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## This is the post-print version of the following article:

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### **Abstract**

Introduction: Caregivers' adherence to Child Primary Care (CPC) health recommendations is particularly relevant for the protection of children's health and promotion of their optimal development. Nevertheless, there are currently no measures to assess it, as the majority of measures are focused on pharmacological treatment adherence instead of adherence to preventive health recommendations. Thus, this paper describes the development and validation of a new instrument to assess caregivers' adherence to CPC health recommendations regarding children aged between 2-6 years old, which would also be sensitive to the specificities of caregivers in more vulnerable conditions – the CPC-Adherence Scale.

**Methods:** 662 parents (93.4% women; 6.6% immigrant), living in Portugal and with children aged between 2 and 6 years, participated in a cross-sectional study using a paper or electronic protocol. The protocol was composed by: 1) the CPC-Adherence Scale; 2) questions regarding experiences in CPC; 3) the European Task Force on Patient Evaluation of General Practice Care (EUROPEP); 4) socio-demographic information.

**Results:** The exploratory and confirmatory factor analyses supported a 2-factor solution: 1)

Adherence to a safe psychomotor development (n = 14 items; Cronbach's Alpha = 0.894); 2)

Adherence to nutritional counselling (n = 6 items; Cronbach's Alpha = 0.608). The CPC
Adherence Scale showed good content and criterion-related validity. It discriminated levels of adherence of caregivers with different levels of knowledge about CPC recommendations, satisfaction with care and different socio-economic and immigrant t status.

**Discussion:** The CPC-Adherence Scale is an innovative and promising measure that may play a relevant role on future research and intervention for the promotion of adherence behaviours in a primary prevention context.

**Keywords:** Early years, Health, Paediatric, Adherence, Scale development

#### Introduction

Child Primary Care (CPC) services are often described as the main source of technical support and advice for children's caregivers (Barak et al., 2010; DGS, 2013; Jenni 2016; Garg, et al. 2017). CPC includes the so-called anticipatory guidance, *i.e.*, prior counselling about what is expected in terms of future stages of child development (e.g. risks of accidents/injuries, sleep patterns/habits), hence, caregivers' adherence to CPC health recommendations minimize unnecessary contact with health services and empower families with more adequate parental competencies (DGS, 2013; Jenni, 2016). CPC also includes health recommendations related with the promotion of healthy behaviors or lifestyle practices (e.g. nutrition, hygiene care), hence, caregivers' adherence to such health recommendations may ensure optimal child development and prevent important health-related problems (e.g. overweight/obesity, dental caries, mental health issues); some of them with a higher prevalence among more vulnerable families (e.g. immigrants and/or with lower SES; van Esso et al., 2010).

Despite the vital role of caregivers' adherence to CPC recommendations on promoting children's health, to the best of our knowledge, there are currently no measures to assess it. This study intended to overcome this gap by developing and validating a scale to assess caregivers' adherence to CPC recommendations – the Child Primary Care Adherence Scale (CPC-Adherence Scale) – which would also be sensitive to the specificities of caregivers in more

vulnerable conditions. This measure can be used both for clinical and research purposes, and ultimately contribute to promote better adherence behaviors in daily CPC practices.

## Caregivers' adherence to CPC health recommendations: From concept to measurement

Mirroring the broad concept of therapeutic adherence (Dunbar-Jacob, Schlenk & McCall, 2012; Mourão & Bernardes, 2014; Straub, 2012), caregivers' adherence to CPC recommendations is a complex and multidetermined phenomenon. Beyond the "classical" adherence to drug prescriptions, it includes adherence to counselling regarding healthy behaviors and lifestyle practices (e.g. nutrition, hygiene care; Barak et al., 2010; DGS, 2013), which contribute to prevent and early detect relevant health issues (e.g. obesity or overweight, asthma, dental caries) that may bear significant impact on children's quality of life (Kuo, Etzel, Chilton, Watson & Gorski, 2012). It also includes adherence to anticipatory guidance, which refers to *a priori* counselling regarding the several stages and domains of child development (e.g. risks related to child injuries, sleep patterns/habits). Anticipatory guidance often meets caregivers' more common concerns, minimizing unnecessary contacts with health services, while empowering families with more adequate parental competencies (DGS, 2013; Jenni, 2016). Thus, children's health might to a large extent depend on the degree to which their families adhere to CPC health recommendations.

Although access to most European CPC services (Portugal included) is universal and free for all children (DGS, 2009; van Esso et al., 2010), the degree to which caregivers adhere to CPC recommendations may greatly vary. Indeed, as adherence behaviors are multidetermined (Bosworth, Weinberger & Oddone, 2006; Byrne, 2013; Mourão & Bernardes, 2014), a myriad of individual, interpersonal, organizational, socio-economic and cultural variables may either

promote or hinder caregiver's adherence to CPC recommendations. Therefore, the ability to identify and target, through effective empirically-based interventions, the underlying mechanisms that promote caregivers' adherence to CPC recommendations may be vital for the protection and promotion of children's health (Barak et al., 2010; DGS, 2013). This can only be achieved by using valid and reliable data collection protocols to identify caregivers' perceived barriers to their non-adherence (Byrne, 2013; Bosworth et al., 2006; Levensky & O' Donohue, 2006). This is particularly important for more vulnerable families that may be at increased risk of disease and non-adherence (e.g. immigrants or socio-economic disadvantaged families; Gimeno-Feliu, Armesto-Gómez, Macipe-Costa & Magallón-Botaya, 2009; Heerman, et al. 2016; Kirkpatrick, Dodd, Reedy & Krebs-Smith, 2012).

The development of a reliable and valid measure of caregivers' adherence to CPC recommendation is a cornerstone for empirically investigating its determinants and assessing the effectiveness of intervention programs. However, most current measures are mainly focused on pharmacological treatment adherence, with little regard to adherence behaviors in preventive health-related contexts, like CPC (Byrne, 2013; McNicholas, 2012). To bridge this gap, we aimed to develop a valid, reliable and sensitive measure to access caregivers' adherence to CPC health recommendations – the CPC-Adherence Scale. This assessment tool may contribute to tailor interventions aiming at promoting adherence to specific CPC recommendations, which will ultimately contribute to children's better health and development.

### Development and validation plan of the CPC-Adherence Scale

The CPC-Adherence Scale was originally developed in Portuguese to measure caregivers' adherence to CPC health recommendations regarding children aged between 2-6

years old, as most well-child visits occur during these developmental stages. First, drawing upon the broader concept of therapeutic adherence (Dunbar-Jacob, et al. 2012; Straub, 2012) and technical information on CPC services activities (DGS, 2013; van Esso et al., 2010; Kuo et al., 2012), an initial pool of items was developed as to cover all relevant domains of CPC recommendations. These included recommendations regarding immunization schedules, developmental surveillance, nutrition, prevention and symptom relief and prevention of childhood injuries.

Afterwards, a three-step validation plan of the CPC-Adherence Scale was defined. The first step aimed at the evaluation by experts (e.g. general practitioners and nurses) of the scale's content validity, i.e. the extent to which the measure covered all relevant domains of CPC recommendations (Furr, 2011; Lima & Bernardes, 2013). The second step, aimed at investigating the measure's construct validity (Lima & Bernardes, 2013; Litwin, 1995), namely its underlying factorial structure, by conducting exploratory and confirmatory factor analyses. Finally, the third step aimed at testing CPC-Adherence Scale's criterion-related validity (Litwin, 1995). More specifically, we aimed to assess the concurrent relationship between caregivers' adherence to CPC recommendations (as measured by the CPC-Adherence Scale) and four criteria:

1. Knowledge of CPC health recommendations: as the access to health services may depend on how users manage the approachability of information about these services (Levesque, Harris & Russell, 2013; Travassos & Martins, 2004), caregivers' adherence to CPC recommendations may depend on their knowledge about those recommendations. Thus, we expected that caregivers' knowledge on CPC health recommendations would be positively associated with their adherence behaviours. We used the reported frequency of child health book reading as a proxy of caregivers'

knowledge of CPC recommendations. In several countries, the child health book is a free booklet provided to caregivers that is used to record child's immunizations, developmental checks and other major health events. This booklet often contains written health recommendations in a format of general tips/useful information (Amorim et al., 2018; Clendon & Dignam, 2010). Thus, we expected that caregivers who reported higher frequency of child health book reading would report higher levels of adherence to CPC recommendations (Hypothesis 1; H1).

- 2. Satisfaction with care: considering that better adherence behaviours were generally associated with higher satisfaction with care (Zolnierek & DiMatteo, 2009; Jack, McLean, Moffet & Gardiner, 2010; Hall & Roter, 2011), we expected that caregivers who reported more satisfaction with medical and nursing care would report higher levels of adherence to CPC recommendations (Hypothesis 2; H2).
- 3. Socio-economic status (SES): better adherence behaviours have been consistently associated with higher SES (Colby, Wang, Chhabra & Pérez-Escamilla, 2012; Sendt, Tracy & Bhattacharyya, 2015; Picorelli, Máximo Pereira, Pereira, Felício & Sherrington, 2014), especially in dimensions related with pharmacological treatments and with some diet recommendations (Mourão & Bernardes, 2014). Thus, we expected that caregivers of a higher SES would report higher levels of adherence to CPC recommendations, as compared to those with a lower SES (Hypothesis 3; H3).
- 4. <u>Immigrant status:</u> immigrants usually report lower levels of adherence than non-immigrants, especially in what concerns pharmacological treatments (Gimeno-Feliu et al., 2009; Heerman et al., 2016; Kirkpatrick et al., 2012). Thus, we expected that immigrant caregivers would report lower levels of adherence to CPC recommendations

when compared with non-immigrant caregivers. Although the immigrants' positive or negative experiences in the host country (e.g. perceived discrimination and stigma) may impact their access to health services and/or adherence levels, immigrants' conditions in the host country (e.g. nationality/legal situation, length of stay) have shown a more consistent influence on their access to health services (Dias, Severo & Barros, 2008; Wafula & Snipes, 2014) and, potentially, on caregivers' adherence behaviours (Gimeno-Feliu et al., 2009). Accordingly, we also expected that immigrant caregivers who had Portuguese citizenship and/or had been in the country for longer periods (i.e. had not recently arrived) would report higher levels of adherence to CPC health recommendations, as compared with immigrant caregivers with no Portuguese citizenship and/or that had been in the country for shorter periods of time (Hypothesis 4; H4).

## Methods

#### **Instruments**

The development of the Child Primary Care Adherence Scale (CPC-Adherence Scale)

As presented above, the CPC-Adherence Scale is an instrument developed in Portuguese that aims to measure caregivers' adherence to CPC health recommendations regarding children aged between 2-6 years old. The identification of CPC recommendations was based on a review of medical literature about CPC services. The selected documents presented the most relevant information on child/pediatric primary health care, regulated for Portugal and other 28 European countries, and also for the United States (DGS, 2013; van Esso et al., 2010; Kuo et al., 2012). The selection of the CPC health recommendations to be included in the measure was also based on the information from a previous qualitative study (Mourão & Bernardes, 2019). In this study a

sample of 35 immigrant and non-immigrant caregivers living in Portugal perceived adherence to CPC health recommendations as a complex and multidimensional concept, which included adherence to pharmacological recommendations (i.e. vaccination and pharmacological treatments for symptom relief) and other recommendations regarding health behaviors and lifestyle practices (e.g. general health advices, nutritional counselling and traditional methods of symptom relief). Thus, the CPC-Adherence Scale initial pool of 24 items included recommendations that covered the variety of domains and activities related with health advice and anticipatory guidance, namely: developmental surveillance (e.g. Encourage the child to play; Around 18 months start potty training); nutritional counselling (e.g. Until 12 months old, give the child only the foods that are recommended in the routine medical appointments); prevention and symptoms relief (e.g. When the child has symptoms such as fever or colic (mild symptoms) give him/her the medicines you are advised; Brush the child's teeth as soon as he/she starts teething); prevention of childhood injuries (e.g. Protect electric plugs to prevent shocks and burns; In car trips transport the baby/child in a car seat suitable for his/her age or size).

A panel of five independent experts on CPC was identified, based on their experience and expertise on intervening in this area (i.e. four general practitioners, one of them that was also a university professor, and a pediatric nurse). They were asked to individually analyze the initial pool of items as to the extent they covered all the relevant domains of CPC recommendations for children aged between 2-6 years old. They were also invited to individually ensure if the CPC-Adherence Scale instructions and questions were clear and understandable for the general caregivers. Basis on their all feedbacks, were identified different level problems (e.g. general, related with content from specific items/instructions, regarding the scale used), whose potential changes to be introduced were discussed by the first and second authors of the paper. At the

final, only 1 item was removed that lacked face validity and language was revised in some other items (e.g. the expression "adopt recommendations" was replaced by "follow advices").

Caregivers were asked to report to which extent they follow(ed) each recommendation in their children's care, on a 5-point Likert scale (from 1-never to 5-always). The specific instruction read as follows "We would like to know to what extent you follow the advice given in your child's routine medical appointments". Caregivers were also given the possibility of reporting whether the advices had not been recommended or if they did not apply to their case. Regarding adherence to vaccination, caregivers were asked the following yes-or-no questions "Has your child received all the vaccines that are recommended by the National Plan of Vaccination (Vaccine Bulletin)?" and "Has your child received other vaccines besides the ones recommended in the National Plan of Vaccination (Vaccine Bulletin)?".

To minimize the problem of social desirability, the introduction and instructions of the measure were written in a non-judgmental style (e.g. *The degree to which parents follow the advice may be very variable, for several reasons: it might be difficult to integrate them into the habits of the family; they might be different from those that are given by other health professionals, family or friends*).

The preliminary version of CPC-Adherence Scale, i.e. before the exploratory and confirmatory analyzes, was pre-tested with a convenience sample of 9 mothers, selected by the following criteria: 1) having children aged between 2-6 years old; 2) being Portuguese or immigrant Portuguese speakers (i.e. 4 Brazilian and 2 Cape Verdean); 3) being heterogeneous in terms of their socio-economic status. They were asked to determine the measure's clarity and based on their feedback minor changes were made in certain items/instructions (e.g. some recommendations were exemplified).

The Portuguese Version of the European Task Force on Patient Evaluation of General Practice

Care (EUROPEP)

The EUROPEP is a valid, reliable and widely used measure to assess users' satisfaction with primary health care (e.g. Wensing, Maiz & Grol, 2000). As to assess the CPC-Adherence Scale criterion validity, the subscales of satisfaction with medical and nursing care of the Portuguese version of the EUROPEP (Roque, Veloso & Ferreira, 2016) were used.

The satisfaction with medical care subscale consists of 18 items and assesses satisfaction with technical care (e.g. *Explanation about medication, treatments, and tests prescribed*) and doctor-patient relationship (e.g. *How did the doctor listened to you*). Caregivers were asked to evaluate their children's family doctor or paediatrician in relation to the presented 18 items. The satisfaction with nursing care subscale consists of 3 items (e.g. *Time devoted to you by the nursing staff*). Caregivers were asked to evaluate the health care centre or clinic in relation to these items. All items were rated on a 5-point Likert scale (1=bad; 5=excellent).

To assess some of the psychometric properties of this measure in our sample, a principal axis factor analysis (PAF with an oblique rotation) was conducted (KMO = 0.962, Bartlett's  $\chi$ 2 (210) = 6356.963, p < 0.001). Based on the Kaiser criterion, the expected two factors were extracted accounting for 67.92% of the total variance: (1) satisfaction with medical care (n = 18 items,  $\alpha$  = 0.969) and (2) satisfaction with nursing care (n = 3 items,  $\alpha$  = 0.940).

Following the procedures proposed by Ferreira and Raposo (2015), the satisfaction scores were converted in a 0% to 100% scale, only taking in consideration the valid answers (i.e. excluding the "not applicable"). Scores closer to 100% indicated higher satisfaction.

Socio-demographic and clinical information

The protocol included several questions assessing participants' socio-demographic information. Some of them were only used to characterize the sample: sex, age, number of children, marital and employment status. Other questions were specifically used to assess the criterion validity of the CPC-Adherence Scale, namely, country of origin, years of education, profession and monthly household income (answered by all the participants); years and legal situation in Portugal (only answered by immigrant caregivers). These socio-demographic characteristics were selected to measure the CPC-Adherence Scale criterion validity since better adherence behaviours have been consistently associated with immigrant versus non-immigrant status (Heerman et al., 2016), higher versus lower socio-economic status (using years of education, profession and income as indicators of these socio-economic conditions; Mourão & Bernardes, 2014) and immigrants' status in the host country (i.e. legal versus irregular situation, longer versus shorter stay periods; Gimeno-Feliu et al., 2009).

A Multiple Correspondence Analysis (MCA) was used to construct a standardized index for socio-economic status (SES). An MCA was performed because educational level, profession and income were categorical variables. An index with good internal reliability was obtained ( $\alpha$  = 0.812). The higher the score the higher the SES (Min = -3.80, Max = 0.98).

The data collection protocol also included questions that assessed caregivers' experiences with CPC: use of public versus private services and frequency of child health book reading, on a Likert-scale from 1-never to 5-always (i.e. "Do you usually read the written recommendations of the child health book?").

#### Procedure and data collection

This study complied with the ethical procedures proposed by the ethics committee of ISCTE-University Institute of Lisbon. Participants were approached at Portuguese keyinstitutions (e.g. kindergartens in the Lisbon area) and groups of parents in social media (e.g. Facebook, blogs). Those who had children aged between 2 and 6 years old were requested to collaborate on a study about well-child visits. This inclusion criterion was used because the CPC-Adherence Scale includes questions essentially related with children aged between 2-6 years old. The Boards of every institution provided an informed consent to collaborate with our research. Participants were also provided information about the study's goals, their voluntary participation, confidentiality and anonymity of data, before giving their written consent to participate.

The data collection protocol was available both electronically (using Qualtrics software) and in paper format, to ensure a more heterogeneous pool of participants and also include caregivers who potentially did not have access to the internet. This protocol was individually filled out by the children's main caregiver (the one who went more often to CPC services). The first part of the protocol was composed by the CPC-Adherence Scale. After the presentation of this measure, participants were presented with the questions regarding their experiences in CPC, the Europep and questions regarding their socio-demographic characteristics. To compensate caregivers' participation in the study six 25€ vouchers were randomly allotted.

## **Statistical analyses**

The CPC-Adherence Scale item distributions were assessed in the total sample (N=662), including items means, standard deviations (SD), skewness and kurtosis coefficients and

respective standard errors (see results-Table 1). To identify the CPC-Adherence Scale underlying structure an Exploratory Factor Analysis (EFA with an oblique rotation) was conducted with a random subsample of about half of the original sample (n=326). Although the Kaiser criterion is most commonly used, the scree test (Cattel, 1966) and parallel analysis (Costello & Osbone, 2005; O'Connor, 2000) were privileged since they were more accurate. Items with loadings below |0.4| were progressively eliminated. Given the high levels of item skewness we also performed a categorical principal component analysis (CatPCA) using items as ordinal variables to validate the results obtained by the PCA.

Then, a confirmatory factor analysis (CFA) was performed using the maximum likelihood (ML) method, with a random subsample (n=336). A CFA was used to test the identified EFA structure of the CPC-Adherence Scale. Several goodness of fit indices were used to determine how well the model fit the sample data. These were: the chi-square ( $\chi^2$ ) and the normed chi-square ( $\chi^2$ /df), which indicated a good fit if  $\chi^2$ /df  $\leq 2$  (Schreiber, Nora, Stage, Barlow & King, 2006); the Comparative Fit Index (CFI) > 0.90 and, the Tucker–Lewis Index (TLI) > 0.90 (Kline, 2011); the Parsimonious Comparative Fit index (PCFI) and the Parsimonious Normed Fit index (PNFI), which should be higher than 0.60 (Hair, Anderson, Tatham & Black, 2010); and, the Root Mean Square Error of Approximation (RMSEA)  $\leq$  0.06 (Hu & Bentler, 1999). A non-parametric method (bootstrap) was also performed in order to validate the results obtained by maximum likelihood.

The criteria-related validity of the CPC-Adherence Scale was assessed using Pearson correlations, Chi-Square and T-student tests. Data analysis was conducted by IBM-SPSS Statistics 24.0 and AMOS 24.0.

#### **Results**

# Participants' characteristics

Six hundred and sixty-two parents (93.4% women) of children aged between two and six years participated in this study. They were mainly Portuguese (91.4%), in a marital relationship (84.1%), and were aged between 17 and 50 years old (M = 35.3, SD = 4.9). They had between 1 and 5 children, but most of them were parents of one or two (88.7%). The majority was employed (85.5%). They had on average 15.3 years of education (SD = 2.8), the majority had a specialized profession (60.6%) and a monthly household income higher than 1500€ (53.2%). Most of the parents reported using private health services (60.1%) and reported reading the child health book recommendations very often (M = 4.30, SD = 0.89). More detailed sample characteristics are presented in Table 1.

## Insert Table 1 here

# **Construct validity**

Items descriptive analysis

The analysis of the distribution of the items on the total sample (N = 662) showed that participants' responses covered the scale range for every item (min = 1 and max = 5). The mean of the items ranged between 3.54 and 4.70 (0.81  $\leq$  SD  $\leq$  1.35) (Table 2).

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Insert Table 2 here

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As presented in Table 2, the distribution of most items presented high levels of skewness (skewness / SE skewness > |1.96|) and kurtosis (kurtosis / SE kurtosis > |1.96|). All items were identified at least once as not having been recommended (Min = 9; Max = 66). Items that were reported as being more recommended were associated with healthy food (i.e. *Avoid giving the child food/drinks with too much salt, sugar or fats*) and child symptom relief (i.e. *When the child has symptoms such as fever or colic (mild symptoms) give him/her the medicines you are advised; When the child presents light symptoms use other measures besides medication [e.g.: warm bath to lower a fever, massages on the belly to alleviate colic]). The item least recommended was related with the potty training (i.e. <i>Around 18 months old start potty training*).

Regarding vaccination, participants' responses covered the two answer options both for free vaccines (adherence = 99.2%; non-adherence = 0.8%) and paid vaccines (adherence = 87.7%; non-adherence = 12.2%).

## Exploratory factor analysis

Results showed that the first solution extracted five factors with eigenvalues above 1 (Kaiser's criterion). Nevertheless, the scree test and the parallel analysis converged in a 2-factor solution (KMO = 0.865; Bartlett's test  $\chi 2$  (190) = 1211.602, p < 0.001), accounting for 42.84% of the total variance (Table 2): 1) Adherence to a safe psychomotor development (14 items); 2) Adherence to nutritional counselling (6 items). The extracted factors presented a moderate and positive correlation (r = 0.532, p < 0.001).

## Confirmatory factor analysis

The two-factor model was tested through a CFA (Figure 1). Results showed that the fit of the data to the two-factor structure was good ( $\Box$ 2 (158) = 279.365, p < 0.001;  $\chi$ 2/df = 1.768; CFI

= 0.94; TLI = 0.91; PCFI = 0.70; PNFI = 0.65; RMSEA = 0.05). All items loaded significantly on their corresponding factor (p < 0.001).

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Insert Figure 1 here

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# **CPC-Adherence Scale sensitivity and reliability**

Following similar scoring procedures for EUROPEP sub-dimensions (Ferreira & Raposo, 2015), the values of each factor of adherence were calculated by a weighted sum, in which the "not recommended/applicable" answers were not included. These scores were also converted from a scale from 1 (never) to 5 (always) to a scale from 0% to 100%, in order to increase their sensitivity.

Reported adherence to a safe psychomotor development ranged from 16.7% to 100.0% and reported adherence to nutritional counselling ranged from 20.8% to 100.0%. The two factors presented mean values corresponding to a relatively high perceived adherence to recommendations for a safe psychomotor development (M = 82.16; SD = 16.46) and to nutritional counselling (M = 80.50; SD = 15.95).

The internal consistency of the factors was assessed through the Cronbach reliability coefficient. Cronbach's alpha values were 0.894 for adherence to a safe psychomotor development and 0.608 for adherence to nutritional counseling. Considering that a small number of items per factor (usually less than 7) can lead to a lower alpha, the mean inter-item correlations for the two factors were also calculated (Clark & Watson, 1995). Results showed

that the mean inter-item correlations for the two factors fell in the recommended range 0.15-0.50: 0.209 and 0.394, respectively.

## **Criterion-related validity**

Table 3 presents the relationship between criteria-related variables and the two dimensions of caregivers' adherence. As their adherence to free vaccines was nearly 100%, Table 3 only reports correlates of caregivers' adherence to paid vaccines.

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Insert Table 3 here

Caregivers' adherence and knowledge of CPC recommendations

As presented in Table 3, caregivers' adherence to a safe psychomotor development and nutritional counselling presented a positive and weak association with their frequency of reading child health book recommendations. Nevertheless, caregivers who reported adhering to paid vaccines did not show significant differences in their frequency of reading the child health book recommendations as compared to those who did not adhere to paid vaccines.

Caregivers' adherence and satisfaction with care

As presented in Table 3, caregivers' adherence to a safe psychomotor development and nutritional counselling showed a positive and weak association with their satisfaction with nursing care. Caregivers' adherence to nutritional counselling was also positively correlated with their satisfaction with medical care.

As for adherence to vaccination, caregivers who reported adherence to paid vaccines reported higher levels of satisfaction with medical (t (66.139) = 5.308, p < 0.001) and nursing care (t (70.338) = 4.741, p < 0.001).

## Caregivers' adherence and SES

Caregivers who reported adhering to paid vaccines reported higher SES (t (86.799) = 7.628, p < 0.001). Caregivers' SES was not significantly correlated with their adherence to a safe psychomotor development recommendations and nutritional counselling.

Caregivers' adherence, immigrant status and conditions in the host country

In Table 3 a moderate and negative correlation is presented between caregivers' adherence to nutritional counselling and their immigrant status; immigrant caregivers adhered less to nutritional counselling (M = 76.16, SD = 17.68) than Portuguese caregivers (M = 81.02, SD = 16.22). Portuguese caregivers also reported higher adherence to paid vaccines, as compared with immigrant caregivers. No significant correlations were found between caregivers' adherence to a safe psychomotor development and their immigrant status.

Among immigrant caregivers, adherence to CPC recommendations was only weakly and significantly associated with their legal status, but not the number of the years in Portugal. Immigrant caregivers with Portuguese nationality or European passport reported lower adherence to nutritional counselling (M = 68.68, SD = 17.83), as compared to immigrant caregivers with legalization in process or resident permission (M = 80.17, SD = 17.45). Caregivers' immigrant status did not show any significant relationship with their adherence to a safe psychomotor development or to paid vaccines.

#### **Discussion**

The present study aimed to develop and validate a measure of caregivers' adherence to CPC health recommendations (CPC-Adherence Scale), especially focused on children aged between 2-6 years old. Overall, our findings suggest that the CPC-Adherence Scale is a valid and reliable measure, sensitive to the specificities of caregivers in vulnerable conditions. A detailed discussion of the CPC-Adherence Scale psychometric properties, as well as a reflection on the limitations and implications of this work for future research directions now follows.

## Content, construct validity and reliability

Drawing upon experts' opinions, the CPC-Adherence Scale showed good content validity, as its items cover the whole and wide range of CPS activities and recommendations.

Despite the large diversity of CPC recommendation topics, the exploratory and confirmatory factor analyses supported a 2-factor solution: 1) Adherence to a safe psychomotor development;

2) Adherence to nutritional counselling. Thus, the CPC-Adherence Scale is constituted by these two main dimensions, which indeed represent the two principal objectives of well-child visits, namely, monitoring children's physical and psychomotor development (DGS, 2013).

"Adherence to a safe psychomotor development" is a broad dimension that includes items essentially related with activities that promote a healthy psychomotor development (e.g. play, speak, walk), while preventing the most common child accidents/injuries that may occur during these activities (e.g. suffocation, burns). Because of its focus on safety issues, this factor also contained items associated with symptom prevention or relief (e.g. dental caries, fever).

"Adherence to nutritional counselling" is a more specific factor that encompasses the recommendations often transmitted to caregivers when their child's physical development (e.g.

weight, height) is being assessed. This dimension includes the item When the child has symptoms such as fever or colic (mild symptoms) give him/her the medicines you are advised, which may not be immediately recognized as a diet recommendation. This may be due to the fact that young children's cramps are usually associated with their feeding practices.

Both factors showed a high positive correlation. This may be accounted for by the fact that several nutritional recommendations may also bear a safety focus (e.g. the early detection of diet intolerances or allergies) and also contribute to the development of certain psychomotor skills (e.g. use of cutlery when children start sharing the meals with the family).

With regards to the internal consistency and sensitivity of the CPC-Adherence Scale, the results were quite positive. Both factors, and especially the "adherence to a safe psychomotor development", showed good values in the Cronbach's alpha and in the mean inter-item correlations. The majority of the items presented a skewed distribution to the higher end of the scale (i.e. higher perceived frequency of adherence), probably reflecting the nature of what is being measured, instead of poor item quality. Indeed, although participants' answers could well be influenced by social desirability, it is expectable that most caregivers would recognize the relevance of CPC recommendations, hence, reporting high adherence. Nevertheless, the transformed scores, ranging from 0% to 100%, showed larger response ranges, reflecting a higher sensitivity to the detection of more subtle differences between caregivers' adherence behaviors (Fok & Henry, 2016).

### **Criterion-related validity**

As expected, caregivers who reported a higher frequency of reading the child health book recommendations reported higher levels of adherence (H1). In line with previous studies

(Levesque et al., 2013; Travassos & Martins, 2004), our findings suggested that more knowledge of CPC recommendations was positively associated with increased adherence behaviors.

Nevertheless, caregivers' knowledge of CPC recommendations was specifically associated with adherence to a safe psychomotor development and nutritional counselling, but not with (paid) vaccination. Indeed, the child health book contains some information about the national vaccination plan, but not explicitly about paid vaccines (DGS, 2013).

Also, as expected, caregivers who reported more satisfaction with care were those who reported higher adherence (H2). Satisfaction with medical care was only related with adherence to safe psychomotor development recommendations and paid vaccines. This suggests a perceived centrality of doctors' interventions at these levels, and not so much at the level of nutritional counselling. Whereas satisfaction with nursing care was positively associated with adherence to safe psychomotor development recommendations, nutritional counselling and vaccination. This is not surprising considering that nurses play an important role in promoting public health, often being major patient counsellors/educators concerning disease prevention and promotion of health behaviors change (Kemppainen, Tossavainen & Turunen, 2013).

Caregivers of a lower SES reported lower levels of adherence to paid vaccines, as compared to those with a higher SES, indicating that our third hypothesis (H3) was also partially confirmed. Our results come in line with previous studies showing the influence of SES on adherence behaviors, especially regarding pharmacological treatments (Bosworth at al., 2006; Martin, Haskard-Zolnierek, & DiMatteo, 2010). In this case, paid vaccines assume the status of "prescribed medication", where its high costs may contribute to lower adherence. Contrary to what has been shown in previous studies (Tijerina, 2006, 2009), caregivers' SES did not influence adherence to nutritional counselling. This may be accounted for the fact that CPC

nutritional recommendations may not imply a significant increase in family expenses, as tends to happen with other recommended dietetic restrictions (e.g. hemodialysis treatment; Tijerina, 2006, 2009).

As expected, as compared to non-immigrants, immigrant caregivers reported lower levels of adherence (H4), especially in what concerns nutritional counselling and paid vaccines. In fact, some feeding practices are particularly influenced by cultural health beliefs, which may lead to lower adherence, especially when these beliefs contrast with some health professionals' recommendations (Gurung, 2006; McNicholas, 2012; Mourão & Bernardes, 2019). Concerning paid vaccines, it is important to highlight that many individuals of minority ethnic groups most often present lower socio-economic conditions (Morrison & Bennet 2009; Straub 2012); which is also true to our subsample of immigrants when compared with the Portuguese subsample. Thus, for certain CPC recommendations, caregivers' SES may be a determinant of adherence that goes over and beyond their immigrant status; an assumption that should be further explored by a specific research about predictors of immigrants' adherence (versus non-immigrants). This result also raises the question of whether CPC health professionals recommend paid vaccines to immigrants or lower income families to the same extent as they do for non-immigrants or higher income families.

As hypothesized, immigrants' conditions in the host country may also influence their adherence behaviors (hypothesis 4); in this case, it was immigrants' legal status in Portugal that was associated with adherence to nutritional counselling. Nevertheless, our results contrast with our initial hypothesis, as the caregivers with Portuguese nationality or European passport were the ones that reported lower adherence as compared to those with legalization in process or resident permission. This conclusion may reflect the influence of social desirability on

participants in a more vulnerable condition in the host country, who may tend to hide their non-adherence behaviors for fear of facing health professionals' prejudice and discrimination (Hannan, 2015; Mourão & Bernardes, 2019). This is particularly relevant considering that some non-adherence behaviors could be interpreted as parental negligence (e.g. not preventing childhood accidents). It could also indicate that caregivers with legalization in process or resident permission may be adopting an assimilative or integrative orientation towards the host culture (Berry, 1997), reflected on a high identification with the Portuguese feeding practices and recommendations.

Overall, our findings indicate that CPC-Adherence Scale had a good criteria-related validity, since our initial hypotheses were mostly confirmed. It is also important to highlight that in some specific circumstances certain caregivers might not be adhering to some of the CPC health recommendations as these may not be suitable to their child's particular needs. Thus, and as presented above, the measure included the "not applicable" answer option, which was considered in the calculation of caregivers' adherence level as to minimize the influence of such situations on the assessment of such adherence behaviors.

## Limitations, implications and directions for further research

Some limitations can be pointed out to our study, which are in turn related to future directions for research. First, the CPC-Adherence Scale convergent validity was not assessed, as there were no other instruments that measured similar constructs. Second, some sampling issues should be noted, as they bear some challenges to the generalization of our findings. Despite the considerable sample size, the participants' demographics were mostly coincident with a medium to high SES. Thus, future studies should include a more heterogeneous sample in terms of

caregivers' socio-economic conditions. Third, although our results pointed to CPC-Adherence Scale sensitivity to certain immigrant caregivers' conditions, this should be further explored with a larger sample of immigrants, ideally with the same cultural background. Finally, the majority of the CPC-Adherence Scale items covered the technical information of the Portuguese Child Health Program (DGS, 2013) and were exclusively evaluated by a panel of Portuguese experts. As such, the extent to which this is a valid measure in other cultures is yet to be investigated. Nevertheless, the development of the CPC-Adherence Scale was also based on international literature on CPC service activities (van Esso et al., 2010; Kuo et al., 2012), which makes it a promising measure to be also used at international level, after proper translation and cultural adaptation processes.

It is also important to highlight that the caregivers' relatively high perceived adherence to CPC health recommendations could be in some way related with the subjective character from the CPC-Adherence Scale, which may condition a higher susceptibility to social desirability than the use of an objective measure (Byrne, 2013; Riekert, 2006). Nevertheless, the preventive focus of the CPC health recommendations is not consistent with the use of objective measures that traditionally assess pharmacological adherence behaviors (e.g. counting of medication, Byrne, 2013; McNicholas, 2012; Riekert, 2006). Even so, it is acceptable that the majority of caregivers recognize the relevance of CPC health recommendations and so reported a high adherence to them, being the CPC-Adherence Scale particularly sensitive to the identification from the specific groups of caregivers more vulnerable to non-adherence behaviors.

Despite the aforementioned limitations, theoretical, methodological and practical implications can be drawn from this study. From a theoretical and methodological point of view, the conceptualization and operationalization of the two sub-dimensions of the broader construct

of adherence to CPC recommendations is quite innovative. It also goes beyond the more traditional biomedical research about therapeutic adherence, which has been mainly focused on adherence to a given pharmacological treatment, at the exclusion of a biopsychosocial or preventive approach with a focus on the adoption of healthy behaviors and/or lifestyle changes.

Also, from a practical point of view, one of the greatest strengths of this study is to provide a valid, reliable and sensitive tool to measure reported caregivers' adherence to CPC recommendations; which is to the best of our knowledge the first measure developed to this purpose. Thus, as of now, the CPC-Adherence Scale can be used both in clinical and in research contexts, and ultimately contribute to promote better adherence behaviors particularly in the daily CPC practices. These applied advantages extend to the fact that the CPC-Adherence Scale seems to be sensitive to the adherence behaviors of caregivers in more vulnerable conditions.

Moreover, it is important to highlight that the empirical knowledge gathered by the CPC-Adherence Scale may constitute a relevant and innovative health indicator which goes beyond what is usually measured in the CPC context; i.e. the coverage rates of the national vaccination program. Accordingly, this piece of research may contribute with additional information to support future public policies on children's health. In sum, the CPC-Adherence Scale is an innovative, valid and reliable tool to assess caregivers' adherence to CPC health recommendations regarding two major domains – safe psychomotor development and nutritional counselling. This tool reveals a particularly relevance since there is some evidence that overall the CPC interventions, including its health recommendations, may connect with better children health and developmental outcomes over a life course (e.g. medium or long-term quality of life; Barak et al., 2010; DGS, 2013; Kuo, Etzel, Chilton, Watson & Gorski, 2012). Besides this, the measure bears important contributions to the development of future research on adherence

behaviors from a primary prevention perspective. It also may contribute to the assessment of interventions aiming at promoting caregivers' adherence to CPC recommendations, which may ultimately protect and promote children's health.

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#### Disclosure statement

The authors have no conflicts of interest to disclose.

# Data availability statement

The data that support the findings of this study are available from the corresponding author, [SM], upon reasonable request.

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