

Quality of Life and Use of Health Care among People with Genital Herpes in France

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In order to assess psychological morbidity in France related to genital herpes infection, we carried out a transversal study comparing infected patients with a control group. A total of 236 patients with genital herpes were first identified by means of a postal survey, then matched against a witness group of 236 non-infected persons. Detailed questionnaires were sent out to each person in the 2 groups. A total of 150 herpes patients and 200 non-infected persons answered the questionnaire, which enabled us to measure the incidence of the disease by means of 2 indicators: a herpes-specific scale and the SF-36 quality of life questionnaire. Emotional trauma due to genital herpes was reported amongst 23% of the participants. Of the participants, 57% indicated that herpes interfered with their sexual relationships; 50% felt it difficult to live with genital herpes; and 37% felt that herpes ruins their lives. An analysis assessing health-related quality of life indicated significant differences between the scores of the 2 groups and showed that quality of life is lower amongst herpes patients. Respondents with genital herpes required more frequent consultations with GPs (81% vs. 73%), and significantly more frequent consultations with specialists (59% vs. 45%). Our study confirms that substantial psychological morbidity exists in patients with genital herpes. *Key words: genital herpes; quality of life; health care consumption.*

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Genital herpes continues to be epidemic throughout most sexually active populations (1–4). In the USA, a sero-epidemiology survey indicated that 21.7% of the population have HSV-2 antibodies, representing a 31% increase in prevalence over the last decade (5). In France, the seroprevalence of HSV-2 in the population over 15 years of age is approximately 14.6% (6).

The natural history of HSV infection includes acute, or subclinical first-episode mucocutaneous infection, followed by neuronal latency and intermittent virus reactivation with or without associated recurrent symptoms (7, 8). Although this sequence of events has been recognized for more than 5 decades, little is known about the long-term natural history of genital herpes. The disease experience of persons who have herpes varies widely and some of these subjects will never have noticeable symptoms (3). In addition, individuals may be unaware of infection caused by either virus (HSV₁, HSV₂), and thus may unknowingly transmit HSV to partners through unprotected sexual activity. Until the recent availability of valacyclovir, acyclovir was the only effective antiviral chemotherapeutic agent against genital herpes. This antiviral drug reduces the duration of recurrences when used occasionally, and almost completely eliminates outbreaks

when used as a suppressive treatment, but cannot cure the infection (9). Despite reassurance by health care workers, genital herpes is usually not perceived by sufferers as a benign condition. It has been suggested that psychological factors rather than clinical features determine the degree of discomfort experienced during outbreaks (10). Surveys have shown that emotional responses to genital herpes diagnosis include fear of rejection, lower self-esteem, anger, guilt, social isolation, decreased libido and depression (11).

We therefore decided to design a transversal study to assess the psychological morbidity of patients in France suffering from genital herpes infection in comparison with a group of control patients. In addition, data related to the incidence of genital herpes in terms of medical consumption was also studied.

SUBJECTS AND METHODS

Survey sample

Between July and December 1995, 20,000 French families on file at the SOFRES survey institute (representative of the general population in terms of region, urban surroundings and socio-professional category) received a questionnaire asking whether they had suffered from either genital herpes or another skin disease, such as oral herpes or dermatitis, over the last 12 months. This last question was asked in order to try to reduce the bias of under-declarations. Of the 20,000 families, 15,991 returned completed surveys on 34,253 subjects. Participants were required to be ≥15 years of age and have been diagnosed with genital herpes. A total of 236 survey respondents with genital herpes were included in the analysis. In addition, a control group was selected containing 236 subjects of roughly the same age, sex and socio-professional category as those in the study group (Table I).

All of the subjects were asked to complete a self-administered detailed questionnaire. The response rate was 83% in the group of patients with genital herpes (196 respondents) and 85% in the control group (200 respondents). Of the 196 respondents with genital herpes, 150 answered the questionnaire (77%). The other 44 respondents did not answer, or refused to answer the questionnaire, deeming the questions too intimate.

Questionnaire

In order to investigate the psychosocial and psychological consequences of genital herpes and the resulting medical consumption, a 58-item self-administered questionnaire was developed to assess the quality of life of patients with genital herpes. Participants were asked to complete the questionnaire anonymously and return it by mail. Patients were assured of confidentiality. The questionnaire itself was divided into 5 sections as follows and was based on a well-established system: 1) the history of genital herpes (2 items); 2) a description of the latest recurrence, including severity of symptoms and treatment (19 items); 3) the impact of genital herpes on non-clinical aspects of the subjects' lives (20 items); 4) a generic quality of life questionnaire (36 items of the MOS SF-36 (Medical Outcome Study Short Form 36-item Health Survey) (16, 17); and 5) health care experience and treatments over the previous 6 months (6 items).

Table I. Profile of herpes patients and control population

	Herpes patients Phase 1 (n=236)	Questionnaire respondents Phase 2 (n=150)	Control population (n=200)
Sex	%	%	%
Male	29	26	25
Female	71	74	73
Age (years)			
Less than 25	10	8	9
25 to 34	17	21	22
35 to 49	32	30	32
50 to 64	23	23	18
65 and over	18	18	18
Individual's socio-professional category			
Active	59	55	56
Agricultural sector	1	1	2
Small businesses, shopkeepers, artisans	6	3	2
Upper management, liberal professions	9	9	4
Other professionals	13	15	17
Employees, service sector	23	23	23
Blue-collar workers	7	5	10
Inactive	40	45	44

The 20-item questionnaire (section 3) was the herpes-specific scale developed by Galen Research to assess the impact of genital herpes on sufferers. Areas such as social life, work, self-image and attitude towards the infection, relationships with friends, family and sexual partners, sexual attitudes and behaviour, psychological states and disease pattern, were explored. Items were written in the form of personal statements in order to remain as close as possible to the words used by the respondents themselves. The survey instrument was pre-tested to evaluate both the sensitivity and clarity of the questions.

Efforts were made to keep questions brief, with limited skip patterns. Several questions were 4- and 6-point Likert scales where answers could easily be circled by respondents. The scale numbers corresponded to increasing responses, with "1" corresponding to "not at all", and "6" to "a great deal" or "very definitely". The instrument was pre-tested to evaluate both the sensitivity and clarity of the questions.

Participants in the control group were asked to answer only the last 2 sections of the questionnaire (sections 4 and 5). A comparative analysis of responses between the study group and the control group enabled the assessment of quality of life in patients with genital herpes.

Statistical analysis

Analysis of the data was descriptive and consisted of observed frequencies and cross-tabulations.

A statistical analysis was performed with a chi-squared test for associations between dichotomous variables ("case"/ "non-case") and the patient group at the 95% threshold; *p* values were noted unless the population was too small.

RESULTS

Demographic data

A total of 236 respondents (168 women, 68 men) from the SOFRES sample were initially identified as having genital herpes (236/34,253=0.7%). Of the 236 subjects, 86 refused to participate or failed to return the questionnaire. Thus, 150 patients (64% of the initial sample) suffering from genital herpes entered the study: 111 women and 39 men. The majority were employed (55%). There were more cases of genital herpes in agglomerations of more than 100,000

inhabitants, and particularly in the Paris area. Of the subjects eligible for pairing, 200 were selected at random.

Genital herpes as described by the sample population

Of the respondents, 45% reported that they had HSV for 6 years or more. Amongst the 27% who reported having had HSV for more than 10 years, the majority were men. The number of outbreaks experienced over the last 12 months is illustrated in Table II.

The mean number of respondents reported their last outbreak as taking place 131 days before recruitment in the study; 30% reported their last outbreak within the past month. The mean duration of outbreaks was 7.6 days. Thirty-five percent of the respondents reported that recurrences ranged from 4 to 6 days, while 30% reported outbreaks of 7–10 days.

Symptom severity

Thirty-one percent of the patients feel a great deal of pain during outbreaks, 52% reported feeling not too much pain, 14% none at all and 3% did not answer.

The symptoms felt by 58% of respondents were burning sensations and prickling defecation. The majority of respon-

Table II. Number of outbreaks over the past 12 months. Total number of herpes patients=150. Average of 3.1 outbreaks per year

Number of outbreaks in last 12 months	% of patients
None	7
1–2	47
3–5	26
More than 5	13
Can't remember	7

dents with relatively severe symptoms were women and participants under 35 years of age (Table III).

Psychosocial consequences of genital herpes

Participants were specifically asked to what extent genital herpes affected their psychological states (depression, feeling dirty, relationships). Emotional impact due to genital herpes was reported among 23% of the participants. The effect of herpes was felt most strongly in the realm of sexual relations. The majority of the participants indicated that herpes interfered primarily with their sexual relationships (54%) and 64% of the respondents were concerned about transmitting herpes to sexual partners. In 30% of cases respondents reported a fear that sexual relations would trigger recurrences. Eighteen percent reported reduced capacity for warmth, and 15% were on edge when they were touched. Genital herpes can have a powerful effect on an individual's social relationships. For example, 13% of those surveyed feared discovery of their disease by friends, and 15% were afraid of rejection. This response corresponds with the high percentage of persons who had feelings of isolation (13%) and less self-confidence (11%).

Assuming the disease was a major difficulty for 44% of the respondents, and fear of future attacks concerned 69%. Participants felt it difficult to live with genital herpes (50%) and not to think about it (40%); 37% felt that herpes actually ruins their lives, while 24% were afraid of finding themselves in uncomfortable situations.

Treatment

Our survey explored the study population's experiences with medical treatments during their last outbreaks. Eighty-six percent of the respondents reported having used a treatment. Oral and topical acyclovir were the most commonly used therapies (74%).

Comparative analysis to assess health-related quality of life in patients with genital herpes infection and the control group

The MOS SF-36 was designed to measure the medical parameters and psychological consequences of genital herpes. The questionnaire contains 36 items and explores 9 areas, including physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, mental health and reported health. Each parameter was

scored and analysed separately. No statistically significant differences were found between the study group and the control group in the mean scores corresponding to physical functioning, physical role, bodily pain, general health, vitality and reported health (Table IV). However, there were significant differences between the mean scores of the 2 groups concerning:

- 1. Emotional role (HSV group and control group averages were 76.01 and 85.35, respectively). Respondents with genital herpes felt more nervous ($p<0.0009$), dejected and dispirited ($p=0.028$).
- 2. Mental health (HSV group and control group averages were 60.75 and 67.03, respectively). Respondents with genital herpes felt a decrease in their desire to be active (34% vs. 18%) and had trouble carrying out actions requiring concentration or attentiveness (27% vs. 19%). In both cases $p<0.0001$.
- 3. Social functioning (HSV group and control group averages were 78.63 and 83.52, respectively). Respondents with genital herpes reported that HSV put a strain on their personal relationships (34% vs. 24%, with $p=0.061$).

A comparative analysis of medical care received during the last half-year between the study group and the control group indicated significant differences. Respondents with genital herpes required more frequent medical consultations with general practitioners (81% vs. 73%), and even more significantly ($p=0.009$) with specialists (59% vs. 45%). The average number of consultations for the 2 groups were 3.6 and 2.8, respectively.

In addition, a significantly higher percentage of herpes patients (84% vs. 48%, with $p<0.0001$) required long-term medical treatments including dermatological, gynaecological, digestive and nutritional and neurological treatments (anti-depressants, tranquillizers). Significant differences were observed in regard to dermatological medication ($p=0.0064$), neurological medication ($p=0.0066$) and in particular the sub-class of anti-depressants, gynaecological medication and nutrition-related consumption.

DISCUSSION

Methodology applied

Means used for gathering data. The first questionnaires sent out to identify herpes patients were addressed to households, not to individuals. Due to the fact that certain persons prefer

Table III. Pain and/or discomfort due to outbreaks

Patients (n=150)	Suffer a great deal or are very disturbed by pain and/or discomfort (%) (n=47)	Suffer little or no pain and/or discomfort (%) (n=99)
Gender		
M (n=39)	17	31
F (n=111)	83	69
Age (years)		
under 35 (n=45)	32	26
35-49 (n=45)	28	31
50 and over (n=60)	40	43

Table IV. Average SF-36 scores

	Herpes patients score (SD) (n=150)	Witness population score (SD) (n=200)
Physical functioning	85.78 (20.82)	85.77 (17.22)
Physical role	83.95 (29.88)	83.63 (29.14)
Bodily pain	73.17 (25.41)	70.19 (24.05)
General health	68.39 (21.74)	67.82 (20.62)
Vitality	55.37 (18.40)	57.48 (18.68)
Social functioning	78.63 (21.54)	83.52 (18.40)
Emotional role	76.01 (32.60)	85.35 (28.77)
Mental health	60.75 (18.81)	67.03 (17.89)
Reported health	47.47 (17.68)	47.60 (15.03)

their illness to remain confidential (even within the family), this step most likely led to false declarations, which are the equivalent of false negative diagnoses. This method of gathering data could partially explain the low response rate (64%). (It must be noted that such a low response rate throws the validity of the results into question and requires extremely cautious interpretation.)

The declarative form of the questionnaire enabled us to come close to the current prevalence of genital herpes, although we were a bit under. Here we are referring to clinical prevalence which, due to the diversity of symptoms and the development of the infection, is much lower than seroprevalence.

Variables overlooked in the questionnaire. It was not possible to take all causal elements, clinical forms of the disease, and means of disease management into consideration in the survey and certain variables were not identified. All the same, the sub-populations were not always large enough to exploit statistically.

1. The identity of the virus (HSV1 or HSV2) remains unknown, even though the 2 infections differ in terms of severity, frequency of recurrence and risk of transmission. In order to distinguish between the 2 groups, it would have been necessary to carry out biological examinations which would have significantly increased the size and weight of the study protocol.
2. Patients who only have had a first outbreak of herpes are grouped together with those who have had previous outbreaks, even though health care consumption and quality of life evaluations are most certainly not identical in most cases, as first-time infections usually last longer and are more severe than future outbreaks. Although the in-depth questionnaire was sent to first-outbreak patients, the high number and precision of the questions most likely dissuaded many of them from answering. Thus, the 25 patients who reported having had herpes for less than 1 year are most probably patients who have already had recurrences.
3. The questionnaire does not enable us to differentiate patients who are taking ongoing preventive acyclovir treatments, even though this type of treatment most certainly modifies perceptual health in a significant manner. It would have been difficult to interpret the various quality of life differences observed and isolate therapeutic incidence for the patients concerned, as they are precisely those who are the most affected.
4. The time factor can also be responsible for distortion. The patient's appreciation of quality of life may fluctuate depending on the amount of time between his or her last outbreak and the moment when the questionnaire was answered. Due to the manner in which a transversal study is constructed, this development cannot be taken into consideration. This type of information can only be gathered in longitudinal studies, which are necessarily much more complex. However insofar as health care consumption is concerned, we estimate that herpes outbreaks are frequent enough to make distortion of recall minimal.

Quality of life scales. Quality of life scales were discriminant tools in this study: applied at given moments they revealed

transversal differences between the two sub-populations and enabled us to describe the effects of genital herpes on a patient's perceptual health in great detail.

The generic scale and the specific scale seem to be complementary. The similarity of the results obtained in the 2 scales leads us to believe that the acceptability, reliability and aptitude of the second one in describing a population of herpes patients is satisfactory. In effect, this herpes-specific questionnaire (QLH: quality of life with herpes) was used in simultaneous studies carried out in 5 European countries (UK, Denmark, Germany, Italy and Spain) for the assessment of quality of life in patients with genital herpes (12). This study was designed to test the psychometric properties of the questionnaires: internal consistency, reproducibility, content validity and construct validity (convergent and discriminate) (13). Once validated, this measure can also be applied in clinical trials in order to evaluate experimental drugs for the treatment of genital herpes. The herpes-specific measure adds depth to the information generated by the SF-36 as it explores dimensions that are specifically affected by genital herpes in a precise and subtle manner.

The SF-36 itself has 2 advantages: 1) the value of the results are guaranteed thanks to the validation of the measurement tool (14–17) and its French version (18, 19); and 2) as it is a generic tool, the impact of various pathologies on quality of life can be compared.

Having thus been tested, these 2 scales can be used from now on as evaluation tools in clinical trials and, when applied to a given group of patients, can highlight longitudinal differences.

Results

Populations with chronic illnesses, skin disorders and sexually transmitted diseases show varying degrees of emotional dysfunction (20–21). There is considerable evidence that there is a psychological impact associated with genital herpes. The principal psychological consequences of genital herpes mentioned in early clinical anecdotal reports are related to altered perceptions of self-esteem, fear of rejection and transmitting the disease, isolation and depression (13).

Our study confirms that there is substantial psychological morbidity in patients with genital herpes in France: 23% of the patients interviewed reported feelings of depression, shame and/or lack of affection. We were also able to make comparisons with American studies: following a survey conducted by the American Social Health Association (22) it was noted that French respondents inform their current sexual partners more frequently of infection (77% vs. 69%), however, decreased sexual enjoyment was greater amongst French respondents (54% vs. 36%). Survey data in US studies shows a greater fear of rejection amongst American patients than amongst French ones (52% vs. 15%), as well as stronger feelings of depression (52% vs. 37%), greater fear of discovery (28% vs. 13%) and feelings of isolation (36% vs. 13%).

In reviewing the results of this survey it is important to keep in mind the fact that the prevalence of genital herpes in our survey sample is low (approximately 0.7%) compared with data in the literature, which estimates prevalence in France at 16% (5). This is explained by the bias of under-declaration generated by the means of data collection

mentioned above, the non-recognition of genital herpes, lack of accessibility to health care, and, because of its connotations, a refusal or general reluctance to talk about it. Understanding the psychological impact of genital herpes will help physicians to reduce the disabling consequences of this disease and prevent its transmission among the population.

Patients' emotional and sexual concerns about genital herpes can be addressed with appropriate anticipatory guidance. Counselling can be provided with a non-judgmental attitude and can help patients overcome the embarrassment of having a sexually transmitted disease (22). It is important not to "close the door" on patients' questions and serious concerns. Non-disclosure and keeping herpes secret reinforces the negative image of both the infection and the patient's self-image. Clinicians can play an important role in counteracting the negative consequences of genital herpes in several ways: by providing the best clinical management available, and by providing psychological support to reinforce the fact that individual is both valuable and loved.

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