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Level of uncertainty of caregivers towards the patient hospitalized pediatric

Nivel de incertidumbre de los cuidadores frente al paciente pediátrico hospitalizado

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Abstract

The hospitalisation of paediatric patients entails various psychological implications for their caregivers. The main objective of this study was to determine the degree of uncertainty experienced by caregivers of hospitalised children using the Parents test at the Instituto Ecuatoriano de Seguridad Social in Riobamba during the years 2021-2022. The research adopted a descriptive, prospective and cross-sectional approach, collecting data through the Parents test in relation to different variables. This test was applied to caregivers of paediatric patients hospitalised in the paediatric service of the IESS

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General Hospital. The results revealed that of the 110 surveys conducted, 0.9% of the respondents showed a low score (less than 55 points), 14.5% obtained a moderate score (between 56 and 85 points), and 84.5% obtained a high score (more than 85 points). It is concluded that there is a significant level of uncertainty among caregivers of hospitalised children, with 84.5% experiencing a high degree of uncertainty, followed by 14.5% with moderate uncertainty, and only 0.9% with a low level of uncertainty.
Key words: uncertainty, parents' test, hospitalised, illness, paediatric, patient

Resumen

La hospitalización de pacientes pediatricos conlleva diversas implicaciones psicológicas sus cuidadores. El objetivo principal de este estudio fue determinar el grado de incertidumbre experimentado por los cuidadores de niños hospitalizados, utilizando el test de Parents en el Instituto Ecuatoriano de Seguridad Social en Riobamba durante los años 2021-2022. La investigación adoptó un enfoque descriptivo, prospectivo y transversal, recolectando datos a través del test de Parents en relación con distintas variables. Se aplicó este test a cuidadores de pacientes pediátricos hospitalizados en el servicio de pediatría del Hospital General IESS. Los resultados revelaron que de las 110 encuestas realizadas, el 0.9% de los encuestados mostraron una puntuación baja (menos de 55 puntos), el 14.5% obtuvo una puntuación moderada (entre 56 y 85 puntos), y el 84.5% obtuvo una puntuación alta (más de 85 puntos). Se concluye que existe un nivel significativo de incertidumbre entre los cuidadores de niños hospitalizados, con un 84.5% experimentando un alto grado de incertidumbre, seguido de un 14.5% con una incertidumbre moderada, y solo un 0.9% con un bajo nivel de incertidumbre.
Palabras clave: incertidumbre, test de parents, hospitalizados, enfermedad, paciente
Pediátrico.

Introduction

Worldwide, illness and hospitalisation are situations known to provoke a high level of stress that impacts both the sick child and their close environment, triggering various emotional responses that make it difficult for parents to adapt and understand the illness, which represents a significant challenge for the child's well-being.

According to Contreras in 2017, hospitalisation has various implications in the psychological sphere of the parents of the sick child. One of the most difficult moments that parents face is receiving the diagnosis, especially if it is a chronic illness, which can generate an initial reaction of denial, characterised by disbelief in the diagnosis or prognosis. To help parents overcome this stage, it is essential to provide them with guidance on the most effective coping strategies to deal with their child's illness (Contreras & Sibri, 2017).

On the other hand, Suarez points out that one of the main emotional challenges faced by parents in this situation is uncertainty, which is defined as the inability to understand the meaning of events related to the illness. It is further described as a cognitive state that arises when individuals are unable to organise or understand events related to the disease and its treatment, which occurs especially in ambiguous, complex situations or when the available information is inconsistent. This uncertainty is experienced as a negative feeling that leads to emotional distress and negatively affects the psychosocial adjustment of both patients and their families. It is suggested that uncertainty in general, and that experienced by parents of sick and hospitalised children in particular, is characterised by four main dimensions: ambiguity in relation to the illness, unpredictability of the course and prognosis of the illness, lack of information about the illness, its treatment and the healthcare system, as well as complexity or lack of clarity in the information available (Suarez-Acuña et al., 2018).

The main objective of this research is to determine the level of uncertainty of parents or caregivers when faced with hospitalised paediatric patients, applying the parents' test in the Instituto Ecuatoriano Seguridad Social. Riobamba 2021-2022.

It is known worldwide that health is considered to be a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization (WHO), n. d.). Illness has an important psychological impact on parents and siblings of paediatric patients, and can interfere with their socio-emotional adjustment and health. The exposure of parents to the illness of a son or daughter has in some cases led to frequent crises of anxiety or depressive disorders.

Contreras conducted a study in Spain in 2017, which mentions that the phases of coping of parents with a diagnosis are characterised by denial and disbelief in the diagnosis or prognosis, in which the family can delay the course of the disease, as a result of which depression, anxiety, feelings of guilt, late treatment, increased hospital stay emerge, all of which can affect the family and the hospital environment (Contreras & Sibri, 2017).

In Ecuador, it is estimated that around 25% of children under the age of 18 have been hospitalised at least once in their lifetime. Between 10% to 37% of hospitalised children would present significant psychological disorders secondary to their hospitalisation. According to a study conducted by Villacís and Sandoval in SOLCA Cuenca-Ecuador in 2015, they found that families, upon learning of the diagnosis of cancer, begin a process of mourning, attributing the origin to hereditary factors and even religious punishments due to their belief system. During the process of observation and interviews with participants, the following emotions were identified in their body and verbal language: feelings of guilt, worry, anguish, sadness, helplessness, anxiety, nervousness, fear when a new evaluation has to be carried out, fear of possible death and despair (Contreras & Sibri, 2017).

Echeverria refers that depending on the diagnosis of acute or chronic illness in the child, it constitutes a stressful experience and represents an enormous burden of anguish and suffering for the family. The lack of studies and information on this topic led us to carry out this research, as it is essential in the field of health because it affects the family in its physical, social and emotional structure (Echeverria, 2017).

The lack of studies and information on this topic in Riobamba leads us to carry out this research, as it is essential in the field of health because it affects the family in its physical, social and emotional structure. We asked ourselves the following question: What is the level of uncertainty of parents or caregivers when faced with the illness of hospitalised paediatric patients?

Worldwide, it is evident that the coping stages of caregivers with a diagnosis are characterised by denial and disbelief of the prognosis, in which the family may delay the course of the disease, resulting in depression, anxiety, feelings of guilt, delayed treatment and increased hospital stay.

Nationally, it is estimated that around 25% of children have been hospitalised at least once in their lives, of which between 10% - 37% have psychological disorders secondary to their hospitalisation, in addition to family problems due to the inability to accept a diagnosis and subsequent treatment. The family situation is a fundamental concern in the health system in our country, which is why there is a need to create strategies to determine the level of uncertainty faced by parents or caregivers when their children are hospitalised.

The scale originally called Parents Perception Uncertainty in Illness Scale (PPUS) designed by Mishel (1983), includes 31 items distributed in 4 factors called ambiguity (13 items), lack of clarity (9 items), lack of information (5 items), and unpredictability (4 items). The range of scores oscillates between 31 and 155 given by a Likert-type response scale that varies between 1 and 5, indicating that the higher the score, the higher the level of uncertainty (Suarez-Acuña et al., 2018).

In the city of Riobamba, there has been no evidence of studies on the level of uncertainty that parents or caregivers have regarding the hospitalisation of their children; therefore, the purpose of this research is to identify the level of uncertainty of parents or caregivers regarding their children's illness, applying the parents' test in paediatric patients at the Hospital Instituto Ecuatoriano Seguridad Social. Riobamba 2021-2022.

Ramírez defines uncertainty as "a cognitive state in which people are not able to determine what the facts that occur due to the disease mean", which develops due to the lack of stimuli and information, which does not allow the individual to process the most relevant facts related to the disease in this case of a paediatric patient, which leads them to construct negative reactions (Ramírez-Perdomo et al., 2018).

The presence of a family member who may require special hospital care generates a stressful situation for the stability of the family nucleus, which affects its members, especially the main caregiver, who bears a greater emotional overload, which has a negative impact on their physical and psychological health (Alcántara-Canabal et al., 2019).

Uncertainty about the disease occurs when family caregivers are unable to determine the meaning of disease-related events due to lack of information about the disease, treatment and comorbidities. Several studies report high levels of uncertainty among caregivers of patients with cancer and other chronic and degenerative diseases.

Learning of the diagnosis of an incurable disease brings with it a restructuring of the caregiver's daily life, as he/she has to deal with basic aspects of patient care such as the management of signs and symptoms, which may change according to the evolution of the disease.

Several studies have shown the effect of uncertainty about the disease and how it relates to social support since the caregiver assumes the

care of their loved one, in addition to the relationship between the caregiver and the patient have constant changes since due to their own illness the patient changes their behaviours which can become harmful to the caregiver.

Given the complexity of this situation, tools are needed to help health professionals measure the level of uncertainty faced by caregivers when faced with the illness of their family members so that care actions can be taken to reduce the number of caregivers who experience high levels of uncertainty.

Therefore, an instrument proposed by Mishel, in its original version, which helps us to measure uncertainty taking into account 4 dimensions comprising: ambiguity, complexity, inconsistency and unpredictability, is applied. However, this scale does not focus on family caregivers of patients in palliative care, as in these cases caregivers face a different reality (Arias et al., 2019).

Suarez refers that the intention of the Parent's Perception Uncertainty in Illness Scale (PPUS) is to measure uncertainty in parents whose children are ill and/or hospitalised in acute or chronic care settings. Its original English version was designed by Mishel (1983) and has good usability and reliability. It has been used with parents of critically ill babies who need hospital treatment, premature babies, babies with leukaemia, cystic fibrosis and with various chronic diseases (Suarez-Acuña et al., 2018).

Since there is no Spanish version, it comes with good indicators of face validity, content and reliability with the original English version. In clinical practice and care management, this version of the scale will enhance the measurement of parental uncertainty in sick children, as a basis for the creation of multidisciplinary intervention strategies with direct or indirect modification of uncertainty and contribution to the institutional strengthening of policies to build quality health care (Suarez-Acuña et al., 2018).

The score range is from 31 to 155 and is determined by a Likert-type response scale, which varies from 1 to 5, indicating that the higher the score, the higher the level of uncertainty. This scale gives good indicators of overall validity and internal consistency, ranging between 0.81 and 0.93. Similarly, for the internal consistency of each component of the original scale, Cronbach's alpha of 0.87 for the ambiguity factor, 0.81 for the low clarity factor, 0.73 for the lack of information factor and 0.72 for the unpredictability factor. In addition, an internal consistency level of 0.90 was reported for the PPUS and a significant association was found in the so-called original version of the Disease Penetrance Scale ($p < 0.05$), one of the aspects that limit the assessment of parental uncertainty and therefore its use in practice and research in Spanish society, the aim of this study was to analyse the psychometric properties of the parental uncertainty perception scale/illness child form, translated into Spanish (Suarez-Acuña et al. , 2018).

Methodology

The type of research carried out was descriptive, prospective and cross-sectional with data obtained previously using the Parents test in relation to the different variables, through the application of surveys to caregivers of hospitalised patients from May 2021 to April 2022. Cross-sectional because it was carried out over a specific period of time. The purpose of the parents' test is to measure the uncertainty of caregivers in relation to children hospitalised for acute and chronic illnesses. Its original version was designed by Mishel (1983), in English. It has been used in parents of hospitalised critically ill children, premature children, children with leukaemia, cystic fibrosis (Suarez-Acuña et al., 2018).

The data used for this study were collected through surveys of caregivers of paediatric patients using the Parents test, in addition to other data on relationship to the patient, age, sex, level of education, economic situation of the respondent, number and days of hospitalisation of the paediatric patient; with which a database was

created in the Excel programme, which was then entered into the SPSS version 21 system for subsequent analysis.

The entire population of paediatric patients requiring hospitalisation who met the inclusion criteria was taken into account. A total of 350 patients were obtained, and subsequently the sample was calculated, taking into account mothers, fathers and carers, since when the surveys were carried out many of the paediatric patients were in the care of other relatives such as grandparents, aunts and uncles or siblings, obtaining a sample of 184 patients, but after accepting and signing the informed consent form, 110 people agreed to participate in the survey.

Results

Table 1. *Summary of socio-demographic variables of respondents*

Variable		n	%
Sex	Male	54	49.1
	Female	56	50.9
Relationship	Mother	50	45.5
	Father	54	49.1
	Grandparents	2	1.8
	Uncles	1	0.9
	Siblings	3	2.7
Age of respondent	<18 years old	4	3.6

	18-24 years old	9	8.2
	25-44 years old	60	54.5
	45-60 years	35	31.8
	>60 years	2	1.8
Education	Illiterate	1	0.9
	Primary	3	2.7
	Secondary	15	13.6
	Higher	91	82.7
Economic position	High	2	1.8
	Medium high	21	19.1
Variable	Lower middle	77	70
	Low	10	9.1

The main demographics of the respondents are detailed in table 1, the results of the Parents test indicate that 84.5% (n=93) of caregivers experience a high level of uncertainty about the hospitalisation of a child, 14.5% (n=16) have a moderate level of uncertainty and only 0.9% (n=1) have a low level of uncertainty.

Table 2. *Results of the parents' test: level of uncertainty*

	n	%
Low (<55 points)	1	0.9
Moderate (56 to 85 points)	16	14.5
High (>85 points)	93	84.5
Total	110	100

A bivariate analysis was performed in table 2, to establish relationships to the most common variables that exist during hospitalisation. When analysing the relationship between the level of uncertainty and the length of hospitalisation, it was determined that the highest percentage of caregivers with a high level of uncertainty had an average hospitalisation of 2 to 5 days (n=42) followed by those who maintained hospitalisations of 5 to 10 days (n=25).

A high level of uncertainty was found in patients with 2 to 4 hospitalisations (n=40), as well as in caregivers of hospitalised preschoolers (n=36).

In relation to the sex of the respondent, the only one who presented a low level of uncertainty was the male, a moderate level was found equally in both sexes, 8 males and 8 females, while a high level predominated in the female sex (n=48) versus the male sex (n=45).

When establishing the relationship between the moderate level of uncertainty and kinship, it is similar when referring to the mother (n=8)

and father (n=8), while a high level of uncertainty is predominant in the father (n=45) compared to the mother (n=42).

Another variable of analysis was to identify the relationship between socio-economic status and the level of uncertainty, where it was found that a high level of uncertainty predominates in the lower middle socio-economic status (n=67).

It can be distinguished that caregivers with a higher level of education have a higher level of uncertainty (n=79) compared to the low and medium levels. Although the most significant relationships have been exposed after the respective statistical analysis, there are no statistically significant relationships.

Table 3. *Summary of the bivariate analysis between the level of uncertainty that parents have about the hospitalisation of their children by means of surveys.*

VARIABLE	STATISTICAL TEST	VARIABLE	STATISTICAL TEST	VARIABLE	STATISTICAL TEST
Days of hospitalisation		RATIONALE	11,286		p=0,080
Number of hospitalisations	CHI person square	There is a relationship between the length of paediatric patient hospitalisation and the uncertainty generated in parents.	6,005		p=0,43
Age of patient	CHI person square	There is a relationship between the	5,47		p=0,706

		number of hospitalisations of paediatric patients and the uncertainty generated in parents.		
Sex of respondent	CHI person square		1,061	p=0,588
Relationship to paediatric patient	CHI person square	The age of the patient influences the degree of parental uncertainty.	2,166	p=0,976
Economic status	CHI person square	A certain gender may be related to a certain level of uncertainty.	5,465	p=0,486
Level of education	CHI person square	Family relationship is related to an increase in the level of uncertainty that arises	5,544	p=0,476

	during a patient's hospitalisation.

In a study carried out by Gudelia Nájera Gutiérrez in 2010, which analysed the level of uncertainty in parents of children with cancer, the sample consisted of 30 parents of children with cancer, the biological personal factors were taken into account, the age that stood out was between 30 and 40 years with an average of 38 years, 63% corresponded to the female sex in terms of the socio-cultural personal factors, the marital status of the participating parents was 84% with a partner, The socio-economic level with more relevance was the middle level with 70%, taking into account the formal education 58% had primary education and finally if they had a family member with cancer 34% said no, these data described is consistent with those presented in this research since 54.5% of respondents were in an age between 25 to 44 years, 50. In terms of level of education, 82.7% were of higher education. Regarding the economic situation, 70% have a medium-low economic level.

According to Nájera and collaborators in the relationship with the study variables of both hypotheses Pearson correlations were used, in the age variable there is no relationship for the existence or not of uncertainty with a p= .023, with respect to sex the female refers high uncertainty p= .010, with respect to the years of formal education a negative correlation of p= -. 025, which means that the more schooling the less uncertainty, with respect to socioeconomic level, it was observed that there is no difference in the socioeconomic level for uncertainty to exist with a p= .523, with respect to the variable social support, it was observed that the more social support the less uncertainty with a p= .008 (Najera et al., 2011).

In the relationship between the variables presented in this research carried out in the paediatric service of the General Hospital IESS in Riobamba, Ecuador, it is evident that the variable patient age is not related to a high level of uncertainty with a p = 0.706, with respect to the sex of the respondent it is not related to a high level of uncertainty with a p = 0.588, 588, since regardless of sex the level of uncertainty is high, with regard to the relationship to the paediatric patient,

grandparents, uncles, aunts and brothers have a high level of uncertainty with a p=0.976, with regard to the economic level we have that a high economic situation produces a higher degree of uncertainty with a p=0.486. With regard to the level of education, it was found that illiterate people and primary education have a high level of uncertainty with a p=0.476, with regard to the length of hospitalisation, those who remain hospitalised for one day generate a high level of uncertainty with a p=0.080, and taking into account the number of hospitalisations with only one hospitalisation that the paediatric patient presents, the parent or carer has a high level of uncertainty with a p=0.43, which despite being striking data are not statistically significant compared to those mentioned by other authors.

According to Matziou, parent-participants in the study reported less pain than their children. The results of suitable studies show that parents, with a percentage of 63%, believe that the pain experienced by their children during their hospital stay is what affects them most emotionally. However, other studies report that parents ignore or overestimate their children's pain. The main cause of this is limited knowledge about the ways in which they can help their child and avoid the overprotective resource that brings with it some intrafamily problems that make communication between parents and children difficult and produce conflicts even with health professionals (Matziou et al., 2016).

According to Matziou's study, parents underestimate children's pain when they present acute pain. The parents' quality of life is affected, especially when the pain reported by the child is caused by life-threatening diseases such as cancer. However, the hope for improvement taking into account the treatment of their children, the care of health professionals and seeing their children's improvement every day makes the level of uncertainty decrease considerably (Matziou et al., 2016).

Conclusions

84.5% of the 110 respondents showed a high level of uncertainty (mean: 102.4 points) while only 0.9% showed a low level of uncertainty. Different socio-demographic variables were analysed to find if there is a relationship with the caregivers' level of uncertainty

about the child's hospitalisation. Caregivers who experienced a high level of uncertainty were related to the following variables:

An average hospitalisation of 2-5 days for the child. Predominantly caregivers of patients with 2-4 hospitalisations. Within age, caregivers of hospitalised preschoolers had a high level of uncertainty as well as predominance of the father over the mother.

A high level of uncertainty predominates in the lower middle socio-economic level. Caregivers with a higher level of education have a high level of uncertainty compared to the lower and middle level.

These relationships are not statistically significant $p>0.05$, so it can be concluded that the level of uncertainty is independent of the mentioned relationships.

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