



Personal views

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Several ethical problems posed by the sexuality of people with paraplegia or tetraplegia

In the vast field of paraplegia, on many occasions doctors experience problems of conscience; for example, giving the prognosis, the request for help with euthanasia, pain and its attendant problems. To these can be added aspects common to other disabled people such as relentless treatment at the end of life, research and its media coverage, the inequality of access to care, discrimination, and the consenting of minors for care.

I have chosen to consider sexuality because it is rarely touched on from this angle and because it varies so much between cultures, countries and even doctors.

Of the three main aspects of sexuality—relationships, eroticism and procreation—I shall be mainly considering interpersonal relationships, particularly drawing on an excellent article by Berard *et al.*,¹ the report of the sociologist Bon² and the limited experiences of a group for ethical reflection, formed from a large association of handicapped people.

One can start by observing that relationships are rarely discussed in the numerous medical articles that are devoted to the sexual problems of the paraplegic (although they are fundamental and the basis of all sexuality). One of the reasons could be the difficulty in generalising about something which for each individual is such an emotionally charged personal matter.

What seems to me to characterise the interpersonal aspects of a paraplegic's sexuality is 'apprehension' with its double meaning of fear and also of seizing and understanding. Because of this, many have a strong desire for information as well as the necessity of being able to lose their inhibitions. For his thesis, a French psychiatrist, P Fiszlewipz, himself a poliomyelitis sufferer, recorded interviews with some of his disabled friends about their experiences.³

One of them who used a calliper said 'I go out with girls but I never get any further because I can always see myself having to take off my callipers.' When, in addition, there is also loss of sensation, of control of erection and of ejaculation, there are several more reasons for being inhibited.

Therefore, what are coming into play are cultural codes of perceptions of reality (for example, in some cultures, lower limb paralysis is lived out as a castration). These are also the general codes of sexuality and of religious beliefs.

There are often sociocultural and educational differences between the carer and the patient which explain the reciprocal difficulties that may be experienced

during discussions undertaken without preliminary precautions, for example the perverse effects of some of the technical explanations.

Faced with a need for information, what precautions can be taken?

With regard to sociocultural codes, Berard advises a dialogue about these subjects using ideas of happiness, a conception of beauty of the body, images of successful femininity and virility, the role of pleasure, the rights of medicine to intervene in the intimate relationships of others.

Religious beliefs have their rules and taboos. It is better to understand them and how they are observed. For example, the Protestant faith allows a greater dissociation between eroticism and procreation than does the Catholic creed.

It is obvious that the greater the difference in culture and religion between patient and carer, the greater will be the need to beware of potential misunderstandings.

Certainly the approach to the problem will vary according to the sex and the age of the paraplegic person and to their past experiences. Bon² notes that a change in sexual function is more marked in men than in women 'who can carry on with sexual relationships in a manner very similar to those pursued before the accident', and who can have children.

Finally, it seems to me that there are three factors to take into consideration in a rehabilitation centre for paraplegic and tetraplegic patients.

- The first is that the body becomes an object under care. With frequent nudity, the subsequent inevitable priapism might be the cause of true episodes of indecent assault to which is added the shame of incontinence. Sex loses its symbolic value and becomes instead a source of greater or less anguish.
- Secondly, the body language that nourishes the tender relationship between mother and infant during massage and toilet can be the source of ambiguous relationships between the carer and the patient, particularly when the procedure results in involuntary erections. The carers must at least be aware of this. It may be necessary to question the functions of the institution which may be unaware of the norms and fantasies of the sexuality of handicapped people.
- The third point arises from the repeated long interviews that Bon² undertook over 2 years with 60 paraplegic and tetraplegic patients in a rehabilitation centre. This is the irritation caused by the lack of



answers to questions about their sexuality. 'What is said is that the doctors are able to broach sexuality from the medicotechnical angle of procreation, but on the other hand there are very few who dare talk about the shared pleasure that can be gained from sexual relationships. The difficulty of coming to grips with sexuality continues during home visits with the exploratory actions often doomed to failure and subsequent problems in the couples' relationships'. Single patients also express a need to be helped in coming to terms with what they can do to experience and offer sexuality and even in being able to establish social relationships with young people of the opposite sex.

Berard, for his part, says 'the discussions between patients increase and continue, being sustained by corridor conversations in which fears and fantasies are expressed. In these impromptu meetings, they discuss the experience of old hands, make comparisons and inappropriate statistical references . . . everything becomes rumour without backup, imagination runs riot. A fantasy is created which contributes further towards the dehumanisation of the genitosexual relationships which are already partly violated by the different techniques of erection and assisted ejaculation'.

We should like to conclude with three comments.

- 1 The more verbose that specialists are about the use of the remaining capabilities for functional autonomy, the more will they be generally reticent about the remaining abilities of a sexual nature. Surely the foundation of rehabilitation is to highlight what remains?

In a rehabilitation centre, neurosexology would seem to merit the same degree of follow up and importance as neurourology or neuro-orthopaedics. The only difference is that for the latter, the consultation takes place at the request of the doctor whereas for sexology, it should be at the request of the patient when they feel the need. One should at least mention the possibility to the interested parties before the first weekend visits, or perhaps when a member of the caring team becomes aware of the questions, that there is the option of specialist consultations?

Who should impart the information? It would seem to us preferable that this should be a doctor from the centre who has the advantage of knowing all aspects of paraplegia.

- 2 There is a danger of over medicalisation. That is why it would seem to us to be sensible that when artificial insemination is necessary the paraplegic patient is taught how to do it himself, and thus the intimacy of procreation is preserved.

It is well known that the motivation of the couple is important for success, but it may be that such perseverance leads to a therapeutic struggle. It is up to their doctor to decide at what moment he should consider talking of other procedures such as adoption.

- 3 In the interviews, some paraplegic persons expressed

regret (particularly with regard to their compensation) that there is only discussion about sensitivity to pain. It is true that with respect to superficial and deep sensation, to heat and to cold, pain may seem solitary and lacking the opposite: ie pleasure. But by what criteria could one discuss in a report: 'loss of sensitivity to pain and to pleasure'?

References:

- 1 Bérard E, Boucand MH, Thevenot X. *Le Medecin Rééducateur Confronté a la Sexualité des Blessés Medullaires: Repères Ethiques. Actualités en Rééducation Fonctionnelle et Réadaptation*. 13eme serie. Masson: Paris 1988, 102-9. (The rehabilitation physician confronted with the sexuality of spinal cord injured patients—ethical standards. Current concepts in rehabilitation).
- 2 Bon C. La reinsertion des personnes victimes d'un traumatisme medullaire après l'hospitalisation. Rapport d'enquête sur le projet COMÈTE Paris 1991. Personal Communication (The re-integration of spinal cord injured patients after hospitalisation.)
- 3 Fiszlewicz P. Le handicapé moteur et la société. Medical thesis, Paris, 1967.

On walking with the use of electrical stimulators in paraplegics

If, in the first few months after the accident or precipitating illness, we were to ask all paraplegic patients what they would like to do most of all, it is probable that the great majority would say 'walk'. One can ask why, given that control of the bladder, the bowels and of genitosexual function have considerable importance in the psychosocial life of the patient and in the protection of their dignity. In a society where appearances are very important, paralysis is what is noticed. The wheelchair is, above all, seen as a stigma of abnormality.

Why does walking seem so important?

Changing between activity and rest is one of the fundamental rhythms of human life and walking has a major place in activity. The need to move is innate and walking is the most common method of movement.

Since the arrival of homo erectus more than 500 000 years ago, evolution of man has programmed into him two-legged walking.

Walking satisfies the instinct of social conformity.

When the brain is free from the need to exercise voluntary control of movements, walking is on 'automatic pilot', by far the most common situation. It seems to give most people relaxation and encourages reflection—the lecturer who talks while pacing the room, the writer who stretches his legs to seek inspiration. What better example than that of Aristotle who philosophised while walking with his pupils?

The benefits of walking for paraplegic individuals

On a physiological basis, it has been known for a long time that changing positions is a good method of



combating visceral stasis. The effort required also assures a certain level of cardiac fitness.

In the past, when we made most of our paraplegic patients walk with long callipers and a corset, we were often astonished by the distances that they could cover without much fatigue. It was the result of the physiotherapists demanding high levels of performance from the upper limb and chest muscles before getting them up and that required several weeks or even months of preliminary training. This was also useful for independence in the sitting position.

It does not seem, however, that the amount of walking would be sufficient to have any effect on bony demineralisation.

From a psychological point of view, it is obvious that standing erect 'as before', being able to move thanks to the stimulation of one's own muscles and to be for a moment at the same height as other members of the discussion is quite important.

Drawbacks of walking for paraplegics

There is the risk of a fall and fracture, the cost of the equipment, time spent to the detriment of other activities and a certain 'medicalisation' of life. One also has to think of the unavailability of the hands compared with the autonomy of free hands that the wheelchair gives.

Some comments

1 The cost must be taken into consideration. From the point of view of the individual, it would be unfair to start somebody walking if ultimately they would not be able to afford the equipment.

Thirty or forty years ago, we did not generally take into account costs, but nowadays, unfortunately, but necessarily, we have to control health costs and choices cannot be ignored. Would it be better to have walking equipment worth 80 000 francs or instead to buy two or three environment control systems for tetraplegic patients? Should we invest in research on walking for paraplegic people or rather on the cause of multiple sclerosis? These are questions which have

to be faced soon in France and no doubt in other countries.

- 2 The main danger for the doctor would be in stopping the assessment and drawing conclusions too quickly. It is necessary to give it a long enough try to see whether walking is a viable activity or whether on the contrary, the apparatus serves only to underline to the patient that hopes of walking should be abandoned.
- 3 A second danger would be to publicise results too quickly. It could be tempting to use a single patient who continues to walk after several years as a demonstration of one's own success and in order to obtain fame and research credits. This would be against ethical considerations since man, paralysed or not, should not be used as a means.
- 4 Would walking with stimulators for a complete lesion paraplegic individual bring about the advantages of relaxation and the liberty of normal walking? For that to be possible, it would be necessary for the computer to be continually informed of plantar pressures, muscular tensions, the position of each joint and of the centre of gravity so that it could make the necessary corrections. That is a great deal to demand. Another question could be raised: would it not be important to explain to the paraplegic person who desires to walk, the differences from normal walking?

What can we conclude

Man has long had the dream of flying. He realised it not long ago. Why should the person with a spinal cord lesion not dream of walking again?

The paraplegic person definitely has the right to dream and to maintain his hopes. The carers should not be allowed to destroy or to encourage this hope. It is only necessary to bear in mind that if hope helps in living, hoping should not prevent living, that is to say, being active. Activity and creativity are powerful motors in the life of the paraplegic person. That is why I believe that, every time the doctor hesitates, he should always consider someone who is paraplegic as a person rather than as an object.