Health and Quality of Life Outcomes

REVIEW

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Exploring assessment measures including psychological aspects in adults with acquired Peripheral Facial Palsy (PFP): a scoping review

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Abstract

Introduction Given the lack of specific assessment measures and consensus on how to evaluate the psychological aspects of acquired peripheral facial palsy, this study aimed to identify the existing instruments in current use, as well as the key psychological domains considered. A secondary objective was to identify mental health-related areas not addressed or under-represented by those instruments.

Method A scoping review was conducted to identify assessment measures, their underlying dimensions, and frequency of use. Findings were thematically synthesized across specific areas and grouped by consensus among the three authors to identify key domains for evaluating facial palsy.

Results 46 instruments were identified, also capturing social and quality-of-life aspects often closely linked to psychological factors. Their dimensions were classified into five generic areas: health-related quality of life perception, symptomatology (emotional and physical), appearance-related matters, intrapersonal and social skills, and care experience. Analysis of the items led to the identification of specific areas, which were classified by relevance into six broader psychosocial domains: (1) social functioning, (2) emotional symptomatology, (3) facial palsy- related QoL, (4) general health-related QoL, (5) psychological functioning, and (6) care experience-satisfaction. The FDI, FaCE, followed by the SF-36, and HADS emerged as the most used instruments.

Conclusions The results showed a lack of consensus due to the heterogeneity of the instruments retrieved for the evaluation of psychological outcomes. This review identified under-represented psychological areas, such as social and appearance-related anxiety, body self-perception, and experience of the care process which may warrant further evaluation. Several of the instruments retrieved were general rather than facial palsy-specific, which could not fully address the specific psychological needs of adults suffering with acquired peripheral facial palsy.

Keywords Peripheral facial palsy, Assessment, Instrument, Psychological, Psychosocial

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Introduction

Peripheral Facial Palsy (PFP) has diverse aetiologies, with Bell's palsy accounting for the largest percentage of cases with acute onset. It results in weakness or complete paralysis of the facial muscles due to an injury of the seventh cranial nerve [1]. It is the most prevalent cranial mononeuropathy, with an incidence of approximately 32 cases per 100,000 inhabitants per year [2]. When the nerve damage happens after the facial nerve nucleus in the pons, it is classified as a peripheral palsy or lower motor neuron lesion. It affects both the upper and lower regions of the face on the same side as the lesion, in contrast to central facial palsy (or upper motor neuron lesion), which typically affects only the lower region of the face on the side opposite the lesion [3]. Significant improvement usually occurs within the first three weeks, with another phase of recovery around 3–6 months post-onset, depending on the cause and severity of the injury. However, if recovery is not evident within this period, the potential for spontaneous recovery diminishes. Around 20–30% of the cases result in varying degrees of permanent disability [2, 4].

PFP can be attributed to congenital or acquired causes, being present from birth or occurring during an individual's lifetime. It is important to note that individuals with acquired facial palsy seem to be at a higher risk of experiencing socioemotional challenges, as they tend to show a lower level of adaptation compared to adults with congenital facial palsy [5]. People with acquired disabilities grieve their loss of function, as they have not yet incorporated their disability into their self-concept, reporting lower satisfaction with life [6]. The face can shape identity, self-perception, and social experiences. It is of paramount significance as it is a source of vocal communication, the expression of emotions, and the revealer of personality traits. 'The face is the person himself', wrote Frances Cooke Macgregor, a social anthropologist who studied facial deformity in the 1940s [7]. Her work opened a field in which medical science, psychiatry, psychology, and sociology could combine to better understand the mental health risks related to a visible facial disfigurement like facial palsy.

Even minor facial irregularities can lead to significant social stigma, discrimination, and psychological distress [8]. Recent studies suggest that the severity of facial palsy may not fully explain the reduction in quality of life and psychological well-being. Consequently, the severity assessment, measured using clinician-graded instruments, might not reliably predict levels of psychological distress [9–14].

Patients afflicted by facial palsy not only report concerns related to facial function, such as eye closure deficits leading to corneal exposure and eye dryness, oral incompetence with difficulties when eating, drinking and speaking, and even nasal obstruction, but also difficulties in conveying emotions and the negative impact of their altered facial expressions on social interactions [15–18]. Patients, primarily women and younger people, describe feelings of shame and fear of facing negative judgments based on their looks. It is worth noting that patients tend to conceal their disfigurement and avoid social interactions [19, 20]. Furthermore, a prevalence of mild to moderate anxiety and depression disorders [14, 21–24], along with restricted sleep quality [25], has been found in this population.

As documented in several qualitative studies, patients reported the need for increased social support and better health care provision including psychological intervention, mainly to cope with unwanted comments, questions and staring, along with the grief for the loss of the old self and the difficulties integrating the old and the new identity [26–28].

In 2014, the Sir Charles Bell Society, a multidisciplinary organization established in 1992 with a professional and scientific interest in the facial nerve, conducted a study showing that 42% of members did not routinely include a patient-reported outcome measure (PROM) in evaluations, whereas only 5% did not use a facial nerve function grading system [29]. This may be explained because a better consensus on how to objectively measure facial nerve damage has been reached through the widespread adoption of the Sunnybrook Facial Grading Scale [30].

Previous studies have addressed a conceptual framework covering outcomes that matter to patients with PFP, including psychological aspects, self-perception of appearance and social perception [13, 28]. However, facial palsy-specific PROMs currently available, such as the 'Facial Clinimetric Evaluation Scale' (FaCE) and the 'Facial Disability Index' (FDI), appear to lack coverage of those outcomes [31].

The aim of this study is to conduct a Scoping Review (ScR) to identify instruments used to assess the psychological aspects of adults who have acquired peripheral facial palsy. Specifically, the objective is to identify the principal domains of interest assessed by clinicians and researchers in this field, and to highlight potentially under-explored domains that may hold relevance in evaluating mental health risks among adults with PFP.

Method

We conducted a Scoping Review (ScR) to systematically map existing trends in the use of psychological measures for assessing adults with acquired peripheral facial nerve damage. The review also examined the frequency of psychological aspects that have been considered in the evaluation of this population. This study was registered with Open Science Framework in October 2023 [https://doi.org/10.17605/OSF.IO/KNAQM].

Search strategy and databases

A ScR was conducted according to Joanna Briggs Institute guidelines [32]. Web of Science, PubMed, Scopus, EBSCOHost, ProQuest, and Lilacs/BVS databases were included, considering literature from January 2000 to October 2023 in English, Spanish, and Italian languages. The search strategy was based on terms associated with assessment measures used within our target population, with a focus on the psychological aspects. For the extraction of descriptors, the vocabularies were consulted in the search tool MeSH (Medical Subject Headings). The boolean logic of database searches was:

((‘facial paralysis’ [Title] OR ‘facial palsy’ [Title] OR ‘facial paresis’ [Title] OR ‘hemifacial paralysis’ [Title] OR ‘hemifacial palsy’ [Title] OR ‘hemifacial paresis’ [Title] OR ‘hemi-facial paralysis’ [Title] OR ‘hemi-facial palsy’ [Title] OR ‘hemi-facial paresis’ [Title] OR ‘Bell paralysis’ [Title] OR ‘Bell palsy’ [Title] OR ‘Bell paresis’ [Title] OR ‘Ramsay Hunt’ [Title] OR ‘facial disfigurement’ [Title])

AND

(psych [Title/Abstract] OR ‘self-concept’ [Title/Abstract] OR identity [Title/Abstract] OR ‘self-perception’ [Title/Abstract] OR ‘self-esteem’ [Title/Abstract] OR ‘self-confidence’ [Title/Abstract] OR ‘self-worth’ [Title/Abstract] OR ‘self-image’ [Title/Abstract] OR ‘body image’ [Title/Abstract] OR stress* [Title/Abstract] OR distress* [Title/Abstract] OR anxi* [Title/Abstract] OR depress* [Title/Abstract] OR ‘emotional impact’ [Title/Abstract] OR ‘mental disorder’ [Title/Abstract]))*

AND

(evaluation [Title/Abstract] OR questionnaire [Title/Abstract] OR ‘self-report*’ [Title/Abstract] OR assessment* [Title/Abstract] OR screening* [Title/Abstract] OR interview* [Title/Abstract] OR inventor* [Title/Abstract] OR scale* [Title/Abstract] OR measure* [Title/Abstract] OR PROM* [Title/Abstract] OR instrument* [Title/Abstract] OR survey* [Title/Abstract])*

The above database search yielded 615 records. Additionally, 8 Systematic Reviews (SRs) met the inclusion criteria and were incorporated as new resources. The new records from the SRs (n = 127 after removing duplicates) were combined with the existing records, resulting in a total number of 742 studies. RefWorks reference management software was utilized to organize the search results and detect potential duplicates arising from overlap between the databases. After screening for duplicates, a total of 342 records remained.

Selection process

Titles and abstracts of articles were subsequently screened by the first reviewer [RPF] applying the inclusion and exclusion criteria (Table 1). Publications that met the inclusion criteria (see Fig. 1), as well as those for which the first reviewer had uncertainties, were subsequently reviewed by two additional reviewers for further evaluation [PP and II]. In cases of disagreement, a discussion between all three reviewers determined inclusion or exclusion. The full text of the selected publications, along

Table 1 Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population demographics	Adults, 18 years and older, regardless of sex and ethnicity	Under 18 years old.
Diagnosis and classification	Acquired and peripheral facial nerve damage, regardless of aetiology and severity	Congenital, rather than acquired, facial palsy Central or upper motor neuron paralysis rather than a peripheral or lower motor neuron lesion Other conditions (i.e., disfigurement or visible differences due to other causes, including cancer diagnosis) but not facial palsy
Facial palsy onset	Over 3 months, whether in a sub-acute or chronic phase	Acute phase, as it could resolve without sequelae
Publication date	From January 2000 to October 2023	All studies published before December 1999 (inclusive)
Language	English, Spanish or Italian	Studies that did not provide English, Spanish or Italian translation
Type of documentation	Articles	Book chapters, theses, conference papers, research protocols, case studies and case series if less than 5 cases. Articles about cosmetic or emotional appreciation by observers or including animal models
Outcome measures	Measures assessing psychosocial wellbeing and quality of life. Even those not validated for this specific population but within the general population or another physical or mental health population	Does not utilise an outcome measure assessing psychological, social or QoL components Ad hoc questionnaires Measures run with biomedical instruments (ultrasound, MRI, CT, or EMG)

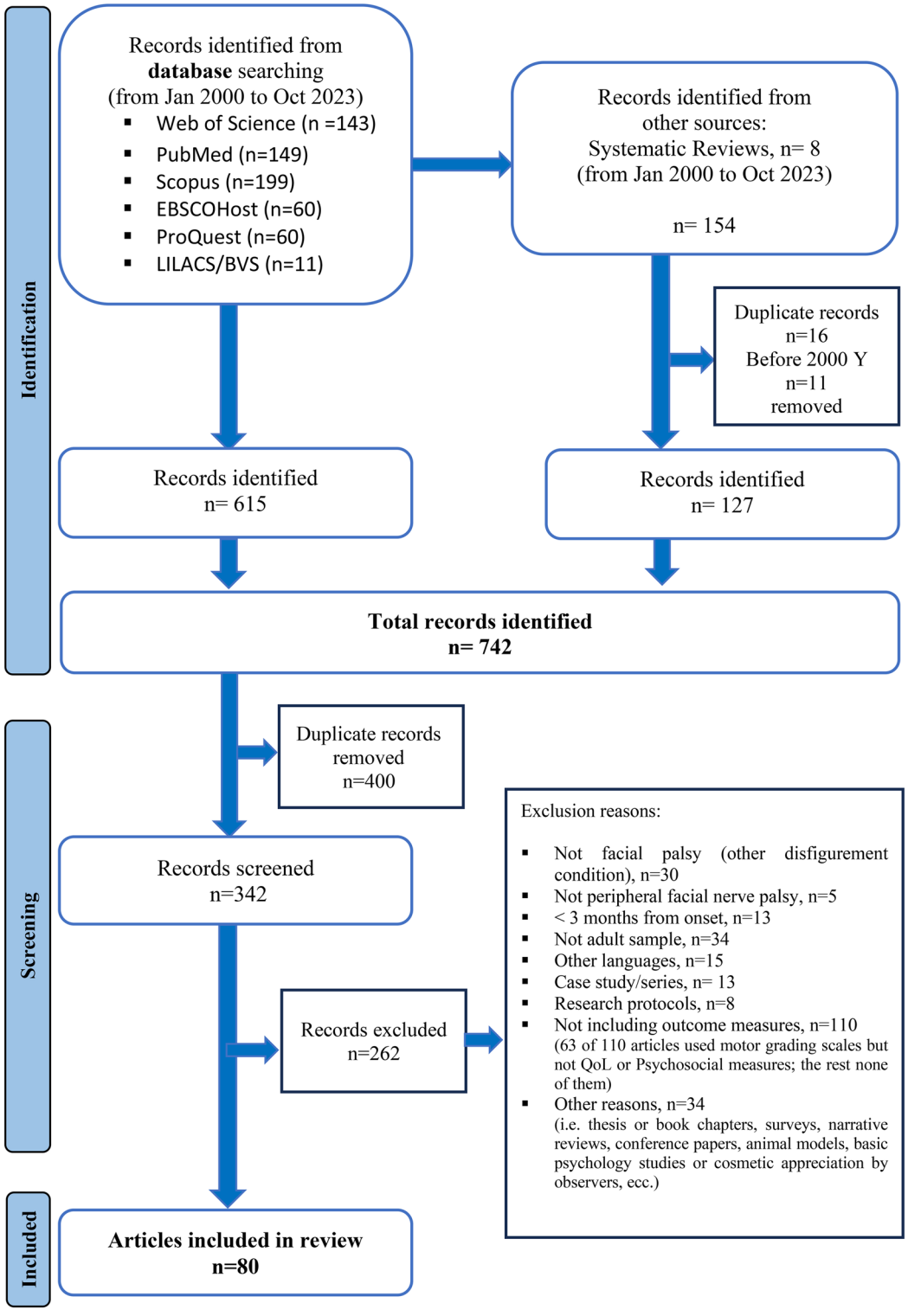

Fig. 1 Flow chart

with those that raised reasonable doubt, was retrieved to facilitate a more accurate decision-inclusion process.

Eligibility: Inclusion and exclusion criteria (Table 1).

Articles were considered eligible for inclusion if they included adults aged 18 years and older that had been diagnosed with an acquired and unilateral peripheral facial palsy, for at least 3 months - not in the acute phase-, regardless of aetiology, laterality, and sex.

Studies with a mixed population, such as those including sub-groups of children and adolescents alongside adults, or those addressing other disfigurements or visible conditions while also encompassing the target population, were considered for inclusion. In studies with mixed populations, the exact number of patients with facial palsy was not always specified. Nevertheless, these studies were included in the review to ensure comprehensive coverage of the relevant literature concerning the measures employed with this population.

The outcome measures included from the literature were not required to be specifically validated in a facial palsy population; however, they needed to have evidence of psychometric validation in the general population or in other physical or mental health cohorts, without performing a comprehensive critical appraisal of their psychometric properties.

Instruments that assessed exclusively physical aspects—such as motor grading scales—were excluded, as they did not align with the objectives of our study. Similarly, ad hoc questionnaires developed for individual studies, even when addressing psychological aspects, were also excluded from the review.

Data extraction and analysis

In each selected publication, the instruments used to assess participants were identified. The first author [RPF] extracted the data into specially designed Excel tables, and a second researcher [II] supervised the process to ensure the appropriateness of the selected measurement instruments. We retrieved the original validation studies for each selected instrument Table 2 was compiled. Each instrument was identified by acronym, the original validation study (author, year), the number of items, the instrument dimensions, the generic area/s of assessment, the number of studies that had used that measure, and an indication of whether the instrument was specifically developed for our target population, recorded as 'Yes' or 'No'.

The extracted instrument dataset (dimensions/items) was analysed using a thematic synthesis–style procedure to generate free codes, with the aim of exploring new conceptual categories as key domains [78]. A consensus group approach was employed to ensure the systematic classification of instrument dimensions and the identification of broader thematic domains. The group consisted of the three authors, who independently reviewed the extracted specific areas from each instrument and then convened to discuss discrepancies and reach agreement on their conceptual grouping. Decisions regarding the assignment of specific areas to broader domains were made through discussion and full agreement (3/3), ensuring that the classification reflected both theoretical considerations and the main research question of the review.

More specifically, the classification of instruments by thematic areas of assessment was guided by the stated dimensions underlying each of the identified instruments. The list of dimensions and classification by common elements was carried out by one of the authors, who proposed a coding by 'generic areas' and identification of other 'specific areas' that are grouped within the former (e.g., 'Symptomatology: emotional' vs. 'anxiety– general, social, appearance–, depression, etc.'). These codes identified the instruments and the number of studies (N_St) in the review in which they had been used. This initial identification and classification into thematic areas was submitted for approval by group consensus among the other authors, reaching full agreement. Finally, the identification of the 'specific areas' and their grouping by thematic approximation led to the proposal of six 'domains' in which the identified instruments are subsumed. The proposal of these domains was also made by group consensus.

Results

The phases of the review process are illustrated in Fig. 1. The flow chart shows the total of 742 references identified of which 615 came from the database search and 127 were obtained from the review of eight systematic reviews on the topic. Excluding duplicates, 342 studies were screened, of which 262 were discarded as they did not meet the inclusion criteria. Finally, a total of 80 original studies were included, all of which utilized at least one psychometrically validated measure– such as self-reported scales or questionnaires– for the assessment of personal perceptions regarding the psychological impact of suffering from facial palsy (Fig. 1). The Excel table with the 80 included studies in the ScR is available upon request from the corresponding author.

A total of 46 instruments were retrieved. The results included measures with a broader range of outcomes than just psychological ones. Although this work focused on exploring the psychological aspects assessed to date in this population, it also captured social and quality-of-life aspects, which are often closely intertwined with psychological factors. We included these to avoid overlooking important, interconnected themes. Accordingly, we adopt the term 'psychosocial' aspects in this work to better capture the findings.

Table 2 Identification and description of Measuring Instruments used in the assessment of the psychosocial consequences of Facial Palsy

Instruments (I)	Acronym	Author, year	N_Items	Instrument dimensions (N_Items)	Generic Area/s	N_St	FP Specific
Facial Disability Index	FDI	Van Swearingen & Branch, 1996 [33]	10	Physical function (FDI-PF= 5) Social/well-being function (FDI-S/WBF= 5)	1 - Health-Related QoL Perception2a –symptomatology: Physical & Emotional	36	Yes
Facial Clinimetric Evaluation	FaCE	Kahn et al., 2001 [34]	15	Social function (4)Facial movement (3)Facial comfort (3) Oral function (2)Eye comfort (2)Lacrimal comfort (1)	1 - Health-Related QoL Perception2c - Symptomology: Physical	34	Yes
Short Form-36 Health Survey Short Form-12 Health Survey	SF-36 SF-12	Ware & Sherbourne, 1992 [35]; Ware, 1993 [36]; Ware et al., 1996 [37]	36 12	Energy and Vitality (4)(1)General Health (5)(1)Mental Health (5)(2) Pain (2)(1) Role limitation due to physical problems (4)(2)Role limitation due to emotional problems (3)(2) Physical Functioning (10) (2)Social Functioning (2)(1)	1 - Health-Related QoL Perception2a - Symptomology: Physical & Emotional	20(16 + 4)	
Hospital Anxiety and Depression Scale	HADS-A	Zigmond et al., 1983 [38]	7	Anxiety	2b - Symptomology: Emotional	13	
Hospital Anxiety and Depression Scale	HADS-D	Zigmond et al., 1983 [38]	7	Depression	2b - Symptomology: Emotional	12	
Glasgow Benefit Inventory	GBI	Robinson et al., 1996 [39]	18	QoL related to ORL interventions:Changes in general health status (including psychosocial health status) (12)Amount of social support (3) Changes in physical health status (3)	1 - Health-Related QoL Perception2a - Symptomology: Physical & Emotional	4	
Social Avoidance and Distress Scale	SADS	Watson & Friend, 1969 [40]	28	Social anxiety	2b - Symptomatology: Emotional	3	
Fear of Negative Evaluation Scale, brief or brief revised	FNEBFNE-II	Leary, 1983 [41]; Carleton, et al., 2006 [42]	12	Social evaluative anxiety	2b - Symptomatology: Emotional	3	
FACE-Q| Paralysis|Appearance distress	FACE-Q_P-AD	Klassen et al., 2022 [43]	8	Appearance distress	3 - Appearance related matters2b - Symptomatology: Emotional	3	Yes
Coping Orientation to Problems Experienced inventory, or brief version	COPEBrief-COPE	Carver et al., 1989 [44]; Carver, 1997 [45]	28	Coping (14 strategies/3scales)	4 - Intrapersonal and social skills	3	
Beck Depression inventory	BDI-II	Beck et al., 1996 [46]	21	Depression	2b - Symptomatology: Emotional	2	
Satisfaction With Life Scale (SWLS)	SWLS	Diener at al., 1985 [47]	5	Satisfaction with life	1 - Health-Related QoL Perception4 - Intrapersonal and social skills	2	

Table 2 (continued)

Instruments (I)	Acronym	Author, year	N_Items	Instrument dimensions (N_Items)	Generic Area/s	N_St	FP Specific
EuroQoL 5D	EQ-5D	Hurst el al., 1997 [48]		Quality of Life Health Related	1 - Health-Related QoL Perception	1	
Illness Perception Questionnaire-Revised	IPQ-R	Moss-Morris et al., 2002 [49]	38	Illness beliefs (7 aspects)	1 - Health-Related QoL Perception	1	
Psychosocial Scale of Facial Appearance	PSFA	Silva et al., 2018 [50]	20	Functional Aspects of Face (FAF= 6)Emotional Aspects (EA= 7)Social Aspects (SA= 7): Social interactions (SA-SI= 3) and Performance in tasks (SA-PT= 4)	1 - Health-Related QoL Perception2a - Symptomatology: Physical & Emotional4 - Intrapersonal and social skills	1	Yes
Penn Acoustic Neuroma Questionnaire of Life	PANQoL	Shaffer et al., 2010 [51]	26	Anxiety (4) Balance (6) Hearing loss (4) Energy (6)Facial dysfunction (3) General health (2) Pain (1)	1 - Health-Related QoL Perception2a - Symptomatology: Physical & Emotional	1	Yes
Self-rating Depression Scale	SDS	Zung et al., 1965 [52]	20	Depression	1 - Health-Related QoL Perception2b - Symptomatology: Emotional	1	
Social Anxiety Questionnaire for Adults	SAQ-A-30	Caballo et al., 2015 [53]	30	Social Anxiety	2b - Symptomatology: Emotional	1	
Self-rating Anxiety Scale	SAS	Zung et al., 1971 [54]	20	Anxiety	2b - Symptomatology: Emotional	1	
Patient Health Questionnaire-2	PHQ-2	Kroenke et al., 2003 [55]	2	Depression	2b - Symptomatology: Emotional	1	
Generalized Anxiety Disorder-2	GAD-2	Sapra et al., 2020 [56]	2	Anxiety	2b - Symptomatology: Emotional	1	
Patient-Reported Outcomes Measurement Information System_ negative affect measures	PROMIS_DAA	Pilkonis et al., 2011 [57]	86	Depression (28) Anxiety (29) Anger (29)	2b - Symptomatology: Emotional	1	
Social Interaction Anxiety Scale	SIAS	Mattick& Clarke., 1998 [58]	19	Social anxiety	2b - Symptomatology: Emotional	1	
Difficulties in Emotion Regulation Scale-Short Form	DERS-SF	Kaufman et al., 2016 [59]	18	Emotion dysregulation (6 aspects)	2b - Symptomatology: Emotional	1	
Derogatis Affects Balance Scale–Short Form	DABS-SF	Derogatis et al.,1996 [60]	20	Emotional experiences: positives and negatives	2b - Symptomatology: Emotional	1	
FACE-Q| Paralysis|Psychological Function	FACE-Q_P-PF	Klassen et al., 2022 [43]	10	Psychological function	2b - Symptomatology: Emotional	1	Yes
Stigma Scale for Chronic Illnesses–Short Form	SSCI-8	Molina et al., 2013 [61]	8	Stigma: internalised and enacted	2b - Symptomatology: Emotional	1	
Self-esteem self-report	SESR	Robson P., 1989 [62]	30	Self-esteem	2b - Symptomatology: Emotional	1	
FACE-Q| Aesthetics| Satisfaction with Facial Appearance| Face Overall	FACE-Q_A-SFA	Klassen et al., 2010 [63]	10	Satisfaction with facial appearance	3 - Appearance related matters1 - Health-Related QoL Perception	1	
Social Appearance Anxiety Scale	SAAS	Hart et al., 2008 [64]	16	Social appearance anxiety Body image dissatisfaction	3 - Appearance related matters2b - Symptomatology: Emotional	1	
Derriford Appearance Scale	DAS-24	Carr et al., 2005 [65]	24	Self-consciousness of appearance	3 - Appearance related matters	1	
Body Image Quality Life Inventory	BIQLI	Cash & Fleming, 2002 [66]	19	Body Image (feelings about their physical appearance and effects on life contexts)	3 - Appearance related matters	1	
Ten-Item Personality Inventory (TIPI)	TIPI(BFQ-5)	Gosling et al., 2003 [67]	10	Personality; 5 dimensions from the Big Five Inventory, BFI: Extraversion (2), Agreeableness (2), Conscientiousness (2), Emotional stability (2), Openness to experiences (2)	4 - Intrapersonal and social skills2b - Symptomatology: Emotional	1	

Table 2 (continued)

Instruments (I)	Acronym	Author, year	N_Items	Instrument dimensions (N_Items)	Generic Area/s	N_St	FP Specific
16 Personality Factor Questionnaire;	16PF	Cattell & Mead,1949 [68]; Cattell & Cattell,1995 [69]	200	Personality (16 factors)	4 - Intrapersonal and social skills	1	
Interpersonal Communication Rating Protocol for Individual Expressive Behaviour	ICRP-IEB	Tickle-Degnen, 2010 [70]	8	Compensatory expressive behaviour	4 - Intrapersonal and social skills	1	
The Relationship Questionnaire	RQ	Bartholomew & Horowitz, 1991 [71]	4	Adult attachment style	4 - Intrapersonal and social skills	1	
Duke University REligion Index	DUREL	Koenig et al., 1997 [72]	5	Religiosity (3 aspects)	4 - Intrapersonal and social skills	1	
Post Traumatic Growth Inventory	PTGI	Tedeschi& Calhoun, 1996 [73]	21	Positive legacy of trauma (5 aspects)	4 - Intrapersonal and social skills	1	
FACE-Q| Paralysis|Social Function	FACE-Q_P-SF	Klassen et al., 2022 [43]	10	Social function	4 - Intrapersonal and social skills	1	Yes
Facial Paralysis Evaluation Measure / Patient Evaluation Measure	PEMFPEM	Dias et al., 2001 [74]; Bradbury et al., 2006 [75]	18	Satisfaction with the process and surgery outcomes	5 - Care Experience2c - Symptomatology: Physical	1	
FACE-Q| Aesthetics| Satisfaction with Outcome	FACE-Q_A-SO	Klassen et al., 2015 [76]	6	Satisfaction with outcome	5 – Care Experience	1	
FACE-Q| Aesthetics| Satisfaction with Treatment Decision	FACE-Q_A-TD	Klassen et al., 2015 [76]	6	Satisfaction with treatment decision	5 - Care Experience	1	
BODY-Q| Satisfaction with Medical team	BODY-Q_S	Klassen et al., 2014 [77]	10	Satisfaction with medical team	5 - Care Experience	1	
BODY-Q| Satisfaction with Doctor	BODY-Q_S	Klassen et al., 2014 [77]	10	Satisfaction with doctor/surgeon	5 - Care Experience	1	
BODY-Q| Satisfaction with Information	BODY-Q_S	Klassen et al., 2014 [77]	10	Satisfaction with information	5 - Care Experience	1	
BODY-Q| Satisfaction with Office staff	BODY-Q_S	Klassen et al., 2014 [77]	10	Satisfaction with office staff	5 - Care Experience	1	

Notes: N_Items: Number of Items; N_St: Number of Studies; FP Specific: Specific instruments designed for people with facial palsy

The distribution of instruments is presented in Table 2, of which 14 belong to four families: 'Medical Outcomes Study: Short Forms' (see MOS: SF-12 and SF-36 items), 'Hospital Anxiety and Depression Scale' (see HADS; assessing Anxiety and Depression separately), 'FACE-Questionnaires' and 'BODY- Questionnaires' (see FACE-Q and BODY-Q; six and four instruments, respectively).

A total of seven instruments have been developed specifically for the assessment of facial palsy: 'Facial Disability Index' (FDI, 36 studies), 'Facial Clinimetric Evaluation' (FaCE, 34 studies), 'FACE-Q Paralysis-Appearance Distress' (FACE-Q P-AD, 3 studies), 'FACE-Q Paralysis-Social Function' (FACE-Q P-SF, 1 study), 'FACE-Q Paralysis-Psychological Function' (FACE-Q P-PF, 1 study), 'Psychosocial Scale of Facial Appearance' (PSFA, 1 study), and 'Penn Acoustic Neuroma Questionnaire of Life' (PANQoL, 1 study).

The two most frequently used instruments, the FDI (N_St = 36) and the FaCE (N_St = 34), were employed in less than 50% of the studies included in this review. The most frequently employed generic assessment was MOS-SF, with 16 studies utilizing the SF-36 and four employing SF-12, as well as the HADS versions for Anxiety (N_St = 13) and Depression (N_St = 12). Most of these 46 instruments identified were used in less than five out of 80 studies: 89.1% of instruments (k = 41).

The dimensions assessed by these instruments (Table 2, Column 5), extracted from the original validation studies, were grouped by the consensus team into generic areas (Table 2, Column 6). Classification was based on the declared dimensions of each instrument, with some overlap depending on item content. The following five generic areas were identified: (1) Perception of health-related quality of life (HRQoL): a multidimensional concept reflecting the patient's overall perception of the effects of illness and treatment on physical, psychological, and social aspects of life. (2) Symptomatology: this generic area encompasses three sub-areas: 2a, which includes both emotional and physical symptoms; 2b, which considers only emotional symptoms, such as mood disorders, irritability, anxiety, and sleep disturbances; and 2c, which addresses only physical symptoms. (3) Appearance-related matters: this area examines how an individual's physical appearance influences their self-perception and the way they are perceived by others. Appearance plays a significant role in shaping self and social identity. (4) Intrapersonal and social skills: these skills refer to the ability to manage one's own behaviour and emotions -intrapersonal skills- and the ability to interact, communicate, and build relationships with others -social or interpersonal skills-. (5) Care experience: this refers to the patient's experiences, the grade of satisfaction during the care process.

The results, based on the number of instruments ($n = 46$) linked to each generic area, showed that most of the instruments retrieved are focused on symptomatology assessment (27/46), with emotional symptomatology being more common (43.5% of the instruments), as opposed to those that assess physical symptomatology (4.3%), or both symptomatic facets (10.8%). The areas of perceived HRQoL and intrapersonal and social skills are addressed by 23.9% (11/46) and 21.7% (10/46) of the instruments respectively. As a minority, the generic areas of care experience and appearance-related matters are covered by fewer instruments: seven and five out of 46, respectively.

Based on the thematic synthesis, additional specific areas were extracted as free codes from the instrument dimensions and items' contents in Table 2. A total of 38 specific areas were identified (Table 3, column 2). The specific areas represent the most relevant outcomes considered in the retrieved literature when assessing the psychosocial impact in the target population. Accordingly, the consensus discussion, led by thematic approximation, to the proposal of six domains: (1) Social Functioning, (2) Emotional Symptomatology, (3) Facial Palsy-Related QoL, (4) General Health-Related QoL, (5) Psychological Functioning, and (6) Care experience- Satisfaction. Domains are ranked in Table 3, column 1, by relevance according to the number of studies (of 80) addressing them. Table 3, column 1, presents, for each domain, the total number of distinct instruments (N_I) and the total number of studies (N_St) that included at least one of these instruments. In column 3, each specific area links with the measurement instrument/s that assess it. When a single instrument addressed more than one specific area, it was recorded in multiple areas. This was observed in a few instances, reflecting the multidimensional nature of certain instruments. For example, the specific area linked to the greater number of instruments (N_I = 9) was the 'affective impact (miscellaneous)' which was measured in 52 out of 80 studies using one or more of these nine instruments. Moreover, up to five different instruments were identified for assessing the specific areas of 'general anxiety', 'social anxiety', and 'depression', while 'facial/oral function' was evaluated using four distinct instruments. For the remaining specific areas, fewer instruments were used. In fact, for 25 of the 38 specific areas identified (65.8%) only a single instrument was found to explore that domain.

Although conceptually like the generic areas identified in Table 2, in the domain-process consensus (Table 3, column 1), we reassigned the generic area 'Symptomatology: Physical' to the 'General Health–Related QoL' domain and merged the generic areas 'Appearance-related matters' and the intrapersonal components of 'Intrapersonal and Social Skills' within the 'Psychological Functioning'

Table 3 Domains and specific areas related to the instruments assessing the psychosocial consequences of facial palsy

Domain	Specific Area	Instrument (Number of Studies in which it is used N_St)	N_I	N_St
Social Functioning [7/61]*	Social aspects	FDI-S/WBF (36), FaCE (34), SF-12-36 (20), FACE-Q_P-SF (1), PSFA (1)	5	59
	Social interactions-Stigma	PSFA-SA-SI (1), SSCI (1)	2	2
	Performance in tasks	PSFA- SA-PT (1)	1	1
	Social Support	GBI (4)	1	4
	Role limitation due to health problems	SF-12-36 (20)	1	20
Emotional Symptomatology [24/58]*	Anxiety, General	HADS (13), PANQoL (1), SAS (1), GAD (1), PROMIS (1)	5	17
	Anxiety, Social	SADS (3), BFNE-R (3), SAQ-A-30 (1), SIAS (1), SAAS (1)	5	4
	Anxiety, Appearance	FACE-Q_ P-AD (3), SAAS (1)	2	4
	Depression	HADS (12), BDI (2), SDS (1), PROMIS (1), PHQ (1)	5	17
	Anger	PROMIS (1)	1	1
	Well-being (hedonic pers.)	SWLS (2)	1	2
	Affective impact (Miscellaneous)**	FDI-S/WBF (36), SF-12-36 (20), FACE-Q_P-PF (1), PSFA-EA (1), PANQoL (1), SESR (1), DERS-SF (1), DABS-SF (1), SSCI (1)	9	52
Facial Palsy-Related Quality of Life [4/57]*	Facial comfort	FaCE (34)	1	34
	Facial movement	FaCE (34)	1	34
	Eye comfort	FaCE (34)	1	34
	Lacrimal comfort	FaCE (34)	1	34
	Hearing loss and Balance	PANQoL (1)	1	1
	Facial/oral function	FDI-PF (36), FaCE (34), PSFA-FAF (1), PANQoL (1)	4	57
General Health-Related Quality of Life [4/25]*	General or Physical Health	SF-12-36 (20), GBI (4)	2	23
	QoLHR	SF-12-36 (20), EQ-5D (1)	2	21
	Physical Functioning	SF-12-36 (20)	1	20
	Energy / Vitality	SF-12-36 (20)	1	20
	Pain	SF-12-36 (20)	1	20
	Illness beliefs	IPQ-R (1)	1	1
Psychological Functioning [11/9]*	Personality	16 PF (1), TIPI (1)	2	2
	Coping	COPE (2)	1	2
	Body Image	FACE-Q_A-SFA (1), BIQLI (1), SAAS (1)	3	3
	Self-consciousness of appearance	DAS-24 (1)	1	1
	Adult attachment	RQ (1)	1	1
	Religiosity	DUREL (1)	1	1
	Compensatory expressive behaviour	ICRP-IEB (1)	1	1
	Positive legacy of trauma	PTGI (1)	1	1
Care Experience – Satisfaction [7/2]*	… with information	BODY-Q_S_I (1)	1	1
	… with office staff	BODY-Q_S_{OF} (1)	1	1
	… with medical team	BODY-Q_S_{MT} (1)	1	1
	… with doctor / surgeon	BODY-Q_S_D (1)	1	1
	… with treatment decision	FACE-Q_A_{TD} (1)	1	1
	… with outcome	FACE-Q_A_O (1), FPEM (1)	2	2

Notes: * [N_I / N_St]: Number of Instruments / Number of Studies; ** [Social/well-being function; Mental Health; Psychological function; Emotional Aspects; Anxiety; Self-esteem; Emotional dysregulation; Emotional/Affects balance; Stigma respectively]

domain. A separate domain, 'Social Functioning', was designated to specifically capture the quality of social relationships. In this work, the domain 'Emotional Symptomatology' refers to internalizing disorders such as anxiety and depression, consistent with DSM-5 and ICD-11 frameworks. It was retained as a distinct category from the 'Psychological Functioning' domain, which focuses on individual differences and encompasses intrapersonal aspects such as coping strategies, attitudes toward symptoms, and body self-perception.

The most explored domain in the current literature appears to be 'Social Functioning', with 61 studies out of the 80 considering it. It is closely followed by the 'Emotional Symptomatology' domain, with a total of 58 studies, and the 'Facial Palsy–Related QoL' domain, with a similar number of studies exploring it (N_St = 57). The 'General Health–Related QoL' domain has been addressed in a total of 25 studies. Finally, two domains were substantially under-represented, with less than ten studies: 'Psychological Functioning' (N_St = 9) and 'Care experience – Satisfaction' (N_St = 2).

The ratio -representing the N_I used in a domain with respect to the N_St included [N_I/N_St]- is a dominance indicator of the use of an instrument in the studies identified in the review. If the ratio is 1, it indicates that an equal number of instruments and studies were used in each domain examined. If the ratio is closer to zero, this indicates that few instruments are used compared to the number of studies. On the contrary, if the value of the ratio is above 1, it indicates that the same study is using two or multiple instruments in the assessment of the target domain.

The domain with the lowest ratio is 'Facial Palsy–Related QoL' (4/57; ratio of 0.07), followed by 'Social Functioning' (7/61; ratio of 0.11), 'General Health–Related QoL' domain (4/25; ratio of 0.16), and 'Emotional Symptomatology' (24/58; ratio of 0.41). Conversely, the 'Psychological Functioning' (11/9; ratio of 1.2) and 'Care experience – Satisfaction' (7/2; ratio of 3.5) domains are the ones using the greatest number of instruments with the lowest number of studies.

Discussion

The objective of this scoping review was to identify the key domains evaluated by clinicians and researchers when exploring psychological aspects in adults with acquired peripheral facial palsy (PFP), and to highlight potential gaps in the assessment of mental health risks in this population.

This study identified 80 studies utilizing a total of 46 measures for the assessment of psychosocial aspects. Through thematic synthesis of the instruments' items and consensus group, 38 specific areas were identified and organized into six domains: (1) Social Functioning, (2) Emotional Symptomatology, (3) Facial Palsy-Related QoL, (4) General Health-Related QoL, (5) Psychological Functioning, and (6) Care experience- Satisfaction.

In 2016, Norris and colleagues [28] after interviewing 24 adults with PFP -including acquired as well as congenital conditions-, defined a conceptual framework with the major domains of concern to patients. They are by order of relevance: (1) Facial function and symptoms, (2) Experience of healthcare, (3) Psychological concerns, (4) Appearance-related concerns, and (5) Social concerns. The specific domains identified in this ScR show similarities with the needs highlighted by patients in the qualitative study conducted by these authors [28]. In contrast to Norris and colleagues, we included appearance-related concerns within the 'Psychological Functioning' domain. This domain focuses on individual differences, including intrapersonal aspects such as attitudes and strategies to cope with symptoms along with body self-perception. Furthermore, our study treated 'Emotional Symptomatology' as a distinct domain. This domain seems to correspond with feelings of apprehension, anxiety, irritation and low mood reported by patients included in Norris's study as psychological concerns.

Our findings indicate that most of the evidence looking into the psychosocial consequences of an acquired PFP is concentrated within the domains of 'Social Functioning' and 'Emotional Symptomatology', as well as aspects related to the QoL of this specific population ('Facial Palsy-Related QoL' domain). A moderate level of attention is observed in the assessment of QoL using overall health-related instruments ('General Health-Related QoL' domain). In contrast, limited attention is given to the evaluation of the 'Psychological Functioning' and 'Care experience–Satisfaction' domains, with only nine and two studies addressing these areas, respectively. Therefore, our findings indicate that researchers and healthcare professionals are only partially addressing the outcomes that matter most to patients with PFP.

Although most of the evidence addressing the psychosocial outcomes is concentrated within the domains of 'Social Functioning' and 'Emotional Symptomatology', and to a lesser extent, within the QoL of this specific population, notable differences were observed. The study identified inconsistencies between the number of studies and instruments used across domains.

Within the 'Facial Palsy-Related QoL' domain, nearly all the evidence derives from two out of four instruments retrieved (FDI and FaCE) and from three out of seven different measures within the 'Social Functioning' domain (FDI, FaCE, and SF-36-12). This suggests convergence towards the use of a low number of instruments as evaluation methods. The ratio establishes that these are the measures mostly used when looking into social and quality of life aspects in this specific population, as previously demonstrated by Ho and colleagues [31].

In contrast, the evaluation of the 'Emotional Symptomatology' involves up to 24 different instruments, a greater heterogeneity in comparison with the above cited domains. Three out of 24 instruments are predominantly used: FDI-S/WB, SF-12-36, and HADS-Anxiety and Depression. This finding could reflect that the domain might be worthy of exploration but that the consensus about which measures might be used has not been reached to date. This trend has already been confirmed in a 2014 study among members of the Sir Charles Bell Society, so it is not a new concern within the scientific community. Among the 46% of participants who reported assessing psychological and social functioning using more holistic methods, 11% used the FDI, 10% the HADS, and only 2% the SF-36, 1% the DAS-24, and a visual analog scale. Additionally, 15% recorded patients' experiences in an unstructured manner, and 6% used other methods that were not clearly specified. The variety of scales highlighted the diverse psychosocial impacts

of facial palsy but also reflected the lack of consensus on what and how to assess [29].

When exploring emotional symptoms, no specific instruments have been developed to capture distress in individuals with facial palsy, apart from the FDI with its subscale of well-being. This subscale has been drawn from the psychological and social function domains of the 'Medical Outcomes Study 36-Item Short-Form Questionnaire' (MOS, SF-36) the 'Functional Status Questionnaire' (FSQ-20) and the 'Beck Depression Inventory' (BDI) adapting the contents according to facial palsy patients' experiences [79]. Instead, the 'Hospital Anxiety and Depression Scale' (HADS), originally developed for use with general hospital populations, was the most employed tool.

However, this review found limited attention was given to specific forms of anxiety, such as social and appearance-related anxiety, despite previous evidence highlighting their relevance in this population, particularly among young individuals and women. These emotional aspects are often associated with avoidance behaviours, like those observed in individuals with other visible disfigurements [20]. The visibility of the face, its limited capacity to be concealed, and its integral role in both self-concept and social identity may warrant further attention in this specific population. Research on stigma remains limited, particularly regarding patients' experiences of discrimination and the internalization of shame. Recent studies have begun to examine the strategies individuals with facial disfigurements, such as facial palsy, employ to disclose their condition and navigate social interactions [80, 81].

Instruments retrieved in literature to assess these dimensions included the condition-specific 'FACE-Q Paralysis-Appearance Distress' (FACE-Q P-AD), as well as tools not originally designed for our target population, such as the 'Social Avoidance and Distress Scale' (SADS) and the 'Brief Fear of Negative Evaluation Revised' (BFNE-R). However, these were under-utilised, each appearing in only three studies. Additionally, only one cited study used a measure assessing both enacted and perceived public stigma: the 'Stigma Scale for Chronic Illnesses' (SSCI-8).

Surprisingly, the 'Psychosocial Scale of Facial Appearance' (PSFA) [82], a facial palsy-specific instrument developed to assess the psychosocial impact of PFP, has not yet been utilised, despite its relevance to key domains. The PSFA is a 20-item scale divided into three domains: functional (6), social (7), and emotional (7). The primary sensitivity and validation study for the PSFA, conducted in 2018 with Brazilian Portuguese speakers, demonstrated substantial sensitivity, convergent validity with HADS, and strong internal consistency (Cronbach's alpha). On the other hand, confirmatory factor analysis showed weak item-level relationships, indicating the need for further validation of the final scale and for establishing an optimal cut-off to assess psychosocial impact in PFP. Furthermore, given that Brazilian Portuguese is a relatively minor language, this may underscore the scale's limited use and reduce cross-cultural relevance, particularly in English-speaking settings.

Regarding the 'Psychological Functioning' domain, the situation is concerning, as there is minimal scientific literature (only 9 studies out of 80) and a lack of homogeneity in the instruments used (up to 11 different instruments were identified). The heterogeneity of the instruments used limits the possibility of conducting a meta-analysis and hinders the establishment of consensus among professionals regarding which instruments should be systematically used. Additionally, the specific areas identified within this domain are diverse and may not all be directly related to facial paralysis.

Within this domain, body image is addressed in a maximum of three out of the nine identified instruments which are not facial palsy-related: 'FACE-Q Aesthetics-Satisfaction with Facial Appearance' (FACE-Q A-SFA), 'Social Appearance Anxiety Scale' (SAAS), 'Body Image Quality Life Inventory' (BIGLI), along with the 'Derriford Appearance Scale' (DAS-24), an instrument assessing appearance-related self-consciousness.

To date, no specific instrument has been developed to evaluate this psychological construct in adults with peripheral facial palsy, except for the 'FACE-Q Paralysis Appearance Distress' (FACE-Q P-AD) [83]. This scale is focused on distress as a response to appearance concerns and has been included in this study as 'Emotional Symptomatology' rather than within the 'Psychological Functioning' domain. Preoccupation with physical appearance can be excessive and it can be accompanied by a distorted self-perception of disfigurement. This may lead to the development of body dysmorphic disorder (BDD). Volk and colleagues suggested in a post-paralytic facial synkinesis sample that this may be an elevated risk for BDD [84].

Future research should reach consensus on assessment within the 'Psychological Functioning' domain, focusing on factors like body image, self-perception of facial appearance, self-esteem along with the exploration of the personality and other internal traits. There is little evidence of the role of personality traits such as extraversion, conscientiousness, and emotional stability driving better social outcomes in facial paralysis patients. Personality traits are related to the selection of coping strategies when dealing with negative self and social perceptions. The discrepancy between symptom severity and associated distress underscores the influence of individual differences, warranting further investigation [85].

Finally, the domain of 'Care experience-Satisfaction' remains similarly under-explored in the literature and is primarily limited to patients undergoing reconstructive surgery [86].

Some limitations of this study are that, although all 46 instruments are standardized, only seven were validated in our population of interest rather than in other medical conditions. Furthermore, these seven tools were included regardless of sample size to avoid overlooking potentially relevant assessment measures. Additionally, our focus on adults with an acquired condition, excluding children, adolescents, and congenital cases, may have limited the scope.

A further limitation is the lack of a critical appraisal of the 46 instruments identified through an extensive review of the literature. Assessing their psychometric properties using a framework such as COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) would help identify the most robust tools for research and clinical practice, support evidence-based practice, and we recommend this as an important avenue for future studies.

As highlighted in recent systematic reviews [13, 87], routine screening is essential to identify patients at risk of mental health issues. Clinical psychologists can be involved when needed to support those experiencing significant distress, providing valuable guidance in understanding of the lived experiences of individuals with PFP. The integration of clinical psychologists into specialist facial palsy multidisciplinary teams, alongside surgical and facial therapy professionals, is recommended.

Given the limited access to specialist facial palsy services, in 2021 a self-guided resource [88] with recommendations for supporting the psychological well-being of this population was developed. An appendix is included [88], providing a comprehensive psychological assessment framework with a selection of potential patient-reported outcome measures (PROMs) suitable for use in this population. Some tools cited in the consensus document were not identified in our review, while others were not further discussed due to infrequent use. For a detailed overview of the instruments retrieved, see Table 2. This ScR may complement and strengthen the comprehensive psychological assessment framework proposed in 2021 by this international group of clinicians and researchers with expertise in facial palsy psychology [88].

This work appears to establish a starting point for developing an initial questionnaire for a Delphi study. This questionnaire would solicit opinions, insights, or predictions from experts, regarding the specific psychological areas identified and their related measurement instruments, from those that already garner significant attention to those that are tentatively emerging.

Conclusion

Although there is growing interest in measuring the mental health risk of facial palsy, a clear consensus on assessment measures to be used has yet to be reached. This study represents a first step toward establishing a stronger consensus on appropriate psychological assessment in this population. However, there appears to be better agreement on key domains, including emotional symptomatology, social and psychological functioning, condition-specific and general health-related quality of life perception, along with satisfaction with the care experience.

Our findings indicate a predominant focus on assessing external symptomatic manifestations, particularly social and emotional symptoms along with quality-of-life perception, while internal changes related to the Self receive limited attention. Notably, there is a scarcity of tools addressing self-image and self-perception of facial appearance in this specific population, constructs which relate to a more positive self-concept. Given the absence of a direct correlation between the objective severity of paralysis and reported distress described in previous studies, greater attention should also be directed toward individual differences, including personality traits and coping styles, as potential resources for psychological adjustment to a new reality.

Acknowledgements
We would like to thank Nicholas Williams for reviewing the English language of this manuscript.

Author contributions
RPF: Conceptualization, screening methodology, data extraction, writing original draft, and preparing figure-tables; PP: Screening methodology, writing review & editing, supervision; II: Screening methodology, data extraction, preparing tables, writing review & editing, supervision.

Funding
Not applicable.

Data availability
An Excel file containing the 80 studies selected for this review is available from the corresponding author upon request.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Received: 22 June 2025 / Accepted: 16 November 2025
Published online: 22 December 2025

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