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SEXUALITY AND CHRONIC SOMATIC ILLNESS

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Information about changes in sexual functioning after medical treatment is not being provided routinely by doctors. The inadequate information about possible effects of diseases and therapeutic interventions in patients' sexual functioning is also reflected in the scarce amount of empirical research available on this issue, nationally and internationally. This article outlines Dutch investigations dealing with the effects of disease or handicap on sexual functioning.

"In a society that has moved rapidly towards an expanded awareness of sexuality at all ages, these patients will demand, not without justification, that medical science passes both appreciation and expertise concerning this dimension of their disease. They will require and expect therapeutic interventions which will assist them in becoming psychosexually as well as physically rehabilitated" (Derogatis, 1980). Although this statement of Derogatis was made already more than 10 years ago and in fact the earliest concern for sexual problems in the physically ill was already expressed in 1952 by Bard and Sutherland, this does not mean that information about changes in sexual functioning after medical treatment is being provided routinely. Vincent et al. (1975) found that 75% of the gynaecological oncology patients had received no information regarding sexual adjustment before, during or after treatment. However, whereas 80% of these women desired this kind of information, they also stated that they would not bring up the subject themselves, but preferred the discussion to be initiated by the medical team. A needs assessment by Bullard et al. (1980) among (non-specific) cancer patients, revealed that 63% of the participants would have liked to have received more information about sexual functioning after treatment and that 64% would participate in a specific counseling programme on this topic if this should become possible. A recent study conducted in The Netherlands on 1700 patients with an ostomy showed that only 23% had received any information about the possible consequences of treatment on their sexual functioning and that, of this informed group, only 55% had regarded this information as adequate (Van de Wiel et al., 1991b).

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Steenderen, B. van (1987). *Homo worden, Homo zijn. Een onderzoek naar vormgeving van homoseksualiteit bij jongens.* Publikatiereeks Homostudies, Utrecht.
Straver, C.J. (1976). Research on homosexuality in The Netherlands. *The Netherlands Journal of Sociology, 12:* 121-137.
Straver, C.J. (1981). Unmarried couples, different from marriage? *Alternative Lifestyles, 4:* 43-74.
Tielman, R. (1982). *Homoseksualiteit in Nederland.* Boom, Meppel.
Vogels, T. and R. van der Vliet (1990). *Jeugd en seks.* SDU, 's-Gravenhage.
Vander Linden, F. and W. Perdaens (1980). Homofiele emancipatie in Vlaanderen. F.W.H., Antwerpen.
Vincke, J. (1990). Risikoseks bij Vlaamse homo-mannen. *Tijdschrift voor Seksuologie, 14:* 11-19.
Vincke, J., R. Bolton and R. Mak (1991). Structural and cultural barriers to AIDS-prevention: the Belgian case. *Medical Anthropology* (special issue on AIDS), in press.
Vincke, J., L. Sabbe and L. Vanhecke (1988). De invloed van omgevingsfaktoren op de relatie tussen seksuele technieken en AIDS. *Tijdschrift voor Seksuologie, 12:* 96-105.
Warmerdam, J.N. and P. Koenders (1987). *Cultuur en ontspanning. Het COC 1946-1966.* Publikatiereeks Homostudies, Utrecht.
Wit, J. de (1984). Van zelfaanvaarding tot actie. Kritiek van de liberale visie op (homo)seksualiteit. *Tijdschrift voor Seksuologie, 8:* 148-158.
Zessen, G. van (1988). *Identiteit en vormgeving. De homoseksuele identiteitsontwikkeling van 282 mannen.* Scriptie RUU, Utrecht.
Zessen, G. van, E. de Vroome, F. van Griensven, R. Tielman and L. van Naerssen (1989). Homoseksuele identiteitsontwikkeling: 'Verloop, beleving en omgevingsfactoren'. *Tijdschrift voor Seksuologie, 13:* 178-189.

The inadequate information about the effect of diseases and therapeutic interventions on people's sexual functioning is also reflected in the scarce amount of empirical research available on this issue, nationally and internationally. We will summarize the international publications by Dutch clinicians and researchers dealing with the effect of a disease or handicap on sexual functioning. Chronic diseases that have received attention from Dutch investigators of sexual functioning are gynaecological cancer (Bos-Branolte, 1987; Weijmar Schultz et al., 1986, 1990, 1991; Van de Wiel et al., 1988, 1990a/b, 1991a/b), testicular cancer (Nijman et al., 1987, 1988), major pelvic surgery (Van Driel et al., 1987), diabetes mellitus (Slob et al., 1990), Peyronie's disease (Van Driel et al., 1991), ostomy (Van de Wiel et al., 1991b), chronic kidney disease (Van Son-Schoones, 1991) and spinal cord injury (Van Son-Schoones, 1992).

Gynaecological cancer

On the topic of sexual functioning after gynaecological cancer treatment relatively many publications have been published the last decade thanks to the financial support of the Dutch Cancer Society.

In her thesis on psychological problems in survivors of gynaecological cancers, Bos-Branolte (1987) evaluated the psychosexual functioning of 69 women treated for ovarian cancer (29), cervical cancer (24), endometrial cancer (12) and vulvar cancer (4) by means of a semistructured interview and questionnaire. The duration of post-treatment follow-up ranged from 0.5-7 years. Results showed a decrease in sexual activity (59%) and intimacy (22%) and an increase in the need of intimacy (19%), emotional support (30%) and open communication (23%). Besides, 30% of these women were of the opinion that there was a negative change in sexual activity in their partners. A considerable number of women had the impression that, although their partners needed emotional support during their illness, they did not receive this kind of support. The author concluded that a positive partner relationship seemed to be more determined by intimacy, emotional support and open communication than by sexuality.

In 1984 Weijmar Schultz and Van de Wiel started an extensive investigation on sexual functioning after gynaecological cancer treatment with a pilot study in women treated for vulvar cancer. Sexual functioning was evaluated in a cohort of 10 women nearly 2 years after the treatment by means of a self-report questionnaire (Weijmar Schultz et al., 1986). Despite many problems, 8 out of the 10 couples accomplished complete or partial sexual rehabilitation. It was demonstrated that sufficient information, sufficient coping and sufficient communication did not guarantee complete sexual rehabilitation. The authors suggested that motivation for sexual expression and mutual affection might be more important for sexual rehabilitation than any physical restriction imposed by the surgery.

To test the validity of this observation a "limited" prospective longitudinal study of the sexual functioning of women treated for vulvar cancer was started (Weijmar Schultz et al., 1990). Ten couples, the women beginning treatment for carcinoma of

the vulva, participated in a two-year longitudinal study on sexual functioning before and after treatment. Sexual functioning was measured on admission and at 6, 12 and 24 months post treatment, by means of a structured interview and self-report questionnaires. An age-matched nonpatient control group was added to the study and the impact of physical variables was also evaluated.

Within 1 year, all women who were sexually active before the treatment had resumed their sexual activities. At the 6-month assessment an increase in relational sexual dissatisfaction could be detected. Over the remaining observation period the women's satisfaction with sexual interaction with the partner was not found to be different from their pretreatment satisfaction and not different from the satisfaction in the control group, in spite of the physical damage and persisting poor perception of genital symptoms of sexual arousal during lovemaking.

The authors concluded that satisfaction with sexual interaction with the partner under these circumstances appears to be more an expression of satisfaction with the intimate aspects of the sexual relationship than of satisfaction with the physiologic arousal aspects of the sexual relationship. They argued that psychological and social variables are more crucial for sexual rehabilitation than physical variables. Therefore, psychosocial issues constitute the most promising focus for intervention.

A detailed assessment of current sexual functioning of 7 women from the same experimental patient population 12 months post-treatment by using both interviews and self-report questionnaires for datacollection (Van de Wiel et al., 1990a) revealed that according to the participant's point of view rather dramatic changes in sexual life occurred because of the cancer and it's treatment. However, when the data of the participants were compared to data from an age-matched control group, no important differences could be traced on the main aspects of sexual functioning, i.e. sexual satisfaction, sexual behaviour and sexual motivation. Only remarkable differences in experienced sexual arousal and orgasm could be noticed.

The authors hypothesize that sexual rehabilitation itself is guided on a higher level by a more general striving for balance in the relationship. Interventions to prevent or reduce sexual problems after gynaecological cancer treatment should not only be directed towards the patient but also towards the partner.

A similar "limited" prospective research design was used while studying the sexual functioning of women treated for cervical cancer (Weijmar Schultz et al., 1991). Twenty-six couples participated. An age-matched nonpatient control group was added to the study. In addition, the results of a one year longitudinal assessment of sexual functioning of women diagnosed and treated by means of simple hysterectomy for benign gynaecologic disease were used for comparison. The impact of physical variables and participation in the research project was also evaluated.

At one-year follow-up sexual functioning of the women who had been treated for carcinoma of the cervix was very similar to sexual functioning of the women who underwent simple hysterectomy for benign disease: in both populations the sexual response was significantly disturbed, whereas current sexual behaviour and motivation for sexual interaction were within the normal range. The women clearly expressed general satisfaction with their sexual functioning and little relational sexual dissatisfaction.

The authors state that a woman's motivation for and satisfaction with sexual interaction with the partner is not limited to the experience of sexual arousal, and that sexual rehabilitation aimed specifically at the diagnosis of cancer and the associated physical variables is not really justified.

Van de Wiel et al. (1988) examined the sexual functioning of 11 women treated for cervical cancer 6-months after their treatment in more detail. Sexual functioning was measured by using self-report questionnaires. A non-patient control group was added to the study. It was found that sexual interaction was valued significantly less by the women treated for cervical carcinoma than by the women from a non-patient control group. After treatment no changes in overt sexual behaviour occurred. Furthermore, an effort was made to identify the most important psychosexual variables underlying the reduction in sexual motivation. It was found that a considerable decrease in the appraisal of oneself as a sexual partner generally formed the base of the problem. Apparently women try to cope by conforming to the sexual demands of their partner and to those of the prevailing sexual norms. It was concluded that cervical carcinoma treatment has a strong negative effect on the sexuality of the patients and that it often amplifies the already existing ambivalence towards sexual interaction which is common in women.

The partners were involved in this study as well. Sixteen partners of women treated for gynaecological cancer were interviewed, 12 months post treatment, about two central themes: "involvement and support" and "sexuality and relationship" (Van de Wiel et al., 1990b). With regard to involvement and support, it appeared that many men experienced the process of providing support as a stressful process and had serious doubts about the support they provided. With regard to sexuality and relationship, it appeared that these partners do have extensive sexual problems, which could not be solved adequately.

As a possible explanation for both phenomena, it is hypothesized that the disease and its treatment also poses a crisis for the partner, which leads to a regression towards a more rigid, male stereotype way of coping. This means that attention should not only be given to the patient during treatment, but also to her partner and to their communication patterns.

Finally, prognostic factors were identified. Based on the literature on sexual functioning after gynaecological cancer treatment a number of so called "prognostic" variables were identified and investigated in a group of 32 patients treated for vulvar cancer (n=7) and cervical cancer (n=25) (Van de Wiel et al., 1991a). The four categories of prognostic variables that could be distinguished were: 1) partner-related variables, 2) health-care-related factors, 3) physical factors, and 4) psychological variables. A "limited" prospective correlational design was used.

Although the authors state that the number of observations in this study is relatively small some cautious conclusions were drawn. Overt sexual behaviour after treatment can be predicted quite accurately by past sexual experience, i.e. pre-treatment sexual behaviour. Other aspects of sexual functioning, such as satisfaction, motivation and sexual response, are less predictable. This indicates that the patterns of expressing sexual and intimate feelings are very strongly rooted in an individual's

way of life. Perhaps it is even better to speak of an individual's social life because, even if the individual's psychological and physical situation have been severely disrupted, the patterns of sexual behaviour remain the same. The results suggest priority of psychological variables over physical variables in this particular situation. The authors state that this conclusion cannot be deduced from the data of this study on predictability alone, but is in fact in agreement with the results of an earlier study (Weijmar Schultz et al., 1991) in which no significant differences could be detected in sexual functioning except for the sexual response, between hysterectomy patients on benign and on malign indication before and after treatment.

Testicular cancer

Nijman et al. (1987) studied the sexual functioning of 101 patients who had undergone bilateral retroperitoneal lymph node dissection for Stages I and II nonseminomatous testicular cancer. All patients were without evidence of disease after at least four years' follow-up. Antegrade ejaculation was present in 12 patients, while 89 patients experienced "dry ejaculation". Urine collected after intercourse or masturbation from 75 patients with "dry ejaculation" showed retrograde ejaculation in 55 and lack of ejaculatory emission into the urethra in 20 patients. Regarding other sexual functions, 17 patients had a diminished sexual desire (especially those patients who had received radiotherapy), 12 patients experienced difficulty reaching orgasm, and 6 patients complained of erectile dysfunction.

A similar study was carried out in a cohort of 54 patients with a nonseminomatous testicular tumor Stages II or III but this time the assessments were made before and after treatment with surgery and combination chemotherapy (Nijman et al., 1988). Two years after completing therapy 54% of the patients experienced sexual dysfunctions. Greatly reduced or absent antegrade ejaculation was reported by 26 patients; 18 of them had been treated with more or less extensive retroperitoneal lymph node dissection, whereas 8 had not. This means that the chemotherapy may have been responsible for ejaculatory disorders in 30% of the patients. Only 2 patients reported a change in the quality of erection; 7 patients experienced a decidedly diminished libido, and 5 patients noticed their orgasm had changed in a negative sense.

The appearance of the contralateral testis changes in 21 patients, who showed "atrophy" of this testis. The findings of this study indicate that sexual and in particular ejaculatory disorders are quite common in men treated for a disseminated nonseminomatous testicular tumor. Many of these disorders seem to be due to causes other than surgical intervention.

Major pelvic surgery

Van Driel et al. (1987) studied the results of intracavernous papaverine-induced erections for impotence of neurogenic causes following major pelvic surgery. For several

years injection of a vasodilating drug directly into the cavernous bodies of the penis was used to induce an erection. In 19 or 25 men suffering from organic impotence, erections adequate for intromission could be achieved with papaverine sulfate within the maximum permitted dose of 100 mg. These men were taught to inject themselves. The long-term follow-up, in terms of systemic and local complications, is currently under study. It is stated that intracavernous papaverine-induced erection will undoubtedly become a first choice of treatment for impotence of neurogenic causes following major pelvic surgery.

Diabetes mellitus

Slob et al. (1990) recorded the subjective and objective psychophysiological responses to erotic visual stimulation for 24 women with diabetes mellitus type I and 10 control women. There were no significant differences in subjective responses (general sexual arousal and genital arousal) between the two groups. The objective response varies with the height of the initial temperature. Since initial temperature was significantly higher in diabetic women, the subsequent rise during erotic visual stimulation was less in diabetic women than in controls. When samples from the two groups were matched for initial temperature, the difference in the increase in labial temperature was no longer statistically significant. In both groups of women there was a significant correlation between the degree of subjective arousal and the rise in labial temperature when women with a high temperature (>37°C) at the start of the visual erotic stimulation were not included. The absence of a statistically significant effect of diabetes mellitus on the parameters studied may be due to a lack of serious neuropathy and angiopathy in the present sample of diabetic women. The authors suggest that future psychophysiological studies should include women with serious neuropathy with or without diabetes mellitus.

Peyronie's disease

A bended penis may be a disorder accompanied by pain during erection, intromission problems, including pain felt by the partner, and impotence. The cause is usually congenital or due to Peyronie's disease. Multiple and different therapeutic modalities have been advocated with various results. There is no agreement about therapy. Van Driel et al. (1991) studied treatment comparing it with natural history.

In the period 1984-1990, 44 patients with a penis curvature were analysed. The subjective symptoms were scored using a check list, objective symptoms were photographically measured. Patients were seen at 3 months' intervals until a steady state was reached.

When pain persisted longer than a year, a Nesbitt operation was performed. It appeared that patients spontaneously showed a decline of their symptoms after 6-12 months. 23 Patients were just followed and 21 had an operation. All surgically treated

patients were satisfied with regard to the functional and cosmetic aspects, in 4 patients, however, a completely straight penis was not accomplished. Neuro-vascular complications or infections did not occur.

Considering the natural history it is concluded that a conservative management is preferable. However, when complaints and dysfunction persist, surgical correction is a good alternative.

Ostomy

From a literature review on sexual functioning after ostomy it appeared that ostomy generally leads towards severe sexual problems, especially for men operated for rectum carcinoma. It also appeares that the sexual consequences of ostomy have been far less studied for women than for men. The effects of urostomy have hardly been studied at all. Furthermore, it has become obvious that nearly all studies show a large amount of methodological and conceptual shortcomings, varying from very small sample sizes to the lack of a definition of sexual dysfunctioning. Therefore a retrospective survey was carried out in which 1507 patients (995 men, 512 women) gave information about the changes in their sexual life following ostomy (Van de Wiel et al., 1990b). The results of this study confirm the hypotheses that men are more hampered in their sexual functioning after ostomy than women and that colostomy has a stronger negative effect on sexual functioning than ileostomy. New are the results on urostomy which appears to have the most serious impact on sexual functioning, especially in men.

Although the results of this study give some clear indications of the deleterious effect of ostomy on sexuality, the authors stress that their study is retrospective and that prospective confirmation is still needed.

Chronic kidney disease

Van Son-Schoones evaluated by means of semi-structured interviews and psychometric questionnaires psychosexual functioning in a cohort of 128 patients with chronic kidney disease (70 males, 58 females) and 81 partners (34 males and 47 females) (Van Son-Schoones, 1991). The effect of treatment method (hemodialysis, continued ambulatory peritoneal dialysis or transplantation) on sexual functioning, personal well-being and coping with the disease was evaluated as well as the quality of information and counseling.

Results showed few differences between the effects of the three different treatment modalities on experienced sexual problems. Organic sexual dysfunctions, psychosocial problems and problems with the acceptance were most frequently found in patients undergoing hemodialysis. The partners, irrespective of the kind of treatment, did have more sexual problems and were less satisfied with the sexual relationship. The quality of information and counseling appeared to be insufficient.

Spinal cord injury

The ongoing research of Van Son-Schoones, to be published in 1992, is an extensive investigation of the effects of sexual education and counseling on sexual experience of 45 male spinal cord injured in-patients (Van Son-Schoones, 1992). As part of this study the relationship between physiological and subjective sexual arousal in spinal cord injured in-patients is investigated in an experimental setting. Sofar the results make clear that subjective sexual arousal is not exclusively determined by physiological determinants. Memories of former sexual experiences may play an important role. The results confirm former investigations on this subject.

References

Bard, M. and A.M. Sutherland (1952). Adaptation to radical mastectomy. *Cancer, 8:* 656-671.

Bos-Branolte, G. (1987). Psychological problems in survivors of gynaecologic cancers, a psychotherapeutic approach. PhD. Theses, State University of Leiden, The Netherlands.

Bullard, D.G., G.G. Causey, A.B. Newman, R. Orloff, K. Schanche and D.H. Wallace (1980). Sexual health care and cancer: a needs assessment. In: J.M. Vaeth (ed.). *Frontiers of radiation therapy and oncology.* Karger S, Basel.

Derogatis, L.R. (1980). Breast and gynaecologic cancers: their unique impact on body image and sexual identity in women. In: J.M. Vaeth (ed.). *Frontiers of radiation therapy and oncology.* Karger S, Basel.

Driel, M.F. van, A.I. de Vries and H.J.A. Mensink (1987). Intracavernous self-injection of papaverine in the treatment of erectile impotence after major pelvic surgery. *Journal of Enterostomal Therapy, 14:* 101-104.

Driel, M.F. van, J.J. Mooibroek, H.B.M. van de Wiel and H.J.H. Mensink (1991). Erectile dysfunction in patients with Peyronie's disease and congenital penile curvature. *Journal of Sexual & Marital Therapy, 6:* 55-60.

Nijman, J.M., H. Schraffordt Koops, J. Oldhoff, J. Kremer and S. Jager (1987). Sexual function after bilateral retroperitoneal lymph node dissection for Stage I and II nonseminomatous testicular cancer. *Archives of Andrology, 18:* 255-267.

Nijman, J.M., H. Schraffordt Koops, J. Oldhoff, J. Kremer and D.Th. Sleijfer (1988). Sexual function after surgery and combination chemotherapy in men with disseminated nonseminomatous testicular cancer. *Journal of Surgical Oncology, 38:* 182-186.

Slob, A.K., J. Koster, J.K. Radder and J.J. van der Werff ten Bosch (1990). Sexuality and psychophysiological functioning in women with diabetes mellitus. *Journal of Sex & Marital Therapy, 16:* 59-69.

Son-Schoones, N. van (1992). Remaining sexual functions after spinal cord injury. Medical and psychological aspects. PhD Thesis, in preparation.

Son-Schoones, N. van (1991). The influence of chronic kidney disease on sexuality and relationships of patients and partners. In: Cohen-Kettenis, P. et al. (eds.). *Proceedings of the 10th World congress for Sexology.* Elsevier, Amsterdam.

Vincent, C.E., B. Vincent, F.C. Greiss and E.G. Linton (1975). Some marital-sexual concomitants of carcinoma of the cervix. *Southern Medical Journal, 68:* 552-558.

Weijmar Schultz, W.C.M., K. Wijma, H.B.M. van de Wiel, J. Bouma and J. Janssens (1986). Sexual rehabilitation of radical vulvectomy patients. A pilot study. *Journal of Psychosomatic Obstetrics and Gynaecology, 5:* 119-126.

Weijmar Schultz, W.C.M., H.B.M. van de Wiel, J. Bouma, J. Janssens and J. Littlewood (1990). Psychosexual functioning after the treatment of cancer of the vulva, a longitudinal study. *Cancer, 66:* 402-407.

Weijmar Schultz, W.C.M., H.B.M. van de Wiel and J. Bouma (1991). Psychosexual functioning after treatment for cancer of the cervix, a comparative and longitudinal study. *International Journal of Gynecologic Cancer.* In press.

Wiel, H.B.M. van de, W.C.M. Weijmar Schultz, A. Hallensleben, F.G. Thurkow and J. Bouma (1988). Sexual functioning following treatment of cervical carcinoma. *European Journal of Gynaecologic Oncology, 4:* 275-281.

Wiel, H.B.M. van de, W.C.M. Weijmar Schultz, A. Hallensleben, F.G. Thurkow, J. Bouma and A.C. Verhoeven (1990a). Sexual functioning of women treated for cancer of the vulva. *Journal of Sexual and Marital Therapy, 5:* 73-82.

Wiel, H.B.M. van de, W.C.M. Weijmar Schultz, J. Wouda and J. Bouma (1990b). Sexual functioning of partners of gynaecological oncology patients; a pilot study on involvement, support, sexuality and relationship. *Journal of Sexual and Marital Therapy, 5:* 123-130.

Wiel, H.B.M. van de, W.C.M. Weijmar Schultz and J. Bouma (1991a). Prognostic variables for sexual functioning after gynaecological cancer treatment. Submitted for publication.

Wiel, H.B.M. van de, W.C.M. Weijmar Schultz, M.W. Hengeveld and A. Staneke (1991b). Sexual functioning after ostomy. *Journal of Sexual and Marital Therapy.* Accepted for publication.