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European Journal of Oncology Nursing

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Measuring invisible nursing interventions: Development and validation of Perception of Invisible Nursing Care-Hospitalisation questionnaire (PINC–H) in cancer patients

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ARTICLE INFO

Keywords: Invisible work Nursing care Patient satisfaction Reliability Validity Psychometrics Nurse Cancer care

ABSTRACT

Visible nursing work is usually associated with formal work and physician-delegated tasks which are protocolised and usually well documented. Nevertheless, nurses carry out many actions and display specific attitudes and behaviours which, despite contributing to the well-being, recovery of patients and satisfaction with the attention received, are not as visible. Previous studies have been conducted in order to define 'invisible nursing interventions', but no quantitative instruments focused on measuring invisible nursing interventions have been found in the literature.

 ${\it Purpose} \hbox{: To test the psychometric properties of the Perception of Invisible Nursing Care-Hospitalisation (PINC-H) questionnaire.}$

Methods: Cross-sectional survey design. A self-administered questionnaire was completed by 381 participants recruited consecutively after discharge from a Spanish hospital. Data were collected from 2012 to 2020. *Results*: Three factors were identified from exploratory factor analysis, namely 'Caring for the person', 'Caring for the environment and the family' and 'Caring presence'. Criterion Validity Coefficient was highly significant (p < 0.001) with values ranging between 0.63 and 0.71. Cronbach's alpha was 0.96. Test-retest reliability was estimated in a subsample of 187 participants; in all the items, correlation coefficients were highly significant (p < 0.001) and within range (0.532–0.811) with a mean value of 0.680. Also, correlations between each dimension and the complete questionnaire indicated good temporal stability between measurements.

Conclusions: The instrument had satisfactory validity and reliability. PINC-H can contribute to highlight nursing interventions and behaviours which are often unseen and, thus, less valued. We argue that PINC-H will also be useful to evaluate the quality of invisible nursing care to oncology inpatients.

1. Introduction

The International Council of Nurses (2017) remarks that taking care of the workforce is a priority because no other goal is attainable without investment in the nursing profession. There is a shortage of nurses globally (Lee et al., 2013); in Europe, the number of qualified nurses has decreased since the beginning of the economic crisis in 2008. In Spain,

nurses frequently complain of a lack of social and professional recognition (Sanclemente-Vinue et al., 2019) and low salaries (Jiménez García et al., 2015). Moreover, according to the 'Registered Nurse Forecasting: Human Resources Planning in Nursing' study (RN4CAST) (Fuentelsaz-Gallego et al., 2013), Spanish nurses suffer high levels of burnout and heavy workloads. A recent e-Delphi study carried out by 40 European experts argued that there is an association between burnout

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https://doi.org/10.1016/j.ejon.2020.101888

Received 5 April 2020; Received in revised form 4 December 2020; Accepted 6 December 2020 Available online 13 December 2020

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and a 'lack of recognition of part of the tasks that nurses perform (invisible care) and praise for a job well-done'. However, this phenomenon has been poorly studied (Manzano-García and Ayala, 2017).

Defining what does and does not constitute nursing work is problematic. Defining nursing's area of practice and integrating the concept of caring as an essential element of the profession have been a constant concern for nurses worldwide. Expressed in different ways but based on a common idea, some authors coincide in defining nursing work as comprising instrumental/technical aspects and humanistic/expressive aspects (Watson, 1979; Zamanzadeh et al., 2010). Both of these dimensions favour patients' well-being and accelerate their recovery (Liaschenko, 2002; Maben, 2008), and they are also indispensable to provide good quality nursing care. However, not all aspects of nursing work are equally visible at institutional, interprofessional and social levels (Germán-Bes et al., 2015).

Although the evolution of the nursing discipline has changed due to variations in the socio-political, economic and historical context, mention of the invisibility of nursing care and/or the nurse in the past few decades has been found in multiple works. Specifically, references to the invisibility of nursing have been made in scientific works in the United States (Bjorklund, 2004; Jacques, 1993; Liaschenko, 2002), as well as in the United Kingdom (Allen, 2015; Maben, 2008), Canada (Corbin, 2008), Sweden (Lydahl, 2017), Brazil (Baggio and Erdmann, 2010) and Spain (Fajardo Trasobares and Germán Bes, 2004; Germán-Bes et al., 2015; Huércanos-Esparza, 2010, 2011, 2013; Medina, 1999).

According to Maben (2008), the invisibility of nursing work derives from the difficulty in "measuring many of the core caring skills" conducted daily by nurses when caring for a patient (Maben, 2008). Allen adds that "nursing work has many features that make visibility problematic. It is a gendered work and falls in a category of work that is often assumed to rest on the natural talents of women" (Allen, 2015). Invisible nursing care encompasses all actions, attitudes and behaviours that are intangible, undervalued and perceived as dependent on the good will of the nurse, and not the result of a reasoned professional judgment based on experience and knowledge. Regrettably, this has impact not only on the (lack of) recognition of the nurses' work in the clinical setting, but also on the position and portrayal of nursing in public and mass media (ten Hoeve et al., 2014).

A previous ethnographic study, conducted to investigate the care delivered by nurses to cardiac and respiratory patients and their families during hospital admission (Huércanos-Esparza, 2010), identified specific caring interventions, attitudes and behaviours which often went unnoticed or became diluted among other more visible tasks, such as nursing techniques and physician-delegated tasks. In the group of invisible nursing interventions were actions performed to educate patients and their families, to offer emotional support through both verbal and non-verbal communication, to increase comfort, to reduce pain through non-pharmacological treatment, and to liaise with other healthcare professionals in order to provide patient-centred care. The latter has been referred to by other European authors as 'organising work' (Allen, 2015) and 'articulating work' (Lydahl, 2017), and was also classified by them as undervalued and unseen, but crucial for the welfare of patients and their family. In a previous study, Huércanos-Esparza (2010) defined invisible nursing care as interventions that are not documented in the nursing records, are not handed-over to colleagues and are not valued institutionally, but which are time-consuming and have a positive impact on the wellbeing, autonomy and safety of patients and their families. Unfortunately, few of these nursing interventions are seen as essential by many Spanish healthcare institutions, and often factors such as heavy workloads and unfavourable working conditions prevent nurses from fully integrating them into their practice. In other words, the more visible tasks are prioritized over the less visible ones (Jacques, 1993), thereby occurring what some researchers call 'care left undone' or 'missed care' (Aiken et al., 2018; Ball et al., 2014). In recent years, studies have been published that show the impact of failing to

deliver these nursing interventions on the patients' experience, safety, trust and satisfaction with the care received, and therefore also on their perception of the quality of care (Aiken et al., 2018; Ball et al., 2014).

There have been previous attempts to design and validate tools in order to ascertain which nursing interventions are significant to patients and which are not, namely the Good Nursing Care Scale for patients (GNCS-P) (Rehnström et al., 2003), the Newcastle Satisfaction with Nursing Scales (NSNS) (Thomas et al., 1996), the Nursing Intensive-Care Satisfaction Scale (NICSS) (Romero-García et al., 2018), and more specifically within the oncology setting the Quality of Oncology Nursing Care Scale (QONCS) (Charalambous and Adamakidou, 2014). These are all valid and reliable tools to measure the quality of nursing care and the level of patient satisfaction with the care received. However, none of them are able to directly quantify invisible nursing care. A systematic review of supportive care needs of people with lung cancer identified the need to develop tools that allow patients to identify their health needs and express their preferences of care in order to improve the standard of nursing work (Maguire et al., 2013). We consider this need extendable to all cancer patients. Additionally, acknowledging and recognizing the work carried out by nurses could be doubly beneficial. On the one hand, it would contribute to increase the self-esteem of the workforce, which would potentially improve quality of care, promote safe practice (Lee et al., 2013) and increase customer satisfaction. On the other hand, employees who feel personally valued would be predictably more satisfied with their jobs and this could result in better engagement with the organisation.

The Perception of Invisible Nursing Care-Hospitalisation (PINC–H) questionnaire was developed in order to measure invisible care interventions provided by nurses to oncology patients and their families during hospital admission. This tool helps to identify nursing interventions based on the patients' perception of their needs and allows for the identification (and recognition) of the nursing care given, the nursing care missed and those interventions which need to be reinforced. Unlike the preceding instruments, the PINC-H was initially designed in Spanish and has been fully adapted to the Spanish context. Therefore, the aim of this study was to design and evaluate the psychometric properties of this tool.

2. Materials & methods

2.1. Study design

This research implemented a cross-sectional design consisting of two phases (Fig. 1).

2.2. Phase 1: item generation and pilot study

Item generation for the initial version of the PINC-H questionnaire was based on a combination of inductive (qualitative exploratory research results) (Huércanos-Esparza, 2010) and deductive methods (literature review and pre-existing scales) (Huércanos-Esparza, 2011). The results of this review highlighted that self-care promotion, relationship of trust and safety, emotional support, touch, listening, comfort, compassion, respect and caring presence were the main aspects of the nurses' work that encompassed invisible care interventions. In addition, and external to nursing care, the social image of nursing was also identified to have an impact on the invisibility of nursing work. As suggested by Sioban Nelson, becoming visible in the health care system implies moving beyond "say little, do much" and achieving a degree of social legitimacy and respect (Nelson, 2011). Thus, we ensured that all of these areas were represented in the questionnaire.

The pilot questionnaire, developed by Huércanos-Esparza (2011), was a self-administered tool comprising 36-items. All the items were assessed using a 5-point Likert scale with a non-response option (1 = never, 2 = a few times, 3 = almost always, 4 = always, 5 = I don't know/I don't have an opinion). We included a non-response option at

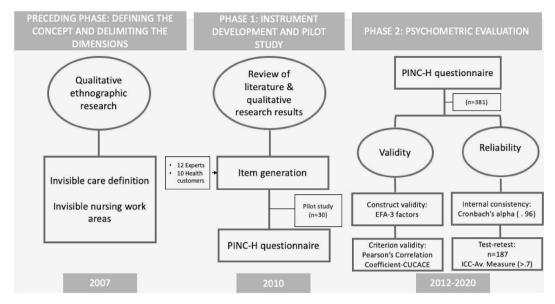


Fig. 1. Outline of the development and validation process.

this stage in order to give our participants the possibility of expressing a lack of opinion or a lack of applicability of any of the items to their experience of nursing care.

The tool included 6 open questions allowing the patients to describe any significant experiences occurring during hospitalisation. A qualitative assessment of the content validity of the initial questionnaire was carried out by a panel of 13 experts (5 Nursing Lecturers from 2 Spanish universities, 7 Registered Nurses from 6 different secondary and tertiary referral hospitals and 1 from a Primary Care Centre). These experts verified the meaning, relevance and pertinence of each item and they also made comments to improve the wording and content of the overall questionnaire (Streiner and Kottner, 2014). The following changes were made according to their suggestions: 1 item was removed due to redundance, 2 items were added (Q36 and Q37), 4 items were reformulated to improve readability and two sociodemographic variables were added, namely previous comorbidities and level of education. Subsequently, 10 healthcare users examined the readability and comprehension of the final items. The pilot study included 30 oncology patients who had been admitted to different medical and surgical services in the previous 12 months for at least 3 days (Huércanos-Esparza, 2011). Data collection and recruitment took place in six primary care centres in the cities of Zaragoza, San Sebastián, Madrid, Salamanca, Soria and Tudela. Potential participants were invited to take part in the study by a qualified community nurse during a routine visit.

The pilot instrument showed a good level of internal consistency reliability ($\alpha=0.946$). This questionnaire was initially conceived as being uni-dimensional and, thus, the Cronbach's alpha coefficient was calculated for the total scale. Stability was assessed by test-retest using intraclass correlation (ICC = 0.95). Both results were promising and reinforced the idea of improving the questionnaire, conducting a new data collection with a larger sample of participants and performing new statistical tests to obtain a more robust demonstration of the reliability and validity of the tool.

After the pilot study, the research team asked the community nurses who participated in the processes of patient enrolment and data collection to report on any obstacles experienced during participant recruitment and to discuss with the patients any difficulties experienced during the self-administration of the instrument. The patients were also asked to suggest additional items to include in the next tool version. We studied the questions left unanswered, compared them with the patients' profile and eliminated all that were not relevant to them. Subsequently, individual in-depth interviews were carried out with a

purposive sample of five oncological patients in order to verify the relevance of the items before starting the second phase of the study. Access to these patients was granted by the psychologists and social workers of the Spanish Cancer Association; they were selected through a sampling of maximum variation procedure taking into account the following criteria: age, sex, time from diagnosis and degree of independence in performing activities of daily living. The inclusion criterion to participate in this phase of the study was having been admitted to hospital in the previous year for at least 3 days. In Spanish culture, the family plays a fundamental role in the accompaniment and informal care of patients both at home and in the hospital. For this reason, we invited the main caregiver of the patients with a moderate to high level of dependence to take part in the interview in order to enrich and complement the information. This was considered appropriate by the investigators as some of the items included in the PINC-H questionnaire are related to the care or attention provided by the nurses to the relatives who accompany them during their hospital stay.

Subsequently, a new comprehensive literature review was conducted in order to update and extend our knowledge of the state-of-the-art on this topic and with the purpose of finding an adequate gold standard to correlate with our tool. Minor changes were made to the formatting of the tool and the administration strategy according to the limitations observed in the prior version in order to guarantee viability before beginning the validation phase (Huércanos-Esparza, 2010).

2.3. Phase 2: validation of the final version of the instrument

2.3.1. Instruments

The final version of the PINC-H tool comprises 3 sections. The first section includes the sociodemographic characteristics of the respondents. The second section contains 31 questions measured using a 5-point Likert scale (1 = never, 2 = a few times, 3 = sometimes, 4 = almost always, 5 = always). We removed the non-response option from the Likert scale in the final version of the questionnaire and added a central response option instead. The non-response option was useful during the pilot stage in order to identify any irrelevant items, however, it was deemed unnecessary in the final stage.

All 31 questions refer to different invisible nursing interventions that patients and their relatives might have experienced during hospital admission. The third section includes 6 dichotomous questions (Yes/No); 3 of them are related to the patient's satisfaction with nursing care, medical assistance and degree of resolution of the primary reason for

admission, and 3 are related to the image and status of the nurses within the multidisciplinary healthcare team. The purpose of this last section is to obtain complementary information about the patients' satisfaction with the care received and ascertain their opinion about different aspects that may influence their perception of invisible care received during hospital admission. All the questions were reviewed to ensure relevance and readability for our target population (Terwee et al., 2007). The score ranged from 1 to 5 in items measured using a 5-point Likert-scale; dichotomous questions scored $1=\mathrm{Yes}$ and $0=\mathrm{No}$. Thus, the total score of the instrument ranged from 31 to 161. The higher the score obtained in the second section of the PINC-H tool, the higher the number of invisible nursing interventions received during hospitalisation; the higher the score obtained in the third section of the tool, the higher the patient's satisfaction, confidence and sense of safety.

We tested the PINC-H questionnaire against the gold standard instrument (GSI), namely the Spanish validated version of the Newcastle Satisfaction with Nursing Scales (NSNS), in Spanish Cuestionario de Calidad de los Cuidados de Enfermería (CUCACE) (Alonso et al., 2005). The CUCACE questionnaire demonstrated high internal consistency (Alonso et al., 2005) and it is one of the few validated instruments available in Spanish. This tool was originally designed to measure the quality of nursing care, as opposed to "invisible nursing interventions". However, many of the interventions described by Alonso at al. (2005) in the CUCACE questionnaire are similar to those included in PINC-H, thus making them comparable.

This tool is divided into 3 sections: 1) the first section includes 26 statements about experiences of nursing care, 15 of them positively and 11 negatively worded. Responses are measured using a 7-point Likert scale; 2) the second section consists of 19 items about satisfaction with nursing care measured using a 5-point Likert scale; all of them are worded in a positive way; 3) the last section includes social and demographic variables. In the first section, the maximum score is 156 and indicates the best possible experience of nursing care; in the second section, the maximum score is 76 and indicates complete patient satisfaction with the care received.

We chose the EQ-5D-3L tool, validated by the multidisciplinary group EuroQol (Cabasés, 2015), to measure quality of life (QoL) in our participants in order to obtain a correlation between QoL perceived and the total score of PINC-H. This allowed us to determine whether a correlation existed between the patients' perception of the nursing care received and their QoL (Wong and Fielding, 2008), as having a poor QoL could be a confounding factor. It includes a first section containing five dimensions of health-related quality of life, namely mobility, self-care, usual activities, pain/discomfort and anxiety/depression, each with three response levels: absence of problem, some problem, serious problem or disability. Additionally, this tool includes a visual analogue scale (VAS) in order to rate the participants' self-perceived health status, ranging from 0 (the worst imaginable health status) to 100 (the best imaginable health status). Answers from the first section were coded using 1 for first level of response, 2 for second level and 3 for third level; answers from the VAS were scored in absolute numbers from 0 to 100. EQ-5D-3L states were converted to a single summary index following the recommendations of the designers (Szende et al., 2007).

2.3.2. Ethical considerations

Permission was sought and granted from the local Research Ethics Committee and the hospital's Director of Nursing prior to commencing with this investigation. All the patients were informed about the study aims and their rights as participants. All the participants who agreed to participate in the study signed the informed consent and they were assured of their anonymity and confidentiality.

2.3.3. Participants

Sample size was estimated based on recommendations from the literature, that is 10 participants per item (Streiner and Kottner, 2014). The study was conducted in a tertiary referral hospital. Permission was

obtained from the hospital to review the medical records of 1171 oncological patients between January 2012 and January 2020. A consecutive sampling technique was applied, whereby every patient who met the selection criteria was invited to participate in the study (n = 414). However, 33 of them did not return the completed questionnaire and so the final validation sample comprised 381 participants (Fig. 2). Inclusion criteria for participation in the study included:

- Adults aged 18 years or over.
- Diagnosed with cancer.
- Admitted to hospital in the 12 months prior to the completion of the PINC-H questionnaire, with a length of stay of 72 h or over.
- Discharged home at the time of participation in the study.
- Able to read and write in Spanish.

Patients who met any of the following exclusion criteria were excluded for participation in this study:

- Had less than 3 months life-expectancy or deteriorated condition.
- Refused to give informed consent.
- Had a formal mental health diagnosis.

2.3.4. Data collection

Data were collected from 2012 to 2020. Previously identified eligible patients were invited to participate in the study when they attended the Oncology Day Centre (ODC) to receive chemotherapy (avoiding the first cycle visit). They were given an instrument pack containing the patients' information sheet, the consent form, a sheet with instructions for completing the questionnaire, the final version of the PINC-H questionnaire, the EQ-5D-3L tool and the GSI (CUCACE). This pack was given to the potential participants by the principal investigator or a trained nurse working in the ODC, who explained the aims of the study and clarified any questions that they may have. They were given the option of completing it during treatment or taking the pack home with them. Each participant took 12–30 min to complete the questionnaires (Fig. 3).

2.3.5. Statistical analysis

Data analysis was conducted using SPSS Statistics 25. The level of significance used throughout the study was $\alpha=0.05.$ Descriptive statistics were used to summarise sociodemographic data. Mean, standard deviation (SD), median, minimum and maximum values were calculated for quantitative variables, and frequencies and percentages for qualitative variables. Questionnaires with missing values were excluded from the validation analysis, resulting in a participant-item ratio 6.81:1 (N = 211)

2.3.6. Validity

Barlett's Test of Sphericity was used to test the homogeneity of variances. Kaiser-Meyer-Olkin (KMO) was conducted to assess the adequacy of sample size. many authors consider reliability as excellent with a result greater than 0.80 (Tavakol and Dennick, 2011). We used principal component analysis (PCA) for factor extraction. The relation between factors was verified using Promax as the rotation method.

Concurrent criterion validity was also estimated using the GSI CUCACE; Spearman Correlation Coefficient was selected to perform the analysis. The strength of the correlation of these results was interpreted as being moderate to strong when the result was within 0.6 and 0.9 (Akoglu, 2018).

2.3.7. Reliability

Cronbach's alpha estimation was used to test internal consistency; this was considered as excellent with a result greater than 0.80 (Gil-Pascual, 2008).

Test-retest reliability refers to the degree to which repeated measurements in the same people provide similar answers (Terwee et al., 2007). In order to verify reproducibility, we performed test-retest on a

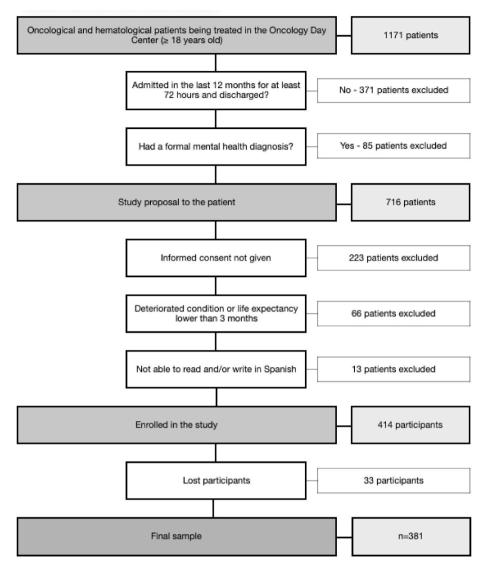


Fig. 2. Flow chart of participant selection.

sample of 187 participants. The analysis was performed using ICC, a result in this test between 0.71 and 0.9 shows good consistency. Time period between test and retest was at least 1 week and a maximum of 8 weeks to avoid both recall bias and clinical change on patients (Terwee et al., 2007). To ensure test-retest comparison, all patients who were hospitalized between test and retest were discarded, as this new admission could potentially affect the stability of the characteristics measured by this questionnaire (Waltz et al., 2017).

2.3.8. Relation between QoL and PINC-H

Finally, a Test U of Mann-Whitney and Test H of Kruskal-Wallis were conducted to explore the relationship between perceived quality of life measured by EQ-5D-3L and PINC-H. This was done in order to rule out low quality of life as a confounding factor for the perception of the nursing care received.

3. Results

The participants' sociodemographic characteristics are presented in Table 1.

The questions in section 3 of the questionnaire yielded information about the satisfaction and image of nursing that users had. It should be noted that 39.6% (n = 151) of the participants did not know the names

of the nurses because the nurses did not introduce themselves when they first met. However, 98.6% (n = 376) of the participants considered that nurses occupy an important place in the healthcare team; 96.06% (n = 366) felt safe with, and trusted, the nurses who looked after them and 97.3% (n = 371) of the participants were satisfied with the nursing care received during hospital admission.

We analyzed the correlation between patient-perceived quality of life and the variables in the PINC-H; we found no statistically significant differences (p > 0.05) or relationships between these variables.

Items with more than 15% of missing values were Q21: 'Did the nurse carry out other actions in order to reduce your pain, temperature, inflammation, nausea, (...) when the medication was not effective, or it was not possible to give you more medication? Can you describe them?' (32% of missing values), Q24: 'Was s/he responsible for coordinating the activities of other healthcare professionals (doctors, social workers, nurse auxiliaries, physiotherapists, porters, etc.) to ensure that you received the right care?' (16,18%) and Q30: 'Did the nurse attempt to maintain your privacy when giving you sensitive information?' (16,8%).

3.1. Construct validity

KMO and Barlett's test results showed that the data were suitable for exploratory factor analysis (EFA). Principal components analysis (PCA)

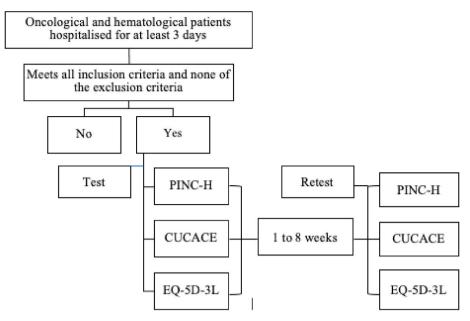


Fig. 3. Procedure of data collection.

Table 1 Participants' sociodemographic characteristics.

Characteristics % n 5 18-30 yrs 1.31 Age 31-40 yrs 14 3.67 41-50 yrs 57 14.96 51-60 yrs 30.18 115 61-70 yrs 122 32.02 68 17.84 \geq 71 yrs Sex Male 202 53.02 Female 179 46.98 Place of residence Urban 215 56.40 43.60 Rural 166 Hospitalisation Ward Oncology 121 31.76 Haematology 27 7.09 Other medical wards 65 17.06 Surgical wards 168 44.09 Length of stay 4-7 days 156 40 94 8-14 days 110 28.87 15-21 days 57 14.96 22-28 days 28 7.35 >29-90 days 30 7.87 Cancer type Digestive system 107 28.08 21.00 80 79 20.73 Lung Reproductive system 40 10.50 Head and neck 21 5.51 Blood and lymphatic system 6.04 Urinary system 16 4.20 Brain, bone and soft tissue 15 3.94 Clinical history Chronic diseases 202 53.02 Only acute diseases 179 46.98

generated 3 factors that explained 63% of the variance. After this analysis we concluded that 5 items should be removed from the PINC-H to improve the observed variance up to 64.1% (Tables 2 and 3). The first factor explains 24.0% of total variance and is called 'Caring for the person'. The second factor explains 21.6% of the total variance and is called 'Caring for the environment and the family' and the third factor explains 17.4% of the total variance and is called 'Caring presence'. The designation was based on the convergence between items included in each factor. The first factor includes aspects related to caring actions oriented directly to the patient, the second involves questions about the nursing care provided to improve the patient's environment during

Table 2
Distribution of Varimax rotation matrix and communalities

Items	Factor 1	Factor 2	Factor 3	Communality
Q6	.851			.599
Q31	.769			.651
Q25	.719			.580
Q12	.694			.629
Q5	.686			.662
Q18	.665			.606
Q16	.597			.647
Q22	.530			.493
Q29	.504			.590
Q27		.815		.691
Q23		.754		.700
Q26		.736		.460
Q24		.683		.598
Q28		.650		.615
Q21		.646		.487
Q20		.619		.727
Q30		.607		601
Q10		.544		.697
Q2			.852	.747
Q3			.775	.674
Q13			.706	.751
Q1			.690	.795
Q15			.687	.701
Q14			.661	.635
Q11			.530	.729
Q9			.513	.698
Percentage of explained variance	24%	21,6%	17,4%	

Table 3Items removed from PINC-H after Exploratory Factor Analysis.

Did the nurse respond promptly to your call?

Was the nurse happy to answer any questions that you may have had during your stay in hospital?

Did the nurse try to calm you by giving you the information that you needed at any given moment?

Did the nurse offer you a cup of tea or coffee, a juice, a magazine, etc., or did s/he ask you if you needed anything?

Did the nurse ensure that the room was comfortable in order to improve your comfort and rest?

hospitalisation and the actions performed to care for the families that accompany the patient. The last factor is related to the invisible nursing interventions that the nurse carries out in order to communicate to the patient their affective presence.

3.2. Criterion validity

The Criterion Validity Coefficient was highly significant (p < 0.001) with values within 0.63 and 0.71, which indicate that the dimensions of PINC-H are highly correlated with CUCACE (Table 4).

3.3. Reliability

Internal consistency was evaluated for the 31-item questionnaire and for each dimension separately. Cronbach's alpha for the total scale was 0.96, indicating a very high level of internal consistency. Independent consistency analyses were performed separately for the 3 dimensions (CI of 95%: 0.95-0.97) (Table 5). In addition, we calculated values based on all the items with each item removed; all of them were found to have good internal consistency.

Regarding temporal stability, in all the items correlation coefficients were highly significant (p < 0.001) and within range (0.532–0.811) with a mean value of 0.680. The correlation between first and second administration of the instrument and of each dimension separately were: Care for the person (0.84), Care for the environment and family (0.82), Caring Presence (0.86), and the complete questionnaire (0.89), indicating good temporal stability.

4. Discussion

This paper describes the design and psychometric properties of the PINC-H tool. This tool was designed to measure satisfaction with, and quantify, invisible care as perceived by oncology patients during hospitalisation.

We carefully analyzed the items with more than 15% of missing data and observed that they fell into one of the following categories: a) interventions which the patients did not observe during their hospital stay; for example, it is unlikely that patients would have been aware of nurses liaising with other healthcare professionals in order to coordinate patient care, due to these interventions being carried out outside of the patients' room and not always communicated to them, and b) interventions which were not needed by patients during their hospital stay due to their condition, such as preserving their dignity and offering complementary therapies when the medication prescribed did not produce the expected result.

With regard to the process of completion, all the questionnaires were completed by the participants after hospital discharge. We discarded the oncology ward as a suitable location for data collection in order to avoid social desirability bias, that is, participants responding in a way that is viewed favorably by others by either over-reporting good behavior or under-reporting bad or undesirable behavior. Previously identified eligible patients were invited to participate in the study when they

Table 4 Criterion validity coefficient. Correlation between PINC-H variables and gold standard dimensions.

R of Spearman Values (P-sig)		
CUCACE: Experience with nursing care	CUCACE: Satisfaction with nursing care	
663 (p < .001)	630 (p < .001)	
655 (p < .001)	635 (p < .001)	
709 (p > .001) 714 (p > .001)	667 (p > .001) 709 (p > .001)	
	CUCACE: Experience with nursing care 663 (p < .001) 655 (p < .001)	

Table 5 Dimensions and Cronbach's alpha of the PINC-H instrument for the total and by fac

Dimensions	Items	Cronbach's Alpha
Caring for the person	Was the nurse attentive and responsive	0.89
	to your needs, even after the situation	
	became less serious?	
	Do you think the nurse gave you the time that you needed?	
	Did the nurse tell you how to call in case	
	you needed anything or had a problem?	
	Did the nurse try to cheer you up when	
	you needed it?	
	Was the language used by the nurse to	
	talk to you easy to understand?	
	Was the nurse caring and attentive?	
	Was the nurse vigilant about your pain to	
	give you painkillers?	
	Did the nurse try to maintain your	
	dignity during washing, bathing and wound dressing?	
	Did the nurse know how act at all times?	
	Was the nurse kind to you during your	
	stay in hospital?	
Caring for the	Did the nurse provide moments and/or	0.90
environment and the	spaces to talk with you and/or your	
family	family about your concerns or your	
	questions about your disease?	
	Have you ever felt that the nurse was	
	trying to put herself or himself in your	
	shoes, in order to better understand your	
	personal situation?	
	Did the nurse keep you involved, asking	
	questions and listening to your opinion? (about your disease, your preferences,	
	your habits, etc.).	
	Did the nurse carry out other actions in	
	order to reduce your pain, temperature,	
	inflammation, nausea, () when the	
	medication was not effective, or it was	
	not possible to give you more	
	medication? Can you describe them?	
	Did the nurse teach you any guidelines	
	(how to take your medication, diet,	
	exercise, etc.) to prevent a relapse or to	
	self-manage your disease at home?	
	Was s/he responsible for coordinating the activities of other healthcare	
	professionals (doctors, social workers,	
	nurse auxiliaries, physiotherapists,	
	porters, etc.) to ensure that you received	
	the right care?	
	Did you think the nurse took her/his	
	own decisions to give you better care?	
	Did the nurse try to engage your	
	relatives in your care, teaching them the	
	necessary skills before you were	
	discharged from hospital?	
	Did the nurse take your relatives, and	
	their personal situation, into account	
	during your stay in hospital, also looking after them somehow?	
	Would you say that the nurse was honest	
	and sincere with you throughout your	
	disease process?	
	Did the nurse attempt to maintain your	
	privacy when giving you sensitive	
	information?	
Caring presence	Even if the nurse was not the usual staff	0.92
	nurse looking after you, did s/he show	
	her/his concern for your situation?	
	Did the nurse check on you, even if you	
	had not called her/him?	
	Did you feel accompanied by the nurse	
	during your hospital stay? Did the nurse sit next to you to talk?	

Table 5 (continued)

Dimensions	Items	Cronbach's Alpha
	Did you feel comforted when you needed	
	it?	
Cronbach's alpha -	Total scale	0.96

attended the Oncology Day Centre (ODC) to receive chemotherapy. The ODC was deemed as an appropriate location to complete the pack as it offers privacy and a relaxing atmosphere. Most of our patients elected to complete the questionnaire whilst receiving chemotherapy treatment in this unit, although they were given the option of taking them home with them and returning it a few days later. This strategy allowed us to have a better response rate (91.3%) than previous studies (Charalambous and Adamakidou, 2014; Thomas et al., 1996) whose reported response rate was 77% and 73% respectively. As proposed by Thomas et al. (1996), the questionnaires were distributed by persons different and independent from the nurses who had been responsible for the patients' care during their hospital admission.

The results suggest that PINC-H has an excellent reliability revealed by a high internal consistency, so none of the items needed to be removed from this version of the questionnaire. Compared with the internal consistency analysis of other questionnaires reviewed, The PINC-H questionnaire has the highest Cronbach alpha. Temporal stability, that guarantees that the results are trustworthy under similar conditions of application, indicated good temporal stability with non-statistically significant differences in scores between test-retest. Although there are few studies that have assessed temporal stability of their questionnaires, the PINC-H has similar results compared to those that have performed this kind of statistical analysis. QONCS correlation with no specified method was r=0.79 (Charalambous and Adamakidou, 2014; Rehnström et al., 2003; Romero-García et al., 2018; Thomas et al., 1996) and NICSS via ICC was 0.83 (Romero-García et al., 2018).

Construct validity is supported by results of the exploratory PCA. According to some authors, this should be performed with 150–200 participants and factor loading should be at least 0.45 (Hair et al., 2006). In this study, sample size was 381 and all the factor loadings were between 0.504 and 0.852, indicating appropriate construct validity. Three factors emerged from EFA, namely 'Caring for the person', 'Caring for the environment and the family' and 'Caring presence'. As no other questionnaires were found that focus on invisible nursing care, different factorial structures could not be compared.

Criterion validity using the Spanish version of the NSNS instrument was demonstrated; there was positive and high correlation in all the questions posed. Not many studies correlate their questionnaire with an existing one, furthermore, there is no agreement in the literature about the index that should be used to stablish this property (Streiner and Kottner, 2014). Only Romero et al. (2018) have measured factor correlation of the NICSS and the Consumer Emergency Care Satisfaction Scale (CECSS); they also found moderate to high correlation in most of the questions posed.

Overall, our findings provide support for the reliability of the instrument in a sample of patients at different disease stages and suffering from different types of cancer, including haematological. Therefore, we argue that this instrument is appropriate for use in this group of patients. Subsequent investigations should test the psychometric properties of the PINC-H in cancer outpatients and patients with other pathologies. Furthermore, the adaptation and validation of this questionnaire to other languages and cultures could contribute to increase our understanding of alternative ways of perceiving and performing nursing care.

In addition, regarding patients' perception, the level of trust and sense of safety with the nurses' care was rated as very high by our participants. Several authors have mentioned the importance of trust for optimal healthcare use (Ozawa and Sripad, 2013), for better patient outcomes (Dugan et al., 2005; Stolt et al., 2016) and for higher levels of

satisfaction with the system and care received (Zarei et al., 2014). According to Stolt et al. (2016), being cared for by "trusted professionals" is especially important for cancer patients due to the nature of cancer treatment.

5. Implications for practice

First and foremost, we believe that the PINC-H questionnaire has the potential to improve the quality of nursing care delivered to oncology patients and their families, and thus also increase patient satisfaction with the care received. Monitoring patients' satisfaction with the care they receive, along with details of their experiences of care, is now an accepted component of quality assurance (Berhane and Enquselassie, 2016). We believe that knowing which invisible nursing interventions are delivered and which are missed (or are not delivered as frequently as desired or expected) can contribute to identify those areas where care is suboptimal and to learn from where satisfaction has increased so that whatever is responsible can be adopted more widely. However, for this information to be acted upon, it is necessary to understand how it is shaped by patients' expectations of the care they will receive (Bowling et al., 2013). The more accurately and frequently patients' expectations are met, the higher the level of quality of care perceived and thus the higher the level of satisfaction with the care received. Furthermore, according to the World Health Organisation (WHO, 2016), allowing patients to evaluate the care received is a way to empower them and promote patient-centred care.

We argue that systematically measuring invisible nursing care delivered by nurses to patients with cancer will help to highlight a range of nursing interventions which are essential to achieve excellent patient care. According to Urcola-Pardo et al. (2017), "recognizing nurses" work content, form and function and the knowledge, skills and logic that underpin it" is vital to improve the quality of the service provided to patients and families. The information elicited from this tool will help nurse leaders and managers to monitor quality of care and impact on patient satisfaction (Hair et al., 2006). We believe that this information could be used to appraise, reorganise and improve the quality of nursing care, and could inform the development of new guidelines and protocols for the management of patients with cancer.

Using PINC-H to evaluate and measure a range of nursing interventions which might otherwise have remained unseen and, thus, undervalued, will help to bring them to light and promote them. We argue that this instrument can offer valuable information to nurse leaders and managers to not only evaluate the quality of nursing care but also measure workload and calculate adequate nurse-patient ratios. However, we wish to add a word of caution. It is possible that recent changes in the organisation and delivery of nursing care brought about by the global COVID-19 pandemic have an impact on future responses to the questionnaire items.

5.1. Limitations

We wish to draw attention to the fact that, although the PINC-H questionnaire was designed to measure the patients' perception of invisible nursing interventions during hospital stay, our participants were no longer inpatients when the tool was completed. We discarded the oncology ward as a suitable location for data collection in order to avoid social desirability bias. However, this resulted in a chronological gap between the patients' hospital stay and the time of completion of the questionnaire, which may have skewed the results due to the possibility of memory bias.

The mood and physical condition of cancer patients, as well as previous negative experiences during hospital admission, could have had an impact on the patients' willingness to participate (even though our acceptance rate is not suggestive of this). As in other studies about patient satisfaction, it is possible that unsatisfied patients did not complete the questionnaires (Romero-García et al., 2018).

Additionally, recall bias may be present in some participants despite having spent at least one week between test and retest, as data were collected not during hospital admission but after discharge from hospital.

Some authors explain that satisfaction and hospitalisation experience are determined by cultural and social issues (Romero-García et al., 2018). The PINC-H questionnaire was administered only to patients who were able to communicate in Spanish. Although both Spanish and international patients were included in the final sample, most of our participants were either Spanish or Latin-American, which means that the results may not be applicable to patients from different cultures.

Our sample size was estimated on 10 participants per item; however, a significant number of participants were withdrawn from the final validation sample due to missing values. This resulted in a slightly lower participant-item ratio (6.81:1) but we ensured that at least 200 participants answered all the items to conduct factor analysis as recommended in the literature (MacCallum et al., 1999).

Finally, the PINC-H questionnaire measures invisible nursing care as delivered by the nursing staff during a hospital admission. Therefore, differences in the way the individual nurses deliver nursing care could affect the participants' responses and, thus, affect generalization.

6. Conclusions

PINC-H is the first instrument to have been designed and validated with the exclusive purpose of measuring and evaluating invisible nursing interventions delivered by nurses to patients with cancer during hospital admission. This study has provided strong evidence for the reliability (internal and temporal stability) and construct and criterion validity of the PINC-H questionnaire so its use is recommended in a Spanish context. Further investigations are needed in order to develop an invisible nursing care theoretical model based on the dimensions suggested by EFA. Additional studies delving into the invisible nursing care domains, characteristics, circumstances and their impact on the health and recovery of patients are needed to strengthen the evidence of the relevance of invisible nursing care.

CRediT authorship contribution statement

Isabel Huércanos-Esparza: Conceptualization, Design of the study, Data curation, Methodology, Investigation, Validation, Data interpretation, Writing - original draft, Writing - review & editing. Isabel Antón-Solanas: Data interpretation, Visualization, Writing - review & editing. Aintzane Orkaizagirre-Gómara: Conceptualization, Data interpretation, Writing - review & editing. Enrique Ramón-Arbués: Visualization, Writing - review & editing. Concepción Germán-Bes: Conceptualization, Data interpretation, Supervision. Lourdes Jiménez-Navascués: Conceptualization, Data interpretation, Supervision.

Declaration of competing interest

The authors declare no conflict of interest, neither direct or indirect.

Acknowledgments

We thank the patients who took part in this study for their patience in completing the questionnaires. The authors wish to acknowledge the dedication and commitment of all the nurses, whose contribution enabled the conduction of this research.

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