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PERCEIVED UNCERTAINTY IN PATIENTS WITH HEART FAILURE IN THE EXPECTATION OF HEART TRANSPLANTATION IN A HIGH-COMPLEXITY CLINIC IN COLOMBIA

JUAN PABLO CERÓN LUBO[1], WENDY JOHANA GÓMEZ DOMÍNGUEZ[2], HILDA EVELIA PRIAS VANEGAS[3]
[1]CANDIDATO A DOCTOR EN ENFERMERÍA, UNIVERSIDAD DE ANTIOQUIA. MAGÍSTER EN ENFERMERÍA.
ENFERMERO CLÍNICO, FUNDACIÓN VALLE DEL LILI, CALI, COLOMBIA.
UNIVERSIDAD DEL VALLE, CALI, COLOMBIA.
juan.pablo.ceron@correounivalle.edu.co
[2]CANDIDATA A DOCTORA EN ENFERMERÍA, UNIVERSIDAD DE ANTIOQUIA. MAGÍSTER EN ENFERMERÍA.
UNIVERSIDAD DE SUCRE, COLOMBIA
wendy.gomez@unisucre.edu.co
[3]ESPECIALISTA EN ENFERMERÍA EN SALUD MENTAL
UNIVERSIDAD DE SUCRE, COLOMBIA
hilda.prias@unisucre.edu.co

Summary

The phenomenon of uncertainty in the face of the disease acquires special relevance in patients with heart failure who are waiting for a heart transplant, constituting a critical dimension for the comprehensive approach to their care. This study aimed to describe the level of uncertainty perceived by patients diagnosed with heart failure classified as having advanced functional stages, within a highly complex clinic in the city of Cali, Colombia. A quantitative, descriptive and cross-sectional approach was adopted, guided by the theory of uncertainty in the face of disease proposed by Merle Mishel. The sample consisted of 45 patients selected for convenience, who answered the Uncertainty Scale against the Disease validated for the Colombian context. The results showed that 100% of the participants presented a high level of uncertainty regarding heart transplantation, particularly in the dimensions related to stimulus frames, cognitive abilities and perceived sources of structure. This high uncertainty is associated with clinical factors such as the presence of ischemic and valvular heart disease, as well as the advanced stage of its functional condition (NYHA IV, stage D). The findings underscore the urgent need to design intervention strategies from nursing that allow identifying, evaluating, and mitigating the levels of uncertainty in this population, favoring more adaptive coping processes and improving quality of life while waiting for the transplant procedure.

Keywords: Uncertainty, heart failure, heart transplantation, nursing care, chronic diseases

INTRODUCTION

Heart failure (CH) is one of the chronic non-communicable diseases with the greatest impact on global public health, not only because of its growing prevalence, but also because of the emotional, functional and economic burden it imposes on patients and their families. It is estimated that, in countries such as Colombia, around 1.1 million people suffer from this condition, which represents a prevalence of close to 2.3% in the adult population (Ministry of Health and Social Protection, 2013). This figure, although already significant, tends to increase in parallel with the aging population, the persistence of risky habits such as sedentary lifestyles, poor nutrition and chronic stress, and the increase in cardiovascular diseases, directly responsible for 48% of deaths from chronic diseases in the country. Advanced heart failure—in NYHA functional stages III and IV or ACC/AHA C and D classifications—implies a progressive deterioration of functional capacity, greater clinical vulnerability, and a guarded prognosis, which makes heart transplantation (CT) one of the few therapeutic alternatives with the potential to modify the natural course of the disease.

However, transplantation not only involves a medical challenge, but also presents itself as a highly uncertain situation for the patient. Official statistics show that, in Colombia, the number of patients on the waiting list for heart transplants has fluctuated significantly. While in 2014 there were 27 active people on the waiting list, by 2015 the number decreased to 20, reflecting both the shortage of donors and the high mortality in the waiting period (Ministry of Health and Social Protection, 2015). The impact of this uncertainty is not minor: it is a subjective phenomenon that affects the way in which the patient interprets their disease, makes decisions and relates to their environment. For those living with end-stage CF, waiting for an organ is intertwined with the possibility of radical improvement, but also with the fear of death, dependence, physical suffering, and ambiguity of outcomes. These tensions can generate emotional, cognitive, and behavioral alterations that compromise their quality of life and adherence to treatment, even before the procedure occurs.

In the context of heart transplantation, addressing uncertainty from nursing practice is not only pertinent, but necessary. This experience, far from depending solely on clinical severity, is influenced by multiple factors that include the patient's educational level, access to understandable information, clarity in the communication of the prognosis, and the type of support received from the health team. Various studies have shown that people with limited schooling, low income, and little familiarity with medical language tend to report higher levels of uncertainty. This situation, in turn, impacts their ability to adequately follow therapeutic indications, make informed decisions about their self-care, and project their situation into the future (Mishel, 1988; Gómez, Castillo & Alvis, 2015). Added to this panorama is the complexity of the health system, where the high turnover of personnel in specialized services makes it difficult to build continuous and meaningful bonds of trust. Faced with this scenario, it is urgent to implement strategies that allow the systematic identification of the levels of perceived uncertainty in patients with advanced heart failure, in order to design educational and emotional interventions that contribute to strengthening their coping capacities during this critical stage.

Within the field of nursing, uncertainty has been recognized as a central dimension in the experience of becoming ill, especially in complex clinical situations. One of the most prominent references on this subject is Merle Mishel, who in the 1980s formulated a theory that, to this day, continues to guide research and care practices. According to his approach, uncertainty arises when a person is unable to clearly interpret what is happening with their health. This difficulty is usually related to the ambiguity of the diagnosis, the absence of precise information or the impossibility of predicting with certainty what will happen later (Mishel, 1988).

The innovative thing about this theoretical proposal is that it transcends the rational or cognitive perspective of the phenomenon. Mishel states that uncertainty is also experienced from the emotional and existential aspects, especially when the patient faces uncertain prognoses, prolonged treatments or outcomes that could be fatal. In the case of those who suffer from advanced heart failure, this feeling becomes a constant presence that runs through the day to day. Clinical instability, frequent hospital admissions, the gradual loss of autonomy and the growing need for support from the health system make up a scenario where uncertainty is not only present, but intensifies as a structural part of their experience.

The theory developed by Mishel organizes uncertainty around three major dimensions. The first is stimulus frames, which refer to how events linked to the disease trigger interpretative processes. The second is cognitive abilities, understood as the patient's ability to understand and process the information they receive. The third dimension refers to the perceived structures, that is, to the resources – both informative and relational – available to make sense of the situation experienced. When any of these three aspects is altered, the patient is more likely to experience a sense of mental and emotional disorganization, which hinders their ability to make active decisions and maintain commitment to their health care (Mishel, 1990). From this perspective, Mishel's model distances itself from conventional medical views focused solely on the biological, and proposes a broader approach, which places at the center the subjective experience of the patient, his or her adaptation process, and the way in which he or she constructs meaning from his or her clinical experience.

Several studies have shown that high levels of uncertainty are associated with depressive symptoms, anxiety, sleep dysfunction, minor cognitive alterations, and difficulties in adherence to treatment (Bailey et al., 2019; Thorne, 2006). In the case of patients waiting for heart transplants, uncertainty acquires an existential connotation, as it is intertwined with the fear of dying before receiving the organ, ambiguity regarding the results of the procedure, the perception of institutional dependence, and the loss of control over their own biography. This situation is especially complex in contexts such as Colombia, where waiting lists are long, donors are scarce, and administrative processes are lengthy and non-transparent (Ministry of Health, 2020). In addition, many patients come from vulnerable socioeconomic backgrounds, with a low level of education and limited access to reliable information, which decreases their cognitive abilities to properly interpret their situation, increasing the feeling of vulnerability and learned helplessness.

The review of the literature in the field of nursing clearly shows that the clinical management of uncertainty cannot be limited only to general emotional accompaniment. On the other hand, the application of specific evaluation, intervention and follow-up strategies that respond to the particularities of each patient is required. Fawole et al. (2018) highlight that nurses, due to their constant proximity to patients, are in a key position to recognize early signs of uncertainty. These can manifest themselves in the form of repetitive questions, difficulty understanding or following directions, avoidance of conversations about the future, or signs of discomfort that are expressed without words. Faced with these signs, it is possible to deploy specific actions that help reduce the perception of ambiguity and increase the feeling of control.

Among the most effective strategies is the clear and organized delivery of information, adapted to each patient's level of understanding. It is also essential to create safe spaces for dialogue, where the patient can express their doubts, fears and expectations. The role of the nurse as a mediator between the medical team and the patient is especially valuable in this process, as it allows clarifying technical messages and contributing to the construction of a shared understanding of the clinical situation. Likewise, promoting personal coping skills – through education, emotional support and constant accompaniment – strengthens the patient's autonomy and improves their well-being.

In fact, recent studies have shown that person-centered care models, when they explicitly include the dimension of uncertainty, generate a positive impact on the perception of quality of life of those living with advanced chronic diseases (Kazer et al., 2011; Gómez et al., 2015). This evidence underscores the need to assume uncertainty not only as a psychological phenomenon, but as an essential component of clinical care, which needs to be addressed systematically and ethically within the therapeutic process.

Therefore, the use of Mishel's theoretical model in this study not only provides a solid conceptual framework for understanding the subjective experience of patients with heart failure awaiting transplantation, but also allows for culturally relevant, emotionally empathetic, and clinically effective care interventions. Recognizing uncertainty not as an isolated symptom, but as a transversal phenomenon that impacts the patient's ability to adapt, implies a transformation in the care paradigm, which ceases to be solely biomedical to assume a holistic and integrative view, in accordance with the ethical and scientific principles of the nursing profession.

METHODOLOGY

The present study adopted a quantitative, descriptive approach with a cross-sectional design, aimed at characterizing the level of uncertainty perceived by patients diagnosed with heart failure (HR) in advanced functional stages, who were on the waiting list for heart transplantation in a highly complex institution in the city of Cali, Colombia. The choice of a cross-sectional design allowed for a punctual evaluation of the phenomenon of interest, capturing the subjective experience of the participants at a specific moment in the clinical process. The study was based on the epistemological foundations of the positivist paradigm, with emphasis on the objective measurement of psychosocial variables using standardized instruments and descriptive statistical analysis. The work was developed under the theoretical orientation of the uncertainty model in the face of the disease proposed by Merle Mishel, which allowed structuring both the operationalization of the construct and the interpretation of the results.

The study population was made up of adult patients, with a confirmed diagnosis of heart failure, who were formally registered on the active waiting list for heart transplantation at the aforementioned institution. The sample was selected through non-probabilistic convenience sampling, with a total of 45 participants who met the inclusion criteria: being over 18 years of age, being lucid and clinically fit to answer the questionnaire autonomously, having been diagnosed with FC in NYHA functional stage III or IV, and being officially registered on the waiting list. Patients with compromised state of consciousness, evident cognitive impairment, or presence of psychiatric comorbidities that interfered with their ability to understand and respond to the instrument were excluded from the study. The sample was approached between the months of September and October 2022, in the cardiovascular hospitalization services of the institution.

The Merle Mishel Disease Uncertainty Scale, validated for the Colombian context by Gómez, Castillo, and Alvis (2015), was used to collect the information. This scale consists of 33 items distributed in three dimensions: stimulus frameworks, cognitive abilities and perceived structure. Each item is evaluated using a five-point Likert scale (1 = never; 5 = always), allowing an overall score and subscales that reflect the degree of uncertainty experienced by the patient to be obtained. Data were collected through individual interviews conducted by the principal investigator in hospital rooms, ensuring an environment of privacy and comfort for the participant. The average application time was 25 minutes per person. Previously, the purpose of the study was explained to each participant and their written informed consent was obtained, in accordance with the ethical principles of the Declaration of Helsinki (World Medical Association, 2013).

Data processing was performed using IBM SPSS Statistics version 26 software. Descriptive statistics were used for the analysis of frequencies, percentages and measures of central tendency, according to the nature of the variables. The levels of uncertainty were categorized into three ranges: low (values between 33–77), medium (78–123), and high (124–165), according to the criteria established in previous studies with this scale. Likewise, a sociodemographic and clinical characterization of the participants was carried out based on variables such as age, sex, etiological diagnosis of heart failure, time on the waiting list and educational level.

This study was approved by the Ethics Committee of the Valle del Lili Clinic Foundation, through Minute No. 225 of June 15, 2018, and classified as research with minimal risk, in accordance with Resolution 8430 of 1993 of the Ministry of Health of Colombia. In all phases of the study, the principles of autonomy, beneficence, non-maleficence and justice were respected, and the confidentiality of personal data was ensured through the anonymised encryption of records and their storage in password-protected databases.

RESULTS

Statistical data

Table 1

Sociodemographic characteristics of participants (n = 45)

Variable	Category	Frequency (n)	Percentage (%)
Sex	Male	31	68.9 %
	Female	14	31.1 %
Age (years)	41 – 50	11	24.4 %
	51 – 60	22	48.9 %
	61 – 70	12	26.7 %
Educational level	Primary or no schooling	15	33.3 %
	Incomplete secondary school	10	22.3 %
	Completed secondary school	13	28.8 %
	Technical or university	7	15.6 %
Marital status	Married or common-law union	29	64.4 %
	Single, separated, or widowed	16	35.6 %

Table 2

Clinical characteristics of the participants (n = 45)

Variable	Category	Frequency (n)	Percentage (%)
Diagnosis of CF	Ischemic cardiomyopathy	21	46.7 %
	Valvular cardiomyopathy	9	20.0 %
	Dilated cardiomyopathy	8	17.8 %
	Others (HTN, congenital, etc.)	7	15.5 %
NYHA Rating	Class IV	45	100.0 %
Waiting List Time	1 – 5 months	18	40.0 %
	6 – 10 months	16	35.6 %
	11 – 14 months	11	24.4 %

Table 3

Levels of perceived uncertainty by dimensions of the Mishel scale (n = 45)

Dimension evaluated	Response category	Frequency (n)	Percentage (%)
Total Level	High uncertainty (124–165 points)	45	100.0 %
	Medium or low uncertainty	0	0.0 %
Stimulus Frameworks	Frequent disorientation	43	95.5 %
	Occasional disorientation	2	4.5 %
Cognitive abilities	Difficulty interpreting information	40	88.9 %
	Partial understanding with gaps	5	11.1 %
Perceived structure	Perceives poor clarity and consistency	41	91.1 %
	Perceives moderate information structure	4	8.9 %

The sample consisted of 45 patients diagnosed with heart failure in advanced functional stages, all registered on the waiting list for heart transplantation in a highly complex clinic in southwestern Colombia. Regarding sociodemographic characteristics, it was identified that 68.9% of the participants were men (n = 31), while 31.1% corresponded to women (n = 14). The average age was 56.6 years, with a range between 41 and 70 years. 55.6% of the patients had a basic level of education (incomplete primary or secondary education), while only 15.6% had reached technical or university studies, which reflects a low level of general schooling. In relation to marital status, 64.4% were married or living in a common-law union, while the rest were single, widowed or separated (see Table 1).

In clinical terms, the predominant etiological diagnosis was ischemic cardiomyopathy, present in 46.7% of cases, followed by valvular cardiomyopathy (20.0%), dilated cardiomyopathy (17.8%), and other causes such as severe hypertension or congenital heart disease (15.5%) (see Table 2). All patients were classified as NYHA functional stage IV (100%), which denotes severe physical limitation and the presence of symptoms at rest. The average time on the waiting list was 6.4 months, with a range ranging from 1 to 14 months. Notably, none of the patients had been hospitalized in intensive care units at the time of the interview, but all were receiving advanced pharmacological treatment for the management of heart failure, including diuretics, beta-blockers, and ACE inhibitors.

In relation to the main variable of the study—the level of perceived uncertainty—the results obtained from the Mishel's Disease Uncertainty Scale showed that 100% of the participants had a high level of uncertainty (total score between 124 and 165), with no cases recorded in the medium or low uncertainty ranges (see Table 3). This finding was consistent across all dimensions assessed by the instrument. In the stimulus frames subscale, 95.5% of patients reported feeling disoriented regarding the evolution of their disease and future procedures, while the remaining 4.5% expressed occasional but not persistent confusion. Regarding cognitive abilities, 88.9% of the participants expressed difficulties in interpreting the medical information received, while 11.1% reported partially understanding the indications, although with important gaps. Finally, in the dimension of perceived structure, 91.1% reported perceiving little clarity in communication with the medical team and lack of consistency in the explanations provided.

These results reflect a generalized pattern of high uncertainty among the patients evaluated, suggesting that, beyond objective clinical conditions, there is a subjective perception of ambiguity, unpredictability, and information insufficiency that affects the experience of the transplant waiting process. The finding of a high uncertainty score in 100% of patients represents an important wake-up call for care teams, particularly for nursing staff, given their privileged role in clinical communication and emotional support. In addition, the predominance of low levels of schooling and highly complex diagnoses contributes to aggravating this perception, indicating the need for interventions adapted to the sociodemographic and educational profile of the population served.

Relationship of the results with the theory

Next, a conceptual representation adapted from the Uncertainty Theory of Disease proposed by Merle Mishel (1981, 1988) is made, applied to the clinical context of patients with heart failure in advanced stages awaiting a heart transplant. This clinical situation is characterized by a high emotional load, prolonged uncertainty, and multiple contextual factors that affect the patient's coping with the chronic disease.

Mishel states that uncertainty is a cognitive experience that emerges when people are unable to structure or categorize the meanings of disease-related events, which occurs more frequently when the available information is ambiguous, complex, or contradictory, or when the individual's cognitive abilities are limited (Mishel, 1988). In the case of heart failure patients on the transplant waiting list, these elements are manifested through changing symptoms, lack of understanding about the treatment, and communication barriers derived from technical language or educational level, which is framed within the "stimulus framework" and "cognitive abilities" according to the theory.

In addition, sources of structure (such as family support, health system affiliation, and relationship with the care team) can act as moderators of uncertainty, facilitating adaptation or, in its absence, exacerbating the risk of uncertainty becoming a threat. This coincides with recent research that highlights the role of social support and effective communication as mediators of the psychological impact on patients waiting for transplantation

The model also takes up an update of the theory of Mishel (1990), who proposes that uncertainty can have two trajectories: one oriented towards risk or "danger" when there is no adaptive coping, or one seen as an opportunity for personal growth, resilience and emotional preparation for the procedure, if adequate structural resources and psychoeducational support are available. In this context, adaptation becomes the critical bridge to transplantation, not only as a clinical event, but as a vital transition process.

Thus, this model provides an integrative understanding of the phenomenon of uncertainty, highlighting the urgency of nursing interventions that proactively address cognitive, informational, and structural factors. Early identification of high levels of uncertainty should guide patient-centred support and education strategies, so as to promote informed decision-making and adherence to treatment while waiting for the donor organ. Figure 1.

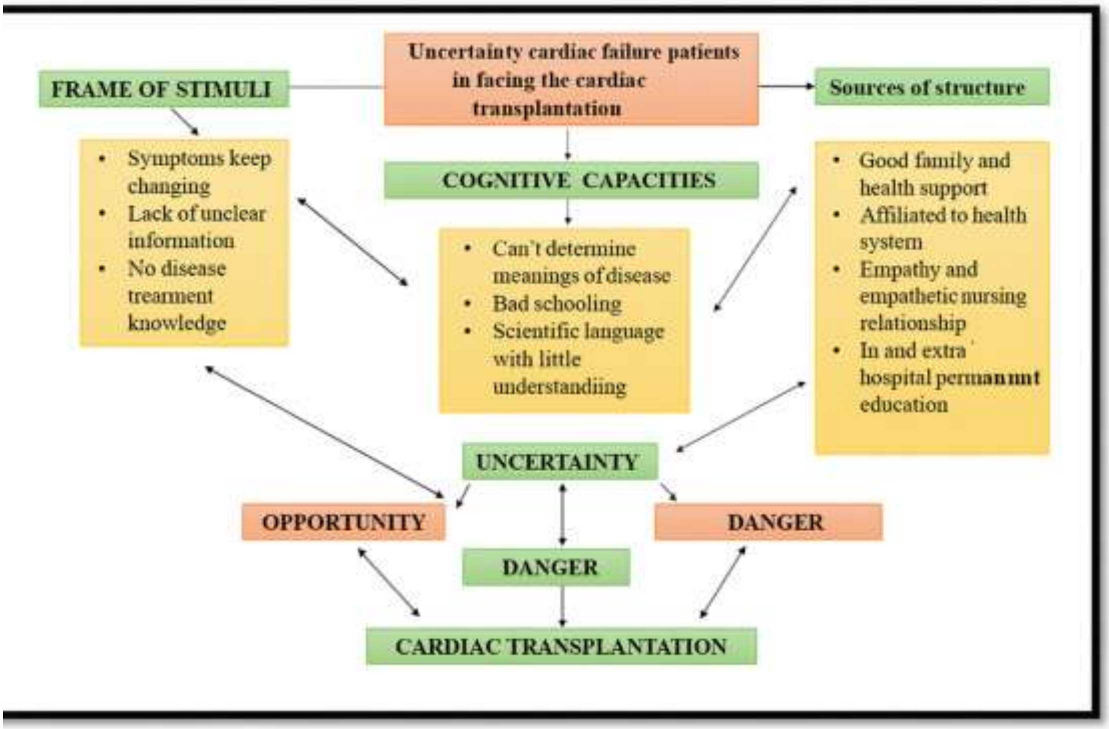

Figure 1 Articulation of the theory of uncertainty in the face of disease with the results of research

DISCUSSION

The results obtained in this study show that 100% of patients with heart failure in an advanced functional stage, registered on the waiting list for heart transplantation, experience high levels of uncertainty, both in the general perception and in each of the dimensions evaluated. This finding, due to its forcefulness, not only confirms the presence of the phenomenon proposed in the objectives of the study, but also reaffirms the central propositions of the theory of uncertainty in the face of the disease developed by Mishel (1988), who argues that the lack of information structure, the ambiguity of the symptoms and the low capacity for interpretation on the part of the patient are key factors that intensify uncertainty and compromise its coping adaptive. All of the patients were in NYHA functional class IV, a condition that by itself implies severe physical limitations, persistent symptoms at rest and a high degree of dependence on the health system, which exacerbates the feeling of vulnerability in the face of the course of the disease.

In the dimension of the stimulus frameworks, most of the participants expressed constant disorientation regarding the evolution of their disease, the criteria for transplantation and the real possibility of receiving the organ. This experience coincides with what was stated by Bailey et al. (2019), who point out that, in patients with advanced chronic diseases, ambiguity in the clinical course and lack of clarity about the waiting time generate a perception of lack of control that intensifies emotional suffering. The fact that patients perceive the course of their disease as unpredictable and that they are unable to identify specific signs that indicate progress or deterioration favors the establishment of catastrophic thoughts, anticipatory anxiety and difficulties in making decisions related to their care. The absence of objective benchmarks and the variability in institutional response times further aggravate this perception of uncertainty, which makes it necessary to establish clearer and more continuous information protocols during hospitalization.

Regarding cognitive abilities, a significant proportion of participants expressed difficulties in understanding the medical information received, a phenomenon that could be related to the low educational level predominant in the sample, as well as to the technical complexity of the clinical language used in specialized services. As Thorne (2006) and Fawole et al. (2018) point out, the way in which information is transmitted has a decisive influence on patients' interpretation of their condition. When the language used is excessively technical, ambiguous or contradictory, a process of confusion is activated that reduces the patient's capacity for informed participation and, therefore, their sense of control. In this study, many of the patients reported not understanding the criteria for organ allocation, the status of the waiting list, or the risks associated with the procedure, which fuels not only uncertainty, but also a sense of exclusion in the decision-making processes about their own treatment.

In the dimension of perceived structure, participants repeatedly pointed out the lack of consistency and clarity in communication with the health team. This data reinforces the importance of the role of nursing staff in generating trust and meaning in the midst of a highly technical clinical environment. As Gómez et al. (2015) explain, when nursing professionals become stable communicative referents, capable of translating medical language, contextualizing procedures, and emotionally containing the patient, a significant reduction in perceived uncertainty and an improvement in coping are achieved. High staff turnover, fragmentation of care, and limited patient participation in clinical discussions are elements that, although not new, continue to negatively affect the hospital experience of those going through critical processes such as heart transplantation.

Overall, the results of this study highlight the urgency of designing nursing interventions aimed at mitigating the levels of uncertainty in patients with end-stage heart failure. These interventions should include effective communication strategies, systematic emotional accompaniment, progressive education about the disease and institutional processes, as well as the strengthening of spaces for dialogue between patient and multidisciplinary team. It is important to note that uncertainty, if not addressed in a timely manner, can lead to hopelessness, deterioration of therapeutic adherence and emotional abandonment of the transplant process, even before it occurs. In this sense, the formal incorporation of the assessment of uncertainty as a relevant clinical variable should be considered within the care protocols in advanced heart failure units.

CONCLUSIONS

This study found that all the patients included —people with a diagnosis of advanced heart failure on the waiting list for transplant in a high-complexity institution in Colombia— experience high levels of uncertainty. This condition manifests itself both in a general way and in each of the dimensions evaluated through the Mishel scale. Beyond being a clinical fact, this finding reflects a complex reality that affects the way patients understand their health status, face their prognosis and actively participate in decisions about their treatment. Uncertainty, as a subjective experience traversed by ambiguity, lack of clarity and difficulty in anticipating the course of the disease, is configured as a profound obstacle to achieving adaptive coping. In this context, Mishel's theoretical model is especially relevant, since it allows us to interpret how people give meaning to their experience in the midst of clinical scenarios loaded with emotional tension and unpredictability.

The data obtained support that the three key components of the theory—stimulus frameworks, cognitive abilities, and perceived structures—show impairment in this group of patients. The course of the disease is usually marked by unexpected episodes and frequent hospitalizations, which aggravates the feeling of instability. In addition, the limited educational level of many participants makes it difficult to fully understand medical information, while the communication offered by the care team is, in several cases, fragmented or insufficient. This set of factors configures an environment of high vulnerability that intensifies emotional distress, reduces adherence to treatments and negatively affects quality of life while waiting for transplantation. These results make visible the urgency of promoting more comprehensive care practices that not only respond to biological needs, but also address the emotional, relational, and cognitive components of the disease process.

From the perspective of nursing care, the role of the professional acquires an even more significant dimension: it is the one who accompanies, contains, guides and helps to resignify the experience of the disease. Early recognition of uncertainty, systematic assessment using reliable instruments, and the design of interventions focused on the particularities of each patient should be a structural part of the care plan. In this line, it is proposed to strengthen the continuous training of health personnel in aspects such as therapeutic communication, emotion management and patient education. Similarly, it is key to incorporate formal spaces for guidance for patients and relatives during hospital stays, as a strategy to reduce the emotional impact of uncertainty.

Finally, the convenience of including uncertainty as a clinical indicator within the institutional protocols that regulate the care of people with advanced heart failure is raised. In addition, it is recommended to develop future research that allows the sample to be expanded, comparisons to be made between transplant patients and those who do not have access to transplantation, and even to evaluate the effectiveness of psychoeducational interventions designed to reduce levels of uncertainty. Only in this way will it be possible to move towards a truly humane model of care, which accompanies with sensitivity, rigor and ethical commitment those who are going through one of the most complex stages of the life cycle.

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