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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

32 herpes can have an adverse effect on work or school, sexual relationships and relationships with friends
33 and family.

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

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

43 **Conclusions**

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

47

48

49 **Keywords**

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

51

52

53 Introduction

54 The herpes simplex virus can be categorised into two types: herpes simplex virus type 1 (HSV-1) and
55 herpes simplex virus type 2 (HSV-2).¹ Herpes simplex virus type 2 is a common sexually transmitted
56 infection which causes the condition genital herpes.² The HSV-1 is more typically associated with non-
57 sexually transmitted oral herpes infection transmitted by oral-oral contact, however it has been increasingly
58 noted as a cause of genital HSV in high-income countries from transmission through oral sex.³ Prior
59 infection with HSV-1 can modify the clinical manifestation of first infection by HSV-2, usually making
60 symptoms less severe.⁴ Globally, the prevalence of genital herpes is increasing with approximately 192
61 million people aged 15-49 years infected with genital HSV-1 infection and an estimated 491 million infected
62 with HSV-2.¹

63
64 Transmission of HSV-2 is usually via direct contact with an infected person who is shedding virus from
65 secretions on oral, genital or anal mucosal surfaces, although genital herpes can also be acquired from
66 contact with lesions at other non-mucosal surfaces.⁴ The number of days of asymptomatic virus shedding
67 in some individuals can exceed the number of days of symptomatic shedding.⁵ Up to two thirds of people
68 infected with HSV-2 will not have any symptoms at the time of acquisition of the virus, with the time between
69 infection and the first symptoms ranging from two days to two weeks.⁵ The majority of people acquiring this
70 infection may therefore be unaware of it, potentially shedding virus and transmitting HSV-2 to their sexual
71 partners unintentionally.²

72
73 A primary episode of genital herpes, which may persist for 20 days⁶ can be distressing for the individual,
74 due to frequently presenting signs which include multiple painful lesions on the external genitalia, the cervix,
75 rectum, thighs and buttocks, which burst to leave erosions and ulcers.⁵ Other symptoms can include
76 dysuria, vaginal or urethral discharge and systemic symptoms such as fever and malaise. Most people with
77 symptomatic primary genital HSV-2 experience symptomatic recurrent episodes, with more than one third
78 of those affected having frequent recurrences.⁷ Recurrent genital herpes is caused by reactivation of the
79 dormant HSV in the nerve roots of the sacral plexus,⁸ which may cause painful lesions. Systemic symptoms
80 are less common than in primary episodes and episodes are usually shorter and less severe,⁷ lasting
81 between 5-10 days.⁶ HSV-2 recurs approximately four times in the first year after a symptomatic first
82 episode and has a recurrence rate of approximately four times that of HSV-1, with recurrences tending to
83 lessen in frequency over time.⁵ Management of a primary episode of HSV-2 includes oral antiviral therapy
84 and self-care measures. Self-care measures can incorporate topical or practical approaches. These may
85 include regular saline baths to prevent secondary infection and the wearing of loose fitting clothing to reduce
86 irritation of lesions, increasing fluid intake to dilute urine and urinating in a bath or shower to reduce
87 stinging.^{4,9} Other interventions may include pain relieving measures such as the application of a topical
88 anaesthetic such as lidocaine 5%, to decrease the pain of micturition; oral analgesia such as paracetamol;
89 and infection control measures including abstinence from penetrative, non-penetrative and orogenital sex

90 until lesions have cleared and avoiding shared personal items such as towels.^{5,9} Recurrent episodes of
91 genital herpes may also require the self-care measures outlined above as well as the avoidance of any
92 identified triggers, for example ultraviolet light and excessive alcohol consumption.⁹ Episodic antiviral
93 treatment and suppressive antiviral therapy are all available options for the standard antiviral treatment of
94 genital herpes.⁷

95
96 Three systematic reviews have examined the effectiveness of antiviral treatment in people with a first
97 episode of genital herpes on the duration of symptoms and time to recurrence.¹⁰⁻¹² All of these reviews
98 identified that oral antiviral treatments decrease symptoms in people with first episodes of genital herpes
99 and that daily maintenance treatment with oral antiviral agents effectively reduces frequency of recurrences
100 and improves quality of life. For recurrent herpes it has been demonstrated that acyclovir, famciclovir, and
101 valacyclovir are all equally beneficial in reducing duration of symptoms, lesion healing time and viral
102 shedding when taken at the start of recurrence¹² and long-term data supports their safety and efficacy with
103 little difference in efficacy or tolerability.¹³ There is insufficient evidence however, to establish which type of
104 oral antiviral drug is most effective in reducing the duration of symptoms.^{11,12}

105
106 Considerable psychosocial distress is associated with a diagnosis of genital herpes,¹⁴ and it is also
107 associated with the stigma of having a sexually transmitted infection.¹⁵ Genital herpes can lead to
108 depression,^{14,16,17} diminished self-concept,¹⁸ withdrawal from intimate relationships¹⁹ and diminished quality
109 of life.^{1,20,21} Other emotional responses include shame and anxiety about having an outbreak or transmitting
110 herpes to someone else.¹⁴ Genital herpes can negatively affect sexual wellbeing,²² particularly when
111 individuals perceive that they are stigmatized by others.^{20,23}

112
113 Several interventions have been developed aimed at improving the quality of life of people who experience
114 both primary and recurrent genital herpes. These include suppressive antiviral therapies including for
115 example: valacyclovir therapy and long-term acyclovir suppression,^{9,17,21} psychological support²⁴ and social
116 support.^{20,25,26}

117
118 There is a growing body of qualitative and quantitative evidence that suggests that the impact of primary
119 and recurrent genital herpes on the quality of life of young people and adults can be ameliorated by
120 psychological and social interventions within primary care and genito-urinary medicine settings.
121 Psychological support can take the form of educational counselling at diagnosis²⁷ and follow-up,²⁸
122 psychotherapy,²⁹ cognitive behavioral therapy,³⁰ cognitive restructuring³¹ and experiential counselling
123 interventions.³² Social support preferences vary but may take the form of virtual support groups, friends,
124 sexual partners, religious/spiritual figures and health providers.²⁰

125

126 A search of several sources specialising in systematic review publication including The Joanna Briggs
127 Institute Database of Systematic Reviews, The Cochrane Database of Systematic Reviews and the
128 PROSPERO International Prospective Register of Systematic Reviews identified no published systematic
129 review on the impact of primary and recurrent genital herpes on quality of life of affected individuals. The
130 previous reviews that have been conducted have focused on screening,^{33,34} pharmacological treatment,<sup>10–
131 12,34–38</sup> transmission¹² and psychological factors in recurrent genital herpes.³⁹ Therefore, the impact for
132 patients concerning the psychological aspect of their health remains unclear.

133
134 In this mixed methods review, both the quantitative and qualitative components explored health related
135 quality of life (HRQoL) of young people and adults with primary or recurrent episodes of genital herpes. For
136 the purposes of this review HRQoL was defined as “those aspects of self-perceived wellbeing that are
137 related to or affected by the presence of disease or treatment”.^{40 p.1384} Combining both quantitative and
138 qualitative studies in the same review has allowed for a more detailed exploration of the review objective
139 which was to identify what it is like to live with and what interventions improve the HRQoL of young people
140 and adults with primary or recurrent episodes of genital herpes within primary care and genito-urinary
141 medicine settings.

142 **Review question**

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

- 145
146 The objectives were to:
- 147 1. examine the effect of genital herpes on HRQoL and other wellbeing outcomes.
 - 148 2. determine the effectiveness of interventions for improving the HRQoL and wellbeing of young people
149 and adults with primary or recurrent genital herpes.
 - 150 3. identify and explore the perceptions and experiences of young people and adults with primary or
151 recurrent genital herpes as a result of living with the signs and symptoms of the virus on their HRQoL.

152
153 The first objective was not included in the original protocol but a deviation from protocol was made following
154 discussions with the Convenor of the JBI Mixed Methods Methodological Group, to reflect the nature of the
155 literature found from the database searches. A further deviation from protocol was made to the second
156 objective, to include ‘wellbeing’ to ensure that all relevant effectiveness studies were captured.
157

158 **Inclusion criteria**

159 ***Population***

160 The review considered studies that included community dwelling participants, aged 15 years and over, who
161 had been diagnosed with genital herpes regardless of ethnicity and geographical location. Studies that

162 focused on patients who were HSV-1 or HSV-2 serologically positive but asymptomatic and studies that
163 focused on carers, family members, partners and healthcare professionals of people who have symptomatic
164 genital herpes, but who did not have symptomatic genital herpes themselves were excluded.

165

166 ***Intervention***

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

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

177

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

182 ***Phenomena of interest***

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

186 ***Outcomes***

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

190

191 Disease specific quality of life scales:⁸

- 192 • Recurrent Genital Herpes Quality of Life scale (RGHQoL)
- 193 • Quality of Life with Herpes Scale
- 194 • Genital Herpes Questionnaire
- 195 • Herpes Research Center Questionnaire

196

197 Generic health related quality of life scales:⁸

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

201

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

205

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

212 ***Context***

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

215 ***Types of studies***

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

225

226 Studies published since 1980 only were included as the initial search of the literature in the subject area
227 did not identify any relevant research prior to this date. In addition, the contribution of any research prior to
228 1980 would be limited in its applicability to current interventions. Studies published in languages other than
229 English were excluded.

230 **Methods**

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

234 ***Search strategy***

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

242 **Information sources**

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

251 ***Study selection***

252 Following the search, all identified citations were collated and uploaded into EndNote⁴³ and duplicates
253 removed. Titles and abstracts were then screened by two reviewers for assessment against the inclusion
254 criteria for the review. Studies that met the inclusion criteria were retrieved in full and their details imported
255 into the JBI System for the Unified Management Assessment and Review of Information package (JBI
256 SUMARI, JBI, Adelaide, Australia)⁴⁷. The full text of selected studies were retrieved and assessed in detail
257 against the inclusion criteria by two independent reviewers. Any disagreements that arose between the
258 reviewers were resolved through discussion.

259 ***Assessment of methodological quality***

260 Eligible studies were critically appraised by two independent reviewers for methodological quality using the
261 standardized critical appraisal instruments from the JBI for the following study types: RCTs,⁴⁴ quasi-
262 experimental studies,⁴⁴ case reports,⁴⁵ analytical cross sectional studies⁴⁵ and qualitative studies.⁴⁶ For
263 mixed methods studies the quantitative and qualitative components were appraised separately using the

264 appropriate JBI critical appraisal instruments. Any disagreements that arose between the reviewers were
265 resolved through discussion. All studies that met the inclusion criteria went forward to critical appraisal and
266 all studies were assessed as suitable for inclusion in the review. When a study met a criterion for inclusion
267 a score of one was given. Where a particular point for inclusion was regarded as “unclear” it was given a
268 score of zero. Where a particular point for inclusion was regarded as “not applicable” this point was taken
269 off the total score. All included studies were assessed using this method and their overall critical appraisal
270 scores presented. No studies were excluded as none were felt to be fatally flawed.

271 ***Data extraction***

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

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

286
287 Any disagreements that arose between the reviewers were resolved through discussion. Five studies
288 compared individuals with genital herpes with other patient groups which included: controls from
289 genitourinary or dermatology departments,⁴⁸ controls from a stress clinic,⁴⁹ or controls with other disease
290 conditions which included gonorrhoea,⁵⁰ genital human papilloma virus or human immunodeficiency virus
291 (HIV)⁵¹ or individuals with other sexually transmitted infections (STI) without any genital signs and
292 symptoms.⁵² For the purposes of this review only data related to the individuals with genital herpes were
293 extracted.

294 ***Data synthesis and integration***

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

299

300 The qualitative findings from the included studies were pooled using JBI SUMARI⁴⁷ and synthesized using
301 the JBI meta-aggregative approach.⁴⁶ This involved the aggregation or synthesis of findings to generate a
302 set of statements that represented that aggregation, through assembling the findings rated according to
303 their quality and categorizing these findings on the basis of similarity in meaning. These categories were
304 then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that
305 can be used as a basis for evidence-based practice.⁴⁶

306
307 Quantitative evidence and qualitative evidence were integrated using configurative analysis. The results of
308 the narrative synthesis of quantitative evidence were combined with the meta-synthesised findings of
309 qualitative evidence. This involved constant comparison of the quantitative evidence and the qualitative
310 evidence, followed by the analysis of interventions, which had been investigated in the quantitative studies,
311 in line with the experiences of participants explored in the qualitative studies in order to link the evidence
312 into a line of argument. Where configuration was not possible the findings are presented in narrative form.

313 Results

314 ***Study inclusion***

315 Citations identified as being potentially relevant to the review totalled 2599. After the duplicates had been
316 removed, the titles and abstracts of 1801 citations were reviewed. One hundred and forty-one full text
317 publications were selected for retrieval and 110 were excluded (see Appendix II). All full text publications
318 that met the inclusion criteria went forward to critical appraisal (n=31). The resulting 31 publications
319 covered 30 studies (one study was described across two publications and each presented findings from
320 different outcomes) that were deemed suitable for inclusion in the review. Of these, two studies^{53,54}
321 contributed to both the quantitative and qualitative components. The Preferred Reporting Items for
322 Systematic Reviews and Meta-Analyses (PRISMA) checklist has been followed for the reporting of this
323 review⁵⁵ and the flow of studies through the review has been presented in a PRISMA flow diagram (see
324 Figure 1). An overview of the included studies are shown in Appendices III to V.

325
326 Insert Figure 1 around here

327 ***Methodological quality***

328 *Randomised controlled trials*

329 Critical appraisal scores for the nine included RCTs ranged from four to 11 out of a possible score of 13
330 (see Table 1). One study scored four,³¹ two scored seven,^{56,57} two scored eight,^{58,59} two scored nine^{60,61}
331 and two scored eleven.^{62,63} All of the studies apart from one³¹ treated the experimental groups identically
332 other than the intervention of interest, participants were analysed in the groups to which they were
333 randomized and appropriate statistical analysis was employed. However, only four of the studies^{58,60,61,63}
334 used true randomization for assignment of participants to treatment groups. Only three studies^{60,62,63}

335 concealed allocation to treatment groups and a further three^{59,61,62} employed treatment groups that were
336 similar at baseline. Just two studies^{62,63} blinded participants and those delivering the treatment to
337 treatment assignment. None of the studies clearly stated that outcome assessors were blind to treatment
338 assignment.

339

340 Insert table 1 around here

341 *Quasi-experimental studies*

342 Critical appraisal scores for the two quasi-experimental studies were four⁶⁴ and five⁶⁵ out of a possible
343 score of six (see Table 2). Three of the questions were not applicable to these particular studies: 'Were
344 the participants included in any comparisons similar?' (Q2), 'Were the participants included in any
345 comparisons receiving similar treatment/care, other than the exposure or intervention of interest?' (Q3)
346 and 'Were the outcomes of participants included in any comparisons measured in the same way?' (Q7).
347 Both studies used a pre-test/post-test design and so did not employ a control group. One of the studies
348 also scored negatively for the sixth question 'Was follow up complete and if not, were differences
349 between groups in terms of their follow up adequately described and analyzed?'⁶⁴

350

351 Insert table 2 around here

352 *Analytical cross-sectional studies*

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

363

364 Insert table 3 around here

365

366 *Qualitative studies*

367 Of the three studies which were appraised (including the qualitative component of the two mixed methods
368 studies^{53,54}) two^{53,54} scored eight and one⁷¹ scored seven out of a possible 10 (see Table 4). None of the
369 studies acknowledged the influence of the researcher on the research and vice versa. Two studies did not

370 situate the researcher culturally or theoretically^{53,54} and one study did not state that the research had
371 received ethical approval.⁷¹

372

373 Insert table 4 around here

374

375 ***Characteristics of included studies***

376 *Study design*

377 The 30 studies (across 31 publications) encompassed a range of both quantitative (n=27, across 28
378 publications), qualitative (n=1) and mixed methods (n=2) study designs. The quantitative designs included
379 RCTs (n=9)^{31,56–63} quasi-experimental before and after studies (n=2)^{64,65} and cross sectional studies
380 (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
381 wider mixed methods studies that also included a qualitative descriptive component.^{53,54} One further study
382 was also qualitative descriptive.⁷¹

383 *Country where research conducted*

384 The majority of studies were conducted in the US (n=18, across 19 publications).<sup>14,20,26,49,53,56–62,64,66–
385 68,70,71,73</sup> The remaining studies were conducted across UK (n=5),^{48,54,65,69,72} Canada (n=1),³¹ France
386 (n=1),²² India (n=1),⁵¹ Sri Lanka (n=1)⁵² and the Netherlands (n=1).⁵⁰ Two further studies were worldwide
387 multi-centre studies.^{17,63}

388 *Participants*

389 All but two studies reported the participants' ages.^{53,54} The mean age was reported across 21 studies
390 (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
391 studies reported a median age of 36 years⁶⁵ and 35 years.⁶⁹ The remaining five studies reported age
392 across a number of different categories.^{14,22,51,56,71}

393

394 All but one study described the gender of the participants.⁵⁴ Four studies included women only.^{14,20,49,56}
395 The remaining studies included both men and women and of these 19 studies (across 20 publications)
396 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
397 men^{50–52,57,64,68} and one⁷¹ had an equal proportion of males and females.

398 *Outcomes*

399 For the experimental studies the outcomes examined were as follows: Seven studies explored the effects
400 of the described interventions on QoL or aspects of QoL.^{31,58–60,62–64} Other aspects of psychological
401 morbidity/impact that were examined were illness concern (n=1),⁶⁴ illness attitude(n=1),⁶⁴ mood
402 (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-
403 efficacy (n=1),⁶¹ self-concept (n=1),⁵⁶ satisfaction with intimate relationships (n=1)⁵⁶ and body image
404 (n=1).⁵⁶

405
406 For the cross-sectional description studies the outcomes examined were as follows: Seventeen studies
407 (across 18 publications) examined QoL or aspects of QoL.^{14,17,20,22,26,48–53,66–70,72,73} Other aspects of
408 psychological morbidity/impact that were examined were illness concern (n=2),^{48,64} illness attitude
409 (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
410 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}
411 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}
412 A number of studies also explored the psychosocial consequences of genital herpes on work/school
413 (n=4),^{49,53,68,69} relationships (n=7)^{14,22,49,50,59,68,69} and sexual behaviour (n=11, across 12
414 publications).^{14,22,26,48–50,53,66–70}

415 *Diagnosis*

416 With regards to confirming a diagnosis of genital herpes, 16 studies (across 17 publications) relied upon
417 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
418 or a physician. Nine studies confirmed the diagnosis of genital herpes (n=10)^{14,26,31,49,51,60,62,64,68,72} which
419 was undertaken by a variety of methods which included polymerase chain reaction (PCR) testing (n=1),⁶⁰
420 HSV-2 type-specific enzyme-linked immunosorbent assay (ELISA) testing,⁵¹ using viral cultures
421 (n=5),^{14,31,49,64,72} a mixture of virological or serological testing (n=1)⁶² or a combination of viral culture, self-
422 reporting or clinical inspection (n=2).^{26,68}

423 *Length of time since diagnosis*

424 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
425 report the length of time since diagnosis this was either reported as the mean (n=9 studies, across 10
426 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
427 5.7⁵⁴ to 6⁶⁹ years or the range (n=8).^{14,20,22,49,59,62,64,72} Three studies^{14,49,52} included newly diagnosed
428 patients who were experiencing their primary episode of genital herpes.

429 *Number of recurrences*

430 The number of recurrences were not stated in 11 studies^{14,31,50–54,56,62,68,71} and for one further study the
431 number of recurrences for one participant was omitted.⁷⁴ Five studies (across six publications) reported
432 the average number of occurrences over any one year period^{26,59,64,66,67,70} which ranged from eight to ten
433 and two studies reported the actual number of occurrences which were up to nine episodes⁵⁹ or at least
434 eight recurrences per year.⁶⁴ A further 11 studies reported the timeframe for which these data were
435 collected as being prior to commencement of the respective studies (3 weeks (n=1),⁴⁹ six weeks (n=1),⁶⁵
436 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}
437 or 22 months²⁰ and described the mean, median, range or the number of occurrences. Of the remaining
438 four studies one reported that participants had had at least two recurrences after the primary attack (66

439 (73%) having had > 10 recurrences),⁶⁹ another reported that that all participants had had at least one or
440 more episodes of genital herpes.⁷³

441 *Interventions*

442 Five studies examined the impact of antiviral suppression treatment on HRQoL.^{58,60,62–64} The anti-viral
443 agents used were Famciclovir,⁶⁰ Acyclovir^{63,64} or Valacyclovir.^{58,62,63} Details of each regimen are
444 summarized in Table 5. Two studies compared suppressive treatment versus episodic treatment,^{58,60} two
445 studies used a placebo as the control^{62,63} and one further study did not use a control group.⁶⁴ Dosage of
446 the antivirals varied from 125mg to 1000mg and one study did not report the dose.⁶⁴ The duration of
447 suppressive treatment varied from 30 days⁵⁸ to 52 weeks⁶³ and the episodic treatment lasted five
448 days.^{58,64}

449

450 Insert table 5 around here

451

452 A further six studies examined the impact of a range of different psychological interventions^{31,56,57,59,61,65}
453 which are summarized in Table 6. The duration of interventions ranged from four weeks⁵⁶ to six
454 months.^{57,61} Three studies^{31,64,65} did not employ a control group, two employed a waiting list control^{57,61}
455 and two compared two types of treatment.^{56,59}

456

457 Insert table 6 around here

458 Findings of the review

459

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

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

463 *Quality of life*

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

- 466 • Herpes Specific Scale²²
- 467 • SF-36^{22,72}
- 468 • GHQ^{48,52}
- 469 • RGHQoL scale^{14,17,20}
- 470 • Genital Herpes Questionnaire,⁵³
- 471 • HELP questionnaire⁴⁹
- 472 • Life Experiences Survey^{26,72}
- 473 • WHO Quality of Life (WHOQOL)-BREF instrument,⁵¹

- 474 • Hopkins Symptom Checklist⁵⁰
- 475 • Symptom Check List-90^{17,26,49,73}

476

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

483

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

493

494 Other aspects of quality of life that were identified from the responses to single item questions were that
495 genital herpes was difficult to live with,²² that it was incompatible with happiness,⁵³ that it had ruined their
496 lives²² and that they felt ashamed of having it.¹⁴ Respondents described finding it difficult not to think
497 about their diagnosis^{14,22} and were pessimistic about the future course of illness.⁵³ A minority indicated
498 that they felt like infecting others⁵³ and had self-destructive feelings because of herpes.⁵³ Having a
499 diagnosis of herpes made participants feel angry.^{14,66,67,69} In relation to gender, findings were conflicting
500 with one study⁶⁷ reporting that women expressed significantly greater anger towards the person who had
501 given them herpes than men ($p < 0.05$) and another finding that women were significantly less likely to
502 report being angry with the person who had given them herpes than men ($p < 0.005$).⁶⁹

503

504 Studies that explored the impact of a diagnosis of herpes over the passage of time showed mixed results.
505 Two studies showed that the impact diminished over time,^{48,70} two studies (across three
506 publications)^{66,67,69} found that the length of time since diagnosis was not significantly associated with
507 perceived impact ($p > 0.05$) and one further study reported no change between diagnosis and follow-up at
508 six to nine months, although no statistical analysis was reported to confirm this statement.⁴⁹ With regard
509 to the studies that identified that the impact diminished over time, Carney et al.⁴⁸ reported that 62% of
510 participants on initial assessment could be defined as GHQ “cases” which is indicative of non-psychotic

511 psychiatric illness, however by the second visit three months later the proportion of participants that could
512 be classed as cases had significantly decreased ($p < 0.01$). Another study demonstrated that levels of
513 depression were lower over the passage of time and those with herpes engaged in fewer coping
514 strategies as they became less bothered by having been diagnosed with genital herpes ($p < 0.05$).⁷⁰

515
516 Similarly, there were mixed findings across the studies regarding number of recurrences and quality of
517 life. One study found that a high number of reported recurrences was not associated with a lower quality
518 of life as measured by a range of psychological measures including anxiety, depression, stress and
519 quality of life (no statistical details reported).⁷² Whereas another study found that recurrence frequency
520 had a significant effect on quality of life, more specifically participants who reported greater than seven
521 episodes of recurrent genital herpes compared to those with 2-4 or 5-7 recurrences had significantly
522 poorer quality of life ($p = 0.002$).¹⁷ It was also demonstrated that participants who reported an increased
523 severity of pain/discomfort during recurrences compared to those who reported no, mild or moderate pain
524 had significantly poorer quality of life ($p < 0.001$).¹⁷

525 *Psychosocial consequences of genital herpes on work*

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

532 *Psychosocial consequences of genital herpes on sexual behaviour*

533 Eleven cross sectional studies (across 12 publications) assessed the effects of genital herpes on sexual
534 behaviour.^{14,22,26,48-50,53,66-70} The studies employed a variety of instruments: one study used two
535 subscales, 'inhibition during intercourse' and '(preferred) frequency of sexual intercourse', of the Sexuality
536 Experiences Scales,⁵⁰ three studies (across four publications) developed their own questionnaires^{48,69,70}
537 and seven studies (across eight publications) reported on single item questions within quality of life
538 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
539 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
540 did not report the individual findings concerning this aspect of their study.

541 Herpes was found to interfere with sexual relationships.^{14,22,26} Frequency of sex was reported to have
542 changed due to herpes in one study²⁶ but participants' reports across studies were inconsistent ranging
543 from no significant difference between first diagnosis and follow-up (no statistics reported),⁴⁸ a reduction
544 in frequency^{68,69} or interest in sexual activity⁵⁹ to some reporting an increased frequency and interest.⁶⁹

545 Two studies explored sexual concerns and identified that there was a fear that sexual activity would
546 trigger recurrences²² and that herpes would be transmitted to sexual partners.^{22,68}

547 With regards to enjoyment of sex, single item question responses identified that some participants
548 reported that they enjoyed sex less^{59,68} whereas others reported a greater enjoyment,⁶⁹ some were less
549 able to achieve orgasm,⁵³ were less spontaneous⁶⁸ and had a diminished sex drive.⁶⁸ Luby et al.⁶⁸ also
550 reported that reductions in the frequency of sexual contact, pleasure, spontaneity and intimacy of sexual
551 contact were significantly related to levels of psychological distress ($p < 0.01$).

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

559 *Psychosocial consequences of genital herpes on relationships*

560 Seven cross sectional studies examined the impact of genital herpes on participants'
561 relationships^{14,22,49,50,59,68,69} and explored existing relationships with friends and family,^{22,49,53} new
562 acquaintances of the same sex⁶⁸ or opposite sex^{53,68,69} and existing romantic relationships.^{14,49,69} These
563 were measured using the Questionnaire on Interpersonal Relationships,⁵⁰ the HELP questionnaire⁴⁹ and
564 single item questions within generic HRQoL or disease specific scales.^{14,22,49,53,68,69}

565
566 Responses from single item questions across the studies showed that participants reported differing
567 levels of impact that having a diagnosis of recurrent genital herpes had on existing relationships with
568 friends and family members^{22,49,53} from very little impact⁴⁹ to having a worse relationship.⁵³ A small
569 number (15%) indicated a fear of rejection because of their diagnosis²² and others reported feeling
570 repugnant to others (serious problem for 15%).⁵³ With regard to being in social situations with new friends
571 and making new acquaintances of the same sex, participants indicated that herpes had had minimal
572 impact.⁶⁸ When meeting new acquaintances of the opposite sex participants indicated that herpes
573 significantly interfered with the enjoyment of meeting people of the opposite sex ($r = 0.63$, $p < 0.01$)⁶⁸ and
574 prevented them from getting to know people to whom they were sexually attracted.⁵³ Participants
575 indicated that they felt that they would not be accepted by others if they were aware of their diagnosis,⁵³
576 although the majority of participants had or would disclose their diagnosis to past or future partners.⁶⁹
577 Participants across studies in existing relationships felt insecure about intimate relationships¹⁴ and
578 reported herpes as having had at least a mildly adverse effect on their romantic relationships, at both
579 diagnosis and six to nine months later.⁴⁹ During symptomatic periods participants appeared to be more

580 bitter towards their partners⁵⁰ and some indicated that herpes had contributed to the breakup of their
581 marriage or long-standing relationship.⁴⁹

582

583 *Depression*

584 Depression was explored across 10 cross sectional studies,^{14,17,48,49,52,53,68,70,72,73} four used the
585 HADS,^{14,48,52,72} two used the BDI^{70,73} and a further four studies asked single item questions within generic
586 HRQoL or disease specific QoL questionnaires.^{17,49,53,68} Between 16%⁶⁴ and 34%¹⁴ of those diagnosed
587 within the last six months could be classified as depression “cases” on the HADS, which is indicative of
588 severe levels of depression. For those with recurrent genital herpes the data is mixed with one study⁵²
589 reporting that 23% were experiencing severe depression whilst another reported that none of the sample
590 population was severely depressed and that the data was comparable with normative data.⁷³ Two studies
591 reported that the mean HADS score for depression was the same regardless of the number of
592 recurrences that a participant experienced, although mean values and statistical significance levels were
593 not reported for either study.^{48,72} Responses from a single item question suggested that those with genital
594 herpes at the time of initial diagnosis and those who had frequent recurrences experienced
595 depression^{17,49,53,68} which was characterized by feelings of estrangement, apprehension, and despair.
596 Manne et al.⁷⁰ did not report mean scores for the BDI but reported the data as part of a regression
597 analysis.

598 *Illness attitude and illness concern*

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

604

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

611 *Stress*

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

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

623

624 Those with genital herpes have been shown to have a range of stress responses at first diagnosis and
625 when the condition recurs compared to normative samples.⁴⁹ Those newly diagnosed with genital herpes
626 were found to have significant levels of acute stress but at follow up, between six and nine months later,
627 levels of stress were found to be significantly lower (mean scores: newly diagnosed 27.25 ± 12.98 ; follow
628 up 13.52 ± 14.31 , $p < 0.01$).⁴⁹ However, there were no significant differences in levels of stress between
629 those newly diagnosed with genital herpes and normative samples when measured using the College
630 Event Scale (mean scores: herpes 1062 ± 492.31 ; normative 891 ± 544), $p > 0.05$).⁴⁹ For those living with
631 recurrent genital herpes the frequency of daily hassles was significantly greater than that for normative
632 samples (mean scores: 36.14 ± 20.43 ; normative 22.40 ± 18.70 , $p = 0.0001$) whereas the intensity of the
633 hassles was comparable (mean scores: herpes 1.58 ± 0.3 ; normative 1.56 ± 0.43 , $p > 0.052$).⁷³ Although the
634 frequency of uplifts was comparable with normative data (mean scores: herpes 62.00 ± 27.30 ; normative
635 69.50 ± 29.10 , $p > 0.05$) the intensity of the uplifts experienced was significantly lower (mean scores: herpes
636 1.80 ± 0.38 ; normative 2.14 ± 0.53 , $p = 0.0002$).⁷³ The degree of recent exposure to stressful life events was
637 directly associated with the duration that a person had been living with genital herpes ($r = 0.37$, $p < 0.005$).²⁶

638

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

644

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

652 *Coping*

653 Six cross sectional studies^{20,26,68,70,72} explored the use of different coping strategies for those with genital
654 herpes. When questions about coping and adjustment were asked within disease specific quality of life
655 questionnaires only a third of participants with recurrent genital herpes indicated that they believed that
656 they had adapted to the disease and most indicated that they felt that adaptation to herpes was a very
657 difficult process.⁶⁸ Three studies^{20,67,72} used the Coping Orientations to Problems Experienced (COPE)
658 scale and two used the Ways of Coping Scale,^{26,70} although Manne et al.⁷⁰ created their own modified
659 version of the scale. The highest ranking of all the strategies were active / problem solving
660 strategies,^{20,26,67,70,72} particularly so for those who experienced high levels of recurrence⁷² or were
661 members of a local self-help group.⁷⁰ Strategies that involved the seeking of emotional support (obtaining
662 moral support, sympathy or understanding) were used infrequently⁶⁷ and were significantly more likely to
663 be used by women ($p < 0.05$).²⁶ Manne et al.⁷⁰ demonstrated a correlation between time and coping and
664 found that participants engaged in significantly less problem-focused coping the longer they had herpes.

665 *Anxiety*

666 Six cross sectional studies measured anxiety using the HADS^{14,48,52,54,64,72} and one further study used the
667 State-Trait Anxiety Inventory.⁵⁰ At the time of the first episode of genital herpes, participants were
668 significantly more anxious than before the infection.⁵⁰ Between 54%⁶⁴ and 64%¹⁴ of those diagnosed
669 within the last six months could be classified as GHQ anxiety “cases” which is indicative of severe levels
670 of anxiety. Three studies^{48,52,54} reported the percentage of patients with recurrent genital herpes that could
671 be classified as GHQ anxiety “cases” which varied between 29% and 43%, although each had a different
672 mean time since diagnosis. Cassidy et al.⁷² reported that the mean HADS score for anxiety was the same
673 regardless of the number of recurrences that a participant experienced, although mean values and
674 statistical significance levels were not reported. On the other hand Carney et al.⁴⁸ demonstrated that
675 those patients who continued to experience regular recurrences tended to continue to experience severe
676 anxiety at the three month time point (proportion defined as cases: baseline 50%, 3 months follow up
677 31%, (p values not reported).

678 *Isolation*

679 Three cross sectional studies explored issues around isolation through specific questions within disease
680 specific quality of life questionnaires.^{22,49,53} Across all the studies there was a wide variation, ranging from
681 13%²² to 65%⁵³, of those with genital herpes who reported some degree of isolation since being
682 diagnosed with the virus.^{22,49,53}

683 *Stigma*

684 Two cross sectional studies investigated stigma^{20,52} using the adapted HIV stigma scale²⁰ and a single
685 item question.⁵² Forty seven percent of those with genital herpes felt stigmatized by others⁵² and lower
686 stigma was significantly associated with better quality of life ($\beta = -0.364$, $t = -4.678$, $p < 0.0001$).²⁰

687 *Self-esteem*

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

699 *Self-concept*

700 Self-concept was measured in one cross sectional study using the Tennessee Self Concept Scale
701 (TSCS)⁷³ and compared the mean scores with normative samples. Young adults with genital herpes had
702 a significantly lower self-concept on two out of the three scales of the TSCS compared to the normative
703 samples (represented by significantly lower mean scores on the physical self-scale: herpes 66.37;
704 normative 71.78, $p=0.005$ and family self-scale: herpes: 67.71; normative 70.80, $p=0.005$). They also had
705 a significantly higher mean score on the social self-scale compared to the normative samples (herpes
706 70.30, normative 68.14, $p=0.031$).⁷³

707 *Self-confidence*

708 Four cross sectional studies asked specific questions about self-confidence and/or how those with genital
709 herpes felt about themselves within disease specific QoL scales.^{14,22,53,69} Generally having a diagnosis of
710 genital herpes had an adverse effect on self-confidence.^{14,22,53,69} The subjective ratings of whether a
711 person felt that they were less confident because of genital herpes varied from 11%²² to 88%⁵³ and
712 women rated themselves as being significantly less confident since having genital herpes compared to
713 men ($t=3.61$, $p<0.001$).⁷² Other aspects of self that affected self-confidence because of herpes were
714 feeling contaminated,⁵³ self-blame,⁵³ feeling repugnant to others,⁵³ feeling unclean¹⁴ or feeling dirty⁶⁹
715 Brookes et al.⁶⁹ also identified that women rated themselves as feeling significantly more dirty since
716 having genital herpes compared to men ($t=2.37$, $p<0.05$).

717 *Social support*

718 Social support was measured across four cross sectional studies^{20,26,70,72} using the Social Provisions
719 Scale,⁷² the Social Support Index,²⁶ a brief version (28 items) of the COPE scale²⁰ and a purposely
720 designed questionnaire.⁷⁰

721

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

732 **The effectiveness of interventions for improving HRQoL and wellbeing**

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

736

737 *Health related quality of life*

738 Seven studies explored the effects of the described interventions on quality of life or aspects of quality of
739 life.^{31,58–60,62–64} Of these, four used the RGHQoL scale,^{58,60,62,63} two the Genital Herpes Questionnaire,^{31,59}
740 one the GHQ⁶⁴ and Fife et al. also used SF-36.⁵⁸

741

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

755

756 **Insert table 9 around here**

757

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

763 *Depression*

764 Four experimental studies^{57,61,64,65} explored the effectiveness of described interventions on levels of
765 depression. Two studies used the HADS,^{64,65} one the BDI⁶¹ and one the Zung Depression Scale.⁵⁷
766 Carney et al.⁶⁴ found that acute depression was uncommon and only reported the percentage of those
767 considered to have severe depression before (14%) and after (14%) the introduction of Acyclovir and did
768 not conduct any statistical analysis. With regard to non-pharmacological interventions, depression was
769 found to significantly decrease after self-hypnosis, regardless of the number of sessions ($F=5.71$, $df=1,15$,
770 $p=0.030$).⁶⁵ For psychosocial interventions, findings were mixed, one study reported significantly lower
771 levels of depression (p values not reported) from baseline (mean score: 36.0 ± 8.93) to 26 week follow up
772 (mean scores: 32.9 ± 9.28) and significantly lower levels of depression (p values not reported) between
773 those receiving psychosocial interventions (mean score $32.9.0\pm 9.28$) and those in the control conditions
774 (mean scores: support group 37.6 ± 7.16 ; waiting list control 41.7 ± 4.98 , p values not reported) at follow
775 up.⁵⁷ Whereas a further study reported no significant changes ($p>0.05$) between baseline and follow up or
776 between those who had attended a group psycho-educational intervention (mean score: 9.74 ± 7.43) or a
777 waiting list control (mean score: 8.42 ± 6.97).⁶¹ The case report demonstrated that self-reported levels of
778 depression improved after 18 counselling sessions that incorporated interventions from experiential
779 therapy to help clients deal with the more psychosocial difficulties in learning to live with this disease.³²

780 *Anxiety*

781 Three experimental studies^{57,64,65} investigated the effect of the described interventions on levels of
782 anxiety. Two used the HADS,^{64,65} and two the State-Trait Anxiety Inventory.^{57,65} Carney et al.⁶⁴ reported
783 that 60% of participants could be defined as “cases” which was indicative of severe levels of anxiety
784 before treatment with acyclovir commenced and at three months post-treatment rates had significantly
785 decreased to 35% ($p<0.01$).⁶⁴ With regard to non-pharmacological interventions there were no significant
786 changes in levels of anxiety after self-hypnosis, regardless of the number of sessions ($F=3.39$, $df=1,15$,
787 $p<0.086$).⁶⁵ One study reported significantly lower levels of anxiety (p values not reported) from baseline
788 (mean score: 13.2 ± 8.47) to 26 week follow up (mean scores: 10.1 ± 5.95) between those receiving
789 psychosocial interventions and those in the control conditions (mean scores: support group 13.2 ± 7.68 ;
790 waiting list control 19.1 ± 5.78 , p values not reported) at follow up.⁵⁷ For the case report, levels of anxiety
791 were reported to lower after a period of hypnosis.⁷⁴

792 *Illness attitude and illness concern*

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

797 *Mood*

798 Three studies explored the effectiveness of non-pharmacological interventions on mood^{57,61,65} and used
799 the Profile of Mood States^{57,61} and the Mood Activation Checklist.⁶⁵ Findings were mixed with two studies
800 reporting no significant changes in levels of mood after self-hypnosis ($r < 0.341$)⁶⁵ or psycho-educational
801 sessions ($p = 0.101$).⁶¹ Whereas, one further study reported significantly lower total mood disturbance (p
802 values not reported) scores from baseline (mean score: 34.3 ± 41.03) to 26 week follow up (mean score:
803 2.8 ± 27.88) and significantly lower total mood disturbance scores (p values not reported) between those
804 receiving psychosocial interventions (mean score 22.8 ± 27.88) and those in the control conditions (mean
805 scores: support group 43.9 ± 39.99 ; waiting list control 65.3 ± 18.21 , p values not reported) at follow up.⁵⁷

806 *Loneliness*

807 The effect of described interventions on levels of loneliness was investigated across two studies using the
808 UCLA Loneliness Scale⁵⁷ and the UCLA Loneliness Scale-Revised.³¹ Participants who received a
809 psychosocial intervention reported a significant decrease in levels of loneliness (no p values reported) at
810 follow up compared (mean scores: 31.7 ± 10.23) to those in the control conditions (mean scores: support
811 group 37.7 ± 9.66 ; waiting list control: 45.9 ± 6.31 , p values not reported).⁵⁷ However, there was no change
812 in levels of loneliness between baseline and follow up for those participants attending two different types
813 of psychological therapy (details of statistical analysis not provided).³¹

814 *Self-image*

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

818 *Self-efficacy*

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

822 *Satisfaction with intimate relationships*

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

826 *Self-concept*

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

830 *Self esteem*

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

834 *Stress*

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

838

839 **Perceptions and experiences**

840 A total of sixty findings from three qualitative studies^{53,54,71} were extracted and aggregated to form eight
841 categories that identified perceptions and experiences of genital herpes. The illustrations for each of
842 these findings can be found in Appendix VI. There were 15 unequivocal findings, six credible findings and
843 39 non supported findings. The eight categories were further synthesized in a meta-synthesis which
844 yielded two synthesized findings (Tables 7-8 and Figures 2-3) which are outlined below.

845 **Insert figure 2 around here**

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

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

854

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

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

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

862

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

865

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

869

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

878

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

880 Three findings from one study⁵⁴ led to the development of the second category: 'Stigma: Impact of
881 diagnosis of herpes', 'Stigma: Diagnosis is linked with sexual promiscuity' and 'Stigma: Skin eruptions are
882 a 'mark". All of the participants talked about feeling like a 'leper' and the virus being 'like a life sentence'
883 because of its enduring nature. Some aligned the diagnosis with sexual promiscuity although this was at
884 odds with their personal sexual practices. Skin eruptions, and the resultant scarring, were seen as a
885 'mark' of the virus with one participant describing how he hated the scars that the virus had left on his
886 penis:

887

888 *"I was very shocked and...ashamed...I thought oh my God what have I got...I felt ashamed".⁵⁴.*
889 *p.591*

890 *"it just seemed like dirty or, you know, promiscuous people that got it".⁵⁴. p591*

891 *"I hate the scars it has left on my penis".⁵⁴. p.591.*

892

893 *Category 3: A diagnosis of genital herpes affected interpersonal relationships*

894 Three findings from one study⁵³ 'Interpersonal relationships: Feeling hurt and alienated from friends who
895 made herpes jokes or more serious derogatory comments', 'Interpersonal relationships: The majority of
896 individuals stated they were seeking psychological help mainly because they could not find sufficient

897 support among their peers' and 'Interpersonal relationships: Many of the subjects regarded the possibility
898 of non-sexual transmission of herpes as creating interpersonal tensions' informed the third category.
899 Feelings of social isolation were outlined⁵³ with participants describing feeling hurt and alienated when
900 friends made jokes and negative comments about how they would feel if someone gave them genital
901 herpes. Some also described seeking psychological help mainly because they could not find sufficient
902 support among their peers. Others described interpersonal tensions arising as a result of disclosure and
903 experiences they had had with friends being concerned about the risk of non-sexual transmission of the
904 virus through shared toilet and handwashing facilities. Illustrations include:

905

906 *"I'd kill a sex partner who gave me herpes".*^{53. p.310.}

907 *"People I've told started getting very anxious about things like the toilet seat and the bar of*
908 *soap".*^{53. p.310.}

909

910 *Category 4: Genital herpes negatively impacts upon work and school*

911 Two findings from one study⁵³ informed the development of category four: 'Self-concept: Most regard
912 having genital herpes as a pervasive and serious problem' and 'Work and school performance: Herpes
913 affects work enjoyment and performance' The pain associated with genital herpes outbreaks adversely
914 affected the mobility and/or concentration of some participants and for others the virus led to pervasive
915 depressing thoughts which negatively affected their concentration. Language used by participants
916 included:

917 *"contaminated", "ugly", "inferior", "damaged".*^{53. p.311.}

918

919 *Category 5: Fear of rejection*

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

930

931 *"I felt I was now tainted and wouldn't be able to find anyone".*^{54. p.591.}

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

935

936 **Insert table 7 around here**

937

938 **Insert figure 3 around here**

939

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

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

945

946 *Category 6: Diagnosis made participants feel morally tainted*

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

955

956 *“I feel like a leper. I hate it because it won’t go away. Six years feels like a sentence”*.⁵⁴. p.591.

957 *“I mean I’m not a slapper...I haven’t been putting it around”*.⁵⁴. p.591.

958

959 *Category 7: Genital herpes diminishes sexual pleasure*

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

964

965 *“I can’t let go in sex anymore”*⁵³. p.310.

966

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

968 *"sexual hermit for 10 years".*^{53, p.309.}

969

970 *Category 8: Genital herpes leads to significant emotional responses*

971 Four findings within one study⁵³ led to the development of this final category. These findings were:

972 'Interpersonal relationships: Herpes had effects upon their overall attitude towards people and
973 relationships making them less sensitive', 'Emotional responses: Depression is by far the most common
974 response', 'Emotional responses: Most regarded herpes as a personal handicap and as a loss of a
975 portion of themselves' and 'Emotional responses: Some subjects reported being angry as a result of
976 contracting genital herpes'. Some participants described how having genital herpes had affected their
977 overall attitude towards people and relationships and had made them less sensitive:

978

979 *"I've really become more callous".*^{53, p.311.}

980

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

983

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

986

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

988

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

990

991 **Insert table 8 around here**

992

993 **Integration of quantitative evidence and qualitative evidence**

994 *Congruence between findings of individual syntheses*

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

997

998 The first meta synthesized finding and the cross-sectional study findings identified that disclosing a
999 diagnosis of genital herpes was a concern and a cause of stress that affected relationships and ultimately
1000 quality of life. Category one and the cross-sectional study findings revealed that the quality of a
1001 relationship influenced individuals' decision-making regarding disclosure. From category two and the
1002 cross-sectional study findings, it was revealed that people with genital herpes felt stigmatized. From
1003 category three it was identified that a diagnosis of genital herpes adversely affected interpersonal
1004 relationships. Similarly, findings from the cross-sectional studies reported interference with relationships

1005 and isolation amongst people with genital herpes, with low levels of social support associated with greater
1006 emotional dysfunction. Two effectiveness studies considered loneliness and found that a psychosocial
1007 intervention significantly decreased levels of loneliness amongst people with genital herpes but there was
1008 no change for participants attending two different types of psychological therapy. From category four and
1009 the cross-sectional study findings it was identified that genital herpes negatively impacts upon work and
1010 school. The fifth category and the cross-sectional study findings revealed a fear of rejection in sexual and
1011 social relationships amongst participants because of their diagnosis.

1012
1013 The second meta synthesized finding identified that a diagnosis of genital herpes has a significant
1014 emotional impact for individuals. Category six identified that genital herpes made participants feel morally
1015 tainted. Although this specific aspect of self-image was not explored in the cross sectional or intervention
1016 studies, the cross-sectional study findings identified a negative relationship between a diagnosis of genital
1017 herpes and self-confidence, self-esteem and self-concept. Effectiveness studies found no significant
1018 changes in self-image or self-efficacy but did find significant improvements in self-esteem and self-
1019 concept. From category seven it was found that genital herpes diminishes sexual pleasure. Likewise, the
1020 cross-sectional study findings identified that genital herpes adversely interferes with sexual relationships
1021 and one effectiveness study found that a self-help module with counselling had a significantly positive
1022 effect on participants' satisfaction with intimate relationships. Category eight and cross-sectional study
1023 findings found that genital herpes leads to significant emotional responses such as depression. This
1024 finding was supported by three out of the four effectiveness studies that explored this concept. However,
1025 results of the experimental studies were mixed, with acyclovir having no impact on depression and
1026 inconsistencies identified regarding the impact of self-hypnosis and psychosocial interventions. A general
1027 lowering of mood was also evident in the qualitative and cross-sectional research. Findings from the
1028 effectiveness studies were, once again, mixed with two reporting no changes in mood after self-hypnosis
1029 or psycho-educational sessions and a further study reporting significantly less mood disturbance among
1030 those receiving psychosocial interventions.

1031
1032 *Strength of qualitative evidence in explaining why interventions were/were not effective*

1033 There was insufficient qualitative data to give an insight into the effectiveness of interventions.

1034
1035 *Strength of qualitative evidence in explaining differences in the direction and size of effect across the*
1036 *included quantitative studies*

1037 There was insufficient qualitative data to explain differences in the direction and size of effect across the
1038 included quantitative studies.

1039
1040 *Aspects of the quantitative evidence which were/were not explored in the qualitative studies*

1041 The qualitative studies did not report on anxiety, but the cross-sectional study findings demonstrated high
1042 levels of anxiety amongst people with genital herpes. These findings were supported by the experimental
1043 studies, however they did not report a reduction in anxiety following treatment with acyclovir or
1044 psychosocial interventions, but mixed outcomes were found with regard to hypnosis.

1045

1046 Stress was not specifically explored in the qualitative studies. However, the cross-sectional studies
1047 identified a range of stress responses and one experimental study did not report any significant impact
1048 from a psychosocial intervention.

1049

1050 Quality of life was not specifically addressed in the qualitative studies but low levels of quality of life and
1051 substantial psychological morbidity were observed among patients with recurrent genital herpes across
1052 the cross-sectional study findings. Outcomes of pharmacological interventions with valacyclovir and
1053 acyclovir and non-pharmacological interventions involving a self-help module with counselling and self-
1054 hypnosis were mixed.

1055

1056 Illness attitude and concern were not specifically explored in the qualitative data, but one cross sectional
1057 study and one effectiveness study reported high levels of illness concern on first diagnosis which had
1058 significantly reduced three months later. One effectiveness study identified no significant changes in
1059 levels of illness attitude following continuous acyclovir.

1060

1061 Coping was not specifically explored in the qualitative research or effectiveness studies, but the cross-
1062 sectional study findings identified that the highest ranking coping strategies for those with genital herpes
1063 were active / problem solving strategies. Better quality of life was significantly associated with the use of
1064 acceptance coping and receiving support from religious/spiritual figures.

1065

1066 *Aspects of the qualitative evidence which were/were not tested in the quantitative studies*

1067 In relation to the first meta synthesized finding, there was alignment between the findings of the
1068 qualitative studies and the cross-sectional study findings regarding the first category which revealed that
1069 the quality of a relationship influenced individuals' decision-making regarding disclosure, the second
1070 category which identified that people with genital herpes felt stigmatized, the fourth category which
1071 identified that genital herpes negatively impacts upon work and the fifth category which revealed a fear of
1072 rejection in sexual and social relationships amongst participants who had genital herpes. Category three,
1073 which identified that a diagnosis of genital herpes adversely affected interpersonal relationships, was
1074 supported by the findings from the cross-sectional and effectiveness studies. However, the effectiveness
1075 studies did not consider the relationship between quality of relationship and decision-making regarding
1076 disclosure. The relationship between genital herpes and stigma, impacts upon work and school, and fear
1077 of rejection were not directly addressed in the effectiveness studies.

1078 In relation to the second meta synthesized finding, cross-sectional and effectiveness study findings
1079 aligned with category seven which found that genital herpes diminishes sexual pleasure and category
1080 eight which identified that genital herpes leads to significant emotional responses such as depression.
1081 However, results of the experimental studies were mixed with acyclovir having no impact on depression
1082 and inconsistencies identified regarding the impact of self-hypnosis and psychosocial interventions. The
1083 sixth category, which identified that genital herpes made participants feel morally tainted was not directly
1084 explored in the cross-sectional and effectiveness studies.

1085 Discussion

1086 This convergent segregated mixed methods systematic review sought to identify what it is like to live with
1087 and what interventions improve the HRQoL of young people and adults with primary or recurrent
1088 episodes of genital herpes within primary care and genito-urinary medicine settings. Integration of the
1089 quantitative and qualitative evidence revealed a consensus that a diagnosis of genital herpes has a
1090 significant emotional impact for individuals and disclosure is stressful, affects relationships and HRQoL,
1091 but there is a lack of consensus regarding efficacy of different interventions.

1092
1093 The findings of the current systematic review suggest little progression within the field, with findings
1094 mirroring those of previous reviews which were published over 30 years ago.^{8,39,75-78} This review identified
1095 that the emotional impact^{53,54} of recurrent genital herpes included feelings of shame, guilt, depression,
1096 anger and sorrow. The cross sectional studies also illuminated a negative association between genital
1097 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-
1098 image,⁴⁹ self-esteem,⁴⁹ self-concept,⁷¹ self-confidence,^{14,22,53,69} quality of life,^{17,22} psychological
1099 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}
1100 Stressors included fear of telling past and future sexual partners,^{14,26,66} interference with relationships,^{66,67}
1101 fears regarding transmission,^{14,26,66} and future recurrences.^{14,22,53,69}

1102
1103 Likewise, Brentjens et al. in their review described the 'devastating psychological impact' of genital
1104 herpes and its relationship with psychological morbidity.^{8. p.857} They identified concerns regarding the
1105 social implications of having the virus, for example fears concerning the risk of transmitting herpes to
1106 partners or loved ones and the fear of revealing their condition to new partners which was, in turn,
1107 associated with depression and social isolation. Their review also reported a relationship between having
1108 the virus and reduced self-esteem, feelings of decreased sexual desirability and compromised
1109 performance at school or at work. Similarly, two other reviews identified difficulties with relationships with
1110 sexual partners, family and friends as well as fears of transmitting the virus to others, sexual problems
1111 and feelings of undesirability amongst people who have recurrent genital herpes.^{39,75} Mindel and Marks⁷⁶
1112 p.³⁰⁵ identified similar findings, however, their cautionary note stating that 'the validity of these

1113 observations is difficult to ascertain' is of relevance to the current review due to a continued paucity of
1114 studies and methodological limitations.

1115

1116 This systematic review revealed that a diagnosis of genital herpes is extremely significant for the
1117 individual. In particular, people who have the virus worry about disclosing their diagnosis because of the
1118 associated fear of rejection in sexual and social relationships.^{53,54,71} In keeping with the findings of this
1119 review, two previous studies identified that disclosure of a genital herpes diagnosis was more likely in
1120 socially committed relationships and disclosure was also influenced by expectations of a partner's
1121 response, with an anticipated negative response serving as a barrier.^{79,80} Moral concerns such as a
1122 partner's right to know and a desire to protect a partner from the virus were motivators for disclosure. In
1123 relating these findings to clinical practice, Caulfield and Willis⁸¹ identified that healthcare professionals
1124 believe that disclosure is the patient's choice and that it is not always required due to the high prevalence
1125 of HSV. Prevalence of the virus was emphasised by several participants when counselling HSV positive
1126 patients to try to reduce the emotional impact associated with the diagnosis.

1127

1128 This review also found that people with genital herpes feel stigmatized. Merin and Pachankis⁸²
1129 emphasised the salience of stigma in the negative psychological consequences associated with recurrent
1130 genital herpes. Bickford et al.⁵⁴ also asserted that stigma is a barrier to disclosure of a genital herpes
1131 diagnosis and management strategies aimed at encouraging disclosure to partners need to address
1132 perceived stigma. This argument was extended further by Fortenberry⁸³ in highlighting that the stigma
1133 associated with genital herpes may negatively influence an individual's care seeking behaviours as well
1134 as decisions regarding disclosure of diagnosis to sexual partners.

1135

1136 The findings of Alexander and Naisbett's⁸⁴ review also concur with ours in highlighting the shame,
1137 embarrassment and stigma that is often associated with having herpes, as well as the anger, guilt and
1138 depression that the studies included in the present review have identified. They also highlighted how
1139 problems with relationships are often associated with the virus, along with low self-esteem and impaired
1140 sexual function. In keeping with the findings of this review, Alexander and Naisbett⁸⁴ also identified the
1141 negative impact that having the virus can have on workplace productivity.

1142

1143 The lack of therapeutic modalities for genital herpes has previously been noted across two reviews^{8,39} as
1144 well as a lack of research into the efficacy of existing interventions; these findings remain relevant today.
1145 In relation to what interventions improve the HRQoL of people with primary or recurrent episodes of
1146 genital herpes, a consensus is limited by the variable quality and dearth of effectiveness studies. In
1147 addition, the lack of use of standardised measures and variations in reporting limits the conclusions that
1148 can be drawn from the effectiveness studies. Nevertheless, this review has identified that self-hypnosis,⁶⁵
1149 psychosocial interventions⁵⁷ and counselling sessions³² can improve levels of depression and anxiety and

1150 psychological morbidity can decrease over time following treatment with acyclovir,⁶⁴ psychosocial
1151 interventions⁵⁷ and hypnosis.⁷⁴ However, these studies did not elucidate whether anxiety may have
1152 decreased with time regardless of intervention. Likewise, illness concern also significantly decreased with
1153 continuous acyclovir⁶⁴ but once again it is unclear as to whether this is an artefact of time. Lower total
1154 mood disturbance was observed following psychosocial interventions among participants at follow up⁵⁷
1155 and a self-help module with counselling had a positive impact on self-esteem.⁵⁶ Pharmacological studies
1156 demonstrated an improvement in QoL⁵⁶⁻⁵⁹ but there were no significant differences between the different
1157 active treatment regimens. A short term cognitive behavioural stress management group intervention was
1158 also reported to enhance quality of life.⁵⁹

1159
1160 The passage of time may alleviate illness concern,^{48,64} depression⁷⁰ and compromised quality of life^{48,70}
1161 but this will not be the case for all patients.^{49,66,67,69} Indeed, Luby and Klinge⁶⁸ identified that only one third
1162 of participants believed that they had adapted to the disease and most felt that adaptation to herpes was
1163 a very difficult process. As Green¹⁶ argued, it is not, therefore, enough to hope that patients' emotional
1164 distress will diminish with time. The cross sectional studies identified that low levels of social support were
1165 associated with greater emotional dysfunction²⁶ and higher levels of internet-based support predicted
1166 poorer quality of life, while higher levels of support from religious/spiritual figures predicted better quality
1167 of life.²⁰ The highest ranking of all the coping strategies across the cross sectional studies were active /
1168 problem solving strategies^{20,26,67,70,72} such as seeking emotional support. Lower stigma was significantly
1169 associated with better quality of life.²⁰ These findings may be useful in guiding health care professionals'
1170 conversations with people when they are diagnosed with genital herpes.

1171

1172 ***Limitations of the review***

1173 The findings of this review are limited by the very small number and low quality of publications that have
1174 been conducted in the field. In addition, the quality of the literature was variable and there was a paucity
1175 of up to date literature with just one included study published since 2010 meaning that the applicability of
1176 findings to the current context may be limited. The majority of research was American with only a very
1177 small number of European studies and none from Africa, Australia or New Zealand. There is, therefore, a
1178 very limited representation of people's experiences of genital herpes and interventions aimed at
1179 enhancing quality of life internationally. This may have been compounded by studies included in the
1180 review being limited to English language studies which means that specific cultural experiences and
1181 cultural issues may not have been captured. In addition, poor reporting was a feature of many of the
1182 studies. In the quantitative studies there was a lack of use standardized instruments and analysis which
1183 meant that comparisons of interventions were not possible. Furthermore, participants varied significantly
1184 in relation to time since diagnosis and frequency of recurrence, which also made comparisons
1185 problematic. A strength of this review was the addition of the first objective to examine the effect of genital
1186 herpes on HRQoL and other wellbeing outcomes. However, this was decided after the searching and

1187 initial screening had been conducted in order to include a large volume of literature that the reviewers felt
1188 would be an important addition to the review. In including this term it became apparent that were a
1189 number of additional wellbeing outcomes that authors of the primary studies had used when investigating
1190 this topic area. These included coping, stigma, illness concern, illness attitude, isolation, loneliness, social
1191 support, mood, coping, self-concept and self-confidence. A limitation of our search was that we did not
1192 specifically search for terms coping, illness concern, illness attitude, isolation, loneliness or self-
1193 confidence. We did revisit the excluded studies list to recheck our initial decisions once this decision had
1194 been made. We are also confident through reading the reference lists of the included studies and using
1195 forward citation tracking within web of science that we would have retrieved other similar articles. We are
1196 mindful however of the potential to have introduced publication bias during this stage of the review which
1197 in turn may have led to reporting bias.

1198 **Conclusions**

1199 This review has illuminated the nuanced and, often, extreme emotional, social, relational and sexual
1200 distress that a diagnosis of genital herpes can surface. Healthcare professionals need to be sensitive to
1201 the dilemmas that disclosure poses for the individual and implement support interventions to enable
1202 patients to minimise the risk of transmission and to be sufficiently knowledgeable so that they can discuss
1203 transmission risk with sexual partners and social contacts. In addition, these findings suggest that health
1204 care professionals should be cognisant of the emotional impact of genital herpes and aim to ameliorate
1205 these emotions by communicating sensitively and non-judgementally with patients and making
1206 psychological support available.

1207

1208 ***Recommendations for practice***

1209 This systematic review has demonstrated that people who are diagnosed with genital herpes are likely to
1210 need psychological support since diagnosis has a significant emotional impact and having the virus can
1211 affect relationships and HRQoL. However, there is currently a lack of knowledge concerning which
1212 interventions are best in addressing the psychological implications of the virus and improving the HRQoL
1213 of people with primary or recurrent episodes of genital herpes. Indications suggest that quality of life,
1214 depression, anxiety and other psychological morbidities may be ameliorated through psychological,
1215 psychosocial and pharmacological interventions but the paucity of literature in the field limits
1216 recommendations for practice.

1217 ***Recommendations for research***

1218 Further high quality, contemporary, mixed methods research is required to examine the effect of genital
1219 herpes on HRQoL and other wellbeing outcomes and to identify and explore the perceptions and
1220 experiences of young people and adults with primary or recurrent genital herpes globally. In addition,
1221 further research is required internationally to determine the effectiveness of interventions for improving
1222 the HRQoL of young people and adults with primary or recurrent genital herpes. In particular, international

1223 quantitative studies which employ standardised measures and analysis to allow for comparison of
1224 interventions among participants at uniform time-points post-diagnosis are required.

1225 **Conflicts and acknowledgments**

1226 ***Conflicts of interest***

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1231

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1415
1416

1417 **Appendix I: Search strategies**

1418 **CINAHL (on the EBSCO platform)**

1419 Searched 25-03-2020

- 1420 S1 (TI ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1421 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2)) OR (AB ("genital herpes" or
1422 "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or herpesvirus or "genital HSV"
1423 or "Herpes genitalis" or hsv2))
1424 S2 (MM "Herpesviruses+") OR (MM "Herpes Genitalis") OR (MM "Herpes Simplex+") OR (MM
1425 "Herpes Zoster+")
1426 S3 S1 OR S2
1427 S4 (TI ((antiviral* or suppression or suppressive) W2 (therap* or treat* or agent* or medication* or
1428 drug*)) OR (AB ((antiviral* or suppression or suppressive) W2 (therap* or treat* or agent* or
1429 medication* or drug*)))
1430 S5 (TI (valacyclovir or acyclovir or famciclovir)) OR (AB (valacyclovir or acyclovir or famciclovir))
1431 S6 TI "prophylactic regimen*" OR AB "prophylactic regimen*"
1432 S7 (TI (psychotherapeutic or psychoeducational or psycho-educational) W1 (intervention or
1433 program*)) OR (AB (psychotherapeutic or psychoeducational or psycho-educational) W1
1434 (intervention or program*))
1435 S8 (TI (counseling or psychotherapy or CBT)) OR (AB (counseling or psychotherapy or CBT))
1436 S9 (TI (cognitive or behavioral or psychological) W2 (therap* or restructuring or intervention*)) OR
1437 (AB (cognitive or behavioral or psychological) W2 (therap* or restructuring or intervention*))
1438 S10 (MM "Counseling+") or (MM "Cognitive Therapy+") or (MM "Psychotherapy+") or (MM "Behavior
1439 Therapy+")
1440 S11 TI "stress reduction" OR AB "stress reduction"
1441 S12 (MM "Stress Management")
1442 S13 (TI (self-care or self-manag*)) OR (AB (self-care or self-manag*))
1443 S14 (TI ((self) W1 (manag* or care))) OR (AB ((self) W1 (manag* or care)))
1444 S15 (MM "Self Care+") or (MM "Self-Management")
1445 S16 TI Coping OR AB Coping
1446 S17 (MM "Coping+")
1447 S18 (MM "Support, Psychosocial+")
1448 S19 TI support OR AB support
1449 S20 TI "social support" OR AB "social support"
1450 S21 (MM "Support Groups+") or (MM "Support Groups+")
1451 S22 (TI ((self-help or "self help" or support) W1 (group*))) OR (AB ((self-help or "self help" or
1452 support) W1 (group*)))
1453 S23 TI ((psychological) W1 (adjustment)) OR AB ((psychological) W1 (adjustment))

1454 S24 TI adjustment OR AB adjustment

1455 S25 (MM "Social Adjustment") OR (MM "Adaptation, Psychological+")

1456 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

1457 S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25

1458 S27 (TI ((Psychosocial or psychosexual or psychological or emotional) W1 (impact or morbidity or

1459 consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or

1460 dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or

1461 outcome*))) OR (AB ((Psychosocial or psychosexual or psychological or emotional) W1 (

1462 impact or morbidity or consequence* or reaction* or factor* or distress or implication* or

1463 symptom* or difficult* or dysfunction* or trauma or response* or aspect* well-being or "well

1464 being" or wellbeing or outcome*)))

1465 S28 (MM "Psychosocial Aspects of Illness+") OR (MM "Diagnosis, Psychosocial+") OR (MM

1466 "Psychosocial Adjustment to Illness Scale")

1467 S29 (TI ("quality of life" or QOL or RGHQoL or RGHQOL)) OR (AB ("quality of life" or QOL or

1468 RGHQoL or RGHQOL))

1469 S30 (TI (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem

1470 or hopelessness or self-concept or "self concept" or "sexual identity" or "self efficacy" or self-

1471 efficacy)) OR (AB (mood or stress* or anxiety or depress* or shame or stigma or "self esteem"

1472 or self-esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self

1473 efficacy" or self-efficacy))

1474 S31 (MH "Stress, Psychological+") OR (MM "Psychological Well-Being") OR (MM "Psychological

1475 Trauma") or (MM "Emotions+") or (MM "Stress+")

1476 S32 (MM "Quality of Life+")

1477 S33 (MH "Affective Disorders+") OR (MH "Affective Symptoms+")

1478 S34 (MM "Depression+")

1479 S35 (MM "Anxiety+") or (MM "Social Anxiety Disorders")

1480 S36 (MM "Stigma") OR (MM "Shame+")

1481 S37 (MM "Self Concept+")

1482 S38 (MM "Sexual Identity") or (MM "Sexuality+") OR (MM "Attitude to Sexuality+")

1483 S39 (MM "Hopelessness")

1484 S40 (MM "Self-Efficacy")

1485 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

1486 S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR

1487 S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR

1488 S38 OR S39 OR S40

1489 S42 S3 AND S26 AND S41

1490 S43 S3 AND S26 AND S41 (Limit to English language)

1491 S44 S3 AND S26 AND S41 (Limit to German)

1492 S45 S43 OR S44

1493

1494 **MEDLINE(R) ALL (on the OVID platform)**

1495 Searched 25-03-2020

1496 1 exp *Herpesvirus 2, Human/

1497 2 exp *Herpes Genitalis/

1498 3 exp *Herpes Simplex/

1499 4 exp *Herpesvirus 1, Human/

1500 5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or

1501 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.

1502 6 1 or 2 or 3 or 4 or 5

1503 7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or

1504 drug*).ti,ab.

1505 8 (valacyclovir or acyclovir or famciclovir).ti,ab.

1506 9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/

1507 10 "prophylactic regimen".ti,ab.

1508 11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or

1509 program*).ti,ab.

1510 12 (counse?ing or psychotherapy or CBT).ti,ab.

1511 13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*).ti,ab.

1512 14 exp *Counseling/

1513 15 exp *Psychotherapy/

1514 16 exp *Cognitive Behavioral Therapy/

1515 17 "stress reduction".ti,ab.

1516 18 (self-care or self-manag*).ti,ab.

1517 19 (self adj1 (manag* or care)).ti,ab.

1518 20 exp *Self Care/ or exp *Self-Management/

1519 21 coping.ti,ab.

1520 22 Support.ti,ab.

1521 23 "social support".ti,ab.

1522 24 exp *Social Support/

1523 25 exp *Self-Help Groups/

1524 26 ((self-help or "self help" or support) adj1 group*).ti,ab.

1525 27 (psychological adj1 adjustment).ti,ab.

1526 28 adjustment.ti,ab.

1527 29 exp *Emotional Adjustment/

1528 30 exp *Adaptation, Psychological/
1529 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
1530 or 25 or 26 or 27 or 28 or 29 or 30
1531 32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or
1532 consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or
1533 dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or
1534 outcome*)).ti,ab.
1535 33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.
1536 34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or
1537 hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.
1538 35 exp *Stress, Psychological/
1539 36 exp *"Quality of Life"/
1540 37 exp *Depression/
1541 38 exp *Affect/
1542 39 exp *Anxiety/
1543 40 exp *Shame/
1544 41 exp *Social Stigma/
1545 42 exp *Self Concept/
1546 43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.
1547 44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
1548 45 6 and 31 and 44
1549 46 limit 45 to English language
1550 47 limit 45 to German
1551 48 46 or 47
1552
1553
1554 **EMBASE (on the OVID platform)**
1555 Searched 25-03-2020
1556 1 exp *Herpesvirus 2, Human/
1557 2 exp *Herpes Genitalis/
1558 3 exp *Herpes Simplex/
1559 4 exp *Herpesvirus 1, Human/
1560 5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1561 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.
1562 6 1 or 2 or 3 or 4 or 5
1563 7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or
1564 drug*)).ti,ab.

1565 8 (valacyclovir or acyclovir or famciclovir).ti,ab.
1566 9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/
1567 10 "prophylactic regimen*".ti,ab.
1568 11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or
1569 program)).ti,ab.
1570 12 (course?ing or psychotherapy or CBT).ti,ab.
1571 13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.
1572 14 exp *Counseling/
1573 15 exp *Psychotherapy/
1574 16 exp *Cognitive Behavioral Therapy/
1575 17 "stress reduction".ti,ab.
1576 18 (self-care or self-manag*).ti,ab.
1577 19 (self adj1 (manag* or care)).ti,ab.
1578 20 exp *Self Care/ or exp *Self-Management/
1579 21 coping.ti,ab.
1580 22 Support.ti,ab.
1581 23 "social support".ti,ab.
1582 24 exp *Social Support/
1583 25 exp *Self-Help Groups/
1584 26 ((self-help or "self help" or support) adj1 group*).ti,ab.
1585 27 (psychological adj1 adjustment).ti,ab.
1586 28 adjustment.ti,ab.
1587 29 exp *Emotional Adjustment/
1588 30 exp *Adaptation, Psychological/
1589 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
1590 or 25 or 26 or 27 or 28 or 29 or 30
1591 32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or
1592 consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or
1593 dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or
1594 outcome*)).ti,ab.
1595 33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.
1596 34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or
1597 hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.
1598 35 exp *Stress, Psychological/
1599 36 exp *"Quality of Life"/
1600 37 exp *Depression/
1601 38 exp *Affect/

1602 39 exp *Anxiety/
1603 40 exp *Shame/
1604 41 exp *Social Stigma/
1605 42 exp *Self Concept/
1606 43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.
1607 44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
1608 45 6 and 31 and 44
1609 46 limit 45 to English language
1610 47 limit 45 to German
1611 48 46 or 47

1612

1613 **Ovid Emcare (On the OVID platform)**

1614 Searched 11-03-2019

1615 1 exp *Herpesvirus 2, Human/ (
1616 2 exp *Herpes Genitalis/ (
1617 3 exp *Herpes Simplex/
1618 4 exp *Herpesvirus 1, Human/
1619 5 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1620 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.
1621 6 1 or 2 or 3 or 4 or 5
1622 7 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or medication* or
1623 drug*)).ti,ab.
1624 8 (valacyclovir or acyclovir or famciclovir).ti,ab.
1625 9 exp *Antiviral Agents/ or exp *Valacyclovir/ or exp *Acyclovir/ or exp *Famciclovir/
1626 10 "prophylactic regimen".ti,ab.
1627 11 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or
1628 program*)).ti,ab.
1629 12 (counse?ing or psychotherapy or CBT).ti,ab.
1630 13 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or intervention*)).ti,ab.
1631 14 exp *Counseling/
1632 15 exp *Psychotherapy/
1633 16 exp *Cognitive Behavioral Therapy/
1634 17 "stress reduction".ti,ab.
1635 18 (self-care or self-manag*).ti,ab.
1636 19 (self adj1 (manag* or care)).ti,ab.
1637 20 exp *Self Care/ or exp *Self-Management/
1638 21 coping.ti,ab.

1639 22 Support.ti,ab.
 1640 23 "social support".ti,ab.
 1641 24 exp *Social Support/
 1642 25 exp *Self-Help Groups/
 1643 26 ((self-help or "self help" or support) adj1 group*).ti,ab.
 1644 27 (psychological adj1 adjustment).ti,ab.
 1645 28 adjustment.ti,ab.
 1646 29 exp *Emotional Adjustment/
 1647 30 exp *Adaptation, Psychological/
 1648 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
 1649 or 25 or 26 or 27 or 28 or 29 or 30
 1650 32 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity or
 1651 consequence* or reaction* or factor* or distress or implication* or symptom* or difficult* or
 1652 dysfunction* or trauma or response* or aspect* well-being or "well being" or wellbeing or
 1653 outcome*)).ti,ab.
 1654 33 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.
 1655 34 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-esteem or
 1656 hopelessness or self-concept or "self concept" or "sexual identity").ti,ab.
 1657 35 exp *Stress, Psychological/
 1658 36 exp *"Quality of Life"/
 1659 37 exp *Depression/
 1660 38 exp *Affect/
 1661 39 exp *Anxiety/
 1662 40 exp *Shame/
 1663 41 exp *Social Stigma/
 1664 42 exp *Self Concept/
 1665 43 exp *Self Efficacy/ or ("self efficacy" or self-efficacy).ti,ab.
 1666 44 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
 1667 45 6 and 31 and 44
 1668 46 limit 45 to English language
 1669 47 limit 45 to German
 1670 48 46 or 47
 1671
 1672 **PSYCinfo (on the OVID platform)**
 1673 Conducted 11-03-2019
 1674 1 exp *HERPES GENITALIS/
 1675 2 exp *HERPES SIMPLEX/

1676 3 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1677 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2).ti,ab.
1678 4 1 or 2 or 3
1679 5 ((antiviral* or suppression or suppressive) adj2 (therap* or treat* or agent* or
1680 medication* or drug*)).ti,ab. (798)
1681 6 (valacyclovir or acyclovir or famciclovir).ti,ab.
1682 7 exp *Antiviral Drugs/
1683 8 "prophylactic regimen".ti,ab.
1684 9 ((psychotherapeutic or psychoeducational or psycho-educational) adj1 (intervention or
1685 program*)).ti,ab.
1686 10 (counse?ing or psychotherapy or CBT).ti,ab.
1687 11 ((cognitive or behavio?al or psychological) adj2 (therap* or restructuring or
1688 intervention*)).ti,ab.
1689 12 exp *COUNSELING/
1690 13 exp *PSYCHOTHERAPY/
1691 14 exp *cognitive therapy/ or exp *cognitive restructuring/
1692 15 "stress reduction".ti,ab.
1693 16 (self-care or self-manag*).ti,ab.
1694 17 (self adj1 (manag* or care)).ti,ab.
1695 18 exp *Self-Care Skills/ or exp *Self-Management/
1696 19 coping.ti,ab. or exp *COPING BEHAVIOR/
1697 20 Support.ti,ab.
1698 21 "social support".ti,ab.
1699 22 exp *SOCIAL SUPPORT/
1700 23 exp *SUPPORT GROUPS/ or exp *Self-Help Techniques/
1701 24 ((self-help or "self help" or support) adj1 group*).ti,ab.
1702 25 (psychological adj1 adjustment).ti,ab.
1703 26 adjustment.ti,ab.
1704 27 exp *Emotional Adjustment/ or exp *Adjustment/
1705 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
1706 or 23 or 24 or 25 or 26 or 27
1707 29 ((Psychosocial or psychosexual or psychological or emotional) adj1 (impact or morbidity
1708 or consequence* or reaction* or factor* or distress or implication* or symptom* or

1709 difficult* or dysfunction* or trauma or response* or aspect* well-being or "well being" or
1710 wellbeing or outcome*).ti,ab.
1711 30 exp *PSYCHOSOCIAL FACTORS/ or exp *PSYCHOSOCIAL REHABILITATION/ or exp
1712 *PSYCHOSOCIAL READJUSTMENT/ or exp *PSYCHOSEXUAL BEHAVIOR/
1713 31 ("quality of life" or QOL or RGHQoL or RGHQOL).ti,ab.
1714 32 (mood or stress* or anxiety or depress* or shame or stigma or "self esteem" or self-
1715 esteem or hopelessness or self-concept or "self concept" or "sexual identity" or "self
1716 efficacy" or self-efficacy).ti,ab.
1717 33 exp *PSYCHOLOGICAL STRESS/
1718 34 exp *EMOTIONAL DISTURBANCES/ or exp *EMOTIONAL INSTABILITY/ or exp
1719 EMOTIONAL RESPONSES/ or exp *EMOTIONAL STATES/ or exp *EMOTIONAL
1720 STABILITY/ or exp *emotional trauma/
1721 35 exp *"Quality of Life"/
1722 36 exp *"DEPRESSION (EMOTION)"/
1723 37 exp *Emotional States/ or exp *Emotions/ or exp *Stress/
1724 38 exp *SOCIAL STRESS/ or STRESS/
1725 39 exp *ANXIETY/ or exp *SOCIAL ANXIETY/
1726 40 exp *SHAME/
1727 41 exp *Social Stigma/
1728 42 exp *Self-Esteem/
1729 43 exp *Self-Efficacy/
1730 44 exp *Self-Concept/
1731 45 exp *Sexuality/
1732 46 exp *HOPELESSNESS/
1733 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
1734 44 or 45 or 46
1735 48 4 and 28 and 47
1736 49 limit 48 to English language
1737 50 limit 48 to German
1738 51 49 or 50
1739
1740 **WHOLIS**
1741 Searched 25-03-2019

1742 ("genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV type* OR
1743 herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2)

1744 **Cochrane Central Register of Controlled Trials**

1745 Searched 25-03-2020

1746 #1 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1747 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2):ti

1748 #2 (antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or
1749 "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-
1750 educational counse?ing or psychotherapy or CBT or cognitive or behavio?al or
1751 psychological or self-care or self-manag* or "self care" or "self manag*" or adjustment):ti

1752 #3 (Psychosocial or psychosexual or psychological or emotional or "quality of life" or QOL
1753 or RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma
1754 or "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or
1755 "sexual identity" or "self efficacy" or self-efficacy):ti

1756 #4 #1 AND #2 AND #3

1757

1758 **EThOS: e-theses online service**

1759 Searched 25-03-2020

1760 #1 ("genital herpes" or "herpes simplex virus" or HSV or HSV-1 or HSV-2 or HSV type* or
1761 herpesvirus or "genital HSV" or "Herpes genitalis" or hsv2)

1762 #2 (antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or
1763 "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-educational
1764 counse?ing or psychotherapy or CBT or cognitive or behavio?al or psychological or self-
1765 care or self-manag* or "self care" or "self manag*" or adjustment)

1766 #3 (Psychosocial or psychosexual or psychological or emotional or "quality of life" or QOL or
1767 RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma or
1768 "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual
1769 identity" or "self efficacy" or self-efficacy)

1770 #4 #1 AND #2 AND #3

1771

1772 **Open Grey**

1773 Searched 25-03-2020

1774 ("genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV type* OR
1775 herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2)

1776
1777 **Web of Science (Indexes=SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, ESCI)**
1778 Searched 25-03-2020
1779 #1 TI=("genital herpes" or "herpes simplex virus" or HSV OR HSV-1 OR HSV-2 OR HSV
1780 type* OR herpesvirus OR "genital HSV" OR "Herpes genitalis" OR hsv2) 37,937
1781 #2 TI=((antiviral* or suppression or suppressive or valacyclovir or acyclovir or famciclovir or
1782 "prophylactic regimen*" or psychotherapeutic or psychoeducational or psycho-educational
1783 course?ing or psychotherapy or CBT or cognitive or behavio?al or psychological or self-care or
1784 self-manag* or "self care" or "self manag*" or adjustment) 554,578
1785 #3 TI=(Psychosocial or psychosexual or psychological or emotional or "quality of life" or
1786 QOL or RGHQoL or RGHQOL or mood or stress* or anxiety or depress* or shame or stigma or
1787 "self esteem" or self-esteem or hopelessness or self-concept or "self concept" or "sexual
1788 identity" or "self efficacy" or self-efficacy) 990,005
1789 #4 #1 AND #2 AND #3 47
1790
1791

1792 **Appendix II: Full text studies that were excluded and reasons for exclusion**

- 1793 1. Alexander and Naisbett 2002: Patient and physician partnerships in managing genital herpes
1794 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1795 *criteria*
1796
- 1797 2. Anonymous 2004: Suppressive antiviral therapy improves quality of life in patients with recurrent
1798 genital herpes
1799 *Reason for exclusion: Not primary research*
1800
- 1801 3. Antoni et al. 2001: Reductions in HSV-2 antibody titers after cognitive behavioral stress
1802 management and relationships with neuroendocrine function, mood, relaxation skills and social
1803 support in HIV plus men
1804 *Reason for exclusion: Conference presentation no further publications available*
1805
- 1806 4. Aral et al. 1987: Recurrent Genital Herpes: What Helps Adjustment?
1807 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified*
1808 *inclusion criteria*
1809
- 1810 5. Au and Sacks 2002: Antivirals in the prevention of genital herpes
1811 *Reason for exclusion: Not primary research*
1812
- 1813 6. Au and Sacks 2003: Therapeutic options for herpes simplex infections
1814 *Reason for exclusion: Not primary research*
1815
- 1816 7. Baeten et al. 2012: Clinical and virologic response to episodic acyclovir for genital ulcers among
1817 HIV-1 seronegative, herpes simplex virus type 2 seropositive African women: A randomized,
1818 placebo-controlled trial
1819 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1820 *criteria*
1821
- 1822 8. Baker 1992: Herpes simplex virus infections
1823 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1824 *criteria*
1825
- 1826 9. Blansett 1992: Explanatory style, depressive response, and severity of herpes simplex virus
1827 *Reason for exclusion: Unavailable*
1828

- 1829 10. Bodsworth et al. 2008: 2-day versus 5-day famciclovir as treatment of recurrences of genital herpes:
1830 results of the FaST study
1831 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1832 *criteria*
1833
- 1834 11. Brentjens et al. 2003: Recurrent genital herpes treatments and their impact on quality of life
1835 *Reason for exclusion: Not primary research*
1836
- 1837 12. Chenitz and Swanson 1989: Counseling clients with genital herpes
1838 *Reason for exclusion: Not primary research*
1839
- 1840 13. Chida and Mao 2009: Does psychosocial stress predict symptomatic herpes simplex virus
1841 recurrence? A meta-analytic investigation on prospective studies
1842 *Reason for exclusion: Not primary research*
1843
- 1844 14. Chilukuri and Rosen 2003: Management of acyclovir-resistant herpes simplex virus
1845 *Reason for exclusion: Not primary research*
1846
- 1847 15. Clark et al. 1995: Management of genital herpes
1848 *Reason for exclusion: Not primary research*
1849
- 1850 16. Connor-Greene 1986: The role of counseling in the treatment of genital herpes
1851 *Reason for exclusion: Not primary research*
1852
- 1853 17. Cook 2014: The sexual health consultation as a moral occasion
1854 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1855 *criteria*
1856
- 1857 18. Cruess et al. 2000: Reductions in herpes simplex virus type 2 antibody titers after cognitive
1858 behavioral stress management and relationships with neuroendocrine function, relaxation skills,
1859 and social support in HIV-positive men
1860 *Reason for exclusion: Does not report baseline data and whether participants are symptomatic*
1861
- 1862 19. Cummings 1999: Experiential interventions for clients with genital herpes.
1863 *Reason for exclusion. Insufficient details of outcomes of interest*
1864

- 1865 20. Davis et al. 2016: Coping strategies and behavioural changes following a genital herpes diagnosis
1866 among an urban sample of underserved Midwestern women
1867 *Reason for exclusion: Concerned with serological diagnosis*
1868
- 1869 21. Derman 1986: Counseling the herpes genitalis patient
1870 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1871 *criteria*
1872
- 1873 22. Doward 1994: Developing a measure of quality of life for patients with recurrent genital herpes
1874 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified*
1875 *inclusion criteria*
1876
- 1877 23. Doward et al. 1998: The international development of the RGHQoL: A quality of life measure for
1878 recurrent genital herpes
1879 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1880 *criteria*
1881
- 1882 24. Dorgan 2001: From behind the screen: Women's use of online disclosures about sexually
1883 transmitted diseases to manage uncertainty
1884 *Reason for exclusion: Unavailable*
1885
- 1886 25. Draeger 2018: Management of genital herpes: a guide for GPs
1887 *Reason for exclusion: Not primary research*
1888
- 1889 26. Faulkner and Smith 2009: A prospective diary study of the role of psychological stress and negative
1890 mood in the recurrence of herpes simplex virus (HSV1)
1891 *Reason for exclusion: Wrong population*
1892
- 1893 27. Fisman 2005: Health related quality of life in genital herpes: A pilot comparison of measures
1894 *Reason for exclusion: Focus on measures rather than individuals' quality of life*
1895
- 1896 28. Fraley 2002: Psychosocial outcomes in individuals living with genital herpes
1897 *Reason for exclusion: Not primary research*
1898
- 1899 29. Gilbert and Wyand 2009: Genital herpes education and counselling: Testing a one-page 'FAQ'
1900 intervention

1901 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1902 *criteria*
1903
1904 30. Goldmeier et al. 1986: Psychological aspects of recurrences of genital herpes
1905 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*
1906
1907 31. Goldmeier et al. 1998: Psychosocial implications of recurrent genital herpes simplex virus infection
1908 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*
1909
1910 32. Gould & Tissler 1984: The use of hypnosis in the treatment of Herpes Simplex II.
1911 *Reason for exclusion. Insufficient details of outcomes of interest*
1912
1913 33. Green and Kocsis 1997: Psychological factors in recurrent genital herpes
1914 *Reason for exclusion: Not primary research*
1915
1916 34. Green et al. 2003: Determinants of disclosure of genital herpes to partners
1917 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1918 *criteria*
1919
1920 35. Green 2004: Psychosocial issues in genital herpes management
1921 *Reason for exclusion: Not primary research*
1922
1923 36. Groves 2016: Genital Herpes: A Review
1924 *Reason for exclusion: Not primary research*
1925
1926 37. Gruzelier 2002: A review of the impact of hypnosis, relaxation, guided imagery and individual
1927 differences on aspects of immunity and health
1928 *Reason for exclusion: Not primary research*
1929
1930 38. Gurevich 1990: Counseling the patient with herpes
1931 *Reason for exclusion: Not primary research*
1932
1933 39. Hamill et al. 2005: Management of recurrent genital herpes: a survey of UK genitourinary medicine
1934 clinics in 2003
1935 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1936 *criteria*
1937

- 1938 40. Harris and Abramson 1988: Personality correlates of the clinical sequelae of genital herpes *Reason*
1939 *for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion criteria*
1940
- 1941 41. Himell 1981: Genital Herpes: the need for counseling
1942 *Reason for exclusion: Not primary research*
1943
- 1944 42. Hofstetter et al. 2014: Current thinking on genital herpes
1945 *Reason for exclusion: Not primary research*
1946
- 1947 43. Hoon et al. 1991: A psycho-behavioral model of genital herpes recurrence
1948 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1949 *criteria*
1950
- 1951 44. Hoon 1986: Life stress: Impact on genital herpes recurrences (social support, illness, locus-of-
1952 control, arousal-seeking)
1953 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*
1954
- 1955 45. Horn et al. 2015: Psychological distress, emotional stability, and emotion regulation moderate
1956 dynamics of herpes simplex virus type 2 recurrence
1957 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*
1958
- 1959 46. Hunt et al. 1993: Genital herpes and quality of life
1960 *Reason for exclusion: Focus on questionnaire development*
1961
- 1962 47. Jadack et al. 1991: Genital Herpes: The Disease Experience Over the First 6 Months
1963 *Reason for exclusion: Full study reported in 1990 paper*
1964
- 1965 48. Kaushal et al. 2017: Evaluation of effectiveness and safety of acyclovir 1 gm once a day single oral
1966 dose for 5 days for treatment of genital herpes
1967 *Reason for exclusion: Conference presentation no further publications available*
1968
- 1969 49. Kelley 1995: Parse's theory in practice with a group in the community
1970 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
1971 *criteria*
1972
- 1973 50. Kleymann 2005: Agents and strategies in development for improved management of herpes
1974 simplex virus infection and disease

1975 *Reason for exclusion: Not primary research*

1976

1977 51. Kleymann 2003: Novel agents and strategies to treat herpes simplex virus infections

1978 *Reason for exclusion: Not primary research*

1979

1980 52. Koch et al. 2008: Inhibitory effect of essential oils against herpes simplex virus type 2

1981 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*

1982 *criteria*

1983

1984 53. Koehn et al. 1993: Applied relaxation training in the treatment of genital herpes

1985 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*

1986 *criteria*

1987

1988 54. Kuritzky 2017: Prophylaxis of genital herpes recurrences with antivirals

1989 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*

1990 *criteria*

1991

1992 55. Lehr and Lee 1990: The psychosocial and sexual trauma of a genital HPV infection

1993 *Reason for exclusion: Unavailable*

1994

1995 56. Leone et al. 2010: One-day famciclovir vs placebo in patient-initiated episodic treatment of

1996 recurrent genital herpes in immunocompetent Black patients

1997 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*

1998 *criteria*

1999

2000 57. Leung and Sacks 2000: Current recommendations for the treatment of genital herpes

2001 *Reason for exclusion: Not primary research*

2002

2003 58. Levenson et al. 1987: Psychological factors predict symptoms of severe recurrent genital herpes

2004 infection

2005 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*

2006

2007 59. Longo and Koehn 1993: Psychosocial factors and recurrent genital herpes: A review of prediction

2008 and psychiatric treatment studies

2009 *Reason for exclusion: Not primary research*

2010

- 2011 60. Longo and Clum 1989: Psychosocial factors affecting genital herpes recurrences Linear vs
2012 mediating models
2013 *Reason for exclusion: Focus on risk factors for recurrences of genital herpes*
2014
- 2015 61. Longo et al. 1988: Psychosocial treatment for recurrent genital herpes
2016 *Reason for exclusion: Duplicate publication (authors published the same study with the same*
2017 *outcomes in two different journals and the one which the most detail was included in the review)*
2018
- 2019 62. Luby and Gillespie 1981: Psychological responses to genital herpes
2020 *Reason for exclusion: Unavailable*
2021
- 2022 63. Lutgendorf et al. 1997: Cognitive-behavioral stress management decreases dysphoric mood and
2023 herpes simplex virus-Type 2 antibody titers in symptomatic HIV-seropositive gay men
2024 *Reason for exclusion: Population do not meet inclusion criteria*
2025
- 2026 64. Madrid and Swanson 1995: Psychoeducational groups for young adults with genital herpes: training
2027 group facilitators
2028 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2029 *criteria*
2030
- 2031 65. Manne and Sandler 1984: Coping and adjustment to genital herpes
2032 *Reason for exclusion: Duplicate study (authors published the same study with the same*
2033 *outcomes in two different journals and the one with the most detail was included in the review))*
2034
- 2035 66. Manns et al. 2018: What are patient experiences of herpes simplex virus (HSV) health promotion?
2036 *Reason for exclusion: Conference presentation no further publications available*
2037
- 2038 67. Meads et al. 2009: Further validation and responsiveness assessment of the Herpes Outbreak
2039 Impact Questionnaire and Herpes Symptom Checklist
2040 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2041 *criteria*
2042
- 2043 68. Merin and Pachankis 2011: The psychological impact of genital herpes stigma
2044 *Reason for exclusion: Not primary research*
2045
- 2046 69. Mindel and Marks 2005: Psychological symptoms associated with genital herpes virus infections:
2047 Epidemiology and approaches to management

2048 *Reason for exclusion: Not primary research*

2049

2050 70. Mindel 1993: Long-term clinical and psychological management of genital herpes

2051 *Reason for exclusion: Not primary research*

2052

2053 71. Mindel 1996: Psychological and psychosexual implications of herpes simplex virus infections

2054 *Reason for exclusion: Not primary research*

2055

2056 72. Mirotznic et al. 1987: Genital herpes: An investigation of its attitudinal and behavioral correlates

2057 *Reason for exclusion: Wrong population*

2058

2059 73. Moore 2014: Early intervention support group for individuals diagnosed with genital herpes

2060 *Reason for exclusion: Unavailable*

2061

2062 74. Mospan and Cluck 2016: Prevention and management of genital herpes

2063 *Reason for exclusion: Not primary research*

2064

2065 75. Newton and McCabe 2005: A theoretical discussion of the impact of stigma on psychological

2066 adjustment to having a sexually transmissible infection

2067 *Reason for exclusion: Not primary research*

2068

2069 76. Nicholson 2016: Getting herpes simplex: Diagnosis, treatments and attitudes of patients and

2070 partners

2071 *Reason for exclusion: Conference presentation no further publications available*

2072

2073 77. Oseso et al. 2016: Attitudes and willingness to assume risk of experimental therapy to eradicate

2074 genital herpes simplex virus infection

2075 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*

2076 *criteria*

2077

2078 78. Owens et al. 2015: Patients with genital herpes infection have an educational deficit regarding how

2079 to prevent further transmission

2080 *Reason for exclusion: Conference presentation no further publications available*

2081

2082 79. Patel Ret 1999: Impact of recurrent genital herpes on health -related quality of life Improvements

2083 obtained with suppressive antiviral therapy

2084 *Reason for exclusion: Conference presentation no further publications available*

2085
2086 80. Patel 2008: Making the most of episodic antiviral therapy for genital herpes
2087 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2088 *criteria*
2089
2090 81. Roe 2004: Living with genital herpes: how effective is antiviral therapy?
2091 *Reason for exclusion: Not primary research*
2092
2093 82. Romanowski et al. 2008: In search of optimal genital herpes management and standard of care
2094 (INSIGHTS): Doctors' and patients' perceptions of genital herpes
2095 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2096 *criteria*
2097
2098 83. Rose and Camp 1988: Genital herpes How to relieve patients physical and psychological
2099 symptoms
2100 *Reason for exclusion: Not primary research*
2101
2102 84. Sacks and Wilson 1997: Genital herpes: Management issues for the next century
2103 *Reason for exclusion: Not primary research*
2104
2105 85. Sauerbrei 2016: Optimal management of genital herpes: Current perspectives
2106 *Reason for exclusion: Not primary research*
2107
2108 86. Shah and Button 1998: The relationship between psychological factors and recurrent genital herpes
2109 simplex virus
2110 *Reason for exclusion: Not primary research*
2111
2112 87. Shaw and Rosenfeld 1987: Psychological and sexual aspects of genital herpes in women
2113 *Reason for exclusion: Did not specifically report on depression subscale*
2114
2115 88. Sinclair-Smith 1989: Stress inoculation training program applied to genital herpes patients
2116 *Reason for exclusion: Unavailable*
2117
2118 89. Spencer et al. 1999: Recurrent genital herpes and quality of life in France
2119 *Reason for exclusion: Unavailable*
2120

- 2121 90. Strachan et al. 2012: A dynamical systems analysis of psychological distress and genital HSV-2
2122 infection in humans
2123 *Reason for exclusion: Conference presentation no further publications available*
2124
- 2125 91. Strachan et al. 2011: The effects of daily distress and personality on genital HSV shedding and
2126 lesions in a randomized, double-blind, placebo-controlled, crossover trial of acyclovir in HSV-2
2127 seropositive women
2128 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2129 *criteria*
2130
- 2131 92. Swanson and Chenitz 1989: Psychosocial aspects of genital herpes: A review of the literature
2132 *Reason for exclusion: Not primary research*
2133
- 2134 93. Swanson and Chenitz 1989: The prevention and management of genital herpes: a community
2135 health approach
2136 *Reason for exclusion: Not primary research*
2137
- 2138 94. Swanson 1999: The biopsychosocial burden of genital herpes: evidence-based and other
2139 approaches to care
2140 *Reason for exclusion: Not primary research*
2141
- 2142 95. Taylor 1978: The psychological and behavioral effects of genital herpes in women: high recurrers
2143 vs low recurrers
2144 *Reason for exclusion: Unavailable*
2145
- 2146 96. VanderPlate and Kerrick 1985: Stress Reduction Treatment of Severe Recurrent Genital Herpes
2147 Virus
2148 *Reason for exclusion: Concerned with predictors of reduced recurrence*
2149
- 2150 97. VanderPlate et al. 1988: The relationship among genital herpes simplex virus, stress, and social
2151 support
2152 *Reason for exclusion: Concerned with predictors of recurrence*
2153
- 2154 98. Van Berkel 1999: A psychoeducational programme increased knowledge and decreased sexual
2155 risk behaviours in young adults with genital herpes
2156 *Reason for exclusion: Not primary research*
2157

- 2158 99. Verma et al. 2015: Acyclovir 1gm twice a day for 3 days for the treatment of recurrent genital herpes
2159 *Reason for exclusion: Conference presentation no further publications available*
2160
- 2161 100. Wagstaff et al. 2004: Management of genital herpes: Defining the role of valacyclovir
2162 *Reason for exclusion: Not primary research*
2163
- 2164 101. Wald et al. 2006: Comparative efficacy of famciclovir and valacyclovir for suppression of recurrent
2165 genital herpes and viral shedding
2166 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified inclusion*
2167 *criteria*
2168
- 2169 102. Whale et al. 2013: A psychological experiment to examine the global impact of stigma on individuals
2170 diagnosed with type 1 herpes simplex virus (HSV-1)
2171 *Reason for exclusion: Audit*
2172
- 2173 103. Whitley et al. 2006: Single-day famciclovir therapy for recurrent genital herpes
2174 *Reason for exclusion: Not primary research*
2175
- 2176 104. Wild et al. 1995: Measuring health-related quality of life in persons with genital herpes
2177 *Reason for exclusion: Did not report on any of the outcomes of interest as per the modified*
2178 *inclusion criteria*
2179
- 2180 105. Woolley and Kinghorn 1986: The psychological-aspects of genital herpes
2181 *Reason for exclusion: Not primary research*
2182
- 2183 106. Zacharioudakis 2001: Doing psychotherapy with patients with genital herpes: Issues and
2184 interventions.
2185 *Reason for exclusion: Not primary research*
2186
- 2187 107. Drob and Bernard 1986: Time-limited group treatment of genital herpes patients
2188 *Reason for exclusion: Not primary research*
2189
- 2190 108. Dibble and Swanson 2000: Gender differences for the predictors of depression in young adults
2191 with genital herpes
2192 *Reason for exclusion: Duplicate data from included studies*
2193
2194

2195
2196
2197

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			
<p>1. Bartlett et al. 2008⁶⁰</p> <p>USA</p> <p>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</p>	<p>Study design</p> <p>RCT</p> <p>Duration of study</p> <p>90 (+/- 5) days initial episodic treatment phase (IETP) plus a 6-month randomised treatment phase</p> <p>Setting and recruitment</p> <p>Recruited from medical centres (n=84)</p>	<p>Participants</p> <p>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)</p> <p>Age (years)</p> <p>Episodic treatment: Range 19-74, Mean 41.2</p> <p>Suppressive treatment: Range 18-69, Mean 39.9</p> <p>Gender (Female)</p> <p>Episodic treatment: 67.9%</p> <p>Suppressive treatment: 66.2%</p> <p>Diagnosis</p> <p>HSV-1 /HSV-2 confirmed by PCR testing (100%)</p>	<p>Intervention</p> <p>(Episodic treatment versus suppressive treatment)</p> <p>Phase 1: IETP:Famciclovir 125mg twice daily for 5 days and then observed for 90 (+/- 5) days</p> <p>Subjects with no symptomatic recurrence during the 3-month IETP were dropped from the study</p> <p>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</p> <p>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)</p>

		<p>Length of time of diagnosis ns</p> <p>Number of recurrences In the previous year Episodic treatment: Mean 7.3±3.48 Suppressive treatment: Mean 7.5±5.41</p>	<p>Outcome/s of interest Disease specific QoL</p> <p>Outcome measure/s Baseline and 6 months fu RGHQoL</p>
<p>2. Carney et al. 1993⁶⁴ UK</p> <p>To assess the psychological impact of recurrent GH and to determine if long term acyclovir has any impact on this morbidity</p>	<p>Study design Pre-test / Post-test</p> <p>Duration of study 15 months</p> <p>Setting and recruitment Patients who attended a department of genitourinary medicine</p>	<p>Participants Individuals with GH (n=102, rr ns)</p> <p>Age (years) Men: Mean 32.0; women: Mean 30.8</p> <p>Gender (Female) 46%</p> <p>Diagnosis GH confirmed by viral culture (100%)</p> <p>Length of time of diagnosis At least one year</p> <p>Number of recurrences At least 8 recurrences per year</p>	<p>Intervention (Suppressive treatment) Intervention group: Continuous (3 months) oral acyclovir (dosage not reported) (n= 102) Control group: None</p> <p>Outcome/s of interest Psychological morbidity (including HRQoL) Anxiety and depression</p> <p>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</p>
<p>3. Fife et al. 2007⁵⁸ USA</p>	<p>Study design RCT</p>	<p>Participants Individuals with GH (n=80, rr ns)</p> <p>Age (years)</p>	<p>Intervention (Episodic treatment versus suppressive treatment)</p>

<p>To compare episodic and suppressive therapy for genital herpes about disease characteristics, disease burden, and psychologic impact</p>	<p>Duration of study 1 year</p> <p>Setting and recruitment Recruited from those who had previously participated genital herpes clinical trials and from advertisements in the local media</p>	<p>Episodic treatment: Mean 35.1; Range 19-56</p> <p>Suppressive treatment: Mean 32.3, Range 19-48</p> <p>Gender (Female) Episodic treatment: 63% Suppressive treatment: 63%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis Episodic treatment: Mean 7.6 Suppressive treatment: Mean 6.1</p> <p>Number of recurrences In previous year Episodic treatment: Mean 6.1; Median 6.0 Suppressive treatment Mean 6.4; Median 6.0</p>	<p>Episodic treatment: Valacyclovir 500 mg twice daily for 5 days (n=40) at first sign of recurrence</p> <p>Suppressive treatment: Valacyclovir 500 mg daily for 30 days (n=40)</p> <p>Outcome/s of interest Disease specific QoL HRQoL</p> <p>Outcome measure/s Baseline, 3, 6, 9 and 12 months fu RGHQoL MOS SF-36</p>
<p>4. Handsfeld et al. 2007⁶² USA</p> <p>To evaluate the effectiveness of suppressive therapy with</p>	<p>Study design RCT</p> <p>Duration of study 6 months</p>	<p>Participants Individuals with primary GH (n=119, rr ns)</p> <p>Age (years) Intervention: 28.3±9.0 Control: 28.8±8.8</p>	<p>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)</p>

<p>valacyclovir initiated within 3 months of infection</p>	<p>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</p>	<p>Gender (Female) Intervention: 58% / Control: 73%</p> <p>Diagnosis Primary GH</p> <p>Length of time of diagnosis Less than 90 days</p> <p>Number of recurrences Not applicable</p>	<p>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</p> <p>Outcome/s of interest Disease specific QoL</p> <p>Outcome measure/s Baseline, 3 and 6 months fu RGHQoL</p>
<p>5. Patel et al. 1999⁶³ USA, UK, Denmark, France, Australia, New Zealand, Italy, Austria and Germany</p> <p>To investigate whether suppressive antiviral therapy improves health related QoL in patients with recurrent GH</p>	<p>Study design RCT</p> <p>Duration of study 1 year</p> <p>Setting and recruitment Multicentre study no further details provided</p>	<p>Participants Individuals with GH (n=1349, rr 92%)</p> <p>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</p>	<p>Intervention (Suppressive treatment versus placebo)</p> <p>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</p> <p>Control group: placebo (n=123) for a period of 52 weeks</p> <p>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)</p>

		<p>Age (years) Mean was between 35 and 36</p> <p>Gender (Female) 52%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis ns</p> <p>Number of recurrences In previous year ≥ 10 occurrences (n=586) < 10 occurrences (n=763)</p>	<p>Outcome/s of interest Disease specific QoL</p> <p>Outcome measure/s Baseline, 3, 6 and 12 months fu RGHQoL</p>
Psychological interventions			
<p>6. Youngkin et al. 1998⁵⁶ USA</p> <p>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</p>	<p>Study design RCT</p> <p>Duration of study 4 weeks</p> <p>Setting and recruitment Recruited from university student health service and a local family planning clinic</p>	<p>Participants HSV-positive women (n=40; rr 54.8%)</p> <p>Age (years – entire sample) 17-22 years (57%) 23-29 years (40%) >29 years (3%)</p> <p>Gender (Female) 100%</p>	<p>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)</p> <p>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</p>

<p>image in young adult women with HSV infections</p>		<p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis ns</p> <p>Number of recurrences ns</p>	<p>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</p> <p>Outcome/s of interest Self-esteem, self-concept, body image</p> <p>Outcome measure/s Baseline and post treatment (4 weeks) Rosenberg Self-esteem Scale; Body Image Scale Self-concept with Intimate Relationships Scale</p>
<p>7. Swanson et al. 1999⁶¹ USA</p> <p>To test the outcomes of group psycho-educational intervention led by nurses on sexual health risks (knowledge, behaviour, disease burden) and psycho-social adaptation</p>	<p>Study design RCT</p> <p>Duration of study 6 months</p> <p>Setting and recruitment Recruited from local newspapers and undertaken in community-based sites</p>	<p>Participants Individuals with GH (n=220, rr 87.3%)</p> <p>Age (years) Intervention: Mean 27.2±4.6 Control: Mean 27.0±4.0</p> <p>Gender (Female) Intervention: 71%; Control: 82.6%</p>	<p>Intervention (Psycho-educational sessions versus waiting list control)</p> <p>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</p> <p>The first session focused on information about herpes during which participants shared information and stories of the process of diagnosis</p>

<p>(depression, mood states, self-efficacy) in young adults with the chronic disease, GH</p>		<p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis ns</p> <p>Number of recurrences In past 3 months Intervention: Mean 1.51±1.32 Control: Mean 1.45±1.41</p>	<p>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</p> <p>Control group (n=117): were offered the intervention at the end of the study</p> <p>Outcome/s of interest Depression, Mood, Self-efficacy</p> <p>Outcome measure/s Baseline, 3 and 6 months fu Beck Depression Inventory; Profile of Mood States Protection from STD Questionnaire</p>
<p>8. Longo 1986⁵⁷ USA</p> <p>To explore the association between psychosocial interventions and stress, social support, health status and emotional distress</p>	<p>Study design RCT</p> <p>Duration of study 26 weeks</p> <p>Setting and recruitment Recruited from local newspaper advertisements, posters displayed around the university and referrals from the University Infirmary</p>	<p>Participants Individuals with GH (n=29, rr ns)</p> <p>Age (years) Mean±SD Virginia PG: 23.8±8.58; SS: 23.0±5.39; WL: 23.4±4.10</p> <p>Pennsylvania PG: 27.6±5.51; SS: 30.0±6.82; WL: 28.0±6.83</p>	<p>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</p> <p>Psychosocial groups involved: HSV information, interpersonal conflict discussions, relaxation training, stress management instructions, and suggestive-imagery techniques</p>

	<p>and local physicians in two cities (Virginia and Pennsylvania)</p>	<p>Gender (Female) Virginia PG: 33%; SS: 13%; WL: 20%</p> <p>Pennsylvania PG: 21%; SS: 36%, WL: 14%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis ns</p> <p>Number of recurrences In the previous year 4-6 (n=ns)., 7-10 (n=ns)., 11-12 (n=ns). and ≥ 13 (n=ns)</p>	<p>The social support groups shared feelings and experiences about the disease, and served as placebo controls</p> <p>Waiting-list control group were offered treatment after the 26-week follow-up period</p> <p>Outcome/s of interest Anxiety, Stress, Depression, Mood, Loneliness, Locus of control</p> <p>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</p>
<p>9. McLarnon and Kaloupek 1988³¹ Canada</p> <p>To examine the relationship between psychological factors and disease expression in the form of GH</p>	<p>Study design RCT</p> <p>Duration of study 5 weeks</p> <p>Setting and recruitment By referral from health professionals connected with sexually transmitted disease clinics at three</p>	<p>Participants Individuals with GH (n=16; rr 72.7%)</p> <p>Age (years) 29.7\pm10.4</p> <p>Gender (Female) 81%</p> <p>Diagnosis GH confirmed by viral analysis</p>	<p>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</p> <p>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</p>

	major hospitals, as well as from several community and university health services and adverts placed at two universities, newspapers and radio	<p>Length of time of diagnosis Mean 16.4 months \pm14.9</p> <p>Number of recurrences ns</p>	<p>Outcome/s of interest Disease specific QoL Loneliness</p> <p>Outcome measure/s Baseline and post treatment and then 3, 6 months fu Genital Herpes Questionnaire UCLA Loneliness Scale</p>
<p>10. Gruzelier et al. 2002⁶⁵ UK</p> <p>To examine both positive and negative personality influences on mood, health and immunity as a result of self-hypnosis training</p>	<p>Study design Pre-test / Post-test</p> <p>Duration of study 6 weeks</p> <p>Setting and recruitment Recruited from Department of GUM</p>	<p>Participants Individuals with GH (n=20, rr ns)</p> <p>Age (years) Range 23 to 64, Median 36</p> <p>Gender (Female) 65%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time of diagnosis ns</p> <p>Number of recurrences In the six weeks before treatment Median 12 (range 6-25)</p>	<p>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</p> <p>Outcome/s of interest Anxiety, Depression, Mood</p> <p>Outcome measure/s Baseline and post treatment (6 weeks) Hospital Anxiety and Depression Scale State-Trait Anxiety Inventory Mood activation checklist</p>
<p>11. Drob et al. 1986⁵⁹ USA</p>	<p>Study design RCT</p>	<p>Participants Individuals with GH (n=42, rr ns)</p>	<p>Intervention (Group psychotherapy versus self-help control)</p>

<p>To compare the efficacy of three forms of group psychological treatment for herpes patients</p>	<p>Duration of study 12 weeks</p> <p>Setting and recruitment Recruited by the principal author at lectures on GH sponsored by the New York HELP support group</p>	<p>Age (years) Mean 34</p> <p>Gender (Female) 58%</p> <p>Diagnosis Recurrent GH diagnosed by their own physician</p> <p>Length of time of diagnosis ≥6 months of GH symptoms</p> <p>Number of recurrences Up to nine episodes per year</p>	<p>Intervention groups: CBSM (n=17) or DOP (n=17) Group sessions both 12¹/₂ hours over 10 weekly sessions</p> <p>Control group: Self-Help control group (n=8) 12 hours over 4 monthly sessions.</p> <p>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</p> <p>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</p> <p>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</p>
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			<p>currently available to herpes patients through a nationwide network of support groups.</p> <p>Outcome/s of interest Psychological Adjustment (Disease specific QoL)</p> <p>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</p>
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2199 **Key:** CBSM: cognitive behavioral stress management CR: cognitive restructuring; DOP: dynamically oriented psychotherapy; fu: follow up; GH:
2200 genital herpes; GUM: Genitourinary Medicine; HELP: a self-help organization for individuals with herpes; HPV: human papilloma virus; HRQoL:
2201 Health related quality of life; HSV: herpes simplex virus; IETP: initial episodic treatment phase; ns: not specified; PCR: polymerase chain reaction;
2202 PG: psychosocial groups; QoL: quality of life; RCT: randomised control trial; RGHQoL: Recurrent Genital Herpes Quality of Life Scale ; MOS SF-
2203 36: Medical Outcome Study 36-tem Short Form Health Survey; STD: sexually transmitted disease; SDi: structured discussion; SD: standard deviation
2204

2205 **Appendix IV: Characteristics of included cross sectional descriptive studies**

Study Country Aim	Methods Setting and recruitment	Participant characteristics	Outcome/s of interest Outcome measures
<p>1.Barnack-Tavlaris et al. 2011²⁰ USA</p> <p>To investigate the psychosocial factors that influence psychological adjustment among women with GH</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods On-line survey</p> <p>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</p>	<p>Participants Women with GH (n=105, rr ns)</p> <p>Age (years) Range 18-30, Mean 23.98±3.90</p> <p>Gender (Female) 100%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis Diagnosed within past 22 months</p> <p>Number of recurrences Mean 2.23±1.98, Range 0-12 in previous 22 months</p>	<p>Outcome/s of interest Disease specific QoL Coping Herpes stigma Social support</p> <p>Outcome measures RGHQoL adapted HIV stigma scale Coping Orientations to Problems Experienced (COPE) Scale Social Support (AOQ)</p>
<p>2.Bickford et al. 2007⁵⁴ UK</p> <p>To assess the nature and effect of stigma on disclosure of diagnosis to sexual partners</p>	<p>Study design Cross sectional descriptive study as part of wider mixed methods study</p> <p>Methods Questionnaires</p>	<p>Participants Individuals with GH (n=70, rr ns) compared to normative values</p> <p>Age (years) ns</p> <p>Gender (Female)</p>	<p>Outcome/s of interest Anxiety</p> <p>Outcome measures Hospital Anxiety and Depression Scale</p>

<p>among those with problematic disease</p>	<p>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</p>	<p>72.5%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis Median 78 months (IQR 41-192 months)</p> <p>Number of recurrences ns</p>	
<p>3.Brookes et al. 1993⁶⁹ UK</p> <p>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</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaire</p> <p>Setting Recruited from people attending a UK genitourinary clinic and via a self-help advocacy group, the Herpes Association</p>	<p>Participants Individuals with GH (n=90, rr 60%)</p> <p>Age (years) Median 34 (range 19-60)</p> <p>Gender (Female) 55.6%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis Median 6 years (range 1-29)</p> <p>Number of recurrences All had had 2 recurrences, with 66 (73%) having had > 10 recurrences</p>	<p>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</p> <p>Outcome measures AOQ</p>
<p>4.Carney et al. 1994⁴⁸ UK</p>	<p>Study design Longitudinal descriptive study</p>	<p>Participants Individuals with GH (n=91)</p>	<p>Outcome/s of interest Psychological morbidity (including HRQoL)</p>

<p>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</p>	<p>Methods Questionnaires distributed at 3, 6 9 & 12 months</p> <p>Setting Patients who attended a department of genitourinary medicine</p>	<p>(3 months fu n=61; 6 months fu n=51; 9 months fu n=40; 12 months fu n=28)</p> <p>Age (years) Mean 28.3 ±8.14</p> <p>Gender (Female) 75%</p> <p>Diagnosis Primary episode of GH confirmed at clinic</p> <p>Length of time since diagnosis ns</p> <p>Number of recurrences 0 initially, ≥1 recurrence at 6 months (43%)</p>	<p>Anxiety, Depression</p> <p>Outcome measure/s General Health Questionnaire Hospital Depression and Anxiety Scale Illness Attitude Scale Illness Concern Scale</p>
<p>5.Cassidy et al. 1997⁷² UK</p> <p>To examine the impact of genital HSV on patients' QoL</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from those attending a GUM clinic and through advertisements in the national press, and via local radio</p>	<p>Participants Individuals with GH (n=116, rr 89%)</p> <p>Age (years) Range 21-69, Mean 35.3</p> <p>Gender (Female) 58.6%</p> <p>Diagnosis Culture positive GH</p> <p>Length of time since diagnosis <1 year 22.4% / 1-5 years 37.9%, 6-10 years 19% / 11 years and more 20.7%</p>	<p>Outcome/s of interest Depression, Anxiety Stress, Coping Life experiences (HRQoL) Social support HRQoL</p> <p>Outcome measures Hospital Anxiety and Depression Scale Life Experiences Survey</p>

		<p>Number of recurrences Mean 3.65 in 6 months Range 0-24 per year</p>	<p>Coping Orientations to Problems Experienced (COPE) Scale Social Provisions Scale Medical outcomes study instrument (QoL items)</p>
<p>6.Drob et al. 1985⁵³ USA To investigate the psychological consequences of GH</p>	<p>Study design Cross sectional descriptive study as part of wider mixed methods study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from those seeking counselling and/or psychotherapy because of their difficulties with GH</p>	<p>Participants Individuals with GH (n=42, rr ns)</p> <p>Age (years) Range 21-56; Mean 34</p> <p>Gender (Female) 57%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis Diagnosed more than 6 months previous Mean 1.4 years</p> <p>Number of recurrences Mean 11 in previous year</p>	<p>Outcome/s of interest Psychological consequences of herpes (Disease specific QoL)</p> <p>Outcome measures Genital Herpes Questionnaire (AOQ)</p>
<p>7.Hillard et al. 1989⁴⁹ USA To quantify the psychological reaction to diagnosis of GH</p>	<p>Study design Longitudinal descriptive study</p> <p>Methods</p>	<p>Participants Women with GH (n=23, rr 85%); 6 or 9 months fu (n=15, rr 65%) compared with a control group (n=35)</p> <p>Age (years) Range 18-36, Mean 21.4</p>	<p>Outcome/s of interest Depression Stress Psychosocial effects (HRQoL and Disease specific QoL)</p>

	<p>Questionnaires distributed at baseline, between 6 and 9 months fu</p> <p>Setting Recruited from a University health centre</p>	<p>Gender (Female) 100%</p> <p>Diagnosis Culture proven GH Primary GH (n=20) / Recurrent GH (n=3)</p> <p>Length of time since diagnosis Newly diagnosed primary genital herpes (n=20) previous outbreaks but previously undiagnosed (n=3)</p> <p>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</p>	<p>Outcome measures Symptom Check List-90 Impact of Event Scale College Event Scale HELP Questionnaire</p>
<p>8.Jayasuriya et al. 2014⁵² Sri Lanka</p> <p>To study the psycho-social impact of HSV on patients attending the Central STD Clinic Sri Lanka</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from those attending central STD clinic</p>	<p>Participants Individuals with GH (n=85, rr ns) compared with individuals with other STI without any genital signs and symptoms (n=85)</p> <p>Age (years) Range 18-67, Mean 34 ±10.4</p> <p>Gender (Female) 39%</p> <p>Diagnosis Self-reported primary or recurrent GH</p>	<p>Outcome/s of interest Psychological impact (HRQoL, stigma) Anxiety and Depression</p> <p>Outcome measures General Health Questionnaire Hospital Anxiety and Depression Scale</p>

		<p>Length of time since diagnosis ns</p> <p>Number of recurrences ns</p>	
<p>9. Jadack et al. 1990⁶⁶ USA</p> <p>To examine gender differences in the disease experience of persons who have GH</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from outpatient university clinic and newspaper advertisements</p>	<p>Participants Individuals with GH (n=60, rr ns)</p> <p>Age (years) Mean 31.7±8.1</p> <p>Gender (Female) 56%</p> <p>Diagnosis Self-reported Recurrent GH</p> <p>Length of time since diagnosis Mean 3.5±5.4 (Range 3 months to 31 years)</p> <p>Number of recurrences Mean 6.4±5.5 per year</p>	<p>Outcome/s of interest Differences in stressors by gender⁶⁶ Stressors^{66,67} Coping⁶⁷ Impact of GH⁶⁶</p> <p>Outcome measures Disease stressors questionnaire (AOQ)^{66,67} Coping Orientations to Problems Experienced (COPE) scale⁶⁷ Single impact question (AOQ)⁶⁶</p>
<p>10. Keller et al. 1991⁶⁷ USA</p> <p>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</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p>	<p>Participants Individuals with GH (n=74; rr ns)</p> <p>Age (years) Mean 33.3; range 20-67</p>	<p>Outcome/s of interest Psychosocial consequences Psychological distress</p> <p>Outcome measures</p>
<p>11. Luby and Klinge 1985⁶⁸ USA</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p>	<p>Participants Individuals with GH (n=74; rr ns)</p> <p>Age (years) Mean 33.3; range 20-67</p>	<p>Outcome/s of interest Psychosocial consequences Psychological distress</p> <p>Outcome measures</p>

<p>To investigate the psychosocial and psychological consequences of GH</p>	<p>Setting Recruited from local HELP support group or refereed from two infectious disease practices</p>	<p>Gender (Female) 35%</p> <p>Diagnosis Recurrent GH Viral culture for private practice patients Self-reported for HELP support group subjects</p> <p>Length of time since diagnosis ns</p> <p>Number of recurrences ns</p>	<p>AOQs</p>
<p>12. Manne et al. 1986⁷⁰ USA</p> <p>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</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from across eight herpes self-help groups and volunteer subjects not affiliated with self-help groups, who responded to newspaper advertisements</p>	<p>Participants Individuals with GH (n=152, rr ns) Members of a self-help group (n=116) Community volunteers (n=36)</p> <p>Age (years) Mean 33.4</p> <p>Gender (Female) 61%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis Mean 62 months, Median 50 months</p>	<p>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</p> <p>Outcome measures Modified Ways of Coping Scale Beck Depression Inventory Rosenberg Self-Esteem Scale</p>

		<p>Number of recurrences</p> <p>Mean 8 per year diagnosis <1 year</p> <p>Mean 10 per year diagnosis >1 year</p>	AOQs
<p>13. Mark et al. 2009¹⁴</p> <p>USA</p> <p>To assess the psychosocial well-being and QoL among women newly diagnosed with symptomatic genital HSV</p>	<p>Study design</p> <p>Cross sectional descriptive study</p> <p>Methods</p> <p>Questionnaires</p> <p>Setting</p> <p>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</p>	<p>Participants</p> <p>Women with primary GH (n=83, rr 82%)</p> <p>Age (years)</p> <p>15-24 (31.3%) / 25-34 (37.3%) / 35-44 (20.5%) / 45-54 (4.9%) / ≥ 55 (6.0%)</p> <p>Gender (Female)</p> <p>100%</p> <p>Diagnosis</p> <p>Culture proven primary GH</p> <p>Length of time since diagnosis</p> <p>Diagnosed in the past six months</p> <p>Number of recurrences</p> <p>Not applicable</p>	<p>Outcome/s of interest</p> <p>Anxiety and Depression</p> <p>Disease specific QoL</p> <p>Outcome measures</p> <p>RGHQoL</p> <p>Hospital Anxiety and Depression Scale</p>
<p>14. Patel et al. 2001¹⁷</p> <p>Australia, Denmark, Italy, The Netherlands and UK</p> <p>To quantify the impact of recurrent GH on health related QoL healthcare resource and workplace productivity</p>	<p>Study design</p> <p>Cross sectional descriptive study</p> <p>Methods</p> <p>Questionnaires</p> <p>Setting</p>	<p>Participants</p> <p>Individuals with GH (n=298; rr 97%) and MPS SF-36 compared with population norms</p> <p>Age (years)</p> <p>Mean 34.9; range 18-66</p> <p>Gender (Females)</p> <p>55%</p>	<p>Outcome/s of interest</p> <p>Disease specific QoL</p> <p>HRQoL</p> <p>Depression</p> <p>Outcome measures</p> <p>RGHQoL</p> <p>MOS SF-36</p>

	Recruited from genitourinary or dermatology clinics	<p>Diagnosis Self-reported recurrent GH</p> <p>Length of time since diagnosis Mean 87.2 months</p> <p>Number of recurrences In the last 12 months 2-4 (50%); 5-7 (25%); >7 (25%) Mean 6.0; range 2-36</p>	Three questions depression screen (AOQ)
<p>15. Raj et al. 2011⁵¹</p> <p>India</p> <p>To compare the health related QoL in patients with HIV, genital HPV and HSV-2 infections and apparently healthy controls</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited from a sexually transmitted disease clinic</p>	<p>Participants Individuals with GH (n=60, rr ns) compared to a control group of healthy persons (n=35)</p> <p>Age <30 years (38.3%)</p> <p>Gender (Female) 21%</p> <p>Diagnosis HSV-2 type-specific confirmed with ELISA (Euroimmun glycoprotein G-2-based HSV-2 type-specific ELISA)</p> <p>Length of time since diagnosis 26.1±40 years</p> <p>Number of recurrences ns</p>	<p>Outcome(s) of interest HRQoL</p> <p>Outcome measures WHO QoL instrument</p>

<p>16. Silver et al. 1986²⁶ USA</p> <p>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</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting Recruited via media announcements and the local HELP support group</p>	<p>Participants Individuals with GH (n=66)</p> <p>Age (years) Range 20-65, Mean 33</p> <p>Gender (Female) 53%</p> <p>Diagnosis Self-reported GH (n=13) Culture proven GH (n=10) Diagnosed by clinical inspection (n=16) No information provided (n=27)</p> <p>Length of time since diagnosis Range 6 months – 8 years Mean 4 years</p> <p>Number of recurrences Mean 9.9 per year</p>	<p>Outcome/s of interest Psychopathology (HRQoL) Life experiences (HRQoL) Coping Social support</p> <p>Outcome measures SCL-90 Life Experiences Survey Ways of Coping Checklist Social Support Index</p>
<p>17. Swanson et al. 1995⁷³ USA</p> <p>To determine the disease characteristics and psychosocial factors in young adults with GH</p>	<p>Study design Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>Setting</p>	<p>Participants Individuals with GH (n=70, rr ns) compared with population norms</p> <p>Age (years) Mean 28.7 ± 4.7</p> <p>Gender (Female) 59%</p>	<p>Outcome/s of interest Stress Depression Self-Concept Psychopathology (HRQoL)</p> <p>Outcome measures</p>

	Recruited from newspaper advertisements and the offices of health professionals (excluding mental-health service)	<p>Diagnosis GH confirmed</p> <p>Length of time since diagnosis Range 1-15 years / Mean 5.01 years \pm 3.31</p> <p>Number of recurrences ≥ 1 no further details reported</p>	<p>Authors' Genital Herpes Questionnaire</p> <p>Symptom Check List-90</p> <p>Beck Depression Inventory</p> <p>Daily Hassles Scale</p> <p>Uplifts Scale</p> <p>Tennessee Self Concept Scale</p>
<p>18. Stronks et al. 1993⁵⁰</p> <p>Netherlands</p> <p>To investigate the psychological consequences of GH compared to those with a curable STD</p>	<p>Study design Cross sectional descriptive study</p> <p>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</p> <p>Setting Recruited from an outpatient department</p>	<p>Participants Individuals with GH (n=27; rr ns)</p> <p>Age (years) Mean 31.4\pm3.6, range 23-47</p> <p>Gender (Female) 22%</p> <p>Diagnosis Self-reported GH</p> <p>Length of time since diagnosis ns</p> <p>Number of recurrences ns</p>	<p>Outcome(s) of interest Sexuality Relationship with partner Anxiety Self-esteem Psychological-somatic complaints (HRQoL)</p> <p>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</p>
19. Taboulet et al. 1999²²	Study design	Participants	Outcome/s of interest

<p>France</p> <p>To assess psychological morbidity in France related to GH infection in comparison with a group of control patients</p>	<p>Cross sectional descriptive study</p> <p>Methods Questionnaires</p> <p>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</p>	<p>Individuals with GH (n=150; rr 77%) compared to a control group representative of general population (n= 200)</p> <p>Age (years) Less than 25-65 (8%), 25-34 (21%), 35-49 (30%), 50-64 (23%), ≥65 (18%)</p> <p>Gender 74%</p> <p>Diagnosis Confirmed GH</p> <p>Length of time since diagnosis ≥6 years (45%); ≥ 10 years (25%)</p> <p>Number of recurrences In the last 12 months None (7%); 1-2 (47%); 3-5(26%). More than 5 (13%); Can't remember (7%)</p>	<p>Disease specific QoL HRQ0L</p> <p>Outcome measures Herpes Specific Scale MOS SF-36</p>
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2206 Key: AOQ: authors own questionnaire; fu: follow up; GH: genital herpes; HELP: a self-help organization for individuals with herpes; HIV: human
2207 immunodeficiency virus; HSV: herpes simplex virus; MOS SF-36: Medical Outcome Study 36-tem Short Form Health Survey; ns: not specified;
2208 NHS: National Health Service; QoL: Quality of Life; RCT: randomised controlled trial; RGHQoL: Recurrent Genital Herpes Quality of Life Scale; rr:
2209 response rate; SCL-90: Symptom Check List-90; SOFRES: Société française d'enquête par sondage; STD: sexually transmitted disease; WHO:
2210 World Health Organisation

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

Study /Country Aim Phenomena of interest	Methods	Participant characteristics Setting
<p>1. Bickford et al. 2007⁵⁴ UK</p> <p>To assess the nature and effect of stigma on disclosure of diagnosis to sexual partners among those with problematic disease</p> <p>Phenomena of interest Stigma Concerns regarding disclosure</p>	<p>Study design Qualitative descriptive survey as part of wider mixed methods study</p> <p>Methods Questionnaires</p>	<p>Participants: Individuals with GH (n=6, rr ns)</p> <p>Age (years): ns</p> <p>Gender: ns</p> <p>Diagnosis: Self-reported GH</p> <p>Length of time since diagnosis Median time since diagnosis 78 months (IQR 41-192 months)</p> <p>Number of recurrences: ns</p>
<p>2. Drob et al. 1985⁵³ USA</p> <p>To investigate the psychological consequences of GH</p> <p>Phenomena of interest Social context of GH</p>	<p>Study design Qualitative descriptive survey as part of wider mixed methods study</p> <p>Methods Interviews</p>	<p>Participants: Individuals with herpes (n=35., rr ns)</p> <p>Age (years): ns</p> <p>Gender: ns</p> <p>Diagnosis: Self-reported GH</p> <p>Length of time since diagnosis: ns</p> <p>Number of recurrences: ns</p>
<p>3. Kelley 1999⁷¹ USA</p>	<p>Study design Qualitative descriptive study</p>	<p>Participants: Individuals with GH (n=8, rr ns)</p>

<p>To evaluate changes in the QoL from the perspective of the person for patients suffering from GH</p> <p>Phenomena of interest QoL; Disclosure Discomfort / comfort</p>	<p>Methods Focus groups</p> <p>Setting Recruited through newspaper ads and the local American health Association self-help group for people with GH</p>	<p>Age (years): 26-42</p> <p>Gender (Female): 50%</p> <p>Diagnosis: Self-reported GH</p> <p>Length of time since diagnosis: ns</p> <p>Number of recurrences: ns</p>
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2212 **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 2007⁵⁴	
Finding 1	Disclosure to sexual partners: Relates to the value placed on the relationship (U)
Illustration	<i>"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"</i> (p591)
Finding 2	Stigma: Association of STIs with moral wrong and punishment (U)
Illustration	<i>"I feel like a leper. I hate it because it won't go away. Six years feels like a sentence"</i> (p591)
Finding 3	Stigma: Impact of diagnosis of herpes (U)
Illustration	<i>"I was very shocked and...ashamed...I thought oh my God what have I got...I felt ashamed..."</i> (p591)
Finding 4	Stigma: Rejection or fear of rejection because of herpes (U)
Illustration	<i>"I felt I was now tainted and wouldn't be able to find anyone"</i> (p591)
Finding 5	Stigma: Diagnosis is linked with sexual promiscuity (U)
Illustration	<i>"...it just seemed like dirty or, you know, promiscuous people that got it..."</i> (p591)
Finding 6	Stigma: Rejection linked with sexual deviance, promiscuity and general 'badness' (U)
Illustration	<i>"I mean I'm not a slapper...I haven't been putting it around"</i> (p591)
Finding 7	Stigma: Skin eruptions are a 'mark' (U)
Illustration	<i>"I also hate the scars it has left on my penis as it's noticeable"</i> (p591)
Study: Kelley 1999⁷¹	
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	<i>"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."</i> (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>"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."</i> (p67)
Study: Drob et al 1985⁵³	
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	<i>"One 31-year-old man stated that because of genital herpes he had become a "sexual hermit for 10 years""</i> (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>"I can't let go in sex anymore"</i> (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 <i>"a handicapped single"</i> "(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>"I'd kill a sex partner who gave me herpes"</i> (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	<i>"One woman stated that a couple she had been friendly with had avoided her since she revealed to them she had herpes"</i> (p310)
Finding 38	Interpersonal relationships: Many of the subjects regarded the possibility of non-sexual transmission of herpes as creating interpersonal tensions (U)
Illustration	<i>"People I've told started getting very anxious about things like the toilet seat and the bar of soap ..."</i> (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>"I'd like to say I've become more sensitive to others but I've really become more callous ..."</i> (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	<i>"A number of subjects reported being <i>"profoundly depressed"</i>"</i> (p311)
Finding 44	Emotional responses: Most regarded herpes as a personal handicap and as a loss of a portion of themselves (U)
Illustration	<i>"It sounded like I was announcing a death in the family when I first told my girlfriend"</i> (p311)
Finding 45	Emotional responses: Some subjects reported being angry as a result of contracting genital herpes (U)
Illustration	<i>"I'm furious that the person I think gave it to me, refused to even get a blood test to confirm he had it!"</i> (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	<i>"contaminated", "ugly", "inferior", "damaged"</i> (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
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2214 Key: C: credible; NS: not supported; U: unequivocal

2215