BMJ Open

Living with long-term conditions: validation of a new instrument for family caregivers in a Spanish-speaking population

Patricia Marín-Maicas ,[1,2] Leire Ambrosio ,[3] Silvia Corchon,[4] Jesús González-Moreno ,[5] Mari Carmen Portillo[3]

To cite: Marín-Maicas P, Ambrosio L, Corchon S, *et al*. Living with long-term conditions: validation of a new instrument for family caregivers in a Spanish-speaking population. *BMJ Open* 2024;**14**:e088773. doi:10.1136/bmjopen-2024-088773

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2024-088773).

Received 15 May 2024
Accepted 27 August 2024

[1]Facultad de Enfermería y Podología, Universitat de Valencia, Valencia, Spain
[2]Faculty of Health Science, Valencian International University, Valencia, Spain
[3]National Institute for Health and Care Research (NIHR) Applied Research Collaboration Wessex, Southampton, UK, School of Health Sciences University of Southampton, Southampton, UK
[4]University of Valencia, Valencia, Spain
[5]Valencian International University, Valencia, Spain

Correspondence to
Dr Silvia Corchon;
silvia.corchon@uv.es

ABSTRACT

Introduction Optimising the management of chronicity has been a global challenge for decades. Individuals with long-term conditions (LTCs) and their families live with them for years. Thus, it is necessary to include both of their perspectives in the management and adaptation of the interventions proposed. The psychometric properties of the living with LTCs scale from the perspective of the family caregiver are unknown. The objective of the present study is to describe the psychometric properties of the EC-PC-Fam in a Spanish-speaking population.

Methods An observational, cross-sectional study was performed with a retest of part of the sample. The fit of the model was optimised with a factorial analysis, and the psychometric properties were verified.

Results A sample of 311 caregivers was recruited. Most of them were women (68.2%) and had a mean age of 58.29±9.91 years (range: 32–84 years). The initial version did not obtain acceptable fit scores. To improve the fit, different versions were tested, refining the distribution of the items until optimisation was reached in V.10 (19 items). Cronbach's alpha was 0.81 for the scale as a whole. The intraclass correlation coefficient was 0.77. The EC-PC-Fam scale is strongly and inversely correlated with a scale that measures the burden of the caregiver (r_s=−0.46), and moderately related to the health-related quality of life (r_s=0.373) and social support (r_s=0.38).

Conclusions The EC-PC-Fam scale from a family perspective is defined as a promising tool for promoting personalised care and for optimising the management of LTCs, and a new approach that includes family caregivers is proposed for clinical practice. The scale is an instrument with a moderate fit and optimum psychometric properties to measure living with LTCs from the perspective of a family caregiver. New validation studies are recommended to verify the fit of the proposed factorial solution.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This validation study used an observational and cross-sectional design, with retesting in a fraction of the sample.
⇒ The sample size is a strength.
⇒ Most psychometric properties, including confirmatory factor analysis, were analysed.
⇒ The sample represented a non-heterogeneous population.

BACKGROUND

The care of individuals with long-term conditions (LTCs) is one of the most important challenges faced by health systems worldwide, and the epidemiological projections for the coming decades suggest that the prevalence of most of the LTCs will increase.[1–3] Thus, optimising the management of LTCs is becoming a priority in healthcare systems, as LTCs cause the highest number of disabilities, deaths and consumption of resources.[4–7]

The WHO defines LTCs a long-term, slow-progressing processes that require the continuous and lasting care of an individual.[8] The impact of LTCs is accentuated by the increasingly frequent condition of a person with a complex or multipathological condition.[1 2] One in three adults lives with more than one LTC, increasing the burden of the disease and its associated costs. The ratio of individuals with more than four LTCs will double between 2015 and 2035 in some parts of the world.[1 9] According to the report published by the WHO,[7] heart disease, diabetes and dementia are the three diseases that produce the most deaths worldwide. However, these do not only cause many deaths but also result in many different disabilities in people, resulting in the greatest loss of healthy years of life. For example, the combination of heart disease, diabetes, stroke, lung cancer and Chronic obstructive Pulmonar Disease (COPD) resulted in the loss of more than 100 million years of healthy life in 2019, as compared with the year 2000.[10] The disability produced by LTCs is not only experienced by the people who are ill, but also by nearest surroundings.[11–14]

Families and patients live with LTCs for many years, which becomes a family matter.[11–14] Long-term care is provided over extended periods of time by family.[15] A family caregiver is considered a non-professional person who provides primary assistance with activities of daily living, either in part or in whole, towards a dependent person in his/her immediate circle.[15 16] The family setting is the place where the disease arises and is managed, and therefore, the function of the family is key in the provision of care.[11] Up to 80% of the long-term care in Europe is provided by informal caregivers.[12 16] Likewise, 38.9 million adults have been taking care of another adult in 2019 in the USA, with 1 out of 5 Americans being caregivers.[17] Thus, it is essential to understand and assess not only how patients live with LTCs but their family too, as both experience the adjustment process.[18]

Following an in-depth review of the literature,[18–20] living with LTCs from the perspective of the patient and the family member has been identified as a process of transition, in which the individual must learn how to live with the disease-related changes in a daily basis.[18–20] In other words, the concept of living with LTCs is understood as a complex, cyclical, dynamic and constantly changing process that affects every person in every area of life.[21] This phenomenon impacts both patients' and family caregivers' lives, which means that clinical assessment tools need to capture both perspectives.[18 22] Currently, there are many difficulties in determining how family caregivers live with LTCs and how they experience the adjustment process, especially when most existing instruments measure quality of life, stress and anxiety or burden. Notwithstanding, no instrument has been found that allows measuring how family caregivers live with LTCs.[18 22] This gap in the literature suggests that there is a strong need to create a new instrument to measure living with LTCs from the perspective of family caregivers.[23] This study is enhancing our understanding of the individual management of LTCs by providing a novel instrument that captures the perspective of the caregiver through the adjustment process.

In a previous study, we published '…A previous study adapted the living with chronic illness scale (EC-PC) to the family caregiver (EC-PC-Fam)'.[23] The initial hypothesis posits that the family caregiver-adapted version of the EC-PC (EC-PC-Fam) is a valid and reliable instrument for measuring living with LTCs in family caregivers. Additionally, we seek to address the following questions: Will the results from the EC-PC-Fam show a positive correlation with higher scores on health-related quality of life scales? Conversely, will the results from the EC-PC-Fam demonstrate a negative correlation with higher scores on caregiver burden scales? With this purpose in mind, the objective of this study is to present the psychometric properties of the EC-PC-Fam for family caregivers in a Spanish-speaking population[23] and validate the instrument.

METHODS

Design and setting of the study

An observational, cross-sectional study was performed with a retest of part of the sample.[24] The study was conducted in three different private health and social-health centres located in the province of Valencia, which provided care to individuals with LTCs.

Participants

The target population of the present study were family caregivers of individuals diagnosed with at least one LTC. The following inclusion criteria were applied: (a) being an adult older than 18 years of age living in Spain, (b) being a family caregiver of a person diagnosed with at least one LTC and (c) being a family caregiver of an individual whose language is Spanish or with sufficient knowledge to be able to complete the questionnaire. The exclusion criteria were: (a) being an informal caregiver who is paid for the services provided and (b) being a family caregiver of institutionalised individuals.

Sampling and sample size

Convenience sampling was performed based on participant accessibility[25] and included individuals who met the previously described inclusion criteria. For this, family members who attended the social-health centre and met the inclusion criteria were invited to participate.

With respect to the adequate sample size needed to perform a validation study, making an exact initial estimation is very complex, as numerous factors intervene that must be considered.[26 27] Nevertheless, it seems that there is a unanimous recommendation that sample sizes to be greater than 100 are needed for estimating correlations and factorial analyses.[26 27] In order to verify the most adequate sample size, the G-Power tool was used, which pointed to the need for a minimum sample size of 262 participants, an effect size of 0.62, and an alpha of 0.05 and a power of 0.95. Likewise, a minimum of 45 participants for the retest was indicated. In addition, following the most common recommendations for performing a factorial analysis,[28] at least 10 subjects per item of the final scale were sought.

Patient and public involvement

Before conducting the present study, a rigorous and comprehensive adaptation protocol was implemented that included the direct participation of the target population, through a pilot study composed of a qualitative phase, through the use of cognitive interviews and a quantitative phase.[23] The result, which was detailed in a previous study,[23] allowed for improving the proposal through the elimination of some items, the modification of others, and even the reconsideration of some difficult concepts. The opinions and suggestions from the patient and public involvement (PPI) group were analysed, which helped eliminate potential barriers from different profiles (social and health professionals, researchers and family

caregivers). The participation of the individuals who were part of the PPI group was voluntary and non-paid.

Variables

The primary variable was living with LTCs.

Sociodemographic data were collected (ie, age, sex or marital status), as well as historical data of the situation of the individual with LTCs and the family caregiver (ie, number of hours spent on the care, having a respite care). Additionally, to establish correlations and associations with the degree of living with LTCs that would allow validating the instrument, health-related quality of life (HRQOL), burden of the caregiver and perceived social support variables were included. All the variables were completed by the family caregiver of a person with one or more LTCs.

Self-reported instruments

- Living with LTCs scale from the perspective of the family caregiver (EC-PC-Fam). This is an instrument adapted from the original EC-PC.[29–31] The adaptation process of the instrument and prior pilot study have been previously described in detail.[23] This initial version has 31 items and 5 domains: (1) acceptance, (2) coping, (3) self-management, (4) integration and (5) adaptation. All the items follow a Likert scale of 5 points answer system, from never or none (0) to always and much (4), except for the items from the acceptance domain, which must be inverted to obtain results such as never or none (4) or always or much (0). The scores range from 0 to 155, with a higher score indicating more positive living with LTCs.
- The EuroQOL-5 Dimensions 5-Level version (EQ-5D-5L) is an instrument designed to generically measure HRQOL, which can be used by both a healthy population and an individual with pathologies. The instrument developed by the EUROQOL group[32] has been validated in many countries, including Spain.[33 34] Different versions can be found, and in the present study, the EQ-5D-5L was selected due to the increase in the specificity of the responses as compared with the EQ-5D-3L. It is a self-administered instrument in which individuals assess their own health, first in a descriptive manner for each of the dimensions (mobility, personal care, everyday activities, pain/discomfort and anxiety/depression), with five levels, from 0 to 5, and then with a more general Visual Analogical Scale. For the Spanish context, the psychometric properties of the EQ-5D-5L scale were analysed in patients[35] with the results indicating a reliability of 0.86. The present project obtained approval from the EUROQOL group (Registration number 45231) for its authorised use.
- WHODAS 2.0: This measurement will be used to verify the relationship between the degree of disability of the patient and living with LTCs in the family caregiver. This scale was designed by the WHO to measure the degree of disability[36] and is useful for the LTCs context.[37] It is available in 12-item or 36-item versions and can be administrated in three different ways: by an interviewer, by the person itself or by a representative. For the present work, the 12-item version was selected, as it provided 81% of the variance of the 36-item version, with adequate psychometric properties in the Spanish context.[38] With respect to how it is administered, the version completed by a representative was selected, who in this case would be the family caregiver. A number of 1 (none) to 5 (extreme, cannot do it) is assigned to each answer, for a final score ranging from 12 to 60, in which higher scores indicate a greater degree of disability. The scale obtained an internal consistency of 0.98 and test–retest reliability of 0.98.
- Zarit test: This scale is included to verify the external validity (divergent validity) of the EC-PC-Fam. This scale, originally named Caregiver Burden Interview, is designed to assess the burden of caregivers of individuals with dementia, from the general theory of the items[39]. It has 22 items that evaluate the negative repercussions on specific areas of daily life associated with caregiving: physical health, psychological health, social activities and economic resources. As opposed to the original, the version validated in Spain[40] includes a 5-point Likert scale, for a total score that ranges from 22 to 110. In this study, different cut-off points were proposed: from 22 to 46, without burden; from 47 to 55, with burden and from 56 to 110, intense burden. The scale obtained an internal consistency of 0.91 and test–retest reliability of 0.96.
- DUKE UNC Functional Social Support Questionnaire (DUKE): This measurement tool was used to verify the relationship between social support and living with LTCs.[41] This self-completed tool provides a generic measurement in order to assess the perceived social support. It is composed of 11 items related to the availability of other people to offer help to another, skills in social relations, and emphatic and emotional communication. The items are scored from 1 (less support than desired) to 5 (all the support I desire). In agreement with the validation to Spanish study, it is a valid and reliable scale for assessing the perceived social support.[42] In the Spanish validation study, a cut-off point was used at the 15 percentile, which corresponded to a score <32. A score equal to or greater than 32 indicates normal support while less than 32 indicates a low social support. Also, the scale was specifically validated with family caregivers, which increases its adequacy for the present study.[43] The scale obtained an internal consistency of 0.89 and test–retest reliability of 0.92.

Data collection

The data collection took place between February and November 2023, in three different private health and social care centre with the participation of family caregivers of people with LTCs, in Spain.

An ad hoc protocol was designed to ensure homogeneity and rigour in the data collection process through all the centre.[44] After obtaining consent from those in charge of each participating centre, the protocol was explained to each of the individuals who contributed to the data collection. For this, necessary initial face-to-face and online meetings were scheduled during the entire data collection process. The completion of the questionnaires was similar for all family caregivers of people with LTCs who participated, and the estimated time was 30 min. Data collection was conducted at the centres, with participants completing the survey through self-reporting methods.

To obtain information on one of the essential characteristics of the tools, such as the stability of the measurement when it was applied at different moments in time, the completion of the EC-PC-Fam scale was repeated 10–15 days after the first completion. The individuals who expressed their desire to continue to collaborate in future phases of the study left their contact information on the survey document and were contacted posteriorly. In this second assessment, the EQ-5D-5L scale was included to have another additional measurement available that allowed the non-observation of large differences in the HRQOL of the participants with respect to the initial point in time. In the retest phase, a total of 50 participants were included, who agreed to participate.

Data analysis

Data were transcribed to an Excel database and cleaned and analysed in SPSS (SPSS Statistics for Windows, V.25.0., IBM) and R (RStudio V.2023.06.1; Build 524; psych package for the confirmatory analysis). Following the recommendations for the development of instruments,[45] to determine the sociodemographic characteristics of the sample and the characteristics related to the process of living with LTCs, descriptive analyses were used (measurements of central tendency, frequency and proportions). For the psychometric properties, the main standard definitions have been previously reviewed.[46 47]

To assess potential common method bias, Harman's criterion[48] was employed. To mitigate potential non-response bias, a simple imputation method was applied to the missing data, which constituted less than 5% of the total dataset.

Acceptability

The quality and acceptability of the data were considered adequate if the missing data were <5%, the floor-ceiling effect was <15% and the asymmetry was within the −1 to +1 interval.[26]

Reliability

The reliability of the instrument included aspects such as internal consistency, stability or the measurement error.[47] The internal consistency is understood as the degree of inter-relation between the items.[47] In this sense, correlations and Alpha values were determined for the scale as a whole and for each of the items separately. The standard criteria were adequate, with interitem values ≥0.20 and ≤0.75, corrected item-total r≥0.40, a homogeneity coefficient of the items r≥0.30 and Cronbach's α>0.70. Additionally, the reliability, understood as the reproducibility of the results,[46] was measured considering the Cohen's weighted Kappa criteria (r>0.21), the intraclass correlation coefficient (ICC≥0.60), the SE of the mean (SEM) and precision (SEM<1/2SD).

Validity

The validity of the domain includes three measurements, content validity, validity of the construct and validity of the criteria.[47] The content validity of the EC-PC-Fam was broadly described in the previous phase of scale adaptation through the participation of experts in the development of the items proposed.[23] The validity of the construct includes, at the same time, the structural validity, the transcultural validity and the proof of the hypothesis.[47] In this sense, there are different proofs of the hypothesis, such as convergent and discriminant validities and known groups. The structural validity was proven through an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA) in order to confirm the existing subscales.[26 47] The reference values for these analyses are included in online supplemental table 1. The structural validity was measured through the correlation between domains (r>0.30–0.70); for the convergent validity, an association hypothesis was posed between the EC-PC-Fam and similar (DUKE, EQ-5D-5L) or divergent (Zarit, WHODAS 1.0) constructs; for the discriminant validity, a hypothesis was made with weak values (r_s<0.20) with different constructs. In addition, for the discriminant validity (magnitude of the difference and significance) for known groups[47] data were grouped and the statistical tests Kruskal-Wallis and Mann-Whitney U were used.

RESULTS

Sample characteristics

A total of 311 family caregivers participated in the study. Most of them were women (68.2%), with a mean age of 58.29±9.91 years (range: 32–84 years). Of the sample, 65.6% were married, employed (36.7%), living in an urban environment (69.8%) and the relationship was most frequently being a spouse (46.9%). In most of the cases, the time dedicated to the care of a family member was around 10–20 hours per week (30.2%), they did not have respite care (66.6%) or a reference nurse (72.3%). As for the degree of disability of the person with the LTCs, it was 34.9±13.85 (range: 11–59 points). Online supplemental table 2 shows the most relevant demographic and social characteristics.

Suitability of the data

After the transcription of the items, 6 lost or missing data were detected that were random, that is, sporadic missing data completely by chance, which comprised <5%

of the total data (specifically, 1.9%). To homogenise the sample, the missing data were completed artificially with the method of simple imputation, more specifically, the substitution with the mean.[26]

The first results obtained from the EC-PC-Fam scale did not provide good values with respect to the reliability of the complete scale (Cronbach's alpha=0.50); or according to domain (only the adaptation domain showed an optimum Cronbach's alpha). This was also true for the variance explained (44.26%), or with respect to the corrected correlation between elements, as 38.7% (12/31) of them were <0.30. Thus, to find a model with a better fit, a factorial analysis was performed of the items of the test, including an EFA and a CFA, following the criteria established in 2022 by Ferrando *et al*.[26]

Suitability of the sample

To perform the EFA to identify latent values and the CFA to verify the hypothesised structure,[27] the sample was randomly divided into two subgroups through the creation of a new variable in SPSS with the function 'RV.UNIFORM(0,1)'. Once the random variables were generated, the sample was divided into two equal parts, selecting half of the cases based on these random values. After dividing the sample into two equal parts, one of them was used to perform the EFA, while the other was saved for the CFA. The number of participants was considered sufficient in each sub-sample,[27] as well as adequate, with the minimum recommendation being five participants per item for each of the analyses.[49 50] This division allowed us to explore the structure and relationships between variables in an independent sample before confirming the findings in the second sample, thus increasing the robustness and validity of the results obtained in the research study.

Factorial analysis of the EC-PC-Fam

With respect to the common variance of EC-PC-Fam, the result of the Kaiser-Meyer-Olkin test (0.699) indicated moderate suitability of the data,[51] which justified a factorial analysis of the items to determine their adequate grouping.[26]

The first EFA and CFA results showed that according to the data analysed, the suitable model was a proposal composed of 9 factors that represented a total of 71% of the variance. The initial version analysed provided non-acceptable fit values with respect to the fit (see online supplemental table 3), and the composition of the items and their factors. Therefore, a process was started to refine it, in order to achieve the greatest fit possible. For this, and considering the complexity, uniqueness, MSA and anti-image correlations (AIC) criteria, different items were discarded throughout the process, and after each elimination, the model was again verified until acceptable fit values in V.10 were obtained. Online supplemental table 4 explains the main reasons for eliminating the items from each version.

The EFA revealed that the first factor accounted for 22.55% of the variance, which is below the 50% threshold suggested by Harman to indicate a significant common method bias issue.[48]

The V.10. of the EC-PC-Fam scale was composed of 19 items grouped into 5 factors. All the factors were within the range of standards established with respect to complexity, uniqueness, MSA and AIC. The communalities were >0.6, with all the factorial loads of the 19 items within the established criteria. In general, the last version showed an adequate factorial fit. When comparing the different standard criteria defined to determine the fit among the different versions, an improvement was observed in the results related to the fit values in the last proposal, as shown in online supplemental table 2. This version ultimately represented 68.44% of the variance. Although this specific result was slightly deteriorated as compared with the earlier version tested, it remains within an acceptable range.[27]

Once the model with the best fit was found (V.10.), the psychometric properties of the new instrument created were determined.

Metric properties of the EC-PC-Fam: V.10 with 19 items

Quality and acceptability of the data

The validity was adequate, although six missing or lost data were detected that were random in nature, meaning that these missing data were due to chance and completely sporadic.[26] They comprised <5% of the total sample, more specifically, 1.9%. To homogenise the sample, as indicated in the previous section, the missing data were completed with the method of simple imputation, by substituting the missing data with the mean.[26] With respect to acceptability, 2 of the items did not encompass the complete possible range of scores (14 and 29). The difference between the mean and the median was found to be higher than 10% in 10 items (1, 2, 4, 9, 15, 17, 19, 22 and 30). Eight of the items showed asymmetry results that were slightly out of range (−1 to +1). The items did not show a floor effect, but the ceiling effect was above the established range. The normality tests were not significant, according to the Shapiro-Wilk and Kolmogorov-Smirnov tests for the total scores; the items and the factors did not have a normal distribution so that non-parametric tests were performed for the total sample.

Internal consistency

The Cronbach's alpha coefficient was 0.809 for the total scale, and all the factors were found within the range established as a standard (see table 1), except for the factor self-management, which obtained a result of 0.595.

The corrected item-total correlation varied between 0.372 and 0.730 and was found within the established range for all the items. The inter-item correlation values oscillated between 0.23 and 0.7; all the values were adequate according to the range established, except for items 15 and 28.

Table 1 Internal consistency results EC-PC-Fam (Escala de convivencia con procesos crónicos versión familiar of Living with Long Term Conditions Scale-Family)

Factors	Cronbach's alpha coefficient	Homogeneity of the items coefficient
Acceptance	0.816	0.56
Coping	0.743	0.72
Self-management	0.595	0.65
Integration	0.712	0.43
Adjustment	0.862	0.78

Reproducibility or stability (test–retest)

A total of 50 family caregivers participated in the retest, by completing the questionnaire once again after 7–10 days. Most of them were women (80%), with a mean age of 56.25±16.65 years, residing in an urban environment. The most common family relationships were child (46%) and spouse (32%). Kappa's coefficient for all the factors was found to be between low-moderate, the ICC was higher than 0.60 and the SEM was lower than ½ SD for all the factors, as shown in table 2.

Construct validity

As table 3 shows, the results of the structural (or internal) validity of the scale indicate that only some of the factors had correlation coefficients above the minimum established (r_s=0.3–0.70). Nevertheless, despite having a low degree of association between some of the factors, most of the results were statistically significant.

With respect to the convergent validity, the results indicated high positive correlations in the total scores of the EC-PC-Fam were positively observed with the DUKE scale (r_s=0.384**), and negative ones with the Zarit scale (r_s=–0.464**), with a moderate correlation observed in both results, as expected (all results of convergent validity are included in online supplemental table 5). Additionally, it must be underlined that the total result of the EC-PC-Fam was significantly and positively correlated with the Index of Health (r_s=0.373**) and negatively with the degree of disability (r_s=–0.246**), as expected.

The factors coping and adjustment obtained moderate-strong correlations with the Zarit scale (r_s=–0.437** and –0.311**, respectively). The factor adjustment was moderately correlated with the Duke scale (r_s=0.370**) and with the Index of health 'today' (r_s=0.379**).

The correlation of the EC-PC-Fam with the domains of the EQ-5D-5L obtained moderately significant values with the EQ-5D-1 (r_s=0.351**) and weak ones with the EQ-5D-3 (r_s=0.293**). Individually, the factors integration and adjustment showed a moderate significance with the EQ-5D-5L (r_s=–0.352** and 0.467**), one negatively and the other positively, respectively.

With respect to the discriminant validity, an association was established for known groups (see table 4), showing that the EC-PC-Fam scale was significantly different according to the hours dedicated to caregiving (Kruskal-Wallis test, p≤0.001), with a higher score obtained in the EC-PC-Fam, the lower the number of hours of daily dedication. A similar result was found in relation to having a reference nurse (Kruskal-Wallis test, p=0.001), with the family caregivers who had a reference nurse available at the health centre obtaining higher scores. On the other hand, having a respite care showed a significant difference as compared with not having it (Kruskal-Wallis test, p≤0.001). No significant differences were found in terms of sex, marital status or employment of the family caregivers.

Additionally, it must be pointed out that significant differences were found with the states defined as a burden in the Zarit scale (Kruskal-Wallis test, p≤0.001), with the participants with a burden or intense burden obtaining a lower score in the EC-PC-Fam degree of living. The relationship between the different levels of burden was verified with post hoc tests, which showed significant differences between the groups not experiencing burden and those experiencing moderate to intense burden (Dunnett's test, p≤0.001), although these differences were not significant between the groups with a burden.

Likewise, significant differences were observed with respect to the levels determined by the DUKE scale (Mann-Whitney U test, p≤0.001), with the family caregivers with a low perceived social support, the ones who also obtained a lower result in the global score of the EC-PC-Fam (Z=2.96, p≤0.001).

Table 2 Test–retest stability by factors

Factors	Kappa coefficient	ICC	SEM	½ SD
Acceptance	0.483	0.634	0.38	1.34
Coping	0.360	0.714	0.33	1.15
Self-management	0.360	0.610	0.26	0.92
Integration	0.270	0.610	0.29	1.01
Adjustment	0.371	0.752	0.70	2.46
EC-PC-Fam total	0.294	0.774	1.02	3.06

EC-PC-Fam, Escala de convivencia con procesos crónicos versión familiar of Living with Long Term Conditions Scale-Family; ICC, intraclass correlation coefficient; SEM, SE of measurement.

DISCUSSION

To our knowledge, this is the first study reporting on the validation and psychometric properties of an instrument to measure how family caregivers living with LTCs. Most of the psychometric properties of the EC-PC-Fam Scale showed optimum results. The CFA did not support the original structure of the scale, but the latest model of the EC-PC-Fam scale (V.10) was achieved, showing a moderate and significantly greater global fit in all the criteria observed, with respect to the previous versions.

Table 3 Internal validity of the EC-PC-Fam: Spearman correlations

Factors	Coping	Self-management	Integration	Adjustment
Acceptance	**0.165****	**0.426****	0.084	**0.188****
Coping	–	**0.326****	**0.256****	**0.254****
Self-management	–	–	0.19	0.14*
Integration	–	–	–	**0.539****

*p<0.05, **p<0.01
EC-PC-Fam, Escala de convivencia con procesos crónicos versión familiar of Living with Long Term Conditions Scale-Family.

This version ultimately represented 68.44% of the variance and remained within an acceptable range.[27] In general terms, the factorial solution proposed for the EC-PC-Fam includes 5 domains and 19 items and is a validated instrument that can be used to measure the degree of living with LTCs from the perspective of the family caregiver, verifying the starting hypothesis.

The acceptability of the data was considered adequate. As for the internal validity, despite the fact that only some of the factors had a strong association between them, most of the results were statistically significant. The weakest correlations were found in domain integration, specifically along with acceptance (0.084) and self-management (0,19). This finding coincides with similar results found in living with an LTC from the perspective of the patient.[52] These results, although they must be interpreted with caution and be revised in future studies to verify this association trend, could indicate inadequate acceptance leads to poorer results in other domains, despite all the domains being necessary for positively living with LTCs. Therefore, demonstrating acceptance seems to be a key aspect in the process of living with an LTC, a result that agrees with those found by Atefi *et al*[53] and is directly related to anxiety or depression of family caregivers.[53]

The results of the convergent validity were expected, answering the research questions that have been raised. The EC-PC-Fam showed strong correlations with the

Table 4 Discriminant validity of the EC-PC-Fam for known groups

Variable	Categories	Mean	SD	Frequency	P value
Hours of dedication	Less than 10 hours per week	57.71	7.89	53	Kruskal-Wallis test, <0.001
	Between 10 and 20 hours per week	54.15	7.46	94	
	Everyday, at least 8 hours	52.03	11.9	79	
	24 hours a day	50.19	9.9	85	
Respite care	Yes, with help from social services	52.11	12.1	39	Kruskal-Wallis test, <0.001
	Yes, I pay for it	57.46	9.04	56	
	Yes, with the help from the Association to which I belong	60.22	7.56	9	
	No	51.82	9.22	207	
Reference nurse	Yes, at the health centre	58.44	8.08	35	Kruskal-Wallis test, <0.001
	Yes, at the reference hospital	49.77	8.57	31	
	Yes, at the association to which I belong	56.5	6.9	20	
	No	52.47	10.1	225	
Period of time since diagnosis	Less than 6 months ago	50.72	8.77	36	Kruskal-Wallis test, <0.001
	Between 6 months and 2 years	52.81	7.25	72	
	Between 2 and 5 years	56.7	10.5	123	
	More than 5 years ago	48.84	9.18	77	
Zarit levels	No burden	58.97	7.63	111	Kruskal-Wallis test, <0.001
	Burden	48.59	8.22	34	
	Intense burden	50.19	9.61	166	
Duke levels	Perceived social support: low	48.68	13.5	53	Mann-Whitney U test; <0.001
	Perceived social support: normal	54.07	8.6	258	

EC-PC-Fam, Escala de convivencia con procesos crónicos versión familiar of Living with Long Term Conditions Scale-Family.

self-perceived Health Index (included in the EQ-5D-5L scale), as well as the perceived social support measured through the DUKE scale. The results obtained with respect to perceived social support are like those in recent studies conducted with family caregivers,[54–56] reinforcing, through our study, that support networks are essential for better living with LTCs, also from the perspective of the family caregiver. Likewise, the strong negative correlation between living with LTCs and caregiver burden is worth discussing. The experience of caregiving for an individual with LTCs was associated with a decline in one's functional capacity affecting physical and mental health.[15] The inadequate financial resources, multiple responsibility conflict, lack of social engagement, and the physical and emotional burden of caregiving for someone with LTCs can lead to increased stress, fatigue and a lack of time for self-care,[57 58] consequently exacerbating the challenges of living with LTCs. Despite the numerous initiatives in clinical practice found in the literature to mitigate caregiver burden, the present study suggests a novel invitation for health and social care professionals to explore interventions that improve the process of living with LTCs (or some of its domains) to positively influence the burden of the caregiver, constituting a novel approach for interventional and implementation studies in primary care.

With respect to the known group results, the participants who dedicated more time to caring, without a respite care, without a carer support nurse, and who had been living with LTCs for less than 6 months or more than 5 years, experienced worse living with LTCs (overall scores). These results are similar to those found by other researchers[59] and could indicate that, in addition to the already known attributes such a gender,[9 15 60] there are specific warning characteristics that must be considered by health and social care professionals. These aspects should be addressed when assessing the living with LTCs and follow-up needs, prioritising support interventions with family caregivers who fit the profile in community settings.

Although there is evidence of interventions with family caregivers targeting some of the domains of living with LTCs, such as self-management or coping,[61–64] this is not a comprehensive approach considering that living with LTCs is multifactorial.[18] Thus, measuring tools should become an asset for health and social care professionals in the assessment of living with LTCs. This could lead to planning and monitoring interventions from different angles that could foster a positive LTC management including the carer. Time restraints in consultations could be eased by asking the carers to complete the scale prior to consultation at home as it is a self-reported instrument. This reflection is congruent with former studies, which concluded that there is a need to include elements specific to the family caregiver in multicomponent interventions destined for people with LTCs.[65 66] Therefore, based on the results obtained, we believe that the EC-PC-Fam scale could be used as a patient-reported outcome measure, complementary to other tools used to assess HRQOL of family caregivers, as it is recommended[14 67–70] solving a decades-long clinical and research gap. On the other hand, the results of the association between the EC-PC-Fam and perceived social support further advocate the hypothetical relationship between these variables. Just as we find in a person with LTCs,[52] it is possible that proposals that mobilise and optimise the use of community resources, and increase the personal and/or social support networks can have a positive influence on living with LTCs, from the perspective of the family caregiver as it has been demonstrated in previous research with carers experiencing high levels of burden.[52 71–74] This finding is congruent with numerous studies, which underline social support as a fundamental element in the management of chronicity.[54 56 64 65 70]

This study and new tool constitute a 'game changer' in the management of LTCs and associated guidelines and policy.[14 15 60 75 76] For many decades, the needs of family caregivers of people with LTCs have been excluded from the management and handling of LTCs.[14] The availability of a new tool could favour the desired policy change to the approach to multiple LTCs, towards a caregiving or family approach centred on the person and not on the pathology. As a result, the effective integration of the family in the management of multiple LTCs could revolutionise clinical practice capability, training of professionals and upskilling, resulting in modifications of the dynamics in LTC consultations. Incorporating family care in the management of multiple LTCs is to support them to evolve as a partner, an ally in the caregiving process. This element must be integrated through assessments, referrals and follow-ups. Therefore, the use of this tool in clinical practice could be the breakthrough of a new paradigm to explore in the care of multiple LTCs, in which both the person with LTCs and the family caregiver play a key role. This innovative approach, based on the person, suggests the critical review of the current social-health policies and calls on stakeholders to promote the integration of the family caregiver as another component when addressing chronicity.

Following this study, the following clinical, research and policy recommendations are proposed: (1) Individual actions: further work is needed to continue exploring the psychometric properties of the EC-PC-Fam by integrating a more heterogeneous population and incorporating new variables such as predictive validity or translating to other language or doing transcultural adaptations. (2) Community responsibilities: this present study suggests a novel invitation for health and social care professionals to explore clinical and community interventions aimed at improving the living with LTCs with the goal of positively influencing caregiver burden. This represents a conceptual leap for intervention and implementation studies in primary care, voluntary organisations and residential settings. The incorporation of this element into clinical consultations could lead to a shift in dynamics, focusing not only on the patient but also on their family members when addressing care for a person with LTCs.

(3) Policy Implications: the use of EC-PC-Fam in clinical practice introduces a new approach to managing long-term care, recognising family caregivers as key partners and elements of care. This shift calls for a reconsideration of health and social care policies to include family caregivers, promoting person-centred care. Governments and healthcare organisations aim to improve care, reduce costs and optimise outcomes, but evidence alone is not enough to change macroeconomic policies.[77] All healthcare stakeholders, including nurses, need to actively promote public health policies that prioritise the individual and their health. Engaging family caregivers actively in care recognises their essential role and provides benefits for both patients, care providers and complex health and social care systems. Supporting and funding programmes to support family carers with specific needs can benefit health systems.[15 66 71] This approach enhances personalised, patient-centred care and reduces the burden on caregivers, improving well-being and optimising healthcare resources.

The strengths of this study are the methodological process followed to reach the most adequate factorial solution, according to the good practices described in the Decalogue,[26] and how the optimum results in most of the preliminary psychometric properties analysed in the EC-PC-Fam provide robustness to the proposal presented. Moreover, the use of the EC-PC-Fam in clinical practice proposes a new model in the management of chronicity. This new model considers the family caregiver not only as an active partner in the delivery of health and social care in LTCs but also as a recipient of care. In fact, our findings advocate for the reconsideration of social-health policies to include the family caregiver, to evolve towards person-centred care. Another strength is found in the active involvement of stakeholders in the design of the tool.[23] Including a small sample of family caregivers in the process of adapting the scale has proven to be highly beneficial for providing an initial assessment of participants' understanding of the items being questioned.[78]

In the interpretation of the results from the present work, some limitations must be considered. First, all the centres used for data collection were private, which could introduce bias according to the socioeconomic status of the families and other regions in Spain. Including only private centres in the study may introduce selection bias, as private centres typically serve a population with specific sociodemographic characteristics, such as higher socioeconomic status and privileged access to healthcare services. This can limit the generalisability of the study's findings, as the results obtained may differ in more diverse populations. The difference in resources and infrastructure between private and public centres can influence the quality of care and, consequently, the study's outcomes, making it necessary to verify this issue in future research. Future studies must include different public centres to promote the homogeneous social representation of the included participants. Second, the ill-fit of the initial scale proposed (V.6.EC-PC-Fam) demanded the performance of different modifications to improve the fit. First, through the exploration of the items through an EFA, and in parallel to the confirmation of the structure and the relationship between the items and the factors through a CFA. To perform this verification, the sample was divided into two subsamples composed of 155 and 156 participants, respectively. Despite both samples including more than 100 participants and at least 5 participants per item (the minimum needed), we believe that future studies must perform new confirmatory analyses of the EC-P-Fam to further verify the adequacy of the proposed factorial solution.[26] Second, although Harman's single-factor test did not indicate a significant common method bias, this approach has recognised limitations.[48] Third, simple imputation used for missing data, while common for low percentages, may affect the relationships between variables.[79] Finally, the lack of analysis of potential non-response bias, as well as early versus late response bias. The only feedback received from participants who were offered to participate but declined (3.52%) was 'no time to respond' or 'no interest in responding to yet another survey'. Additionally, bias between early and late responses could not be calculated, which would have provided valuable insights into potential non-response biases.[80] Future studies could benefit from additional methods for assessing common method bias, advanced techniques for handling missing data and strategies for evaluating bias between early and late responses.

CONCLUSIONS

The EC-PC-Fam scale emerges as a promising tool for promoting personalised care for optimising the management of LTCs, proposing a new model to explore in clinical practice that includes the family caregiver in the management of multiple LTCs.

After the fitting was performed, the EC-PC-Fam scale showed satisfactory psychometric preliminary properties. Future validation studies are recommended with a broader sample that includes other socioeconomic contexts in order to increase the robustness of the findings. In addition, future studies should continue to investigate different psychometric properties such as the responsiveness, interpretability of the questionnaire and the predictive validity of the scale and implementation in clinical practice.

With caution and considering the limitations discussed, the scale can be used in clinical practice in pilot studies to enhance the experience of family caregivers of people with LTCs.

Acknowledgements The authors would like to thank the collaboration of the family members with LTCs who participated, as well as the socio health professionals who participated in data collection and the organisations that participated in facilitating the recruitment of participants (AFAV, QuironSalud Hospital of Valencia, Levante U.D. Foundation).

Contributors PM-M: principal author of the scale, conception and design of the work, interpretation of the findings, data collection, drafting the article, critical revision and substantial contribution of the article, approval of the final version for

publication. LA and SC: design of the work and critical revision and substantial contribution of the article, approval of the final version for publication. JG-M: data analysis, interpretation of the findings, critical revision and substantial contribution of the article, approval of the final version for publication. MCP: conception and design of the work, critical revision and substantial contribution of the article, approval of the final version for publication. All the authors (PM-M, SC, JG-M and MCP) controlled the decision to publish. PM-M is the guarantor.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval Ethical approval was obtained from the University of Valencia Ethics Committee (Ref. 1648640757145) and also received a favourable 'Impact Evaluation Report' issued by the Organic Law on Data Protection (OLDP) department of said entity (UV-INV_ETICA-1936963), as personal data were going to be included in the study. At the same time, the necessary permits were obtained to carry out the project. To safeguard the privacy of the participant's data, they were informed orally and in writing about the study, by providing an information letter and an informed consent form through which the nature of the study was explained, their voluntary participation within it, and the confidentiality of the data obtained in accordance with the OLDP/2018. All procedures performed were managed confidentially and adhered to the ethical standards established in the 1964 Declaration of Helsinki and its later amendments.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. All data relevant to the study are included in the article or uploaded as online supplemental information.

ORCID iDs
Patricia Marín-Maicas http://orcid.org/0000-0001-9763-9502
Leire Ambrosio http://orcid.org/0000-0002-9450-7210
Jesús González-Moreno http://orcid.org/0000-0002-3968-8864

REFERENCES

1 Hajat C, Stein E. The global burden of multiple chronic conditions: A narrative review. *Prev Med Rep* 2018;12:284–93.
2 Mármol-López M, Miguel Montoya I, Montejano Lozoya R, *et al*. Impacto De Las Intervenciones Enfermeras En La Atención A La Cronicidad En España Revisión Sistemática. *Rev Esp Salud Publica* 2018;92:1–15. Available: www.msc.es/resp
3 Ministerio de Derechos Sociales y Agenda 2030. Agenda 2030. Vol. 2021. 2021. Available: https://www.mdsocialesa2030.gob.es/agenda2030/index.htm
4 Ministerio de Sanidad SS e I. Estrategia para el Abordaje de la Cronicidad en el Sistema Nacional de Salud. 2012.
5 Ministerio de Sanidad. Informe de evaluación y líneas prioritarias de actuación. Estrategia para el abordaje de la cronicidad en el Sistema Nacional de Salud. 2021.
6 Ministerio de sanidad. Informe anual del Sistema Nacional de Salud. 2022. Available: https://www.sanidad.gob.es/estadEstudios/estadisticas/sisInfSanSNS/tablasEstadisticas/InfAnSNS.htm
7 World Health Organization. Enfermedades no transmisibles. 2023. Available: https://www.who.int/es/news-room/fact-sheets/detail/noncommunicable-diseases
8 World Health Organization. Global status report on noncommunicable diseases, 2014. Available: https://www.who.int/topics/chronic_diseases/es/
9 Organisation for Economic Co-operation and Development. Who Cares? Attracting and Retaining Elderly Care Workers. 2020.
10 Global Burden of Disease Study. Global Burden of Disease Collaborative Network. 2020. Available: https://vizhub.healthdata.org/gbd-results/
11 Årestedt L, Persson C, Rämgård M, *et al*. Experiences of encounters with healthcare professionals through the lenses of families living with chronic illness. *J Clin Nurs* 2018;27:836–47.
12 Zigante V. Written by Informal care in Europe Exploring Formalisation, Availability and Quality. 2018.
13 NICE. Dementia: assessment, management and support for people living with dementia and their carers (NICE guidline, NG97). *Seishin Igaku* 2020;62:682–8. Available: https://webview.isho.jp/journal/detail/abs/10.11477/mf.1405206094
14 NICE. *Supporting adult carers (NG150)*. National Institute for Health and Care excellence, 2020. Available: https://www.nice.org.uk/guidance/ng150
15 World Health Organization. *Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region*. Copenhagen: World Health Organization. Regional Office for Europe, 2022. Available: https://iris.who.int/handle/10665/353912
16 Confederation of family organizations in the European Union. Disability. European Charter for family carers. 2021. Available: http://www.coface-eu.org/wp-content/uploads/2017/01/COFACE-Disability-CharterEN.pdf
17 Public Policy Institute A. 2020 - Caregiving in the US 2020 - AARP Research Report 2019. Available: www.greenwaldresearch.com
18 Marín-Maicas P, Corchón S, Ambrosio L, *et al*. Living with Long Term Conditions from the Perspective of Family Caregivers. A Scoping Review and Narrative Synthesis. *Int J Environ Res Public Health* 2021;18:7294.
19 Kralik D, Van Loon AM. Editorial: Transition and chronic illness experience. *J of Nursing and Healthcare* 2009;1:113–5.
20 Ambrosio L, Senosiain García JM, Riverol Fernández M, *et al*. Living with chronic illness in adults: a concept analysis. *J Clin Nurs* 2015;24:2357–67.
21 Ambrosio L, Navarta-Sánchez MV, Portillo MC, *et al*. Psychosocial Adjustment to Illness Scale in family caregivers of patients with Parkinson's Disease: Spanish validation study. *Health Soc Care Community* 2021;29:1030–40.
22 Ambrosio L, Navarta-Sánchez MV, Carvajal A, *et al*. *Living with chronic illness from the family perspective: an integrative review. Clinical Nursing Research*. SAGE Publications Inc, 2020.
23 Marín-Maicas P, Portillo MC, Corchón S, *et al*. Methodological Proposal for the Adaptation of the Living with Long-Term Conditions Scale to the Family Caregiver. *Nurs Rep* 2024;14:532–44.
24 Bryman A. *Social research methods*. Oxford university press, 2016.
25 Etikan I, Alkassim R, Abubakar Musa S, *et al*. Comparison of Convenience Sampling and Purposive Sampling. *AJTAS* 2016;5:1.
26 Ferrando PJ, Lorenzo-Seva U, Hernández-Dorado A, *et al*. Decálogo para el Análisis Factorial de los Ítems de un Test. *Psicothema (Oviedo)* 2022;34:1–11. Available: https://www.psicothema.com/pi?pii=4715
27 Lloret-Segura S, Ferreres-Traver A, Hernández-Baeza A, *et al*. El análisis factorial exploratorio de los ítems: una guía práctica, revisada y actualizada. *analesps* 2014;30:1151–69.
28 Beavers AS, Lounsbury JW, Richards JK, *et al*. Practical considerations for using exploratory factor analysis in educational research. *Pract Assess Res Eval* 2019;18:6.
29 Ambrosio L, Perez-Manchon D, Carvajal-Carrascal G, *et al*. Psychometric Validation of the Living with Chronic Illness Scale in Patients with Chronic Heart Failure. *Int J Environ Res Public Health* 2021;18:1–13.
30 Ambrosio L, Portillo MC, Rodríguez-Blázquez C, *et al*. Living with chronic illness scale: international validation of a new self-report measure in Parkinson's disease. *NPJ Parkinsons Dis* 2016;2:16022.
31 Meneses Monroy A, Rodríguez-Blázquez C, Ursúa ME, *et al*. Validación de la escala de convivencia con artrosis en la población española. *Aten Prim* 2021;53:102044.
32 EUROQOL. Helping the world make better health decisions, Available: https://euroqol.org/
33 Herdman M, Badia X, Berra S. El EuroQol-5D: una alternativa sencilla para la medición de la calidad de vida relacionada con la salud en atención primaria. *A P* 2001;28:425–9.

34 Badia X, Roset M, Montserrat S, *et al*. The Spanish version of EuroQol: a description and its applications. European Quality of Life scale. *Med Clin (Barc)* 1999;112 Suppl 1:79–85.
35 García-Pérez L, Ramos-García V, Serrano-Aguilar P, *et al*. EQ-5D-5L utilities per health states in Spanish population with knee or hip osteoarthritis. *Health Qual Life Outcomes* 2019;17:164:164:.
36 Ustun TB, Kostanjesek N, Chatterji S, *et al*. Measuring health and disability: manual for WHO Disability Assessment Schedule (WHODAS 2.0) / edited by T.B. Üstün, N. Kostanjsek, S. Chatterji. WHODAS 2.0 versions. *J Rehm* 2010;88.
37 Garin O, Ayuso-Mateos JL, Almansa J, *et al*. Validation of the "World Health Organization Disability Assessment Schedule, WHODAS-2" in patients with chronic diseases. *Health Qual Life Outcomes* 2010;8:51:1–15:.
38 Luciano JV, Ayuso-Mateos JL, Fernández A, *et al*. Psychometric properties of the twelve item World Health Organization Disability Assessment Schedule II (WHO-DAS II) in Spanish primary care patients with a first major depressive episode. *J Affect Disord* 2010;121:52–8.
39 Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–55.
40 Martín M, Salvadó I, MLCN S, *et al*. Adaptación para nuestro medio de la Escala de Sobrecarga del Cuidador (Caregiver Burden Interview) de Zarit. *Rev Gerontol* 1996;6:338–46.
41 Broadhead WE, Gehlbach SH, de Gruy FV, *et al*. The Duke-UNC Functional Social Support Questionnaire. Measurement of social support in family medicine patients. *Med Care* 1988;26:709–23.
42 Bellón Saameño JA, Delgado Sánchez A, Luna del Castillo J de D, *et al*. Validez y fiabilidad del cuestionario de apoyo social funcional Duke-UNC-11. *Aten Primaria* 1996;18:153–63. Available: https://www.elsevier.es/es-revista-atencion-primaria-27-articulo-validez-fiabilidad-del-cuestionario-apoyo-14325
43 Cuéllar Flores I, Dresch V. Validación del cuestionario de Apoyo Social Funcional Duke-UNK-11 en personas cuidadoras. *Rev iberoam diag eval psicol* 2012;2:89–101. Available: https://dialnet.unirioja.es/servlet/articulo?codigo=6929562&info=resumen&idioma=SPA
44 Argimon Pallas JM, Jimenez Villa J. *Métodos de Investigación Clínica y Epidemiológica. Métodos de Investigación Clínica Y Epidemiológica*. Elsevier, 2019:181.
45 Streiner DL, Kottner J. Recommendations for reporting the results of studies of instrument and scale development and testing. *J Adv Nurs* 2014;70:1970–9.
46 Kottner J, Audige L, Brorson S, *et al*. Guidelines for Reporting Reliability and Agreement Studies (GRRAS) were proposed. *Int J Nurs Stud* 2011;48:661–71.
47 Mokkink LB, Terwee CB, Patrick DL, *et al*. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *J Clin Epidemiol* 2010;63:737–45.
48 Podsakoff PM, MacKenzie SB, Lee JY, *et al*. Common method biases in behavioral research: a critical review of the literature and recommended remedies. *J Appl Psychol* 2003;88:879–903.
49 Carretero-Dios H, Pérez C. *Normas Para El Desarrollo y Revisión de Estudios Instrumentales*. International Journal of Clinical and Health Psychology, 2005.
50 Stevens JP. *Applied multivariate statistics for the social sciences*. Routledge, 1992.
51 Suárez OM. Aplicación del análisis factorial a la investigación de mercados. *Caso de estudio Sci et technica* 2007;1.
52 Ambrosio L, Hislop-Lennie K, Serrano-Fuentes N, *et al*. First validation study of the living with long term conditions scale (LwLTCs) among English-speaking population living with Parkinson's disease. *Health Qual Life Outcomes* 2023;21:69.
53 Atefi GL, de Vugt ME, van Knippenberg RJM, *et al*. The use of Acceptance and Commitment Therapy (ACT) in informal caregivers of people with dementia and other long-term or chronic conditions: A systematic review and conceptual integration. *Clin Psychol Rev* 2023;105:S0272-7358(23)00099-5.
54 Zhang Y, Ding Y, Liu C, *et al*. Relationships Among Perceived Social Support, Family Resilience, and Caregiver Burden in Lung Cancer Families: A Mediating Model. *Semin Oncol Nurs* 2023;39:S0749-2081(22)00133-4.
55 Puga F, Wang D, Rafford M, *et al*. The relationship between daily stressors, social support, depression and anxiety among dementia family caregivers: a micro-longitudinal study. *Aging Ment Health* 2023;27:1291–9.
56 Ong HL, Vaingankar JA, Abdin E, *et al*. Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry* 2018;18:18–27.
57 Papastavrou E, Kalokerinou A, Papacostas SS, *et al*. Caring for a relative with dementia: family caregiver burden. *J Adv Nurs* 2007;58:446–57.
58 Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis, 2020. Available: https://doi.org/10.1016/j.ijnss.2020.07.012
59 Gagliardi C, Piccinini F, Lamura G, *et al*. The Burden of Caring for Dependent Older People and the Resultant Risk of Depression in Family Primary Caregivers in Italy. *Sustainability* 2022;14:3375.
60 EPP Group Position Paper on a European Care Strategy, Available: https://www.eppgroup.eu/newsroom/epp-group-position-paper-on-a-european-care-strategy
61 Rouch SA, Fields BE, Alibrahim HA, *et al*. Evidence for the Effectiveness of Interventions for Caregivers of People With Chronic Conditions: A Systematic Review. *Am J Occup Ther* 2021;75:7504190030.
62 Kuang Y, Wang M, Yu NX, *et al*. Family resilience of patients requiring long-term care: A meta-synthesis of qualitative studies. *J Clin Nurs* 2023;32:4159–75.
63 Whitehead L, Jacob E, Towell A, *et al*. The role of the family in supporting the self-management of chronic conditions: A qualitative systematic review. *J Clin Nurs* 2018;27:22–30.
64 Corry M, While A, Neenan K, *et al*. A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. *J Adv Nurs* 2015;71:718–34.
65 Schulman-Green D, Feder SL, Dionne-Odom JN, *et al*. Family Caregiver Support of Patient Self-Management During Chronic, Life-Limiting Illness: A Qualitative Metasynthesis. *J Fam Nurs* 2021;27:55–72.
66 Moran N, Arksey H, Glendinning C, *et al*. Personalisation and Carers: Whose rights? Whose benefits? *Br J Soc Work* 2012;42:461–79.
67 Sullivan AB, Miller D. Who is Taking Care of the Caregiver? *J Patient Exp* 2015;2:7–12.
68 WHO. Preventing chronic diseases: a vital investment, 2005. Available: https://www.who.int/chp/chronic_disease_report/en/
69 WHO. Noncommunicable diseases, 2021. Available: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases
70 IFNA. Position statement on advanced practice competencies for family nursing. Switzerland. 2017.
71 Soilemezi D, Palmar-Santos A, Navarta-Sánchez MV, *et al*. Understanding support systems for Parkinson's disease management in community settings: A cross-national qualitative study. *Health Expect* 2023;26:670–82.
72 Navarta-Sánchez MV, Palmar-Santos A, Pedraz-Marcos A, *et al*. Perspectives of people with Parkinson's disease and family carers about disease management in community settings: A cross-country qualitative study. *J Clin Nurs* 2023;32:5201–18.
73 Vester LB, Haahr A, Nielsen TL, *et al*. A Parkinson care-coordinator may make a difference: A scoping review on multi-sectoral integrated care initiatives for people living with Parkinson's disease and their caregivers. *Pat Educ Couns* 2023;116:S0738-3991(23)00311-7.
74 Hjelle EG, Rønn-Smidt H, Haahr A, *et al*. Filling the gap in service provision. Partners as family carers to people with Parkinson's disease: A Scandinavian perspective. *Chronic Illn* 2024;20:258–70.
75 The NHS Long Term Plan, 2019. Available: www.longtermplan.nhs.uk
76 European Comission. *Union of equality: strategy for the rights of persons with disabilities 2021-2030. EDF: European Disability Forum*. 2021.
77 Grinspun D, Bajnok I. n.d. Sigma Theta Tau International, Registered Nurses' Association of Ontario. Transformar la enfermería a través del conocimiento: desarrollo de guías de buenas prácticas, ciencia de la implantación y evaluación.
78 Barham L. Public and patient involvement at the UK National Institute for Health and Clinical Excellence. *Patient* 2011;4:1–10.
79 Schafer JL, Graham JW. Missing data: our view of the state of the art. *Psychol Methods* 2002;7:147–77.
80 Groves RM, Peytcheva E. The Impact of Nonresponse Rates on Nonresponse Bias: A Meta-Analysis. *Public Opin Q* 2008;72:167–89.