

The influence of Huntington's disease on partner relationship and sexuality.

*A study among partners of patients and partners of at-risk individuals*

### Introduction

The Huntington-study was carried out at NISSO, short for Netherlands Institute of Social Sexological Research. The study was part of the programme called "relationships and sexuality of chronically ill and handicapped persons".

### What does the illness entail

Huntington's disease is an autosomal dominant heritable, irreversible, neurodegenerative disorder. Autosomal means that men and women have an equal chance to get the disease, and that once you have inherited the gene, you will definitely develop the symptoms. The disease is characterized by 3 groups of clinical features.

- Motor abnormalities: the most striking feature is chorea, which means 'dance', characterized by excessive, sudden, quick, involuntary movements of almost any part of the body. The frequency and pervasiveness of the movements increase with time. Because of loss of control over muscles of the mouth patients have difficulty with speech and swallowing.
- Cognitive impairment: usually there is a decline of intellect, memory loss, reduced capacity for conceptual thinking and problems with attention and concentration.
- Changes in personality, mood and behaviour: patients can become irritable, demanding and aggressive. They may also become apathetic and increasingly self-centred. Affective disorders, most commonly depression, are often seen in HD-patients. Furthermore there is an increased risk for suicide or suicidal behaviour.

Symptoms can differ between patients.

Symptoms usually appear in adult life between the ages of 35 and 45. Life expectancy after the onset of the symptoms is on the order of 15 years. Death comes as a result of secondary infections, heart failure or aspiration. Treatment is only marginally effective.

In the Netherlands there are about 1000 patients, and about 2 to 3000 risk-carriers (children of patients, who stand a 50% chance to have inherited the gene). Half of those risk-carriers will also get the disease.

Worldwide prevalence rate is approximately 50 per million (Caucasian population).

You must keep in mind that this disease not only affects an individual, but a whole family (brothers and sisters, children, uncles, aunts etc.)

## Consequences for sexuality

The study was an initiative of the Huntington Association in the Netherlands. Over the years the Association has been confronted with many questions and problems concerning sexuality and relationships, such as aggressive behavior of the patient, uninhibited sexual behaviour etc. So far very little systematic research has been done on these specific problems, so this study was intended as a first exploration.

On the grounds of the symptoms of the illness it is to be expected that Huntington's disease has a serious influence on sexuality, both on a physical and psychological level.

### Physical effects:

- choreatic movements can make sexual contact very difficult
- because of neurological dysfunction problems with erection or lubrication may occur.

### Psychological effects:

- depressions and feelings of inferiority can be of consequence to the libido.
- the attractiveness of the patient can diminish, both on a physical and a mental level.
- often the relationship has changed in the course of the illness, from a partnerrelationship to a caregiving-relationship.

Aside from this the medicine taken to suppress choreatic movements, antidepressants etc. can have an effect on sexual functioning.

## Participants and methods

We intended to interview 20 partners of patients and 20 partners of individuals at risk. Patients themselves were not involved in the study, because the interview would be too demanding for most of them. Moreover patients in later stages of the disease are generally not capable of giving reliable answers. Another reason to interview only partners is that partners often do not get the attention they need, while they have their own specific problems.

In order to find out whether being at risk influences the relationship, partners of individuals at risk were also interviewed.

The interview was semi-structured.

Most of the questions focused on how the disease affected the relationship with the partner in general and the sexual relationship in particular. Respondents were interviewed about their perceived relationship-satisfaction, about what they feel has changed in the relationship since the onset of the disease, and about the problems they encountered in their relationship because of it. Questions concerning the sexual relationship included topics such as changes in frequency and initiative, changes in the meaning of sexuality, sexual harassment etc.

Beside this main topic, we also asked for (demographic information), information about the disease, the effect of the disease on life and feelings of the partner, the relationship with the children, social support, and the predictive test.

## Results

19 partners of patients and 13 partners of riskcarriers, all members of the Association, consented to participate. 10 partners of patients are male, 9 are female. 8 patients are institutionalized. 4 patients have died, of whom 2 by suicide. The partners of these partners responded retrospectively.

From the partners of individuals at risk, only 2 are male and 11 are female.

### Areas that have changed

	partners of patients	partners of risk-carriers
contact with friends	14 (73.7%)	4 (30.8%)
contact with family	8 (42.1%)	6 (46.2%)
contact with partner	18 (94.7%)	5 (38.5%)
seksuality	18 (94.7%)	5 (38.5%)
freedom	18 (94.7%)	5 (38.5%)
independance	15 (78.9%)	3 (23.1%)
work	9 (47.4%)	3 (23.1%)
financial situation	10 (52.6%)	1 (7.7%)
health	7 (36.8%)	4 (30.8%)
other	6 (31.6%)	3 (23.1%)

(At 'other' partners of patients reported among other things: never being able to feel really happy, the relationship with their family-in-law, not getting any support and the lack of rest. Partners of risk-carriers reported religious faith and and their conviction in life (living from day to day) as having changed.)

I will focus now on partners of patients.

Contact with the partner, sexuality and freedom are the areas most mentioned by the partners of patients.

As greatest loss partners of patients mention contact with the partner.

On the question: "Do you feel you still have a partnerrelationship with your partner?", 9 resp. reply yes, and 10 reply no.

*Measure of influence on the relationship*

	N=19
very much	12
much	4
slightly/average	3

*Kind of influence on the relationship*

	N=19
positive influence	2
negative influence	9
pos as well as neg influence	8

Positive: some feel that the relationship has grown more intense, and that they are living more consciously.

Negative: there are a lot of fights, arguments and conflicts. Patients display aggressive and demanding behavior and undergo changes in their character.

All respondents report they can no longer discuss everything with their partner. Patients tend to deny their illness. Communication is also disrupted by speech problems.

Being at risk doesn't seem to have a negative influence on the relationship and the sexual relationship.

Almost all the partners of individuals at-risk report satisfaction with both the partner-relationship and the sexual relationship. Some of them however did experience problems in the past, and somehow came in terms with these problems. This group is not representative: people who f.e. divorced a risk-carrier are probably no longer a member of the Association, and for that reason not asked to participate.

When satisfaction with the partnerrelationship among partners of patients is compared with that among partners of risk-carriers, there is a significant difference to be noted.

*Satisfaction with partnerrelationship*

	partners of patients (N=16)	partners of risk-carriers (N=13)
1 very satisfied	3	8
2 satisfied	4	4
3 neutral	3	-
4 unsatisfied	5	1
5 very unsatisfied	1	-

	(N)	mean	std	(N)	mean	std
satisfaction	(16)	2.8	1.3	(13)	1.5	0.9

p < 0.004

*Thinking of splitting up*

	N=19
regularly/very often	4
seldom	6
never	9

*Need for another partner*

	N=19
very often	4
often	2
regularly	8
seldom	4
never	1

Most respondents (i.e. 15) do not or seldom consider separation, but 14 respondents feel the need for an intimate relationship with someone else, and 7 respondents in fact have another partner, or did so in the recent past. All 7 have sexual contact with this partner. For these respondents this need has to do with the illness of the partner.

(Note: What is meant by intimate contact with someone else differs. Some respondents need a good friend, not so much a sexpartner. People who reported having had a relationship with another, also had a sexual relationship with the other person.)

Grenzen stellen: niemand nooit, 3 zelden en de rest (16) regelmatig tot zeer vaak.  
Mannen doen dat vooral fysiek, vrouwen vinden dat moeilijker. (Meer mannen zijn opgenomen!)

Relationele problemen vooral als de symptomen geestelijk zijn.

When satisfaction with the sexual relationship among partners of patients is compared with that among partners of risk-carriers, there is a significant difference to be noted.

*Satisfaction with sexual relationship*

	partners of patients (N=14)	partners of risk-carriers (N=13)
1 very satisfied	1	6
2 satisfied	3	5
3 neutral	1	
4 unsatisfied	7	2
5 very unsatisfied	2	

	(N)	mean	std	(N)	mean	std
satisfaction	(14)	3.4	1.2	(13)	1.9	1.1

The difference is significant ( $p < 0.001$ )

When asked about the influence on sexuality, partners of patients reply the following:

*Measure of influence*

	N=16
very much	12
much	3
slightly/average	1

*Kind of influence on sexuality*

	N=18
positive influence	1
negative influence	14
pos. and neg. influence	1
no influence	2

*Frequency of intercourse before and during the illness among partners of patients*

	before the illness (N=18)	during the illness (N=19)
never		7
seldom	1	4
regularly	9	5
often	8	1
very often		1

*Frequency of physical contact before and during the illness among partners of patients*

	before the illness (N=18)	during the illness (N=18)
never	1	6
seldom	1	4
regularly	10	3
often	4	3
very often	2	2

You see that the frequency of both intercourse and physical contact remarkably has gone down.

When we look at how much pleasure respondents experience from intercourse and physical contact during the illness we see that pleasure also declines.

*Measure of pleasantness concerning intercourse before and during the illness among partners of patients*

	before the illness (N=17)	during the illness (N=12)
very unpleasant	1	1
unpleasant		3
neutral	1	4
pleasant	12	3
very pleasant	3	1

*Measure of pleasantness concerning physical contact before and during the illness among partners of patients*

	before the illness (N=16)	during the illness (N=12)
very unpleasant		
unpleasant		2
neutral	2	1
pleasant	7	5
very pleasant	7	4

*Changes in sexual functioning comparing the illness-stage with the previous period among partners of patients*

	desire (N=17)	excitement (N=17)	lubrication (N=6)	erectile functioning (N=10)	orgasm (N=17)
don't know				1	1
disappeared	4	5	2	2	5
decreased	7	5	1	1	3
the same	4	6	3	4	8
increased	2	1		2	

*Changes in sexual functioning comparing the illness-stage with the previous period among patients, according to the respondents*

	desire (N=17)	excitement (N=17)	lubrication (N=10)	erectile func- tioning (N=7)	orgasm (N=15)
don't know	2	3		1	1
disappeared	6	4	1	2	5
decreased	4	4	3	2	3
the same		4	4	1	2
increased	5	2	1	1	4

With 7 patients (3 men and 4 women) a period of uninhibited sexual need has occurred. This excessive need abruptly stopped (after an incident, or the diagnosis). The 3 female respondents reported not being able to resist the patient. One male respondent refused sexual contact, 2 indulged, and 1 in fact was happy with the increased interest in sex of his wife. So for 6 out of these 7 this excessive need was a problem, some even called it disgusting.

8 respondents (4 men and 4 women) find their partner no longer attractive. The patients had become very skinny, or didn't take care of themselves any longer.

Sexual contact is usually hampered by the physical tiredness/exhaustion of the patient and his choreatic movements. A solution to this problem is f.e. that 1 respondent satisfies the patient orally or by hand, because the patient can no longer keep up the intercourse. Another respondent shortens the foreplay, so the patient does not get too tired. 1 respondent can't kiss her partner on the mouth, because there is a chance that he will bite.

Women seem to accept it more easily when there is no sexual contact any more. Men have more difficulty with this, and more often try to find a surrogate relationship.

6 respondents report that at the time of the interview they had sexual problems, but reading the transcripts of the interviews you see that others had sexual problems in the first stadiums of the disease.

## Conclusions

These results are of course not representative, and I think it is necessary to do a large-scale follow-up. What we can conclude however is that the disease has a serious impact on the partnerrelationship as well as the sexual relationship.

Moreover, patients said that they get a lot of information about the disease itself, but not about sexuality, and they made clear they want this information.

I got the impression that professionals tend to protect these people; some said the respondents shouldn't undergo an interview on such a difficult and intimate topic. But in general, respondents were happy to talk about the issue. They feel they can't talk to anybody about these problems.

So in my opinion sexuality should be part of counseling.