

Instruments for quality of life assessment in individuals with human papillomavirus

Instrumentos para avaliação da qualidade de vida em indivíduos com papilomavírus humano
Instrumentos para evaluación de la calidad de vida en individuos con papillomavirus humano

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ABSTRACT

Objective: To identify scientific evidence on quality of life measurement instruments used in individuals with infections caused by human papillomavirus. **Method:** This was an integrative review carried out from April 1995 to March 2017 in the LILACS, SciVerse Scopus, ISI Web of Science, CINAHL, and PubMed databases. The controlled descriptors adopted were: *Infeções por Papilomavírus; Qualidade de Vida; Papillomavirus Infections; and Quality of Life*. **Results:** Of the 416 articles found, 12 were selected. Thirteen different types of instruments to evaluate the quality of life of individuals with human papillomavirus were identified, in that nine were generic and four specific. **Conclusion:** Different generic and specific instruments were used to evaluate the quality of life of individuals with human papillomavirus, which means no consensus or preference among the studies was identified. However, a lack of use of specific instruments to evaluate this construct in this population was observed.

Descriptors: Quality of Life; Papillomavirus Infections; Sexually Transmitted Diseases; Psychometrics; Scales.

RESUMO

Objetivo: Identificar as evidências científicas acerca dos instrumentos utilizados para a mensuração da Qualidade de Vida em indivíduos com infecções causadas pelo Papilomavírus Humano. **Método:** Trata-se de uma revisão integrativa realizada no período de abril de 1995 a março/2017, nas bases de dados online LILACS, SciVerse Scopus, ISI Web of Science, CINAHL e PubMed. Os descritores controlados adotados foram: *Infeções por Papillomavírus; Qualidade de Vida; Papillomavirus Infections e Quality of Life*. **Resultados:** Foram encontrados 416 artigos, dos quais 12 foram selecionados. Identificaram-se 13 diferentes tipos de instrumentos para avaliar a Qualidade de Vida de pessoas com Papilomavírus Humano, nove genéricos e quatro específicos. **Conclusão:** Identificamos que diferentes instrumentos, genéricos e específicos, são utilizados para avaliar a Qualidade de Vida das pessoas com Papilomavírus Humano, sugerindo não haver consenso ou preferência entre os estudos identificados. Porém, observa-se a carência no uso de instrumentos específicos para avaliação desse construto nessa população.

Descritores: Qualidade de Vida; Infecções por Papilomavírus; Doenças Sexualmente Transmissíveis; Psicometria; Escalas.

RESUMEN

Objetivo: Identificar evidencias científicas sobre los instrumentos utilizados para medir la Calidad de Vida en individuos con infecciones causadas por Papillomavirus Humano. **Método:** Revisión integrativa realizada entre abril de 1995 y marzo de 2017, en las bases online LILACS, SciVerse Scopus, ISI Web of Science, CINAHL y PubMed. Los descriptores controlados adoptados fueron: "Infecciones por Papillomavirus", "Calidad de vida", "Papillomavirus Infections" y "Quality of Life". **Resultados:** Fueron hallados 416 artículos, de los que 12 resultaron seleccionados. Se identificaron 13 tipos diferentes de instrumentos para evaluar Calidad de Vida en personas con Papillomavirus Humano, nueve genéricos y cuatro específicos. **Conclusión:** Identificamos que son utilizados diferentes instrumentos, genéricos y específicos, para evaluar la Calidad de Vida de las personas con Papillomavirus Humano, sugiriendo inexistencia de consenso o preferencia entre los estudios identificados. No obstante, se observa la escasez del uso de instrumentos específicos para evaluación de dicho construto en esta población.

Descritores: Calidad de Vida; Infecciones por Papillomavirus; Enfermedades de Trasmisión Sexual; Psicometría; Escalas.

INTRODUCTION

Human papillomaviruses (HPV) are viruses with the capacity to infect skin or mucous membranes. There are more than 150 different types of HPV, of which 13 are considered oncogenic, offering a higher probability or risk of causing persistent infections and being related to precursor lesions⁽¹⁾. Types 16 and 18 are responsible for most cases of cervical cancer (approximately 70%), whereas types six and 11 are responsible for approximately 90% of genital warts. In addition, HPV may lead to the incidence of oropharynx tumors, which can be benign or malignant⁽²⁾.

The Information Centre on HPV and Cervical Cancer (ICO) estimates that six million people around the world are infected by HPV; of these, 2.5 million are women aged 15 years or more⁽³⁾. HPV is a great precursor for cervical cancer, classified as the third greatest and most common type of cancer among women worldwide⁽³⁾. In Brazil, 16,340 new cases of cervical cancer were predicted for 2016, with an estimated risk of 16.34 cases per each 100,000 women⁽¹⁾.

Genital infections by HPV have a significant impact on quality of life (QoL), especially when associated with the incidence of warts⁽⁴⁾. QoL assessment in individuals with HPV has been reported as an important strategy to direct interventions regarding physical, psychosocial, and economic impact⁽⁴⁻⁷⁾.

The theme of QoL has been widely discussed in the literature. The World Health Organization Quality of Life (WHOQOL) group defines QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"⁽⁸⁾.

In 1995, this same group developed an instrument to evaluate the QoL of the general population⁽⁸⁾ and, later, the WHOQOL-HIV-bref for people living with HIV/AIDS⁽⁹⁾, after verifying the need for the development of specific instruments.

The QoL assessment among HPV carriers has been guided by different generic or specific instruments^(4-7,10-17).

OBJECTIVE

To identify scientific evidence from QoL measurement instruments used in individuals with infections caused by HPV.

METHOD

This was an integrative literature review, which consisted of one of the research methods used in evidence-based practice. Its purpose was to gather and synthesize, in a systematic and organized way, research results on a specific topic or matter, in order to deepen knowledge on the theme researched⁽¹⁸⁾.

The present study was conducted in accordance with the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁽¹⁹⁾.

The PICO⁽²⁰⁾ strategy was used for the development of the guiding question, with P: individuals with HPV; I: QoL measurement instruments; C: comparison of these instruments with other possible instruments; and O: instruments used to measure QoL in individuals with infections caused by HPV. This led to the following guiding question: Which instruments have been used to measure QoL in individuals with infections caused by HPV?

The search was carried out in the LILACS (Latin American Literature and Caribbean Health Sciences Literature), SciVerse Scopus, ISI Web of Science, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and PubMed databases, with the following controlled descriptors (DeCS and MeSH): *Infecções por Papillomavirus*, *Qualidade de Vida*; Papillomavirus Infections; and Quality of Life.

Cross-checking of the descriptors was carried out with the use of the Boolean AND: *Infecções por Papillomavirus AND Qualidade de Vida*; Papillomavirus Infections AND Quality of Life.

The inclusion criteria were: Full original articles that approached QoL and HPV, published in English, Spanish, or Portuguese. Those with secondary data and those repeated in the databases were excluded, because these included those found in the first database searched.

According to specific characteristics of each of the five databases selected, strategies to search the articles were adapted, with the guiding question and previously established inclusion criteria as the central axis. Limited publication periods were not determined.

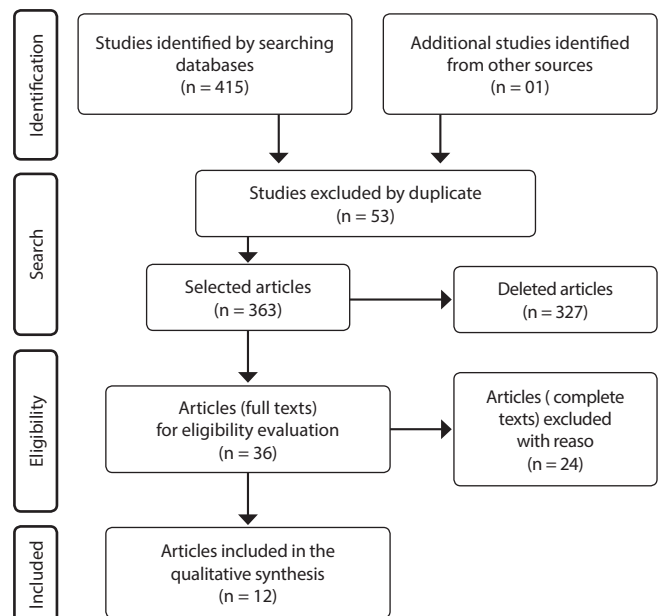


Figure 1 – Diagram of search and selection of the studies according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁽¹⁹⁾, 2017

For extraction of the information from the articles selected, an adapted instrument was used, which comprised the main data to be extracted from the article, such as identification, introduction, objectives, and results found, in addition to indicating the framework of evidence levels⁽²¹⁾.

The evidence level of the studies was organized by means of evaluation of their methodological design: Level I – evidence from systematic reviews or meta-analysis of multiple controlled and randomized clinical studies; Level II – evidence from at least one well-designed controlled randomized clinical trial; Level III – evidence from well-designed non-randomized clinical trials; Level IV – evidence from well-designed cohort and case-control studies; Level V – evidence from systematic reviews by means of descriptive and qualitative methodologies; Level VI – evidence from

only one descriptive or qualitative study; and Level VII – evidence from concepts of authorities or report of expert committees⁽²²⁾.

RESULTS

The articles selected were found in nine scientific journals from different healthcare areas, with the first publication dated April 1995.

With regard to the settings of the studies, five (42%) were carried out in hospitals; four (33%) in specialized care centers; one (8%) through newspaper advertisement; and two (17%) did not report.

Regarding data collection, two (17%) articles made use of only one QoL assessment instrument; two (17%) were carried out with two instruments; and the remaining (66%) made use of three or

more instruments. It is worth mentioning that only seven (58%) made use of combined instruments (specific and generic) and five (41%) used only generic instruments.

The synthesis is presented in Chart 1, organized according to title; year of publication; objective; instrument used; and the main results of each study.

When proceeding with the analysis of evidence level, ten studies (1, 2, 3, 4, 6, 7, 8, 9, 10, 11), according to Chart 1, presented evidence level IV (nine case-control studies and one cohort study) and two descriptive studies (5, 12) presented evidence level VI.

When analyzing the sample selected, thirteen different types of instruments to evaluate the QoL of individuals with HPV were identified, among which, nine were characterized as generic and only four as specific, as shown in Chart 1.

Chart 1 - Publications included in the integrative literature review, 2017

N	Title/Year of publication	Objective	Instruments used	Main results
1	Impact of human papillomavirus-related genital diseases on quality of life and psychosocial wellbeing: results of an observational, health-related quality of life study in the UK ⁽¹⁶⁾ 2013	To evaluate the psychosocial burden and impact of HPV lesions and genital warts on QoL in the United Kingdom, with the use of specific instruments.	HIP ^I EQ-5D ^{II} / EQ-VAS ^{III} CECA-10 ^{IV} CSFQ ^V	HPV-related lower genital lesions caused a negative impact on the QoL and psychosocial well-being of women. Women with neoplasms caused by HPV reported depression, anxiety, pain, discomfort, and mobility and self-care problems.
2	Impact of genital warts on health related quality of life in men and women in mainland China: a multicenter hospital-based cross-sectional study ⁽⁶⁾ 2012	To measure the impact of genital warts on the QoL of men and women in mainland China, with the use of the EQ-5D generic instrument.	EQ-5D/ EQ-VAS	Patients with genital warts presented reduced QoL. Women reported more problems related to anxiety/depression, pain/discomfort, and mobility when compared with men.
3	The impact of anogenital warts on health-related quality of life: A six-month prospective study ⁽¹³⁾ 2011	To evaluate changes caused by anogenital warts in QoL over time. To estimate prospectively the QoL lost due to anogenital warts.	EQ-5D/ EQ-VAS HIP SF-36 ^{VI} SF-12 ^{VII}	Anogenital warts have negative and significant psychosocial impacts on these patients' lives.
4	Health-related quality of life in patients with anogenital warts ⁽¹⁴⁾ 2011	To evaluate QoL in patients with anogenital warts at the time of diagnosis and during one month of follow-up.	SF-36	Patients with anogenital warts presented an improvement in vitality and mental health between the time of diagnosis and one month after the beginning of the treatment. However, it was not possible to determine the influence on the QoL of these patients.
5	Quality of life in patients with anogenital warts ⁽¹⁷⁾ 2013	To describe the health condition of patients with genital warts and evaluate the impact of the disease on QoL, with the use of specific and generic dermatological instruments.	SF-36 Skindex-29 ^{VIII} GHQ-12 ^{IX}	The presence of anogenital warts may substantially influence QoL, causing significant mental alterations.
6	The impact of genital warts: loss of quality of life and cost of treatment in eight sexual health clinics in the UK ⁽¹⁵⁾ 2011	To estimate QoL loss and care cost for economic evaluations of vaccination against HPV.	EQ-5D/ EQ-VAS	The greatest damages to the QoL of the participants in the study were found in the pain and anxiety dimensions, indicating moderate or extreme problems such as anxiety or depression and pain or discomfort.
7	Impact of HPV vaccination on young women's quality of life—A five year follow-up study ⁽⁴⁾ 2011	To evaluate the impact of vaccination against HPV on the QoL of a population of vaccinated and unvaccinated young women aged from 16 to 18 years, five years after vaccination.	RAND-36 ^{IX} EQ-5D/ EQ-VAS CECA10	HPV genital infections have a significant impact on the QoL of young women.

To be continued

Chart 1 (concluded)

N	Title/Year of publication	Objective	Instruments used	Main results
8	The psychological impact of illness among women experiencing human papillomavirus-related illness or screening interventions ⁽¹²⁾ 2010	To quantify the psychological impact among women diagnosed with different results of health status or HPV infection, through Papanicolaou screening test or HPV test, with the use of the HPV impact profile (HIP).	HIP	The group of women with normal Papanicolaou tests achieved lower scores and lower psychological impact. The group of women with genital warts presented significant increases in scores compared with all other groups, indicating a greater psychosocial burden.
9	Patients with genital warts have a decreased quality of life ⁽⁵⁾ 2009	To measure the decrease in QoL associated with genital warts, with the use of the SF-6D and EQ-5D instruments.	SF-6D ^{xi} EQ-5D/ EQ-VAS	When compared with the uninfected population, the participants in the study had a much lower mean score, indicating worse QoL.
10	Estimation of the impact of genital warts on health-related quality of life ⁽¹¹⁾ 2008	To provide data on the impact of genital warts on QoL, to be used in the evaluation of the effective cost of HPV vaccination.	EQ-5D/ EQ-VAS CECA-10	Genital warts are associated with a significant impairment in QoL, especially regarding psychological alterations such as anxiety and depression.
11	Impact of an HPV diagnosis on the quality of life in young women ⁽¹⁰⁾ 2007	To evaluate the impact of the communication of an HPV diagnosis in the cognitive aspect, performance, emotional experiences, psychological/physical well-being, and psychosexual sphere on young women aged between 20 and 45 years.	CBA 2.0 ^{xii} SAT-P ^{xiii} BISF-W ^{xiv}	An HPV diagnosis creates impacts on young women's lives, causing higher levels of anxiety, obsessions, compulsive behaviors, and concerns.
12	Impact of genital warts on emotional and sexual well-being differs by gender ⁽⁷⁾ 2014	To verify the existence of significant factors that have a different impact on the QoL of women with genital warts in comparison with the QoL of men with genital warts.	EQ-5D/ EQ-VAS CECA-10	Genital warts have a higher impact on women than on men. In women, sexual and clinical factors influenced the impact of genital warts on well-being, whereas in men, none of these factors were found.

Note: ⁱHPV Impact Profile; ⁱⁱEuropean Quality of Life Index Version 5D; ⁱⁱⁱEuropean Quality Visual Analogue Scale; ^{iv}Cuestionario Especifico en Condilomas Acuminados; ^vChange in Sexual Functioning Questionnaire; ^{vi}Short Form-36; ^{vii}Short Form-12; ^{viii}Skindex-29; ^{ix}General Health Questionnaire; ^xRAND 36-Item Health Survey; ^{xi}Short-Form 6 Dimensions; ^{xii}Cognitive Behavioral Assessment 2.0; ^{xiii}Satisfaction Profile; ^{xiv}Brief Index of Sexual Functioning for Woman.

DISCUSSION

It was observed that most studies that used QoL assessment instruments in individuals with infections caused by HPV reported that these genital infections have a negative impact on QoL regarding social, affective/sexual, and psychological aspects^(4-7,11-13,15-16).

With regard to the difference among genders, it was shown that HPV causes more damages among women than men⁽²³⁾. Women reported more complaints, especially depression and anxiety in the face of HPV diagnoses⁽⁶⁻⁷⁾. The following instruments found for QoL assessment in individuals with infections caused by HPV were most generic: EQ-5D/EQ-VAS; SF-36; SF-12; RAND-36; SF-6D; CBA 2.0; SAT-P; BISF-W; and GHQ-12.

The EQ self-administered questionnaire was developed in 1987 in the Netherlands, with the purpose of measuring the impact of a specific disease on the general health status. It includes the EQ-5D index and the EQ-VAS analogical scale. The EQ-5D index is based on a classification system that presents health in five dimensions: anxiety/depression; self-care; mobility; pain/discomfort; and normal activities, whereas the EQ-VAS evaluates the momentary health status on a 0-100 scale⁽²⁴⁾. In the sample selected, the use of the EQ-5D self-administered questionnaire was observed in eight studies^(4-7,10,12,14-15).

Considering that generic questionnaires may be applied in several situations, the EQ-5D instrument was used to evaluate QoL in older adults submitted to hip reconstruction surgeries⁽²⁵⁾. This instrument was validated into Portuguese, showing good

acceptability and validity in the health status measurement of individuals with different pathologies such as cataract, asthma, chronic obstructive pulmonary disease, and rheumatoid arthritis⁽²⁶⁾.

The SF-36 instrument was developed in the United States and validated into Portuguese in 1999, presenting appropriate validity and reliability. It consists of 36 items distributed in eight dimensions: general health status; functional capacity; social aspects; physical aspects; mental health; emotional aspects; pain; and vitality⁽²⁷⁾. In the findings of the present study, the SF-36 and its derivations (SF-12 and SF-6D) were applied to individuals diagnosed with HPV on four occasions; however, their use may be observed in other situations^(5,13-14,16). The SF-12 instrument was used in a global multicenter study involving five continents for QoL assessment in people living with HIV/AIDS⁽²⁸⁾.

The CSFQ is an instrument developed in the United States in 1997. It consists of 36 items distributed in five sexual functioning scales and includes a demographic section. Using a 5-point Likert-type scale, the CSFQ offers patients the opportunity to self-evaluate their sexual behaviors or problems in several areas. It presents satisfactory reliability and validity, presenting a 0.89 Cronbach's alpha coefficient for the male version and 0.90 for the female version⁽²⁹⁾.

The GHQ is a self-administered questionnaire with Likert-type responses with the purpose of detecting minor psychiatric disorders in community and primary healthcare environments. The version containing 12 items (GHQ-12) is the most used⁽³⁰⁾. The study that used the GHQ-12 instrument showed that GHQ-12

“positive” patients, that is, with a chance of development minor psychiatric disorders, presented worse QoL scores when compared with GHQ-12 “negative” patients⁽¹⁷⁾.

The CBA-2.0 questionnaire was developed by Italian psychologists and makes use of computer programs of psychological tests for behavioral therapy use. It consists of a series of nine cards that measure cognitive/behavioral aspects⁽³¹⁾. Among the findings in the use of this instrument, a significant increase in anxiety and fear shown at the time of diagnosis was found⁽¹⁰⁾.

The RAND self-administered questionnaire, developed in the Netherlands in 1992, aims at measuring different health aspects, such as physical functioning, energy, emotional well-being, pain, and social functioning; it is not specific for any disease, and, due to its extension, was reduced to a 36-items version called RAND-36. It consists of eight dimensions: physical limitations; pain; physical functioning; general health perception; social functioning; vitality; mental health; and change in habits. The internal consistency of the RAND-36 presented good results, with discriminant and convergent validity widely supported by the data⁽³²⁾.

The SAT-P allows subjective QoL satisfaction measures, by means of an analytical score of 32 items distributed in five areas: physical functionality; social functionality; work; psychological functionality; and free sleep/nutrition time⁽³³⁾.

The BISF-W self-assessment questionnaire, which measures sexual functioning for women, consists of 22 questions of 49 items that evaluate quantitative and qualitative aspects of sexual behavior.

The questionnaire consists of seven dimensions (pleasure/orgasm; thought/fantasy; frequency, receptivity/initiative; problems; arousal; and satisfaction) and four factors (self-erotic sexuality; anal sexuality; couples' sexuality; and satisfaction/dissatisfaction)⁽³⁴⁾. Legitimizing the importance of the use of specific instruments, one of studies analyzed, making use of the SF-36 generic instrument, found that QoL was not influenced in patients with anogenital warts and recommended the use of specific instruments for the measurement of this construct in HPV carriers⁽¹⁴⁾. However, in the present study, only the following four specific instruments to evaluate QoL in individuals with infections caused by HPV were found: the CECA-10; the HIP; the Skindex-29; and the CSFQ.

The CECA-10 and the HIP were used in six studies^(4,7,12-14,17). The CECA-10 was developed in Spain in 2005, with the purpose of evaluating the QoL of patients with genital warts; it consists of 10 items distributed in two dimensions: sexual and emotional. The instrument presents satisfactory reliability and validity⁽³⁵⁾. However, the HIP, developed in the United States in 2009, was specifically developed to measure the psychosocial burden in women with diseases associated with HPV. It consists of 29 items distributed in seven dimensions: health control; problems and concerns; sexual impact; emotional impact; issues related to partners and transmission; impact on life; interactions with physicians; and self-image. The HIP presents a Cronbach's alpha between 0.64 and 0.90, thus showing a satisfactory reliability⁽³⁶⁾.

The Skindex is a specific QoL assessment instrument used in dermatology, with the capacity of measuring the effects of skin diseases on patients' lives over the last four weeks. This specific dermatology questionnaire has been widely studied and improved in different populations. It is structured in eight scales: physical discomfort; cognitive effects; depression; anger; social effects;

fear; physical limitations; and constraint. The Cronbach's alpha of the eight scales ranged from 0.76 to 0.86, thus presenting consistent reliability⁽³⁷⁾. The effects of the Skindex-29 in terms of specific dermatological aspects were less expressive, but still represented a negative impact on the emotional state of sick patients⁽¹⁷⁾. Similar results were observed in Dutch soldiers when indicating the negative influence on QoL, especially regarding shame, concern, and intimacy⁽³⁸⁾.

Few studies have used specific instruments to quantify the impact of infections caused by HPV on QoL⁽³⁹⁾. Specific instruments for each disease or situation are required to measure the QoL construct, not just for greater urgency, but to ensure the sensitivity of small yet clinically significant alterations in health conditions and severity levels of the disease⁽⁴⁰⁾.

Study limitations

Considering the objective presented, the possibility of the occurrence of gaps is not disregarded, because other studies approaching the theme in question may use different keywords from those used in the present study.

Contributions to the healthcare and nursing area

The present study brings relevant reflections for the nursing area, such as the importance of the availability of specific instruments to measure QoL, especially in patients with HPV infections, because the early identification of symptoms such as anxiety, sadness, discouragement, and depression may contribute to referrals and prompt interventions, thus minimizing future complications.

In addition, the use of QoL assessment instruments provides further information to healthcare professionals about the health status of patients, which complements clinical results, facilitating communication among healthcare professionals and promoting an understanding of the problems experienced, thus benefiting the assessment of the impact of the disease.

It is worth mentioning that, considering the increasing involvement of nurses in the development and validation of research instruments, the results of the present study encourage the development of specific instruments for assessment of this construct.

CONCLUSION

The instruments found presented satisfactory psychometric properties; however, it was observed that there was a lack of specific instruments to measure QoL in individuals with infections caused by HPV.

However, even making use of different instruments, most studies described a worsening of the QoL of individuals with HPV infections influenced by psychosocial and health-related factors.

Therefore, identifying characteristics and peculiarities of instruments used to evaluate the QoL of patients with HPV contribute to their application in daily practice, enabling the improvement of quality of care.

Consequently, for a greater sensitivity to peculiar factors, encouraging the use of specific QoL assessment instruments in HPV carriers is of utmost importance.

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