies into memes or lifestyle posts (P14, P18) to blend into platform norms. These strategies align with prior work where sociotechnical systems merge audiences with different norms (context collapse) [90] and where users maintain “context integrity” by managing the appropriateness of sharing certain aspects of their identity across different settings [98]. This layered visibility highlights social media as a dynamic space where individuals toggle their identities rather than being simply “visible” or “invisible.” Our framing of “on-and-off” identities captures the intentional toggling of visibility that helps presenting food allergy identities in a way that feels safer and less vulnerable.

This complexity suggests that designers of social technology should consider the broader implications of algorithmic curation and connectivity for stigmatized patient populations like those with food allergies. Allowing users more control over what platforms learn from their behaviors—and how this information is shared across platforms—could empower individuals through better navigating their online presence. Furthermore, the ability to toggle aspects of one’s identity on and off is critical, not just in response to social and emotional needs, but also to manage the algorithms that shape people’s health experiences and reflection of identity. In doing so, people can more effectively balance visibility with personal boundaries, leveraging social media to both express themselves and safeguard their well-being.

The discussion around visibility intersects with identity work, where disclosing one's food allergy status could serve both protective and empowering roles. While visibility fosters connection and information-sharing, it also risks overexposure and emotional distress from triggering content. Participants navigated a balance between authentic self-expression and protecting themselves from anxiety-inducing content or algorithmic assumptions about their condition.

Our findings emphasize that the layers of visibility for people with food allergies are highly situational, shaped by individual preferences, severity of health issues, the type of content, and the specific platform being used. For those with chronic health conditions, we see design opportunities for creating flexible yet nuanced controls for turning food allergy identities on and off, and supporting reflection on the ongoing negotiation of how, when, and to whom one discloses their health condition.

6.2 Designing for Mindful Information and Identity Work on Social Media: Agency and Vulnerability

Mindful social media use involves intentional reflection and engagement, balancing opportunities for self-expression with the potential for harm, and fostering positive online experiences [139]. Managing health conditions like food allergies requires navigating between user *agency*² (the ability to control one's digital experience, e.g. making intentional and meaningful choices that shape their health management and self-presentation), and vulnerability, the risk of being exposed to negative content, including harm from algorithms and trolls. By setting boundaries, filtering content, and reflecting on their interactions with platforms, individuals can create a safer and more positive digital environment that supports their well-being. This mindful engagement is particularly important for people living with chronic health conditions, as maintaining both mental and physical health in a space that can be simultaneously empowering and overwhelming.

6.2.1 Affordances for Supporting Identity Work. People with food allergies use social media to actively shape how they manage their conditions—learning new dietary practices, making well-being choices, and reflecting on how they engage with food both online and offline. Rather than seeing health behavior as entirely within individual control—especially given the influence of algorithms—our findings highlight the interplay of vulnerability and agency across online and offline spaces. Participants with food allergies navigated sociotechnical, medical, and environmental challenges, but used social media as a tool for agency, seeking knowledge, managing their visibility, and sharing their experiences.

At other times, however, participants viewing content sought an escape from the constant reminder of their health condition. In their offline lives, food allergies were an unavoidable reality, impacting every meal and daily decision. Online, on the other hand, participants desired more control over how much allergy-related content they encountered, wishing for more agency in shaping what the algorithms presented to them. Participants used multiple

strategies across social media platforms to achieve some type of health anonymity to algorithms online and respite from thinking about their food allergies (as described in 5.4).

This strong desire for on-and-off identities could be designed as more flexibility in social media systems. Platforms could introduce a control option or mode to temporarily disable triggering food or allergy-related content. While there are several “modes” one could switch on and off on platforms such as TikTok, including the “restricted mode”³ and the “STEM mode,”⁴ currently, platform settings lack personalization, and enabling modes requires complex navigation. A streamlined design could enable users to quickly toggle content filters, giving them immediate control over their exposure to potentially distressing material.

Building on prior work on health-related communities that support dis/ability identities [84, 111], content-creating participants in our study exercised agency by sharing positive food and lifestyle experiences, inspiring others to embrace, rather than overcome, their food allergy identities. They also built communities of identity support, reframing life with food allergy restrictions as diverse and thriving. To support this, we propose exploring positive technology [9] design implications to amplify food allergy narratives. For example, inspired by the dynamic between viewers and creators, a collaborative content creation feature with prompts and templates could encourage storytelling and meaningful engagement.

6.2.2 Identity Reflections and Mindfulness in Food Allergy Information Work. When curating content, participants often reflected on past health experiences to create supportive spaces for themselves and others. While many sought to validate their food allergy experiences with those facing similar challenges, sharing traumatic events, such as anaphylaxis, could emotionally burden others by reviving distressing memories.

In the cognitive process of “thinking of the self” [92] while navigating social media content, two distinct outcomes can emerge: *reflection*—a process of examining and contemplating one's past, present, and future actions related to health and well-being [105], often driven by curiosity about oneself [96, 97]—and *rumination*, which involves a focus on loss and failures [40, 130]. These processes can lead to markedly different impacts on emotional well-being and behavior. While reflection may lead to insights and adaptive coping strategies, rumination, by contrast, can result in a repetitive cycle of negative thoughts, where individuals with food allergies (or other chronic health conditions) focus on their limitations and the perceived inescapability of their condition [130]. This distinction is critical in understanding how engagement with social media content can either foster emotional resilience that leads to healthier choice making, or exacerbate feelings of frustration and inadequacy and trigger self-harm.

For individuals managing food allergies, setting boundaries with technology is essential to keeping social media a source of support, inspiration, and encouragement rather than stress. Constant exposure to food-related content, especially posts featuring foods they

²Agency here primarily focuses on the extent and directness of a user's decision-making and actions in alignment with their personal values, drawing on the concept of self-causality/identity [6] within the HCI literature of human agency.

³Restricted Mode limits potentially inappropriate content on TikTok, particularly for younger users. It filters out videos flagged as mature or sensitive, and can be activated via settings with a passcode for parental control [128].

⁴The STEM feed is a dedicated section on TikTok showcasing educational content in Science, Technology, Engineering, and Math. It encourages learning through videos like experiments, coding tutorials, and STEM-related projects [129].

cannot eat or dietary trends they cannot follow, can lead to feelings of exclusion or anxiety over comparisons of the “typical” lifestyle. Similar to findings on eating disorder-related content exacerbating health issues [107], participants reported harmful effects, such as overly restricting their food intake after encountering triggering content related to food allergies, food, or body image.

Setting mindful limits on social media consumption is potentially beneficial for people with food allergies to prevent digital fatigue. Current digital well-being strategies have largely concentrated on decreasing social media usage by introducing friction, restricting screen time, and modifying app design elements to reduce user engagement [83, 102, 112, 140]. While participants in our research have employed these strategies, we see other design opportunities that have the potential to further support individuals with a greater sense of control over their sense of self and digital well-being.

One opportunity for such design is the concept of “safe zone”, aiming to allow users to better control their health journeys and foster reflection without feeling overwhelmed by the broader digital environment. However, the concept of a “safe zone” must be flexible, as it would vary for each individual based on how much they wish to explore and how deeply they want to engage with their food allergy experiences. This aligns with the need for platforms to balance user agency and personalization, ensuring that reflection can be a constructive, rather than overwhelming, process. By incorporating this personalized approach, platforms could offer a more adaptive reflection space that responds to users’ evolving needs and comfort levels.

Another design opportunity lies in translating offline behaviors into online mechanisms. Participants in our study constantly filtered and inspected what they consumed and where they went to ensure food safety. Offline, they relied on friends and family to help “filter” their food, either by reviewing what they are eating, cooking for them, viewing these actions as expressions of care and support (as in 5.2.1). They also enjoyed consuming trusted content from these individuals, even if they did not actively search for such content themselves. This filtering behavior aligns with the social support framework [30], where online interactions often provide informational support (guidance on safe foods) and emotional support (reassurance and community connection). However, in the context of food allergies, this support extends to tangible support—directly influencing what individuals eat and how they manage safety. Our findings suggest that social media can serve as a bridge, facilitating tangible food-related assistance alongside emotional and informational support. While previous studies have explored filtering food content for those with eating disorders [21], our findings suggest that people with food allergies often find food content valuable and social support is crucial to overcome the feeling of isolation. Compared with the individualized design affordances proposed earlier, health community-oriented systems could integrate a social media filter that prioritizes or curates content shared by trusted friends, family members, or influencers who focus on safe, allergy-friendly food content.

6.2.3 Cross-Platform Considerations for Health Communities in the Social Media Ecology. Identity work is a continuous process that individuals engage in throughout their lives, especially in managing chronic health conditions like food allergies that change

and evolve over time [120]. Medical sociology concepts like “trajectories,” “illness biographies” and “health journeys” have been commonly used in HCI research to understand the complexities of chronic illness temporalities and patient identity in relation to system design [14, 61]. For those living with a chronic health condition, this process involves ongoing negotiations with how to present and how others perceive their identities, particularly in relation to one’s health. In the evolving social media landscape, such work also includes choosing where, when, and how to engage with the content across different platforms [137].

Text-based platforms like Reddit and Twitter are widely used in health communities. Reddit hosts large groups focused on addiction recovery [49, 126], eating disorders [18], and more, while Twitter is primarily used for bite-sized health information [137]. In contrast, TikTok’s short, dynamic videos enable creators to share real-life scenarios—such as dining experiences and safe travel tips—enhancing emotional connection [13, 115]. Beyond format, platform norms heavily influence posting decisions [125]. Participants in our study found TikTok’s informal video style and unpredictable algorithm supportive of identity play, allowing casual experimentation with food allergy content. Instagram facilitated social connection and self-expression, with participants switching between personal and allergy-focused accounts for flexible identity work. Facebook, in contrast, was used for controlled sharing and reflection, offering a more selective and private space for discussing allergy experiences.

However, participants in our study did not consistently track their food allergies in the long-term, as it often reminded them of negative experiences and reinforced a sense of technological control, echoing prior research on the downsides of self-tracking [20, 27, 33, 41]. Instead, participants achieved similar self-tracking benefits by narrating their food allergy journeys through social media posts, occasionally reflecting back on these narratives.

Systems could support this narrative-based reflection by curating cross-platform identity archives, blending casual TikTok vlogs with polished Instagram food reviews. However, revisiting past content can be emotionally difficult, especially for those whose allergies have worsened [68]. Designs should address this tension by allowing users to engage with past content at their own pace, ensuring reflection remains meaningful and supportive.

While cross-platform content integration can support healthy behaviors, identity work introduces important trade-offs. Though some value the cohesion of cross-platform integrity and connectivity, there are distinct advantages to maintaining siloed identities, particularly for stigmatized populations, as Haimson’s work on social media as a tool for social transition suggests [52]. Instead of fully merging platforms for people with food allergies, giving users more control over how their social media platforms share information would better support their ability to navigate and shape their presence. Participants used multiple social platforms in collaboration, allowing them to manage fragmented identities. This separation can empower users, enabling them to more conveniently toggle aspects of their identity on and off and maintain distinct audiences. Designers should carefully consider the benefits of connectivity and the specific contexts in which platforms are used when determining whether and how to integrate social media, keeping in mind the importance of user agency and need for managing the complex identities across online social spaces.

Living with chronic health condition like food allergies, particularly at a time in life when young people are naturally seeking to develop their independence presents unique challenges for designers. The participant experiences detailed in this paper illustrate the push/pull of illness identities—needing detailed health information, but also wishing to be free to think of pleasanter things; discovering a desire to explore new places, but being afraid to travel; craving diverse food experiences, but being on a restricted diet to stay alive. While designers can not reconcile all those tensions, technology can better support people amid the messy reality of food allergies and point to several ways the HCI community might move forward toward this goal.

Our work also argues for HCI researchers and designers to carefully attend to emergent forms of identity work connected to people's interactions with information/data/algorithms, be it on a new social media platform or mediated by artificial intelligence. In our discussion of *on-and-off identities*, we draw attention to one such type of identity work deeply tied to visibility on social media for those with food allergies, but future research is needed to better articulate a design space around illness identities in other patient communities.

7 Conclusion

This paper offers the HCI community a nuanced picture of people's experiences with food allergies, focusing on their social media use. Social media, for our participants, was a space of empowerment and community, but also stigma and emotional harms. Our findings highlight the strategies people developed to take care of themselves in those online spaces, including carefully managing their identities and desired online visibility on algorithm-driven social media platforms. We propose the sensitizing concept of *on-and-off identities* as a way to capture the complexities of these activities as an important type of identity work for those with a chronic health condition. Finally, we outline several design considerations for the HCI community: 1) design implications for promoting mindful social media engagement that help individuals with food allergies assert agency while managing vulnerability in identity and information work; and 2) a reflection on the challenges of designing for health within a changing landscape of chronic illness and social media ecologies. We argue for HCI researchers and designers to adopt a holistic perspective on identity and information work for people with chronic health needs, emphasizing the importance of this connection in designing for marginalized populations.

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