

Gender differences in the representation of congenital physical disability. how disability intervenes in the formation of gender

Abstract

The present study examines gender differences regarding the experience of congenital physical disability. Taking into account both stereotypical social ideals that frame the formation of gender identity, together with qualitative differences regarding the relation that both genders form with the primary object, the present study reveals that women tend to metabolize differently congenital physical disability than men do. Seven participants took part in this study (4 males and 3 females) who were facing either a congenital physical disability, or a disability with a very early onset (during the first year of life). The research method that was used was that of biographical approach (life narratives) and the conclusions that were conducted reflected deviations regarding the formation of masculine identity in a greater frequency and intensity than that of female participants.

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Introduction

It is widely accepted that disability and gender are two interdependent factors in the lives of people with disabilities that need further research. "There is a delay in the investigation of the correlation between gender – what does it mean to be a female or a male – and disability".¹ As it has been highlighted by many researchers,² the need to study disability within a social framework - where the relation between gender and disability will be described in psychosocial terms - will promote a better understanding, contributing in the long term in reversing the social oppression and social isolation that these people face.³ Acknowledging this need, the present study tries to bridge the gap between the social and the personal (intrapsychic). In achieving a holistic understanding approach, a bidirectional recognition is needed, where the social metabolizes through psychic procedures and becomes personal, and also the personal as a unique experience that has been recorded in the intrapsychic reality needs to have a public imprinting.⁴ Therefore, the subject's psychic construction encompasses the reconciliation between micro and macro-sociocultural factors together with the constitutional elements of the subject's intrapsychic reality.

In a "normal-like" society, in which members try their best to reach perfection and disclaim any form of "dependence" that may trigger the agony and the threat of fixation in an earlier stage of development¹, the pieces of the self that are not accepted are expelled from our consciousness as they produce a breach with reality.⁵ In the content of those intrapsychic procedures, the formation of gender identity will constitute another factor that will mediate the experience of disability, taking into account that the "disabled body" seems insufficient when compared with the stereotypical social ideals of masculinity and femininity, producing in both genders conscious and unconscious conflicts regarding their identity.⁶ In other words, the need for social acceptance requires the compliance to the ideological construct of gender, as it has been formed by different socio-cultural contents in different periods of time.

"Those who do not behave within the socially constructed manner of masculinity and femininity face the danger of isolation".⁷

The fact that even today more often women, though in a less apparent way, are socially presented either as individuals who are

passive and need protection or even as caregivers or sexual objects, demonstrates how they share many of those social characteristics that tend to describe people with disabilities. Therefore, disabled individuals seem to be equated more or less with those socially formed characteristics that better describe femininity,⁵ deviating from the "heroic model of masculinity."

"... Theheroicmodel of masculinity is anattempt to strength enandstabilizetherepresentationoftheselfinrelationtogender".⁸

As it has been noted by Diamond,⁹ the fact that seems to socialize males in a regulatory way, compiling them with the social standards of masculinity is the feeling of "shame" that drives them to renounce any sign of need in case they are characterized by others as "sissy boys".^{9,10} Therefore, the requirement that seems to determine masculine identity refers to the capacity to disclaim any characteristic, attitude or desire that refers to this "passive" period in the life cycle of the individual, identified with femininity. In that sense, the formation of masculine identity doesn't necessarily refer to all these things that a man has achieved or has gained, but to those that he has renounced in order not to reveal an earlier "passive" past, giving a lifelong fight to try and to prove "what he is not" (*Real 1997, as it is sited in Elise*).¹⁰ In order for men to avoid their possible "feminization", resulting from taking a passive role, they tend to adopt a "reactive type restless behaviour" as it has been clearly described in the narratives of the majority of male participants, by expressing a need for a constant search of action. As Christiansen points out:

"An activemasculinity can be seen as a defence against the pleasure that offers a passive femininity".¹¹ This idea was postulated by other researchers,¹² who claimed that congenital disability intervenes in the primary object relation and as a result hampers the separation-individuation procedure, making males to struggle more than women in the construction of gender identity.¹³ Such an acknowledgment throws light on the parental role, revealing that the way parents will metabolize disability will have, in the long run, an effect in the construction of gender identity.

¹An earlier stage of development where the ego was in an undifferentiated form.

Method

Design

Seven participants took part in this study, 4 males and 3 females who were facing either a congenital disability or a disability with a very early onset (within the first year of life). In more detail, two out of the three female participants were born with a congenital absence of the proximal part of the right and left lower limb respectively. Out of the three participants that were facing cerebral palsy, one female had a spastic hemiplegia due to cerebral hemorrhage, while the other two male participants were facing spastic paraplegia due to perinatal suffocation (asphyxia) in one occasion and due to premature birth in the other. Also, one participant had an absent part of the right scapula, whilst the last participant was born with arthrogryposis, a disability that rendered him partially functional. The research tool that was used was that of “life histories” adopting the principles and the ideas of the biographical approach, aiming to identify and study how participants represent themselves in relation to others, focusing on the relationship with parental figures. The analysis of the narrative material was based upon the principles of content analysis,¹⁴ following the stages of thematic / topic coding. In order to deal with the need to highlight and interpret the latent content of the narratives, which in any case is one of the goals of content analysis,¹⁵ psychoanalytic theory was used where language is considered as a “psychic semiotic system”. The term “psychic semiotic system” represents a variation of the term “social semiotic system” that was used by Halliday¹⁶ in order to describe the dialectic relation between the use of language and that of social ideologies introducing the need for the analysis of language within different socio-cultural contexts. Therefore, psychoanalytic theory was used as an interpretative tool, in order to give meaning to the empirical data, but also to form a theoretical frame through which it could be correlated broadly with other research data.

Procedures

Participants were selected in accordance to whether they had a congenital physical disability or a disability with a very early onset (within the first year of life). Interviews lasted approximately 50 minutes and participants were encouraged to describe their experience of disability bringing to the fore whatever they thought would be relevant and meaningful to them. The total number of interviews conducted was 35 with an average number of 5 interviews for each participant. The participants were encouraged to speak freely regarding the experience of their disability, without any interference from the side of the researcher in terms of trying to direct the interviews in accordance to the purposes of his research agenda.

Results

The contribution of the present study in the relevant literature refers to the analytic description of those conditions that tend to reveal possible deviations regarding the formation of gender identity by focusing on the way disability intervenes in the relationship with parental figures. At this point it is important to mention that disability is not an explicit issue with certain psychosocial implications to the individuals who experience it. Thus, it would be inadequate and inappropriate to consider that the material outcome of the research procedure offers a sufficient insight on the topic, since it only represents the subjective experience of a small sample. Focusing on how congenital disability mediates parental relationship with regard to the construction of gender identity, certain deviations were pointed out where male participants tended to face more difficulties

in mentally metabolizing congenital physical disability than female participants did. According to the research outcome regarding deviations in the formation of masculine identity, two out of the four male participants expressed a different sexual orientation addressing their sexual interest to same - sex partners. Additionally, another male participant reported that at the age of 34 had never had sexual intercourse, expressing his sexual interest for the opposite sex, whilst the fourth male participant expressed a rampant sexual desire already from “infancy”, invested with sexual fantasies addressing a constant and open erotic request to the opposite sex of such an intensity that tended to overshadow any other investment in his life. Of great interest in the narratives of the male participants was the maternal representation. These men describe their mothers as weak, helpless and depressive, requiring help and support and preventing in that way any centrifugal movement on behalf of their sons by bringing forward their obligations towards them.

Conclusion

The present study points out differences in the way congenital physical disability mediates parental relation. Regarding our experimental hypothesis, we studied the qualitative characteristics of the relationship that participants of both sexes had with their parents. By carefully studying the participant’s narratives, it became clear that fathers tended to metabolize differently their childrens’ disability than mothers did. As it has been noted, fathers tend to advocate a difference in the degree of cancellations regarding parental expectations, relating especially to their sons rather than to their daughters with disabilities. In particular, fathers were described in the narratives of male participants as distant, withdrawn and absent, having abandoned them in a “suffocating” relationship with their mothers, a fact that tended to weaken the Oedipal complex in accordance to a fixation that took place due to the boys’ narcissistic identification with the mother.

*“Little boys lacking in this unconscious, inersubjective recognition of their maleness thus compensate by relying on a more defensive, rather than adaptive, phallicity”.*¹⁷

Though in the males’ narratives paternal absence doesn’t necessarily refer to physical absence but also to emotional unavailability, these fathers were described as having an overwhelming interest in their work responsibilities that keep them away from home for many hours per day. As it has been already well postulated in the relevant research,¹⁸ paternal unavailability tends to have more dramatic consequences to the developmental procedure of males than that of females, since the son tends to incarnate the ideal self of the father, bearing in mind that the daughter cannot become aware of the idealized masculinity in the way sons do.¹⁹

Of great interest is also the representation that male participants have regarding their mothers, a relationship that was built in the shadow of paternal absence.

In particular, male participants described their mothers as isolated, helpless, feeble and weak, with symptoms that fit within the psychiatric spectrum of depression. They constantly presented to their sons a need for help and support, preventing in that way any centrifugal movement towards autonomy by filling up their sons with remorse and obligations if they brought in front the intention to “leave” them. According to Pittman²⁰ the weak mothers and not the strong ones are those who keep hostage their sons. *“If the mother is weak or dismal or aroused or even abandoned, the son has no possibility to reach masculinity if he abandons her he will feel guilt and failure and if he stays with her he would have to sacrifice the dream of a heroic journey”.*²⁰ This idea was

well postulated in the narratives of male participants. For example, a male participant trying to fill the gap created through paternal absence from the marital relation, became the companion and the protector of his mother. This position was taken by another male participant of the study who provided psychological support to his mother, who in turn had suffered the consequences of a violent partner. Another participant watched his mother resign, became mentally unstable after the separation with her husband,² and “stayed back” in order to look after her and ensure her wellbeing. Therefore the narcissistic needs of these mothers seem to preserve the dependent relationships with their sons who constantly try to feed them narcissistically, by satisfying the expectations projected on them in order to “keep alive” the fantasy of the ideal child. As a result, the Oedipus complex seemed to take place in the shadow of a fixation where the boy had made a narcissistic identification with a phallic mother.²¹ As Blos has pointed out, although a narcissistic identification with a phallic mother is a necessary step to the resolution of the Oedipus complex in the stage of puberty, the inability of these boys to idealize an available father figure will increase the likelihood of a fixation.

“...the prolonged intensity of this symbiosis together with the mutual enjoyment that stems from it, form a greater chance of feminization of the boy. The effeminacy would prevail if the child's father does not prevent this contact qualitatively and quantitatively.”²²

In contrast to the above, the narratives of the female participants seemed to describe a father who was “present”.³ in the relationship, taking in many cases an overprotective role towards them, even if he was described as “absent” due to a work overinvestment.

As far as the descriptions of the relationship with the mother were concerned, the majority of female participants described their mothers as active and assertive, coming forward in order to provide a safe, secure and supportive environment, facilitating in that way the identifications with their daughters. Bearing all the above in mind, it seems that paternal absence prevents male participants from extricating themselves from the symbiotic relation with the mother by relieving the anxiety and the feelings of loss that accompany any attempt to disengage from the maternal object.^{9,17,23} As a result these men didn't seem to successfully complete the separation – individuation stage, together with the opportunity to clarify their bisexual identifications.

In conclusion, we are still learning about the effects that congenital physical disabilities or disabilities with a very early onset (within the first year of life) have on the mental health of disabled people and their families. Engaging in systematic research on the relevant field will hopefully gradually eliminate the considerable variations that exist today in the everyday practice with disabled people, based on the different and in many cases antithetical ideological approaches. In regard to our findings, it could be argued that the birth of a child with congenital disability or a disability with a very early onset, requires a set of interventions in the whole family. Acknowledging beforehand that disability has a great impact on the “male soul,” we should seriously take into account the paternal needs in any form of family intervention we intend to make. By focusing on the father – son relationship we tend to strengthen identifications that are so essential in the construction of masculine identity,²⁴ and promote a reinforcing environment for the disabled child that will contribute a great deal in the positive outcome of any therapeutic target.²⁵

²Obviously there were more factors that contributed in the maternal withdrawal.

³Not necessarily physically but emotionally present.

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Conflicts of interest

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