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Cross-cultural adaptation and validation of Work Productivity and Activity Impairment questionnaires for caregivers of patients with pediatric inflammatory bowel disease in Spain. A multicenter study

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ABSTRACT

Introduction. The WPAI-UC/CD-Caregiver questionnaires assess the impact of ulcerative colitis (UC) or Crohn's disease (CD) on parents'/caregivers' work life and daily activities. Our objective was to adapt and validate these questionnaires in the Spanish population.

Methods. A translation and back-translation were done. The document was assessed by an expert committee and a pilot group of families of patients with pediatric inflammatory bowel disease (p-IBD). For validation, the parents/caregivers of patients with p-IBD (10–18 years old) were recruited. The expert committee and the pilot group conducted a subjective assessment of the format and time necessary to complete the questionnaires.

Cronbach's alpha coefficient was estimated and a factor analysis with varimax rotation was done. Kaiser-Meyer-Olkin (KMO) coefficients and Bartlett's sphericity test were estimated to test the adequacy of the factor analysis.

Results. A total of 370 patients (median age: 14.1 years) and 263 parents/caregivers of patients with UC or unclassified IBD and 261 parents/caregivers of patients with CD were included. The KMO coefficients (0.6947 and 0.7179) and Bartlett's sphericity test ($p < 0.001$) confirmed the adequacy of the factor analysis. The 6 items targeted the same domain. The factor model accounted for 99.99% and 94.68% of variance, and Cronbach's alpha coefficients (0.6581 and 0.6968) showed an adequate consistency. The format and the median time of 2 minutes to complete the questionnaires were considered optimal.

Conclusions. The versions of the WPAI-Caregiver questionnaires validated in the Spanish population may be used in families whose children have IBD.

Keywords: *inflammatory bowel conditions; surveys and questionnaires; WPAI-UC-Caregiver and WPAI-CD-Caregiver; validation study.*

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INTRODUCTION

Studies involving pediatric patients with chronic diseases reflect the impact of these conditions on various aspects of the lives of their family or caregivers.[1–3] The need for care of these patients may decrease their time and energy in relation to work, leisure, self-care, or even interfere in their relationship with a partner, the patient, or other siblings.[4–8]

Inflammatory bowel disease (IBD) encompasses 3 chronic inflammatory diseases affecting the gastrointestinal tract: ulcerative colitis (UC), Crohn's disease (CD), and unclassified inflammatory bowel disease (u-IBD). The incidence of IBD in pediatrics has increased in recent decades, with an earlier age at diagnosis.[9–11] The chronic nature, potential severity, and unpredictability of the course of IBD may have an impact on the quality of life (QoL) of patients and their families or caregivers.[12,13] Patients with pediatric IBD (p-IBD) require frequent hospital visits for consultations, complementary tests, treatment, or hospitalization due to a flare-up or complication. All this results in school absenteeism and the need to be accompanied by their caregivers, who are forced to adapt their working hours or take a day off work.[14–16]

The Work Productivity and Activity Impairment (WPAI) questionnaires were designed by Reilly et al. to assess the impact on work and daily activities of different chronic diseases, for both patients and their caregivers.[17,18] The Work Productivity and Activity Impairment Questionnaire for Ulcerative Colitis-Caregiver (WPAI-UC-Caregiver) version and the Work Productivity and Activity Impairment Questionnaire for Crohn's disease-Caregiver (WPAI-CD-Caregiver) version aim to measure this aspect of parents/caregivers of pediatric patients with UC or CD, respectively.[16,19] These questionnaires had been translated into Spanish, but the versions for caregivers had not yet been validated among Spanish families.[20,21] In addition, some linguistic expressions that are difficult to understand were identified in the available Spanish versions. Our objective was to carry out the cultural adaptation and validation of these tools in the Spanish population.

METHODS

Instrument description

The WPAI-UC-Caregiver and WPAI-CD-Caregiver questionnaires include 6 questions regarding the past week in the life of the patient's parent/caregiver. The first question requires a dichotomous answer (yes/no) regarding their employment status. The other 5 questions require a numerical value answer: hours of work missed due to the child's disease, hours of work missed for other reasons, hours actually worked, and the extent to which the child's disease affected their productivity during the workday and their daily activities, from 0 (no impact) to 10 (maximum impact). Scores are estimated using the formulas available in http://www.reillyassociates.net/WPAI_Scoring.html and are described as percentage of involvement/productivity loss; a higher score indicates a greater impact.[22]

Initial translation and validation

The original questionnaires were obtained from the Reilly et al.'s website (http://www.reillyassociates.net), which offers them for research studies. Based on the original questionnaires (in English), the methodology proposed by Beaton et al. of translation, back-translation, and assessment by an expert committee —made up of the team of translators, the experts in methodology, and the corresponding healthcare professionals (6 of the project's investigators, with experience in the translation and validation of quality of life questionnaires and who see patients with p-IBD in their clinical practice)— was applied to achieve a consensual version.[23] Subsequently, a pilot group of 12 families of patients with p-IBD were invited to complete the questionnaires to identify any potential unclear items.

Field test

Population

Members of the Spanish Society of Pediatric Gastroenterology, Hepatology and Nutrition (Sociedad Española de Gastroenterología Hepatología y Nutrición Pediátrica, SEGHNP) were invited to recruit patients with p-IBD aged 10 to 18 years, who attended follow-up consultations between February 2021 and June 2023, and at least one of their parents/caregivers. The WPAI-UC-Caregiver or WPAI-CD-Caregiver questionnaires were administered to the caregivers of patients diagnosed with UC/u-IBD, or CD, respectively. The patient's physician was responsible for explaining the study, obtaining the consents, and delivering the questionnaires, offering the option to complete them on the spot or returning them

at the following visit. A minimum sample size of 60 questionnaires of each type was estimated, according to the standard recommendations of including 10 subjects for each item.[24]

Collected variables

Patients' sex, age at diagnosis and at the time of participation, diagnosis, Paris classification, clinical activity index, treatment, and physician's global assessment were recorded. To assess the feasibility of the questionnaires, both the expert committee and the pilot group of participants considered the format and time required to complete them. To this end, participants were asked to measure and write on the questionnaire the time spent completing it, and to respond verbally to the questions: "Do you find the format of the questionnaire adequate?", "Do you find the time taken to complete it adequate?". Face validity was established by subjectively considering the degree to which the questionnaires appeared to measure their objective, covering all aspects relevant to the purpose of the analysis (impact on work and daily activities).

Analysis plan

Feasibility

The assessment of both the expert committee and the pilot group of participants regarding the adequacy of the format and the time needed to complete them was analyzed.

Questionnaire reliability and validation

The sample adequacy for the exploratory factor analysis was estimated using the Kaiser-Meyer-Olkin (KMO) test (considering values above 0.5 as an adequate correlation) and Bartlett's test of sphericity ($p < 0.05$) to check the adequacy of the exploratory factor analysis. For validation, Cronbach›s alpha coefficient was estimated, which is expressed in values between 0 and 1; values between 0.7 and 0.9 are usually considered to indicate an excellent internal consistency. To analyze the construct validity, a confirmatory factor analysis with varimax rotation (with desirable values above 0.5) was performed. Face validity was analyzed by considering the subjective assessment of the expert committee and the pilot group of patients regarding the extent to which the test appeared to measure what it was intended to measure.[25]

Data were collected and stored in REDCap® (Research Electronic Data Capture) under the SEGHNP´s license. Qualitative variables were expressed as percentages, while quantitative variables, as mean and 95% confidence interval in the case of a normal distribution, and as median and interquartile range in the absence of a normal distribution. Data were analyzed using the SPSS® software, version 24.0 (SPSS Inc., Chicago, IL, USA).

The study was approved by the Drug Research Ethics Committee of Hospital Infantil Universitario Niño Jesús, in Madrid, the sponsoring site (internal code: R-0090/20). All parents/caregivers signed the corresponding informed consents and completed the Spanish language versions of the questionnaires. Children gave their consent or assent, as applicable for their age.

RESULTS

A total of 382 families were recruited from 37 hospitals, of which 370 patients with their parents/caregivers were finally included in the study. The rest were excluded due to lack of data or errors in the completion of the forms that turned them invalid for statistical analysis. *Table 1* describes the patients' demographic and clinical variables. A total of 524 questionnaires were analyzed: 263 completed by parents/caregivers of children with UC or u-IBD and 261 by parents/caregivers of children with CD. Of all questionnaires included in the study, 54% were completed by women. In addition, 31% of the entire sample had completed graduate or postgraduate education. At the time of completing the questionnaire, 60% worked for an employer and up to 23% were unemployed.

The WPAI-UC-Caregiver and WPAI-CD-Caregiver versions in Spanish that were obtained after the cross-cultural adaptation process conducted based on the model proposed by Beaton et al. were similar to previous translations. The original versions of both questionnaires (in English for US), the translations available until that moment (in Spanish for Spain, 2015 version), and both cross-cultural adaptations resulting from this study are shown in *Tables 2 and 3*.

Both the expert committee and the group of pilot participants unanimously considered that the design of both instruments (6 simply worded questions answered dichotomously or using a numerical value) as well as the median response time of 2 minutes (interquartile range: 1–5) were optimal. They also unanimously concluded that both questionnaires showed an adequate face validity because they covered all relevant aspects for assessing the impact on caregivers' work

Table 1. Demographic and clinical characteristics of patients with pediatric inflammatory bowel disease (n = 370)

Male sex (%)	207 (56)
Age at diagnosis, years, median (IQR)	11.3 (8.7–13.3)
Age at the time of participation, years, median (IQR)	14.4 (12.4-16.1)
Type of IBD diagnosed, n (%)	
Crohn's disease (CD)	226 (61.1)
Ulcerative colitis (UC)	128 (34.6)
Unclassified IBD (u-IBD)	16 (4.3)
Paris classification of UC and u-IBD, n (%)	144 (38.9)
E: extension (maximal macroscopic inflammation)	
E1: ulcerative proctitis	11 (8)
E2: left-sided UC (distal to the splenic flexure)	27 (19)
E3: extensive UC (distal to the hepatic flexure)	10 (7)
E4: pancolitis (proximal to the hepatic flexure)	95 (66)
S: severity (severe defined by PUCAI >65)	
S0: never severe	95 (66)
S1: ever severe	49 (34)
Paris classification of CD, n (%)	226 (61.1)
A: age at diagnosis	
A1a: 0 to <10 years	77 (34)
A1b: 10 to <17 years	149 (66)
L: location	
L1: distal 1/3 ileum +/- limited cecal disease	52 (23)
L2: colonic	29 (13)
L3: ileocolonic	144 (64)
L4a: upper disease proximal to ligament of Treitz	40 (18)
L4b: upper disease distal to ligament of Treitz and proximal to distal 1/3 ileum	11 (5)
B: behavior	
B1: nonstricturing and nonpenetrating	187 (83)
B2: stricturing	23 (10)
B3: penetrating	11 (5)
B2-B3: both penetrating and stricturing	5 (2)
P: perianal disease	61 (27)
G: growth	
G0: no evidence of growth delay	169 (75)
G1: growth delay	57 (25)
PUCAI at the time of participation, median (IQR)	0 (0-10)
Patients in remission, n (%)	108 (75)
wPCDAI at the time of participation, median (IQR)	0 (0-10)
Patients in remission, n (%)	179 (79.2)
Treatments received at the time of participation, n (%)	
Biological therapy	114 (30.8)
Immunosuppressive therapy	165 (44.6)
Corticosteroids	22 (6)
5-ASAs	125 (33.7)
Other	103 (27.8)
***Physician's global assessment (PGA),* n (%)**	
Normal	259 (70)
Mild	52 (14)
Moderate	37 (10)
Severe	22 (6)

IQR: interquartile range.
IBD: inflammatory bowel disease.
PUCAI: Pediatric Ulcerative Colitis Activity Index.
wPCDAI: weighted Pediatric Crohn's Disease Activity Index.

Table 2. Work Productivity and Activity Impairment Questionnaire for Ulcerative Colitis-Caregiver (WPAI-UC-Caregiver). Original version (English for USA), previous translated version (Spanish for Spain, 2015), and proposed version

Original version (English for USA) WPAI:UC-Caregiver V2.0 (English for USA) 23/JAN/2015	**Previous version (Spanish for Spain)** WPAI:UC-Caregiver V2.1 (Spanish for Spain) 23/JAN/2015	**Proposed version (Spanish for Spain)** Version from January 2021, adapted by the Task Force for IBD of the SEGHNP
WPAI-UC-Caregiver	***WPAI-CU-Cuidadores***	***WPAI-CU-Cuidadores***
The following questions ask about the effect of your child's ulcerative colitis on your ability to work and perform regular activities. *Please fill in the blanks or circle a number, as indicated.*	Las siguientes preguntas se ocupan del efecto que la colitis ulcerosa de su hijo/a tiene sobre la capacidad que usted tiene para trabajar y realizar actividades cotidianas. *Tenga a bien completar los espacios en blanco o encerrar un número en un círculo, según corresponda.*	Las siguientes preguntas están relacionadas con el efecto que la colitis ulcerosa de su hijo/a tiene sobre su capacidad para trabajar y realizar actividades cotidianas. *Rellene los espacios en blanco o rodee un número, según corresponda.*
1. Are you currently employed (working for pay)? _____ NO _____ YES *If NO, check "NO" and skip to question 6.*	¿Está actualmente empleado (tiene un trabajo remunerado)? _____ NO _____ SÍ *Si la respuesta es NO, marque "NO" y pase a la pregunta 6.*	1. ¿Trabaja actualmente (trabajo remunerado)? _____NO _____SÍ *Si la respuesta es negativa, marque "NO" y pase a la pregunta 6.*
The next questions are about the past seven days, not including today.	Las siguientes preguntas se refieren a los últimos siete días, sin incluir el día de hoy.	Las siguientes preguntas se refieren a los últimos siete días, sin incluir el día de hoy.
2. During the past seven days, how many hours did you miss from work because of problems associated with your child's ulcerative colitis? *Include hours you missed on sick days, times you went in late, left early, etc., because of your child's ulcerative colitis. Do not include time you missed for your child to participate in this study.* _____HOURS	2. Durante los últimos siete días, ¿cuántas horas de trabajo perdió debido a problemas relacionados con la colitis ulcerosa de su hijo/a? *Incluya las horas que perdió por días de enfermedad, las veces que llegó tarde o se fue temprano, etc., por causa de la colitis ulcerosa de su hijo/a. No incluya el tiempo que perdió por la participación de su hijo/a en este estudio.*_____HORAS	2. Durante los últimos siete días, ¿cuántas horas faltó al trabajo debido a problemas relacionados con la colitis ulcerosa de su hijo/a? *Incluya las horas que faltó por días de baja por enfermedad, las veces que llegó tarde o se fue antes del trabajo, etc., debido a la colitis ulcerosa de su hijo/a. No incluya el tiempo que faltó para que su hijo/a participase en este estudio.* _____ HORAS
3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off for your child to participate in this study? ____HOURS	3. Durante los últimos siete días, ¿cuántas horas de trabajo perdió debido a cualquier otra causa, tal como vacaciones, un día de fiesta o tiempo que se tomó para que su hijo participara/a en este estudio? _____ HORAS	3. Durante los últimos siete días, ¿cuántas horas faltó al trabajo por cualquier otra causa, tal como vacaciones, festivos o los días libres que se tomó para que su hijo/a participase en este estudio? ____ HORAS
4. During the past seven days, how many hours did you actually work? ____HOURS *(If "0", skip to question 6.)*	4. Durante los últimos siete días, ¿cuántas horas realmente trabajó? _____ HORAS *(Si la respuesta es "0", pase a la pregunta 6.)*	4. Durante los últimos siete días, ¿cuántas horas trabajó realmente? ___ HORAS *(Si la respuesta es "0", pase a la pregunta 6).*

5. During the past seven days, how much did your child's ulcerative colitis affect your productivity while you were working? *Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If your child's ulcerative colitis affected your work only a little, choose a low number. Choose a high number if your child's ulcerative colitis affected your work a great deal.* Consider only how much your child's ulcerative colitis affected productivity while you were working. My child's ulcerative colitis had no effect on my work. 0 1 2 3 4 5 6 7 8 9 10 My child's ulcerative colitis completely prevented me from working. CIRCLE A NUMBER	5. Durante los últimos siete días, ¿cuánto afectó la colitis ulcerosa de su hijo/a a su productividad mientras estaba trabajando? *Piense en los días en que estuvo limitado en cuanto a la cantidad o el tipo de trabajo que pudo realizar, los días que hizo menos de lo que hubiera querido o los días en los que no pudo realizar su trabajo con la dedicación habitual. Si la colitis ulcerosa de su hijo/a afectó poco a su trabajo, escoja un número bajo.* *Escoja un número alto si la colitis ulcerosa de su hijo/a afectó mucho a su trabajo.* Tenga en cuenta únicamente cuánto afectó la colitis ulcerosa de su hijo/a a su productividad mientras estaba trabajando.. La colitis ulcerosa de mi hijo/a no afectó a mi trabajo 0 1 2 3 4 5 6 7 8 9 10 La colitis ulcerosa de mi hijo/a me impidió completamente trabajar. ENCIERRE EL NÚMERO EN UN CÍRCULO	5. Durante los últimos siete días, ¿cuánto afectó la colitis ulcerosa de su hijo/a a su productividad mientras trabajaba? *Piense en los días en los que estuvo limitado/a en cuanto a la cantidad o el tipo de trabajo que pudo realizar, los días que hizo menos de lo que le gustaría o los días en los que no pudo realizar su trabajo con la dedicación habitual. Escoja un número bajo si la colitis ulcerosa de su hijo/a afectó solo ligeramente a su trabajo. Escoja un número alto si la colitis ulcerosa de su hijo/a afectó mucho a su trabajo.* Tenga en cuenta únicamente cuánto afectó la colitis ulcerosa de su hijo/a a su productividad mientras trabajaba. La colitis ulcerosa de mi hijo/a no tuvo ningún efecto en mi trabajo. 0 1 2 3 4 5 6 7 8 9 10 La colitis ulcerosa de mi hijo/a me impidió trabajar. RODEE UN NÚMERO
6. During the past seven days, how much did your child's ulcerative colitis affect your ability to do your regular daily activities, other than work at a job? By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If your child's ulcerative colitis affected your activities only a little, choose a low number. Choose a high number if your child's ulcerative colitis affected your activities a great deal. My child's ulcerative colitis had no effect on my daily activities. 0 1 2 3 4 5 6 7 8 9 10 My child's ulcerative colitis completely prevented me from doing my daily activities. CIRCLE A NUMBER	6. Durante los últimos siete días, ¿cuánto afectó la colitis ulcerosa de su hijo/a a su capacidad para realizar las actividades diarias habituales, excluyendo las de su trabajo remunerado? Por actividades habituales, nos referimos a las actividades cotidianas que realiza, tales como tareas hogareñas, compras, cuidado de los niños, deportes, estudios, etc. Piense en las veces en que estuvo limitado en la cantidad o la clase de actividad que pudo realizar y en las veces en las que hizo menos de lo que hubiera querido. Si la colitis ulcerosa de su hijo/a afectó poco a sus actividades, escoja un número bajo. Escoja un número alto si la colitis ulcerosa de su hijo/a afectó mucho a sus actividades. Tenga en cuenta únicamente cuánto afectó la colitis ulcerosa de su hijo/a a su capacidad para realizar las actividades diarias habituales, La colitis ulcerosa de mi hijo/a no afectó a mis actividades habituales. 0 1 2 3 4 5 6 7 8 9 10 La colitis ulcerosa de mi hijo/a me impidió completamente hacer mis actividades habituales. ENCIERRE EL NÚMERO EN UN CÍRCULO	6. Durante los últimos siete días, ¿cuánto afectó la colitis ulcerosa de su hijo/a a su capacidad para realizar sus actividades cotidianas que no estuviesen relacionadas con su trabajo remunerado? Por actividades cotidianas, nos referimos a aquellas actividades normales que realiza, como las tareas del hogar, hacer la compra, cuidar de niños, hacer ejercicio, estudiar, etc. Piense en las veces en que estuvo limitado/a en lo que respecta a la cantidad o el tipo de actividades que pudo realizar y en las veces en las que hizo menos de lo que le gustaría. Escoja un número bajo si la colitis ulcerosa de su hijo/a afectó solo ligeramente a sus actividades. Escoja un número alto si la colitis ulcerosa de su hijo/a afectó mucho a sus actividades. Tenga en cuenta únicamente cuánto afectó la colitis ulcerosa de su hijo/a a su capacidad para realizar sus actividades cotidianas que no estuviesen relacionadas con su trabajo remunerado. La colitis ulcerosa de mi hijo/a no tuvo ningún efecto en mis actividades cotidianas. 0 1 2 3 4 5 6 7 8 9 10 La colitis ulcerosa de mi hijo/a me impidió realizar mis actividades cotidianas. RODEE UN NÚMERO

Table 3. Work Productivity and Activity Impairment Questionnaire for Crohn's Disease-Caregiver (WPAI-CD-Caregiver). Original version (English for USA), previous translated version (Spanish for Spain, 2015) and proposed version

Original version (English for USA) WPAI:CD-Caregiver V2.0 (English for USA) 23/JAN/2015 ***WPAI-CD-Caregiver***	**Previous version (Spanish for Spain)** WPAI:CD-Caregiver V2.1 (Spanish for Spain) 23/JAN/2015 ***WPAI-EC-Cuidadores***	**Proposed version (Spanish for Spain)** Version from January 2021, adapted by the Task Force for IBD of the SEGHNP ***WPAI-EC-Cuidadores***
The following questions ask about the effect of your child's Crohn's disease on your ability to work and perform regular activities. *Please fill in the blanks or circle a number, as indicated.*	Las siguientes preguntas se ocupan del efecto que la enfermedad de Crohn de su hijo/a tiene sobre la capacidad que usted tiene para trabajar y realizar actividades cotidianas. *Tenga a bien completar los espacios en blanco o encerrar un número en un círculo, según corresponda.*	Las siguientes preguntas están relacionadas con el efecto que la enfermedad de Crohn de su hijo/a tiene sobre su capacidad para trabajar y realizar actividades cotidianas. *Rellene los espacios en blanco o rodee un número, según corresponda.*
1. Are you currently employed (working for pay)? _____ NO _____ YES *If NO, check "NO" and skip to question 6.*	¿Está actualmente empleado (tiene un trabajo remunerado)? _____ NO _____ SÍ *Si la respuesta es NO, marque "NO" y pase a la pregunta 6.*	1. ¿Trabaja actualmente (trabajo remunerado)? _____NO _____SÍ *Si la respuesta es negativa, marque "NO" y pase a la pregunta 6.*
The next questions are about the past seven days, not including today.	Las siguientes preguntas se refieren a los últimos siete días, sin incluir el día de hoy.	Las siguientes preguntas se refieren a los últimos siete días, sin incluir el día de hoy.
2. During the past seven days, how many hours did you miss from work because of problems associated with your child's Crohn's disease? *Include hours you missed on sick days, times you went in late, left early, etc., because of your child's Crohn's disease. Do not include time you missed for your child to participate in this study.* _____HOURS	2. Durante los últimos siete días, ¿cuántas horas de trabajo perdió debido a problemas relacionados con la enfermedad de Crohn de su hijo/a? *Incluya las horas que perdió por días de enfermedad, las veces que llegó tarde o se fue temprano, etc., por causa de la enfermedad de Crohn de su hijo/a. No incluya el tiempo que perdió por la participación de su hijo/a en este estudio.* _____HORAS	2. Durante los últimos siete días, ¿cuántas horas faltó al trabajo debido a problemas relacionados con la enfermedad de Crohn de su hijo/a? *Incluya las horas que faltó por días de baja por enfermedad, las veces que llegó tarde o se fue antes del trabajo, etc., debido a la enfermedad de Crohn de su hijo/a. No incluya el tiempo que faltó para que su hijo/a participase en este estudio.* _____ HORAS
3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off for your child to participate in this study? ____HOURS	3. Durante los últimos siete días, ¿cuántas horas de trabajo perdió debido a cualquier otra causa, tal como vacaciones, un día de fiesta o tiempo que se tomó para que su hijo participara/a en este estudio? _____ HORAS	3. Durante los últimos siete días, ¿cuántas horas faltó al trabajo por cualquier otra causa, tal como vacaciones, festivos o los días libres que se tomó para que su hijo/a participase en este estudio? ____ HORAS
4. During the past seven days, how many hours did you actually work? ____HOURS *(If "0", skip to question 6.)*	4. Durante los últimos siete días, ¿cuántas horas realmente trabajó? _____HORAS *(Si la respuesta es "0", pase a la pregunta 6.)*	4. Durante los últimos siete días, ¿cuántas horas trabajó realmente? ___ HORAS *(Si la respuesta es "0", pase a la pregunta 6).*

5. During the past seven days, how much did your child's Crohn's disease affect your productivity while you were working? *Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual. If your child's Crohn's disease affected your work only a little, choose a low number. Choose a high number if your child's Crohn's disease affected your work a great deal.* Consider only how much your child's Crohn's disease affected productivity while you were working. My child's Crohn's disease had no effect on my work. 0 1 2 3 4 5 6 7 8 9 10 My child's Crohn's disease completely prevented me from working. CIRCLE A NUMBER	5. Durante los últimos siete días, ¿cuánto afectó la enfermedad de Crohn de su hijo/a a su productividad mientras estaba trabajando? *Piense en los días en que estuvo limitado en cuanto a la cantidad o el tipo de trabajo que pudo realizar, los días que hizo menos de lo que hubiera querido o los días en los que no pudo realizar su trabajo con la dedicación habitual. Si la enfermedad de Crohn de su hijo/a afectó poco a su trabajo, escoja un número bajo. Escoja un número alto si la enfermedad de Crohn de su hijo/a afectó mucho a su trabajo.* Tenga en cuenta únicamente cuánto afectó la enfermedad de Crohn de su hijo/a a su productividad mientras estaba trabajando. La enfermedad de Crohn de mi hijo/a no afectó a mi trabajo. 0 1 2 3 4 5 6 7 8 9 10 La enfermedad de Crohn de mi hijo/a me impidió completamente trabajar. ENCIERRE EL NÚMERO EN UN CÍRCULO	5. Durante los últimos siete días, ¿cuánto afectó la enfermedad de Crohn de su hijo/a a su productividad mientras trabajaba? *Piense en los días en los que estuvo limitado/a en cuanto a la cantidad o el tipo de trabajo que pudo realizar, los días que hizo menos de lo que le gustaría o los días en los que no pudo realizar su trabajo con la dedicación habitual. Escoja un número bajo si la enfermedad de Crohn de su hijo/a afectó solo ligeramente a su trabajo. Escoja un número alto si enfermedad de Crohn de su hijo/a afectó mucho a su trabajo.* Tenga en cuenta únicamente cuánto afectó la enfermedad de Crohn de su hijo/a a su productividad mientras trabajaba. La enfermedad de Crohn de mi hijo/a no tuvo ningún efecto en mi trabajo. 0 1 2 3 4 5 6 7 8 9 10 La enfermedad de Crohn de mi hijo/a me impidió trabajar. RODEE UN NÚMERO
6. During the past seven days, how much did your child's Crohn's disease affect your ability to do your regular daily activities, other than work at a job? *By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If your child's Crohn's disease affected your activities only a little, choose a low number. Choose a high number if your child's Crohn's disease affected your activities a great deal.* Consider only how much your child's Crohn's disease affected your ability to do your regular daily activities, other than work at a job. My child's Crohn's disease had no effect on my daily activities 0 1 2 3 4 5 6 7 8 9 10 My child's Crohn's disease completely prevented me from doing my daily activities. CIRCLE A NUMBER	6. Durante los últimos siete días, ¿cuánto afectó la enfermedad de Crohn de su hijo/a a su capacidad para realizar las actividades diarias habituales, excluyendo las de su trabajo remunerado? Por actividades habituales, nos referimos a las actividades cotidianas que realiza, tales como tareas hogareñas, compras, cuidado de los niños, deportes, estudios, etc. Piense en las veces en que estuvo limitado en la cantidad o la clase de actividad que pudo realizar y en las veces en las que hizo menos de lo que hubiera querido. Si la enfermedad de Crohn de su hijo/a afectó poco a sus actividades, escoja un número bajo. Escoja un número alto si la enfermedad de Crohn de su hijo/a afectó mucho a sus actividades. Tenga en cuenta únicamente cuánto afectó la enfermedad de Crohn de su hijo/a a su capacidad para realizar las actividades diarias habituales, excluyendo las de su trabajo. La enfermedad de Crohn de mi hijo/a no afectó a mis actividades habituales. 0 1 2 3 4 5 6 7 8 9 10 La enfermedad de Crohn de mi hijo/a me impidió completamente hacer mis actividades habituales. ENCIERRE EL NÚMERO EN UN CÍRCULO	6. Durante los últimos siete días, ¿cuánto afectó la enfermedad de Crohn de su hijo/a a su capacidad para realizar sus actividades cotidianas que no estuviesen relacionadas con su trabajo remunerado? Por actividades cotidianas, nos referimos a aquellas actividades normales que realiza, como las tareas del hogar, hacer la compra, cuidar de niños, hacer ejercicio, estudiar, etc. Piense en las veces que estuvo limitado/a en lo que respecta a la cantidad o el tipo de actividades que pudo realizar y en las veces en las que hizo menos de lo que le gustaría. Escoja un número bajo si la enfermedad de Crohn de su hijo/a afectó solo ligeramente a sus actividades. Escoja un número alto si la colitis ulcerosa de su hijo/a afectó mucho a sus actividades. Tenga en cuenta únicamente cuánto afectó la enfermedad de Crohn de su hijo/a a su capacidad para realizar sus actividades cotidianas que no estuviesen relacionadas con su trabajo remunerado. La enfermedad de Crohn de mi hijo/a no tuvo ningún efecto en mis actividades cotidianas. 0 1 2 3 4 5 6 7 8 9 10 La enfermedad de Crohn de mi hijo/a me impidió realizar mis actividades cotidianas. RODEE UN NÚMERO

and daily activities, and no irrelevant items were included.

The sample adequacy for the exploratory factor analysis was confirmed for both the WPAI-UC-Caregiver and WPAI-CD-Caregiver questionnaires, with the KMO test obtaining values of 0.6947 and 0.7179, respectively, and Barttlet's test of sphericity, which obtained a *p* value < 0.001 for both. The 6 items targeted the same domain, as a solution for the factor analysis. The factor model accounted for 99.99% and 94.68% of variance, and Cronbach's alpha coefficients (0.6581 and 0.6968) showed an adequate internal consistency.

DISCUSSION

This was the first study to conduct the cross-cultural adaptation and validation of the WPAI-UC-Caregiver and WPAI-CD-Caregiver questionnaires in the Spanish population. Both questionnaires have proven their validity and reliability to assess the impact on the work and activities of daily living of the families of children with of p-IBD in our setting.

The need for a comprehensive assessment and care of the well-being of pediatric patients with chronic diseases is increasingly clear, considering not only the sphere of physical symptoms, but also the emotional and social impact on both the child and their parents/caregivers.[1–3] Health-related quality of life (HRQoL) is defined as the patient's perception of their physical and mental health status in different spheres of life, in the context of their values, beliefs, expectations, and sociocultural environment.[26,27] Patients with lower HRQoL scores suffer greater interference of the disease in different aspects of their life. In addition, parents and/or caregivers may also be adversely affected, and their perception of the child's disease may in turn have an impact on the child's experience.[13,28–31]

Children with IBD may require hospitalizations or frequent visits to a health center for tests, treatment, follow-up visits, or even surgery. In addition, the symptoms caused by IBD may sometimes prevent patients from maintaining their daily activities and they miss school more frequently, compared to a control group.[14,15,32,33] Eloi et al. analyzed a sample of 106 children with p-IBD in France and reported a school absenteeism rate of almost 5%, compared to 3% in the control group ($p = 0.034$). In this study, approximately 27% of school absenteeism was due to planned events, such as an endoscopy or a consultation.[15] Barnes et al. studied a sample of 169 patients with p-IBD from the United Kingdom; in that study, almost 40% of participants missed 10% or more of the days of the school year; and only 3% completed 100% of school attendance.[14] This may mean that the adult caregiver may have to be absent from work or have their working hours reduced or adapted. Such rate of absenteeism and/or loss of productivity has a direct impact on the socioeconomic status and emotional well-being of the family as a whole, but it also implies a series of global secondary costs.[16,34,35]

The WPAI questionnaires were developed by Reilly Associates (http://www.reillyassociates.net/Index.html), a research company specializing in the design and analysis of quality of life and economic studies. Reilly Associates has designed tools to assess the quality of life of patients/caregivers with chronic conditions, such as IBD, irritable bowel syndrome, arthritis, diabetes, dermatitis, or hypertension. The WPAI-UC-Caregiver and WPAI-CD-Caregiver versions aim to measure the impact of p-IBD on parents'/caregivers' work life and daily activities.[16,19] Klomberg et al. used these instruments to prospectively assess the impact of p-IBD on the productivity of caregivers at diagnosis, 3 months, and 12 months. They observed that such impact declined over time and was related to the extent of disease activity.[16] The translation of these questionnaires into Spanish is available and has been used both in clinical trials and in daily practice. However, the Spanish-language versions for caregivers had not yet been validated among Spanish families.[20,21]

The methodology proposed by Beaton et al. for the cultural adaptation of questionnaires aims to optimize participants' understanding, including the participation of translators, a group of experts —in this case, a group of investigators who provided care for patients with p-IBD in their daily clinical practice—, and a group of volunteers from the target population.[23] In this study, both questionnaires demonstrated to be simple and reliable, with adequate face validity. The median time of 2 minutes to complete the questionnaires facilitates their use in daily clinical practice. The psychometric assessment using a factor analysis and Cronbach's alpha coefficient suggested that the Spanish-language versions of the WPAI-UC-Caregiver and WPAI-CD-Caregiver questionnaires had an adequate internal structure. It is worth noting that there is controversy about

the optimal cut-off point for the alpha coefficient. A low value may be due to a small number of questions, a poor interrelation among questions, or heterogeneous constructs; however, a very high value may suggest that some items are redundant. Therefore, values between 0.7 and 0.9 are usually considered indicators of excellent internal consistency, and those above 0.9, of suboptimal internal consistency. Our results may be considered indicators of adequate internal consistency given their value close to 0.7 for instruments containing only 6 items. Finally, our study suggests a single-factor structure.

One of the strengths of this study is its multicenter design, with the participation of 37 sites and the inclusion of a larger sample than in previous studies. In addition, the geographical distribution of the sites allows us to assume an adequate representation of the Spanish population of families with children with IBD. With this adaptation, the text has been perfected and a rigorous validation has been carried out by means of a confirmatory factor analysis. This study also has certain limitations, such as its cross-sectional design and the inclusion of patients at different times in the temporal course of their disease, which may result in a varied impact on caregivers.

To conclude, the Spanish-language versions of the WPAI questionnaires for caregivers of children with p-IBD are useful tools in both clinical and research settings. Our findings suggest that both instruments have an adequate validity and reliability. ■

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