

Re-building of Sexual Intimacy in the Spouse of a Man Who has Become Motor Disabled

(La reconstruction de l'intimité sexuelle chez la conjointe d'un homme devenu handicapé moteur)

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ABSTRACT

Changes in sexuality and sexual intimacy in the couple of a man who has become motorically disabled can present a major challenge for his able-bodied partner, who does not remain passive in the face of her man's motor and sexual difficulties. This study analyzes the sexual experience of a woman whose partner became paraplegic following a road accident. Using the single-case method, the study attempts to understand how this spouse subjectively and objectively works to reconstruct the couple's sexual intimacy after such an event. Semi-directive interviews, structured around the life story, were conducted with this single participant. Transcribed and then analyzed using thematic data analysis, they show that the couple's sexual intimacy was gradually rebuilt around two main drivers: coitus made possible by a gradually manifested virility, and a benevolent attitude on the part of the partner with sentimental and erotic overtones of complicity, kindness, flirtation, seduction, and respect for the now disabled partner, but imagined as strong, robust, and able-bodied. Attitudes that are an integral part of human relationships, but which tend to disappear when trauma strikes. So much so that his work takes up all the psychic space. This highlights the need to set up support programs for the spouses of disabled people.

Key words: Experience, Spouse of a disabled man, Sexual intimacy, Re-building, Disability.

RESUME

Les changements au niveau de la sexualité et de l'intimité sexuelle dans le couple d'un homme devenu handicapé moteur peuvent constituer un défi de taille pour sa conjointe valide qui ne reste pas passive face aux difficultés motrices et sexuelles de son homme. Cette étude analyse le vécu sexuel d'une femme dont le conjoint est devenu paraplégique à la suite d'un accident de la voie publique. Par le biais de la méthode du cas unique, cette étude tente de comprendre comment cette conjointe travaille subjectivement et objectivement à reconstruire l'intimité sexuelle du couple après un tel évènement. Des entretiens semi-directifs, structurés autour du récit de vie ont été menés avec cette unique participante. Re transcrites puis analysées via la technique d'analyse thématique des données, elles montrent que l'intimité sexuelle de ce couple s'est progressivement reconstruite autour de deux moteurs principaux : le coït rendu possible par une virilité graduellement manifestée et une attitude bienveillante de la conjointe aux allures sentimentales et érotiques faits de complicité, de gentillesse, de flirt, de séduction et de respect du conjoint désormais handicapé, mais fantasmé comme fort, robuste et valide. Des attitudes qui font partie intégrante des relations humaines mais qui ont tendance à disparaître quand survient le trauma. Tellement son travail prend tout l'espace psychique. Ce qui met en évidence la nécessité de mettre en place des programmes de soutien pour les conjoints de personnes handicapées.

Mots clés : Vécu, Conjointe d'un homme handicapé, Intimité sexuelle, Reconstruction, Handicap.

INTRODUCTION

Sexuality is central to men. It affects and determines all human behavior. Every human being, whether with a disability or not, is driven by the sexual drive. Expressed or not, it is present in each of us and can be repressed, frustrated, or sublimated. It is expressed from birth. Its source is bodily, its goal is the search for pleasure. Throughout life it evolves and manifests itself differently from childhood to adolescence. Along with sexual intimacy as a couple, it represents a normal and positive way of communicating and thriving. On the individual and social level, they constitute essential dimensions of quality of life. It involves not only sex, but also affectivity, the possibility of having children, the anatomy, and the sexual development of spouses.

Numerous studies (Toumebise & Alli, 1997; Corbin & Strauss, 1988; Parker, 1993; Shakespeare, 1999; Jouvencel & Narcyz, 2001; McCabe & Taleporos, 2003; Rainey, 2011; Fournier, 2016) have addressed the question of sexuality and that of sexual intimacy among people with disabilities. These studies state that the occurrence of a disability in the couple has negative consequences on the marital relationship. Some studies emphasize the fact that the stay in an institution which generally follows the onset of the disability is a weakening factor for the intimate and sexual life of couples (Colomby & Giami, 2008; Berthou, 2012; Fournier, 2016).

Changes in sexuality and sexual intimacy in the relationship of a man who has become disabled can pose a significant challenge for people with disabilities and for their spouses when they are in a relationship. In these lines, Shakespeare (1999) mentions that after the onset of the disability, the person is no longer considered sexual: he or she is no longer a real man, nor a real woman. In most couples, romantic relationships with the disabled spouse constitute, after acceptance of the disability, the most significant difficulty (Toumebise & Alii, 1997). Given this, adjusting to a new physical and emotional reality may require time and open communication between partners. Shildrick (2007) mentions that the sexual development of people with disabilities is inhibited because of a lack of romantic/sexual models offered by society. Along the same lines, Siebers (2012) emphasizes that people with disabilities constitute a sexual minority because their sexuality tends to be controlled and pathologized. It is sometimes considered dangerous, immoral, and perverse. The study by Dupras (2014) shows that among men with disabilities, the desire to make love is fueled by the need to be recognized as virile and valid. These people, suffering from being dehumanized, infantilized and devirilized, claim the right to autonomy and sexual satisfaction.

Giami & De Colomby (2008) show that motor difficulties reduce the probability of living as a couple. In fact, people with deficiencies and disabilities live with couples as much as the general population: 70% say they have a sexual partner compared to 75% of this population. Regardless of age, Roussel & Sanchez (2001) note that 92% of people with disabilities are in marital isolation. Furthermore, in their study Banens & Marcellini (2007), mention that the presence of a disability before entering a couple greatly reduces the probability of starting a life as a couple and the appearance of a disability in the couple is monitored of a long process of changes. According to these authors, people with disabilities are very rarely approached for romantic relationships and even less for marriage; and therefore, a disability situation after marriage is very delicate and difficult for both spouses to experience.

In summary, the motor disability, when it appears after marriage, constitutes an obstacle in the development of the couple (Corbin & Strauss, 1988; Parker, 1993). These studies have highlighted the negative impact, on marital life, of the arrival of a motor deficiency in one of the spouses, through the establishment of a relationship of "conjugal care", which plays a rather negative role on the relationships of dependence, autonomy, seduction, and power between spouses.

Working on the question of intimate life in couples where one of the partners suffers from physically serious trauma, De Jouvencel & Narcyz (2001), observe that approximately one couple on five separated between two and six years after the onset of the disability. In the same line, couples evoke a sexuality that has become problematic with the main difficulty mentioned being the acceptance of disability (Toumebise & Ali, 1997) and the decline in the frequency of romantic relationships (Jouvencel & Narcyz, 2001).

A study on the virility and masculinity of disabled men highlights the fact that a disabled man can be physically paralyzed, but be active genitally (Ancet, 2011). Sexual virility is then linked to the image of physical domination

of the male, of an active man over a woman passive to penetration. For this author, it is largely unknown that a disabled person can have erections and fine genital sensitivity, when there is no rupture of the spinal cord. As a result, the paternity of people with disabilities is often questioned (Nuss, 2008). Virility in the sense of performance or sexual power.

In view of the above, while considering the very notable developments in research, care and support offered to subjects with disabilities, in Cameroon and elsewhere, we have observed that many studies are clearly of interest on the person with a disability, to the detriment of the experience of close family members and/or caregivers, they have little interest in what they experience or in the way in which this disability intervenes in their subjective, intrapsychic and intersubjective lives. During a doctoral internship in clinical psychology with people with a motor disability, we were interested in the subjective experience of women who were in a relationship with a man who had found himself in a situation of motor disability.

From a psycho-phenomenological perspective (Vermersch, 2012), this article attempts to understand how the partner of a man with a motor disability manages subjectively to reconstruct the intimate, sensual and sexual life of her couple, while his partner found himself disabled following a traffic accident.

METHODOLOGY

This study is descriptive, qualitative (Pelletier & Demers, 1994) and exploratory. His approach is inspired by the clinical method known as of the singular case (Fernandez & Pardinielli, 2016; Widlöcher, 1990).

Framework and Participants Under Study

The study took place within the National Center for the Rehabilitation of Disabled Persons (CNRPH) of Etoug-Ebé in Yaoundé. The participant is from a population consisting of women, spouses of a person with a motor disability occurring during marriage and not placed in an institution. Six spouses were met, but only one freely consented to a collection of the data in connection with her sexual life as a couple. A question doubly intimate: sexual intimacy and the disability situation which is not without its taboos. Furthermore, we noticed among most women not – consented, a shame or a difficulty to talk about it. It is possible that they have viewed their spouse's disability as a taboo. It is also possible that these women simply demonstrate, through this refusal, the desire not to talk about their privacy to the researcher who is invested as a stranger. In this sense, the one who agreed to participate in this research probably felt more comfortable with the researcher.

Therefore, this study will focus on a single case. Hermine aged 34 years.

Instrument, Procedure for Data Collection and Analysis

We met her nine times during semi-structured clinical interviews. Their setting was a listening room at the Center, when Hermine accompanied her partner for visits, but also, fortuitously outside the Center, when she requested it. Each interview was recorded using a Dictaphone whose use had been reported. The information collected was transcribed using Word software. They were then the subject of a logico-semantic content analysis (Mucchielli, 1991), constructed according to the recommendations of the theoretical approach to sexual intimacy Dahms (1972), which suggests organizing the discourse of the participant around three dimensions: physical, emotional, and intellectual.

Ethical Considerations

An informed consent form was offered to each female member of the study population. The terms and objectives of the research were explained to them beforehand. This form and these explanations highlighted the freedom they had to leave the study at any time without this altering the quality of their care as well as their relationship with the support team present at the Center.

Hermine agreed to participate in the research by signing the said form. To preserve her anonymity, a fictitious name has been assigned to her.

RESULTS

The analysis of the interview stories shows that sexual intimacy was of good quality before the disability situation. The occurrence of disability came and broke this balance.

Case History

34 years old, second child of three, Hermine who has been married for fifteen years is mother of three children. Her parents and her mother-in-law are all alive at the time of the interviews. A dedicated catholic christian, she says she draws strength and courage from her religious devotion and her daily routine. She rarely misses the six o'clock service. It was this that kept her on the right path and alongside her husband who became disabled following a road accident six years ago.

Internship with people with motor disabilities at the Rehabilitation Center for Disabled People, we meet him during one of their follow-up visits. On occasion, she shows herself attentive and devoted to her partner whom she accompanies and tries to reassure. They come to see the occupational therapist for functional rehabilitation. We notice her many gestures of affection and attention. She gives us the image of a person who is both serious in her approach, but pleasant and pleasant in her interactions. Benevolence drips and combines with character traits such as reserve, maturity, and dignity, but also warmth, friendliness, and kindness.

A duality that we interpret as a resource. A skill, an asset allowing her to adapt to various situations and establish harmonious relationships with others. During subsequent interviews, we observed that she seemed to feel no pressure, or anger, or pain. There were moments of silence and great emotions of course. But these only betrayed the sadness and suffering felt when recalling this period which she several times described as “dark”. In four meetings, Hermine was able, without taboos and with many details, to address with us questions as intimate and sensitive as her sexual and personal life.

She works as a surface technician. A job that she keeps for its flexible hours. This gives them greater freedom to organize their day, fulfill their family responsibilities and adapt to unforeseen circumstances. This allows her to devote a lot of time to her partner while remaining productive for herself and her family. After the shock of the accident which cost them both of her husband's legs, the young woman who always benefited from the support of her mother was able to rebuild a fulfilling social life. Very organized in her social, family, and professional life, she maintains a rich and authentic relationship with her “people”. During the interviews, she said she could count on the support of a social network made up of people from different backgrounds and ages. “I was very angry [...]. But it wasn't anyone's fault, so I decided to stay positive and talk to people.”

As events that negatively marked her childhood, Hermine evokes a parental decision which, she says, “determined forever” her life. When she begins her second year of secondary school, her father deprives her of her right to education. He “refuses to let me continue my studies,” she says. A decision that caused my “early marriage”. “I used to sell yellow yams at the market. [...] Afterwards, my aunt showed me my husband.” Hermine then expresses a feeling of pride – for the path traveled – and acceptance of her past. She says she learns from her experience and has taken the measure of her choice. “...I couldn't do what I wanted...It's not what I wanted, but I'm not afraid and I have no regrets.” “Time has proven me right,” she says. “I still had the opportunity and the chance to give birth... I had a daughter after the accident. It filled us with happiness, it did us good.” Even if the paternity of Claude, her partner, is questioned by her in-laws and some of her relatives, she prefers to concentrate on the essential: family development and the education of their children. She also appears extremely concerned about this last question. She does not want them to experience what she herself painfully experienced. Education will empower them with the “lack of knowledge and money” to provide better support and care to their father.

Hermine represents disability as something “painful” and “very very difficult”. Disability is a source of suffering for her: “Seeing your partner like a baby made me cry every day,” she says. “When you have a disabled husband it's like you've just given birth to a newborn, because you have to remove his poop, wash him, feed him, you take care of everything...”. A loss of autonomy which will introduce novelties, no less important – loss of desire, erectile dysfunction, and pain during intercourse. New developments that have impacted their life as a couple,

their intimacy, their practices, and their sexual experiences. So many problems and annoyances to sexual satisfaction which fueled her frustration.

Emotionally, Hermine quickly felt overwhelmed. She says she was massively overcome by “bizarre” feelings of anger, guilt, shame, and fear. “I was panicking... I felt more and more alone,” she admits. Her partner can no longer satisfy her sexually, she says she has withdrawn into herself. She carried out her marital obligations and duties in a mechanical and impersonal manner. This is when she realizes that she is as if blocked and “eaten from the inside by things” that she kept for herself. She also realizes that she had started to function like a robot, in silence. She only returned to her husband – his body, to be more precise – to provide him with care. During these, she manipulates him like a simple object, without consideration, without attentive gestures and without signs of affection, like an automaton. Sometimes, she did it while crying or humming, to take away from the situation, its “bizarre” and unreal character. Care that he sometimes refuses. A refusal of care which can be interpreted as a burst of pride identity, an attitude of opposition to care which he feels as violence, because reduced to his handicap and the harm – anatomical and functional – that it caused him.

He had to readjust. Readjust to live and “do” with this real body, damaged and disabled, symbolically experienced as inert, unfit, and insensitive, object of embarrassments and unpleasant concerns.

Reconstruction of Sexual Intimacy

The participant has a two-dimensional conception of sexual intimacy: a physical dimension and an emotional/affective dimension. She alludes to it in one way or another when she verbalizes about the way in which she decided to restore after the shock of the “accident which made her husband a disabled man”.

The physical dimension of sexual intimacy is characterized by coitus, but also by the presence of caresses, kisses, embraces and looks. Before the onset of the disability, Hermine considers that she was a woman, married and sexually fulfilled. They desired each other frequently; sexual relations were regular and satisfying. They always ended in coitus. However, the sudden onset of the disability will induce a physical and functional incapacity, complicate access to genital sexuality and modify their “way of being together in the bedroom”. Initially very close, Hermine came to feel emotionally empty, indifferent, sad, and alone. She says she experienced a massive loss of desire. His body felt “frozen”, frozen. Physically, she no longer felt sexual attraction for him – this “unfamiliar” body that she only manipulated to heal –. It took him a good five years to heal from this trauma: “I had lost the taste for making love, I lost that for five years, the taste there... So, the desire for man, I didn’t have that anymore...”. It no longer aroused his desire.

From there, the young woman felt dissatisfied, sad, thoughtful, and depressed. The most trying and the most frustrating will be the impossibility of a complete physical union with her spouse who is no more – for at least for a moment – in the anatomical and probably psychological conditions of having penetrative sex. The situation requires changes but, for a long time, Hermine remains blocked by the perception and the representations that it has about of the latter, on the one hand, sexuality, and sexual roles on other parts.

First, it seemed extremely difficult for her to conceive of him as anything other than a “handicapped” and because of this, he was sometimes perceived as a child - and therefore without sexual urges -: “it’s as if you have a newborn”, sometimes perceived as a deformed, deficient, handicapped body – which cannot create desire in the other –. It seemed to her both: “very difficult to reconnect with the sexual act” and “...very painful to make love with a person with a disability”. At first, she didn’t think it would be possible again. She only goes to her body to provide her care. For Nuss (2008), it is the fear of difference which maintains this type of difficulty in the relationship with a person with a disability. The morphological changes induced by the accident make him “strange”, while imposing, on the one hand, a situation of incapacity, a novelty, a shift from the norm, and on the other hand, a sexual frustration - which she struggles to develop - at the same time as a “penis envy” which will determine, for the most part, her categorical refusal to resign herself to having sexual intimacy with her husband without genitality and therefore, motivate, in some ways, her quest for solutions for “normal” sexual intimacy. “I wanted it to go back to the way it was...” she repeats.

At the same time, Hermine remains locked in a representation, a conception of sexual life where the man, a virile

male, dominates or “pilots the sexual act”. A classic conception of sexuality, sexual roles (active-passive) and male virility which invalidate her mentally and make her incapable of enjoying a sexual life without penetration. “...He couldn’t penetrate me with his cock. We were only doing the foreplay... It tired me [angered or frustrated me] until...” We can see that at least at this moment she has the feeling that it is not normal to only have sex without penetration. And this worries her greatly: “...When he wants to make love, he takes time...he does the foreplay correctly, but at the time of penetration he is blocked because he doesn't have the balance in his back... And it's up to you, the woman, to do the work.... Hmmm, that got me thinking...”

Combative – and this is also another character of her resilience –, she refuses to see in this situation something she could live with. She doesn't consider it to be sex. She had known better, and she wanted to relive it, and she could not resign herself to this prejudice – anatomical – which tended to compromise his “desires” and his “desire”.

From the perspective of one's personal history, normal sexual play refers to foreplay which is only a step towards coitus or the sexual act itself: building up desire to penetration, the ultimate step which creates satisfaction. Kisses, caresses, and stimulation of all kinds are experienced as “empty of meaning”. She found pleasure there, but also a lot of dissatisfaction if they did not open to penetration. The most important thing for her was coitus, sexual penetration: “...I wanted to feel him...I wanted him to penetrate me” she said, thus expressing a feminine inclination – quite natural – to be taken, to “possess the penis” (Freud, 1905) and to be possessed by a virile, phallic and active male who dominates and submits her as a non-virile, castrated and passive being.

To boost sexual desire or treat problems of erectile dysfunction noted in his spouse, Hermine carried out research in his entourage. She says she resorted to all kinds of informal treatments: “grandmother's recipes” and aphrodisiac products offered in the streets and markets of Yaoundé. In this context, erectile dysfunction is still experienced as a disease of shame. It is often the cause of problems within couples and is mostly the subject of domestic care.

At the time of the interviews, Claude, her partner, had regained his sexual sensitivity and virility. Despite a dominant position during intimate relationships, which she says she is not satisfied with, this has improved the satisfaction and frequency of their intimate relationships: “...Today there is sensitivity, but the problem is that it is you the woman who must go up and make love as if you were the man of the house... Sometimes I'm tired, it hurts my back, but the pleasure is there and that cancels everything out”.

DISCUSSION

The analysis of Hermine's protocol shows that the reconstruction of sexual intimacy in her relationship took place gradually. At the beginning, the first sexual contacts were very difficult, especially at the time of coitus: “The first moments we made love, when I got on top of him, urine came out, sometimes it hurt him [...]. It really bothered me.” Like other results, this suggests that disabled women or men encounter difficulties in their intimate relationships and that this constitutes one of the most important challenges after accepting the disability (Toumebise & Alii, 1997; Shildrick, 2007). In addition, faced with these sexual dysfunctions due to an alteration in the functions of the small pelvis and the perineum, the study shows that the participant is initially disgusted. Indeed, according to Dupras (2014), people with disabilities may encounter challenges in finding an intimate partner due to the prejudices surrounding disability and the disgust that some experience.

To rebuild sexual intimacy in her relationship, one notable thing about Hermine's resilience is her combativeness, her tendency to immediately look for solutions to the problem in her social network. She will take her courage in both hands, overcome her shame, to talk about her difficulties to those around her, and to her mother-in-law who, despite her own embarrassment, will give her advice on the situation while giving her a product – from the traditional African pharmacopoeia – supposed to improve the libido of one's spouse. Other studies also show that with the onset of a disability, it can be difficult for those around them to address questions relating to the sexuality of people with disabilities (Chapelle, 2004; Daure & Combeau, 2022). However, as this study shows, it is an important step towards recovery. Possibly, a healing, a “groping” or step-by-step rehabilitation, made up of re-learning, re-appropriation, acceptance (progressive and difficult), mastery, listening, understanding of symptoms, or suffering, of renunciations... A healing, a restoration, a reestablishment of sexual intimacy in the

couple which it is important not to understand in reference to: another couple, a clinical cure or a disappearance of symptoms or suffering, but in reference to the couple themselves, to the possibilities they themselves have offered to give meaning to their lives through healthy sexuality that produces joy, activities and a lifestyle that satisfies the partners.

Combative in the face of her partner Claude's disability and the difficulties it imposes on the couple's intimate sexual life, Hermine knows how to be alert and creative. She deploys many strategies to restore and this intimacy: the sensual look, the erotic game, the humor, moments of seduction and relaxation, flattery, the smile, small gifts, sweet. Words participate in the eroticization of inabilities by transforming an objective limit into resources and potentialities (Chalet & Roux, 2017). They allow Hermine to resolve her differences with her partner and for partners to share, to express their desires and to adjust behavior to the desires of the other partner. In other words, words facilitate sexual interactions to the point of becoming an original ingredient. It's as if the disability forces the able-bodied person to adapt by leading them to revisit their life and their vision of existence (Ancet, 2017). Faced with disability, through communication, words and gestures, couples free themselves from prejudices and re-invent their sexual relationships (Chalet & Roux, 2017): the constraints, the obstacles imposed by the disability become sources and resources which end up breaking taboos and makes possible another way of being in intimacy and the loving exchange. Disability allows us to free ourselves from stereotypical conceptions of sexuality (Brasseur, 2012).

However, these results can be qualified by the attitude and dissatisfaction that Hermine showed as long as her husband remained incapable of penetrating her or having real coitus with her. For her, normal sexual play refers to foreplay which only constitutes a step towards coitus: building desire up to penetration, the final step which establishes satisfaction. An attitude which can be understood through the work of Shakespeare (1999) which shows that the major concern of men is the maintenance or restoration of the erection while that of women expresses the inclination - quite natural - to be taken, to "to possess the penis" (Freud, 1905) and to be possessed by a virile, phallic and active male who dominates and submits them as non-virile, castrated and passive beings.

CONCLUSION

This study analyzes the sexual experience of a woman whose partner became paraplegic following a road accident. By means of the single case method, it attempts to understand how this partner works subjectively and objectively to reconstruct the sexual intimacy of the couple after such an event. The data collected tends to confirm that there is a physical dimension and an emotional dimension of sexual intimacy. In this couple, the physical dimension participated in the reactivation of the emotional dimension. However, the sexual intimacy of this couple was rebuilt gradually around two main driving forces: coitus made possible by a gradually manifested virility and a caring attitude of the partner and respect for the spouse now disabled, but fantasized as strong, robust, and virile. Hermine, the participant felt entirely satisfied from the moment when Claude, her partner showed himself capable of possessing her again during coitus. Without coitus cuddling, the caresses seemed empty of meaning to her. One of the main limitations of this study is the number of participants. Most of the people we met were reluctant to take part in the study. This was certainly because they found it difficult to talk about their disabled partner's sexuality, but also because of the stereotype that sees disabled people as asexual and sex with them as dangerous, immoral and perverse. This study shows that it is necessary to support the spouses of people who have become disabled to help them build a fulfilling relationship. In so doing, future research could explore the effectiveness of different interventions and support strategies to help couples rebuild their intimate relationship.

Links of interest

The authors declare that they have no link of interest in the data published in this article.

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