



ANTHOLOGY ON DISABILITY

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Sexuality, chronic illness and physical disability: can sexuality be rehabilitated?

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People living with a chronic physical disability have often problems in the sexual functioning and the sexual experiences. Sexual problems that appear to this target group are very divers and there are biological, psychological and social factors that can explain sexual problems. Sexological assistance for people living with a chronic physical disability is in many cases not accessible. Rehabilitation centers don't frequently have a sexology treatment and sexologists in the private sector don't often see these group of people. Yet also these people have the same right on a good sexual health

Sexuality in our society appears to be almost absent of taboo. This is very much connected to the idealized image of being sexy, young, beautiful and wild. Even though the majority of the population does not fit this description, they do consider relationships and sexuality to be an important part of their lives. Why would people with chronic illnesses and physical handicaps feel any differently?

In light of this, the observation that sexuality is almost structurally avoided in the health care system in Holland is rather disconcerting. It is only coincidences of patient and caregiver variables that determine whether or not sexuality ever gets discussed in the context of a chronic illness or disability. This article focuses on the following issues. What is the impact of chronic physical problems and disabilities on sexuality? What does this mean to those who are confronted with them? What can a sexologist do to help and what are the important themes a sexologist should be aware of?

Introduction

Sexuality is being discussed more and more openly in society. In particular, this seems to be the case among those who fit the description of being young, beautiful and wild: "Millennial Generation," in other words. Experience has shown that the majority of the population, who do not exhibit this so-called ideal image, consider sexuality part of their lives and relationships. So why should people with chronic illness or physical disability feel any differently? Yet sexuality is one area of life that seems to be systematically excluded from the broad scope of the healthcare system. It is only coincidences in patient and caregiver variables that determine

whether or not sexuality ever gets discussed in the context of a chronic physical illness.

This article will focus on a number of key questions. What is the impact of chronic physical problems and disability on sexuality? What does this mean for the people who face them? What can sexologists do to help and what are the important themes they need to be aware of? Last but not least, this article will review the options for assistance in this area.

Sexuality gets a lot of attention these days, be it sex on TV and in advertising, sexual violence, AIDS, STDs, unwanted pregnancies, erectile dysfunction pills, contraceptives, etc. And that is just the tip of the iceberg. Yet what does sexuality have to do with

people who are chronically ill or who have a physical disability? Is it not a contradiction in terms?

Physical illness, serious accidents and chronic illness are often quite extensive. People are faced with pain, injury, oftentimes with serious disabilities, disfigurement and occasionally with a risk to their lives. The way their bodies let them down can come as a shock.

Healthcare is primarily aimed at helping these people survive. Then they go home and try to make the best of it. In serious cases they receive “follow-up care” in the form of rehabilitation. As part of this, people are supervised in order to minimise the physical disabilities as much as possible and, if necessary, to learn to live with the lasting disabilities. The purpose of all this is to maintain the best quality of life possible. The fact that serious changes will affect sexuality and relationships is unsurprising. Scientific research in this area is revealing more and more indications of a high prevalence of sexual problems in the case of various somatic diseases. Multiple sclerosis, arthritis, diabetes, heart and vascular diseases and kidney diseases are linked to a high prevalence of sexual problems: between 50% and 75% (Vruggink, Kornips, van Kerrebroeck, & Meuleman, 1995; van Berlo, Vennix, Rasker, van Rijswijk, Taal, Weijmar Schultz & van de Wiel, 1999; Diemont, Vruggink, Meuleman, Doesburg, Lemmens & Berden, 2000; Bancroft, 1989). The impact is even more far-reaching in the case of paraplegia (Sipski & Alexander, 1997).

This data is in stark contrast to the clinical attention for any sexual issues/problems experienced by people with a chronic illness or physical disability. During information meetings for people with chronic illness the audience (on average, 50 to 100 people) was asked how often a caregiver discussed sexuality with them, in relation to their illness, of their own accord. There were rarely more than two affirmative responses (Bender, 2002 communication).

On a regular basis people did not receive any information on the illness or disability, with respect to sexuality, and people cannot discuss it with anyone, not even with their own partner. They often feel

guilt and shame in relation to their partners and themselves. The result of this complex dynamic is often unnecessary chronic sexual problems.

This article will try to answer a number of questions. What is the impact of chronic physical problems and disability on sexuality? What does this mean for the people who face them? What role can sexologists play in this respect and what do they need to pay attention to? Last but not least, the options for assistance in this area will be reviewed.

The biopsychosocial approach to the sexuality of people with chronic illness and physical disabilities

The biopsychosocial model of sexuality represents a framework for understanding people's sexual functioning and sexual experiences. This is the best context in which to address the sexual satisfaction and sexual problems of people with chronic illness or physical disabilities. In the case of this group of people both the explanation of and the treatment methods for sexual problems seem to be determined by a biological disorder. However, assessment errors can be made by failing to involve psychosocial factors in the diagnosis and as a result, the caregiver may be wide of the mark. The three factors (biological, psychological and social) will be explained in succession, using concise practical examples.

Biological aspects

Case 1: a young couple of which the male partner, who had serious dystrophy in his legs, could no longer perform active sexual acts. Their request for assistance was as follows: how can we adapt to this seemingly impossible sexual change and how can we ever realise our wish to have children, if we can no longer have sex? The sex therapy focused on expressing their sexual intercourse more by way of shared eroticism, for example by using sexy clothing and telling each other erotic stories). Artificial insemination using the man's sperm proved feasible, once they had accepted this as the best alternative. Careful referral proved essential to the subsequent fertility treatment.

Direct influences

- Neurological disorders can have a direct impact on sexuality. Multiple sclerosis and paraplegia are examples of neurological disorders that often lead to problems with erections/lubrication and orgasm (Bancroft, 1989; Sipski, 1997; Vruggink et al., 1995).
- Vascular disease can have a direct impact on sexual problems as it decreases circulation to the genitals, leading to dysfunction. Serious vascular disease – for example, as caused by diabetes or high blood pressure – often causes sexual dysfunction (Bancroft, 1989).
- Hormonal disorders can lead to problems with libido. This rarely occurs in adults with an otherwise normal physical development. Some congenital anomalies will lead to problems in this area, and they often appear during puberty. One example of this is Klinefelter’s syndrome (Bancroft, 1989; Kaplan, 1979).

Indirect influences

Indirect influences on sexuality are physical complaints that disrupt sexual functioning and the sexual experience, albeit not because they directly affect the “sexual system.” There are numerous complaints that can lead to sexual disabilities and dysfunction. Paralysis, fatigue, loss of strength and energy, pain and stiffness, incontinence, dizziness and sensory disturbances are all examples of common complaints that have a big influence on one's general quality of life, including one's sex life. There are few illnesses that do not entail these kinds of complaints. The more intensive the experience of these complaints, the greater the impact they will have on sex (Bancroft, 1989; van Berlo et al., 1999; Diemont et al., 2000; Sipski, 1997; Vruggink et al., 1995).

Iatrogenic influences

These are medical treatments that are necessary and which (prove to) have an unintended negative effect, in this case on sexuality. The side effects of drugs such as antidepressants, beta blockers and cytostatics are known iatrogenic influences. Damage to the sexual system from operations on the pelvic region, for example, can lead to

serious sexual dysfunction. Prolonged and intensive medical treatments, such as long-term rehabilitation treatment, can lead to problems. The “disownment of body and mind,” mentally distancing oneself from one's body, in order to cope with the treatment, can result in physical estrangement, which in turn can lead to sexual problems (Diemont et al., 2000; Moors-Mommers, 1994; Sipski, 1997).

Psychological aspects

Case 2: *A woman in her thirties presents for sexological assistance, together with her partner. The stated problem was that the woman was less interested in sex. She was an attractive woman who had suffered a foot injury a few years earlier. Two operations did not provide any improvement. The woman in question knew why she was no longer interested in sex. Previously, she only wore high heels and sexy clothes to go with them. Due to her foot injury she could no longer wear high heels and therefore, she was forced to dress in a completely different fashion. This was so difficult for her sexual self-image that she was no longer open to sex. The therapy focused on processing this loss and investigating how she could feel sexy and desirable once again.*

Psychological aspects always play a role in human sexuality, in the case of both healthy and ill people.

Impact on body image

An illness or physical disability always has a direct influence on how a person experiences his or her body. For many people, the first time they experience a far-reaching disease is a shocking experience. Your body lets you down. As opposed to proper control over basic bodily functions, a loss of control can arise. Urinal or faecal incontinence is one poignant example of this. Many people with these kinds of complaints are scared to death of having an “accident” during sex and they avoid sexual activity. Sexual problems can arise the moment the body looks different. Scars, amputations, paralysis, muscle atrophy or cosmetic disfigurement are traumatic events with respect to the experience of physical integrity. “My body is different, which means it is no longer mine.” For people who have a lot of difficulty with this, it can become almost im-

possible to imagine their partner still finding them sexually attractive. This estrangement usually leads to avoiding sexual activity with a partner, which is often labelled as a “loss of libido” (van Berlo et al., 1999; Diemont et al., 2000).

Impact on self-image

The way people look at and value themselves determines their self-image. A solid self-image will emerge if someone is happy with his or her roles in life. These roles are the pillars of one's self-image. One's self-image will be greatly affected as soon as one is made unhappy due to unattainable ideals or as soon as one is limited to fulfilling those roles. Anyone who suffers from chronic illness or serious physical disability will automatically struggle with the major loss of his or her life roles. The basic roles in life such as mother and father, spouse, employee, lover, etc. are often radically changed due to a physical condition. One can discuss most of the losses within these roles with those in one's environment. However, due to the taboo surrounding sexuality, discussing the changes in this area is by no means a given. If the losses are not processed and no new roles are defined, then broadly speaking, the impact on the person, including their sexuality, cannot be underestimated (Bancroft, 1989; Meihuizen de Regt, 2000; Sipski, 1997).

Ability to adapt

Physical conditions put a person's ability to adapt to the test, to varying degrees. The initial reaction, namely denying or playing down the need to adapt, is almost standard. Most people would rather hold on to the familiar and they cannot stand their lives changing in this way due to their physical problems. This detail plays an important role in terms of sexual adjustments. Chronic physical disabilities require adjustments in all areas of one's life. Sexuality is no exception. In addition to sexual dysfunction, problems such as pain, stiffness, paralysis, loss of power and energy can lead to sexual adjustments (van Berlo et al., 1999). In comparison with other areas of adjustment, sex is affected due to the difficulty most patients and their partners have in discussing it, the lack of professional attention to this and the general taboo surrounding sexual aids.

Significance of sexuality to the individual

Everyone interprets and defines sexuality in his or her own way. For example, one's age, stage of life, gender, personality, education and culture all play a role in a person's understanding of sexuality. This will be an important factor in determining when, how and even if a person is capable of adjusting himself to his new situation, sexually speaking (Meihuizen de Regt, 2000; Sipski, 1997).

Social aspects

Case 3: *A couple, both in their forties, consulted me a year-and-a-half after the man had an operation for a tumour in his back. The man was ready for sexual contact with his wife. However, his naked body evoked in her intrusive images of how she saw him taken care of in the hospital after the operation. As a result, she avoided all possible situations that came close to sex. By placing and understanding her aversion in this context, she was able to disregard her misconceptions in this regard. As a result, it was possible to gradually build on the amount of physical contact they shared.*

Relationship skills

Communication and social skills, as well as the ability to deal with problems and conflicts are examples of relationship qualities that partly determine how a couple will deal with the chronic illness or disability of one of the partners. (In this article, a “couple” may be of a heterosexual or homosexual orientation; Hawton, 1995; Lange, 2000; Schnarch, 1991).

Role reversal and role confusion

If a physical condition results in serious disabilities, there is often a forced change of roles. Depending on how the roles are defined and divided in life, this will also co-determine the consequences of that change. Many of the roles are specifically determined by gender and can lead to bigger problems the more one's gender-specific roles are affected. This phenomenon can also play a role, from a sexual perspective. If a man is unable to play the leading and active role in sex due to his physical disabilities, then in the case of a traditional couple, both partners may become sexually disordered. In

this situation rigid roles can make adjustment very difficult. Another example of how role patterns can result in problems is the assumption of the role of patient and caregiver. For example, dependence and (over-)anxiety can place a label on a relationship and as a result, the equal role of lovers may become almost impossible (Sipski, 1997; Jans & Vansteenwegen, 1999). One poignant example of this is the situation in which a partner may have to wipe a partner's bum, then lay the person in bed and then sexual contact is supposed to take place.

Stage of life and significance of sexuality to the relationship

What is the place of sexuality in a relationship? People who focus on sex and who do not feel bonded to one another in many other ways are at a greater risk of divorce, in the event of major changes to their sex life. Physical problems can change their appearance in such a way that the partner may lose his or her attraction to the other. The gravity of these changes and the importance the partner attaches to these may determine the viability of a relationship. The stage of life in which a couple finds themselves at such time as an illness or disability arises will be significant to their expectations in relation to sexuality after the illness. In addition, in some cases – for example, in the event of non-congenital brain injury – changes in character may arise which cause the person to lose his or her attraction to the other. A couple that has been together for 40 years will experience the sexual changes differently than a couple who only know one another for 1 year or 5 years (Schnarch, 1991; Sipski, 1997).

What sexual problems are experienced by people with physical illnesses?

Sexual dysfunction

Case 4: *A young man, around 30 years of age, who presented with an image of a cauda [equina] lesion caused by a hernia, had lost his erection during sex a month after the lesion arose. Both his urologist and his rehabilitation doctors confirmed his major anxiety (without having actually performed a diagnosis in this area) that the erectile*

dysfunction was caused by his hernia. Since his nerves had had relatively little time for any recovery and the effect of a partial lesion on sexuality can remain unpredictable, he was able to give himself the benefit of the doubt – under psychological supervision. It was only after a few months and following conclusion of his clinical rehabilitation that he was confident enough to perform a masturbation test which evidenced that he was able to achieve an erection and ejaculation.

The four-phase model of sexual functioning by Kaplan forms the basis of the subdivision of sexual dysfunctions (1979). Disorders during the phase of desire; arousal disorders that lead to erection and lubrication problems; and problems during the orgasm phase. The sexual problems that most often occur due to these concepts include a lack of interest in sex and problematic differences in the partner's respective levels of interest in sex. Reduced lubrication and erectile dysfunction can be problems during the arousal stage and may lead to dyspareunia. Difficulty with orgasm occurs more frequently among this target group. In particular, greater difficulty achieving orgasm occurs more frequently in the event of somatic problems (Bancroft, 1989; Moors-Mommers, 1992; Luyens & Smits, 1996; Sipski, 1997).

Sexual dysfunctions are very discomfiting. Sexual activities proceed differently than expected. Some people are not disturbed this. However, many people react with shock and occasionally panic. Shame and communication issues always lead to a deterioration in the complaints and can often lead to chronic problems.

Since the somatic aspects should not be overestimated and certainly not underestimated, a proper diagnosis for people with chronic illnesses and physical disabilities is indispensable. A sexological history investigating the complaint in relation to the illness should form the basis of this diagnosis. This history should take serious account of any psychosocial problems related to illness or other factors. As opposed to somatic suffering, the stress of being ill often causes these sexual difficulties. Asking simple questions, e.g. as to when the problems started,

will often provide more information than expensive technical diagnoses (Bancroft, 1989; Hawton, 1990; Lange, 2000; Ijff, 1997).

Problems with the sexual experience

Case 5: *A woman with MS suffers from lipedema. The sensitivity of her genitals is dramatically reduced. She has stated that she no longer wishes to have sex with her husband, as she no longer enjoys it. They soon stop having any sexual contact altogether. Her husband feels that their sex life is incomplete without intercourse. Her difficulties with sexuality forced both partners to examine their norms and values, especially in relation to intercourse. It was only when they were able to investigate this in an open and equal manner that they resumed physicality and, ultimately, intercourse with renewed motivation.*

Sexual dysfunction often occurs in this case. However, sex is experienced differently. Occasionally, there are significant changes in the physical experience such as in the case of paraplegia or other sensitivity issues. In addition, sexuality can be experienced differently, from an emotional perspective. Having sex can evoke feelings of sadness or grief, instead of lust (Jans & Vansteenwegen, 1999). Understandably, a man or a woman with an amputation above the knee having sex for the first time since the amputation will experience sex differently than before. As long as a person experiences sex as an area of loss, the experience will be considerably less positive.

Sexual relationship problems

Case 6: *The male partner of a woman suffering from chronic pain constantly loses his erection when attempting to have sex. Although his wife states that she wants to have sex with him, her pain is so visibly present that losing his erection seems to be more socially acceptable than having successful intercourse. This detail soon became even more complicated when his wife's response to his loss of erection was to feel extremely rejected. The misunderstandings surround his loss of erection needed to be clarified before they could investigate their options for sex.*

Illness and physical disability influence not only patients' lives but also the lives of their partners. Their partners are largely overwhelmed, certainly during the acute phase of an illness. The partner can be traumatised if there is an acute danger to the patient's life or, for example, if there is a serious accident or operation. Since patients are given priority in the context of caregiving, it may so happen that the partner does not receive enough attention, if any, for his or her experience. Depending on the severity of the illness, life will have changed dramatically for both people in the short-term and the long-term. What effect does this have on sex in a relationship? Due to excessive stress the partner may not be interested in sex or experience sexual dysfunction. Fear of a relapse, e.g. in the case of a CVA or a heart attack, a partner may be hesitant when it comes to having sex, even if the patient is ready for sexual contact. Physical contact may bring back the experience of the trauma and as a result, the partner will avoid sex. Certain actions in sexual behaviour may have become impossible for the partner due to the physical disabilities, which in turn can seriously affect the experience (Lange, 2000; Sipski, 1997). Chronic illness or physical conditions always put a relationship to the test. Most people do not reflect on the fact that the sexual relationship is also put to the test.

Problems with sexual adjustment

Case 7: *A single, 35-year-old homosexual man was left almost fully blind due to his illness. He said that he did not know how to cope with the new situation, including in the area of sexuality. How was he supposed to come into contact with men now? In addition, all of the qualities that he found attractive in a man were of a visual nature.*

Problems with sexual adjustment are present if a person or couple fail to achieve a new sexual balance after a period of processing the situation. Communication issues in this area and oppressive norms and values often play an inhibiting role. To more limited and rigid a couple's repertoire of sexual behaviour, the more difficulty they will have in making adjustments to their sexual behaviour on their own. Adjustments may be required in terms of

the type of actions or who should take the initiative. Sex will almost always become less spontaneous and require greater preparation if physical disabilities play a role. People find it more difficult to adjust to this fact than they do to change their behaviour (Sipski, 1997).

Practical sexual problems

Case 8: *A woman who can only achieve orgasm by way of manual stimulation. Due to the consequences of her partner's CVA, namely paralysis on one side of the body and overwhelming fatigue, he is no longer capable of satisfying her in this manner. They successfully overcame these two limitations by purchasing a vibrator.*

Practical problems require practical solutions, and this also applies to sex. Unfortunately, many people cannot summon such a matter-of-fact attitude in the area of sexuality. Physical conditions and illness entail a lot of practical inconvenience, and this also applies in the area of sexuality. Fatigue and a lack of energy may force a person to take a nap or to have sex in the morning time. Incontinence occurs quite frequently and most people do not experience this as erotic. Practical measures such as a protective cover for the mattress and drinking less before sex seem obvious and yet people largely fail to conceive of them (Jans & Vansteenwegen, 1999; Sipski, 1997).

Sexual integration problems

Case 9: *A young woman, aged 31, who was born spastic due to a birth trauma, has never had a sexual experience, neither with herself nor with another. She becomes curious about her own sexuality after watching erotic programmes on television. She notices all kinds of feelings within herself when watching these programs but she does not know what to do with them. Nor does she know what the images on television have to do with marriage (sexual relations). Her confusion was largely resolved by adequate education about sexuality. Furthermore, she started exploring her own sexuality by talking to girlfriends about their experiences, by reading erotic literature and by learning to masturbate. She used discussions with a sexologist to discuss her experiences and doubts.*

Problems with sexual integration can include all five of the above-mentioned problems, albeit in another context. In particular, problems with sexual integration arise in people who became chronically ill or physically disabled during or prior to puberty. This fact played a disruptive role in the person's sexual development. As a result, these people must often develop their social sexual skills at a later stage.

Many factors play a role in this. Young people with a congenital condition or a condition they acquired at an early age often miss the boat, in terms of socialisation. As a result, they often fail to form relationships and experiment sexually during puberty. Information on sexuality which focuses on *their stories* is a rarity. The image people form of these young people is that they are "sexless" or that sex is "not for them." Parents often adopt a protective stance with respect to sexuality and relationships. The short-sighted attitude of some parents/caregivers is still, "Let sleeping dogs lie." These young people receive far too little education for the purpose of identifying sexual abuse and promoting safe sex. Due to the lack of acknowledgement of this group's sexuality, they are extra vulnerable to sexual difficulties and sexual abuse (Meihuizen de Regt, 2000; Sipski, 1997). Practical experience with this group has shown that these facts can lead to delayed relationship and sexual development, whereby people only address these issues in their twenties, thirties and forties.

What can a (rehabilitation) sexologist do to help people with chronic illness and sexual complaints?

Most sexologists, including those without formal medical training, have a lot to offer people with chronic physical disabilities with respect to any sexual problems, perhaps more than they realise. The first and often most important thing is being able to discuss sexuality openly with another person. Unfortunately, the sexologist is often the very first person with whom a person can discuss sexual concerns (in enough detail). An open, inviting attitude on the part of the sexologist during the first meeting is often liberating for those people who are surrounded by care but who have no-one to talk to

about their sexual concerns (Bancroft, 1997; Hawton, 1990; IJff, 1997).

The biopsychosocial model of sexuality is often the basis of the sexological history for people with a physical condition. It is essential for the sexologist to maintain this. Direct causal connections are often incorrectly made between chronic physical conditions and sexual problems. Sometimes it is the patient or the referring party who has not looked beyond the somatic context. In addition to investigating the biopsychosocial impact of the chronic physical condition in connection with the sexual complaint, it is also necessary to gather sexologically relevant information that is separate from the somatic complaints. For example, one must also have a clear picture of a patient's premorbid sexuality, in order to make a proper assessment of the current issues and treatment topics (Bancroft, 1989; Lange, 2000; IJff, 1997).

It may be useful to provide the patient with adequate information about sexuality in general and in connection with the illness or disability in question, and this may lead to a more clear understanding of what is going on in this area. People in the general population are often taken in by societal sexual perceptions of ideal beauty, the need to perform and all kinds of potential sexual "shoulds," and these perceptions hit people with physical problems even harder (Hawton, 1990; Hengeveld & Brewaeys, 2001; van Lankveld, 1999; IJff, 1997).

A proper analysis of the sexual problems can lead to practical interventions that often prove to be surprisingly simple. Examples of this include other positions in the case of difficulties with balance, the use of a vibrator if it is difficult to achieve orgasm and having sex in the morning time in the event of fatigue issues. Many people come up with these on their own, while others do not. Putting one's heads together and figuring it out together are often the first interventions. The sexologist must use the power of his or her imagination more often than in the case of other clients, in order to imagine the impact of physical limitations on sexual behaviour. This is often required, in order to help them in the adjustment process.

Targeted referrals or pronounced problems may require a more intensive therapy. Although the somatic details are important, often they are not the starting point for adequate guidance. The partner's involvement in these therapies is usually indicated, even if this is only during the diagnostic phase (Annon & Robinson, 1978; Hengeveld & Brewaeys, 2001; Sipski, 1997).

The timing of the interventions is determined by the grieving process that surrounds being ill or disabled. Sexual losses are rarely recognised by the person in question or by healthcare providers and this is precisely why it is essential that they can be discussed. Caregivers that offer solutions such as erectile dysfunction pills while a person is grieving his/her losses, are regularly wide of the mark.

The starting point in sexological rehabilitation assistance is to achieve the most *satisfactory level of sexual functioning* within the limitations defined by the somatic limitations (Rol & Bender, 1996). Usually, adults who are seen as chronically ill or disabled individuals have already developed a sexual frame of reference and almost always suffer losses in this regard. Sexual adjustment is the process encouraged and guided by the (rehabilitation) sexologist. The therapy is aimed at processing losses and, subsequently, investigating what can be achieved. Processing psychosocial obstacles that stand in the way of a positive new balance is essential to this process.

In the case of people with sexual integration problems no sexual basis has been developed. They need to start from scratch. In that case the therapy will comprise more than a "coaching" process, in which respect the therapist will encourage the person in question, make suggestions and provide information, and help create the prerequisites to enable the person to start their sexual development. In Israel this process is sometimes accelerated (in the case of young, single soldiers who have become disabled) by using surrogate sexual partners for this therapy (Aloni, Dangur, & Chigier, 1994).

Other disciplines are used for all forms of therapy at the rehabilitation centre. This has an added value in terms of the quality of the responses to any specific

sub-issues. For example, an ergotherapist can provide handy tips for adjusting devices and, if required, the rehabilitation doctor can explain complex questions from a somatic perspective.

A sexologist who is not working in a rehabilitation setting would do well to build up a network that can offer supplemental expertise. Physiotherapists, ergotherapists, medical experts, e.g. experts on neurological problems and incontinence nurses can be found in rehabilitation centres and hospitals and they often have their own practices. An increasing number of teams specialising in specific illnesses have been created in hospitals. Examples include teams specialising in MS, arthritis, renal disease, diabetes, non-congenital brain injury. There is an almost structural lack of sexological expertise within this range of specialists.

Many interventions from the arsenal of standard sexological interventions can be used. They often require a creative twist, in order to match the somatic story in question. Sensate focus exercises are a good example of this. A person with a sensory disorder must literally look for new erogenous zones and sensate focus is a suitable method for doing so. Many people struggle with strict norms and values, as well as a lot of myths and misinformation in relation to how things should be when it comes to sex. The techniques used in cognitive behavioural therapy are frequently indicated for helping people adapt their blocked cognition to the new reality of an often radically changed body. Communication issues and the ensuing misunderstandings are often addressed during treatment. For couples, this is often the cause of problems with adjustment. Holding up a therapeutic mirror to patients gives them the opportunity to make more conscious choices in terms of how they wish to act on their sexuality under these changed circumstances (Hawton, 1990; Hengeveld & Brewaeys, 2001; van Lankveld, 1999; Luyens, 1996; Schnarch, 1991; IJff, 1997).

Discussion

People with chronic illnesses and/or physical disabilities are extra vulnerable to difficulties with sexuality, for a variety of reasons. Caregivers often fail to identify these difficulties. Prejudice may play a role in this omission. As a result, it regularly happens that before a patient starts seeing a sexologist, he/she has already unsuccessfully turned to other caregivers with the same questions. Having no partner, being too old, not needing to procreate and having no opportunity for sex are all examples of reasons why these people are sent away none the wiser. When asked, most people can clearly articulate why sexuality is so essential to them that they wish to discuss this delicate subject with a caregiver.

At present only 4 of the 25 rehabilitation centres in the Netherlands have a modest range of sexology treatment. Sexological outpatient clinics in hospitals offer this target group assistance on a regular basis. Presumably, it is only by coincidence that sexologists in the private sector (the largest group of sexologists) see patients with a disability or chronic illness in their offices. One can also presume that the scope of these services is insufficient for the more than 2 million people in this highly diverse target group.

The question is whether people with chronic conditions have sufficient access to sexological assistance. This access is determined by physical and financial factors, and by one's attitude. Sexologists can do a lot for these people by adapting and applying their expertise. If a caregiver is open to this, then he or she can make a contribution to this particularly human area of life, which is often difficult to discuss. This will give patients a better chance of good sexual health, even if their general health lets them down.

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Islam and disability

By Inge Huysmans

In different cultures there are different ways to think about disability. One culture can see a person living with a disability as a person who is weak and needs help. Also there are cultures that approach these people as a “divine gift” or contrary, as a shame. Other cultures then will approach people with a disability as a normal person with the same rights and duties as others. But every culture has to take into account that the way a culture thinks about people living with a disability, determines the manners to this target group.

Disability and the value of an individual

In those families that view disability as a ‘divine gift’ children with a disability are considered so valuable that they are often rather spoiled. However, this in turn can impede the rehabilitation process and as a result, the child is not given the opportunity to learn to live as independently and autonomously as possible. Children with a mental disability can learn to dress themselves, to eat and to play. However, those children who are so spoiled that they don't have to do anything themselves will not learn these things.

Islam states that people with a disability should be surrounded by love. This falls under the scope of the general rule which states that people who are weak because they are ill, a child or an elderly person should receive more love and assistance than those who are strong and healthy. However, this love should not go so overboard that the person becomes entirely dependent on others. Independence is a very precious commodity in Islam.

In other families children with a disability are viewed as some kind of shame. Some parents would rather that no-one outside the family know they have a child with a disability. This attitude is partly related to the misconception that someone with a disability is inferior. In Islam, however, neither health nor physical strength nor wealth plays a role in determining a person's value. The most important factors for doing so are a good heart and good deeds.

Medical treatment

Some Muslims are more focused on the use of traditional remedies which they call, “Islamic cures.” In such cases healing prayer and Quran recitation are used, amulets are made and exorcism rituals are performed. Some people refuse medical treatment because they feel it is contrary to their beliefs. This includes the belief that everything is in the hands of Allah and that He is the Healer. That is also the reason some Muslims do not wish to avail themselves of the available mainstream healthcare facilities. According to Islam, however, the term “Islamic cures” is much broader than its current definition. In fact, what is currently defined as mainstream healthcare also comes under the scope of Islamic cures.

On the other hand, some Muslims have very high expectations of mainstream healthcare. They expect that it is always possible to resolve any limitations. This is mainly based on the belief among Muslims that nothing is impossible for Allah.

The Prophet said, “Allah has not sent down an illness without sending down a cure for it [...] that is known by some people and unknown to others.” Therefore, the fact that some illnesses or limitations cannot be cured at present does not affect the belief that Allah is the Healer. The therapy is simply not yet known.

Marriage

Research among Moroccan and Turkish families who have a child with a mental disability reveals that there is a high frequency of blood relationship between the parents. Half of the parents are related to one another, and a third of these parents are full cousins. If generations have been married within the family for a long time, the chances of having a child with a serious disability increase by almost 20%.

Marriage within the family was a point of discussion within Islam from the outset. People agree that any marriage which could endanger the health of the spouse(s) or any children they may have should be discouraged. From a religious perspective, medical investigation prior to the endogamous marriage (marriage between relatives) .

Another situation involves marrying off persons with a disability. The family of a man or woman with a limitation will sometimes want the person to get married and a partner is arranged in their country of origin. They believe that the marriage will heal the person with the disability. "Everything will be alright if you get married," their family members and friends often say. Furthermore, their future partner will also help out with caring for and super-

vising the person with a disability, thereby relieving the family to some degree.

However, Islamic sources do not proscribe any absolute decision about marrying off persons with a disability. This depends on a variety of factors. The most important factor is the nature and severity of the disability. This mainly has to do with the term 'equality' which is central to Islamic jurisprudence, when determining whether a marriage is acceptable. The consent of both partners is also decisive in this case. The man or the woman must be clearly and honestly informed of the medical condition of the future partner and agree to the marriage in advance. The story of Mohammed Ghaly shows how in certain situations some Muslims act on the basis of popular beliefs that are not always in agreement with the authoritative Islamic sources. Due to the lack of Islamic sources that address medical ethical issues, sometimes it is difficult for caregivers to work with Muslims with a disability or Muslim families with a child who has a disability. After all, our starting point in the healthcare profession is to respect every faith as much as possible. Professor Ghaly recommends that caregivers seek advice from a well-educated imam or islamologist who has specialist knowledge in this field.