Preventing the onset of "Social Appearance Anxiety" in visible chronic dermatological diseases

Traumatic memories of social and medical experiences give rise to Post-Traumatic Stress

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A large majority of children affected by a visible dermatological disease or abnormality live a normal social, familial, emotional, and professional life, and manage to fully integrate their abnormality, as testified by many affected families. Nevertheless, it is clear that these peculiarities require adaptation on the part of these individuals, as well as a mobilisation of personal resources to face these conditions. In addition, certain dermatological abnormalities are more difficult than others to integrate.

A child is not born conscious of their bodily difference. They acquire this consciousness through their life experiences, as highlighted by de Vries (21), via learning mechanisms. Parents have the delicate task of accompanying their child on the path to awareness, while simultaneously conveying a sense of normalcy and security, and encouraging the child's autonomy. This complex and fragile balance is to be maintained throughout the child's life. Parents are the child's first rampart against the world.

Any bodily peculiarity naturally induces curiosity and fear among the "other", as humans are afraid of what they do not know or do not understand and have a need to understand the thing they are confronting, as well as whether it represents a menace to the self. It is therefore necessary to allow him to access this information in order to defuse the negative attitudes and consequences induced by this fear, which include stigmatisation, aggression, rejection, abuse, and humiliation (1, 5, 6, 11, 13, 14, 20).

We believe that this curiosity is one of the essential concepts of this issue, as comprehension and understanding help limit the negative consequences of the "stare of the other" on the construction of the child. How can we help and accompany children on this path?

What are the child's feelings in the face of their difference?

In our approach, we thought it useful to resort to three categories to describe the mental states induced by a congenital or acquired bodily difference. However, rather than three distinct categories, feelings lie on a continuum. The affected individual moves from one category to another over the course of their life, experiences, and encounters.

Schematically, we distinguish:

Acceptance (or integration): The bodily peculiarity provokes little or no particular social or emotional discomfort, preoccupation, or repercussions. The awareness of its presence is realistic and healthy. Acceptance should not be confused with a total absence or overvaluation of perception, both of which are abnormal.

Vulnerability: The individual lives a normal life but finds that their well-being in society is impacted, but not limited, by their peculiarity. Crucially, facing the peculiarity demands adaptation and mobilisation of resources on the part of the individual, which can at times be exhausting to the individual.

Invasion: This state manifests itself as a genuine and disabling anxiety-type chronic suffering that can include revivification, invasions of physical life associated with avoidance behaviours, isolation, fear of staring from and judgements of others, and at times even depressive states, perfectionism taken to the extreme, or a search for a "normalcy to over 150%", as reported by several patients.

Faced with these patients' elevated anxiety and shame, Clarke, Thompson, Jenkinson, Rumsey, and Newell (5) are the first to endorse the fact that this clinical picture can evoke authentic social appearance anxiety (SAA), even though bodily differences are currently excluded from the DSM-V's definition of the condition.

Social appearance anxiety arises from the discrepancy between the affected individual's ideal appearance to which they aspire and their actual appearance. SAA is defined as an overwhelming concern about one's physical appearance and a fear of situations in which one's appearance may be evaluated negatively by others (3,7). The individuals who perceive and evaluate their body negatively tend to pay special attention to and be overwhelmed by the way they are perceived by others. Consequently, SAA is intimately dependent on one's body image (3).

Traumatic origins

With a visible physical peculiarity, a child will, along with their friends and family, experience a range of challenging circumstances, including stigmatisation, mockery, iterative and painful medical and/or surgical interventions, which make up the child's personal and familial history over time.

These difficult experiences are a form of learning in which individuals acquire emotional, relational, cognitive, and behavioural reactions that are recorded in long-term memory and maintained over time, constituting traumatic memories (17). The formation of a traumatic memory exposes a child to its activation upon encountering a stimulus associated with the memory at any time throughout their life—including at times when the child seems to be doing well. A violent reaction to these stimuli can present clinically as post-traumatic stress disorder, of which a large part is manifested as an SAA, as highlighted by H de Vries.

Painful emotional reactions bring about compensatory behaviours such as avoidance, withdrawal into oneself, and automatic negative cognitions among many children, in order to cope and reduce suffering (21).

This is another form of learning: avoidance of interpersonal situations can temporarily appease the child, who will consequently use these increasingly (21). The child therefore develops habits that may not be optimal for their age, leading them to have no or few friends, for example. In the long term, this avoidance increases the child's SAA (21).

In the face of these traumatic experiences, repetition, accumulation, and the child's developmental stage can induce serious repercussions on the child's growth. Among some, this can induce the formation of complex psychological traumas. These traumas are characterised by six symptom categories: change in affect and impulse regulation, change in attention and consciousness, change in self-perception, change in interpersonal relations, somatisation, and disturbances in beliefs and values (19).

What do we propose in practice?

It is necessary to question our pre-conceived notions on the subject, as neither the lesion's visibility, severity, and size, nor the child's age or sex are factors to be considered (20). Instead, the child's life and learning experiences in this area are of primary importance (21). This explains why all children are not equal in their resilience.

Denial, avoidance, and fear are reactions acquired in the face of these situations and explain families' wariness in expressing complaints to professionals. During consultations, it is important to understand the child's lived experiences associated with their bodily peculiarity. Unease on the child's part upon mention of this peculiarity should elicit caution and an in-depth evaluation of the situation. The same should be applicable for parents who are themselves also at risk of traumatic memories.

Resisting the formation of a traumatic memory is essential and requires engagement in preventative actions to limit potentially traumatic events. Social skills programmes that train individuals in coping skills are a precious resource, as evidenced by several studies (5, 20). Such programmes support children in acquiring suitable and effective communication in the face of the curiosity elicited by their state (4, 5, 18). This curiosity is at the heart of their experiences of interpersonal relationships due to the existence of their peculiarity and the stare of the other. One must therefore be equipped to respond appropriately to this curiosity to be able to engage with social relations in the best circumstances. Curiosity is expressed in three forms: natural, invasive, and malicious. A child must learn to position themselves appropriately, both physically and emotionally, to respond to each type of curiosity, as this response will shape future interpersonal relationships.

We have associated each type of curiosity with an acronym that synthesises the strategy to be undertaken. For example, LET'S GO (**L**ook confident, **E**ye contact, **T**one of Voice – firm but friendly, **S**mile, **G**aze forward and stand upright, **O**pen up) in anxiogenic situations, ERD (Explanation-Reassurance-Diversion) for natural curiosity, ERS (Explain-Reassure-Stop) for intrusive curiosity, and ACTION (**A**ctive listening, **C**larify, **T**one of voice, **I**nquiry, **O**ppose with spirit and repartee, **N**aturel) for malicious curiosity. Through regular and personalised practice, the child's posture becomes natural and fluid. This method promotes effective and suitable communication, while simultaneously extinguishing the emotional and negative experiences associated with these interpersonal situations. Simply invoking the acronym ultimately leads to it being implemented. Through a specific social skills training programme, a child can discover, explore, and self-appropriate coping tools and strategies in a safe environment.

Barabara Kammere Quales in the 70s (8, 9, 10) and James Partridge in the 80s (16), both victims of vehicular accidents in which they were burned and disfigured, are behind this approach. They developed coping strategies based on their personal experiences. Partridge is one of the pioneers of the understanding of the psychological mechanisms at play when disfigurement occurs. Through the experience of his own burn, he comes to understand that it is his behaviour, rather than his facial disfigurement, that influences the quality of his relationships with others. His behaviour is intimately related to the feelings of shame or aggression that he experiences. According to him, it is behaviour and a lack of interpersonal savoir-faire, not appearance, that are the source of the problem.

It is crucial to maintain a feeling of normaly among these children, to remove them from the role of victim or superhero that is often ascribed to them. For this, however, it is necessary to give them the tools to change their position.

If a clinical presentation of SAA, post-traumatic stress disorder, or complex psychological trauma is suspected, it is crucial to refer the child or adult to professionals trained in this type of highly specialised care. Cognitive Behavioural Therapy has been shown to be effective in this area (5, 17, 19, 20). The Derriford Appearance Scale (15) and Social Appearance Anxiety Scale (7, 12) are validated and specific scales that enable identification and follow-up of patients. However, these have not been adapted to children.

In cases of birth defects, providing support from birth is essential. This support should be undertaken by neonatal teams trained in the pathology and how to broach the subject with the parents to promote secure attachment with the child.

Conclusion

Traumatic experiences, repeated and elicited by bodily differences are the source of traumatic memories responsible for psychosocial and emotional difficulties. Serious forms present clinically as social appearance anxiety, post-traumatic stress disorder, or complex psychological traumas. These clinical presentations can appear with a delay, and even in adulthood. Understanding and correctly naming these phenomena allows for direct and effective help to be provided to affected children.

Using appropriate terminology is essential in order not to aggravate feelings of difference and enables the acquisition of a feeling of safety, essential in treating traumatic memories. The emergence of the new concepts of "aesthetic or appearance disability" will not help a child to acquire this all-important sense of safety and belonging. As well as being unfounded, do these concepts not make direct reference to value judgements on what is beautiful in reference to what is not, with all the consequences that this can bring about when one is not in the right category? And who can or should be responsible for determining the boundaries between what is unacceptable and what is not in this domain? Would one have a "aesthetic or appearance disability" because they are categorised as ugly?

We are dealing with learning mechanisms that lead to unsuitable behaviours and difficulties affecting the affected individual's quality of life. Cognitive behavioural therapy has been shown to be effective in this type of situation.

Giving families access to suitable coping strategies to help them establish effective communication in the face of the curiosity elicited by their condition is essential. This may take the form of a social skills programme with a strong awareness and understanding of the key issues in order to avoid potential pitfalls. Introducing these strategies to families as early as possible would help prevent and limit the formation of traumatic memories.

Comprehension and implementation of these complex elements would allow for the establishment of and a serene transmission towards a feeling of normalcy, security, and autonomy, all of which are critical in a child's development.

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