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Title: Parenting on the margins: "parental exhaustion" in the context of disability

Abstract: This presentation originates from our experiences as psychologists working with children having disabilities. My colleague, Margarita Merucci, works in a Medical Educational Institution for individuals with poly handicaps, while I work in a Medical Educational Institution for mild intellectual disabilities and autistic disorders.

Introduction

We aim to highlight the interplay between the emotional and educational aspects of parenting. The emotional side, which is very spontaneous and empathetic, is based on the intuitive and immediate response to other's needs in a climate of exchange through touch and holding or carrying, and in seeking pleasure, if possible, reciprocally. The educational aspect involves distancing oneself and implementing an intentional educational strategy to help the child become a social being, integrated into his/her community. Here I want to introduce a well-known French psychologist, G. Poussin (1999) who once stated that the parent's educational role includes " to help his/her child to build his/her self-preservation behavior" (ibid.p.141) and become an autonomous person. Parenthood is woven in time: the child's growth and the parent's journey both unfold together. However, even this time dimension is disrupted in situations of handicap. Development is not predictable, often slower, and sometimes several milestones are never achieved.

In the context of Erikson's theory (1968), the concept of parenthood aligns with the seventh stage known as "generativity versus stagnation." According to this theory, generativity is the drive to create and guide the next generation. It's a significant aspect of parenthood since it involves the emotional and mental investment required for raising a child. In simpler terms, becoming a parent connects to the need to contribute to the growth and development of the next generation, which is a crucial part of the generativity stage in Erikson's theory.

Parental roles develop over time, but disability disrupts this process. The integration of emotional and educational aspects is troubled in these circumstances, impacting both parent and child. When the situation is perceived as non-evolving and the child is

perceived as condemned to dependency until his or her death, the evolution of the parent, his or her future stops. Sometimes, caught in this dilemma, only the parent's body language expresses all the experienced pain and the *double constraint* that imprisons him/her.

Observation: Some mothers of children with multiple disabilities develop a severe illness or even die.

Theoretical Framework: We rely on Systemic, developmental and psychodynamic approaches to consider disability as a traumatic event and stress factor unsettles this emotional, affective and psycho-social construction from the start, making it (these construction) particularly vulnerable.

Hyupotheses:

H1. We propose that inadequate understanding of parental experiences isolates these parents. They may retreat into solitude or reinforce their belief that only they can support their disabled child effectively.

H2. Another hypothesis suggests that these parents, instead of embarking on a long process of transformation, become trapped in their *bad* precarious situation, leading to silence and ineffable suffering.

Procedure: Through clinical examples, we examine the analogical language expressed through the body.

Clinical examples

Marie, aged 12, faced a challenging start. Her mother left their homeland upon realizing the severity of Marie's health issues – her inability to move, hold her head, and danger of choking with every sip of milk. Her mother sought medical treatment in France, leaving behind her husband. Despite unwavering care, Marie's condition persisted. Upon arriving in France, she began being fed through a gastrostomy tube, a practice that continues today due to her persistent health issues. These issues brought about disruptive sleep patterns, causing nightly struggles for both mother and child, a pattern that persisted until Marie reached twelve years old.

Every time she comes home, day after day, a little ritual was established: Marie asks for a chicken snack and her mother prepares it for her according to her family recipe.

But each piece represents a risk for Marie. The mother is torn between her daughter's increasingly pressing demands and the critical and reproachful gaze of the medical corps. Her loneliness as a single parent, and her guilt of having given birth to an abnormal

daughter, her diverging doings versus cultural and family expectations are pushing her to become autonomous in a social context where she does not know or understand the codes. In return, she is criticized for wanting to do everything by herself amidst a cacophony of interventions and a multitude of stakeholders. No reliable support is possible because who-and wherever she turns to, she is met with critics or indifferent looks at her situation and her needs. So, she keeps silent, withdraws, sacrifices herself and after a while becomes ill. She is diagnosed with an autoimmune disease.

Her life is organized around the various medical and institution appointments. Her hopes to break free from this life once her daughter would be cured is fading away. Faced with a lack of future prospects, she prefers to fight beyond her forces, motivated no doubt by her fear of not being strong enough for her child. In addition to this, a failure of co-parenting is underlined by the physical and psychical absence of her husband, the father of their child whose existence is never even mentioned.

Jeremiah's family is facing challenges. The father avoids all daily tasks and medical responsibilities for the 12 years old boy, leaving them to his wife. Exhausted, she strives to maintain a semblance of normal family life and portrays it as harmonious despite the reality imposed by the handicap. She strives to ease things, pacify her husband, and also support her other child who she is determined not to neglect. However, Jeremiah's excessive weight poses a significant issue. His obesity prevents even basic movements he could manage if he were lighter. His weight becomes a conflict point with institutions and the family. The team worries about Jeremiah's future as his weight hampers physical development, hindering simple tasks like using the bathroom independently. The mother focuses on the present, viewing any weight loss as a potential threat to her child's survival. Different timelines collide—family time stands still while the institution's time progresses. The mother aims to avoid conflict with her husband, who distances himself, criticizing her efforts. She wants to uphold the family's peaceful image where men are strong yet protective, and women foster unity. Hurt by the lack of appreciation for her care, she safeguards family equilibrium, assuming the role of a sentinel for the system until her own health falters—ultimately, without recovery.

Discussion

An individual and systemic perspective is essential, acknowledging interaction with the environment. Fragile parents, unsupported and misunderstood, may internalize rigid family myths. Despite silence, their vulnerability surfaces through repetitive behaviors and by extreme denial of their difficulties.

Manciaux (1999), taking up the work of J. May Anthony, proposes an interactional hypothesis of vulnerability and illustrate it by the example of the dolls, the doll will break more or less easily depending on the nature of the ground, the force of the throw and the material it is made of. It is clear from his words that the intrinsic fragility and vulnerability

of the subject is only one element that comes into play. The force of the trauma (the force of the throw) and the condition of the environment (the nature of the ground) also play a key role.

Environmental factors are therefore involved in the construction of vulnerability. D. Houzel (1999) proposes a model of parenthood on three levels: **legal parenthood**, which recognizes the rights and duties of parents; **intimate parenthood**, linked to the experience and history of each of the parents; and **practical parenthood**, made up of daily acts and care.

However, as S. Karsz (2015) states, this typology serves "not the subjects for whom this typology will be activated, but the subjects who will have to activate it: not so much the parents but, above all, the stakeholders (intervenants). This typology prescribes to the ones what they will have to observe in the others [...] It is a question of evaluating the adequacy of the reality (the parents) with respect to the ideal (parenthood) in order to help those to achieve it" (p.141). A model of societal parenthood marked by sometimes opposing injunctions, including institutions that are themselves caught up in paradoxes, and surrounded by a policy of accompaniment or institutional reception that is insufficiently and unknowingly respectful of the intimate experience of the parent.

According to Neuburger (2005) "trauma is the mark, the immediate and distant consequence of a physical shock, isolated or repeated, voluntary or not, affecting the integrity of the body" (ibid. p.19). Again, according to this author, trauma is the product of a violence that leads to a **rupture of identity because it attacks the two dimensions of human dignity: the personal one and the one of belonging**. The parents on the margins, whose stories we have mentioned in the two examples, are impacted in their intimate and personal space. We notice that they are also affected in their identity support provided by the family and/or the group to which they belong. The family myth shapes the individual destiny of each member of a given group, telling him or her how to behave towards other members of the family and "how to think and act towards others, those who are strangers to the group" (ibid. p.24). Trauma always attacks the family myth and is "always caused by partial or total alterations of the group identity, what kept it alive, and what justified its existence" (ibid. p.45).

All these conflicts cannot be spoken of because it is carried out on several fronts in an incoherent and paradoxical way. The most vulnerable parents, whose psychological integrity is affected, can only withdraw in silence, letting their bodies express all their distress.

In conclusion, these parents' suffering defies elaboration, yet their exhausted bodies reflect their pain. The child often becomes a lifeline. Eventually, the parent's autonomy dwindles, and their bodies embody a premature end to their personal and social story.

To define dignified existence, dialogue with families is crucial. The mothers of disabled children grapple with unworthiness and extreme dependence, leaving no room for autonomy. These parents are no longer social subjects but encapsulated a self-contained world.

To delve deeper, these mothers may feel guilty for not transmitting a worthy life. They become hyperqualified, outshining professionals. Their race ends in isolation, devoid of recognition. The analogical language thus cries out the aches of these parents by gnawing at the body, freeing them at the same time from their incapacity to explore the world. By this fundamentally radical act, they authorize their child to separate from them to finally access the pluralistic world that surrounds him/her.

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