



Families & Facial Difference: An Analysis of Current and Future Research

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Understanding the impact that a child's facial difference has on the family has been an area of particular interest since the 1970s. Though a wealth of research has been done in this area, most of the studies are limited in their focus, theory and methods; there exists a number of potentially valuable perspectives and models that could serve to enrich society's overall understandings of families touched by facial difference, if the area was explored in new ways. As a Master's Student at the University of Guelph in the Family Relations and Human Development program, I decided to undertake a thesis project that investigates the mother-daughter relationship when the daughter is living with a facial difference. It is my hope moving forward with the project to "disrupt" some of the dominant discourses put forth about families touched by facial difference, and by consulting the existing literature, it became increasingly clear what steps should be taken by future research to present a more balanced, accurate, and critical account of what it means to live with or raise a child with a facial difference.

To start the process, I summarized the existing literature on the family impact of facial difference. In general, research in the field spans four broad areas:

Family Adjustment

- Families experience unexpected challenges and intense negative emotions
- Transition through cycle of adaptation

Attachment

- Warm relationship with parents critical to healthy child development
- Higher rates of insecure attachment among infants with FDs

Parenting

- High levels of parental overprotectiveness, compensatory behaviours
- Parental tendency to "spoil" children and tolerate misbehaviour

Family Stress

- Large proportion of parents are separated and struggle with mental health issues
- Mothers especially susceptible to stress and experiences of family conflict
- Limited contact with social support networks
- Significant changes in familial behaviour (i.e. employment, sleeping patterns, family planning)

Facing Forward



A B O U T F A C E

Many problems are inherent within the dominating research narratives of families and facial difference. These include:

The research assumes that there exists specific, measurable ways in which facial differences affect all families and relationships, and therefore commonly uses questionnaires and statistical tests to produce results that are said to apply to all families affected by facial difference.

- However, by reducing results to mathematical relationships, many individual experiences are lost or undermined. These methods also significantly oversimplify the complex issues inherent around family adjustment to facial difference, and omit the context-specific issues that surround each family or individual member.

Very little research exists regarding the impact that a facial difference has on a family as a unit. Instead, lots of research emphasizes specific relationships within the unit, specifically the parent-child interaction.

- Mothers in particular remain the primary focus of research on facial difference, serving most often as the primary “person of interest” in many studies; either being observed in their interactions with their children, or completing all of the required measurements and inventories.
- While it may be true that mothers often occupy the role of primary caregiver based on the gendered ideology of care, this bias in research is problematic as it posits the mother as solely responsible for the psychological outcomes of their children affected by facial difference. It also results in an omission of other key family members, who may be impacted by facial difference in a multitude of ways based on their unique location within, and responsibilities to the family (i.e. fathers, siblings, grandparents, etc.). Together, this may inappropriately inform programs for families seeking support.

Attachment theory remains the most prevalent in informing the methods and goals of facial difference research, emphasizing the importance of warm, sensitive relationships with parents early in a child’s life to their later psychological development.

- However, attachment theory does not take into account the external, economic and social factors that may influence parents and their abilities to form these relationships. It is also a rigid psychological theory where the stability of insecure relationships negates the possibility of forming secure, trusting relationships with family members later in life.

The majority of research is rooted in the deficit model of disability, which discusses bodily differences as pathological, “imperfect”, and insurmountable barriers to a “normal” life. Accordingly, an individual who possesses, or a family touched by disability, is subject to a reduced quality of life, stigma and oppression. Hence, a large wealth of the research focuses on the ways families suffer and struggle.

- Consequently, this framework serves only to strip individuals touched by facial difference of a sense of dignity, and invalidates their unique identities. This model may also inappropriately inform families’ understandings of disability and difference causing anxiety; in looking to the literature, families may come to assume that facial difference will have the same negative effect on their relationships and lifestyle.

Facing Forward



A B O U T F A C E

So where should research go from here?

Begin using Interpretivist methods

- Goal is to understand the complex lived experiences from the perspectives of people who live them
- Use more interviews and focus groups to capture, in individuals' own voices the multiple, and complex ways families experience facial difference

Study other key player in the family

- Broadening research focuses to include perspectives of other family members (i.e. fathers, siblings, and grandparents) may provide an understanding of information that remains to be uncovered
- Can begin to resolve issues of mother-blame

Study the family as a unit

- Can illuminate how the family system as a whole experiences and adjusts to a facial difference
- Brings the added benefit of situating the family within various interacting systems (i.e. an extended family, culture and class), liberating it from the "vacuum" that current research restricts it to

Get critical!

- Start framing disability and difference as a unique and multifaceted experience for each individual and family
- Valuing the experiences of each individual family member will empower and enhance the identity and dignity of those touched by facial difference
- Make space in research to explore the potential positive aspects of living with a facial difference and the strengths that it may foster within a family

The proposed project, *My Mother, My Daughter, My Self: Mother-Daughter Relationships and the Influence of Facial Differences*, looks to fill in some of the gaps in the existing socio-psychological literature on facial difference, and adopts a critical, feminist framework to present an alternative means of understanding facial difference. The specific objectives of the project include: exploring how mothers support their daughters in navigating social interactions, family adjustment, and encounters with the medical system; examining the ways in which mothers help their daughters transition through adolescence, and develop a sense of self, body and gender; understanding what facial differences can uniquely contribute to a girl's sense of self and the mother-daughter relationship; and analyzing the way in which a woman might mother differently when she too is living with a facial difference. Moving forward with a graduate education, I hope to extend these questions and research themes beyond mothers, and examine other important familial relationships.

To read the full study, click [here](#) now.