The impact of primary and recurrent genital herpes on the quality of life of young people and adults: A mixed methods systematic review.

Abstract

Objective

This review sought to identify what it is like to live with and what interventions improve the health related quality of life (HRQoL) of adults with primary or recurrent genital herpes.

Introduction

Genital herpes is frequently associated with psychosocial challenges. However, a growing body of evidence suggests that its impact can be ameliorated through pharmacological and psycho-social interventions.

Inclusion Criteria

All English language studies concerning community dwelling males and females, of all ethnicities, aged 15 years and over, who had primary or recurrent genital herpes and were able to report on the virus's impact on their HRQoL and/or the efficacy of interventions in improving their HRQoL were included.

Methods

Eleven databases were interrogated from January 1980 to March 2020. The JBI approach to Mixed Methods Systematic Reviews was followed at each stage of the review and a convergent segregated approach to synthesis and integration was adopted.

Results

Of 2599 citations initially identified as potentially relevant, 31 were deemed suitable for inclusion. Studies encompassed quantitative (n=27, across 28 publications), qualitative (n=1) and mixed methods (n=2) designs.

Critical appraisal scores were variable, particularly among the RCTs and the analytical cross-sectional studies. All studies were included regardless of methodological quality.

The qualitative component of the review led to the identification of two synthesized findings: 'Disclosure of a diagnosis of genital herpes poses a dilemma for people who have the virus' and 'A diagnosis of genital herpes has a significant emotional impact for the individual'.

The quantitative components identified that depression, illness concern, stress, anxiety, isolation, stigma and a lowering of self-esteem, self-concept, self-confidence and HRQoL may be experienced by both those newly diagnosed with genital herpes and those with recurrences. It was also identified that genital herpes can have an adverse effect on work or school, sexual relationships and relationships with friends and family.

Depression was found to significantly decrease after self-hypnosis and certain psychosocial interventions. Anxiety significantly decreased following pharmacological treatment, psychosocial interventions and hypnosis respectively. Psychosocial interventions significantly improved mood and a self-help module with counselling significantly improved participants' satisfaction with intimate relationships and their self-esteem. Pharmacological treatment significantly improved HRQoL, however there were no significant differences between different active treatment regimens.

Integration of quantitative and qualitative evidence revealed a consensus that a diagnosis of genital herpes has a significant emotional impact for individuals and disclosure is stressful, affects relationships and HRQoL, but there is a lack of consensus regarding efficacy of different interventions.

Conclusions

Genital herpes can lead to extreme emotional, social, relational and sexual distress but there is insufficient knowledge concerning which interventions best improve HRQoL. High quality research is, therefore, required.

Keywords

Experiences; genital herpes; health related quality of life; interventions; perceptions.

Introduction

The herpes simplex virus can be categorised into two types: herpes simplex virus type 1 (HSV-1) and herpes simplex virus type 2 (HSV-2).[1] Herpes simplex virus type 2 is a common sexually transmitted infection which causes the condition genital herpes.[2] The HSV-1 is more typically associated with non-sexually transmitted oral herpes infection transmitted by oral-oral contact, however it has been increasingly noted as a cause of genital HSV in high-income countries from transmission through oral sex.[3] Prior infection with HSV-1 can modify the clinical manifestation of first infection by HSV-2, usually making symptoms less severe.[4] Globally, the prevalence of genital herpes is increasing with approximately 192 million people aged 15-49 years infected with genital HSV-1 infection and an estimated 491 million infected with HSV-2.[1]

Transmission of HSV-2 is usually via direct contact with an infected person who is shedding virus from secretions on oral, genital or anal mucosal surfaces, although genital herpes can also be acquired from contact with lesions at other non-mucosal surfaces.[4] The number of days of asymptomatic virus shedding in some individuals can exceed the number of days of symptomatic shedding.[5] Up to two thirds of people infected with HSV-2 will not have any symptoms at the time of acquisition of the virus, with the time between infection and the first symptoms ranging from two days to two weeks.[5] The majority of people acquiring this infection may therefore be unaware of it, potentially shedding virus and transmitting HSV-2 to their sexual partners unintentionally.[2]

A primary episode of genital herpes, which may persist for 20 days[6] can be distressing for the individual, due to frequently presenting signs which include multiple painful lesions on the external genitalia, the cervix, rectum, thighs and buttocks, which burst to leave erosions and ulcers.[5] Other symptoms can include dysuria, vaginal or urethral discharge and systemic symptoms such as fever and malaise. Most people with symptomatic primary genital HSV-2 experience symptomatic recurrent episodes, with more than one third of those affected having frequent recurrences.[7] Recurrent genital herpes is caused by reactivation of the dormant HSV in the nerve roots of the sacral plexus,[8] which may cause painful lesions. Systemic symptoms are less common than in primary episodes and episodes are usually shorter and less severe,[7] lasting between 5-10 days.[6] HSV-2 recurs approximately four times in the first year after a symptomatic first episode and has a recurrence rate of approximately four times that of HSV-1, with recurrences tending to lessen in frequency over time.[5] Management of a primary episode of HSV-2 includes oral antiviral therapy and self-care measures. Self-care measures can incorporate topical or practical approaches. These may include regular saline baths to prevent secondary infection and the wearing of loose fitting clothing to reduce irritation of lesions, increasing fluid intake to dilute urine and urinating in a bath or shower to reduce stinging.[4,9] Other interventions may include pain relieving measures such as the application of a topical anaesthetic such as lidocaine 5%, to decrease the pain of micturition; oral analgesia such as paracetamol; and infection control measures including abstinence from penetrative, non-penetrative and orogenital sex until lesions have cleared and avoiding shared personal items such as towels.[5,9] Recurrent episodes of genital herpes may also require the self-care measures outlined above as well as the avoidance of any identified triggers, for example ultraviolet light and excessive alcohol consumption.[9] Episodic antiviral treatment and suppressive antiviral therapy are all available options for the standard antiviral treatment of genital herpes.[7]

Three systematic reviews have examined the effectiveness of antiviral treatment in people with a first episode of genital herpes on the duration of symptoms and time to recurrence.[10–12] All of these reviews identified that oral antiviral treatments decrease symptoms in people with first episodes of genital herpes and that daily maintenance treatment with oral antiviral agents effectively reduces frequency of recurrences and improves quality of life. For recurrent herpes it has been demonstrated that acyclovir, famciclovir, and valacyclovir are all equally beneficial in reducing duration of symptoms, lesion healing time and viral shedding when taken at the start of recurrence[12] and long-term data supports their safety and efficacy with little difference in efficacy or tolerability.[13] There is insufficient evidence however, to establish which type of oral antiviral drug is most effective in reducing the duration of symptoms.[11,12]

Considerable psychosocial distress is associated with a diagnosis of genital herpes,[14] and it is also associated with the stigma of having a sexually transmitted infection.[15] Genital herpes can lead to depression,[14,16,17] diminished self-concept,[18] withdrawal from intimate relationships[19] and diminished quality of life.[1,20,21] Other emotional responses include shame and anxiety about having an outbreak or transmitting herpes to someone else.[14] Genital herpes can negatively affect sexual wellbeing,[22] particularly when individuals perceive that they are stigmatized by others.[20,23]

Several interventions have been developed aimed at improving the quality of life of people who experience both primary and recurrent genital herpes. These include suppressive antiviral therapies including for example: valacyclovir therapy and long-term acyclovir suppression,[9,17,21] psychological support[24] and social support.[20,25,26]

There is a growing body of qualitative and quantitative evidence that suggests that the impact of primary and recurrent genital herpes on the quality of life of young people and adults can be ameliorated by psychological and social interventions within primary care and genito-urinary medicine settings. Psychological support can take the form of educational counselling at diagnosis[27] and follow-up,[28] psychotherapy,[29] cognitive behavioral therapy,[30] cognitive restructuring[31] and experiential counselling interventions.[32] Social support preferences vary but may take the form of virtual support groups, friends, sexual partners, religious/spiritual figures and health providers.[20]

A search of several sources specialising in systematic review publication including The Joanna Briggs Institute Database of Systematic Reviews, The Cochrane Database of Systematic Reviews and the PROSPERO International Prospective Register of Systematic Reviews identified no published systematic review on the impact of primary and recurrent genital herpes on quality of life of affected individuals. The previous reviews that have been conducted have focused on screening,[33,34] pharmacological treatment,[10–12,34–38] transmission[12] and psychological factors in recurrent genital herpes.[39] Therefore, the impact for patients concerning the psychological aspect of their health remains unclear.

In this mixed methods review, both the quantitative and qualitative components explored health related quality of life (HRQoL) of young people and adults with primary or recurrent episodes of genital herpes. For the purposes of this review HRQoL was defined as “those aspects of self-perceived wellbeing that are related to or affected by the presence of disease or treatment”.[40 p.1384] Combining both quantitative and qualitative studies in the same review has allowed for a more detailed exploration of the review objective which was to identify what it is like to live with and what interventions improve the HRQoL of young people and adults with primary or recurrent episodes of genital herpes within primary care and genito-urinary medicine settings.

Review question

What is it like to live with and what interventions improve the HRQoL of young people and adults with primary or recurrent episodes of genital herpes?

The objectives were to:

1. examine the effect of genital herpes on HRQoL and other wellbeing outcomes.
2. determine the effectiveness of interventions for improving the HRQoL and wellbeing of young people and adults with primary or recurrent genital herpes.
3. identify and explore the perceptions and experiences of young people and adults with primary or recurrent genital herpes as a result of living with the signs and symptoms of the virus on their HRQoL.

The first objective was not included in the original protocol but a deviation from protocol was made following discussions with the Convenor of the JBI Mixed Methods Methodological Group, to reflect the nature of the literature found from the database searches. A further deviation from protocol was made to the second objective, to include ‘wellbeing’ to ensure that all relevant effectiveness studies were captured.

Inclusion criteria

Population

The review considered studies that included community dwelling participants, aged 15 years and over, who had been diagnosed with genital herpes regardless of ethnicity and geographical location. Studies that focused on patients who were HSV-1 or HSV-2 serologically positive but asymptomatic and studies that focused on carers, family members, partners and healthcare professionals of people who have symptomatic genital herpes, but who did not have symptomatic genital herpes themselves were excluded.

Intervention

The quantitative component of the review considered studies that evaluated the impact of the following on HRQoL:

- Antiviral suppression therapies, for example: suppressive oral valacyclovir, acyclovir and famciclovir.
- Psychological interventions, for example: educational counselling, psychotherapy, cognitive behavioral therapy, cognitive restructuring and experiential counselling interventions.
- Self-care measures, for example: stress reduction and self-managed episodic antiviral therapy.
- Social support, for example: virtual support groups, friends, sexual partners, religious/spiritual figures and health providers.
- A combination of the above interventions.

There were no limits to dosage, frequency, duration and intensity of interventions. Other interventions as identified by the literature were also included. The review compared interventions against usual care or placebo, where applicable. In addition, our review aimed to compare the efficacy of the above interventions against one another.

Phenomena of interest

The qualitative component of this review considered studies that investigated the perceptions and experiences of young people and adults with primary or recurrent genital herpes regarding the impact of the virus on their HRQoL.

Outcomes

The quantitative component of this review, which investigated the impact of antiviral therapies, psychological interventions, self-care measures and social support, considered studies where the primary outcome of interest was HRQoL. This included the following outcome measures:

Disease specific quality of life scales:[8]

- Recurrent Genital Herpes Quality of Life scale (RGHQoL)
- Quality of Life with Herpes Scale
- Genital Herpes Questionnaire
- Herpes Research Center Questionnaire

Generic health related quality of life scales:[8]

- Medical Outcomes Study 36-item Short-Form Health Survey (SF-36)
- Health Related Quality of Life Scale
- General Health Questionnaire (GHQ)

A deviation from the protocol was made to reflect the wide range of additional concepts that authors used to explore HRQoL. These included the psychosocial consequences of genital herpes on work/school, relationships and sexual behaviour and satisfaction with intimate relationships and body image.

Secondary outcomes were stress, anxiety, depression or self-esteem. Scales included: Hospital Depression and Anxiety Scale (HADS), State-Trait Anxiety Inventory, Beck Depression Inventory (BDI) and Rosenberg Self Esteem Scale (RSES). A further deviation to the protocol was made to reflect the wide range of additional wellbeing outcomes that authors used when investigating this topic area. These included coping, stigma, illness concern, illness attitude, isolation, loneliness social support, mood, coping, self-concept and self-confidence.

Context

The qualitative component of this review considered studies that investigated the impact of genital herpes on individuals' HRQoL in the primary care and genito-urinary medicine settings worldwide.

Types of studies

The review considered quantitative, qualitative and mixed methods studies. Quantitative studies included both experimental and quasi-experimental study designs including randomized controlled trials (RCTs), non-randomized controlled trials, before and after studies and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies and analytical cross-sectional studies were considered for inclusion. This review also considered descriptive observational study designs including case series, individual case reports and descriptive cross-sectional studies for inclusion. Qualitative studies included designs such as phenomenology, grounded theory and ethnography, action research and feminist research. Mixed method studies were considered if data from the quantitative or qualitative components could be clearly extracted.

Studies published since 1980 only were included as the initial search of the literature in the subject area did not identify any relevant research prior to this date. In addition, the contribution of any research prior to 1980 would be limited in its applicability to current interventions. Studies published in languages other than English were excluded.

Methods

This review was a JBI mixed methods systematic review which employed a convergent segregated approach to synthesis and integration.[41] The methods used in this review were specified in advance and documented in a *priori* protocol that was published in the JBISRIR .[42]

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. First, an initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract and the index terms used to describe the articles. The search strategy, including all identified keywords and index terms was adapted for each included information source. The full search strategies are provided in Appendix I. Finally, the reference list of all studies selected for critical appraisal were screened for additional studies and a hand search of relevant journals and forward citation tracking were conducted.

Information sources

The databases that were searched were on the OVID platform: Medline, EMBASE, PsycINFO, EMCARE (replaced British Nursing Index (BNI) as University library no longer subscribed to BNI); on the ProQuest platform: CINAHL and on other platforms: Web of Science and Cochrane Central Register of Controlled Trials. Sources of unpublished studies and grey literature included the British Library Thesis Index (EThOS), ProQuest Digital Dissertations, OpenGrey (now includes all records from System for Information on Grey Literature in Europe - SIGLE) and the World Health Organization's library database (WHOLIS). As the Conference Papers Index is no longer available on ProQuest, Web of Science Conference Proceedings Citation Index was used as an alternative.

Study selection

Following the search, all identified citations were collated and uploaded into EndNote[43] and duplicates removed. Titles and abstracts were then screened by two reviewers for assessment against the inclusion criteria for the review. Studies that met the inclusion criteria were retrieved in full and their details imported into the JBI System for the Unified Management Assessment and Review of Information package (JBI SUMARI, JBI, Adelaide, Australia)[47]. The full text of selected studies were retrieved and assessed in detail against the inclusion criteria by two independent reviewers. Any disagreements that arose between the reviewers were resolved through discussion.

Assessment of methodological quality

Eligible studies were critically appraised by two independent reviewers for methodological quality using the standardized critical appraisal instruments from the JBI for the following study types: RCTs,[44] quasi-experimental studies,[44] case reports,[45] analytical cross sectional studies[45] and qualitative studies.[46] For mixed methods studies the quantitative and qualitative components were appraised separately using the appropriate JBI critical appraisal instruments. Any disagreements that arose between the reviewers were resolved through discussion. All studies that met the inclusion criteria went forward to critical appraisal and all studies were assessed as suitable for inclusion in the review. When a study met a criterion for inclusion a score of one was given. Where a particular point for inclusion was regarded as “unclear” it was given a score of zero. Where a particular point for inclusion was regarded as “not applicable” this point was taken off the total score. All included studies were assessed using this method and their overall critical appraisal scores presented. No studies were excluded as none were felt to be fatally flawed.

Data extraction

Quantitative and qualitative data were extracted from included studies by two independent reviewers using the standardized data extraction tool available from JBI-SUMARI.[47] For quantitative studies, data extracted included specific details about the populations, interventions, study methods and outcomes of significance to the review question. For qualitative studies, data extracted included specific details about the population, context, culture, geographical location, study methods and the phenomenon of interest relevant to the review question. Findings with their corresponding illustrations were also extracted and assigned a level of credibility (unequivocal, credible, or not supported).

- Unequivocal (U): evidence beyond reasonable doubt, which may include findings that are matter of fact, directly reported / observed, and not open to challenge.
- Credible (C): related to those findings that are, albeit interpretation, plausible in light of the data and theoretical framework. They can be logically inferred from the data. Because the findings are essentially interpretative, they can be challenged.
- Not Supported (NS): is when the findings are not supported by the data. These findings were excluded from the final synthesis but are listed in Appendix VI.

Any disagreements that arose between the reviewers were resolved through discussion. Five studies compared individuals with genital herpes with other patient groups which included: controls from genitourinary or dermatology departments,[48] controls from a stress clinic,[49] or controls with other disease conditions which included gonorrhoea,[50] genital human papilloma virus or human immunodeficiency virus (HIV)[51] or individuals with other sexually transmitted infections (STI) without any genital signs and symptoms.[52] For the purposes of this review only data related to the individuals with genital herpes were extracted.

Data synthesis and integration

For the quantitative data, statistical pooling was not possible for this systematic review as the experimental studies included used a range of different types of interventions or included various types and dosages of the antivirals. Quantitative findings from the experimental and descriptive observational studies have therefore been presented in a narrative form.

The qualitative findings from the included studies were pooled using JBI SUMARI[47] and synthesized using the JBI meta-aggregative approach.[46] This involved the aggregation or synthesis of findings to generate a set of statements that represented that aggregation, through assembling the findings rated according to their quality and categorizing these findings on the basis of similarity in meaning. These categories were then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.[46]

Quantitative evidence and qualitative evidence were integrated using configurative analysis. The results of the narrative synthesis of quantitative evidence were combined with the meta-synthesised findings of qualitative evidence. This involved constant comparison of the quantitative evidence and the qualitative evidence, followed by the analysis of interventions, which had been investigated in the quantitative studies, in line with the experiences of participants explored in the qualitative studies in order to link the evidence into a line of argument. Where configuration was not possible the findings are presented in narrative form.

Results

Study inclusion

Citations identified as being potentially relevant to the review totalled 2599. After the duplicates had been removed, the titles and abstracts of 1801 citations were reviewed. One hundred and forty-one full text publications were selected for retrieval and 110 were excluded (see Appendix II). All full text publications that met the inclusion criteria went forward to critical appraisal (n=31). The resulting 31 publications covered 30 studies (one study was described across two publications and each presented findings from different outcomes) that were deemed suitable for inclusion in the review. Of these, two studies[53,54] contributed to both the quantitative and qualitative components. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist has been followed for the reporting of this review[55] and the flow of studies through the review has been presented in a PRISMA flow diagram (see Figure 1). An overview of the included studies are shown in Appendices III to V.

Insert Figure 1 around here

Methodological quality

Randomised controlled trials

Critical appraisal scores for the nine included RCTs ranged from four to 11 out of a possible score of 13 (see Table 1). One study scored four,[31] two scored seven,[56,57] two scored eight,[58,59] two scored nine[60,61] and two scored eleven.[62,63] All of the studies apart from one[31] treated the experimental groups identically other than the intervention of interest, participants were analysed in the groups to which they were randomized and appropriate statistical analysis was employed. However, only four of the studies[58,60,61,63] used true randomization for assignment of participants to treatment groups. Only three studies[60,62,63] concealed allocation to treatment groups and a further three[59,61,62] employed treatment groups that were similar at baseline. Just two studies[62,63] blinded participants and those delivering the treatment to treatment assignment. None of the studies clearly stated that outcome assessors were blind to treatment assignment.

Insert table 1 around here

Quasi-experimental studies

Critical appraisal scores for the two quasi-experimental studies were four[64] and five[65] out of a possible score of six (see Table 2). Three of the questions were not applicable to these particular studies: 'Were the participants included in any comparisons similar?' (Q2), 'Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?' (Q3) and 'Were the outcomes of participants included in any comparisons measured in the same way?' (Q7). Both studies used a pre-test/post-test design and so did not employ a control group. One of the studies also scored negatively for the sixth question 'Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?'[64]

Insert table 2 around here

Analytical cross-sectional studies

Critical appraisal scores for the analytical cross-sectional studies (including the quantitative component of the two mixed methods studies[53,54]) ranged from three to eight out of a possible eight (see Table 3). However, five of the studies (across six publications)[17,53,66–69] were purely descriptive and therefore questions which deal with confounding factors were deemed to be not applicable (Q5, Q6). All of the studies defined the criteria for inclusion in the sample clearly and the setting and study subjects were also described in detail. Eleven studies (across 12 publications) provided insufficient detail regarding the confirmation of HSV diagnosis.[17,20,22,26,52–54,66–70] Amongst those who scored positively for question five, 'Were objective, standard criteria used for measurement of the condition?', it is important to note that four studies[17,20,49,53,70] employed previously validated tools in addition to instruments that they had designed themselves which were lacking in measures of reliability and validity.

Insert table 3 around here

Qualitative studies

Of the three studies which were appraised (including the qualitative component of the two mixed methods studies[53,54]) two[53,54] scored eight and one[71] scored seven out of a possible 10 (see Table 4). None of the studies acknowledged the influence of the researcher on the research and vice versa. Two studies did not situate the researcher culturally or theoretically[53,54] and one study did not state that the research had received ethical approval.[71]

Insert table 4 around here

Characteristics of included studies

Study design

The 30 studies (across 31 publications) encompassed a range of both quantitative (n=27, across 28 publications), qualitative (n=1) and mixed methods (n=2) study designs. The quantitative designs included RCTs (n=9)[31,56–63] quasi-experimental before and after studies (n=2)[64,65] and cross sectional studies (n=16, across 17 publications).[14,17,20,22,26,48–52,66–70,72,73] Two of the cross sectional studies were part of wider mixed methods studies that also included a qualitative descriptive component.[53,54] One further study was also qualitative descriptive.[71]

Country where research conducted

The majority of studies were conducted in the US (n=18, across 19 publications).[14,20,26,49,53,56–62,64,66–68,70,71,73] The remaining studies were conducted across UK (n=5),[48,54,65,69,72] Canada (n=1),[31] France (n=1),[22] India (n=1),[51] Sri Lanka (n=1)[52] and the Netherlands (n=1).[50] Two further studies were worldwide multi-centre studies.[17,63]

Participants

All but two studies reported the participants' ages.[53,54] The mean age was reported across 21 studies (across 22 publications)[17,20,26,31,48–50,52,53,57–60,62–64,66–68,70,72,73] and ranged from 23.0 to 41.2 years. Two studies reported a median age of 36 years[65] and 35 years.[69] The remaining five studies reported age across a number of different categories.[14,22,51,56,71]

All but one study described the gender of the participants.[54] Four studies included women only.[14,20,49,56] The remaining studies included both men and women and of these 19 studies (across 20 publications) had a greater proportion of women,[17,22,26,31,48,53,54,58–63,65–67,69,70,72,73] six included a greater proportion of men[50–52,57,64,68] and one[71] had an equal proportion of males and females.

Outcomes

For the experimental studies the outcomes examined were as follows**:** Seven studies explored the effects of the described interventions on QoL or aspects of QoL.[31,58–60,62–64] Other aspects of psychological morbidity/impact that were examined were illness concern (n=1),[64] illness attitude(n=1),[64] mood (n=3),[57,61,65] depression (n=4),[57,61,64,65] anxiety (n=3),[57,64,65] stress (n=1),[57] loneliness (n=2),[31,57] self-efficacy (n=1),[61] self-concept (n=1),[56] satisfaction with intimate relationships (n=1)[56] and body image (n=1).[56]

For the cross-sectional description studies the outcomes examined were as follows: Seventeen studies (across 18 publications) examined QoL or aspects of QoL.[14,17,20,22,26,48–53,66–70,72,73] Other aspects of psychological morbidity/impact that were examined were illness concern (n=2),[48,64] illness attitude (n=2),[48,64] depression (n=11),[14,17,48,49,52,53,64,68,71–73] anxiety (n=6),[14,48,50,52,54,64] stress, (n=10 over 11 publications)[14,22,26,49,53,66,67,69,70,72,73] isolation (n=3),[22,49,53] social support (n=4),[20,26,70,72] stigma (n=2),[20,52] coping (n=4),[20,26,67,68,70,72] self-esteem (n=3),[49,50,70] self-concept (n=2)[53,73] and self-confidence (n=3).[22,53,69] A number of studies also explored the psychosocial consequences of genital herpes on work/school (n=4),[49,53,68,69] relationships (n=7)[14,22,49,50,59,68,69] and sexual behaviour (n=11, across 12 publications).[14,22,26,48–50,53,66–70]

Diagnosis

With regards to confirming a diagnosis of genital herpes, 16 studies (across 17 publications) relied upon self-reporting[17,20,50,52–54,56–58,61,63,65–67,69–71] and four studies[22,48,59,73] relied on clinical confirmation by a nurse or a physician. Nine studies confirmed the diagnosis of genital herpes (n=10)[14,26,31,49,51,60,62,64,68,72] which was undertaken by a variety of methods which included polymerase chain reaction (PCR) testing (n=1),[60] HSV-2 type-specific enzyme-linked immunosorbent assay (ELISA) testing,[51] using viral cultures (n=5),[14,31,49,64,72] a mixture of virological or serological testing (n=1)[62] or a combination of viral culture, self-reporting or clinical inspection (n=2).[26,68]

Length of time since diagnosis

Twelve studies did not state the length of time since diagnosis.[48,50,52,53,56,57,60,61,63,65,68,71] For those that did report the length of time since diagnosis this was either reported as the mean (n=9 studies, across 10 publications)[17,26,31,51,53,58,66,67,70,73] which ranged from 1.4 to 7.6 years; the median (n=2)[54,69] of between 5.7[54] to 6[69] years or the range (n=8).[14,20,22,49,59,62,64,72] Three studies[14,49,52] included newly diagnosed patients who were experiencing their primary episode of genital herpes.

Number of recurrences

The number of recurrences were not stated in 11 studies[14,31,50–54,56,62,68,71] and for one further study the number of recurrences for one participant was omitted.[74] Five studies (across six publications) reported the average number of occurrences over any one year period[26,59,64,66,67,70] which ranged from eight to ten and two studies reported the actual number of occurrences which were up to nine episodes[59] or at least eight recurrences per year.[64] A further 11 studies reported the timeframe for which these data were collected as being prior to commencement of the respective studies (3 weeks (n=1),[49] six weeks (n=1),[65] three months (n=1),[61] six months (n=2),[48,72] 12 months (n=7, mean ranging from 6.1 to 11)[17,22,53,57,58,60,63] or 22 months[20] and described the mean, median, range or the number of occurrences. Of the remaining four studies one reported that participants had had at least two recurrences after the primary attack (66

(73%) having had > 10 recurrences),[69] another reported that that all participants had had at least one or more episodes of genital herpes.[73]

Interventions

Five studies examined the impact of antiviral suppression treatment on HRQoL.[58,60,62–64] The anti-viral agents used were Famciclovir,[60] Acyclovir[63,64] or Valacyclovir.[58,62,63] Details of each regimen are summarized in Table 5. Two studies compared suppressive treatment versus episodic treatment,[58,60] two studies used a placebo as the control[62,63] and one further study did not use a control group.[64] Dosage of the antivirals varied from 125mg to 1000mg and one study did not report the dose.[64] The duration of suppressive treatment varied from 30 days[58] to 52 weeks[63] and the episodic treatment lasted five days.[58,64]

Insert table 5 around here

A further six studies examined the impact of a range of different psychological interventions[31,56,57,59,61,65] which are summarized in Table 6. The duration of interventions ranged from four weeks[56] to six months.[57,61] Three studies[31,64,65] did not employ a control group, two employed a waiting list control[57,61] and two compared two types of treatment.[56,59]

Insert table 6 around here

Findings of the review

The effect of genital herpes on HRQoL quality of life and other wellbeing outcomes

Data were obtained from 16 cross sectional studies (presented across 17 publications); a narrative summary is reported below.

Quality of life

Seventeen cross sectional studies (across 18 publications) examined quality of life or aspects of quality of life.[14,17,20,22,26,48–53,66–70,72,73] Measures used included the following:

- Herpes Specific Scale[22]
- SF-36[22,72]
- GHQ[48,52]
- RGHQoL scale[14,17,20]
- Genital Herpes Questionnaire,[53]
- HELP questionnaire[49]
- Life Experiences Survey[26,72]
- WHO Quality of Life (WHOQOL)-BREF instrument,[51]

- Hopkins Symptom Checklist[50]
- Symptom Check List-90[17,26,49,73]

A number of authors developed their own tool[68,69] or used single item questions[66,67,70] to assess the psychosocial consequences of genital herpes. Due to the diversity of instruments used, it was not possible to compare means across studies. Better quality of life was significantly associated with the use of acceptance coping and receiving support from religious/spiritual figures whereas poorer quality of life was significantly associated with support received from the internet and the use of denial coping.[20] Perceived stigma and acceptance coping was also found to predict quality of life.[20]

Low levels of quality of life[17,17,22] and substantial psychological morbidity were experienced by patients with recurrent genital herpes.[17,22,26,48–52,72,73] Better quality of life was significantly associated with the use of acceptance coping ($p<0.001$) and receiving support from religious/spiritual figures ($p<0.001$) whereas poorer quality of life was significantly associated with support received from the internet ($p<0.01$) and the use of denial coping ($p<0.001$).[20] Perceived stigma was also found to significantly predict poorer quality of life ($p<0.01$).[20] Worry over transmitting herpes to a sexual partner and the magnitude of this fear was significantly associated with the SCL-90 scores ($p<0.05$).[26] It should also be noted that the degree to which subjects perceived themselves as having changed their frequency of intercourse due to herpes was also significantly associated with SCL-90 scores ($r=0.32$, $p<0.05$).[26]

Other aspects of quality of life that were identified from the responses to single item questions were that genital herpes was difficult to live with,[22] that is was incompatible with happiness,[53] that it had ruined their lives[22] and that they felt ashamed of having it.[14] Respondents described finding it difficult not to think about their diagnosis[14,22] and were pessimistic about the future course of illness.[53] A minority indicated that they felt like infecting others[53] and had self-destructive feelings because of herpes.[53] Having a diagnosis of herpes made participants feel angry.[14,66,67,69] In relation to gender, findings were conflicting with one study[67] reporting that women expressed significantly greater anger towards the person who had given them herpes than men ($p<0.05$) and another finding that women were significantly less likely to report being angry with the person who had given them herpes than men ($p<0.005$).[69]

Studies that explored the impact of a diagnosis of herpes over the passage of time showed mixed results. Two studies showed that the impact diminished over time,[48,70] two studies (across three publications)[66,67,69] found that the length of time since diagnosis was not significantly associated with perceived impact ($p>0.05$) and one further study reported no change between diagnosis and follow-up at six to nine months, although no statistical analysis was reported to confirm this statement.[49] With regard to the studies that identified that the impact diminished over time, Carney et al.[48] reported that 62% of participants on initial assessment could be defined as GHQ “cases” which is indicative of non-psychotic psychiatric illness, however by the second visit three months later the proportion of participants that could be classed as cases had significantly decreased ($p<0.01$). Another study demonstrated that levels of depression were lower over the passage of time and those with herpes engaged in fewer coping strategies as they became less bothered by having been diagnosed with genital herpes ($p<0.05$).[70]

Similarly, there were mixed findings across the studies regarding number of recurrences and quality of life. One study found that a high number of reported recurrences was not associated with a lower quality of life as measured by a range of psychological measures including anxiety, depression, stress and quality of life (no statistical details reported).[72] Whereas another study found that recurrence frequency had a significant effect on quality of life, more specifically participants who reported greater than seven episodes of recurrent genital herpes compared to those with 2-4 or 5-7 recurrences had significantly poorer quality of life ($p=0.002$).[17] It was also demonstrated that participants who reported an increased severity of pain/discomfort during recurrences compared to those who reported no, mild or moderate pain had significantly poorer quality of life ($p<0.001$).[17]

Psychosocial consequences of genital herpes on work

Four cross sectional studies asked if having genital herpes had an adverse effect on work or school.[49,53,68,69] For some participants across the studies the responses from single item questions suggested that herpes mildly interfered with their work or school performance,[49,53,68] work satisfaction or enjoyment[53,68] and their relationships with their colleagues.[68] Whereas others indicated these issues were considered serious problems, especially with regard to work or school performance.[53] Brookes et al.[69] did not report the findings from this question.

Psychosocial consequences of genital herpes on sexual behaviour

Eleven cross sectional studies (across 12 publications) assessed the effects of genital herpes on sexual behaviour.[14,22,26,48–50,53,66–70] The studies employed a variety of instruments: one study used two subscales, ‘inhibition during intercourse’ and ‘(preferred) frequency of sexual intercourse’, of the Sexuality Experiences Scales,[50] three studies (across four publications) developed their own questionnaires[48,69,70] and seven studies (across eight publications) reported on single item questions within quality of life scales.[14,22,26,49,53,66–68] Findings across the studies pertained to frequency of sex,[22,26,48,53,68,69] enjoyment of sex,[53,68,69] sexual inhibition,[49,50,66,68] desirability[22,59,68,69] and general sexual concerns.[22,68] Manne et al.[70] did not report the individual findings concerning this aspect of their study.

Herpes was found to interfere with sexual relationships.[14,22,26] Frequency of sex was reported to have changed due to herpes in one study[26] but participants’ reports across studies were inconsistent ranging from no significant difference between first diagnosis and follow-up (no statistics reported),[48] a reduction in frequency[68,69] or interest in sexual activity[59] to some reporting an increased frequency and interest.[69]

Two studies explored sexual concerns and identified that there was a fear that sexual activity would trigger recurrences[22] and that herpes would be transmitted to sexual partners.[22,68]

With regards to enjoyment of sex, single item question responses identified that some participants reported that they enjoyed sex less[59,68] whereas others reported a greater enjoyment,[69] some were less able to achieve orgasm,[53] were less spontaneous[68] and had a diminished sex drive.[68] Luby et al.[68] also reported that reductions in the frequency of sexual contact, pleasure, spontaneity and intimacy of sexual contact were significantly related to levels of psychological distress ($p<0.01$).

Responses from single item questions across the studies showed that participants reported being more sexually inhibited since diagnosis[49,50,68] with some participants reporting that they abstained from sexual activity entirely since diagnosis and a small percentage continued to abstain six to nine months later.[49] Participants also reported that they felt less desirable because of herpes,[53] were less capable of physical warmth and intimacy[22,53] and were less spontaneous sexually.[66,67] Participants who frequently reported impotence and other physical difficulties with sexual activity were significantly more likely to experience psychological distress ($p<0.01$).[68]

Psychosocial consequences of genital herpes on relationships

Seven cross sectional studies examined the impact of genital herpes on participants' relationships[14,22,49,50,59,68,69] and explored existing relationships with friends and family,[22,49,53] new acquaintances of the same sex[68] or opposite sex[53,68,69] and existing romantic relationships.[14,49,69] These were measured using the Questionnaire on Interpersonal Relationships,[50] the HELP questionnaire [49] and single item questions within generic HRQoL or disease specific scales.[14,22,49,53,68,69]

Responses form single item questions across the studies showed that participants reported differing levels of impact that having a diagnosis of recurrent genital herpes had on existing relationships with friends and family members[22,49,53] from very little impact[49] to having a worse relationship.[53] A small number (15%) indicated a fear of rejection because of their diagnosis[22] and others reported feeling repugnant to others (serious problem for 15%).[53] With regard to being in social situations with new friends and making new acquaintances of the same sex, participants indicated that herpes had had minimal impact.[68] When meeting new acquaintances of the opposite sex participants indicated that herpes significantly interfered with the enjoyment of meeting people of the opposite sex ($r=0.63$, $p<0.01$)[68] and prevented them from getting to know people to whom they were sexually attracted.[53] Participants indicated that they felt that they would not be accepted by others if they were aware of their diagnosis,[53] although the majority of participants had or would disclose their diagnosis to past or future partners.[69] Participants across studies in existing relationships felt insecure about intimate relationships[14] and reported herpes as having had at least a mildly adverse effect on their romantic relationships, at both diagnosis and six to nine months later.[49] During symptomatic periods participants appeared to be more bitter towards their partners[50] and some indicated that herpes had contributed to the breakup of their marriage or long-standing relationship.[49]

Depression

Depression was explored across 10 cross sectional studies,[14,17,48,49,52,53,68,70,72,73] four used the HADS,[14,48,52,72] two used the BDI[70,73] and a further four studies asked single item questions within generic HRQoL or disease specific QoL questionnaires.[17,49,53,68] Between 16%[64] and 34%[14] of those diagnosed within the last six months could be classified as depression “cases” on the HADS, which is indicative of severe levels of depression. For those with recurrent genital herpes the data is mixed with one study[52] reporting that 23% were experiencing severe depression whilst another reported that none of the sample population was severely depressed and that the data was comparable with normative data.[73] Two studies reported that the mean HADS score for depression was the same regardless of the number of recurrences that a participant experienced, although mean values and statistical significance levels were not reported for either study.[48,72] Responses from a single item question suggested that those with genital herpes at the time of initial diagnosis and those who had frequent recurrences experienced depression[17,49,53,68] which was characterized by feelings of estrangement, apprehension, and despair. Manne et al.[70] did not report mean scores for the BDI but reported the data as part of a regression analysis.

Illness attitude and illness concern

Two cross sectional studies explored illness attitude and illness concern using the Illness Attitude Scale and Illness Concern Scale respectively.[48,64] The Illness Attitude Scale assessed fears, attitudes and beliefs associated with hypochondriacal concerns and abnormal illness behaviour. However, the findings for this scale from both studies, by the same author, were poorly reported[48,64] and only reported that there were no statistically significant changes in scores across all the time points assessed.

The Illness Concern Scale assesses the actual and potential emotional impact caused by an illness, in this case herpes. High levels of concern were reported for those who presented with their first episode of genital herpes but by three months follow up the level of concern was significantly less (mean scores: first episode 15.8, follow up 12.3, $p<0.0001$).[48,64] However, no further significant reductions were seen over time (up to 15 months later).[64] When patterns of recurrence were explored only those with no recurrences had significantly lower illness concern scores three months after their outbreak (14.7 vs 12.3, $p=0.003$).[48]

Stress

Stress was explored across 10 cross sectional studies (over 11 publications)[14,22,26,49,53,66,67,69,70,72,73] using questionnaires that the authors designed themselves,[66,67,70] single item questions within disease specific QoL scales[14,22,53,69] or a variety of validated questionnaires which included:

- College Event Scale which measures life change events which may have an impact on college students.[49]
- Impact of Event Scale which measures the amount of distress that is associated with a specific event.[49] Daily Hassles and Uplifts Scale which measures the respondent's attitudes about daily situations defined as "hassles" (describing negative events) and "uplifts" (describing positive events).[73]
- Life experiences survey which asks individuals to evaluate 60 events in terms of the extent to which they viewed the event as having a positive or negative impact on their lives.[26]

Those with genital herpes have been shown to have a range of stress responses at first diagnosis and when the condition recurs compared to normative samples.[49] Those newly diagnosed with genital herpes were found to have significant levels of acute stress but at follow up, between six and nine months later, levels of stress were found to be significantly lower (mean scores: newly diagnosed 27.25 ± 12.98; follow up 13.52 ± 14.31, $p<0.01$).[49] However, there were no significant differences in levels of stress between those newly diagnosed with genital herpes and normative samples when measured using the College Event Scale (mean scores: herpes 1062 ± 492.31; normative 891 ± 544), $p>0.05$).[49] For those living with recurrent genital herpes the frequency of daily hassles was significantly greater than that for normative samples (mean scores: $36.14+20.43$; normative 22.40 ± 18.70, $p=0.0001$) whereas the intensity of the hassles was comparable (mean scores: herpes 1.58 ± 0.3; normative 1.56 ± 0.43, $p>0.052$).[73] Although the frequency of uplifts was comparable with normative data (mean scores: herpes 62.00 ± 27.30; normative 69.50 ± 29.10, $p>0.05$) the intensity of the uplifts experienced was significantly lower (mean scores: herpes 1.80 ± 0.38; normative 2.14 ± 0.53, $p=0.0002$).[73] The degree of recent exposure to stressful life events was directly associated with the duration that a person had been living with genital herpes ($r=0.37$, $p<0.005$).[26]

A wide range of individual stressors, often expressed as fear, worry or concern, were identified from the responses to single item questions. One study showed that women reported on average a significantly greater number of stressors compared to men (mean scores: men 7.1 ± 3.6; women 8.0 ± 3.3, $p<0.02$) and these were related to interference with normal, daily activities.[66] The majority of stressors reported across studies were those related to the consequences of the disease.[26,66,67]

Among the most frequently identified consequence-related stressors, captured from responses to single item questions, were fear of telling past and future sexual partners,[14,26,66] interference with relationships,[66,67] stressors related to issues of transmission,[14,26,66] future recurrences.[14,22,53,69] and complications in future pregnancies.[26] Women reported that they were significantly more likely to worry about future attacks compared to men ($t=2.01$, $p<0.05$) .[72] There was also concern about developing other illnesses,[53] a fear of negative effects on health[66,67] and a fear that herpes may complicate future pregnancies.[26]

Coping

Six cross sectional studies[20,26,68,70,72] explored the use of different coping strategies for those with genital herpes. When questions about coping and adjustment were asked within disease specific quality of life questionnaires only a third of participants with recurrent genital herpes indicated that they believed that they had adapted to the disease and most indicated that they felt that adaptation to herpes was a very difficult process.[68] Three studies[20,67,72] used the Coping Orientations to Problems Experienced (COPE) scale and two used the Ways of Coping Scale,[26,70] although Manne et al.[70] created their own modified version of the scale. The highest ranking of all the strategies were active / problem solving strategies,[20,26,67,70,72] particularly so for those who experienced high levels of recurrence[72] or were members of a local self-help group.[70] Strategies that involved the seeking of emotional support (obtaining moral support, sympathy or understanding) were used infrequently[67] and were significantly more likely to be used by women ($p<0.05$).[26] Manne et al.[70] demonstrated a correlation between time and coping and found that participants engaged in significantly less problem-focused coping the longer they had herpes.

Anxiety

Six cross sectional studies measured anxiety using the HADS[14,48,52,54,64,72] and one further study used the State-Trait Anxiety Inventory.[50] At the time of the first episode of genital herpes, participants were significantly more anxious than before the infection.[50] Between 54%[64] and 64%[14] of those diagnosed within the last six months could be classified as GHQ anxiety “cases” which is indicative of severe levels of anxiety. Three studies[48,52,54] reported the percentage of patients with recurrent genital herpes that could be classified as GHQ anxiety “cases” which varied between 29% and 43%, although each had a different mean time since diagnosis. Cassidy et al.[72] reported that the mean HADS score for anxiety was the same regardless of the number of recurrences that a participant experienced, although mean values and statistical significance levels were not reported. On the other hand Carney et al.[48] demonstrated that those patients who continued to experience regular recurrences tended to continue to experience severe anxiety at the three month time point (proportion defined as cases: baseline 50%, 3 months follow up 31%, (p values not reported).

Isolation

Three cross sectional studies explored issues around isolation through specific questions within disease specific quality of life questionnaires.[22,49,53] Across all the studies there was a wide variation, ranging from 13%[22] to 65%[53], of those with genital herpes who reported some degree of isolation since being diagnosed with the virus.[22,49,53]

Stigma

Two cross sectional studies investigated stigma[20,52] using the adapted HIV stigma scale[20] and a single item question.[52] Forty seven percent of those with genital herpes felt stigmatized by others[52] and lower stigma was significantly associated with better quality of life ($\beta=-0.364$, $t=-4.678$, $p<0.0001$).[20]

Self-esteem

Self-esteem was measured across three cross sectional studies[49,50,70] using either the RSES[50,70] or subjectively using a single item question.[49] Manne et al.[70] did not present the mean scores for the RSES and only stated that self-esteem scores were not significantly different between the two groups of participants which were those who were members of a genital herpes self-help group and those who were not. Similarly, Stronks et al.[50] did not provide any details of how the RSES was scored so it cannot be determined whether the mean scores presented are indicative of high or low self-esteem; it was only reported that levels of self-esteem were no different as a result of a diagnosis of genital herpes. Whereas Hillard et al.[49] reported that at diagnosis and at follow-up, between six and nine months later, over 70% of patients subjectively rated herpes as having an effect on self-image. A smaller percentage of patients reported that they felt that their work performance had suffered due to a loss of self-esteem associated with herpes (41% at diagnosis and 20% at 6 to 9 months follow up).[49]

Self-concept

Self-concept was measured in one cross sectional study using the Tennessee Self Concept Scale (TSCS)[73] and compared the mean scores with normative samples. Young adults with genital herpes had a significantly lower self-concept on two out of the three scales of the TSCS compared to the normative samples (represented by significantly lower mean scores on the physical self-scale: herpes 66.37; normative 71.78, p=0.005 and family self-scale: herpes: 67.71; normative 70.80, p=0.005). They also had a significantly higher mean score on the social self-scale compared to the normative samples (herpes 70.30, normative 68.14, p=0.031).[73]

Self-confidence

Four cross sectional studies asked specific questions about self-confidence and/or how those with genital herpes felt about themselves within disease specific QoL scales.[14,22,53,69] Generally having a diagnosis of genital herpes had an adverse effect on self-confidence.[14,22,53,69] The subjective ratings of whether a person felt that they were less confident because of genital herpes varied from 11%[22] to 88%[53] and women rated themselves as being significantly less confident since having genital herpes compared to men (t=3.61, p<0.001).[72] Other aspects of self that affected self-confidence because of herpes were feeling contaminated,[53] self-blame,[53] feeling repugnant to others,[53] feeling unclean[14] or feeling dirty[69] Brookes et al.[69] also identified that women rated themselves as feeling significantly more dirty since having genital herpes compared to men (t=2.37, p<0.05).

Social support

Social support was measured across four cross sectional studies[20,26,70,72] using the Social Provisions Scale,[72] the Social Support Index,[26] a brief version (28 items) of the COPE scale[20] and a purposively designed questionnaire.[70]

Low levels of social support were associated with greater emotional dysfunction (F(1,54 =5.35, p<0.02).[26] The majority of participants received herpes-related social support from the internet, followed by friends, exclusive sexual partners and health providers.[20] Higher levels of internet-based support predicted poorer quality of life ($\beta=-0.213$, $t=-2.768$, $p<0.01$), while higher levels of support from religious/spiritual figures predicted better quality of life ($\beta=0.210$, $t=2.721$, $p<0.01$).[20] There were significant differences between quantity of support and perceived helpfulness of that support ($p<0.05$). Participants perceived support from the internet to be most helpful, but this type of support did not predict better psychological adjustment ($p>0.05$).[20] In another study, self-help group members significantly perceived the social support they received as less helpful than people who were not members of support groups ($p<0.001$).[70] Cassidy et al.[72] did not report mean scores for the Social Provision Scale.

The effectiveness of interventions for improving HRQoL and wellbeing

Eleven studies investigated the effectiveness of different types of interventions to explore HRQoL and a variety of associated wellbeing concepts s. The studies were too diverse to undertake a meta-analysis so a narrative summary is reported below.

Health related quality of life

Seven studies explored the effects of the described interventions on quality of life or aspects of quality of life.[31,58–60,62–64] Of these, four used the RGHQoL scale,[58,60,62,63] two the Genital Herpes Questionnaire,[31,59] one the GHQ[64] and Fife et al. also used SF-36.[58]

Pharmacological treatment was the focus of five studies.[58,60,62–64] Fife et al. reported no significant changes in generic quality of life for those undergoing episodic treatment or suppressive treatment for genital herpes (study data not provided). However, when disease specific quality of life was measured using the RGHQoL[58,60,62,63] (see table 9), three studies showed significant improvements in total RGHQoL scores from baseline to follow up for all treatment arms.[58,60,63] However there were no significant differences between the different active treatment regimens.[58,60,63] P values are presented in table 9. One further study compared active treatment to a placebo and found that treatment with valacyclovir was associated with improved quality of life among patients infected with HSV-2 who were followed for six months.[62] However, there was no difference in the change in total RGHQOL between valacyclovir and placebo for those with HSV-1 (numbers were too small to detect a true difference).[62] Carney et al.[64] investigated psychological morbidity and reported that 63% of participants could be defined as GHQ “cases” before treatment with acyclovir commenced and at three months after treatment this had significantly decreased to 26%.

Insert table 9 around here

Findings for non-pharmacological interventions were mixed. With regard to psychological therapy there were no significant differences in quality of life at the end of treatment for those who underwent cognitive restructuring or structured discussion (statistical data not presented).[31] Whereas participants attending a short term cognitive behavioural stress management group reported significantly greater quality of life than those attending a short-term psychotherapy group or a self-help psychotherapy group (p>0.05).[59]

Depression

Four experimental studies[57,61,64,65] explored the effectiveness of described interventions on levels of depression. Two studies used the HADS,[64,65] one the BDI[61] and one the Zung Depression Scale.[57] Carney et al.[64] found that acute depression was uncommon and only reported the percentage of those considered to have severe depression before (14%) and after (14%) the introduction of Acyclovir and did not conduct any statistical analysis. With regard to non-pharmacological interventions, depression was found to significantly decrease after self-hypnosis, regardless of the number of sessions (F=5.71, df=1,15, p=0.030).[65] For psychosocial interventions, findings were mixed, one study reported significantly lower levels of depression (p values not reported) from baseline (mean score: 36.0±8.93) to 26 week follow up (mean scores:32.9±9.28) and significantly lower levels of depression (p values not reported) between those receiving psychosocial interventions (mean score 32.9.0±9.28) and those in the control conditions (mean scores: support group 37.6±7.16; waiting list control 41.7+4.98, p values not reported) at follow up.[57] Whereas a further study reported no significant changes (p>0.05) between baseline and follow up or between those who had attended a group psycho-educational intervention (mean score: 9.74±7.43) or a waiting list control (mean score: 8.42±6.97).[61] The case report demonstrated that self-reported levels of depression improved after 18 counselling sessions that incorporated interventions from experiential therapy to help clients deal with the more psychosocial difficulties in learning to live with this disease.[32]

Anxiety

Three experimental studies[57,64,65] investigated the effect of the described interventions on levels of anxiety. Two used the HADS,[64,65] and two the State-Trait Anxiety Inventory.[57,65] Carney et al.[64] reported that 60% of participants could be defined as “cases” which was indicative of severe levels of anxiety before treatment with acyclovir commenced and at three months post-treatment rates had significantly decreased to 35% (p<0.01).[64] With regard to non-pharmacological interventions there were no significant changes in levels of anxiety after self-hypnosis, regardless of the number of sessions (F=3.39, df=l,15, p<0.086).[65] One study reported significantly lower levels of anxiety (p values not reported) from baseline (mean score: 13.2±8.47) to 26 week follow up (mean scores: 10.1±5.95) between those receiving psychosocial interventions and those in the control conditions (mean scores: support group 13.2±7.68; waiting list control 19.1±5.78, p values not reported) at follow up.[57] For the case report, levels of anxiety were reported to lower after a period of hypnosis.[74]

Illness attitude and illness concern

One study investigated the effectiveness of receiving continuous acyclovir on levels of illness attitude and illness concern using the Illness Attitude Scale and the Illness Concern Scale respectively.[64] There were no significant changes in levels of illness attitude, however levels of illness concern significantly decreased at three months follow up ($p<0.0001$).[64]

Mood

Three studies explored the effectiveness of non-pharmacological interventions on mood[57,61,65] and used the Profile of Mood States[57,61] and the Mood Activation Checklist.[65] Findings were mixed with two studies reporting no significant changes in levels of mood after self-hypnosis ($r<0.341$)[65]or psycho-educational sessions ($p=0.101$).[61] Whereas, one further study reported significantly lower total mood disturbance (p values not reported) scores from baseline (mean score: $34.3\underline{+}41.03$) to 26 week follow up (mean score: $2.8\underline{+}27.88$) and significantly lower total mood disturbance scores (p values not reported) between those receiving psychosocial interventions (mean score $22.8\underline{+}27.88$) and those in the control conditions (mean scores: support group $43.9\underline{+}39.99$; waiting list control $65.3\underline{+}18.21$, p values not reported) at follow up.[57]

Loneliness

The effect of described interventions on levels of loneliness was investigated across two studies using the UCLA Loneliness Scale[57] and the UCLA Loneliness Scale-Revised.[31] Participants who received a psychosocial intervention reported a significant decrease in levels of loneliness (no p values reported) at follow up compared (mean scores: $31.7\underline{+}10.23$) to those in the control conditions (mean scores: support group $37.7\underline{+}9.66$; waiting list control: $45.9+6.31$, p values not reported).[57] However, there was no change in levels of loneliness between baseline and follow up for those participants attending two different types of psychological therapy (details of statistical analysis not provided).[31]

Self-image

One study explored the effect of a self-help module, with counselling versus counselling alone, on participants' perceptions of self-image using the Body Image Scale and found no significant change from baseline to four weeks follow up ($p=0.229$).[56]

Self-efficacy

One study explored the effect of psycho-educational sessions versus waiting list control on participants' feelings of self-efficacy in preventing the transmission of STDs and found no significant change from baseline to three or six months follow up.[61]

Satisfaction with intimate relationships

One study explored the effect of a self-help module, with counselling versus counselling alone, on participants' satisfaction with intimate relationships using the Satisfaction with Intimate Relationships Scale and found no significant change from baseline to four weeks follow up ($p=0.964$).[56]

Self-concept

One study explored the effect of a self-help module, with counselling versus counselling alone, on participants' perceptions of self-concept using the Self-Concept Scale and found no significant change from baseline to four weeks follow up (p=0.345).[56]

Self esteem

One study explored the effect of a self-help module with counselling versus counselling alone on participants' perceptions of self-esteem using the RSES and found a significant improvement from baseline to four weeks follow up compared to those in the control group (p=0.49).[56]

Stress

One study looked at the impact of the described intervention on levels of stress using the Hassles scale and reported no significant change between those participating in the psychosocial intervention compared to those participating in social support control or waiting list control (no statistical details provided).[57]

Perceptions and experiences

A total of sixty findings from three qualitative studies[53,54,71] were extracted and aggregated to form eight categories that identified perceptions and experiences of genital herpes. The illustrations for each of these findings can be found in Appendix VI. There were 15 unequivocal findings, six credible findings and 39 non supported findings. The eight categories were further synthesized in a meta-synthesis which yielded two synthesized findings (Tables 7-8 and Figures 2-3) which are outlined below.

Insert figure 2 around here

Synthesis 1: Disclosure of a diagnosis of genital herpes poses a dilemma for people who have the virus

A total of thirteen findings from three studies[53,54,71] formed the five categories synthesized into synthesis one. This synthesis revealed that disclosure of a diagnosis of genital herpes poses a dilemma for people who have the virus because of the associated risk of rejection in sexual and social relationships. It was identified that the quality of a relationship influenced decision making regarding disclosure of diagnosis. It was also found that genital herpes made people feel stigmatized, that it affected interpersonal relationships and negatively impacted upon work and school.

Category 1: The quality of a relationship influenced decision making regarding disclosure

Two findings, 'Disclosure to sexual partners: Relates to the value placed on the relationship' and 'Tell or not tell: The ways people are together influences the way the telling or not telling issue unfolds' across two studies[54,71] led to the development of the first category which identified that the quality of a relationship influenced their decision making with regards to disclosure of their genital herpes diagnosis.

Decisions were influenced by the value placed on relationships.[54] and disclosure of the condition was less likely in the context of casual sex and more likely with longer term partners:

> *"I told my ex-girlfriend who I was with for 18 months about the herpes but none of my one night stands as it would turn them off sex with me".*[54. p.591.]

It was felt that people's reactions were unpredictable and although some reported having had positive experiences of disclosure they had also been made to feel "dirty" as a result of revealing their diagnosis, for example:

> *"I am confronting the issue about telling others about herpes. I had a negative experience recently and although we ended up making love (after I told), I felt dirty. He or she made me feel dirty; the way he or she was touching. You never know what kind of reaction you are going to get. I have had many positive ones but I am starting to grapple with the issues of herpes, although I am comfortable. The issue is still when and how to tell. For some reason I am re-evaluating that and thinking to myself that there might be situations where I shouldn't say anything, because of the interference it causes. Making love probably would have been a lot more spontaneous and fun if I hadn't said anything, and that is the issue".*[71. p.67.]

Category 2: A diagnosis of genital herpes made participants feel stigmatised

Three findings from one study[54] led to the development of the second category: 'Stigma: Impact of diagnosis of herpes', 'Stigma: Diagnosis is linked with sexual promiscuity' and 'Stigma: Skin eruptions are a 'mark''. All of the participants talked about feeling like a 'leper' and the virus being 'like a life sentence' because of its enduring nature. Some aligned the diagnosis with sexual promiscuity although this was at odds with their personal sexual practices. Skin eruptions, and the resultant scarring, were seen as a 'mark' of the virus with one participant describing how he hated the scars that the virus had left on his penis:

> *"I was very shocked and…ashamed…I thought oh my God what have I got…I felt ashamed".*[54. p.591]
>
> *"it just seemed like dirty or, you know, promiscuous people that got it".*[54. p591]
>
> *"I hate the scars it has left on my penis"*.[54. p.591.]

Category 3: A diagnosis of genital herpes affected interpersonal relationships

Three findings from one study[53] 'Interpersonal relationships: Feeling hurt and alienated from friends who made herpes jokes or more serious derogatory comments', 'Interpersonal relationships: The majority of individuals stated they were seeking psychological help mainly because they could not find sufficient support among their peers' and 'Interpersonal relationships: Many of the subjects regarded the possibility of non-sexual transmission of herpes as creating interpersonal tensions' informed the third category. Feelings of social isolation were outlined[53] with participants describing feeling hurt and alienated when friends made jokes and negative comments about how they would feel if someone gave them genital herpes. Some also described seeking psychological help mainly because they could not find sufficient support among their peers. Others described interpersonal tensions arising as a result of disclosure and experiences they had had with friends being concerned about the risk of non-sexual transmission of the virus through shared toilet and handwashing facilities. Illustrations include:

> *"I'd kill a sex partner who gave me herpes".*[53. p.310.]
> *"People I've told started getting very anxious about things like the toilet seat and the bar of soap".*[53. p.310.]

Category 4: Genital herpes negatively impacts upon work and school

Two findings from one study[53] informed the development of category four: 'Self-concept: Most regard having genital herpes as a pervasive and serious problem' and 'Work and school performance: Herpes affects work enjoyment and performance' The pain associated with genital herpes outbreaks adversely affected the mobility and/or concentration of some participants and for others the virus led to pervasive depressing thoughts which negatively affected their concentration. Language used by participants included:

> *"contaminated", "ugly", "inferior", "damaged".*[53. p.311.]

Category 5: Fear of rejection

Three findings across three studies informed category five:[53,54,71] 'Stigma: Rejection or fear of rejection because of herpes', 'Tell or not tell: The struggle to tell or not tell another about having genital herpes and its related aspects of guilt, fear, rejection, isolation and acceptance' and 'Interpersonal relationships: Staying in comfortable but unfulfilling relationships because of herpes'. Some participants described their dilemma regarding whether to reveal their diagnosis or not, along with the associated guilt, fear, rejection, isolation and acceptance.[71] Others talked about feeling "tainted" by the virus and they felt that their diagnosis would stymie their chance of securing future partnerships.[54] Several described remaining in comfortable but unfulfilling relationships because of herpes rather than risking being an unattractive single.[53] Rejection was a frightening prospect for participants with non-disclosure perceived as the only true safeguard against it but this, in turn, posed a moral dilemma.[71] Illustrations included:

> *"I felt I was now tainted and wouldn't be able to find anyone".*[54. p.591.]

> *"Rejection is such a frightening prospect. To be rejected socially means loneliness. I have to risk either telling people and facing their rejection or not telling and dealing with my own guilt feelings. It is a complicated moral issue".*[71. p.66.]

Insert table 7 around here

Insert figure 3 around here

Synthesis 2: A diagnosis of genital herpes has a significant emotional impact for the individual

A total of eight findings from two studies[53,54] formed the three categories synthesized into synthesis two. This synthesis revealed that a diagnosis of genital herpes leads to significant emotional responses; it can make people feel ashamed, guilty, depressed, angry and bereft. It can also make people feel morally tainted and it can diminish sexual pleasure.

Category 6: Diagnosis made participants feel morally tainted

Two findings in one study,[54] 'Stigma: Association of STIs with moral wrong and punishment' and 'Stigma: Rejection linked with sexual deviance, promiscuity and general 'badness' informed the development of category six. Some participants identified that a diagnosis of genital herpes was associated with moral wrong and punishment, particularly because of the enduring nature of the virus. Others expressed a perceived relationship between the virus and promiscuity, although they did not view their personal behaviours as such. It was identified that participants' language revealed perceptions regarding sexual improprieties and the association of sexually transmitted infections with sexual deviance, promiscuity and general 'badness' from a moral perspective:

> *"I feel like a leper. I hate it because it won't go away. Six years feels like a sentence".*[54. p.591.]
> *"I mean I'm not a slapper...I haven't been putting it around".*[54. p.591.]

Category 7: Genital herpes diminishes sexual pleasure

Two findings, 'Sexual functioning: Those who reported that they had contracted herpes from one of their first sexual partners reported a retreat from, fear of, and loss of interest in sexuality' and 'Sexual functioning: Diminished sexual pleasure' within one study.[53] led to the development of category seven. Illustrations included:

> *"I can't let go in sex anymore"*[53. p.310.]

and one man stated that because of genital herpes he had become a

> *"sexual hermit for 10 years"*.53. p.309.

Category 8: Genital herpes leads to significant emotional responses

Four findings within one study[53] led to the development of this final category. These findings were: 'Interpersonal relationships: Herpes had effects upon their overall attitude towards people and relationships making them less sensitive', 'Emotional responses: Depression is by far the most common response', 'Emotional responses: Most regarded herpes as a personal handicap and as a loss of a portion of themselves' and 'Emotional responses: Some subjects reported being angry as a result of contracting genital herpes'. Some participants described how having genital herpes had affected their overall attitude towards people and relationships and had made them less sensitive:

> *"I've really become more callous".* 53, p.311.

Depression was the most common emotional response with some participants also reporting feeling angry because of contracting genital herpes:

> *"I'm furious that the person I think gave it to me, refused to even get a blood test to confirm he had it!"*.53. p.311.

Most regarded herpes as a personal handicap and as a loss of part of themselves:

> *"It sounded like I was announcing a death in the family when I first told my girlfriend".* 53, p.311 .

Insert table 8 around here

Integration of quantitative evidence and qualitative evidence

Congruence between findings of individual syntheses

Results from the individual syntheses were supportive with some inconsistencies and gaps in the literature, as outlined below.

The first meta synthesized finding and the cross-sectional study findings identified that disclosing a diagnosis of genital herpes was a concern and a cause of stress that affected relationships and ultimately quality of life. Category one and the cross-sectional study findings revealed that the quality of a relationship influenced individuals' decision-making regarding disclosure. From category two and the cross-sectional study findings, it was revealed that people with genital herpes felt stigmatized. From category three it was identified that a diagnosis of genital herpes adversely affected interpersonal relationships. Similarly, findings from the cross-sectional studies reported interference with relationships and isolation amongst people with genital herpes, with low levels of social support associated with greater emotional dysfunction. Two effectiveness studies considered loneliness and found that a psychosocial intervention significantly decreased levels of loneliness amongst people with genital herpes but there was no change for participants attending two different types of psychological therapy. From category four and the cross-sectional study findings it was identified that genital herpes negatively impacts upon work and school. The fifth category and the cross-sectional study findings revealed a fear of rejection in sexual and social relationships amongst participants because of their diagnosis.

The second meta synthesized finding identified that a diagnosis of genital herpes has a significant emotional impact for individuals. Category six identified that genital herpes made participants feel morally tainted. Although this specific aspect of self-image was not explored in the cross sectional or intervention studies, the cross-sectional study findings identified a negative relationship between a diagnosis of genital herpes and self-confidence, self-esteem and self-concept. Effectiveness studies found no significant changes in self-image or self-efficacy but did find significant improvements in self-esteem and self-concept. From category seven it was found that genital herpes diminishes sexual pleasure. Likewise, the cross-sectional study findings identified that genital herpes adversely interferes with sexual relationships and one effectiveness study found that a self-help module with counselling had a significantly positive effect on participants’ satisfaction with intimate relationships. Category eight and cross-sectional study findings found that genital herpes leads to significant emotional responses such as depression. This finding was supported by three out of the four effectiveness studies that explored this concept. However, results of the experimental studies were mixed, with acyclovir having no impact on depression and inconsistencies identified regarding the impact of self-hypnosis and psychosocial interventions. A general lowering of mood was also evident in the qualitative and cross-sectional research. Findings from the effectiveness studies were, once again, mixed with two reporting no changes in mood after self-hypnosis or psycho-educational sessions and a further study reporting significantly less mood disturbance among those receiving psychosocial interventions.

Strength of qualitative evidence in explaining why interventions were/were not effective

There was insufficient qualitative data to give an insight into the effectiveness of interventions.

Strength of qualitative evidence in explaining differences in the direction and size of effect across the included quantitative studies

There was insufficient qualitative data to explain differences in the direction and size of effect across the included quantitative studies.

Aspects of the quantitative evidence which were/were not explored in the qualitative studies

The qualitative studies did not report on anxiety, but the cross-sectional study findings demonstrated high levels of anxiety amongst people with genital herpes. These findings were supported by the experimental studies, however they did not report a reduction in anxiety following treatment with acyclovir or psychosocial interventions, but mixed outcomes were found with regard to hypnosis.

Stress was not specifically explored in the qualitative studies. However, the cross-sectional studies identified a range of stress responses and one experimental study did not report any significant impact from a psychosocial intervention.

Quality of life was not specifically addressed in the qualitative studies but low levels of quality of life and substantial psychological morbidity were observed among patients with recurrent genital herpes across the cross-sectional study findings. Outcomes of pharmacological interventions with valacyclovir and acyclovir and non-pharmacological interventions involving a self-help module with counselling and self-hypnosis were mixed.

Illness attitude and concern were not specifically explored in the qualitative data, but one cross sectional study and one effectiveness study reported high levels of illness concern on first diagnosis which had significantly reduced three months later. One effectiveness study identified no significant changes in levels of illness attitude following continuous acyclovir.

Coping was not specifically explored in the qualitative research or effectiveness studies, but the cross-sectional study findings identified that the highest ranking coping strategies for those with genital herpes were active / problem solving strategies. Better quality of life was significantly associated with the use of acceptance coping and receiving support from religious/spiritual figures.

Aspects of the qualitative evidence which were/were not tested in the quantitative studies

In relation to the first meta synthesized finding, there was alignment between the findings of the qualitative studies and the cross-sectional study findings regarding the first category which revealed that the quality of a relationship influenced individuals' decision-making regarding disclosure, the second category which identified that people with genital herpes felt stigmatized, the fourth category which identified that genital herpes negatively impacts upon work and the fifth category which revealed a fear of rejection in sexual and social relationships amongst participants who had genital herpes. Category three, which identified that a diagnosis of genital herpes adversely affected interpersonal relationships, was supported by the findings from the cross-sectional and effectiveness studies. However, the effectiveness studies did not consider the relationship between quality of relationship and decision-making regarding disclosure. The relationship between genital herpes and stigma, impacts upon work and school, and fear of rejection were not directly addressed in the effectiveness studies.

In relation to the second meta synthesized finding, cross-sectional and effectiveness study findings aligned with category seven which found that genital herpes diminishes sexual pleasure and category eight which identified that genital herpes leads to significant emotional responses such as depression. However, results of the experimental studies were mixed with acyclovir having no impact on depression and inconsistencies identified regarding the impact of self-hypnosis and psychosocial interventions. The sixth category, which identified that genital herpes made participants feel morally tainted was not directly explored in the cross-sectional and effectiveness studies.

Discussion

This convergent segregated mixed methods systematic review sought to identify what it is like to live with and what interventions improve the HRQoL of young people and adults with primary or recurrent episodes of genital herpes within primary care and genito-urinary medicine settings. Integration of the quantitative and qualitative evidence revealed a consensus that a diagnosis of genital herpes has a significant emotional impact for individuals and disclosure is stressful, affects relationships and HRQoL, but there is a lack of consensus regarding efficacy of different interventions.

The findings of the current systematic review suggest little progression within the field, with findings mirroring those of previous reviews which were published over 30 years ago.[8,39,75–78] This review identified that the emotional impact[53,54] of recurrent genital herpes included feelings of shame, guilt, depression, anger and sorrow. The cross sectional studies also illuminated a negative association between genital herpes and depression,[14,17,49,52,53,64,69] stress,[26,49,71] anxiety,[14,48,50,52,54,64] isolation,[22,49,53] stigma,[52] self-image,[49] self-esteem,[49] self-concept,[71] self-confidence,[14,22,53,69] quality of life,[17,22] psychological morbidity,[17,22,26,48–52,72,73] work,[49,53,68] sexual behaviour,[14,22,26,49,50,53,63,67-69,72] and relationships.[14,22,49,53,68] Stressors included fear of telling past and future sexual partners,[14,26,66] interference with relationships,[66,67] fears regarding transmission,[14,26,66] and future recurrences.[14,22,53,69]

Likewise, Brentjens et al. in their review described the ‘devastating psychological impact’ of genital herpes and its relationship with psychological morbidity.[8. p.857] They identified concerns regarding the social implications of having the virus, for example fears concerning the risk of transmitting herpes to partners or loved ones and the fear of revealing their condition to new partners which was, in turn, associated with depression and social isolation. Their review also reported a relationship between having the virus and reduced self-esteem, feelings of decreased sexual desirability and compromised performance at school or at work. Similarly, two other reviews identified difficulties with relationships with sexual partners, family and friends as well as fears of transmitting the virus to others, sexual problems and feelings of undesirability amongst people who have recurrent genital herpes.[39,75] Mindel and Marks[76] [p.305] identified similar findings, however, their cautionary note stating that ‘the validity of these observations is difficult to ascertain' is of relevance to the current review due to a continued paucity of studies and methodological limitations.

This systematic review revealed that a diagnosis of genital herpes is extremely significant for the individual. In particular, people who have the virus worry about disclosing their diagnosis because of the associated fear of rejection in sexual and social relationships.[53,54,71] In keeping with the findings of this review, two previous studies identified that disclosure of a genital herpes diagnosis was more likely in socially committed relationships and disclosure was also influenced by expectations of a partner's response, with an anticipated negative response serving as a barrier.[79,80] Moral concerns such as a partner's right to know and a desire to protect a partner from the virus were motivators for disclosure. In relating these findings to clinical practice, Caulfield and Willis[81] identified that healthcare professionals believe that disclosure is the patient's choice and that it is not always required due to the high prevalence of HSV. Prevalence of the virus was emphasised by several participants when counselling HSV positive patients to try to reduce the emotional impact associated with the diagnosis.

This review also found that people with genital herpes feel stigmatized. Merin and Pachankis[82] emphasised the salience of stigma in the negative psychological consequences associated with recurrent genital herpes. Bickford et al.[54] also asserted that stigma is a barrier to disclosure of a genital herpes diagnosis and management strategies aimed at encouraging disclosure to partners need to address perceived stigma. This argument was extended further by Fortenberry[83] in highlighting that the stigma associated with genital herpes may negatively influence an individual's care seeking behaviours as well as decisions regarding disclosure of diagnosis to sexual partners.

The findings of Alexander and Naisbett's[84] review also concur with ours in highlighting the shame, embarrassment and stigma that is often associated with having herpes, as well as the anger, guilt and depression that the studies included in the present review have identified. They also highlighted how problems with relationships are often associated with the virus, along with low self-esteem and impaired sexual function. In keeping with the findings of this review, Alexander and Naisbett[84] also identified the negative impact that having the virus can have on workplace productivity.

The lack of therapeutic modalities for genital herpes has previously been noted across two reviews[8,39] as well as a lack of research into the efficacy of existing interventions; these findings remain relevant today. In relation to what interventions improve the HRQoL of people with primary or recurrent episodes of genital herpes, a consensus is limited by the variable quality and dearth of effectiveness studies. In addition, the lack of use of standardised measures and variations in reporting limits the conclusions that can be drawn from the effectiveness studies. Nevertheless, this review has identified that self-hypnosis,[65] psychosocial interventions[57] and counselling sessions[32] can improve levels of depression and anxiety and psychological morbidity can decrease over time following treatment with acyclovir,[64] psychosocial interventions[57] and hyponosis.[74] However, these studies did not elucidate whether anxiety may have decreased with time regardless of intervention. Likewise, illness concern also significantly decreased with continuous acyclovir[64] but once again it is unclear as to whether this is an artefact of time. Lower total mood disturbance was observed following psychosocial interventions among participants at follow up[57] and a self-help module with counselling had a positive impact on self-esteem.[56] Pharmacological studies demonstrated an improvement in QoL[56-59] but there were no significant differences between the different active treatment regimens. A short term cognitive behavioural stress management group intervention was also reported to enhance quality of life.[59]

The passage of time may alleviate iIllness concern,[48,64] depression[70] and compromised quality of life [48,70] but this will not be the case for all patients.[49,66,67,69] Indeed, Luby and Klinge[68] identified that only one third of participants believed that they had adapted to the disease and most felt that adaptation to herpes was a very difficult process. As Green[16] argued, it is not, therefore, enough to hope that patients' emotional distress will diminish with time. The cross sectional studies identified that low levels of social support were associated with greater emotional dysfunction[26] and higher levels of internet-based support predicted poorer quality of life, while higher levels of support from religious/spiritual figures predicted better quality of life.[20] The highest ranking of all the coping strategies across the cross sectional studies were active / problem solving strategies[20,26,67,70,72] such as seeking emotional support. Lower stigma was significantly associated with better quality of life.[20] These findings may be useful in guiding health care professionals' conversations with people when they are diagnosed with genital herpes.

Limitations of the review

The findings of this review are limited by the very small number and low quality of publications that have been conducted in the field. In addition, the quality of the literature was variable and there was a paucity of up to date literature with just one included study published since 2010 meaning that the applicability of findings to the current context may be limited. The majority of research was American with only a very small number of European studies and none from Africa, Australia or New Zealand. There is, therefore, a very limited representation of people's experiences of genital herpes and interventions aimed at enhancing quality of life internationally. This may have been compounded by studies included in the review being limited to English language studies which means that specific cultural experiences and cultural issues may not have been captured. In addition, poor reporting was a feature of many of the studies. In the quantitative studies there was a lack of use standardized instruments and analysis which meant that comparisons of interventions were not possible. Furthermore, participants varied significantly in relation to time since diagnosis and frequency of recurrence, which also made comparisons problematic. A strength of this review was the addition of the first objective to examine the effect of genital herpes on HRQoL and other wellbeing outcomes. However, this was decided after the searching and initial screening had been conducted in order to include a large volume of literature that the reviewers felt would be an important addition to the review. In including this term it became apparent that were a number of additional wellbeing outcomes that authors of the primary studies had used when investigating this topic area. These included coping, stigma, illness concern, illness attitude, isolation, loneliness, social support, mood, coping, self-concept and self-confidence. A limitation of our search was that we did not specifically search for terms coping, illness concern, illness attitude, isolation, loneliness or self-confidence. We did revisit the excluded studies list to recheck our initial decisions once this decision had been made. We are also confident through reading the reference lists of the included studies and using forward citation tracking within web of science that we would have retrieved other similar articles. We are mindful however of the potential to have introduced publication bias during this stage of the review which in turn may have led to reporting bias.

Conclusions

This review has illuminated the nuanced and, often, extreme emotional, social, relational and sexual distress that a diagnosis of genital herpes can surface. Healthcare professionals need to be sensitive to the dilemmas that disclosure poses for the individual and implement support interventions to enable patients to minimise the risk of transmission and to be sufficiently knowledgeable so that they can discuss transmission risk with sexual partners and social contacts. In addition, these findings suggest that health care professionals should be cognisant of the emotional impact of genital herpes and aim to ameliorate these emotions by communicating sensitively and non-judgementally with patients and making psychological support available.

Recommendations for practice

This systematic review has demonstrated that people who are diagnosed with genital herpes are likely to need psychological support since diagnosis has a significant emotional impact and having the virus can affect relationships and HRQoL, However, there is currently a lack of knowledge concerning which interventions are best in addressing the psychological implications of the virus and improving the HRQoL of people with primary or recurrent episodes of genital herpes. Indications suggest that quality of life, depression, anxiety and other psychological morbidities may be ameliorated through psychological, psychosocial and pharmacological interventions but the paucity of literature in the field limits recommendations for practice.

Recommendations for research

Further high quality, contemporary, mixed methods research is required to examine the effect of genital herpes on HRQoL and other wellbeing outcomes and to identify and explore the perceptions and experiences of young people and adults with primary or recurrent genital herpes globally. In addition, further research is required internationally to determine the effectiveness of interventions for improving the HRQoL of young people and adults with primary or recurrent genital herpes. In particular, international quantitative studies which employ standardised measures and analysis to allow for comparison of interventions among participants at uniform time-points post-diagnosis are required.

Conflicts and acknowledgments

Conflicts of interest

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Appendix I: Search strategies

CINAHL (on the EBSCO platform)

Searched 25-03-2020

S1	(TI ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2)) OR (AB ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2))
S2	(MM "Herpesviruses+") OR (MM "Herpes Genitalis") OR (MM "Herpes Simplex+") OR (MM "Herpes Zoster+")
S3	S1 OR S2
S4	(TI ((antiviral* or suppression or suppressive) W2 (therap* or treat* or agent* or medication* or drug*)) OR (AB ((antiviral* or suppression or suppressive) W2 (therap* or treat* or agent* or medication* or drug*)))
S5	(TI (valacyclovir or acyclovir or famciclovir)) OR (AB (valacyclovir or acyclovir or famciclovir))
S6	TI "prophylactic regimen*" OR AB "prophylactic regimen*"
S7	(TI (psychotherapeutic or psychoeducational or psycho-educational) W1 (intervention or program*)) OR (AB (psychotherapeutic or psychoeducational or psycho-educational) W1 (intervention or program*))
S8	(TI (counse?ing or psychotherapy or CBT)) OR (AB (counse?ing or psychotherapy or CBT))
S9	(TI (cognitive or behavio?al or psychological) W2 (therap* or restructuring or intervention*)) OR (AB (cognitive or behavio?al or psychological) W2 (therap* or restructuring or intervention*))
S10	(MM "Counseling+") or (MM "Cognitive Therapy+") or (MM "Psychotherapy+") or (MM "Behavior Therapy+")
S11	TI "stress reduction" OR AB "stress reduction"
S12	(MM "Stress Management")
S13	(TI (self-care or self-manag*)) OR (AB (self-care or self-manag*))
S14	(TI ((self) W1 (manag* or care))) OR (AB ((self) W1 (manag* or care)))
S15	(MM "Self Care+") or (MM "Self-Management")
S16	TI Coping OR AB Coping
S17	(MM "Coping+")
S18	(MM "Support, Psychosocial+")
S19	TI support OR AB support
S20	TI "social support" OR AB "social support"
S21	(MM "Support Groups+") or (MM "Support Groups+")
S22	(TI ((self-help or "self help" or support) W1 (group*))) OR (AB ((self-help or "self help" or support) W1 (group*)))
S23	TI ((psychological) W1 (adjustment)) OR AB ((psychological) W1 (adjustment))

S24	TI adjustment OR AB adjustment
S25	(MM "Social Adjustment") OR (MM "Adaptation, Psychological+")
S26	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27	(TI ((Psychosocial or psychosexual or psychological or emotional) W1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*))) OR (AB ((Psychosocial or psychosexual or psychological or emotional) W1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*)))
S28	(MM "Psychosocial Aspects of Illness+") OR (MM "Diagnosis, Psychosocial+") OR (MM "Psychosocial Adjustment to Illness Scale")
S29	(TI ("quality of life" or QOL or RGHQoL or RGHQOL)) OR (AB ("quality of life" or QOL or RGHQoL or RGHQOL))
S30	(TI (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy)) OR (AB (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy))
S31	(MH "Stress, Psychological+") OR (MM "Psychological Well-Being") OR (MM "Psychological Trauma") or (MM "Emotions+") or (MM "Stress+")
S32	(MM "Quality of Life+")
S33	(MH "Affective Disorders+") OR (MH "Affective Symptoms+")
S34	(MM "Depression+")
S35	(MM "Anxiety+") or (MM "Social Anxiety Disorders")
S36	(MM "Stigma") OR (MM "Shame+")
S37	(MM "Self Concept+")
S38	(MM "Sexual Identity") or (MM "Sexuality+") OR (MM "Attitude to Sexuality+")
S39	(MM "Hopelessness")
S40	(MM "Self-Efficacy")
S41	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40
S42	S3 AND S26 AND S41
S43	S3 AND S26 AND S41 (Limit to English language)

S44 S3 AND S26 AND S41 (Limit to German)

S45 S43 OR S44

MEDLINE(R) ALL (on the OVID platform)

Searched 25-03-2020

1 exp *Herpesvirus 2, Human/

2 exp *Herpes Genitalis/

3 exp *Herpes Simplex/

4 exp *Herpesvirus 1, Human/

5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.

6 1 or 2 or 3 or 4 or 5

7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or drug*)).ti,ab.

8 (valacyclovir or acyclovir or famciclovir).ti,ab.

9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/

10 "prophylactic regimen*".ti,ab.

11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or program*)).ti,ab.

12 (counse?ing or psychotherapy or CBT).ti,ab.

13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.

14 exp *Counseling/

15 exp *Psychotherapy/

16 exp *Cognitive Behavioral Therapy/

17 "stress reduction".ti,ab.

18 (self-care or self-manag*).ti,ab.

19 (self adj1 (manag* or care)).ti,ab.

20 exp *Self Care/ or exp *Self-Management/

21 coping.ti,ab.

22 Support.ti,ab.

23 "social support".ti,ab.

24 exp *Social Support/

25 exp *Self-Help Groups/

26 ((self-help or "self help" or support) adj1 group*).ti,ab.

27 (psychological adj1 adjustment).ti,ab.

28 adjustment.ti,ab.

29 exp *Emotional Adjustment/

30 exp *Adaptation, Psychological/

31 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30

32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*)).ti,ab.

33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.

34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.

35 exp *Stress, Psychological/

36 exp *"Quality of Life"/

37 exp *Depression/

38 exp *Affect/

39 exp *Anxiety/

40 exp *Shame/

41 exp *Social Stigma/

42 exp *Self Concept/

43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.

44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43

45 6 and 31 and 44

46 limit 45 to English language

47 limit 45 to German

48 46 or 47

EMBASE (on the OVID platform)

Searched 25-03-2020

1 exp *Herpesvirus 2, Human/

2 exp *Herpes Genitalis/

3 exp *Herpes Simplex/

4 exp *Herpesvirus 1, Human/

5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.

6 1 or 2 or 3 or 4 or 5

7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or drug*)).ti,ab.

8 (valacyclovir or acyclovir or famciclovir).ti,ab.

9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/

10 "prophylactic regimen*".ti,ab.

11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or program*)).ti,ab.

12 (counse?ing or psychotherapy or CBT).ti,ab.

13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.

14 exp *Counseling/

15 exp *Psychotherapy/

16 exp *Cognitive Behavioral Therapy/

17 "stress reduction".ti,ab.

18 (self-care or self-manag*).ti,ab.

19 (self adj1 (manag* or care)).ti,ab.

20 exp *Self Care/ or exp *Self-Management/

21 coping.ti,ab.

22 Support.ti,ab.

23 "social support".ti,ab.

24 exp *Social Support/

25 exp *Self-Help Groups/

26 ((self-help or "self help" or support) adj1 group*).ti,ab.

27 (psychological adj1 adjustment).ti,ab.

28 adjustment.ti,ab.

29 exp *Emotional Adjustment/

30 exp *Adaptation, Psychological/

31 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30

32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*)).ti,ab.

33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.

34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.

35 exp *Stress, Psychological/

36 exp *"Quality of Life"/

37 exp *Depression/

38 exp *Affect/

39 exp *Anxiety/
40 exp *Shame/
41 exp *Social Stigma/
42 exp *Self Concept/
43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.
44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45 6 and 31 and 44
46 limit 45 to English language
47 limit 45 to German
48 46 or 47

Ovid Emcare (On the OVID platform)

Searched 11-03-2019

1 exp *Herpesvirus 2, Human/ (
2 exp *Herpes Genitalis/ (
3 exp *Herpes Simplex/
4 exp *Herpesvirus 1, Human/
5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.
6 1 or 2 or 3 or 4 or 5
7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or drug*)).ti,ab.
8 (valacyclovir or acyclovir or famciclovir).ti,ab.
9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/
10 "prophylactic regimen*".ti,ab.
11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or program*)).ti,ab.
12 (counse?ing or psychotherapy or CBT).ti,ab.
13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.
14 exp *Counseling/
15 exp *Psychotherapy/
16 exp *Cognitive Behavioral Therapy/
17 "stress reduction".ti,ab.
18 (self-care or self-manag*).ti,ab.
19 (self adj1 (manag* or care)).ti,ab.
20 exp *Self Care/ or exp *Self-Management/
21 coping.ti,ab.

22 Support.ti,ab.
23 "social support".ti,ab.
24 exp *Social Support/
25 exp *Self-Help Groups/
26 ((self-help or "self help" or support) adj1 group*).ti,ab.
27 (psychological adj1 adjustment).ti,ab.
28 adjustment.ti,ab.
29 exp *Emotional Adjustment/
30 exp *Adaptation, Psychological/
31 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*)).ti,ab.
33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.
34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.
35 exp *Stress, Psychological/
36 exp *"Quality of Life"/
37 exp *Depression/
38 exp *Affect/
39 exp *Anxiety/
40 exp *Shame/
41 exp *Social Stigma/
42 exp *Self Concept/
43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.
44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45 6 and 31 and 44
46 limit 45 to English language
47 limit 45 to German
48 46 or 47

PSYCinfo (on the OVID platform)

Conducted 11-03-2019

1 exp *HERPES GENITALIS/
2 exp *HERPES SIMPLEX/

3 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.

4 1 or 2 or 3

5 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or drug*)).ti,ab. (798)

6 (valacyclovir or acyclovir or famciclovir).ti,ab.

7 exp *Antiviral Drugs/

8 "prophylactic regimen*".ti,ab.

9 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or program*)).ti,ab.

10 (counse?ing or psychotherapy or CBT).ti,ab.

11 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.

12 exp *COUNSELING/

13 exp *PSYCHOTHERAPY/

14 exp *cognitive therapy/ or exp *cognitive restructuring/

15 "stress reduction".ti,ab.

16 (self-care or self-manag*).ti,ab.

17 (self adj1 (manag* or care)).ti,ab.

18 exp *Self-Care Skills/ or exp *Self-Management/

19 coping.ti,ab. or exp *COPING BEHAVIOR/

20 Support.ti,ab.

21 "social support".ti,ab.

22 exp *SOCIAL SUPPORT/

23 exp *SUPPORT GROUPS/ or exp *Self-Help Techniques/

24 ((self-help or "self help" or support) adj1 group*).ti,ab.

25 (psychological adj1 adjustment).ti,ab.

26 adjustment.ti,ab.

27 exp *Emotional Adjustment/ or exp *Adjustment/

28 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27

29 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or consequence* or reaction* or factor* or distress or implication* or symptom* or

difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or outcome*)).ti,ab.

30 exp *PSYCHOSOCIAL FACTORS/ or exp *PSYCHOSOCIAL REHABILITATION/ or exp *PSYCHOSOCIAL READJUSTMENT/ or exp *PSYCHOSEXUAL BEHAVIOR/

31 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.

32 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy).ti,ab.

33 exp *PSYCHOLOGICAL STRESS/

34 exp *EMOTIONAL DISTURBANCES/ or exp *EMOTIONAL INSTABILITY/ or exp EMOTIONAL RESPONSES/ or exp *EMOTIONAL STATES/ or exp *EMOTIONAL STABILITY/ or exp *emotional trauma/

35 exp *"Quality of Life"/

36 exp *"DEPRESSION (EMOTION)"/

37 exp *Emotional States/ or exp *Emotions/ or exp *Stress/

38 exp *SOCIAL STRESS/ or STRESS/

39 exp *ANXIETY/ or exp *SOCIAL ANXIETY/

40 exp *SHAME/

41 exp *Social Stigma/

42 exp *Self-Esteem/

43 exp *Self-Efficacy/

44 exp *Self-Concept/

45 exp *Sexuality/

46 exp *HOPELESSNESS/

47 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46

48 4 and 28 and 47

49 limit 48 to English language

50 limit 48 to German

51 49 or 50

WHOLIS

Searched 25-03-2019

(genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV type* OR herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2)

Cochrane Central Register of Controlled Trials

Searched 25-03-2020

#1 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2):ti

#2 (antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-educational counse?ing or psychotherapy or CBT or cognitive or behavio?al or psychological or self-care or self-manag* or "self care" or "self manag*" or adjustment):ti

#3 (Psychosocial or psychosexual or psychological or emotional or "quality of life" or QOL or RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy):ti

#4 #1 AND #2 AND #3

EThOS: e-theses online service

Searched 25-03-2020

#1 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2)

#2 (antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-educational counse?ing or psychotherapy or CBT or cognitive or behavio?al or psychological or self-care or self-manag* or "self care" or "self manag*" or adjustment)

#3 (Psychosocial or psychosexual or psychological or emotional or "quality of life" or QOL or RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy)

#4 #1 AND #2 AND #3

Open Grey

Searched 25-03-2020

(“genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV type* OR herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2)

Web of Science (Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI)

Searched 25-03-2020

#1 TI=(“genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV type* OR herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2) 37,937

#2 TI=((antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-educational counse?ing or psychotherapy or CBT or cognitive or behavio?al or psychological or self-care or self-manag* or "self care" or "self manag*" or adjustment) 554,578

#3 TI=(Psychosocial or psychosexual or psychological or emotional or "quality of life" or QOL or RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-efficacy) 990,005

#4 #1 AND #2 AND #3 47

Appendix II: Full text studies that were excluded and reasons for exclusion

1. Alexander and Naisbett 2002: Patient and physician partnerships in managing genital herpes
   Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

2. Anonymous 2004: Suppressive antiviral therapy improves quality of life in patients with recurrent genital herpes
   Reason for exclusion: Not primary research

3. Antoni et al. 2001: Reductions in HSV-2 antibody titers after cognitive behavioral stress management and relationships with neuroendocrine function, mood, relaxation skills and social support in HIV plus men
   Reason for exclusion: Conference presentation no further publications available

4. Aral et al. 1987: Recurrent Genital Herpes: What Helps Adjustment?
   Reason for exclusionDid not report on any of the outcomes of interest as per the modified inclusion criteria

5. Au and Sacks 2002: Antivirals in the prevention of genital herpes
   Reason for exclusion: Not primary research

6. Au and Sacks 2003: Therapeutic options for herpes simplex infections
   Reason for exclusion: Not primary research

7. Baeten et al. 2012: Clinical and virologic response to episodic acyclovir for genital ulcers among HIV-1 seronegative, herpes simplex virus type 2 seropositive African women: A randomized, placebo-controlled trial
   Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

8. Baker 1992: Herpes simplex virus infections
   Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

9. Blansett 1992: Explanatory style, depressive response, and severity of herpes simplex virus
   Reason for exclusion: Unavailable

10. Bodsworth et al. 2008: 2-day versus 5-day famciclovir as treatment of recurrences of genital herpes: results of the FaST study

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

11. Brentjens et al. 2003: Recurrent genital herpes treatments and their impact on quality of life

Reason for exclusion: Not primary research

12. Chenitz and Swanson 1989: Counseling clients with genital herpes

Reason for exclusion: Not primary research

13. Chida and Mao 2009: Does psychosocial stress predict symptomatic herpes simplex virus recurrence? A meta-analytic investigation on prospective studies

Reason for exclusion: Not primary research

14. Chilukuri and Rosen 2003: Management of acyclovir-resistant herpes simplex virus

Reason for exclusion: Not primary research

15. Clark et al. 1995: Management of genital herpes

Reason for exclusion: Not primary research

16. Connor-Greene 1986: The role of counseling in the treatment of genital herpes

Reason for exclusion: Not primary research

17. Cook 2014: The sexual health consultation as a moral occasion

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

18. Cruess et al. 2000: Reductions in herpes simplex virus type 2 antibody titers after cognitive behavioral stress management and relationships with neuroendocrine function, relaxation skills, and social support in HIV-positive men

Reason for exclusion: Does not report baseline data and whether participants are symptomatic

19. Cummings 1999: Experiential interventions for clients with genital herpes.

Reason for exclusion. Insufficient details of outcomes of interest

20. Davis et al. 2016: Coping strategies and behavioural changes following a genital herpes diagnosis among an urban sample of underserved Midwestern women
Reason for exclusion: Concerned with serological diagnosis

21. Derman 1986: Counseling the herpes genitalis patient
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

22. Doward 1994: Developing a measure of quality of life for patients with recurrent genital herpes
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

23. Doward et al. 1998: The international development of the RGHQoL: A quality of life measure for recurrent genital herpes
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

24. Dorgan 2001: From behind the screen: Women's use of online disclosures about sexually transmitted diseases to manage uncertainty
Reason for exclusion: Unavailable

25. Draeger 2018: Management of genital herpes: a guide for GPs
Reason for exclusion: Not primary research

26. Faulkner and Smith 2009: A prospective diary study of the role of psychological stress and negative mood in the recurrence of herpes simplex virus (HSV1)
Reason for exclusion: Wrong population

27. Fisman 2005: Health related quality of life in genital herpes: A pilot comparison of measures
Reason for exclusion: Focus on measures rather than individuals' quality of life

28. Fraley 2002: Psychosocial outcomes in individuals living with genital herpes
Reason for exclusion: Not primary research

29. Gilbert and Wyand 2009: Genital herpes education and counselling: Testing a one-page 'FAQ' intervention

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

30. Goldmeier et al. 1986: Psychological aspects of recurrences of genital herpes
Reason for exclusion: Focus on risk factors for recurrences of genital herpes

31. Goldmeier et al. 1998: Psychosocial implications of recurrent genital herpes simplex virus infection
Reason for exclusion: Focus on risk factors for recurrences of genital herpes

32. Gould & Tissler 1984: The use of hypnosis in the treatment of Herpes Simplex II.
Reason for exclusion. Insufficient details of outcomes of interest

33. Green and Kocsis 1997: Psychological factors in recurrent genital herpes
Reason for exclusion: Not primary research

34. Green et al. 2003: Determinants of disclosure of genital herpes to partners
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

35. Green 2004: Psychosocial issues in genital herpes management
Reason for exclusion: Not primary research

36. Groves 2016: Genital Herpes: A Review
Reason for exclusion: Not primary research

37. Gruzelier 2002: A review of the impact of hypnosis, relaxation, guided imagery and individual differences on aspects of immunity and health
Reason for exclusion: Not primary research

38. Gurevich 1990: Counseling the patient with herpes
Reason for exclusion: Not primary research

39. Hamill et al. 2005: Management of recurrent genital herpes: a survey of UK genitourinary medicine clinics in 2003
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

40. Harris and Abramson 1988: Personality correlates of the clinical sequelae of genital herpes *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria*

41. Himell 1981: Genital Herpes: the need for counseling
Reason for exclusion: Not primary research

42. Hofstetter et al. 2014: Current thinking on genital herpes
Reason for exclusion: Not primary research

43. Hoon et al. 1991: A psycho-behavioral model of genital herpes recurrence
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

44. Hoon 1986: Life stress: Impact on genital herpes recurrences (social support, illness, locus-of-control, arousal-seeking)
Reason for exclusion: Focus on risk factors for recurrences of genital herpes

45. Horn et al. 2015: Psychological distress, emotional stability, and emotion regulation moderate dynamics of herpes simplex virus type 2 recurrence
Reason for exclusion: Focus on risk factors for recurrences of genital herpes

46. Hunt et al. 1993: Genital herpes and quality of life
Reason for exclusion: Focus on questionnaire development

47. Jadack et al. 1991: Genital Herpes: The Disease Experience Over the First 6 Months
Reason for exclusion: Full study reported in 1990 paper

48. Kaushal et al. 2017: Evaluation of effectiveness and safety of acyclovir 1 gm once a day single oral dose for 5 days for treatment of genital herpes
Reason for exclusion: Conference presentation no further publications available

49. Kelley 1995: Parse's theory in practice with a group in the community
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

50. Kleymann 2005: Agents and strategies in development for improved management of herpes simplex virus infection and disease

Reason for exclusion: Not primary research

51. Kleymann 2003: Novel agents and strategies to treat herpes simplex virus infections
Reason for exclusion: Not primary research

52. Koch et al. 2008: Inhibitory effect of essential oils against herpes simplex virus type 2
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

53. Koehn et al. 1993: Applied relaxation training in the treatment of genital herpes
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

54. Kuritzky 2017: Prophylaxis of genital herpes recurrences with antivirals
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

55. Lehr and Lee 1990: The psychosocial and sexual trauma of a genital HPV infection
Reason for exclusion: Unavailable

56. Leone et al. 2010: One-day famciclovir vs placebo in patient-initiated episodic treatment of recurrent genital herpes in immunocompetent Black patients
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

57. Leung and Sacks 2000: Current recommendations for the treatment of genital herpes
Reason for exclusion: Not primary research

58. Levenson et al. 1987: Psychological factors predict symptoms of severe recurrent genital herpes infection
Reason for exclusion: Focus on risk factors for recurrences of genital herpes

59. Longo and Koehn 1993: Psychosocial factors and recurrent genital herpes: A review of prediction and psychiatric treatment studies
Reason for exclusion: Not primary research

60. Longo and Clum 1989: Psychosocial factors affecting genital herpes recurrences Linear vs mediating models

Reason for exclusion: Focus on risk factors for recurrences of genital herpes

61. Longo et al. 1988: Psychosocial treatment for recurrent genital herpes

Reason for exclusion: Duplicate publication (authors published the same study with the same outcomes in two different journals and the one which the most detail was included in the review)

62. Luby and Gillespie 1981: Psychological responses to genital herpes

Reason for exclusion: Unavailable

63. Lutgendorf et al. 1997: Cognitive-behavioral stress management decreases dysphoric mood and herpes simplex virus-Type 2 antibody titers in symptomatic HIV-seropositive gay men

Reason for exclusion: Population do not meet inclusion criteria

64. Madrid and Swanson 1995: Psychoeducational groups for young adults with genital herpes: training group facilitators

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

65. Manne and Sandler 1984: Coping and adjustment to genital herpes

Reason for exclusion: Duplicate study (authors published the same study with the same outcomes in two different journals and the one with the most detail was included in the review))

66. Manns et al. 2018: What are patient experiences of herpes simplex virus (HSV) health promotion?

Reason for exclusion: Conference presentation no further publications available

67. Meads et al. 2009: Further validation and responsiveness assessment of the Herpes Outbreak Impact Questionnaire and Herpes Symptom Checklist

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

68. Merin and Pachankis 2011: The psychological impact of genital herpes stigma

Reason for exclusion: Not primary research

69. Mindel and Marks 2005: Psychological symptoms associated with genital herpes virus infections: Epidemiology and approaches to management

Reason for exclusion: Not primary research

70. Mindel 1993: Long-term clinical and psychological management of genital herpes
Reason for exclusion: Not primary research

71. Mindel 1996: Psychological and psychosexual implications of herpes simplex virus infections
Reason for exclusion: Not primary research

72. Mirotznik et al. 1987: Genital herpes: An investigation of its attitudinal and behavioral correlates
Reason for exclusion: Wrong population

73. Moore 2014: Early intervention support group for individuals diagnosed with genital herpes
Reason for exclusion: Unavailable

74. Mospan and Cluck 2016: Prevention and management of genital herpes
Reason for exclusion: Not primary research

75. Newton and McCabe 2005: A theoretical discussion of the impact of stigma on psychological adjustment to having a sexually transmissible infection
Reason for exclusion: Not primary research

76. Nicholson 2016: Getting herpes simplex: Diagnosis, treatments and attitudes of patients and partners
Reason for exclusion: Conference presentation no further publications available

77. Oseso et al. 2016: Attitudes and willingness to assume risk of experimental therapy to eradicate genital herpes simplex virus infection
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

78. Owens et al. 2015: Patients with genital herpes infection have an educational deficit regarding how to prevent further transmission
Reason for exclusion: Conference presentation no further publications available

79. Patel Ret 1999: Impact of recurrent genital herpes on health -related quality of life Improvements obtained with suppressive antiviral therapy
Reason for exclusion: Conference presentation no further publications available

80. Patel 2008: Making the most of episodic antiviral therapy for genital herpes
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

81. Roe 2004: Living with genital herpes: how effective is antiviral therapy?
Reason for exclusion: Not primary research

82. Romanowski et al. 2008: In search of optimal genital herpes management and standard of care (INSIGHTS): Doctors' and patients' perceptions of genital herpes
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

83. Rose and Camp 1988: Genital herpes How to relieve patients physical and psychological symptoms
Reason for exclusion: Not primary research

84. Sacks and Wilson 1997: Genital herpes: Management issues for the next century
Reason for exclusion: Not primary research

85. Sauerbrei 2016: Optimal management of genital herpes: Current perspectives
Reason for exclusion: Not primary research

86. Shah and Button 1998: The relationship between psychological factors and recurrent genital herpes simplex virus
Reason for exclusion: Not primary research

87. Shaw and Rosenfeld 1987: Psychological and sexual aspects of genital herpes in women
Reason for exclusion: Did not specifically report on depression subscale

88. Sinclair-Smith 1989: Stress inoculation training program applied to genital herpes patients
Reason for exclusion: Unavailable

89. Spencer et al. 1999: Recurrent genital herpes and quality of life in France
Reason for exclusion: Unavailable

90. Strachan et al. 2012: A dynamical systems analysis of psychological distress and genital HSV-2 infection in humans
Reason for exclusion: Conference presentation no further publications available

91. Strachan et al. 2011: The effects of daily distress and personality on genital HSV shedding and lesions in a randomized, double-blind, placebo-controlled, crossover trial of acyclovir in HSV-2 seropositive women
Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

92. Swanson and Chenitz 1989: Psychosocial aspects of genital herpes: A review of the literature
Reason for exclusion: Not primary research

93. Swanson and Chenitz 1989: The prevention and management of genital herpes: a community health approach
Reason for exclusion: Not primary research

94. Swanson 1999: The biopsychosocial burden of genital herpes: evidence-based and other approaches to care
Reason for exclusion: Not primary research

95. Taylor 1978: The psychological and behavioral effects of gential herpes in women: high recurrers vs low recurrers
Reason for exclusion: Unavailable

96. VanderPlate and Kerrick 1985: Stress Reduction Treatment of Severe Recurrent Genital Herpes Virus
Reason for exclusion: Concerned with predictors of reduced recurrence

97. VanderPlate et al. 1988: The relationship among genital herpes simplex virus, stress, and social support
Reason for exclusion: Concerned with predictors of recurrence

98. Van Berkel 1999: A psychoeducational programme increased knowledge and decreased sexual risk behaviours in young adults with genital herpes
Reason for exclusion: Not primary research

99. Verma et al. 2015: Acyclovir 1gm twice a day for 3 days for the treatment of recurrent genital herpes

Reason for exclusion: Conference presentation no further publications available

100. Wagstaff et al. 2004: Management of genital herpes: Defining the role of valacyclovir

Reason for exclusion: Not primary research

101. Wald et al. 2006: Comparative efficacy of famciclovir and valacyclovir for suppression of recurrent genital herpes and viral shedding

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

102. Whale et al. 2013: A psychological experiment to examine the global impact of stigma on individuals diagnosed with type 1 herpes simplex virus (HSV-1)

Reason for exclusion: Audit

103. Whitley et al. 2006: Single-day famciclovir therapy for recurrent genital herpes

Reason for exclusion: Not primary research

104. Wild et al. 1995: Measuring health-related quality of life in persons with genital herpes

Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria

105. Woolley and Kinghorn 1986: The psychological-aspects of genital herpes

Reason for exclusion: Not primary research

106. Zacharioudakis 2001: Doing psychotherapy with patients with genital herpes: Issues and interventions.

Reason for exclusion: Not primary research

107. Drob and Bernard 1986: Time-limited group treatment of genital herpes patients

Reason for exclusion: Not primary research

108. Dibble and Swanson 2000: Gender differences for the predictors of depression in young adults with genital herpes

Reason for exclusion: Duplicate data from included studies

Appendix III: Characteristics of included experimental studies

Study **Country** **Aim**	**Study design** **Methods** **Duration of study** **Setting and recruitment**	**Participant characteristics**	**Intervention** **Outcome/s of interest** **Outcome/s**
Antiviral suppression treatments			
1.Bartlett et al. 2008[60] USA To investigate the efficacy and safety of oral famciclovir as episodic (125mg twice daily for 5 days) and suppressive (250mg twice daily) treatment of recurrent GH	**Study design** RCT **Duration of study** 90 (+/- 5) days initial episodic treatment phase (IETP) plus a 6-month randomised treatment phase **Setting and recruitment** Recruited from medical centres (n=84)	**Participants** Individuals with GH were enrolled into the initial IETP (n=864). Of these 384 were randomized into the randomised treatment phase; 262 completed the trial (129 episodic, 133 suppressive) **Age (years)** Episodic treatment: Range 19-74, Mean 41.2 Suppressive treatment: Range 18-69, Mean 39.9 **Gender (Female)** Episodic treatment: 67.9% Suppressive treatment: 66.2% **Diagnosis** HSV-1 /HSV-2 confirmed by PCR testing (100%)	**Intervention** **(Episodic treatment versus suppressive treatment)** Phase 1: IETP:Famciclovir 125mg twice daily for 5 days and then observed for 90 (+/- 5) days Subjects with no symptomatic recurrence during the 3-month IETP were dropped from the study Subjects who experienced another outbreak were randomized 1:1 into randomised treatment phase. A genital swab was obtained for PCR testing. Subjects whose recurrence was negative via PCR testing were dropped from the study Phase 2: Randomised treatment phase: Episodic treatment versus suppressive treatment Episodic treatment: Famciclovir 125mg twice daily for 5 days (n=189) Suppressive treatment: Famciclovir 250mg twice daily for 6 months (n=129)

		Length of time of diagnosis ns **Number of recurrences** In the previous year Episodic treatment: Mean 7.3±3.48 Suppressive treatment: Mean 7.5±5.41	**Outcome/s of interest** Disease specific QoL **Outcome measure/s** Baseline and 6 months fu RGHQoL
2. Carney et al. 1993[64] UK To assess the psychological impact of recurrent GH and to determine if long term acyclovir has any impact on this morbidity	**Study design** Pre-test / Post-test **Duration of study** 15 months **Setting and recruitment** Patients who attended a department of genitourinary medicine	**Participants** Individuals with GH (n=102, rr ns) **Age (years)** Men: Mean 32.0; women: Mean 30.8 **Gender (Female)** 46% **Diagnosis** GH confirmed by viral culture (100%) **Length of time of diagnosis** At least one year **Number of recurrences** At least 8 recurrences per year	**Intervention (Suppressive treatment)** Intervention group: Continuous (3 months) oral acyclovir (dosage not reported) (n= 102) Control group: None **Outcome/s of interest** Psychological morbidity (including HRQoL) Anxiety and depression **Outcome measure/s** Baseline, 3 monthly while on treatment (1 year) and 3 months post treatment fu General Health Questionnaire Hospital Depression and Anxiety Scale Illness Attitude Scale Illness Concern Scale
3. Fife et al. 2007[58] USA	**Study design** RCT	**Participants** Individuals with GH (n=80, rr ns) **Age (years)**	**Intervention** **(Episodic treatment versus suppressive treatment)**

To compare episodic and suppressive therapy for genital herpes about disease characteristics, disease burden, and psychologic impact	**Duration of study** 1 year **Setting and recruitment** Recruited from those who had previously participated genital herpes clinical trials and from advertisements in the local media	Episodic treatment: Mean 35.1; Range 19-56 Suppressive treatment: Mean 32.3, Range 19-48 **Gender (Female)** Episodic treatment: 63% Suppressive treatment: 63% **Diagnosis** Self-reported GH **Length of time of diagnosis** Episodic treatment: Mean 7.6 Suppressive treatment: Mean 6.1 **Number of recurrences** In previous year Episodic treatment: Mean 6.1; Median 6.0 Suppressive treatment Mean 6.4; Median 6.0	Episodic treatment: Valacyclovir 500 mg twice daily for 5 days (n=40) at first sign of recurrence Suppressive treatment: Valacyclovir 500 mg daily for 30 days (n=40) **Outcome/s of interest** Disease specific QoL HRQoL **Outcome measure/s** Baseline, 3, 6, 9 and 12 months fu RGHQoL MOS SF-36
4. Handsfeld et al. 2007[62] USA To evaluate the effectiveness of suppressive therapy with	**Study design** RCT **Duration of study** 6 months	**Participants** Individuals with primary GH (n=119, rr ns) **Age (years)** Intervention: 28.3±9.0 Control: 28.8±8.8	**Intervention** **(Suppressive treatment versus placebo)** Intervention group: 1.0 g valacyclovir daily for 6 months (n=60) Control group: placebo for 6 months (n=59)

valacyclovir initiated within 3 months of infection	**Setting and recruitment** Recruited from a public health STD clinic and a private clinic that specialized in STD care or referred by local healthcare providers	**Gender (Female)** Intervention: 58% / Control: 73% **Diagnosis** Primary GH **Length of time of diagnosis** Less than 90 days **Number of recurrences** Not applicable	Recurrent herpes outbreaks, whether diagnosed at a return visit or by telephone evaluation, were treated with Placebo group: 500 mg valacyclovir twice daily for 5 days, during which time the study drug was withheld **Outcome/s of interest** Disease specific QoL **Outcome measure/s** Baseline, 3 and 6 months fu RGHQoL
5. Patel et al. 1999[63] USA, UK, Denmark, France, Australia, New Zealand, Italy, Austria and Germany To investigate whether suppressive antiviral therapy improves health related QoL in patients with recurrent GH	**Study design** RCT **Duration of study** 1 year **Setting and recruitment** Multicentre study no further details provided	**Participants** Individuals with GH (n=1349, rr 92%) Patients who had experienced at least six recurrences of GH in the 12 months before screening. Alternatively, if they had previously received suppressive antiviral therapy for part of that period, they were to have experienced at least one recurrence since discontinuing suppressive treatment in the 3 months immediately before entry to the study	**Intervention** **(Suppressive treatment versus placebo)** Intervention groups: valacyclovir 1000mg once daily (n=249); valacyclovir 500mg once daily (n=246); valacyclovir 250mg once daily (n=240); valacyclovir 250mg twice daily (n=247); acyclovir 400mg twice daily (n=244) for a period of 52 weeks Control group: placebo (n=123) for a period of 52 weeks Patients were required to visit the clinic on days 1 and 5 of a genital herpes recurrence, during which time they received treatment with open label valacyclovir (1000 mg twice daily for 5 days)

		Age (years) Mean was between 35 and 36 **Gender (Female)** 52% **Diagnosis** Self-reported GH **Length of time of diagnosis** ns **Number of recurrences** In previous year ≥ 10 occurrences (n=586) < 10 occurrences (n=763)	**Outcome/s of interest** Disease specific QoL **Outcome measure/s** Baseline, 3, 6 and 12 months fu RGHQoL
Psychological interventions			
6. Youngkin et al. 1998[56] USA To test the impact of the use of a self-help module on knowledge of disease and the cognitive perceptual variables of self-esteem, self-concept, satisfaction with intimate relationships and body	**Study design** RCT **Duration of study** 4 weeks **Setting and recruitment** Recruited from university student health service and a local family planning clinic	**Participants** HSV-positive women (n=40; rr 54.8%) **Age (years – entire sample)** 17-22 years (57%) 23-29 years (40%) >29 years (3%) **Gender (Female)** 100%	**Intervention (Self-help module with counselling versus counselling alone)** Intervention group: Disease specific self-help module plus routine clinic counselling (HSV: n=23) Control group: Routine clinic counselling alone (HSV: n=17; HPV: n=30) Routine clinic counselling by the healthcare provider consisted of information about diagnosis, treatment, and behaviours to prevent the spread of infection and a pamphlet on HSV or HPV. Individual counselling lasted 10-15 minutes

image in young adult women with HSV infections		**Diagnosis** Self-reported GH **Length of time of diagnosis** ns **Number of recurrences** ns	The self-help module consisted of a packet of materials that provided information on HSV or HPV about the disease definition, disease process transmission, diagnosis, prognosis, medical management options, self-help advice, disease spread prevention, and information to assist women in dealing with emotional effects of the disease, including how to talk with a current partner about the viral infection **Outcome/s of interest** Self-esteem, self-concept, body image **Outcome measure/s** Baseline and post treatment (4 weeks) Rosenberg Self-esteem Scale; Body Image Scale Self-concept with Intimate Relationships Scale
7. Swanson et al. 1999[61] USA To test the outcomes of group psycho-educational intervention led by nurses on sexual health risks (knowledge, behaviour, disease burden) and psycho-social adaptation	**Study design** RCT **Duration of study** 6 months **Setting and recruitment** Recruited from local newspapers and undertaken in community-based sites	**Participants** Individuals with GH (n=220, rr 87.3%) **Age (years)** Intervention: Mean 27.2±4.6 Control: Mean 27.0±4.0 **Gender (Female)** Intervention: 71%; Control: 82.6%	**Intervention (Psycho-educational sessions versus waiting list control)** Intervention group (n=103): At least three 90-minute psycho-educational sessions facilitated by a nurse practicing in a community-based site which covered problem solving, skills-building and peer and professional support The first session focused on information about herpes during which participants shared information and stories of the process of diagnosis

(depression, mood states, self-efficacy) in young adults with the chronic disease, GH		**Diagnosis** Self-reported GH **Length of time of diagnosis** ns **Number of recurrences** In past 3 months Intervention: Mean 1.51±1.32 Control: Mean 1.45±1.41	The second session focused on feelings about having herpes and strategies for disclosing the diagnosis to others, particularly a partner or potential partner. The third session focused on prevention of transmission of the disease to self and others Control group (n=117): were offered the intervention at the end of the study **Outcome/s of interest** Depression, Mood, Self-efficacy **Outcome measure/s** Baseline, 3 and 6 months fu Beck Depression Inventory; Profile of Mood States Protection from STD Questionnaire
8. Longo 1986[57] USA To explore the association between psychosocial interventions and stress, social support, health status and emotional distress	**Study design** RCT **Duration of study** 26 weeks **Setting and recruitment** Recruited from local newspaper advertisements, posters displayed around the university and referrals from the University Infirmary	**Participants** Individuals with GH (n=29, rr ns) **Age (years) Mean±SD** Virginia PG: 23.8+8.58; SS: 23.0±5.39; WL: 23.4±4.10 Pennsylvania PG: 27.6±5.51; SS: 30.0±6.82; WL: 28.0±6.83	**Intervention (Psychosocial Treatment versus waiting list control)** Psychosocial groups and social support groups for six, consecutive, weekly, 90 minute five-member group treatment sessions were conducted Psychosocial groups involved: HSV information, interpersonal conflict discussions, relaxation training, stress management instructions, and suggestive-imagery techniques

	and local physicians in two cities (Virginia and Pennsylvania)	**Gender (Female)** Virginia PG: 33%; SS: 13%; WL: 20% Pennsylvania PG: 21%; SS: 36%, WL: 14% **Diagnosis** Self-reported GH **Length of time of diagnosis** ns **Number of recurrences** In the previous year 4-6 (n=ns)., 7-10 (n=ns)., 11-12 (n=ns). and ≥13 (n=ns)	The social support groups shared feelings and experiences about the disease, and served as placebo controls Waiting-list control group were offered treatment after the 26-week follow-up period **Outcome/s of interest** Anxiety, Stress, Depression, Mood, Loneliness, Locus of control **Outcome measure/s** Baseline and post treatment (26 weeks) State Trait Anxiety Scale; UCLA Loneliness Scale; Zung Depression Scale; Profile of Mood States Multidimensional Health Locus of Control; Hassle Scale
9. McLarnon and Kaloupek 1988[31] Canada To examine the relationship between psychological factors and disease expression in the form of GH	**Study design** RCT **Duration of study** 5 weeks **Setting and recruitment** By referral from health professionals connected with sexually transmitted disease clinics at three	**Participants** Individuals with GH (n=16; rr 72.7%) **Age (years)** 29.7±10.4 **Gender (Female)** 81% **Diagnosis** GH confirmed by viral analysis	**Intervention (Psychological group therapy)** Psychological group therapy involving SDi or CR procedures for weekly for 5 weeks. The SDi procedure was selected as the control intervention Both methods provided the groups with the opportunity to reduce social isolation and receive support from others. The SDi group provided only this opportunity, whereas the CR group also included systematic cognitive restructuring exercises, role playing and homework assignments

	major hospitals, as well as from several community and university health services and adverts placed at two universities, newspapers and radio	**Length of time of diagnosis** Mean 16.4 months ±14.9 **Number of recurrences** ns	**Outcome/s of interest** Disease specific QoL Loneliness **Outcome measure/s** Baseline and post treatment and then 3, 6 months fu Genital Herpes Questionnaire UCLA Loneliness Scale
10. Gruzelier et al. 2002[65] UK To examine both positive and negative personality influences on mood, health and immunity as a result of self-hypnosis training	**Study design** Pre-test / Post-test **Duration of study** 6 weeks **Setting and recruitment** Recruited from Department of GUM	**Participants** Individuals with GH (n=20, rr ns) **Age (years)** Range 23 to 64, Median 36 **Gender (Female)** 65% **Diagnosis** Self-reported GH **Length of time of diagnosis** ns **Number of recurrences** In the six weeks before treatment Median 12 (range 6-25)	**Intervention (Self-hypnosis)** After a group hypnosis session, they were given self-hypnosis cassette recordings to take home and were recommended to practise a minimum of three times a week, a total of 18 times; the mean was 17 sessions, ranging from 3 to 33 sessions. Hypnosis involved instructions of relaxation, immune imagery, cognitive alertness and ego strengthening, as for the original student study **Outcome/s of interest** Anxiety, Depression, Mood **Outcome measure/s** Baseline and post treatment (6 weeks) Hospital Anxiety and Depression Scale State-Trait Anxiety Inventory Mood activation checklist
11. Drob et al. 1986[59] USA	**Study design** RCT	**Participants** Individuals with GH (n=42, rr ns)	**Intervention (Group psychotherapy versus self-help control)**

To compare the efficacy of three forms of group psychological treatment for herpes patients	**Duration of study** 12 weeks **Setting and recruitment** Recruited by the principal author at lectures on GH sponsored by the New York HELP support group	**Age (years)** Mean 34 **Gender (Female)** 58% **Diagnosis** Recurrent GH diagnosed by their own physician **Length of time of diagnosis** ≥6 months of GH symptoms **Number of recurrences** Up to nine episodes per year	Intervention groups: CBSM (n=17) or DOP (n=17) Group sessions both 12$^{1}/_{2}$ hours over 10 weekly sessions Control group: Self-Help control group (n=8) 12 hours over 4 monthly sessions. The CBSM intervention was designed to instruct subjects in three techniques for coping with and controlling life stress, especially those stresses associated with GH herpes. The techniques utilized were relaxation training, rational-emotive training, and assertiveness training. These groups were highly structured, directive, and problem oriented The DOP intervention was designed to provide subjects with an opportunity to explore the issues and conflicts associated with GH herpes, including (but not limited to) the following: sexuality and intimacy, interpersonal relations, self-concept, guilt, and the expression of affect. These groups were less structured, relatively non-directive and person oriented The Self-Help intervention was designed as a control for the nonspecific effects (information, contact, and support) of the other two psychological treatments and to model the kind of self-help groups that are

			currently available to herpes patients through a nationwide network of support groups. **Outcome/s of interest** Psychological Adjustment (Disease specific QoL) **Outcome measure/s** Post treatment only (12 weeks) Client Posttherapy Questionnaire (AOQ) Part 1 contained 50 items of which 35 were the 25-item Genital Herpes Questionnaire

Key: CBSM: cognitive behavioral stress management CR: cognitive restructuring; DOP: dynamically oriented psychotherapy; fu: follow up; GH: genital herpes; GUM: Genitourinary Medicine; HELP: a self-help organization for individuals with herpes; HPV: human papilloma virus; HRQoL: Health related quality of life: HSV: herpes simplex virus; IETP: initial episodic treatment phase; ns: not specified; PCR: polymerase chain reaction; PG: psychosocial groups; QoL: quality of life; RCT: randomised control trial; RGHQoL: Recurrent Genital Herpes Quality of Life Scale ; MOS SF-36: Medical Outcome Study 36-tem Short Form Health Survey; STD: sexually transmitted disease; SDi: structured discussion; SD: standard deviation

Appendix IV: Characteristics of included cross sectional descriptive studies

Study **Country** **Aim**	**Methods** **Setting and recruitment**	**Participant characteristics**	**Outcome/s of interest** **Outcome measures**
1.Barnack-Tavlaris et al. 2011[20] USA To investigate the psychosocial factors that influence psychological adjustment among women with GH	**Study design** Cross sectional descriptive study **Methods** On-line survey **Setting** Recruited via postings in on-line forums and recruitment fliers were sent to approximately 200 clinics and college campuses in popular cities across the USA	**Participants** Women with GH (n=105, rr ns) **Age (years)** Range 18-30, Mean 23.98±3.90 **Gender (Female)** 100% **Diagnosis** Self-reported GH **Length of time since diagnosis** Diagnosed within past 22 months **Number of recurrences** Mean 2.23±1.98, Range 0-12 in previous 22 months	**Outcome/s of interest** Disease specific QoL Coping Herpes stigma Social support **Outcome measures** RGHQoL adapted HIV stigma scale Coping Orientations to Problems Experienced (COPE) Scale Social Support (AOQ)
2.Bickford et al. 2007[54] UK To assess the nature and effect of stigma on disclosure of diagnosis to sexual partners	**Study design** Cross sectional descriptive study as part of wider mixed methods study **Methods** Questionnaires	**Participants** Individuals with GH (n=70, rr ns) compared to normative values **Age (years)** ns **Gender (Female)**	**Outcome/s of interest** Anxiety **Outcome measures** Hospital Anxiety and Depression Scale

among those with problematic disease	**Setting** Recruited from people attending a genital herpes clinic within a UK NHS genitourinary clinic and via a self-help advocacy group, the Herpes Viruses Association	72.5% **Diagnosis** Self-reported GH **Length of time since diagnosis** Median 78 months (IQR 41-192 months) **Number of recurrences** ns	
3.Brookes et al. 1993[69] UK To assess whether adverse psychological consequences and impaired sexual and interpersonal functioning, as a result of GH infection, are present in individuals who have had the infection over a lengthy period of time	**Study design** Cross sectional descriptive study **Methods** Questionnaire **Setting** Recruited from people attending a UK genitourinary clinic and via a self-help advocacy group, the Herpes Association	**Participants** Individuals with GH (n=90, rr 60%) **Age (years)** Median 34 (range 19-60) **Gender (Female)** 55.6% **Diagnosis** Self-reported GH **Length of time since diagnosis** Median 6 years (range 1-29) **Number of recurrences** All had had 2 recurrences, with 66 (73%) having had > 10 recurrences	**Outcome/s of interest** Sexual behaviour Attitudes to sexual performance, and enjoyment, work, relationships with partners, family and friends, self image and attitudes to the infection **Outcome measures** AOQ
4.Carney et al. 1994[48] UK	**Study design** Longitudinal descriptive study	**Participants** Individuals with GH (n=91)	**Outcome/s of interest** Psychological morbidity (including HRQoL)

To assess the psychological morbidity of patients with a first episode of GH infection, to monitor whether this changes over time and to assess whether subsequent episodes had any bearing on adjustment to the illness	**Methods** Questionnaires distributed at 3, 6 9 & 12 months **Setting** Patients who attended a department of genitourinary medicine	(3 months fu n=61; 6 months fu n=51; 9 months fu n=40; 12 months fu n=28) **Age (years)** Mean 28.3 ±8.14 **Gender (Female)** 75% **Diagnosis** Primary episode of GH confirmed at clinic **Length of time since diagnosis** ns **Number of recurrences** 0 initially, ≥1 recurrence at 6 months (43%)	Anxiety, Depression **Outcome measure/s** General Health Questionnaire Hospital Depression and Anxiety Scale Illness Attitude Scale Illness Concern Scale
5.Cassidy et al. 1997[72] UK To examine the impact of genital HSV on patients' QoL	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited from those attending a GUM clinic and through advertisements in the national press, and via local radio	**Participants** Individuals with GH (n=116, rr 89%) **Age (years)** Range 21-69, Mean 35.3 **Gender (Female)** 58.6% **Diagnosis** Culture positive GH **Length of time since diagnosis** <1 year 22.4% / 1-5 years 37.9%, 6-10 years 19% / 11 years and more 20.7%	**Outcome/s of interest** Depression, Anxiety Stress, Coping Life experiences (HRQoL) Social support HRQoL **Outcome measures** Hospital Anxiety and Depression Scale Life Experiences Survey

		Number of recurrences Mean 3.65 in 6 months Range 0-24 per year	Coping Orientations to Problems Experienced (COPE) Scale Social Provisions Scale Medical outcomes study instrument (QoL items)
6.Drob et al. 1985[53] **USA** To investigate the psychological consequences of GH	**Study design** Cross sectional descriptive study as part of wider mixed methods study **Methods** Questionnaires **Setting** Recruited from those seeking counselling and/or psychotherapy because of their difficulties with GH	**Participants** Individuals with GH (n=42, rr ns) **Age (years)** Range 21-56; Mean 34 **Gender (Female)** 57% **Diagnosis** Self-reported GH **Length of time since diagnosis** Diagnosed more than 6 months previous Mean 1.4 years **Number of recurrences** Mean 11 in previous year	**Outcome/s of interest** Psychological consequences of herpes (Disease specific QoL) **Outcome measures** Genital Herpes Questionnaire (AOQ)
7.Hillard et al. 1989[49] **USA** To quantify the psychological reaction to diagnosis of GH	**Study design** Longitudinal descriptive study **Methods**	**Participants** Women with GH (n=23, rr 85%); 6 or 9 months fu (n=15, rr 65%) compared with a control group (n=35) **Age (years)** Range 18-36, Mean 21.4	**Outcome/s of interest** Depression Stress Psychosocial effects (HRQoL and Disease specific QoL)

	Questionnaires distributed at baseline, between 6 and 9 months fu **Setting** Recruited from a University health centre	**Gender (Female)** 100% **Diagnosis** Culture proven GH Primary GH (n=20) / Recurrent GH (n=3) **Length of time since diagnosis** Newly diagnosed primary genital herpes (n=20) previous outbreaks but previously undiagnosed (n=3) **Number of recurrences** The three women with recurrent herpes had had episodes lasting an average of 7 days beginning 3 weeks prior to data collection	**Outcome measures** Symptom Check List-90 Impact of Event Scale College Event Scale HELP Questionnaire
8.Jayasuriya et al. 2014[52] Sri Lanka To study the psycho-social impact of HSV on patients attending the Central STD Clinic Sri Lanka	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited from those attending central STD clinic	**Participants** Individuals with GH (n=85, rr ns) compared with individuals with other STI without any genital signs and symptoms (n=85) **Age (years)** Range 18-67, Mean 34 ±10.4 **Gender (Female)** 39% **Diagnosis** Self-reported primary or recurrent GH	**Outcome/s of interest** Psychological impact (HRQoL, stigma) Anxiety and Depression **Outcome measures** General Health Questionnaire Hospital Anxiety and Depression Scale

		Length of time since diagnosis ns **Number of recurrences** ns	
9.Jadack et al. 1990[66] USA To examine gender differences in the disease experience of persons who have GH **10. Keller et al. 1991**[67] USA To examine the disease experience of persons who have GH by identifying the nature and frequency of disease-related stressors and coping responses associated with these stressors	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited from outpatient university clinic and newspaper advertisements	**Participants** Individuals with GH (n=60, rr ns) **Age (years)** Mean 31.7±8.1 **Gender (Female)** 56% **Diagnosis** Self-reported Recurrent GH **Length of time since diagnosis** Mean 3.5±5.4 (Range 3 months to 31 years) **Number of recurrences** Mean 6.4±5.5 per year	**Outcome/s of interest** Differences in stressors by gender[66] Stressors[66,67] Coping[67] Impact of GH[66] **Outcome measures** Disease stressors questionnaire (AOQ)[66,67] Coping Orientations to Problems Experienced (COPE) scale[67] Single impact question (AOQ)[66]
11. Luby and Klinge 1985[68] **USA**	**Study design** Cross sectional descriptive study **Methods** Questionnaires	**Participants** Individuals with GH (n=74; rr ns) **Age (years)** Mean 33.3; range 20-67	**Outcome/s of interest** Psychosocial consequences Psychological distress **Outcome measures**

To investigate the psychosocial and psychological consequences of GH	**Setting** Recruited from local HELP support group or refereed from two infectious disease practices	**Gender (Female)** 35% **Diagnosis** Recurrent GH Viral culture for private practice patients Self-reported for HELP support group subjects **Length of time since diagnosis** ns **Number of recurrences** ns	AOQs
12. Manne et al. 1986[70] **USA** To investigate the relationship of the passage of time and membership in a self-help group with coping behaviors and distress among people with GH	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited from across eight herpes self-help groups and volunteer subjects not affiliated with self-help groups, who responded to newspaper advertisements	**Participants** Individuals with GH (n=152, rr ns) Members of a self-help group (n=116) Community volunteers (n=36) **Age (years)** Mean 33.4 **Gender (Female)** 61% **Diagnosis** Self-reported GH **Length of time since diagnosis** Mean 62 months, Median 50 months	**Outcome/s of interest** Social support Coping variables Disease management strategies Stress thoughts Degree to which subject is bothered by having herpes (HRQoL) Self-esteem Depression **Outcome measures** Modified Ways of Coping Scale Beck Depression Inventory Rosenberg Self-Esteem Scale

		Number of recurrences Mean 8 per year diagnosis <1 year Mean 10 per year diagnosis >1 year	AOQs
13. Mark et al. 2009[14] USA To assess the psychosocial well-being and QoL among women newly diagnosed with symptomatic genital HSV	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited via clinicians who practiced in one of the specialities that commonly diagnose HSV: primary care (general practice, family medicine, and internal medicine) or obstetrics and gynaecology	**Participants** Women with primary GH (n=83, rr 82%) **Age (years)** 15-24 (31.3%) / 25-34 (37.3%) / 35-44 (20.5%) / 45-54 (4.9%) / $\geq$ 55 (6.0%) **Gender (Female)** 100% **Diagnosis** Culture proven primary GH **Length of time since diagnosis** Diagnosed in the past six months **Number of recurrences** Not applicable	**Outcome/s of interest** Anxiety and Depression Disease specific QoL **Outcome measures** RGHQoL Hospital Anxiety and Depression Scale
14. Patel et al. 2001[17] Australia, Denmark, Italy, The Netherlands and UK To quantify the impact of recurrent GH on health related QoL healthcare resource and workplace productivity	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting**	**Participants** Individuals with GH (n=298; rr 97%) and MPS SF-36 compared with population norms **Age (years)** Mean 34.9; range 18-66 **Gender (Females)** 55%	**Outcome/s of interest** Disease specific QoL HRQoL Depression **Outcome measures** RGHQoL MOS SF-36

	Recruited from genitourinary or dermatology clinics	**Diagnosis** Self-reported recurrent GH **Length of time since diagnosis** Mean 87.2 months **Number of recurrences** In the last 12 months 2-4 (50%); 5-7 (25%); >7 (25%) Mean 6.0; range 2-36	Three questions depression screen (AOQ)
15. Raj et al. 2011[51] India To compare the health related QoL in patients with HIV, genital HPV and HSV-2 infections and apparently healthy controls	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited from a sexually transmitted disease clinic	**Participants** Individuals with GH (n=60, rr ns) compared to a control group of healthy persons (n=35) **Age** <30 years (38.3%) **Gender (Female)** 21% **Diagnosis** HSV-2 type-specific confirmed with ELISA (Euroimmun glycoprotein G-2-based HSV-2 type-specific ELISA) **Length of time since diagnosis** 26.1±40 years **Number of recurrences** ns	**Outcome(s) of interest** HRQoL **Outcome measures** WHO QoL instrument

16. Silver et al. 1986[26] USA To investigate the relationship among stress, coping style, emotional dysfunction, social support, and severity of symptoms (frequency of recurrence, and pain, duration, and bother of recurrences) in those suffering from severe cases of GH infection	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting** Recruited via media announcements and the local HELP support group	**Participants** Individuals with GH (n=66) **Age (years)** Range 20-65, Mean 33 **Gender (Female)** 53% **Diagnosis** Self-reported GH (n=13) Culture proven GH (n=10) Diagnosed by clinical inspection (n=16) No information provided (n=27) **Length of time since diagnosis** Range 6 months – 8 years Mean 4 years **Number of recurrences** Mean 9.9 per year	**Outcome/s of interest** Psychopathology (HRQoL) Life experiences (HRQol) Coping Social support **Outcome measures** SCL-90 Life Experiences Survey Ways of Coping Checklist Social Support Index
17. Swanson et al. 1995[73] USA To determine the disease characteristics and psychosocial factors in young adults with GH	**Study design** Cross sectional descriptive study **Methods** Questionnaires **Setting**	**Participants** Individuals with GH (n=70, rr ns) compared with population norms **Age (years)** Mean 28.7± 4.7 **Gender (Female)** 59%	**Outcome/s of interest** Stress Depression Self-Concept Psychopathology (HRQ0L) **Outcome measures**

	Recruited from newspaper advertisements and the offices of health professionals (excluding mental-health service)	**Diagnosis** GH confirmed **Length of time since diagnosis** Range 1-15 years / Mean 5.01 years ± 3.31 **Number of recurrences** ≥1 no further details reported	Authors' Genital Herpes Questionnaire Symptom Check List-90 Beck Depression Inventory Daily Hassles Scale Uplifts Scale Tennessee Self Concept Scale
18. Stronks et al. 1993[50] Netherlands To investigate the psychological consequences of GH compared to those with a curable STD	**Study design** Cross sectional descriptive study **Methods** Questionnaires completed shortly after diagnosis according to their present situation and then again one week later according to how they felt before the diagnosis **Setting** Recruited from an outpatient department	**Participants** Individuals with GH (n=27; rr ns) **Age (years)** Mean 31.4±3.6, range 23-47 **Gender (Female)** 22% **Diagnosis** Self-reported GH **Length of time since diagnosis** ns **Number of recurrences** ns	**Outcome(s) of interest** Sexuality Relationship with partner Anxiety Self-esteem Psychological-somatic complaints (HRQoL) **Outcome measure(s)** Inhibition during intercourse and (preferred) frequency of sexual intercourse subscales of the Sexuality Experience Scale State-Trait Anxiety Inventory Rosenberg's Self-Esteem Scale Hopkins Symptom Checklist The Questionnaire on Interpersonal Relationships
19. Taboulet et al. 1999[22]	**Study design**	**Participants**	**Outcome/s of interest**

France To assess psychological morbidity in France related to GH infection in comparison with a group of control patients	Cross sectional descriptive study **Methods** Questionnaires **Setting** French families on file at the SOFRES survey institute were asked whether they had suffered from either genital herpes, over the last 12 months	Individuals with GH (n=150; rr 77%) compared to a control group representative of general population (n= 200) **Age (years)** Less than 25-65 (8%), 25-34 (21%), 35-49 (30%), 50-64 (23%), ≥65 (18%) **Gender** 74% **Diagnosis** Confirmed GH **Length of time since diagnosis** ≥6 years (45%); ≥ 10 years (25%) **Number of recurrences** In the last 12 months None (7%); 1-2 (47%); 3-5(26%). More than 5 (13%); Can’t remember (7%)	Disease specific QoL HRQ0L **Outcome measures** Herpes Specific Scale MOS SF-36

Key: AOQ: authors own questionnaire; fu: follow up; GH: genital herpes; HELP: a self-help organization for individuals with herpes; HIV: human immunodeficiency virus; HSV: herpes simplex virus; MOS SF-36: Medical Outcome Study 36-tem Short Form Health Survey; ns: not specified; NHS: National Health Service; QoL: Quality of Life; RCT: randomised controlled trial; RGHQoL: Recurrent Genital Herpes Quality of Life Scale; rr: response rate; SCL-90: Symptom Check List-90; SOFRES: Société française d'enquête par sondage; STD: sexually transmitted disease; WHO: World Health Organisation

2211 **Appendix V: Characteristics of included qualitative studies**

Study /Country **Aim** **Phenomena of interest**	**Methods**	**Participant characteristics** **Setting**
1. Bickford et al. 2007[54] UK To assess the nature and effect of stigma on disclosure of diagnosis to sexual partners among those with problematic disease **Phenomena of interest** Stigma Concerns regarding disclosure	**Study design** Qualitative descriptive survey as part of wider mixed methods study **Methods** Questionnaires	**Participants:** Individuals with GH (n=6, rr ns) **Age (years):** ns **Gender:** ns **Diagnosis:** Self-reported GH **Length of time since diagnosis** Median time since diagnosis 78 months (IQR 41-192 months) **Number of recurrences:** ns
2. Drob et al. 1985[53] USA To investigate the psychological consequences of GH **Phenomena of interest** Social context of GH	**Study design** Qualitative descriptive survey as part of wider mixed methods study **Methods** Interviews	**Participants:** Individuals with herpes (n=35., rr ns) **Age (years):** ns **Gender:** ns **Diagnosis:** Self-reported GH **Length of time since diagnosis:** ns **Number of recurrences:** ns
3. Kelley 1999[71] USA	**Study design** Qualitative descriptive study	**Participants:** Individuals with GH (n=8, rr ns)

To evaluate changes in the QoL from the perspective of the person for patients suffering from GH **Phenomena of interest** QoL; Disclosure Discomfort / comfort	**Methods** Focus groups **Setting** Recruited through newspaper ads and the local American health Association self-help group for people with GH	**Age (years):** 26-42 **Gender (Female):** 50% **Diagnosis:** Self-reported GH **Length of time since diagnosis:** ns **Number of recurrences:** ns

Key: GH: genital herpes; QoL: quality of life; HSV: herpes simplex virus; ns: not stated; rr: response rate

Appendix VI: List of Study Findings with Illustrations

Study: Bickford et al 2007[54]	
Finding 1	Disclosure to sexual partners: Relates to the value placed on the relationship (U)
Illustration	*"I told my ex-girlfriend who I was with for 18 months about the herpes but none of my one night stands as it would turn them off sex with me"* (p591)
Finding 2	Stigma: Association of STIs with moral wrong and punishment (U)
Illustration	*"I feel like a leper. I hate it because it won't go away. Six years feels like a sentence"* (p591)
Finding 3	Stigma: Impact of diagnosis of herpes (U)
Illustration	*"I was very shocked and…ashamed…I thought oh my God what have I got…I felt ashamed..."* (p591)
Finding 4	Stigma: Rejection or fear of rejection because of herpes (U)
Illustration	*"I felt I was now tainted and wouldn't be able to find anyone"* (p591)
Finding 5	Stigma: Diagnosis is linked with sexual promiscuity (U)
Illustration	*"…it just seemed like dirty or, you know, promiscuous people that got it…"* (p591)
Finding 6	Stigma: Rejection linked with sexual deviance, promiscuity and general 'badness' (U)
Illustration	*"I mean I'm not a slapper...I haven't been putting it around"* (p591)
Finding 7	Stigma: Skin eruptions are a 'mark' (U)
Illustration	*"I also hate the scars it has left on my penis as it's noticeable"* (p591)
Study: Kelley 1999[71]	
Finding 8	Discomfort and comfort for self: Self as separated or isolated from others (NS)
Illustration	No quotes
Finding 9	Discomfort and comfort for self: rejection, loneliness, fear, loss, punishment, control and burdens related to living with herpes. (NS)
Illustration	No quotes
Finding 10	Discomfort and comfort for self: There was little reference to others, except in relation to how others contributed to painful experiences. (NS)
Illustration	No quotes

Finding 11	Discomfort and comfort for self: Desire to reach out to others (NS)
Illustration	No quotes
Finding 12	Discomfort and comfort for self: Occasional acceptances they encountered from others (NS)
Illustration	No quotes
Finding 13	Discomfort and comfort for self: On-going struggles (NS)
Illustration	No quotes
Finding 14	Discomfort and comfort for self: The positive and negative experiences related to life with herpes (NS)
Illustration	No quotes
Finding 15	Tempering struggles for pursuit of personal goals: Finding self, having fun and helping others to help eliminate their fears (NS)
Illustration	No quotes
Finding 16	Tempering struggles for pursuit of personal goals: Doors closing, missing the party, giving away, and not telling or admitting to the herpes situation (NS)
Illustration	No quotes
Finding 17	Tempering struggles for pursuit of personal goals: Personal achieving and growing. (NS)
Illustration	No quotes
Finding 18	Tempering struggles for pursuit of personal goals: Looking forward to starting a family, facing change, and learning to be an intelligent risk-taker (NS)
Illustration	No quotes
Finding 19	Tempering struggles for pursuit of personal goals: Considered alternatives about relating with others, and clarified their wishes for a permanent partner (NS)
Illustration	No quotes
Finding 20	Tell or not tell: The struggle to tell or not tell another about having genital herpes and its related aspects of guilt, fear, rejection, isolation and acceptance (U)
Illustration	*“Rejection is such a frightening prospect. To be rejected socially means loneliness. I have to risk either telling people and facing their rejection or not telling and dealing with my own guilt feelings. It is a complicated moral issue.”* (p66)

Finding 21	Tell or not tell: The ways people are together influences the way the telling or not telling issue unfolds. (U)
Illustration	*“I am confronting the issue about telling others about herpes….I had a negative experience recently and although we ended up making love (after I told), I felt dirty. He or she made me feel dirty; the way he or she was touching….You never know what kind of reaction you are going to get. I have had many positive ones but I am starting to grapple with the issues of herpes, although I am comfortable. The issue is still when and how to tell. For some reason I am reevaluating that and thinking to myself that there might be situations where I shouldn’t say anything...because of the interference it causes. Making love probably would have been a lot more spontaneous and fun if I hadn’t said anything, and that is the issue.”* (p67)
Study: Drob et al 1985[53]	
Finding 22	Sexual functioning: Those who had been leading active sex lives with a variety of partners reported greatly limiting the variety and frequency of their sexual contacts (NS)
Illustration	No quotes
Finding 23	Sexual functioning: Those who reported that they had contracted herpes from one of their first sexual partners reported a retreat from, fear of, and loss of interest in sexuality (C)
Illustration	*“*One 31-year-old man stated that because of genital herpes he had become a *"sexual hermit for 10 years””* (p309)
Finding 24	Sexual functioning: Sexual isolation as a result of sexual and interpersonal anxieties generated by herpes (NS)
Illustration	No quotes
Finding 25	Sexual functioning: Diminished sexual pleasure (U)
Illustration	*“I can’t let go in sex anymore”* (p310)
Finding 26	Sexual functioning: Altering sexual behaviour in an effort to reduce the chances of transmitting the disease (NS)
Illustration	No quotes
Finding 27	Interpersonal relationships: The majority of subjects felt less desirable sexually as a result of genital herpes (NS)
Illustration	No quotes
Finding 28	Interpersonal relationships: The majority of subjects felt that they would not be accepted by others as a result of genital herpes (NS)
Illustration	No quotes
Finding 29	Interpersonal relationships: The majority of subjects felt limited in their interpersonal contacts as a result of genital herpes

Illustration	No quotes
Finding 30	Interpersonal relationships: Fear of transmitting herpes to others contributed to their tendency toward social isolation (NS)
Illustration	No quotes
Finding 31	Interpersonal relationships: Attempting to limit sexual contacts who already have herpes because of anxiety of rejection and contagion (NS)
Illustration	No quotes
Finding 32	Interpersonal relationships: Staying in comfortable but unfulfilling relationships because of herpes (C)
Illustration	*“*Rather than take the risk of being *“a handicapped single””*(p310)
Finding 33	Interpersonal relationships: Only going out with men who do not belong to their own social circles for fear that word of illness would spread (NS)
Illustration	No quotes
Finding 34	Interpersonal relationships: Only dating people they were not really interested in in order to prevent disappointment (NS)
Illustration	No quotes
Finding 35	Interpersonal relationships: Feeling hurt and alienated from friends who made herpes jokes or more serious derogatory comments (C)
Illustration	e.g. *“I’d kill a sex partner who gave me herpes”* (p310)
Finding 36	Interpersonal relationships: Many received support from close friend and family members (NS)
Illustration	No quotes
Finding 37	Interpersonal relationships: The majority of individuals stated they were seeking psychological help mainly because they could not find sufficient support among their peers (C)
Illustration	*“One woman stated that a couple she had been friendly with had avoided her since she revealed to them she had herpes”* (p310)
Finding 38	Interpersonal relationships: Many of the subjects regarded the possibility of non-sexual transmission of herpes as creating interpersonal tensions (U)
Illustration	*“People I’ve told started getting very anxious about things like the toilet seat and the bar of soap …”* (p310)

Finding 39	Interpersonal relationships: Anguish over using bathroom facilities in their friends’ and relatives’ homes during times when they have herpes lesions (NS)
Illustration	No quote
Finding 40	Interpersonal relationships: Herpes had effects upon their overall attitude towards people and relationships with some reporting they had become more sensitive to the handicaps of others (NS)
Illustration	No quote
Finding 41	Interpersonal relationships: Herpes had effects upon their overall attitude towards people and relationships making them less sensitive (U)
Illustration	*“I’d like to say I’ve become more sensitive to others but I’ve really become more callous …”* (p311)
Finding 42	Emotional responses: Herpes had a pervasively negative effect upon their personal life (NS)
Illustration	No quotes
Finding 43	Emotional responses: Depression is by far the most common response (U)
Illustration	“A number of subjects reported being “*profoundly depressed*”” (p311)
Finding 44	Emotional responses: Most regarded herpes as a personal handicap and as a loss of a portion of themselves (U)
Illustration	*“It sounded like I was announcing a death in the family when I first told my girlfriend”* (p311)
Finding 45	Emotional responses: Some subjects reported being angry as a result of contracting genital herpes (U)
Illustration	*“I'm furious that the person I think gave it to me, refused to even get a blood test to confirm he had it!”* (p311)
Finding 46	Emotional responses: Others felt angry at the insensitive treatment by medical personnel and at the insensitivity of friends and acquaintances (NS)
Illustration	No quotes
Finding 47	Emotional responses: Several expressed feelings of guilt and shame over contracting a venereal disease (NS)
Illustration	No quotes
Finding 48	Emotional response: Many experienced anxiety and nervousness over the possibility of future recurrences, non-symptomatic contagion, potentially serious medical sequelae and transmission of the herpes virus to their offspring (NS)
Illustration	No quotes
Finding 49	Emotional responses: Several subjects expressed jealousy of the freedom on non-sufferers (NS)

Illustration	No quotes
Finding 50	Self-concept: Lowering of self confidence as a result of having genital herpes (NS)
Illustration	No quotes
Finding 51	Self concept: Most regard having genital herpes as a pervasive and serious problem (C)
Illustration	*“contaminated", "ugly", "inferior", "damaged"* (p311)
Finding 52	Work and school performance: Herpes affects work enjoyment and performance (C)
Illustration	“One woman reported feeling considerably less comfortable at work after confiding in several co-workers about her disease and receiving an unsympathetic response” (p311)
Finding 53	Ethical issues: Whether, when and with whom the sufferer ought to engage in sexual relations (NS)
Illustration	No quotes
Finding 54	Ethical issues: Under what circumstances should sufferers inform a prospective sex partner about the disease (NS)
Illustration	No quotes
Finding 55	Ethical issues: Subjects agreed that it would be unethical to have sexual relations with an uninformed partner when there was any risk of transmitting the disease (NS)
Illustration	No quotes
Finding 56	Ethical issues: Do I ever know for certain that I am not contagious? (NS)
Illustration	No quotes
Finding 57	Ethical issues: Some participants believed it is unethical for a person suffering from herpes to have sex with anyone, whether informed or not, under any circumstances (NS)
Illustration	No quotes
Finding 58	Ethical issues: Anguish over informing prospective sexual partners (NS)
Illustration	No quotes
Finding 59	Ethical issues: Several stated they would be willing to have ‘casual’ sex when they were symptom-free without informing their partner of the disease (NS)
Illustration	No quotes
Finding 60	Ethical issues: Some subjects who had ongoing sexual relationships often kept herpes secret from their lovers (NS)

Illustration	No quotes

Key: C: credible; NS: not supported; U: unequivocal