




# Information concealment in palliative patients: Development and pilot study of a new scale for caregivers

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## Abstract

Previous studies on palliative care have assessed the phenomenon of Information Concealment (IC), confirmed its relevance and emphasised the need to have a scale for its assessment. The aim of this study was to design and validate such an instrument. The sample comprised 150 palliative caregivers (23 men and 127 women). The dimensionality of the items of the Information Concealment Scale for Caregivers (ECOI) was assessed using Exploratory Factor Analysis and an optimal implementation of parallel analysis. Reliability and criterion validity were analysed using sample data. The ECOI comprises three factors: Concealment or dissimulation about the disease, misrepresentation of the real situation and control of the information. The scale has excellent reliability and shows criterion validity. Therefore, the ECOI is a reliable and valid instrument to objectively measure IC among Spanish caregivers in palliative care settings.

## KEYWORDS

communication, information concealment, palliative care, psychometric properties, validation study

## 1 | INTRODUCTION

According to the WHO (2020), the aim of palliative care is to improve the quality of life of people with life-threatening illnesses, as well as that of their families, and to address their physical, psychological and spiritual needs. One aspect of this aim is to provide patients with sufficient and accurate information about the entire disease process. The right to this information is specified at the global level in the Universal Declaration on Bioethics and Human Rights. The latter declaration was approved by UNESCO on October 19, 2005 based on the Universal Declaration of Human Rights of December 10, 1948. Thus, a relevant issue in the setting of palliative care is the phenomenon of concealment or misrepresentation of information that patients may need or require.

This phenomenon is known in English as Withdrawing or Withholding Information. It is rare in Anglo-Saxon countries, but very

common in Southern European cultures (Gysels et al., 2012) and in Latin cultures (Costa, Francioli, et al., 2019; Costa, Teixeira, et al., 2019; Sampaio et al., 2019). In these regions, the phenomenon is understood as the nondisclosure of information. It has typically been called a conspiracy of silence and is understood generically as a situation in which information that patients may need to know or require is withheld from them (Costa, Francioli, et al., 2019; Costa, Teixeira, et al., 2019; Espinoza-Suárez et al., 2017). It is also a common phenomenon in some Asian and Muslim cultures and is known under the same term (e.g. Kemp & Chang, 2002; Pinyopornpanish et al., 2017). The word collusion is sometimes used as a synonym (Sutar et al., 2019). In addition, it tends to be categorised into two levels: withholding the diagnosis and prognosis or only withholding the diagnosis (Alfaya-Góngora et al., 2021; Bermejo et al., 2013; Cejudo et al., 2015; Ruiz-Benítez, 2007). Given the many terms used to refer to it, this article uses the term information

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concealment (IC) to refer to the process by which information is withheld from patients.

Previous studies have shown that some caregivers withhold information from relatives with terminal diseases in the belief that they are protecting them from themselves, thus preventing the patients from knowing about their real situation, (Alsirafy et al., 2017; Bermejo et al., 2013; Martín-Fortea et al., 2020; Pinyopornpanish et al., 2017; Ruiz-Benítez, 2007). Other caregivers avoid passing on accurate information to such family members due to their own emotional difficulties in dealing with the situation (Bermejo et al., 2013; Ruiz-Benítez, 2007). However, IC has been shown to have relevant negative psychological effects on patients, including higher reported pain, decreased autonomy, depressive symptoms, lack of control, fear, anguish, lack of communication, isolation and feelings of loneliness and being deceived (Costa, Francioli, et al., 2019; Costa, Teixeira, et al., 2019; Díaz-Cordobés et al., 2012; Lemus-Riscanevo et al., 2019; Martín, 2011; Montoya et al., 2010; Sutar et al., 2019; Tuca et al., 2020). On the other hand, associations have been found between the desire to receive information or actually receiving it and greater perceived satisfaction and greater satisfaction with the information received (Kitamura et al., 2011; Rumpold et al., 2015). In addition, well-informed patients have better quality of life and less anxiety (Montoya et al., 2010). In general, they also have fewer physical and psychological symptoms and have better emotional and social functioning (Lee et al., 2011).

Despite the relevance of the IC phenomenon, there are no scientifically validated assessment instruments for its measurement. In fact, the literature shows that IC has almost always been qualitatively assessed through open interviews with relatives and/or patients. (e.g. see Font-Ritort et al., 2016; Gil et al., 2014; Lope & Díaz, 2019; Pinyopornpanish et al., 2017). Although previous studies have assessed IC or some of its characteristics (Alsirafy et al., 2017; Díaz-Cordobés et al., 2012; Font-Ritort et al., 2016; Gil et al., 2014; Lope & Díaz, 2019; Martín-Fortea et al., 2020; Nipp et al., 2016; Pinyopornpanish et al., 2017), none used a validated measurement instrument. However, although a previous study did not assess IC behaviour, it did assess the opinion of family members about it and the reasons that would or would not justify such behaviour (Ruiz-Benítez, 2007). Specifically, the authors developed the Silence Conspiracy Scale (SCS) to assess the reasons why families avoid informing their relatives suffering from cancer about their illness (Ruiz-Benítez & Coca, 2008).

Therefore, given that there is no reliable and valid assessment instrument to measure IC behaviour, the aim of this study was to create and validate a questionnaire to assess IC in caregivers of patients with advanced disease. In addition to the clinical usefulness of such an instrument, it will also facilitate research into this phenomenon. We fulfilled the study aims by analysing its psychometric characteristics (factorial structure, reliability and validity).

## 2 | METHODS

### 2.1 | Participants

The sample comprised 150 caregivers of relatives in palliative care situations in the province of Malaga (Spain). In all cases, the caregivers were primary family caregivers. Given the difficulties involved in

### What is known about this topic?

- Previous studies have shown that some people withhold information from relatives with terminal diseases.
- Information concealment has been shown to have relevant negative psychological effects on patients.
- Despite the relevance of this phenomenon, there are no scientifically validated assessment instruments for its measurement. The Information Concealment Scale for Caregivers (ECOI) was therefore designed to assess information concealment.

### What this paper adds

- A new assessment instrument to measure information concealment behaviour in the setting of palliative care and validated for its use in the Spanish population.
- This brief instrument can be used not only in clinical settings, but also in palliative care research.
- Its application can detect behaviour that hinders communication in palliative care settings. Interventions could be conducted based on the results.

creating a sample of terminally ill people, we followed the recommendations of Muñoz & Fonseca-Pedrero (2019) (i.e. at least five people per item) to achieve adequate sample size. Inclusion criteria were as follows: (a) having a relative in palliative care situation due to advanced disease, (b) having sufficient knowledge of Spanish and (c) being at least 18 years old. Exclusion criteria were as follows: (a) having difficulties in understanding the items of the questionnaire (i.e. attention difficulties, cognitive difficulties associated with advancing age) or having a level of awareness that prevented them from answering the tests.

Each caregiver was in charge of a patient and all patients were asked for their participation. The patients comprised 66 women and 84 men. Their average age was 71.22 years ( $SD = 14.36$ ; range 18–98 years). According to their medical records, all the patients were terminally ill and were being cared for in a palliative care unit. Inclusion criteria were as follows: (a) having sufficient knowledge of Spanish, (b) being at least 18 years old and (c) being able to understand the items in the questionnaire or having a level of awareness that allowed them to answer the tests.

All individuals fulfilling the eligibility criteria were informed and invited to participate by their physicians at the palliative care unit of the hospital or by the psychologist of the charity-based association in which patients were being attended.

### 2.2 | Measures

#### 2.2.1 | Sociodemographic and clinical characteristics

The participants (carers) were asked about their age, sex, work occupation, educational level, their marital status and that of the patient

and their relationship to the patient. Likewise, information was collected on the period elapsed (in months) since the patient was diagnosed and on any symptoms due to the disease.

## 2.2.2 | The Information Concealment Scale for Caregivers

Information concealment was assessed using the Information Concealment Scale for Caregivers (ECOI). The questionnaire comprises 15 items that are answered on a Likert-type scale with responses ranging from 0 (never) to 3 (always). Thus, the higher the scores, the higher the IC. The scale assesses how often caregivers have tried to withhold, falsify or modify information about the disease.

To ensure evidence of content validity, the scale items were generated by conducting an exhaustive review of studies on IC. Thus, we searched the PubMed, Medline and PsycInfo databases for papers published in English and Spanish between 2000 and 2017. We found and reviewed a total of 25 articles with content specifically related to IC. The reviewers identified 25 examples of typical IC behaviour, which were grouped into three initial categories related to the avoidance of personal communication (i.e. not talking about the disease and concealing their negative feelings about the situation), the control of external information (i.e. the attempt to control the information that the patient may receive from medical practitioners and other family members) and deception and false hope (i.e. minimising the seriousness of the disease and its consequences).

Based on these three categories, we created a pool of 25 items: eight were related to distorting information about the disease or to misrepresenting the true situation, nine were related to attempts by family members for patients to receive information from others and eight were related to the concealment or distortion of reality about the disease, thus leading to false hopes. The ECOI is a new instrument. Thus, before it was administered to the carers, it was tested on a sample of 30 people from the general population in order to detect inconsistencies or difficulties in interpreting the items. Semantic errors were corrected and the wording of some items was modified to increase their comprehensibility. Subsequently, three items were reformulated. The initial version was independently reviewed by two researchers, both with PhDs, and with more than 25 years of experience in the construction and adaptation of assessment instruments and with knowledge of the field of palliative care and communication processes. The subsequent review by the research group led to the reformulation of some items and the elimination of eight items because they were too confusing or redundant. The final IC scale comprised 15 items: five were related to direct communication (e.g. Do you talk openly with your relative about everything that has to do with his/her illness?), five to preventing other people from giving information (e.g. Do you prevent certain information from being given to your relative about his/her illness?) and five to concealing and distorting information (e.g. Do

you try not to mention your relative's illness in front of him/her?) (Appendix S1).

## 2.2.3 | Preferences and satisfaction with the information received

The patients were asked about what they wanted to know about their disease and their satisfaction with the information received. To this end, 2 questions with several answer options were administered. Question 1 took the following form: 'Regarding your disease, (1) do you prefer to be completely unaware of any details; (2) do you want to know about your disease, but only if it is good news; and (3) do you want to know everything about the disease, both good and bad. Question 2 asked patients about the degree to which they agreed with the following statement: "At the moment, you are satisfied with the information you have received about your illness". Patients responded on a scale ranging from 0 (completely disagree) to 3 (totally agree).

## 2.2.4 | Professional judgement

Physicians were asked if their patients knew about their diagnosis and prognosis. They recorded their responses on a Likert-type scale ranging from 0 to 5 (where 0 = it seems that they do not know all the information, and 5 = it seems that they know all the information).

## 2.2.5 | Silence Conspiracy Scale

The SCS (Ruiz-Benitez, 2007). This instrument comprises an 18-item Likert-type scale with five response options ranging from 1 (totally disagree) to 5 (totally agree). It assesses the protection of information by family members. The items are grouped into two factors: (1) "Need to protect patients". This factor addresses whether carers believe that IC protects the patients; and (2) "Difficulty in communication". This factor addresses self-perceived communication skills. In this study, the scale had a Cronbach's  $\alpha$  value of 0.89.

## 2.3 | Procedures

The ECOI is a new instrument. Thus, before it was administered to the carers, it was tested on a sample of 30 people from the general population in order to detect inconsistencies or difficulties in interpreting the items. Subsequently, any inconsistencies were corrected and some items were reformulated.

A total of 150 relatives of people receiving palliative care were contacted through the palliative care units of the Antequera Regional Hospital (Málaga, Spain) and the psychosocial team of the Asociación Girasol (Málaga, Spain). The latter body is a charity based in the Antequera region that offers support to terminal patients with

advanced diseases. Likewise, patients were asked for their collaboration. The general idea of the study was explained to the carers. If they consented to participate, a qualified experienced psychologist contacted them to arrange a day and time for the interview. In this first contact, the specific aim of the study was explained and the need to interview the patient.

The interviews were performed at home unless they had to be conducted in the hospital due to the condition of the patient. After clarifying any questions about the study, the family member and the patients gave signed informed consent. The interviews were conducted independently to ensure their privacy and confidentiality. The psychologist who ensured that all the questions were answered also conducted all the interviews. Data were collected from 2018 to 2021.

The study received approval from the hospital's Research Ethics Committee and followed the guidelines established by the Declaration of Helsinki in 1964.

## 2.4 | Statistical analysis

We first analysed the data related to the characteristics of the relatives and patients and then analysed the descriptive statistics for each item of the ECOI. The number of dimensions were assessed using indices based on parallel analysis (PA) and exploratory factor analysis (EFA) (principal axis with oblimin rotation). PA was performed using exploratory robust maximum likelihood. Goodness-of-fit was evaluated using the following indices (Hu & Bentler, 1999): standardised root mean square residual (SRMR, value close to or less than 0.08 indicates an acceptable fit), root mean square error of approximation (RMSEA, value equal to or less than 0.06 indicates a good fit) and the comparative fit index (CFI, values close to or more than 0.95 indicate an acceptable fit).

The reliability of internal consistency was determined using Cronbach's alpha coefficient. The omega coefficient was calculated for the general scale and each of the subscales suggested by the EFA.

Criterion validity was assessed with respect to two criteria related to IC: (1) the patients' satisfaction with the information on their disease, and (2) and professional judgement. We calculated Pearson's bivariate correlations between the total score on the ECOI and the patients' satisfaction with the information received, and between the total score on the ECOI and the physicians' judgement regarding the information the patients had about their disease. Associations between the ECOI score and the SCS score were calculated using Pearson's correlation coefficient. We followed the guidelines proposed by Evers et al. (2013) for interpreting correlations, according to which validity values can be considered inadequate ( $r < 0.20$ ), adequate ( $0.20 < r < 0.35$ ), good ( $0.35 < r < 0.50$ ) or excellent ( $r = 0.50$ ).

All statistical analyses were performed using the IBM SPSS Statistics programme, version 23. The PA was performed using the FACTOR programme, version 11.02.02.

## 3 | FINDINGS

### 3.1 | Description of the participants

Most of the carers were partners (41%) or children (41%) of the patient. Their mean age was 55.57 years ( $SD = 14.53$ : range 22–88 years). The mean length of time as primary caregivers was 36.27 months ( $SD = 58.53$ : range  $\leq 1$ –360 months).

We could only use the data of 134 (54 women and 80 men) of the 150 participating patients due to the high mortality rate in this population (some patients could not be interviewed because of severe worsening of the disease or even premature death). Their average age was 71.22 years ( $SD = 14.36$ : range 18–98 years). The mean length of time since the start of the disease was 3 years ( $SD = 5.23$ ). According to medical judgement, in all cases the life expectancy of the patients was equal to or less than 6 months. In total, 19% of the patients had a nononcological palliative disease and the others had an oncological disease, the most common being lung cancer (26%) followed by gastrointestinal cancer (17%). Table 1 shows the other characteristics of the participants.

### 3.2 | Parallel analysis

The PA-based principal component analysis yielded a three-factor structure. The results of the chi-squared-based test ( $p < 0.001$ )

TABLE 1 Descriptive statistics of the sample by sociocultural and civil status (%)

	Caregivers (N = 150)	Patients (N = 134)
Civil status		
Single	14	6
Married	66.7	58.7
Cohabiting	10.1	8.7
Separated	6.5	6.6
Widowed	2.7	20
Educational level		
None	29	47.3
Primary	26.9	24
Secondary	33.4	20
University	10.7	8.6
Current employment		
Unemployed	11.4	4
Retired	35.4	72
Homemaker	12	6
Service sector	16	4
Unskilled worker	5.4	1.3
White-collar workers	6.8	4
Farmworker	4.7	4
Others	7	5

and the  $\chi^2/df$  value (1648.3/105) reached statistical significance ( $p < 0.001$ ). The RMSEA (0.06), SRMR (0.06) and CFI (0.98), values indicate an acceptable fit.

### 3.3 | Factorial structure

The Kaiser–Meyer–Olking (KMO) index was 0.87. The subject-to-item ratio was 10:1, indicating that the EFA was adequate for this sample. The three-factor solution explained 59.09% of the variance, with eigenvalues of 7.46 for factor 1, 1.94 for factor 2 and 1.67 for factor 3. All the loadings were greater than 0.30 and the communalities were between 0.48 and 0.86, except for item 7. Intercorrelation was 0.60 between factors 1 and 2, 0.50 between factors 1, and 0.51 between factors 2 and 3. The means of the items ranged from 0.80 to 2.11. All the items had asymmetry and kurtosis of less than  $\pm 1.7$ . No items had a highly leptokurtic or platykurtic distribution (Table 2).

Factor 1 comprised six items related to withholding information about the disease and/or its severity, factor 2 comprised five items related to distorting information about the disease and factor 3 comprised four items related to the management and control of information. Based on their content, factor 1 was called 'Concealment or dissimulation about the disease', factor 2 was called 'Misrepresentation of the situation' and factor 3 was called 'Control of the information'.

### 3.4 | Reliability

Cronbach's alpha was calculated for both the general scale and its subscales. The general questionnaire showed excellent internal

consistency ( $\alpha = 0.90$ ), with alpha values of 0.86, 0.86 and 0.82 for the 3 factors, respectively. Values of the omega coefficient were 0.89, 0.84, 0.86 and 0.82 for the general scale and its three factors, respectively.

### 3.5 | Criterion Validity

A significant positive association was found between the ECOI and the SCS ( $r = 0.75$ ,  $p < 0.001$ ). Pearson correlation indices of the subscale scores ranged from 0.50 to 0.72 ( $p < 0.001$ ), except for one correlation ( $r = 0.21$ ,  $p = 0.007$ ) between the Communication Difficulty (SCS) and Information Control (ECOI) subscales.

A negative association was found between the patients' level of information as perceived by the physicians and the total score of the ECOI ( $r = -0.48$ ,  $p < 0.001$ ). A significant negative association was found between the scores of subscales 1, 2 and 3 and professional judgement criteria ( $-0.41$ ,  $-0.34$  and  $-0.45$ , respectively). Thus, the higher the scores on the ECOI, the less informed the patients (i.e. lower scores on level of information according to professional judgement).

In total, 21% of patients indicated that they totally disagreed or somewhat disagreed with the statement: 'You are currently satisfied with the information you have received about your disease/s'. In fact, significant negative associations were found between scores on the patients' satisfaction with the information and the total score of the ECOI ( $r = -0.33$ ,  $p < 0.001$ ) and the scores of subscales 1 and 2 ( $r = -0.30$  and  $-0.38$ ,  $p < 0.001$ , respectively). The association between the scores of subscale three and satisfaction with the information did not reach statistical significance (Table 3).

TABLE 2 ECOI items: descriptive statistics and factor loading after oblique (Promax) rotation

ECOI items	Descriptive statistics				Factor loadings			
	<i>M</i>	<i>SD</i>	Skewness	Kurtosis	1	2	3	<i>h</i> <sup>2</sup>
1	1.01	1.09	0.70	-0.83	0.27	0.37	0.20	0.53
2	1.07	1.10	-0.34	-1.18	0.89	0.10	-0.16	0.70
3	1.68	1.12	-0.31	-1.26	0.92	0.12	-0.20	0.74
4	1.08	1.20	0.55	0.129	0.13	0.08	0.69	0.57
5	2.10	1.06	-0.85	-0.60	0.82	0.11	0.06	0.53
6	1.63	1.25	-0.15	-1.60	0.08	0.84	-0.17	0.62
7	1.44	1.26	0.03	-1.66	0.73	-0.15	0.10	0.41
8	1.53	1.17	-0.09	-1.46	-0.26	0.12	0.82	0.52
9	0.89	1.17	0.82	-0.83	0.29	0.40	0.19	0.58
10	1.17	1.24	0.41	-1.47	0.30	0.10	0.58	0.71
11	1.25	1.24	0.37	-1.47	-0.14	0.94	0.07	0.75
12	1.43	1.29	0.04	-1.69	0.52	0.12	0.29	0.64
13	0.80	1.12	1.10	-0.33	-0.13	0.86	0.11	0.61
14	1.55	1.15	-0.11	-1.40	-0.15	0.06	0.89	0.64
15	2.11	1.08	-0.79	-0.80	0.56	0.07	0.09	0.33

Abbreviation: ECOI, Information Concealment Scale for Caregivers.

TABLE 3 Descriptive statistics and correlations between the ECOI scores and their subscales with the scores of the variables for criterion validity

Variable	Range	M	SD	ECOI subscale 1	ECOI subscale 2	ECOI subscale 3	ECOI total score
Total score of SCS	18–83	50.91	16.33	0.72 <sup>***</sup>	0.63 <sup>***</sup>	0.45 <sup>***</sup>	0.75 <sup>***</sup>
Need to protect patients (SCS)	11–55	32.73	11.66	0.65 <sup>***</sup>	0.57 <sup>***</sup>	0.50 <sup>***</sup>	0.71 <sup>***</sup>
Difficult on communication (SCS)	7–35	18.18	7	0.59 <sup>***</sup>	0.50 <sup>***</sup>	0.22 <sup>*</sup>	0.56 <sup>***</sup>
Professional judgement	0–5	3.48	1.67	-0.47 <sup>***</sup>	-0.38 <sup>***</sup>	-0.42 <sup>***</sup>	-0.54 <sup>***</sup>
Satisfaction with information	0–3	2.16	0.97	-0.31 <sup>**</sup>	-0.40 <sup>***</sup>	-0.12	-0.35 <sup>***</sup>

Abbreviations: ECOI, Information Concealment Scale for Caregivers; SCS, Silence Conspiracy Scale.

\* $p < 0.05$ ; \*\* $p < 0.005$ ; \*\*\* $p < 0.001$ .

## 4 | DISCUSSION

The main aim of this study was to create and validate a reliable scale to assess IC. Thus, we analysed the ECOI factor structure, its criterion validity, and its reliability.

The analysis of the factorial structure of the ECOI showed that it had three intercorrelated dimensions. A structured literature review was conducted to ensure content validity. However, because we only conducted EFA, the factor structure of the ECOI should be confirmed in future studies using CFA. Nevertheless, the preliminary psychometric exploration of the ECOI revealed adequate criterion validity and good internal consistency, suggesting that all the items measure the same construct.

The three factors of the ECOI differentiate three complementary ways in which main caregivers try to prevent patients from being informed about the real situation. This aspect has traditionally been known as the conspiracy phenomenon or conspiracy of silence (Espinoza-Suárez et al., 2017; Machado et al., 2019), which terms clearly have negative connotations. This phenomenon could be described as an implicit and explicit attempt by the patient's family and healthcare professionals to change the information provided to patients. However, the conspiracy of silence should not be understood as a deliberate attempt to harm the patient, even though harm is often the result.

Factor 1 of the ECOI, called 'Concealment or dissimulation about the disease', comprised items related to the way in which family members in the role of main carer withhold or conceal the illness and its severity from the patient. Previous studies have confirmed the existence of this type of concealment (Bermejo et al., 2013; Pinyopornpanish et al., 2017; Ruiz-Benítez, 2007; Sutar et al., 2019). Furthermore, Font-Ritort et al. (2016) found that information is hidden from many patients by using a euphemism for the word 'cancer'. Cejudo et al. (2015) found that relatives hide their emotions in the presence of patients in order to conceal their emotional discomfort. This dimension is in agreement with the results of a recent study by Cremonese et al. (2020), who found that many carers withhold or disguise their feelings in front of patients when they are overwhelmed by the situation. Lope and Díaz (2019) suggested that there is an emotional component to IC as well as a cultural component. In line with this result, Corradi-Perini et al. (2021) found an association

between 'emotional distress' and communication problems and false hopes. It therefore seems that relatives try to ameliorate or regulate their emotions through concealment, although more studies are needed to investigate this possibility.

Factor 2 of the ECOI, called 'Misrepresentation of the real situation', comprised items related to deception or distorting information about the disease (i.e. misrepresenting the true). Previous studies have reported this aspect as characteristic of the IC phenomenon (Cejudo et al., 2015; Font-Ritort et al., 2016; Nipp et al., 2016). In contrast, Gil et al. (2014) found that many patients sincerely wanted to have information on the effectiveness of their treatments. Thus, obstacles remain to the patients having their rights fulfilled and satisfying their desire to have accurate information about the role and limitations of the treatments they receive.

Factor 3 of the ECOI, called 'Control of the information', comprised items related to the way in which carers manage and control the information patients receive from others (i.e. physicians, staff members and other relatives). Previous studies have shown that some family members ask physicians about what information they should provide or ask physicians not to inform patients about their condition or (Cejudo et al., 2015; Díaz-Cordobés et al., 2012; Romero et al., 2013). Hancock et al. (2007) showed that some physicians are willing to negotiate with family members about the information that patients can receive. These authors and Rio-Valle et al. (2009) have suggested that there is a tendency among physicians to underestimate the information needs of patients and to overestimate their knowledge about prognosis. These findings were confirmed by Bermejo et al. (2013), who also found that although some families did not refuse to inform the patients, some physicians decided not to inform patients who wanted to receive the information.

Regarding the criterion validity of the ECOI, a significant inverse association was found between the ECOI score and the patients' level of satisfaction with the information received. This result is expected in the sense that their level of satisfaction is shaped by the extent to which family members withhold or falsify information. It must be borne in mind that some patients (around 21%) were not satisfied with the information they received about their disease. This finding is in line with those reported by Font-Ritort et al. (2016) or Sampaio et al. (2019). This is a striking finding, because most



research on IC does not take into account the opinions of both the carers and the patients.

We also investigated the physicians' opinions about the degree to which patients were informed. A significant negative association was found between this variable and the ECOI: that is, there is an association between higher levels of IC and less knowledge about the situation on the part of patients. The promotion of patient engagement in treatment decisions entails improved patient knowledge and better preparation to make treatment choices, which, in turn, means improving the quality of communication between patients and providers (Austin et al., 2015). Thus, the more family members withhold information (i.e. higher scores on the ECOI), the less informed patients will be (i.e. lower scores on level of information according to professional judgement). This finding is another indicator of the validity of the scale.

A significant association was found between the SCS (Ruiz-Benítez, 2007) and the ECOI, which was also an indicator of the validity of the scale. This finding suggests that motivations to conceal information are linked to acts of concealment. Family members who wrongly believe that they are protecting patients or who find it difficult to communicate openly with patients about their disease will tend to hide their feelings, control information and deceive the patients or give them false hopes. This result points to the need provide palliative caregivers with appropriate advice.

The present study has some limitations. The sample of palliative caregivers mainly comprised people from rural areas (i.e. areas with less than 6000 inhabitants). Most of them had primary education alone and the great majority were unemployed. Furthermore, their mean age was quite high (55.57 years). A sample with different characteristics may have yielded different results. In fact, there is some evidence of an association between a lower educational level (family members) and advanced age (patients) and an increased tendency to withhold information on the part of the caregiver (Alsirafy et al., 2017; Ruiz-Benítez, 2007). In addition, the sample was mainly comprised of female carers. Another limitation is that the study included patients receiving palliative care in an area with fewer healthcare resources, which meant that some of them died before they were able to take part in the study. Likewise, to test the replicability of the ECOI, the results obtained with the EFA should be confirmed using confirmatory factor analysis.

Further studies could determine the degree of IC that has negative psychological effects on patients (i.e. the critical point at which it is clearly harmful to withhold information). More studies are also needed to analyse the psychological factors associated with IC as measured with the ECOI. In addition, to test the replicability of the ECOI, the results obtained by EFA should be confirmed using confirmatory factor analysis. Furthermore, it would be interesting to study the psychological profile of family members who score higher or lower on the ECOI. Likewise, more research is needed not only on the validity evidence of the ECOI (i.e. construct validity), but also on its cross-cultural validity. Thus, the ECOI needs to be translated into English and to be further tested in English. Moreover, even in Spanish-speaking Latin American countries, the language of the questionnaire might

affect the way people respond to questions related to cultural values.

## 5 | CONCLUSION

Given that IC is a common phenomenon in various cultures, the ECOI could be adapted to other languages. It is a brief instrument, which would facilitate its use not only in clinical settings, but also in advanced disease research. Its application would be useful in detecting behaviour that hinders communication in palliative care settings and interventions could be conducted based on the results. However, as noted above, the results on the ECOI are preliminary and further research with larger samples are required.

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## CONFLICT OF INTEREST

None declared.

## AUTHOR CONTRIBUTIONS

All the authors have made substantial contributions to and have read and approved this manuscript.

## DATA AVAILABILITY STATEMENT

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

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