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Review Article

The Sexuality of Spinal Injured Women

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Abstract

After a reminder of the intimate, relational and social situation of today's women, the question of the sexual life of women with spinal cord injuries after severe vertebrospinal trauma is addressed. As soon as the traumatic attack occurs, an acute section syndrome manifests itself, with sublesional sensorimotor, sphincter and neuro-vegetative damage.

Amenorrhea is systematic. It is experienced as a psychophysiological regression or as a sanction. It can last several months during which sexuality does not manifest itself, whatever its form. Sexuality reappears shortly after the return of pelvi-perineal reflexes, which provide access to learning intermittent urinary catheterization.

On the sexual level, the problem posed is twofold, physical and psychological, and some possible solutions are considered. On the one hand, to help and preserve a sexuality adapted to the disability and on the other hand to take into account the subjective, identity and relational values which are also one's own.

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INTRODUCTION

Before addressing the question of the sexual life of the woman with a spinal cord injury and its psychophysiological impact on her daily life, it seems necessary to me to discuss the contemporary context in which every young woman evolves.

She has always shown great inventiveness in what we call cosmetics and the search for beauty, where what takes precedence is the enhancement of one's body or, if you prefer, its narcissistic eroticization. In a distant era, the vast hips and the opulence of the breasts proved the aptitude of the woman for the reproductive function. Today [1], without mentioning the exponential growth of pelvic cosmetic surgery, she adorns herself with broad-lined false eyebrows, oversized false eyelashes, turgid lips and piercings, sometimes with Japanese-style foundation, very long false nails, silicone breast and buttock prostheses, dizzying stiletto heels and is enveloped in a cloud of deliberately heady perfume. Are we only in the art of theatrical makeup, which would indicate a trompe-l'oeil social posture with simple adornment, or would it be a desperate struggle against a supposed imperfection of one's being?

Menstrual cycles carry the weight of one's femininity, we try to take this into account in the world of work. Can this femininity persist if amenorrhea occurs? What is it all about, when we are asked to believe that a young woman would spend 120 minutes a day in her bathroom, putting on makeup or removing make-

up? But why would she do it, since we are in an era where, like man, woman claims her freedom and testifies since Plato, that the human being comes from primitive Man divided into two magnetic sexes one by the other and therefore of opposite polarities.

It would be vain to stick to appearances, even if our century is made up of appearances, influences and influencers. There exists in every human being a phenomenon of sustained tension to connect biology to metaphysics, which are two opposite poles and indispensable to each other. Man is a being of desire, that is to say a being of lack. It is commonplace to say that his entire life is structured by desire, perhaps of a hormonal essence at the beginning, but which animates his impulses, his emotional and intellectual life and his research, whatever the fields and the moments. In certain religions, clothing must undoubtedly mask the woman's entire body like a second skin, so that the man does not succumb to the dizziness of desire. We could question the passive or active position of women on a social level. But we can also affirm that, going beyond simple modesty and the primacy of the material, the clothing mask has a spiritual vocation of protection against what we sometimes call our base instincts.

What happens in women, in an acute spinal cord injury, where everything concerning the "lower instincts" is erased in an instant by paraplegia [2]? And what about his sexuality?

On a physio pathological level, there is no longer any motor

skills or sensitivity in the sub-lesional areas, except for the presence of dull pain that the patient has difficulty locating. Muscle wasting is considerable and extremely rapid in all sub-lesional areas. However, just as in limb amputations, phantom limbs very quickly appear, which are born at approximately the same level as the usual limbs, or very slightly above. These members are endowed with motor skills or often fanciful positions and, although invisible, they are felt as real members and as a recourse against the absence of life in their paralyzed limbs. In paraplegic women, they take a remarkable place in this virtual anatomy which allows them to believe that they are always walking or even that they dance during their dreams, which are often erotic dreams. How can we articulate dreamlike phenomena, sensorymotor illusions and denial which is a powerful screen against the fear of a de-subjectivation of the body which invaded them from the very first hours?

Indeed, in traumatic lesions of the spinal cord, there is no longer any sphincter control while the periods disappear for several months due to ovarian blockage as well as vulvovaginal secretions. It is not satisfactory to explain that stress disrupted cortico-thalamic-diencephalic functioning, which is true but insufficient. Amenorrhea is correlated with the loss of all desires and in particular that of being a woman. Some feel caught in the consequences of pathological castration, they see themselves returning to an age of "pre-pubertal little girls", dependent as the care requires with their protocols which make them assisted and passive. Others have such motor inhibitions that they live in a state of stress and constant reliving of the accident that cut their lives in two. They may be in such a state of psychomotor astonishment that it is necessary to remind them that they must eat their meals without help since they do not have quadriplegia.

They discover their absence of periods, they have lost their skin-mucosal sensitivity and their pelvi-perineal sensitivity, at the same time losing the biological, relational and psychosexual functions which are the proof of their femininity. On the other hand, as if it were a punishment and whatever their age, some say they are hit by early menopause, which in their eyes implies the disappearance of their sexual desire. The degraded image they have of the lower part of their body projects them into the anatomical and physiological decay of an old age that heralds death. In their relationships with others, and in particular with their friends or their partners but especially with caregivers, there is no eroticization of contacts, there is only hygiene care from top to bottom, this body. He "only belongs to them half dead," as they say.

They confide very little in caregivers, who are often young and whose actions are justified as anti-infection prevention and guaranteed to have only a pure hygienic purpose. Indeed, body care is rigorously applied, which certifies the disappearance of others' desire for them. On the other hand, it seems that the denial which manifests itself in these circumstances and which is summed up in these two words: "I will walk again", occupies a function of reassurance and of protection against a depressive collapse. Indeed, we note that when denial ends in the face of the

persistence of deficits and the skepticism or sometimes mocking disbelief of caregivers with regard to their phantom members, a severe depressive syndrome occurs in 75% of cases [3], with as main complaint that of having lost half of his body, which was only virtual for the observer.

From the first weeks after the accident, sudden shocks also appear below the injured areas, in the form of extremely violent crises that can affect the entire body. In fact, from T6 and above, all spinal cord injured people have attacks of autonomic hyper reactivity (66% for lesions lower down) [4]. They are accompanied by intense throbbing headaches, profuse sweating, bristling of the hairs and lipothymic tendencies with bradycardia and an extremely dangerous surge of high blood pressure. They result from a dysregulation between orthosympathetic and parasympathetic [5], which can take on dramatic dimensions.

Generally speaking, and despite the pain, anxiety and lipothymic tendencies, these attacks of autonomic hyper reactivity give them the illusion that their body is coming back to life that its movements and its aesthetic presence announce an imminent return to normal, which is in the realm of illusion. Despite the risk of putting themselves in danger (cardio-circulatory accident or cerebral edema), certain male or female patients provoke these attacks, because they bring back in a dazzling manner the entire sensory-motor body silhouette, thus repairing the erasure of the lower part of the body.

To better understand the meaning of this challenge to their own lives, it would be necessary to further research the complex relationships between pleasure and pain, the desire for life and the desire for death, which already appeared in what we simply call an "accident" of the public highway. But in a certain sense, we can say that these vegetative discharges reinforce the psychological mechanisms of denial as well as the temporary benefits they derive from it. In fact, these crises oppose the need to detach themselves from their existence prior to the accident, which they do not yet feel able to undertake. As they quite frequently confide: "I can't turn the page".

In complete section syndromes, after a few months the clitoral-anal reflex reappears, generally when washing the pelvic region. The reappearance of this reflex indicates the end of the spinal cord stupor phase, which will soon be followed by the resumption of menstrual cycles. This is also the time when exploratory gestures sometimes trigger congestion of the external genitalia and reflex vaginal secretions. But each person discovers the silence of her body, which feels nothing and manifests nothing when she herself experiences an emotion with a sexual connotation. His emotional life and his physical body are out of tune and completely foreign to each other. A part of mystery and animality are imposed on it, when the spontaneous appearance or obtaining of vaginal lubrication is accompanied neither by the sensations nor by the hoped-for pleasure. His body shows signs of sexual pleasure without transmitting them to his perception or his feelings. If there is enjoyment, it is located somewhere else that cannot be reached. She expresses this by saying that "it's the

body that keeps its pleasure to itself [6]. Everything happens as if his body being cut in two, the sub-lesional area had become the distant territory of a sexuality which this lower part would enjoy for its own sake and would henceforth be inaccessible to it.

However, the healthcare team can begin to teach the paraplegic woman the technique of evacuative rectal examination and the gestures of intermittent probing through which she will regain a certain autonomy and relative bodily privacy. Although the urethral canal is very short in women and due to the involvement of the paravertebral and abdominal-lumbar muscles, psoas included, this learning is not as easy as in men. She must overcome the unfavorable image reflected by the considerable muscle wasting of her lower limbs, and especially the collapse of the tissues and mucous membranes of the perineal region, which are no longer accessible to direct gaze, but which require the use of a mirror during the first days of learning.

Paradoxically, some women do not rejoice at the reduction in their dependence, which perhaps served as a shield against the distress and fear of greater autonomy since they learn to manage the functioning of their sphincters on their own. This difficult moment in their journey is also the one where they find the desire to change their hairstyle, to wear makeup again and to accept more easily leaving the rehabilitation establishment for a day or two. But showing yourself to others is not an easy business. They all tend to protect themselves by adopting a precise and fairly contrasting clothing style. The upper body is highlighted by light or colored fabrics, which emphasize discreet makeup, the lower body is taken in a vast dull-colored jogging suit, as if it were a question of erasing the anatomical location of the sexuality. Hence certain ambiguities in their first contacts with possible partners when they try to verify their power of seduction, despite the feelings of transgression mixed with anxiety that they experience in the face of their resurgent sexual desire.

If their partner is present (in eight cases out of ten, the man leaves the woman, while it is two times out of ten when the man is paraplegic) [7], it is necessary to encourage him to participate in the recovery of their life as a couple, in particular by teaching them the modalities, with regard to the erogenous sensitivity of the juxta-lesional zones where what we call "a para orgasm" can be triggered. He must also learn the longer duration of cutaneous-mucosal stimulation, and the most favorable positions for carrying out the act of penetration. This act and its duration are very different depending on whether the paraplegia is flaccid or spastic. We must note that, despite the freedom of morals and so-called women's literature, there persists a surprising lack of knowledge of the apparent perineal anatomy and the female genital system, which caregivers do not always take into account, due to lack of time, they say.

Rehabilitation work is therefore necessary, which takes into account several parameters. I would like to suggest a few:

- Good understanding and dialogue within the couple are a priority to preserve and encourage, with psychological support also for the partner, who has a whole personal journey to

accomplish to discover the necessities and new possibilities of a completely sexual life upset. For women, how can they embrace the rebirth of their sexual desires and express them "without being ashamed"? For the man who accompanies her, how can we agree to recreate a new journey with "a woman in a wheelchair", a woman who often still thinks about a technically feasible pregnancy, but above all about the educational problems that will have to be mastered together, or thanks to the family. It is therefore necessary to call on a psychologist trained in interviews with a couple in whom finding harmony while respecting the freedom of each person is a priority.

- Do not rule out in principle the question of pregnancy, another period of amenorrhea - which is very often part of one's fantasies. For the paraplegic woman, fantasies of pregnancy and motherhood are quite frequently transferred to the subinjured part of the body, when she feels the desire to "pamper or cuddle" her limbs despite her feelings charged with ambivalence about it, with regard to this inert part of his body. During psychotherapeutic interviews, this wrapping gesture depicts the protection of a virtual newborn. He doesn't move yet, but "he has nothing to do with a doll", a statement often expressed, but which is always in the realm of denial or denial. In the same way, carrying a child and giving birth to it represents the paradox of a life that will be born from the dead part of one's body, through a painless birth since there is no uterine sensitivity, which poses the question of the mutation of a fantasy into reality and the future of the child. Depending on the progress of his mourning work, this fantasy may be exceeded.
- Take into account the existence of a family which generally becomes a place of welcome again after the accident, but which often has a compassionate tendency to place the young woman in a position of dependence and regression to compensate her for the trauma. It is necessary to support the family so that it does not close itself on the young woman, because the risk is always that the parents take possession of her identity, hedonic and relational territory, which can call into question the future of the young couple. Hence, the essential importance of encouraging her to reconnect with neighbors, neighborhood life and social life in general, with the precious certainty that she can once again be looked at, touched, she who no longer looked at herself and who only touched his body with repugnance.
- Maintain the link for a very long time with the care team with whom support for several months was provided. Although the Rehabilitation Center remains the essential point of reference for each patient thanks in particular to the respect and patience it has shown her, the caregiver does not always realize that he was the first stranger to have access to this privacy. The physiotherapist, nurse, care assistant and service staff were all a mark of her journey during her time at the Centre. In particular, the body care gave everyone a mother-like function, while the patient struggled to understand and slowly reclaim the extinguished part of her body.
 - The participation of a sexual caregiver (male or female)

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seems essential to me, rather than letting the couple get by with "instructions" in a room at the Functional Rehabilitation Center dedicated to planned attempts at sexual rapprochement, after an anal and bladder emptying itself programmed. But France has not yet decided to legislate on this issue and separate it from what is similar to prostitution, or what some do not hesitate to call "commodification of the female body" or even "confinement in a sexual ghetto" which would deprive the woman of the emotional values of the sexual relationship. One thing is certain: sexual assistants do not want to be taken for sex professionals [8], and their wish would be to be closer to healthcare professionals [9]. Of course, it is useful to refer to the opinions of the CCNE (National Consultative Ethics Council) to which "it seems difficult to admit that sexual assistance is a right-claim assured as an obligation on the part of society and that it depends on other than individual initiatives [10]. Hence his refusal.

Finally, if it has been possible to write that "love for one's own person is perhaps the secret of beauty" [11], as long as she has not regained her self-esteem, the woman with a spinal cord injury can no longer feel beautiful. If she can no longer consider herself as a trigger and receptacle of the man's desire, this feeling pushes her towards a position which exposes the partner to moving away from life as a couple, because the desire is no longer there. Its place. No doubt, we must find an explanation in the idea that our society places man more easily on the side of desire than on the side of love. However, this is a point of view which is far from being entirely shared, once we accept the fact that the woman is ready to be satisfied with it, whereas for her the sexual relationship must be above all an exchange where there is about giving, receiving and feeling together. In reality, only the woman who lives in a relationship of trust with her body can rebuild a satisfactory relational life. The evolution of the relationship she maintains with her own body is a faithful reflection of the evolution of her journey despite the state of mourning caused by the spinal cord injury.

It is at the cost of this simultaneous process of detachment and discovery that suffering can give way to acceptance and anticipation. No person with a spinal cord injury can move forward on the path to rehabilitation until the page of the past has been completely turned. This journey towards resolving grief is achieved through rehabilitation, which offers new perspectives for carrying the weight of the disabled body and supporting it in the life to come. It is through the refusal or acceptance of this responsibility delegated to her that the woman sometimes fails, or sometimes succeeds, in including the past in her own history and in opening herself to a new history.

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