

A Summary of Research on the Mother-Daughter Relationship & the Influence of Facial Difference

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THE GOALS OF THE PROJECT

The purpose of this Master's thesis was to understand what the mother-daughter relationship looked like when the daughter was living with a facial difference.

It sought to answer four distinct research questions, including:

1. What role do mothers play in helping their daughters navigate their social environment, experiences in the medical system, and family relationships?
2. In what ways do mothers influence their daughters' development of self, body and gender in adolescence?
3. How has a daughter's facial difference contributed to her sense of self and her relationship with her mother?
4. Is there a difference in the experiences of the mother-daughter relationship when the mother is also living with a facial difference?



WHY STUDY MOTHERS AND DAUGHTERS?



We decided to focus on young women because of the prevalence of body-image issues and low self-esteem in young women living with facial differences. This issue arises not only in studies of young girls' adolescence, but is one conclusion made time and time again in studies of young girls living with facial difference. Moreover, we decided to study daughters because they are said to lie at the intersection of two "minority" identities. Not only are they female and challenged by some of the familiar issues with developing into womanhood, but they are also doing so looking different. This intersection adds a certain layer of complexity to the project as it is critical to understanding the experiences of these young women's moving through the world.

Mothers were selected as the primary person of interest given that an overwhelming majority of research suggests that they are the most significant female role model in a young woman's life, and that through their relationship with their daughters, their girls learn to develop and become confident in their sense of self. The added layer of raising a child with a physical difference was critical to our decision to study mothers. It has been noted in research that caring for children, specifically, children with differences and disabilities, falls almost entirely on the shoulders of mothers: They are the caregiver who often seeks out services and care, confronts certain stigmas and barriers that their children similarly face. As such, they are said to occupy a very unique position in the lives of their children.

WHY ARE THESE QUESTIONS IMPORTANT TO STUDY?

In the last 50 years, the study of facial differences has grown immensely. What is interesting about the existing literature on facial difference however, is that most of the research is not done by garnering the opinions and experiences of individuals actually living with the facial difference. Instead, much of the research is done by interviewing or surveying parents, family members and teachers. Therefore, the entire subjective experience of what it is like to live with a facial difference is lost. Moreover, in many cases, surveys and questionnaires are used to investigate what it is like to live with a difference. These methods however,

often result in a significant oversimplification or omission of the complex subjective experiences and relationships of individuals touched by a facial difference.

There is also very little research to be found that concerns family relationships in the context of facial difference. It was difficult to come across any previous research that specifically looked at any aspect of the parent-child relationships when the child was living with a facial difference, let alone the mother-child relationship specifically. Those studies that I did come across however, were primarily focused on attachment processes, and specifically focused on infancy. While these topics and themes are important to our overall understanding of facial difference and how it impacts the family, there are many, many more areas that are still left untouched.



Finally, one trend in the research that has spanned across all topics and studies is the almost exclusive focus on the ways in which facial differences takes away from or impedes one's ability to lead a normal life. The majority of results focus on the ways in which individuals living with a facial difference struggle with social interaction and are isolated, do poorly in school, and often suffer from various mental health issues like depression and anxiety. Any studies on the impact of facial difference on the family speak to the ways in which mothers are unable to form secure attachments with their children, the ways in which parents become overcompensating and permissive, or how marriages often fall apart because of the stress of having child with a difference. While it is important to recognize these experiences, research does little to unpack how these experiences come into being, and the overwhelming majority does not consider what facial difference could perhaps contribute to an individual's life or a family, nor does it consider how an individual or family can positively work within their circumstance.

WHAT WE DID



A B O U T F A C E

For the purpose of the study, we performed 22 in-depth interviews with young girls, ages 13-22 living with facial differences and their mothers, whose ages were unrestricted. In total, ten daughters and twelve mothers took part. All participants were recruited through AboutFace, and the majority were located in Canada, while one mother was living in the United States.

Interviews were done individually with a mother or a daughter, either in person, by telephone, or by Skype. Interview questions centered around the research questions, with emphasis on the relationship experienced by mother and daughter, the roles that mothers played in all aspects of their daughters lives and the ways in which facial difference has been experienced by the mother as an individual, the daughter as an individual, and the relationship as a whole. Interviews lasted anywhere from twenty-five minutes to two hours.

A variety of congenital facial differences were represented within the sample, including, Cleft Lip and Palate, Treacher Collins Syndrome, Cruzon Syndrome, Goldenhar Syndrome, Port Wine Stains, Microtia, and Neurofibromatosis. There was also one acquired facial difference included within the sample, Juvenile Arthritis. Within the sample of mothers interviewed, three mothers were also living with the same facial difference as their daughters. However, each of the mothers stipulated that they did not consider their facial difference to be as severe, pronounced, or influential as their daughters'.

WHAT WE FOUND

In asking participants about the roles they felt mothers played in the various systems daughters encountered, a number of common themes arose. In the social system, or interactions with known and unknown persons, mothers were found to play the role of:



COORDINATOR: The majority of mothers often took charge in ensuring that their daughters had a group of friends that they were involved with. They encouraged their daughters to engage with other children, or actively sought to make their daughters part of a community group that fostered close friendships. In some cases, mothers were instrumental in planning and organizing social events for their daughters to spend time with other children in an effort to ensure that these connections were maintained. In some instances, this coordinating role was upheld and considered even when it impacted important family decisions, or meant a reconfiguration of the mother's own social circle.

EDUCATOR: The role of social educator was three-fold for mothers. First, mothers and daughters both recognized that mothers were proactive in educating daughters on others' perceptions and opinions of facial difference, especially the myths and stereotypes that society may hold. Mothers also engaged their daughters in dialogues around their conditions in an effort to afford them the necessary skills to not only defend themselves in times that they feel marginalized, but to educate other people. The majority of the mother-daughter pairs recalled how mothers provided their daughters with age-appropriate language and quick summary phrases to explain their condition to unfamiliar and curious. In other instances, mothers were personally responsible for the education of others around their daughters' facial difference; specifically, what it is and how it developed. In either case, this role was undertaken with the intention of helping others understand their daughters' difference, and therein breeding an environment of awareness, comfort and acceptance that is potentially less hurtful and more supportive of their child.

DEFENDER: Daughters and mothers both recognize that in social environments or interactions where the daughters were made to feel uncomfortable or overwhelmed, mothers were responsible for confronting or diffusing the situation.

Within the medical system, which played a large role in the lives of all the mothers and daughters interviewed, mothers were considered the:

PHYSICAL & EMOTIONAL SUPPORT: Every mother was very active in their daughter's medical treatment, accompanying their daughters to many, if not all, of their appointments and consultations; a gesture welcomed and appreciated by their girls, regardless of their age. Mothers and daughters alike acknowledged that mothers are also highly involved before and after surgical procedures and treatments. Many of the daughters recalled how mothers were able to discuss upcoming appointments and procedures with them in a way that informed them of what was going to take place while alleviating some of their anxieties. Many of the mothers also took time off work to be with their daughters when they came out of surgeries, taking on a very supportive, nurse-like role during their recovery.



ADVOCATE: Many of the mothers noted the importance of asking questions of the medical system and various medical teams they came in contact with. Many daughters would regularly take up the medical issues, questions or concerns they had with their mothers prior to the appointments, and had their mothers act as their voice. Some of the mothers also mentioned how they have advocated for their daughters through defending and supporting their decisions to put non-functional surgeries on hold. Moreover, many mothers discussed how they petitioned for increased support outside of the hospital; switched doctors or medical teams when they felt it was in their daughter's best interest; and voiced their opinions, suggestions and recommendations to medical teams so their concerns or issues were addressed in a timely fashion. There was however, recognition on behalf of both members of the dyad that the mother assumes this role to ensure and prepare the daughter to advocate for herself in the future.

Within their own unique family systems, either nuclear or extended, mothers played the important role of:

LIAISON: Mothers and daughters alike recognized that the mothers were very open with all members of their family around their daughters' difference. Many mothers felt that they never hid their daughters from their family, but rather, fostered acceptance within the family through their honesty. Mothers were also responsible for keeping their family members in the loop regarding upcoming surgeries and treatments. In families that had other children, mothers and daughters were equally sensitive to the needs of siblings, and many pairs discussed how mothers incorporated siblings in their daughters' lives; bringing them along to medical appointments, having discussions with them regarding the daughters' difference, and answering whatever questions they may have.

Finally, although we did not intend to research mothers' and daughters' relationships with the media, it was one system that continued to surface in a number of the interviews. Here, the mothers assumed the important role of:



GATEKEEPER: Mothers actively regulated what types of media their daughters engaged with. Many of the pairs also noted that mothers would engage their daughters in open discussions about models and actresses depicted in the media, refuting the messages that they found prevalent regarding beauty and perfectionism with critiques of photo-shop and other editing procedures. Other mothers chose to de-emphasize the importance of physical appearance, and instead focus on the significance of character to redefine beauty for their girls.

These roles however, were not without their own challenges. In fact, a number of mothers discussed how tiring the assumption of these roles can be, especially social coordinator and defender. Other mothers noted the tensions involved with being their daughters' medical advocate and support, emphasizing the internal struggle of wanting to care for and comfort their daughters without coddling them, and wanting to respect their daughters' decisions about their own bodies while still valuing the professional opinion of medical teams. Daughters also experienced tensions around these roles: a number of girls cited how they were sometimes made uncomfortable when their mothers acted as an educator or because many felt they were old enough to navigate social interactions on their own. Similarly, the majority of daughters felt uncertain as to how to engage with their doctors given their inexperience with handling these scenarios personally. Moreover, although they appreciated their mothers efforts to control some of their anxieties

around surgeries, some daughters noted that conversations concerning upcoming appointments, resulted in more anxiety about the upcoming procedure, and more uncertainty in their physical appearance.

In discussing mothers' roles in their daughters' adolescence, there were a number of themes that arose within the narratives of both the daughters and mothers. These themes both concerned what mothers were communicating to their daughters about adolescence and becoming women, but also *how* these messages were being communicated.

Within all of the dyads, two messages communicated by the mothers were validation and empowerment. Many mothers made a concerted effort to help their daughters feel like their adolescent experiences were akin to not only their own growing up, but also the experiences of many other teenage girls in an effort to normalize their experiences, and help their daughters feel comfortable with themselves. Some mothers placed particular emphasis on issues of body, gender and identity, and suggested that their daughters needn't be ashamed of who they are, what they looked like, or how they carried themselves. Many mothers promoted their daughters' pursuit of education, and emphasized their intellectual abilities. Moreover, mothers encouraged and supported their daughters' participation in various extra-curricular activities, such as Girl Guides, sports, music, and volunteer work, so to ensure their girls remained connected to a social network and expressed their individuality in a constructive way. Many mothers also sought to boost their girls' sense of self in relationships; reinforcing that their daughters were strong, independent, and capable women, who deserve partners that treat them with respect and dignity.

Many of the mother-daughter pairs mentioned that they felt the mother had communicated these messages in a number of very specific ways. Firstly, many pairs noted that the mother had served as a role model for the daughter, influencing their daughter's character through embodying and exemplifying specific traits on a regular basis. This was especially true around topics such as make-up, dress code, exercise, and healthy eating. Many of the dyads also discussed how the relationship witnessed between the mother and her husband motivated the daughters to seek out loving and committed partners. Moreover, almost every mother-daughter dyad included within the study made reference to very explicit conversations, where mothers clearly and directly addressed certain adolescent topics with their girls. For others, subjects were broached in a more indirect or implicit manner; situations were addressed based on what was taking place in the life of the daughter's peers, or situations that their daughters witnessed in the media. Additionally, the majority of mothers used stories of their own adolescence as an effective means of teaching their girls a variety of important lessons.



By having open, validating and empowering discussions with their daughters, the majority of mothers sought to reframe some of the challenges their daughters face regarding body image, gender, identity, relationships and sexuality, and help them resist the erosion of self, imparted by the intersection of adolescence and physical difference. As such, the relationship with their mothers may serve as a unique form of armour or hardiness for the daughters, protecting them in the face of marginalization and stigmatization. Many of the daughters confirmed that their mothers' lessons helped them to feel confident in who they are as individuals and young women. Similarly, despite feeling uncertain at times, mothers considered these discussions an important and successful means of guiding their adolescence, and felt validated that they

were doing the best they could, despite what other people thought or said. As such, these conversations and lessons may also serve as a unique sense of armour for mothers.

We also wanted to address the ways in which mothers and daughters may experience facial difference in positive way. While we tried to reflect some of the challenges mothers and daughters felt living with a facial difference presented on a daily basis, we also wanted to make space for the pairs to reflect on the possible contributions facial difference may have made to them as individuals and to their relationship. In asking these questions we found that facial difference contributed the following to the individuals:

PERSONAL STRENGTH: Many of the mothers discussed how raising a child with a facial difference has made them a stronger, more resilient person. The majority of the mothers suggested that they and their daughters have personally experienced many difficult events, and transitioned through challenging periods that people not touched by facial difference could not or would not understand. Some mothers used these trying experiences as motivation to continue to overcome life's obstacles. Moreover, a number of mothers noted that their experiences, especially encounters with doctors and strangers, pushed them to develop assertiveness and critical thinking. However, although mothers were readily able to identify with this personal strength and acknowledge it in their girls, daughters were not as keep in recognizing this quality in themselves.

AWARENESS & RESPECT OF OTHERS: A number of the dyads also alluded to facial difference making them more aware of and respectful of other individuals. Mothers described feeling compassionate towards and tolerant of others, regardless of differences or disabilities, often citing that something had changed within them after having a daughter born with or acquire a facial difference. Mothers were equally as likely to recognize this trait in their daughters. Daughters however, were much more willing to discuss how facial difference made them kinder and more accepting of other people. This empathy stemmed from their unique insights into how it felt to be marginalized or stigmatized.



To the mother-daughter relationship however, the contributions of facial difference were vast. We presented each of the individual contributions in one larger, umbrella theme we uniquely titled:

EXQUISITE ATTUNEMENT: Many mothers and daughters described countless ways in which their relationship was made stronger because of facial difference. The majority of the pairs noted their relationship was more like best friends than mother-daughter because they were extremely close. For many, this closeness stemmed from the significant amount of time spent together. For others, it revolved around the intimacy, openness and honesty they felt characterized their conversations and bonds. Moreover, while many of the mothers and daughters were readily able to identify the ways in which the other member of the dyad was a unique individual, with their own thoughts, opinions, beliefs and interests, many expressed a desire to learn from and emulate the other person. Moreover, the dyads appeared to be very in-tune with each other: mothers were extremely aware of and sensitive to their daughters' emotions and experiences, often how their daughters felt about certain events and encounters without an explicit discussion; and interestingly, many of the daughters, regardless of age, demonstrated this same sensitivity to their mothers' emotions and experiences.

Finally, as stated above, three of the twelve mothers interviewed were living with the same facial differences as their daughters, albeit milder forms. In comparing the mothering among women with and without facial differences, there were more similarities found than there were differences, as summarized below.

SIMILARITIES: Mothers and daughters' responses to the first set questions were particularly consistent; mothers were found to occupy the same roles in their daughters' lives, regardless of their personally living with a difference or not. Furthermore, mothers made similar use of both personal stories and explicit and implicit messages of validation and empowerment. The large majority of mothers, with or without facial differences, also discussed a profound sense of guilt in regards to their daughters' differences, many feeling that they had done something to cause them. Similarly, moving beyond birth and infancy, many mothers felt guilty around some of the decisions that they had made regarding their daughters' care, or the consequences that had stemmed from some of the roles they assumed in their daughters' lives.

DIFFERENCES: The mothers with facial differences felt that they shared a unique part of their identity with their daughters but were quick to note that there were significant differences in their journey and their daughters; namely, all of the mothers acknowledged that their differences were by no means as pronounced as their daughters, and that facial difference did not play an extremely influential role in their development. The nine mothers who did not have a facial difference were just as cognizant of the fact that their daughters had endured stigma that they were personally unfamiliar with in their own adolescence. However, in an effort to be supportive and nurturing, these mothers sought to comfort their daughters by reminding them that every person had something they disliked about themselves, or something they were uncomfortable with. Although many daughters understood that their mothers had good intentions, these messages were often not appreciated or well-received.

SO...WHAT DOES IT ALL MEAN?

As demonstrated in the results summarized above, it is safe to say that mothers are extremely active in their daughters' lives, particularly in the realm of social interactions, the medical system, family relationships and the media. Understandably, some of these roles are unique to raising a child with a physical difference, disability or chronic illness. Of course, the types of interactions between mothers and these systems will differ based on the child and type of facial difference, but it is important to remember that the distinct events involved in raising a child with a physical difference thrust mothers into situations that unaffected families may not otherwise encounter. However, we cannot say that mothers raising children with physical differences are *entirely* different from those who are not. Instead, there exists a large overlap in the roles assumed by the two groups, suggesting that families touched by facial differences are not abnormal. In fact, many of the mothers interviewed suggested that they assumed the same roles in the lives of their children without facial differences. Naturally, because mothers are aware of and sensitive to the stigma their children can face living with a facial difference, mothers may adopt these



common roles more frequently, or earlier in development. Overall however, the acknowledgement of these underlying similarities is vital to changing our understanding of families touched by facial difference.

The tensions and challenges inherent to some of these roles are important to consider as well. For the mothers in this study, attempts at keeping their daughters well-connected were mentally and physically exhausting. They wanted to ensure that their daughters were accepted regardless of others' discomfort and uncertainty about their facial difference. Thus, it could be said that mothers are worn out by consistently trying to compensate for and buffer against society's ignorant attitudes towards physical differences. The same may be true for the tensions around the medical system: mothers are repeatedly trying to strike the correct balance between making life-changing medical decisions and caring for their daughters, and this process is complicated further by messages from professionals within the system that directly and indirectly dictate what is "acceptable", "normal", or "best" for their children, or what constitutes a "good" parent. If the cultural views on disability and difference were less negative however, and if the medical system did away with some of its' prescriptive tendencies, mothers would perhaps shed some of their internal conflict, and feel less obliged to uphold some of these roles and therein, feel less drained.

The exquisite attunement dynamic that was found to exist between mothers and daughters demonstrates the importance of the relationship to both women. More importantly however, the themes of validation and empowerment that arose within the interviews closely related to those that the American Psychological Association (APA) (2014) deem essential to the healthy development of young women. According to this association, hearing positive messages about oneself, learning to trust oneself as knowledgeable, participating in extra-curricular activities such as athletics, and witnessing non-traditional sex-typing, strong female role models, and close family relationships are all vital to girls' ability to resist the abundance of negative incoming societal messages regarding their bodies, gender, sexuality and relationships. The APA goes further to propose that female adults in girls' environments, especially mothers and "other mothers" should be responsible for creating space for girls to "understand, engage with, and transform" these damaging cultural forces and messages so they can grow into responsible, critically thinking young women. The themes found also reflect those that Bell and Nkomo (1998) put forth in their work on armouring; the conversations of encouragement and validation from the mothers in this study served to likewise defend the daughters against the oppressing and intersecting forces of sexism and ableism they encountered in many of the systems they move through on a daily basis.

It is however, important to note that currently, a wealth of research exists that looks to both criticize and instruct families touched by difference and disabilities. Instead, it is critical for researchers and clinicians alike to recognize that many mothers have little to no experience with disability before the birth or diagnosis of their own child, and there exists no guide to appropriate parenting of children with disabilities. Moreover, while previous research states that the family unit is the critical site for supporting and nurturing children with physical differences and disabilities, these family members are just as vulnerable to the harms and hurts experienced by the individuals living with the differences. As demonstrated by the narratives of the mothers in this study, families touched by facial difference are equally subject to the stigmas and pressures from the systems that surround them. As such, we must acknowledge that these individuals and their families exist within a social milieu that is unlike the one that individuals and



families without differences are exposed to, and thus, it is inappropriate to deem the actions of some mothers as “bad parenting” or “abnormal”; oppressive or normalizing. Just as the mothers in this study do, parents of children with physical differences navigate the numerous issues that arise in their lives as best they can, all the while assuming the roles daughters ask of them, as well as those they personally feel are vital to their daughters’ health and success. Every mother felt responsible for guiding their daughters to safeguard their physical and emotional health, but also for “training” their daughters to care for and believe in themselves. What this looked like for each dyad however, was distinct given the uniqueness of each mother-daughter bond. Still, and perhaps most importantly, each daughter felt they were being “mothered” well, and every mother had moments of profound confidence in the way they “mothered” their daughters.

Altogether, these results suggest that there is no “right way” of mothering a daughter living with a facial difference. Instead, while there were consistent themes, the distinct narratives from each mother-daughter pair may serve to endorse the idea of “improvisational parenting”: the creation of patterns, routines and relationships that make sense and work for *individual* mothers, daughters and family units. In revising the mother-daughter relationship as a site of resistance that is negotiated in the moment by the parties involved, research can begin to appreciate the diversity of families living with facial differences and steer away from labelling any relationship as abnormal or dysfunctional. Consequently, fewer mothers will fall subject to the influences of guilt and the pressure to “get it right”, and daughters will feel empowered by and secure in their relationship with their mothers.

NOW WHERE DO WE GO? WHAT HAPPENS NEXT?

While the intention of this study was mainly exploration, the findings serve to open up doors for future research, and have important implications for clinical practice and community organizations.



NEXT STEPS FOR RESEARCHERS, CLINICANS, & ORGANIZATIONS:

- Include more families where both parents and children are living with facial differences to more accurately assess the possible similarities and differences in parenting.
- Recruit families from outside AboutFace given they may encounter without the support and resources that AboutFace provides. Their voices are equally valuable in understanding the influence of facial difference on family processes.
- Include more stories of acquired differences as this too, may provide a more complete understanding of the influence of facial difference on families.
- Involve boys in the research process given they experience different pressures, stigmas and relationships.
- Look to fathers! To date, only one study has focused *exclusively* on fathers of children with facial differences. Thus, there still exists a large amount of research that needs to be done on the father-child relationship. **(Note: This project will be the focus of my upcoming doctoral dissertation. Stay tuned for more information!)**
- Begin reconceptualising and developing resources that reflect a better understanding of the role mothers play in their children’s lives, with particular emphasis on the influence of gender.
- Help mothers identify their own guilt around their child’s facial difference and recognize that it is a common emotional experience among mothers.
- Acknowledge the potentially positive contributions that facial difference can make to individuals and their relationships rather than exclusively focusing on the negative influences it may have.