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Memorable Messages Parents of Children with Vascular Birthmarks Receive from Others: Implications for Stigma and Identity

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ABSTRACT

Parents of children with visible illnesses and physical differences, such as vascular birthmarks (VBs), often fear that their child will be stigmatized by others. Despite their use of various strategies to minimize this stigma, parents still frequently receive comments and questions from others about their child's condition. In the current study, we explore the source, content, and valence of these messages using a memorable messages framework. We also examine how parents react to messages from others and why those messages are considered memorable. To collect data, we administered a cross-sectional online survey through the website and social media pages of a national support group for parents of children with vascular birthmarks. A total of 70 parents completed the survey and, altogether, recalled 92 memorable messages. Our analyses revealed that the significance of the memorable messages coalesced around identity. Specifically, the messages described carried implications for a) participants in terms of their identities as parents, and b) participants' children in terms of their identities as stigmatized individuals. When messages were directed at parents, parents appraised them negatively or positively to the extent that they made parents feel judged or validated as parents of children with VBs. When messages were directed at children, parents appraised them negatively or positively to the extent that they labeled children and their VB as abnormal, unattractive, and undesirable, or accepted and complimented children as unique, special, and beautiful. The current research extends previous research exploring the role of memorable messages in negotiating identity.

Our self-identity does not exist in isolation; it is, in part, shaped through our interactions with and relationships to others (Hecht, 1993). While these interactions can serve to reinforce one's desired self-concept (Swann, 1987), they can also be stigmatizing. Goffman (1963) suggests that individuals may be stigmatized due to three primary characteristics: physical abnormalities, character flaws, and cultural identities (e.g., race, religion, etc.). For individuals with visible chronic illnesses, stigma typically stems from physical signs and symptoms that are noticeable to others. Thus, a person with a visible illness may be discredited or devalued by others because they have physical characteristics that make them different.

Interactions between stigmatized and non-stigmatized individuals can be stressful and they often require the stigmatized individual to engage in identity management (Goffman, 1963). Many individuals try to minimize the frequency of painful interactions by isolating themselves and using covering strategies to minimize stigma (Joachim & Acorn, 2000). Relevant to the current study, parents of young children with stigmatizing conditions often try to minimize the influence of stigma by providing unconditional acceptance at home (Goffman, 1963; Schneider & Conrad, 1980). Likewise, parents of children with craniofacial anomalies try to bolster their children's self-esteem

by talking positively about their differences and encouraging them to partake in typical childhood activities (Klein, Pope, Getahun, & Thompson, 2006). However, less is known about parents' interactions with others about their child's condition. Parents of children with physical differences frequently receive comments about their child's condition from family and friends, health care providers, and strangers; while some comments can be supportive and accepting, many are insensitive comments that highlight the child's differences (Nelson, Glenny, Kirk, & Caress, 2012; Tanner, Dechert, & Frieden, 1998). In the current study, we explore the content of the positive and negative messages parents receive and how parents respond to them. Doing so has the potential to uncover helpful strategies parents use to communicatively manage potentially stigmatizing messages that have implications for their and their children's identity.

Psychosocial influence of vascular birthmarks

Approximately 30% of infants are born with vascular birthmarks (VB; Fishman & Mulliken, 1998), which are congenital anomalies of the vascular system that result in visible imperfections of the skin and soft tissue (Buckmiller, Richter, & Suen, 2010). While many birthmarks will remain inconsequential or resolve

on their own, others can be disfiguring and sometimes life-threatening. Even those that appear minor at the skin's surface can be indicative of underlying conditions. For example, some capillary malformations (e.g., port-wine stains) are associated with Sturge-Weber syndrome – a condition associated with seizures and cognitive and motor delays. Accordingly, parents of children with VBs worry about their child's ability to be a “normal” child and the potential for their child to be stigmatized because of their birthmark (Kerr & Haas, 2014).

Many children with birthmarks experience social stigmatization and bullying (Kenny et al., 2016; Weinstein & Chamlin, 2005). Consequently, VBs can have an influence on the psychosocial well-being of children (Espinel & Bauman, 2018; Hoornweg, Grootenhuys, & van der Horst, 2009), and individuals with birthmarks frequently report feelings of distress and sadness (Kenny et al., 2016; Weinstein & Chamlin, 2005). Many birthmarks develop on the head and neck (Fishman & Mulliken, 1998), causing higher distress due to the cultural stigma of facial abnormalities (Shaw, 1981). In many cases, children with facial birthmarks experience stigmatizing behaviors from others such as staring and teasing (Masnari et al., 2012).

Parents of children with VBs also experience psychological distress due to their child's condition (Miller, Pit-Ten Cate, Watson, & Geronemus, 1999; Williams et al., 2003). Parents of children born with visible abnormalities experience a range of emotions immediately after the child's birth. Many report initial feelings of sadness and guilt (Bradbury & Hewison, 1994; Tanner et al., 1998). For some, the distress transforms into feelings of acceptance and relief that their child *only* has a physical anomaly; however, others live with sadness and guilt much longer. Parents also fear that their child will be teased (Sandler, Adams, & Taylor, 2009) and some experience anxiety taking their new baby out into social situations, fearing the reactions of others (Bradbury & Hewison, 1994). Tanner et al. (1998) found that public reactions to children's VBs include whispers, stares, questions, and unsolicited advice. These reactions were distressing for parents, often due to their “repetitive, relentless quality” (Tanner et al., 1998, p. 448).

Previous research confirms that individuals with facial abnormalities and their parents must manage constant reactions to their condition (Bradbury, 2012). However, little is known about the content or implications of these reactions. The current study seeks to explore the messages parents of children receive from others about their child's birthmark. We rely on a memorable messages framework (Knapp, Stohl, & Reardon, 1981; Stohl, 1986) to systematically explore the messages that have had a significant influence on parents of children with VBs.

Memorable messages

Although individuals receive many messages throughout the lifespan, some messages resonate for a long period of time and impact behavior and identity formation, negotiation, and management (Knapp et al., 1981; Stohl, 1986). Memorable messages are the sticky messages that layer, linger, and influence an individual's self-concept (Cooke-Jackson & Rubinsky, 2018). They also can influence an individual's assessment of their own behavior (Smith &

Butler Ellis, 2001). Although memorable messages may take many forms, typically they are characterized as brief, positive, and interpersonal communication (Knapp et al., 1981; Stohl, 1986). However, recent memorable message scholarship has explored the ways in which negative messages also influence individual's self-concept and identity (Holman & Koenig Kellas, 2018; Kranstuber, Carr, & Hosek, 2012). Memorable messages provide an especially suitable framework through which to study interpersonal health (Cooke-Jackson & Rubinsky, 2018), including interactions that can potentially stigmatize children with VBs and their parents.

Memorable messages provide a useful analytic framework because they reveal the ways in which communication implicates personal and social identity (Heisler & Butler Ellis, 2008). Memorable messages may also advance anticipatory socialization, preparing individuals for what to expect as a result of some aspect of their identity (Nuru, Coleman, & Saxton Coleman, 2018; Rubinsky & Cooke-Jackson, 2016). For parents of children with VB, memorable messages may function as anticipatory socialization by revealing how influential communicative moments prepare them for challenges, public commentary, or medical choices, while likely balancing messages about their role as a parent (Heisler & Butler Ellis, 2008). Overall, memorable messages serve to challenge or affirm salient aspects of identity by dismissing, erasing, or sharing hateful messages or, alternatively, by validating, supporting, or sharing encouraging messages (Heisler & Butler Ellis, 2008; Reno & McNamee, 2015; Rubinsky & Cooke-Jackson, 2016). Previous research has investigated parents as the source of messages that shape children's behavior and identity (see Koenig-Kellas, 2010); however, few scholars have examined parents as the target of memorable messages (e.g., Heisler & Butler Ellis, 2008). Therefore, we aim to extend the current literature by exploring how memorable messages influence parents' behavior and identity.

In sum, utilizing a memorable messages framework helps us extend the literature on managing visible, stigmatized conditions by calling attention not only to the content and saliency of other's reactions, but also to the implications of those reactions for identities. Consistent with existing memorable message research, one of our core goals was to document the content and characteristics of the memorable messages parents of children with VBs receive. Our other primary goal was to contextualize these messages, providing rich description of the memorability of these messages and how parents responded to the message giver.

Methods

We collected data using an online cross-sectional survey and recruited participants using purposive sampling. After obtaining approval from the institutional review board, we announced the study on multiple Facebook vascular birthmark support groups. The study invitation was also posted on the Vascular Birthmarks Foundation (VBF) website and distributed to the VBF Global Ambassadors, a group of advocates dedicated to raising awareness and support for the birthmark community. Eligible participants included parents who could recall at least one memorable message about their child's birthmark.

The survey was administered via Qualtrics (Provo, UT). First, we presented participants with Stohl's (1986) definition of memorable messages and asked them whether they could recall at least one memorable message about their child's birthmark. Participants who responded "yes" were asked to describe the message they received, who communicated the message, the situation in which the message was received, and why they believe the person chose to communicate the message. Participants then rated the valence of the experience using a 5-point Likert-type scale ranging from "very negative" to "very positive." Finally, we asked participants to describe their reaction to the message and why it was memorable. The survey was set up with a loop function to enable participants to describe as many memorable messages as they could recall. We also asked participants to report standard demographic variables and to describe their child's diagnosis, condition severity, and frequency of treatment.

Sample

A total of 70 parents completed the survey. The sample was primarily female (95.7%). Parents identified themselves as White/Caucasian (88.6%), Hispanic (4.3%), Multiracial (4.3%), Asian (1.4%), Black/African American (1.4%), and "None of the Above" (1.4%). Education levels ranged from high school degree or equivalent (1.4%), some college (20.0%), Associate's degree (10.0%), Bachelor's degree (41.4%), Master's degree (14.3%), and doctoral or professional degree (8.6%). The average household income included: less than \$25,000 to \$34,999 (14.2%), \$35,000 – \$74,999 (14.3%), \$75,000 – \$99,999 (14.3%), \$100,000 – \$149,000 (31.4%), and \$150,000 or more (17.1%). Three parents did not complete the demographic items.

Children's diagnoses included hemangioma (49.3%), capillary malformation/port-wine stain (29.6%), venous malformation (12.7%), arteriovenous malformation (2.8%), and lymphatic malformation (1.4%). Two parents were not sure of their child's specific diagnosis (2.8%). On a scale of 1 to 10, parents reported a moderate level of condition severity ($M = 4.78$, $SD = 2.46$) and a moderate frequency of care ($M = 4.62$, $SD = 3.00$). Approximately 39% of the children were male and 53% of the children were female (six parents did not report their child's sex). We asked parents to report their child's current age and how long ago they received the memorable message. These numbers enabled us to calculate how old the children were when the memorable messages were received. At the time of the message, the average age of the child was 1.42 years (Range: newborn–13 years).

Analysis

We analyzed demographic items using SPSS 24 (IBM Corporation) and entered all memorable message survey responses into NVivo 11.4.3 (QSR International) for qualitative analysis. Each author independently read all responses to gain a thorough understanding of the data. We first inductively coded for message type, with the entire message as the unit of analysis. Three message types emerged: advice, questions, and comments. After our initial round of coding, we ran a coding comparison in NVivo. Our percent agreements for each category were high:

96.9% for advice, 98.3% for questions, and 83.97% for comments. We met to resolve any discrepancies, and the results reported here represent 100% agreement. Next, we coded all responses for message source and valence, which was reported by the participants. Finally, using a process consistent with constant comparative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990), we read participants' full accounts of the messages (message content, sender's perceived motive, receiver's reaction, and memorability of message) and coded for salient themes. We completed another round of open coding individually and met to discuss any discrepancies and to refine the emergent conceptual framework. In the final round of coding, we applied our conceptual framework to the data to further refine categories and produce a cohesive narrative representing the participants' experiences.

Findings

Parents could report as many messages as they desired; therefore, the 70 parents recalled a total of 92 messages. The majority of messages (55.8%) were comments. Most comments were directed at the child's birthmark or appearance (e.g., "Oh, she has a hemangioma, poor girl."), but some were directed toward the parents (e.g., "It's pretty ironic because you were so overly cautious with everything during pregnancy."). Approximately 37.2% of the messages were questions. Most questions were straightforward inquiries (e.g., "What is that?"). However, some questions were rhetorical in nature, (e.g., "You know she won't like that when she is older, right?"). Because our unit of analysis was the recalled message in its entirety, some messages included both a comment and question (5.8%; e.g., "Ewh look at her face. What is it? It's so red and ugly."). Finally, 15.1% of the messages offered advice. Messages in this category offered either medical advice (e.g., "It will get bigger until she is 9 months and then it will go away.") or advice on how to handle the child's condition (e.g., "You need to accept your daughter for who she is and accept that this is how she will be.).

The sources of the 92 messages included strangers (37.2%), family or friends (26.7%), health care professionals (18.8%), and colleagues or acquaintances (15.1%). The contexts included public places (e.g., grocery store, church; 32.6%), interpersonal conversations (27.9%), health care facilities (e.g., doctor's office, pharmacy; 17.4%), small group events (e.g., music class, family gathering; 10.5%), or places of employment (5.8%). The messages were overwhelmingly negative (74.4%); yet, 21.9% were positive and 16.3% were neutral. Approximately 72.3% of the positive and neutral messages were in the form of comments and were relatively distributed across sources. Of the negative messages, most were from strangers (41.7%) and were in the form of comments (45.2%) and questions (42.5%). The average time since the recalled message was received was 4.07 years ($SD = 5.86$; Range: 0–37 years).

Central to the purpose of the study, we explored the content of the memorable messages, participants' reports of what made the messages memorable, and their reactions to receiving the messages. Our analyses revealed that the significance of the memorable messages coalesced around identity. Specifically,

the messages described carried implications for a) participants in terms of their identities as parents, and b) participants' children in terms of their identities as stigmatized individuals. When messages were directed at parents, parents appraised them negatively or positively to the extent that they felt judged or validated as parents of children with VBs. When messages were directed at children, parents appraised them negatively or positively to the extent that they labeled children and their VB as abnormal, unattractive, and undesirable, or accepted and complimented children as unique, special, and beautiful. In the following sections, we offer examples of positively and negatively appraised messages, exploring why parents considered these messages to be memorable and how they reacted. First, we describe messages that implicated parents by suggesting that they were "good" or "bad" parents in relation to their child's VB. Then, we describe messages that commented on the child's condition – characterizing them as different because of their birthmarks.

Parents

Many of the memorable messages commented on the participants' identity or responsibilities as a parent. Within this broader theme, we identified messages that were interpreted by parents as either a) judging their parenting by conveying blame and dismissal, or b) validating their abilities as parental caregivers by offering support and relief.

Blaming or dismissing parents

Parents recalled messages that judged their identity as a parent. The messages either blamed parents for the child's condition or dismissed their concerns as being overly protective or vain. Messages of blame most often occurred when the other person presumed the child's birthmark was a bruise or other injury. For example, one parent recalled a pharmacy employee's remark about her five-year-old son, "Excuse me, why is your sons arm covered in bruises? Have you beaten him?!" (Participant 70). Another parent described an interaction with a stranger who exclaimed, "Oh my god! That's terrible! How can you allow a baby to get sunburnt like that?" (Participant 22) while she was on a walk with her daughter. Parents acknowledged that these messages were likely the result of others being concerned for the well-being of their child; yet, they were offended that anyone would accuse them of deliberately causing harm to their child.

Other messages of blame suggested that the mother did something while pregnant that caused the child to be born with a birthmark. For example, one mother described the experience of introducing her 12-month-old daughter to family for the first time; her aunt remarked, "Does she have that because of something you ate while you were pregnant?" (Participant 24). Another mother recalled a conversation she had with a friend – explaining her newborn daughter's port-wine stain birthmark and the concerns she had about her daughter's future. The friend commented, "It's pretty ironic because you were so overly cautious with everything during pregnancy" (Participant 42). Both mothers in these examples acknowledge that the sender was likely motivated by curiosity and unaware of the negative connotation of their messages;

yet, both found the experience to be negative and insensitive as both came during times when the mothers themselves were trying to come to terms with their child's new diagnosis.

In addition to messages of blame, parents recalled messages that dismissed their concerns about their child's symptoms – threatening their identity as a capable caregiver for their child. One mother recalled the time she sought advice from a family friend, who was also a nurse, about her 2-month-old son's birthmark, "She basically told me worrying was going to affect my son – that his hemangioma wasn't going to grow and he was too young to do anything about it anyway" (Participant 38). The friend's advice was ultimately incorrect and the child required medication to control the rapidly progressing hemangioma. Another parent described a conversation with a dermatologist about her newborn daughter: "He told me I was vain and should find a way to support my daughter as she aged as the mark would eventually go away" (Participant 63). Similarly, another parent recalled that, when she expressed concerns that her 2-month-old daughter's birthmark did not seem to be a traditional port wine stain, a dermatologist said, "You need to accept your daughter for who she is and accept that this is how she will be" (Participant 18).

Reactions of blame/dismissal. Parents experienced many negative emotions in response to the judgmental messages. Some parents reacted by explaining their child's birthmark to refute the perception that they were causing harm to their child. One mother explained her reaction to a comment about her 8-month-old son, "I just tried to explain everything about birthmarks but I was angry" (Participant 55). Some parents said nothing in response to the message. While some parents chose to not respond, others were left speechless due to the shock of receiving the message. For example, the mother of a 12-month-old daughter recalled, "I was too stunned to say anything and the lady walked away while I just stood in shock" (Participant 22). And some parents, like this mother of a 4-year-old girl, found themselves at a loss for how to respond, "I didn't say anything because I didn't know what to say back" (Participant 44).

Parents were also upset by messages of dismissal. As one mother of a 10-month-old girl explained, "I could not believe that my very trusted pediatrician and family friend was telling me to essentially not worry about it" (Participant 32). They experienced anger and frustration from the lack of validation of their concerns. Another mother explained similar feelings of abandonment after receiving a message about her 2-month-old daughter:

I felt I wasn't listened to, I felt frustrated and didn't know who I could turn to for medical advice. Then I began doubting my gut feeling that it wasn't a PWS. I began questioning myself and asking myself if I really wasn't accepting my daughter's diagnosis rather than actually believing it was an incorrect diagnosis (Participant 18).

For some parents, dismissal caused them to doubt the health care system. One mother explained the doubts she experienced seeking care for her 9-month-old son: "I lost faith and trust in most of the children's treating doctors at that point." (Participant 68). However, others, like this mother seeking

care for her 2-month-old daughter, described how the dismissal motivated them to take action: “It really upset me at the time. However, I didn’t give up on my gut feeling [...] I contacted the Vascular Birthmark Foundation and spoke to [doctors] who confirmed I was right and my daughter actually has segmental hemangioma” (Participant 18). Overall, many parents who received messages of dismissal just wanted validation of their concerns and confirmation that they were not being vain: “I felt that her response negated or downplayed my [12-year-old] daughter’s pain. My ‘mama bear’ feelings came out and I wanted people to know that my child is hurting” (Participant 65).

Memorability of blame/dismissal. For many parents, these messages of blame and dismissal stuck with them for years after they were received. Most parents considered these messages memorable because they were hurtful. This was especially true if the message came from someone they expected to be supportive. For example, one mother explained that she found the message about her 4-year-old daughter memorable “because it was one of the meaner things said and it was from family so it was unexpected” (Participant 44). Similarly, parents considered negative messages memorable if it was the first of its kind. While recalling a message of blame from a stranger while grocery shopping with her 6-month-old daughter, one mother explained, “It was one of the first times anyone had commented on my daughter’s VMs to me, and it felt like an accusation that I was hurting her” (Participant 41). Parents also considered messages of blame to be memorable because they were delivered during a particularly vulnerable or uncertain time. One mother who received a negative message from a stranger explained why the experience was memorable:

[B]ecause it was the most horrible feeling that someone thought I could have been the cause of her birthmark (after convincing myself for the 3 months of her life that it wasn’t my fault that she was born with it; Participant 22).

Other parents described how dismissive messages impacted their own coping. One mother explained that receiving the message while seeking care for her 10-month-old daughter “was the beginning of the very lonely and stressful journey of being a parent of a child with a hemangioma” (Participant 32).

Supporting parents

Positive messages directed at parents were supportive messages that validated their identity as a caregiver offering advice, showing support, and conveying empathy. For example, one mother recalled her conversation with a nurse about her newborn son:

I had a nurse tell me that others would react according to how I acted, i.e., if everyone saw me being able to cope then they would know what to say or how to act and it is so true. That was the most simple but best advice I heard and use it in other situations 11 years later (Participant 11).

Parents also described messages from others who understand the experience of caring for a child with a birthmark. One mother described a message from a parent in an online support group when her daughter was 11 months old:

Know there is a group for you. There are other families and mothers that are going through the same thing. The anxiety of what the future holds, will she have KT syndrome, will the port wine stain lighten, will she be made fun of, will she be bullied? Just know that we are all here for you so message me at any time when you are feeling depressed or anxious or frustrated and even when you are happy (Participant 15).

This support gave her the validation she needed to take on the role of caregiver for her daughter. Another mother reported similar relief when a complete stranger acknowledged her 18-month-old daughter’s birthmark. She described the exchange:

Stranger: Your daughter is beautiful!

Me: Thank you! I’m not used to hearing that!

Stranger: I know about hemangioma. Your daughter is beautiful and has a great mom! Me: Thank you so much! (Participant 10).

This simple statement both validated the daughter’s appearance and the mother’s identity as a “good parent.” Parents also positively appraised messages from health care providers that relieved the guilt they felt about their child’s birthmark. One mother, whose daughter was 12-months old at the time, recalled a specialist saying, “You didn’t do anything to cause this. It is in no way your fault” (Participant 68).

Reactions to support. Unlike negative messages, which often prompted a communicative response from parents, supportive messages elicited emotional responses from parents in our sample. Specifically, parents described feeling positive emotions and crying tears of joy after receiving these validating messages. One mother explained, “I cried profusely and felt a sense of peace and calm” (Participant 15). Another recalled, “I swelled up with emotions. I was proud, happy, relieved” (Participant 10).

Memorability of support. These validating messages were memorable because they provided a sense of relief during a vulnerable and uncertain time. Parents still recalled these messages years after they were received, suggesting that they were instrumental in their ability to care for (and cope with) their child’s birthmark. For example, some parents felt that it helped them to feel less guilty about their child’s condition. The mother whose physician assured her she did nothing to cause her toddler son’s birthmark explained:

I think I looked anxious (I was) and the treating doctor put her hand on my knee and said those two sentences. It meant so much for someone to say that because I was carrying that burden for so long. [...] It was like she was reading my mind and I felt a great sense of guilt lift off my shoulders (Participant 68).

Another mother recalled the relief she felt when a stranger acknowledged her 18-month-old daughter’s birthmark. She explained “for once someone saw my daughter as a beautiful girl. Someone else saw what I see. I also didn’t have to explain her hemangioma for once” (Participant 10). This mother’s comment demonstrates the relief many parents experience they are not burdened with the task of explaining their child’s condition to others.

Children

Messages were memorable not only because they carried implications for parents and their identities as caregivers, but also because they commented on the physicality of children's birthmarks in ways that were potentially stigmatizing. Specifically, we identified two types of messages that functioned to: a) stigmatize children and their VB as abnormal, unattractive, and undesirable, or b) accept and compliment the child as unique, special, and beautiful.

Stigmatizing the child

Messages that stigmatized the child and his or her VB as abnormal, unattractive, and undesirable focused on the physicality of the VB as a "mark" (Smith, 2011) or difference. The first type of stigmatizing message explicitly characterized the VB in negative ways. For example, some message senders blatantly expressed disgust at the sight of the VB. One mother recalled a time when a little girl was staring at her 18-month-old daughter at a garage sale. She hoped the little girl would ask a question, but instead she said, "Ewh, look at her face. What is it? It's so red and ugly" (Participant 63). Many parents recalled messages that were posed as questions and seemingly benign, such as, "What is wrong with his face?" (Participant 6) and "What happened to her head?" (Participant 58). These inquiries were troubling to parents because "wrong" and "happened" carry negative connotations and effectively cast the VB as a negative attribute of the child. Expressions containing "poor" had a similar effect. One mother shared that a physician and co-worker said about her 4-month-old daughter, "Oh she has a hemangioma, poor girl" (Participant 23). Labels assigned to the child were also impactful. One mother recalled taking her 3-month-old daughter to a bookstore and sitting with her in a chair as they read books together. A stranger walked up to the two and said, "It's so nice that you have your disabled daughter out for the day" (Participant 3). Hence, even messages that, on the surface, were framed as questions, sympathy, and compliments carried stigmatizing connotations.

The second type of stigmatizing message parents recalled suggested the child's appearance could "return to normal" according to objective standards of beauty. These messages referenced how children's VBs could become less visible, either on their own or by parents taking action. For example, a stranger told one mother of a 3-year-old, "Oh, it's a good thing that will go away. You wouldn't want that on her face forever" (Participant 40). Other message givers told parents that the VB could and should be covered; for example, the mother of a newborn recalled being told, "He should just get tattoos all over his arms when he is older...everyone is doing it now, and it will cover it up" (Participant 13). Similarly, a family member told one mother of a 12-month-old, "Well, she is beautiful despite her birthmark. She is lucky she is a girl and can wear makeup to cover it up" (Participant 44). Other parents reported similar messages that their children are "still gorgeous" "despite birthmarks." Again, these qualifiers transformed a message intended to be supportive into one that implied the child would be more attractive without the birthmark.

Other message-givers offered advice to parents on removing the VB surgically, such as one aunt (also a nurse) who told a parent in a straight-forward manner: "That will have to be surgically removed" (Participant 33). Some comments were directed at the child. For example, a mother recalled a stranger saying to her 12-month-old: "Oh you poor thing, hopefully one day your mommy will have that removed for you" (Participant 64). Another mother shared about her experience while in China adopting her four-year-old son:

Person after person THERE told him directly how very thrilled they were for him to be going to America with new parents so that we could REMOVE all of his birthmark!? That is not any kind of a possibility, then or now, but it apparently was their own universal belief or hope or both (Participant 19).

This mother explained that "adults felt they needed to 'assure' the child that he would soon be 'fixed'." She felt the comment was "nearly impossible to counteract" because of perceived cultural differences concerning attractiveness.

Reactions to stigmatizing messages. Parents felt confused and hurt by stigmatizing messages, often trying to make sense of why someone would say them. One mother explained: "I didn't understand why he felt the need to say something negative about my daughter. As if she had a horrible disfigurement" (Participant 23). Another mother recalls the impact of a stigmatizing message from a stranger: "It was the first remark a stranger made about my daughter's birthmark, and by far the most surprising and hurtful" (Participant 3). Parents' confusion and hurt often stemmed from the contradictory nature of stigmatizing messages – especially those that were intended to be compliments, but clearly implied that the child's beauty was contingent on making the VB invisible. As the mother above who was told her daughter (who was 12 months old) is "lucky" because she can wear makeup to cover her VB shared, "I don't want to hear that she is beautiful despite anything or even with it. I also have no plans to tell my daughter to cover it up" (Participant 44).

Parents' reactions also included direct responses to the message senders. Some parents responded by defending their child and refusing to believe their child was somehow abnormal. One mother responded to her father-in-law's comment by telling him "that I will raise her to be confident and to ignore any negative comments toward her about the hemangioma. And that she is beautiful and it doesn't matter if anyone else likes it or not!" (Participant 23). However, while some parents shared how confident they felt in defending their children from stigmatizing remarks, one mother explained feeling conflicted when someone said that it appeared her one-year-old daughter had fallen in some gravel. She was embarrassed because "everyone at the tables near us had been wondering what was on her [daughter's] face" (Participant 14). However, she responded to the person by explaining daughter's Port Wine Stain. She shared, "I was grateful to have the opportunity to tell someone about PWS but that always makes me feel bad because I don't want people to treat her differently because of her PWS." Still, messages received in public places were appraised particularly negatively by parents, as they drew attention to how children were different in front of others, and they were often the first

comments and questions parents received about their child's VB. One mother shared, "It's memorable because it was one of the first times someone in public had pointed out my son's birthmark and I thought it was a rude comment to be made" (Participant 17).

Memorability of stigmatizing messages. Some parents described stigmatizing messages that occurred nearly a decade ago, suggesting that the hurt they felt at the time persists to some degree today. Stigmatizing messages were memorable to parents because they elicited strong emotions associated with the belief that others saw their child as "less than" because of the birthmark. Messages commenting on the undesirability of the birthmark or the notion that it should be removed were upsetting for parents. As one mother explained, "the underlying message we could hear also was 'you are not good enough as you are; you are broken'" (Participant 19). Parents who were told their child is beautiful *despite* the birthmark often acknowledged that the other person was likely trying to offer support, but considered the message to be negative. As one mother explained, "they believed it would help me feel confident," but "the person who said this seemed to be concerned with my child's 'attractiveness,' or lack of, because of his hemangioma" (Participant 43).

Many of the stigmatizing messages were directed at very young children, causing parents to worry about how their child would be treated by others. For many parents, a negative remark about the child's VB was a preview into the child's future of receiving similar stigmatizing messages that would make them feel badly about themselves. They worried their children would be excluded, bullied, and picked on. For example, one mother confided her fears: "I already feel terrible when I see people do a double take on my baby thinking of the day he notices" (Participant 31). Another shared:

I see my daughter as beautiful but I know the world can be a cruel place. When her birthmark grew to a noticeable bump on her head my fear has always been that the first thing people will see is her bump, instead of her gorgeous eyes, chubby cheeks, and ear to ear grin. When the first thing my coworker chose to comment on was her bump it made some of those fears a reality (Participant 58).

Sometimes these fears seem to be realized as children grew. While reflecting about her daughter with a VB being told, "No dirty faces!" one mother shared, "It was the first time a peer of my child's picked on my daughter for her mark. Excluding her because of it. It broke my heart" (Participant 42). These fears were also reinforced explicitly for some parents when message givers commented directly on the potential for the child to be teased at school. One mother recalled a comment about her 2-month-old son: "Oh your kid is going to be the kid in middle school that everyone says ewww he has something, don't talk to him" (Participant 31). Messages like this one suggest to parents that the stigma of the child's VB may be long-lasting.

Accepting and complimenting the child

The second type of memorable messages centering on children's identities accepted and complimented the child as unique, special, and beautiful. Whereas the previous kind of child-centered messages positioned VBs as different and undesirable, messages in this category encouraged parents to re-claim their child's

birthmark and even celebrate it. For example, "She's beautiful! You don't need to get rid of it" (Participant 42). Instead of making parents feel as if they had to hide their children's VBs, accepting messages directed parents to actively *not* cover their children's VBs. For example, "It's part of her. Don't worry about covering it up. It makes her who she is" (Participant 45). Similarly, one mother recalled the message, "It's perfectly shaped like a heart. It's special and it's her" (Participant 63). Together, these two messages convey the uniqueness of the birthmark and encourage parents to take pride in their child's VB.

Other messages in this category recognized VBs as different but emphasized how they are beautiful (versus unpleasant). One mother recalled a message from her grandmother who framed the VB as "a star [he hit] on the way down from Heaven" (Participant 56). This was a turning point for her because, "after that his birthmark became a non-issue with everyone in the family." Similarly, another parent recalled being told that, "birthmarks are a sign of a child who has been blessed" (Participant 69). One mother recalled how her younger son (without a birthmark) asked a face painter at a festival to make him a birthmark like the one on his older brother's face. She expressed relief from the acceptance conveyed by the request. As an uncommon, albeit powerful message that came from the child with the VB, one mother recalled her 23-month-old with a Port Wine Stain birthmark running her right hand up her left hand and forearm saying "Pretty" (Participant 27).

Reactions to accepting messages. Parents reacted to these messages positively, but no less emotionally than the negative, stigmatizing messages. Some said they felt happy and proud, but many shared how accepting messages brought them an overwhelming sense of relief, as it did for one mother who said that in that moment she believed that "strangers could look past her [daughter's] birthmark and see her beauty" (Participant 42). Several parents said they cried upon receiving the accepting message. Parents described how these emotional reactions also included a renewed sense of "hope" and re-commitment to being "strong" for their child (Participant 63). As one mother shared:

I cried...I snuggled my son in tight and swore to always make sure no matter what people thought of how he looked that I was make sure he had no doubt he was anything less than beautiful, since he was of course, from Heaven:) (Participant 56).

Memorability of accepting messages. Some parents recalled accepting messages that occurred many years ago (one parent recalled a message that she received 18 years ago), suggesting that the impression they leave is just as lasting as negative messages. Accepting messages were memorable for two major reasons. First, they were often surprising to parents because they violated parent's expectations; parents anticipated receiving or were used to receiving negative messages about their child's VB. For example, when asked what was memorable about the message she received, one mother's telling response was simply that it was "a positive view towards birthmarks" (Participant 69). This was particularly true when the message-giver was not someone they expected to receive a positive message from (e.g., "My grandmother and I did not always get along"; Participant 56).

The second major reason that accepting messages were memorable to parents was that they seemed to bring immediate realizations and changes in perspective. As examples, parents shared how messages of acceptance “forced me to find a new approach and perspective for my daughter’s sake” (Participant 63) and “made me realise there is more to life than worrying about what you look like” (Participant 45). They said they began to believe and internalize that their child was, indeed, beautiful, despite the negative things they had been told (or were afraid to hear) from others. The mother of the child who called herself “pretty” shared what the experience meant to her: “I tell her all the time that she is beautiful. I feel she was showing me that she agreed” (Participant 27). Acceptance from others, even the child with the VB, helped parents gain confidence in this belief.

Discussion

The goal of the current study was to explore the memorable messages parents of children with VBs receive from others. Overall, our findings illustrate how issues of identity are central to the messages that parents of children with VBs consider memorable. Parents received messages that either undermined or validated their personal, family, and children’s identities. Indeed, research and theorizing suggest that memorable messages may be confirming or disconfirming in nature (Reno & McNamee, 2015), and often serve to affirm or challenge salient aspects of personal and social identity (Heisler & Butler Ellis, 2008).

Though a vast majority of the recalled messages were negative and disconfirming, messages that validated parents’ identity or their child’s identity served to internalize notions of acceptance and support. For parents, messages conveying that they were a “good” parent or that they were doing a “good job” managing their child’s condition were appraised positively and helped parents cope. Parents go through a period of psychosocial adjustment when their child is born with a physical abnormality (Bradbury & Hewison, 1994). In the current study, parents described this adjustment period as a vulnerable, uncertain, and lonely time and often attributed the memorability of supporting and validating messages to the fact that they were received during this particularly fragile time. Messages confirming children’s identities were appraised positively and seen as supportive to the extent that they downplayed the physical aspect of the child’s VB but also celebrated the VB as something unique, special, and beautiful. These findings underscore the importance of receiving confirming messages from others – and giving these types of messages as would-be support providers – as research suggests that parents’ acceptance of their child’s birthmark is contingent on support from family who unconditionally accept the child and do not define the child by their birthmark (Tanner et al., 1998).

In contrast, disconfirming messages threatened a positive parental identity by implying it was the parent’s “fault.” This is consistent with previous research finding that parents of children with VBs are often accused of abuse or neglect (Williams et al., 2003), and that parents of children with VBs often blame themselves for their child’s condition. When parents feel this guilt, they are often more sensitive to comments from others,

especially those implying they are to blame for their child’s birthmark (Tanner et al., 1998). In the current study, many of the messages reinforced parents’ feelings of guilt – either by directly accusing the mother of unhealthy behaviors during pregnancy or by presuming the child had suffered an injury due to parental negligence. Even messages that appeared to be innocent inquiries or comments (e.g., “What happened to her head?”) were interpreted by parents as judgmental. Many parents in our sample were still coming to terms with their child’s condition and learning to manage their feelings of guilt. Therefore, these seemingly innocuous messages likely confirmed parents’ internal fear of being blamed by others for their child’s condition. This internal, or felt, stigma can be just as, if not more, distressing than enacted stigma (Scambler & Hopkins, 1986). Parents of children with autism have reported that this fear of stigma often causes them to avoid social situations and ordinary public activities such as shopping (Gray, 2002). The fear of stigmatization is likely to affect parents’ ability to cope with their child’s condition.

Negative messages that came from trusted family, friends, and providers were particularly memorable because they were surprising in nature. Parents of children with clefts of the lip and/or palate have reported similar reactions from family and friends who disapprove of the child’s condition or blame the mother for the condition (Adeyemo, James, & Butali, 2016). These memorable messages from familiar others are important because they may affect and reflect relationships between the sender and receiver of the message (Greenwell, 2018; Kranstuber et al., 2012). For example, memorable messages young adults receive about mental health are significantly related to perceptions of relational closeness with the source of the message (Greenwell, 2018). Thus, parents of children with VBs may also re-evaluate relationships with individuals who deliver their memorable messages depending on the content and valence of the message.

Disconfirming messages also reinforced VBs as a site of stigma for young children, reflecting the societal stigma toward people with physical differences (Goffman, 1963). Many of the stigmatizing messages were about children who were only a few months old, suggesting that parents of children with VBs manage stigma for many years. These intrusive comments often forced parents to engage in facework to prevent judgment about their parenting abilities, and to prevent others from judging their child as “less than.” Typically, facework refers to the communication behaviors individuals engage in to protect their own identity or identity of the other person (Goffman, 1967). In the current study, parents also engaged in facework *on behalf* of their young child’s identity. This form of surrogate facework has been found in romantic partners (McBride, 2010), but less is known about the “proxy” facework that parents do on behalf of their children, especially those with stigmatizing conditions. Many parents in our study were also forced to engage in spontaneous disclosure (Charmaz, 1991), which is an unplanned, emotional response to intrusive requests. These spontaneous disclosures are often more distressful than deliberate disclosures and can result in further feelings of stigma and isolation (Joachim & Acorn, 2000). In the current study, this was particularly true if

parents did not feel prepared with an explanation that preserved their and their child's identity. Parents were often too shocked or hurt to respond with a thorough explanation, and a few parents were still unsure of their child's diagnosis and found explaining it to others to be difficult. Indeed, parents often experience a great deal of uncertainty because they receive inconsistent information about their child's diagnosis and treatment from providers, especially those who are unfamiliar with VBs (Kerr, Harrington, & Scott, 2019). This can make responding to others' inquiries challenging when parents are still learning about their child's diagnosis and prognosis themselves.

Theoretical and practical implications

The current study extends memorable messages literature in at least two ways. First, we explored the influence of negative messages. Historically, memorable messages have been characterized as brief, positive messages (Knapp et al., 1981; Stohl, 1986). Only recently have scholars focused on negative messages and the influence of message valence in addition to message content (Koenig-Kellas, 2010; Kranstuber et al., 2012). The majority of messages recalled by the parents in our sample were memorable because they were hurtful and isolating and threatened either their identity as a parent or their child's identity as a stigmatized individual. The second contribution of this study is in its findings that memorable messages can come from complete strangers, and that these messages can have significant impacts on recipients' identity. Previous literature has often focused on messages from individuals who are in respected authorities (e.g., teachers, parents) with whom recipients have frequent contact (Stohl, 1986). In the current study, it was evident that messages from strangers were influential; positive comments helped to support parents as caregivers and to validate the child's internal and external beauty, and negative comments reinforced the public stigma of physical differences and the significance of cultural standards of beauty, even in young children. Overall, our findings contribute to existing literature demonstrating that an important function of memorable messages is to negotiate internalized evaluations of identity. In addition, our findings extend these claims into the role of memorable messages, both positive and negative, in balancing multiple sites of identity (i.e., one's own identity as a parent and concern for the child's identity).

Our study also has many practical implications connecting memorable messages and the provision of social support. First, our results suggest that support providers (i.e., medical providers, family, and even strangers) should avoid expressions of surprise and disgust entirely. This may seem obvious, and yet, many parents still reported receiving these kinds of messages (e.g., gasps, "ew,"). Next, supportive others should exercise caution asking questions – specifically, rhetorical questions (e.g., "You know she won't like that when she's older, right?") and those questions including words such as "wrong" or insinuating blame should be avoided (e.g., "What's wrong with her nose?"). Moreover, our results support previous research suggesting that advice is complex and can present face-threatening dilemmas for the receiver

(Goldsmith & Fitch, 1997; MacGeorge, Feng, & Thompson, 2008). Parents in the current study recalled advice and support that were seemingly well-intended but were interpreted as intrusive and insulting. As examples, messages intended to reduce parents' anxiety about their child's well-being actually dismissed the parents' feelings and concerns, and messages that attempted to reassure parents that their child's birthmark can be easily concealed or removed insinuated that the parents need (or even want to) modify their child's appearance. Indeed, advice, at the very least, should not focus on the physicality and unattractiveness of the birthmark. Instead, our findings suggest that comments, questions, and advice messages that *both* affirm parents in their role as caretakers and accept children and/or their birthmarks may be the most supportive.

In addition to the potential for problematic support, the current study supports the need to equip parents with the skills to respond effectively to intrusive requests or insensitive comments. An opportunity exists for health care providers to help prepare parents to expect these everyday messages and know how to respond in a way that minimizes the potential stigma. To start, providers should assure parents that they did not cause their child's birthmark, which can help mitigate the impacts of both felt and enacted stigma on parents' self-concept. Additionally, providers can share with parents some of the strategies uncovered in this study. One strategy is defending the child through expressing their unconditional love for him or her, which parents in this study felt modeled acceptance and served as a guide for others. Another strategy was to explain the child's birthmark to a) eradicate any assumptions that parents harmed their child, or b) minimize the stigma placed on the child. This finding is consistent with previous research (Link, Mirotznik, & Cullen, 1991) suggesting that education is a common strategy used to respond to stigmatizing messages "to persuade others to change their stereotypes, to generate acceptance, and to ward off rejection" (Smith, 2011, p. 460). Given the continuing lack of public awareness of VBs (Tanner et al., 1998), education may be a productive form of facework that helps protect both the parent's and child's identity.

Conclusion

The goal of the current study was to explore the memorable messages parents receive from others about their child's vascular birthmark (VB). Due to the physical appearance of VBs and the lack of public awareness of the condition, parents receive frequent comments and questions from family, friends, health care providers, and even strangers about their child's appearance. Our findings suggest that these messages can significantly influence parents' socially constructed perceptions of their own and their child's identity. Consequently, parents engage in facework to manage their own identity *and* the identity of their child – especially in response to insensitive comments. Health care providers may be able to prepare parents for the emotional experience of receiving these messages and equip them with the information needed to respond in a way that helps minimize the influence of stigmatizing messages.

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