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# Enfermería

–Nursing Research and Education–



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# Influence of the COVID-19 Pandemic in Higher Education Courses in the Health Field

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Editorial



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It is a fact that no one expected what took place in the world as of the end of 2019. And yes, I am talking about the ill-fated, damned and inconvenient COVID-19, which quickly spread around the globe, having been declared a pandemic by the World Health Organization in March 2020.<sup>(1)</sup> In the face of such a threat, not virtual, but very real, the need existed to undertake various measures that could interrupt the transmission of the infection by implementing, for example, restrictions on the movement of people, social distancing, use of personal protective equipment, measures of respiratory protocol, social confinement, among others.<sup>(2)</sup>

Education, namely, higher education, also suffered immensely the consequences of COVID-19, right from the start, because there was a cessation of all classroom teaching activity, practically all over

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the world, which caused major modifications/alterations in the teaching-learning process.<sup>(3)</sup> From the outset, closing of Higher Education Institutions, globally, caused severe changes in teaching-learning processes because measures of social distancing and circulation restrictions were imposed.<sup>(4,5)</sup>

Teaching has, provisionally, become – we hope – remote learning, supported by digital platforms. The need emerged to invest in e-learning platforms and teacher training. However, several important questions arose, such as: were the platforms used for remote learning adequate and safe, and did students have the appropriate technological means at their disposal, in terms of internet access and computer equipment.<sup>(6,7)</sup> No doubt, students and teachers have had to adapt to the new reality of education: the transition from face-to-face to remote learning. However, the following question can be raised: were teachers trained for remote learning, both in terms of technological skills and in terms of teaching-learning strategies?<sup>(8)</sup>

Since March 2020, classrooms throughout the globe, engaged in remote learning and some Higher Education Institutions opted for mixed education, that is, theoretical classes in remote learning and practical classes in the classroom. Health students saw their clinical internships/teaching interrupted with clear consequences in the teaching-learning process. “Incoming” and “outcoming” mobility was also severely affected.<sup>(9)</sup>

The isolation of students, with the consequent lack of social interaction, had effects on stress and anxiety levels,<sup>(10)</sup> and caused some fear, in the students, of not completing the courses.<sup>(11)</sup> A major concern arises and may arise, quite naturally, did Higher Education Institutions care about their students, their needs and the teaching-learning process? The answer to this question deserves careful attention and studies at a global level. And to identify the problems/constraints that the COVID-19 pandemic causes/caused in the teaching-learning process to students attending master’s courses in health, the best way to know

this is to ask the interested parties directly what happened, what problems existed, and what needs were present.

In view of this challenge, and to highlight the relevance of the influence of the COVID-19 pandemic in higher education courses in health, an exploratory and transversal study was conducted with students, in the 2020/2021 academic year, from five courses (Master’s in Community Nursing, Master’s in Nursing for People in Critical Situation, Master’s in Gerontology: Physical Activity and Health in the Elderly, Master’s in Health Services Management, and Master’s in Biomedical Engineering), seeking to know the opinion of Master’s students from courses in the health area on the teaching-learning process during the COVID-19 pandemic.

Data collection took place in February 2021, at a University in northern Portugal, using a self-completed questionnaire created on Google Docs, where data anonymity and confidentiality was ensured and its completion was voluntary. The questionnaire was answered by 58 students, 75.9% female and 24.1% male, with a mean age of 33.6 years and a minimum of 21 years and a maximum of 52 years. Regarding their employment situation, 72.4% of the students were working. A total of 37.9% of the students reported feeling constraints that interfered with the frequency of the course. Among the constraints mentioned, they highlight the accumulation of hours at work, making it impossible to attend all classes, constant changes in work scales and overtime due to the pandemic, physical and mental wear, and difficulty in reconciling work, classes, and family life.

When students were asked if professors provided support documents to conduct the curriculum, 55.2% reported a high/very high satisfaction. As for the feedback professors provide regarding the work used in the evaluation, 53.4% of the students reported medium/low satisfaction. Regarding the adequacy of the required workload and schedule for each curricular unit, 62.1% of students reported medium/low satisfaction. As



per student motivation, on the part of professors, for the frequency of curricular units, 53.5% reported medium/low satisfaction. With respect to the adequacy of the curricular units' evaluation processes to the context of the COVID-19 pandemic, 55.2% of the students reported medium/low satisfaction.

We also wanted to know, and taking into account the teaching-learning process, amid the COVID-19 pandemic, aspects that students considered as most negative. Of the most negative aspects mentioned by the students, we highlight the following: the classes and assessments are "online", lack of practical classes, huge workload to be delivered in very short deadlines, lack of conviviality, interaction, and socialization with

colleagues and professors, lack of understanding by professors with students who worked on the COVID-19 front lines and the little flexibility by some professors to adapt syllabus, ways of teaching, and assessment methods.

It is quite evident, in the aforementioned, that the COVID-19 pandemic caused/causes several constraints in students attending master's degrees in health and that it is necessary to minimize/eliminate them. And here the role of Higher Education Institutions and, in particular, teachers is fundamental and indispensable for the adequacy of the teaching-learning process, so that the most vulnerable students are not further unprotected and social and economic inequalities are not intensified.

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# Cost-effective Evaluation of an Educational Intervention based on Multiple Intelligences Versus Traditional Care to Improve Exclusive Breastfeeding in Mothers' Clubs in Peru

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Original article



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## Cost-effective Evaluation of an Educational Intervention based on Multiple Intelligences Versus Traditional Care to Improve Exclusive Breastfeeding in Mothers' Clubs in Peru

### Abstract

**Objective.** This work sought to evaluate the cost-effectiveness of two educational interventions to improve exclusive maternal breastfeeding in mothers' clubs in Peru.

**Methods.** This is a retrospective, longitudinal descriptive study, which reviewed 113 information registries of mothers participating in a traditional educational intervention and 104 mothers with intervention based on multiple intelligences, evaluating the level of knowledge and exclusive maternal breastfeeding practices through observation visits. **Results.** The intervention based on multiple intelligences achieved greater cost-effectiveness than the traditional intervention given that with lower investment, it managed to get 56.73% of the mothers to increase their knowledge and 68.27% to practice exclusive

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maternal breastfeeding from six months to more months in comparison with the traditional intervention in which 41.59% and 43.36% improved, respectively. Moreover, for its effective application, on every 100 mothers, its investment would result lower than the traditional program. **Conclusion.** Upon applying satisfactorily the cost-effectiveness evaluation, as model to compare educational interventions on exclusive maternal breastfeeding, better results were determined with the intervention based on multiple intelligences compared with the traditional intervention, given that with lower investment, it was possible to benefit a greater number of mothers in their level of knowledge and practices of maternal breastfeeding.

**Descriptors:** breast feeding; health education; mothers; cost-benefit analysis; knowledge

## Evaluación de la costo-efectividad de una intervención educativa basada en inteligencias múltiples versus atención tradicional para mejorar la lactancia materna exclusiva en clubes de madres en Perú

### Resumen

**Objetivo.** Evaluar el costo-efectividad de dos intervenciones educativas para mejorar la lactancia materna exclusiva en clubes de madres en Perú. **Métodos.** Es un estudio descriptivo, retrospectivo y longitudinal. Se hizo revisión de 113 registros de información de madres participantes de una intervención educativa tradicional y 104 madres con intervención basada en inteligencias múltiples, evaluando el nivel de conocimiento y las prácticas de lactancia materna exclusiva mediante visitas de observación. **Resultados.** La intervención basada en inteligencias múltiples consiguió mayor costo-efectividad que la intervención tradicional debido a que, con menor inversión, se logró que el 56.73% de las madres incrementaran sus conocimientos y el 68.27% practicaran lactancia materna exclusiva de seis a más meses en comparación a la intervención tradicional en la cual el 41.59% y 43.36% mejoraran respectivamente. Además, para su aplicación efectiva, sobre cada cien madres, su inversión resultaría menor que el programa tradicional. **Conclusión.** Al aplicar satisfactoriamente la evaluación costo-efectividad como modelo para la comparación de intervenciones educativas sobre lactancia materna exclusiva, se determinaron mejores resultados con la intervención basada en inteligencias múltiples en

comparación con la intervención tradicional, pues, con una menor inversión, se logró beneficiar a una mayor cantidad de madres en su nivel de conocimientos y prácticas de lactancia materna.

**Descriptor:** lactancia materna; educación en salud; madres; análisis costo-beneficio; conocimiento.

## **Avaliação do custo-efetividade de uma intervenção educativa baseada em inteligências múltiplas versus atenção tradicional para melhorar a amamentação materna exclusiva em clubes de mães no Peru**

### **Resumo**

**Objetivo.** Avaliar o custo-efetividade de duas intervenções educacionais para melhorar o aleitamento materno exclusivo em clubes de mães no Peru. **Métodos.** Estudo descritivo, retrospectivo e longitudinal, baseado na revisão de 113 fichas de informações de mães participantes de uma intervenção educativa tradicional e 104 mães com uma intervenção baseada em inteligências múltiplas, avaliando o nível de conhecimentos e práticas da amamentação exclusiva por meio de visitas de observação. **Resultados.** A intervenção baseada em múltiplas inteligências obteve maior custo-efetividade do que a intervenção tradicional, pois com menor investimento conseguiu que 56.73% das mães aumentassem seus conhecimentos e 68.27% praticasse o aleitamento materno exclusivo por 6 meses ou mais, em comparação com a intervenção tradicional em que 41.59% e 43.36% melhoraram respectivamente; além disso, para sua aplicação efetiva a cada cem mães, seu investimento seria inferior ao do programa tradicional. **Conclusão.** Ao aplicar com sucesso a avaliação de custo-efetividade como modelo de comparação de intervenções educativas em aleitamento materno exclusivo, foram determinados melhores resultados a favor da intervenção baseada em múltiplas inteligências, em comparação à intervenção tradicional, constatando que, com menor investimento, A maior número de mães foi beneficiado em seu nível de conhecimento e práticas de amamentação.

**Descritores:** aleitamento materno; educação em saúde; mães; análise custo-benefício; conhecimento.

# Introduction

Exclusive breastfeeding (EB) provides the natural, essential, and energy nutritional requirements needed by human beings during their first months of life.<sup>(1)</sup> Its consumption during the six months after birth guarantees optimal effectiveness to assimilate its multiple benefits that last during the following years of life.<sup>(2,3)</sup> Exclusive breastfeeding constitutes a priority in public health because, besides favoring the child's growth and healthy development, it provides immunological protection, thus, reducing the risk of having infectious diseases and preventing conditions of malnutrition.<sup>(4)</sup> The benefits for the mother imply enhancing the affective and protective bond of their child, in addition to diminishing the risk of breast and ovarian cancer, post-partum hemorrhage, osteoporosis, and cardiovascular diseases.<sup>(5)</sup> Further, the impact on the economy is positive, becoming a savings by eliminating the use of complementary feeding and avoiding health costs due to possible causes of infant morbidity and mortality in all socioeconomic levels.<sup>(6)</sup>

In spite of seeking multiple benefits, some factors, like inadequate knowledge and practices, socio-economic aspects, difficulties in producing milk, rejection by the child, mother's concerns, and health problems, could influence on early abandonment of EB.<sup>(7)</sup> The social factors associated with EB correspond to the young age of the pregnant women and to aspects regarding the composition, ontogenesis, integrality, and family functionality, while the cultural factors are related with customs and beliefs of the immediate environment. In that sense, family beliefs sometimes operate as cultural barriers.<sup>(3,8)</sup> In this respect, beliefs like "breastfeeding weakens the mother", "EB is insufficient to satisfy the child's hunger", "it should be replaced by the infant formula bottle to better control the child's feeding", "breastfeeding damages the mother's bodily image", besides other erroneous ideas,<sup>(1,9)</sup> evidence and justify the need to implement educational interventions that promote maternal breastfeeding. Precisely, prior experiences have managed to prove their contribution. Researchers, like Hernández *et al.*,<sup>(10)</sup> were able to increase the level of knowledge and attitudes of a group of adolescents from Tenerife, demonstrating the effectiveness of an educational intervention on MB based on talks, videos, information leaflets, stories, and role playing. In another experience, Rojas *et al.*,<sup>(11)</sup> implemented educational workshops for pregnant women and mothers of children under two years of age in Venezuela, reporting a significant increase of their knowledge on themes of maternal breastfeeding. While Márquez *et al.*,<sup>(12)</sup> after applying the educational program "breastfeed me mommy" to a group of mothers of children under six months of age from Trujillo in Peru, reached significant effectiveness in the level of knowledge with respect to EB.

Although it is true that these experiences, as well as other similar experiences, have achieved favorable results, comparing intervention and control groups, the

contribution of the current study lies in applying the evaluative approach of cost-effectiveness used in other disciplinary areas. According to its procedure, said evaluation is determined in function of the cost per unit benefitted, so that it permits projecting how much investment is needed to achieve greater effectiveness on a group of participants that should benefit from a preventive health intervention.<sup>(13)</sup> Thus, it is proposed as a valid experience to compare different EB promotion programs, which must consider baseline measurements, as well as control and follow up to identify strengths and weaknesses in timely manner and, thus, achieve higher effectiveness indices. This initiative seeks to benefit those responsible for designing, managing, developing, and evaluating prevention interventions in the field of nursing, socializing the scope of the research with competent authorities from the health sector and encouraging the possibility of consolidating public policies that promote a culture of preventive health in favor of EB. Regarding these considerations, the aim of the study corresponded to evaluating the cost-effectiveness of two educational interventions to improve exclusive breastfeeding in mothers' clubs from Pimentel in Perú.

## Methods

A study was conducted with descriptive, retrospective and longitudinal design, based on the cost-effectiveness evaluation of two educational interventions on maternal breastfeeding, applied in 2018, with follow up in 2019, which required reviewing registries of knowledge and practices of MB obtained from two groups of pregnant women from the mothers' clubs in the locality of Pimentel in Chiclayo, Lambayeque (Peru). The population was comprised of 217 registries of information from pregnant women who attended mothers' clubs in four communal associations, distributed into 59 from the association "Los Jardines" and

54 from "Villa del Mar", which participated in an educational intervention with the traditional methodology. In addition, the study had access to 55 registries of pregnant women from the association "Virgen de Fátima" and 49 from "Perla del Pacífico", who participated in the educational intervention with the methodology based on multiple intelligences. Given that these were accessible amounts, the sample was represented by the entire study population.

In accordance with the selection criteria, the study included registries on knowledge and practices of MB from pregnant women from low socio-economic level who had no diseases that meant a risk for their health and that of the child, besides considering registries that were legible and with the required information for their control and follow up. Likewise, the study excluded registries whose evaluators did not undergo a prior calibration process, dispensing with registries of pregnant women who participated simultaneously in other training on maternal breastfeeding or who, at the moment of their evaluation and follow up, did not have an informed consent or that of their parents or legal guardians in case they were minors.

The information registries corresponded to a questionnaire on knowledge and a sheet for practical observation on MB. The questionnaire was used in previous studies, verifying its validation through expert judgment, a pilot test, and statistical reliability with Cronbach's alpha coefficient ( $\alpha = 0.86$ ). This had 12 questions, each with five response options and a score of 1 was assigned for every correct item and 0 for each wrong answer, so that the level of knowledge was categorized as deficient (0 - 3 points), regular (4 - 6), good (7 - 9), and excellent (10 - 12). The practical observation sheet gathered information with respect to time of EB, verification of the technique used, and observation of any inconvenience that hindered the practice of EB. In addition, it was corroborated that the team of three nurses who conducted the surveys had passed satisfactorily through a prior calibration process ( $k = 0.81$ ). A simple instrument was



also used in which information was transcribed regarding the investment costs of both educational interventions, number of participants from both groups of pregnant women, and the dates of starting and ending the information registries.

Specifically, for the cost-effectiveness evaluation, it was necessary to divide the investment cost of each of the two educational interventions into the number of mothers who improved their knowledge and practices of EB in each group, so that it was possible to obtain the cost per unit benefited. This comparison permitted knowing which of the interventions required less investment to achieve a greater number of beneficiary mothers, which

permits deciding between two health programs with different educational methodologies if greater preventive effectiveness were sought on a target population with the most productive use of resources. Gathering of information with respect to knowledge and practices of EB required three moments: a baseline registry and of immediate results conducted between April and July of 2018 and, then the follow-up registry between April and July of 2019, that is, one year after having applied the interventions. These were carried out in 2018 by three nurses previously trained by an expert instructor on traditional educational methodologies and on multiple intelligences, whose characteristics are described in Table 1.

**Table 1. Comparison of the educational interventions with traditional and constructivist approaches to promote maternal breastfeeding**

Comparison criteria	Traditional educational intervention	Intervention based on multiple intelligences
Facilitators from each educational intervention.	Team of three trained nurses from Universidad Señor de Sipán.	Team of three trained nurses from Universidad Señor de Sipán
Time of applicability of each educational intervention.	10 sessions (between April and July of 2018).	10 sessions (between April and July of 2018).
Hours per session	Between 2 and 3 hours.	Between 2 and 3 hours.
Place of implementation.	Mothers' clubs from the communal associations "Los Jardines" and "Villa del Mar".	Mothers' clubs from the associations "Virgen de Fátima" and "Perla del Pacífico".
Population benefited	113 pregnant women in 2018 (mothers in 2019).	104 pregnant women in 2018 (mothers in 2019).
Content of the interventions	EB: benefits. Nutritional contributions. Duration and frequency. Conservation and storage. Technique and correct position for breastfeeding. Importance of the mother-child bond and interaction. Signs of adequate suction. Problems associated with breastfeeding.	EB: Benefits. Nutritional contributions. Duration and frequency. Conservation and storage. Technique and correct position for breastfeeding. Importance of the mother-child bond and interaction. Signs of adequate suction. Problems associated with breastfeeding.
Educational materials	Leaflets, flip charts, videos, posters, brochures, mockups, whiteboard and markers of passive and static application.	Recycled materials that facilitated active participation with group, playful, and experiential dynamics.

**Table 1. Comparison of the educational interventions with traditional and constructivist approaches to promote maternal breastfeeding (Cont)**

Comparison criteria	Traditional educational intervention	Intervention based on multiple intelligences
Methodology	The active role was performed by the facilitators with educational and conversation-type demonstrative sessions in which the pregnant women listened, observed, and repeated the messages. Formulation of questions to verify that participants can repeat and memorize the messages from the educational sessions. Use of massive-type audio-visual educational material to propitiate individual responses.	The active role was performed by the pregnant women with dynamic educational and experiential sessions in which the mothers interacted actively. Formulation of questions to recover prior knowledge, verifying that they have found their own meaning of the messages. Use of dynamic, personalized and ludic material to propitiate group and individual dynamics.
Technique and collection instrument	Information registered through survey with validated questionnaire and sheet for practical observation of EB.	Information registered through survey with validated questionnaire and sheet for practical observation of EB.
Evaluation, control and follow up	Baseline evaluation (pretest), immediate evaluation and follow-up evaluation (post-test).	Baseline evaluation (pretest), immediate evaluation and follow-up evaluation (post-test).
Cost of investment	USD \$765	USD \$605

The traditional methodology is that which has been widely disseminated in the “Technical guide for advisory on maternal breastfeeding”, elaborated by the Health Promotion Direction of the Peruvian Ministry of Health.<sup>(14)</sup> The multiple intelligences methodology is based on the theory by Howard

Gardner, who held that human intelligence is not limited to their intellectual capacity, but to a set of abilities and skills organized into eight types of intelligences. Table 2 shows the activities performed within the framework of this methodology.

**Table 2. Activities conducted during the educational intervention based on multiple intelligences**

Multiple intelligences	Activities conducted
Linguistic-verbal intelligence	Stories, riddles, acrostics and popular sayings were elaborated related with the EB practice, healthy eating, and importance of pregnancy control. Oral interventions, debates, exchange of opinions, expositions and questions to verify their progress were also encouraged.
Musical intelligence	Songs were created by changing the lyrics of known songs, adapting them to EB promotion. Healthy eating and periodic visits to pregnancy control were promoted. Besides organizing and carrying out educational activities with respect to an artistic musical show with song and dance alluding to EB promotion.
Logical-mathematical intelligence	The mothers were asked to participate in practical exercises that propitiated the calculation of time and frequency of EB, besides making a list of healthy foods organized according to the nutritional content, size of ration, cost, and access to establishment where these are sold. Se les asked, additionally, to follow the practical and logical order of EB and to organize probable dates for their follow up and control.
Bodily-kinesthetic intelligence	Simulations were made with the technique and logical sequence of EB, controlled by the nursing staff and supervised by the expert instructor. Participants recognized the safe settings and services where they can carry out EB and engage in controlled physical activity. Activities were conducted, like simple Taiichi competitions and games alluding to EB.
Intrapersonal intelligence	Reflection on the importance of evaluating the child's health and their own and analyzing how they would feel after their EB practices, propitiating the affective bond with their child. They commented how they felt every time they attend medical controls and assumed the commitment to continue and respect health care.
Interpersonal intelligence	Helping each other to improve their simulated technique of EB. Groups were created to solve situations posed by the instructor, related with health care during pregnancy. Through games and dynamics, they appraised teamwork and recognized the importance of the family's participation to achieve healthy behaviors.
Visual-spatial intelligence	Comparison of healthy foods with foods harmful for their condition as pregnant women. The study verified and recorded the types of foods sold in the establishments and near to their immediate environment. Identification of settings to engage in physical activities as part of their healthy lifestyles.
Naturalistic intelligence	Dynamics were carried out to promote and propitiate safe and healthy environments to practice EB. Analysis was made of the importance of consuming natural foods (water, proteins, fruits and vegetables) rather than artificial and processed foods.

With regards to bioethical principles, the research complies with the Helsinki International Declaration, besides adhering to the guidelines of the Code of Ethics for Research by the Vice-rectory of Research at Universidad Señor de Sipán, approved through Directory Resolution N°199 –

2019 / PD – USS, having been a requirement that the women participating in the study had granted their corresponding signed informed consent. The Kolmogorov-Smirnov test was applied in the data processing to demonstrate compliance of the assumption of normality in the data distribution.

The cost-effectiveness evaluation used simple descriptive statistics calculations, like sums, averages, and percentages, based on the ratio of investment costs and the effectiveness reached according with the number of mothers benefitted with better MB knowledge and practices. With the purpose in mind, the Wilcoxon test was used for the before and after comparison with respect to the level of knowledge in each group. Thereafter, the analysis included the comparison of both groups through the Mann-Whitney U test, using 95% confidence interval. The data processing used the SPSS program version 22.

## Results

According with the information registries obtained from the mothers' clubs from the Communal

Associations in Pimentel, 11 were excluded because they were minors whose parents refused the informed consent, selecting 217 information registries of pregnant women. Table 3 shows the distribution of the women in the study according with their stage of life at the moment of the pregnancy, identifying that 48.67% of the pregnant women were adolescents and 51.33% of the pregnant women were adults who participated in the group of educational intervention with traditional methodology in comparison with 47.12% of the pregnant women in adolescent stage and 52.88% of the adult pregnant women from the group of intervention based on multiple intelligences. Moreover, according to their experience as mothers, it was evidenced that, in both educational intervention groups, there were primiparous mothers in higher percentage than women who mothers for the second or more times.

**Table 3. Distribution of mothers participating in both educational interventions according to the life stage as pregnant women and experience as mothers**

Life stage of the pregnant woman	Experience as mothers											
	Traditional intervention (n = 113)						Intervention with Multiple intelligences (n = 104)					
	Primiparous		For a second time		3 to more times		Primiparous		For a second time		3 to more times	
	n	%	n	%	n	%	n	%	n	%	n	%
Early adolescence	7	6.19	0	0	0	0	8	7.69	0	0	0	0
Medium adolescence	11	9.73	2	1.77	0	0	9	8.65	0	0	0	0
Late adolescence	28	24.78	7	6.19	0	0	22	21.15	9	8.65	1	0.96
Young adult	22	19.47	17	15.04	4	3.54	19	18.27	21	20.19	2	1.92
Medium adult	5	4.42	4	3.54	3	2.65	4	3.85	5	4.81	2	1.92
Mature adult	0	0	1	0.88	2	1.77	0	0.00	1	0.96	1	0.96

Regarding mothers who benefitted in increasing their level of knowledge with respect to MB, Table 4 shows that mothers with a good level went from

4.8% to 30.8% after the intervention with multiple intelligence in comparison with the traditional group that went from 6.2% to 23%, while those

who achieved excellence level were 11.5% from the first group and 5.3% from the second. After the paired analysis, it was concluded that mothers who benefitted, going from good to excellent level, from regular to good, and from deficient to regular, corresponded to 47 from the traditional group and

59 from the group with MI; finding significant difference according to the Mann Whitney U test ( $p = 0.002$ ). Additionally, upon determining the difference of 41.5% (47/113) versus 56.7% (59/104), it was possible to obtain ( $p = 0.0019$ ), confirming statistical significance.

**Table 4. Knowledge of maternal breastfeeding by mothers before and after their participation in both educational interventions**

Level of knowledge	Experience as mothers							
	Traditional intervention ( <i>n</i> = 113)				Intervention with multiple intelligences ( <i>n</i> = 104)			
	Pretest		Post-test		Pretest		Post-test	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Deficient	59	52.2	12	10.6	62	59.6	3	2.9
Regular	47	41.6	69	61.1	37	35.6	57	54.8
Good	7	6.2	26	23.0	5	4.8	32	30.8
Excellent	0	0	6	5.3	0	0	12	11.5
Total	113	100	113	100	104	100	104	100
Median	3		4		3		5	
Mean	3.67		5.27		3.5		6.07	
Wilcoxon	$p < 0.0001$				$p < 0.0001$			
Benefitted	47				59			
Mann Whitney U	$p = 0.384$ (pretest)				$p = 0.002$ (post-test)			
	No difference between intervention groups				Significant difference between intervention groups			

Kolmogorov Smirnov = <0.0001 (no normal distribution in any case)

Regarding the mothers who benefitted with the best MB practices, Table 5 evidences that 68.27% of the mothers who participated in the intervention with multiple intelligences practiced EB from six to more months in comparison with 43.36% of the group with traditional intervention, finding a higher percentage of mothers with MB interrupted prior to six months in the latter group.

Additionally, from this table it may be determined that 63.46% of the mothers in the group with multiple intelligences reached an optimal MB technique against 38.05% in the traditional group. Difficulties that propitiated interrupting EB, in both groups, were unfavorable family environment and, more frequently, job conditions and mothers' poor nutrition.

**Table 5. Maternal breastfeeding practices after the mothers participated in the educational interventions**

MB practices	Groups of pregnant women			
	Traditional intervention		Intervention with MI	
	<i>n</i>	%	<i>n</i>	%
Duration of MB				
Interrupted between 1 and 3 months	7	6.19	4	3.85
Interrupted between 3 and 6 months	57	50.44	29	27.88
Up to 6 months	49	43.36	71	68.27
MB technique				
Insufficient	11	9.73	7	6.73
Regular	59	52.21	31	29.81
Optimal	43	38.05	66	63.46
Difficulties for MB				
Mother's poor nutrition	14	12.39	2	1.92
Unfavorable family environment	23	20.35	11	10.58
Job condition	11	9.73	13	12.50
None	65	57.52	78	75.00

With respect to the cost-effectiveness evaluation, Table 6 shows that with an investment of USD \$605 for a group of women with the intervention based on multiple intelligences, although lower than the USD \$765 for the cost of the traditional intervention, a greater number of mothers was benefitted: 59 women increased their level of knowledge and 71 demonstrated EB practices of six to more months compared with the 47 mothers who increased their knowledge and 49 who improved their practices with the traditional intervention.

With respect to the level of knowledge, it is evidenced that with intervention using MI, when dividing its investment cost between the number of

mothers benefitting, cost per unit of USD \$10.25 was obtained, so that if effectiveness were sought in 100 mothers, the investment would have to be USD \$1025, that is, a lower investment than with the traditional intervention, which would cost USD \$1628 to benefit the same number of mothers: thus, needing an additional USD \$603 to obtain effectiveness achieved by the other program. The results of cost-effectiveness with respect to EB practices also indicated an advantage in favor of the beneficiaries of care based on multiple intelligences upon having determined that to intervene 100 mothers, the investment cost of USD \$852 would be lower than the USD \$1561 needed by the traditional program, requiring an additional USD \$709.

**Table 6. Cost-effectiveness valued in US Dollars in both educational interventions to promote MB knowledge and practices**

Educational interventions	Total cost of interventions	Proportion of mothers benefitted	Cost- effectiveness per unit benefitted	Cost-effective-ness for 100 mothers
Traditional intervention	\$ 765			
Knowledge		47 (41.59% of 113)	\$ 16.28	\$ 1628
MB practices		49 (43.36% of 113)	\$ 15.61	\$ 1561
MI intervention	\$ 605			
Knowledge		59 (56.73% of 104)	\$ 10.25	\$ 1025
MB practices		71 (68.27% of 104)	\$ 8.52	\$ 852

It must be indicated that the favorable cost-effectiveness results for the intervention with multiple intelligences are not due to greater investment, but to a more effective ratio of the investment cost with respect to the higher number of mothers benefitted.

## Discussion

In accordance with that estimated by the Pan-American Health Organization (PAHO) and the World Health Organization (WHO),<sup>(2,15)</sup> EB practices could save each year approximately 220 000 lives around the world due to the antibodies it contains and which protect the infants from frequent diseases during childhood. Madrid *et al.*,<sup>(5)</sup> indicate that its consumption contributes to diminishing the risk of having diarrheic and respiratory diseases, as well as asthma, type-I diabetes, sudden death, high blood pressure, and leukemia. Studies by Oyarzún *et al.*,<sup>(16)</sup> found association between antecedent of inconclusive MB and obesity and metabolic syndrome in school-age children. In another research, Binda *et al.*,<sup>(17)</sup> report that interrupting EB delays the child’s psychomotor and cognitive development. This reality becomes worrisome when the POHA<sup>(15)</sup> reveals that in

the Region of the Americas only 38% of infants receive EB for up to six months.

The Direction of Health Promotion of the Peruvian Ministry of Health<sup>(14, 18)</sup> reports that the EB practice is far below the values considered optimal by the WHO; for this reason, in 2017 the commission of experts from the Ministry of Health<sup>(14)</sup> elaborated the “Technical guide for advisory on maternal breastfeeding” for the purpose of establishing the conceptual, methodological, and instrumental criteria to conduct the advisory on MB that propitiates the exercise of the right of mothers to breastfeed their children for up to two years of age or more. The recommendations in this technical guide, as well as those established in studies by Pérez and Valdés<sup>(19)</sup> and Ortega,<sup>(20)</sup> are based on MB being considered a behavior susceptible to being learned, so that it is necessary to provide to the mothers training settings, given that by still being in a vulnerable stage, they require physical and emotional guidance with optimal support from the health system and the family environment. Within this context, experiences and investigations are widely justified with respect to EB promotion.

Regarding the results obtained in this work, participation is evidenced of nearly 50% of pregnant women in adolescent stage, whose



condition, according to Pinilla *et al.*,<sup>(21)</sup> exposes them to their inexperience to assume, within a short period, the self-care of their health and that of their child, as well as the affective relations with the child and the family environment; challenges that lead them to endure a strong emotional burden, thus, becoming a risk factor for healthy MB. With respect to the effectiveness reached, better results were determined in favor of the intervention based on multiple intelligences, managing to benefit 56.73% of the mothers in their level of knowledge, compared to 41.59% of the participants benefitted from the group with traditional intervention. Similar results were reported by Rojas *et al.*,<sup>(11)</sup> who achieved 28.8% of the participants with deficient level knowledge changing to a good level in 60.8% of 1,132 pregnant women and mothers from different regional states of Venezuela after attending educational and participative workshops on MB. Another study by Rodríguez *et al.*,<sup>(22)</sup> managed to get the level of good knowledge to go from 21.81% to 70.9%, after an intervention based on six educational sessions of MB, applied to a group of 55 mothers from a poly-clinical institution in Camagüey, Cuba. In a similar experience, Melo *et al.*,<sup>(23)</sup> upon implementing an educational program with 201 pregnant women from a Maternal Hospital in Fortaleza, Brazil, reported an increase from 74.1 to 79.1 points (of 100 possible) in the level of knowledge, after an educational intervention based on a flip-chart about MB in comparison with the control group that dropped from a level of 72.8 to 70.7 points.

In more encouraging results, Márquez *et al.*,<sup>(12)</sup> after applying the educational program “breastfeed me mommy” to a group of 55 mothers of children under six months of age from a health center in Trujillo, Peru, managed to change the level of knowledge with respect to MB, from 93.4% with intermediate level to 100% with high level. Guerra *et al.*,<sup>(24)</sup> also reported a significant impact when intervening with an educational strategy on MB based on participative dynamics applied in 1,343 future mothers from a poly-clinical institution in

Cuba, so that from an initial result with 47.3% of women with low level of knowledge managed to get 96.7% to reach a high level after the intervention; while Hernández *et al.*,<sup>(10)</sup> upon implementing an educational intervention on MB based on talks, videos, informative leaflets, participative stories, and role playing in 970 adolescents from Tenerife, managed to increase the level of knowledge from 48.75% (3.9 points of 8 possible) to 86.25% (6.9 points) after the experience, compared to a control group that only went from 3.8 to 4.3 points.

With respect to EB practices, this study determined that 43.36% of the mothers with traditional intervention prolonged EB from 6 months to more, in comparison with the intervention based on MI, where better results were found upon evidencing that 68.27% of them practiced breastfeeding during that period of time. Similar results were revealed in the research by Melo *et al.*,<sup>(23)</sup> reporting that EB practices up to 6 months were conducted by 64.31% of the participants from the educational intervention group, against 56.96% by a control group. Rodríguez *et al.*,<sup>(22)</sup> unlike prior results, found greater effectiveness when reporting that mothers with EB practices up to 6 months went from 32.72% before the intervention to 76.36% after it. Reaching greater impact, Guerra *et al.*,<sup>(24)</sup> reported that 90.42% of the mothers evidenced EB practices up to 6 months after an educational intervention. In turn, Escalona *et al.*,<sup>(25)</sup> also found good results when implementing an intervention based on Leininger’s Transcultural Nursing theory on 30 mothers cared for in a Hospital in Carabobo, Venezuela, managing to improve the EB practices from 44.9% to 85.4% of the participants after the intervention.

It must be indicated that among the difficulties limiting the extension of EB for an optimal time and which coincided with López *et al.*,<sup>(7)</sup> and Quispe *et al.*,<sup>(9)</sup> were the mother’s poor nutrition, unfavorable family environment, job conditions, and young age. Regarding the adequate MB technique, following the recommendations by the

Peruvian Ministry of Health <sup>(14,18)</sup> and coinciding with studies by Melo *et al.*,<sup>(23)</sup> 63.46% of the mothers from the group with MI and 38.05% from the traditional group evidenced favorable signs of bonding between mother and child and a comfortable and sustained position that propitiated optimal suction for the child, with these groups of mothers practicing EB up to 6 months.

As observed, reference studies coincide in having determined the effectiveness of the educational interventions from the comparison of an intervention group with a control group, unlike the present research in which both were evaluated with different methodological bases, highlighting as additional contribution that of having tested the applicability of the cost-effectiveness approach as a valid alternative to compare health promotion programs.

The findings, herein, evidence the contribution to improve the nursing practice, given that they propitiate the likelihood of being involved in health promotion programs, appealing to educational methodologies that enrich and guarantee the effectiveness of health education processes, whose interventions can be evaluated from a cost-effectiveness analysis as a valid model that can contribute to measuring the real impact of programs promoting maternal breastfeeding, as well as other thematic axes related to preventive nursing care. Moreover, a limitation that hindered follow up of the mothers was the difficulty to locate them in their homes because, in many cases, they had begun their work activity, which meant greater time dedicated to culminate the follow up and evidenced one of the reasons why they

had suspended EB. Another difficulty is the lack of experiences directly related with the present study, which could have enriched the discussion further. Due to this, additional scientific work must continue to address that line of research, making it necessary to socialize the findings with pertinent authorities to propitiate healthy EB promotion policies that manage to establish a culture of preventive health in our country, especially in vulnerable communities.

Finally, careful control of possible bias was guaranteed after conducting a strict selection process of the criteria of the information registries, so that the results to determine the costs and effectiveness were attributed exclusively to the educational interventions and not to other factors that could have influenced.

This study concludes that when applying satisfactorily the cost-effectiveness evaluation as model to compare educational interventions on EB, better results were achieved in favor of the intervention based on multiple intelligences, finding that, with a lower investment, it was possible to benefit a greater number of mothers in their level of knowledge and maternal breastfeeding practices compared with a traditional educational intervention.

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# The capacity of informal caregivers in the rehabilitation of older people after a stroke

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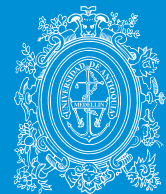
## The capacity of informal caregivers in the rehabilitation of older people after a stroke

### Abstract

**Objective.** To characterize informal caregivers of dependent older people after a stroke related to aspects of care, and to describe the activities performed and the difficulties faced by these caregivers. **Methods.** Cross-sectional, descriptive study, held in southern Brazil with 190 informal caregivers of older adults after stroke. The sociodemographic data instrument and the Capacity Scale for Informal Caregivers of Elderly Stroke Patients (ECCIID-AVC), adapted and validated for use in Brazil by Dal Pizzol *et al.*, were used. **Results.** Most caregivers were women (82.6%) or children (56.3%), had average schooling of 9.6 years, and the majority (68.3%) provided care for people with moderate to severe disability. The main activities carried out included: providing materials and/or support for eating (99%), dressing (98.4%), and administering medications (96.2%). Caregivers had the most difficulty with transferring and



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positioning activities. **Conclusion.** Most caregivers have adequate capacity to provide essential care to the dependent older adult after a stroke. However, a significant portion had difficulty in the activities of transferring and positioning the older person due to the lack of guidance regarding the posture to carry out these activities. The assessment of nurses regarding the activities performed and the difficulties faced by caregivers is an important strategy to identify problems and effectively attend to the needs of these individuals at all levels of health care.

**Descriptors:** caregivers; aged; stroke; nursing.

## Capacidad de los cuidadores informales en la rehabilitación de las personas ancianas dependientes después de un accidente cerebrovascular

### Resumen

**Objetivo.** Caracterizar a los cuidadores informales de personas mayores dependientes tras un ictus en cuanto a los aspectos relacionados con los cuidados y describir las actividades realizadas y las dificultades a las que se enfrentan. **Métodos.** Estudio transversal y descriptivo realizado en el sur de Brasil con 190 cuidadores informales de ancianos tras sufrir un accidente cerebrovascular (ACV). Se utilizó un formulario de datos sociodemográficos y la Escala de Capacidades del Cuidador Informal de Ancianos Dependientes por Accidente Cerebrovascular (ECCIID-AVC) adaptada y validada por Dal Pizzol *et al.* **Resultados.** La mayoría de los cuidadores eran mujeres (82.6%), hijos (56.3%), con 9.6 años de educación en promedio y el 68.4% cuidaba de personas con discapacidades entre moderadas a graves. Las principales actividades realizadas fueron proporcionar materiales y/o apoyo para la alimentación (99%) y el vestido (98.4%), así como ocuparse de la medicación (96.2%). El traslado y la posición de los ancianos fueron las actividades en las que los cuidadores presentaron más dificultad debido a la falta de orientación sobre la postura adecuada que debían tener para realizar estas actividades. **Conclusión.** La mayoría de los cuidadores tienen una capacidad adecuada para brindar los cuidados esenciales a los ancianos dependientes después de un ictus, sin embargo, una

parte importante de ellos enfrentan dificultades que deben ser identificadas por enfermería con el fin de intervenir las necesidades educativas de estos sujetos en todos los niveles de la atención sanitaria.

**Descriptor:** cuidadores; anciano; accidente cerebrovascular; enfermeros

## Capacidade dos cuidadores informais na reabilitação de idosos após Acidente Vascular Cerebral

### Resumo

**Objetivo.** Caracterizar cuidadores informais de idosos dependentes após Acidente Vascular Cerebral (AVC) quanto a aspectos relacionados ao cuidado e descrever as atividades realizadas e as dificuldades enfrentadas por esses cuidadores. **Método.** Estudo transversal, descritivo, realizado no Sul do Brasil com 190 cuidadores informais de idosos após AVC. Utilizaram-se formulário de dados sociodemográficos e Escala de Capacidades do Cuidador Informal de Idosos Dependentes por Acidente Vascular Cerebral (ECCIID-AVC) adaptada e validada por Dal Pizzol *et al.* **Resultados.** Os cuidadores, em sua maioria, eram do sexo feminino (82.6%), filhos (56.3%), com escolaridade média de 9.6 anos e 68.4% cuidavam de pessoas com incapacidade moderada a severa. As principais atividades realizadas foram fornecer materiais e/ou apoio para alimentar-se (99%) e vestir-se (98.4%), bem como cuidar das medicações (96.2%). Transferência e posicionamento foram as atividades que os cuidadores apresentaram maior dificuldade. **Conclusão.** A maioria dos cuidadores possui adequada capacidade para realizar os cuidados essenciais ao idoso dependente após AVC, no entanto uma parte significativa apresentava dificuldade nas atividades de transferência e posicionamento do idoso, devido à falta de orientação quanto à postura adequada para realizar essas atividades. A avaliação dos enfermeiros quanto às atividades realizadas e às dificuldades enfrentadas pelos cuidadores é uma importante estratégia para identificar problemas e intervir nas necessidades desses sujeitos em todos os níveis de atenção à saúde.

**Descritores:** cuidadores; idoso; acidente vascular cerebral; enfermagem.



# Introduction

Stroke is a neurological syndrome with a high incidence in the older population. In Brazil, approximately 153 thousand people between January and December 2020 were hospitalized due to stroke, in which approximately 110 thousand (72%) were older people, and around 18 thousand older adults (16.4%) died.<sup>(1)</sup> These data highlights the need for special attention to the older population with stroke. Usually, older people with stroke remain with some functional disability, needing help to carry out activities of daily living, which results in challenges for the family, as the demand for care does not cease at the time of hospital discharge. Thus, there is a need to choose a person to assume the role of caregiver.<sup>(2)</sup> In Brazil, most caregivers of older people after a stroke are informal.<sup>(3)</sup> Informal caregivers are those who perform non-professional care, without employment or remuneration, and may be a family member, friend, neighbor, or other people in the community.<sup>(4)</sup>

The informal caregiver plays a fundamental role in rehabilitation of dependent patients after a stroke at home, but he/she needs support to provide qualified care.<sup>(2)</sup> Although some studies show the characteristics of these caregivers and the care provided, they do not specify the activities of care and the difficulties faced due to the demands of care.<sup>(5,6)</sup> In Brazil, the government has reduced responsibilities to supporting the older population, attributing to the family the responsibility for most of the home care to dependent people.<sup>(7)</sup> Also in Brazil, informal care has not yet entered into the public policies,<sup>(8)</sup> making the family to provide care of the older adult without the necessary information and resources. However, at an international level, the support networks for the older people and their informal caregivers seem to be more strengthened, mitigating the negative repercussions of dedication to caring for dependent older people after stroke. In Canada, for example, the older patients and their caregivers have numerous public policies that aim to provide financial support to informal caregivers, adaptations in the homes of the older person, and information programs for caregivers and the older patient, guiding them on how to provide care and take care of their physical and mental health.<sup>(9)</sup>

In this context, it is the nurses' responsibilities to use their skills as an educator to assist the family in the continuity of patient care after hospital discharge.<sup>(2)</sup> Nurses who work in the most varied points of care in the health care network, such as hospitals, Primary Health Care, and Home Care, play a fundamental role in guiding and supporting family members of the older patients through pre-discharge preparation and home visits after discharge. Thus, getting to know the informal caregivers of older people after a stroke and the characteristics of this work is essential for planning health care, improving educational strategies, and being able to direct effective public policies, which take into account their potential and limitations.

Given the above, the objective of this study was to characterize informal caregivers of dependent older people after a stroke related to aspects of care. Furthermore, it aims to describe the activities performed and the difficulties faced by these caregivers.

## Methods

This is a cross-sectional, descriptive study with informal caregivers of older people after stroke who are being followed up in one of the outpatient clinics of two public hospitals in the city of Porto Alegre, Rio Grande do Sul, Brazil, or in the Home Care Service in the same region. These services are part of the *Rede Brasil AVC* and receive patients through a health care network linked to the Mobile Emergency Care Service. The sample was derived from a larger research project,<sup>(10)</sup> and calculated from the recommendations of Beaton<sup>(11-13)</sup> and Hair<sup>(14)</sup> that foresee the inclusion of at least 30 individuals in the pre-test and the use of at least five times more individuals per item than the number of items to be analyzed. Thus, the study sample was characterized by 30 pre-test individuals + 160 individuals (scale with 32 items with five observations each), totaling a non-probabilistic sample of 190 informal caregivers of the older patients (60 years old or more) after a stroke.

We included caregivers (aged at least 18 years old) of older people with a medical diagnosis of stroke and informal caregivers who had taken care of the family member after hospital discharge for at least 15 days and at most 12 months. This temporal delimitation is because we consider it necessary for the caregiver to have the experience of providing care for the older adult after a stroke so that we could identify the activities performed and the difficulties faced by them. In this sense, we considered that, after 12 months, the caregiver has already acquired the necessary skills in the care process, without presenting the initial difficulties. Also, we selected older adults with a

minimum score of two and a maximum of five at the time of discharge from the Modified Rankin Scale (mRankin)<sup>(15)</sup>. mRankin is a scale that allows the functional evaluation of stroke patients, applied during the patient's hospitalization and discharge. The mRankin score ranges from zero to six (0-asymptomatic; 1-symptoms without disability; 2-mild disability; 3-moderate disability; 4-moderately severe disability; 5-severe disability; 6-death). This scale was not validated for Brazil, but it is widely used in clinical practice and research.<sup>(15)</sup> We excluded the caregivers who did not answer the calls after three attempts on different days and shifts, and caregivers of older adults who lived in long-term facilities.

We collected data from May to December 2017 in person, before or after the outpatient health consultation, or by telephone. We had 52 face-to-face data collections and 138 by telephone contact, according to the caregiver's availability. The care activities were not observed, we considered the caregivers' report on how they performed the activities, as data were collected in an outpatient area or by telephone contact. For that, we used a questionnaire of sociodemographic data of the caregivers, with the following variables: age, gender, education, marital status, and occupation. We also asked questions to informal caregivers such as degree of kinship with the older person, live with the older person, time spent in the activity of caregiver, age of the older person, presence of another person to assist in the provision of care, time spent per week to provide care (including, in addition to physical care, care management, and emotional, financial and instrumental support for the older person), weekly time spent by others in providing care for the older adult, the income of the older person, expense taken from the caregiver's income for expenses with the older person, and receiving or not receiving financial aid. Also, some data were extracted from the computerized system of the two institutions under studies, such as: length of hospital stay for the older patient, the time between hospital discharge and the interview, mRankin score, and type of stroke.

The activities for which the caregiver helped the older person were extracted from the sum of the items “demonstrates” (2) and “demonstrates completely” (3) of the Capacity Scale for Informal Caregivers of Elderly Stroke Patients (*Escala de Capacidades do Cuidador Informal de Idosos Dependentes por AVC - ECCIID-AVC*).<sup>(10)</sup> The difficulties faced by caregivers were obtained from the sum of the items “does not demonstrate” (0) and “demonstrates partially” (1) of the same scale. These last two items correspond to the difficulties faced in providing care to dependent older people due to a stroke because the caregivers do not demonstrate the ability to perform some care activity or because they proved to be partially capable, needing help from other people. The items that compose the *ECCIID-AVC* are items related to essential to care performed by informal caregivers of the older adult after a stroke, such as: food, medications, skin care, personal hygiene, bathing, eliminations, clothing, transfer, and positioning.<sup>(10)</sup>

The *ECCIID-AVC* was adapted and validated for use with informal caregivers of older adults after a stroke in Brazil, presenting a satisfactory test-retest reliability (intraclass correlation coefficient = 0.94; 95% confidence interval = 0.91–0.96) and an excellent internal consistency reliability (Cronbach’s alpha = 0.914).<sup>(10)</sup> This scale evaluates the different capacities that informal caregivers have or need to improve in providing care for dependent older people after a stroke. This is the first specific existing scale to assess the ability of informal caregivers of dependent older people after a stroke.<sup>(10,16)</sup> The *ECCIID-AVC* has 29 items that evaluate several factors related to provide care, with the following answer options: “NA - not applicable”; “0 - Does not demonstrate”: Not performing the activity; “1 - Demonstrates partially”: needs help to perform the activity; “2 - Demonstrates”: can perform the activity with encouragement and/or supervision; “3 - Demonstrates completely”: performs the activity correctly and autonomously.<sup>(10)</sup> The answer option “NA – not applicable” is used in cases in which the caregiver does not perform the

activity because the older person does not need that care, such as care with a nasogastric tube for older people with an oral diet. In this study, the percentage of continuous variables was calculated on the number of caregivers who needed to perform the activity, discounting the cases of NA for each item. The total score of the scale varies from 0 to 87 points and the calculation is done proportionally, that is, the options marked as NA - not applicable are considered.<sup>(10)</sup> Thus, a caregiver who does not perform the activity for not having to do it (independent older person) will not be compared to those who do not, for not knowing how to do it. The higher the score, the more qualified the caregiver. The total score was calculated by averaging the scores of the responses, ranging from 0 to 3. The scale has no cut-off point.

The *ECCIID-AVC* is a scale intended to be applied by nurses or health professionals, with the professional assigning the score based on the observation of the performance of the care activities or through the report of the caregivers. In this study, the *ECCIID-AVC* was applied by a properly trained team, who questioned each item on the scale to the caregivers, assigning the score according to the caregiver’s report. The interviewers used a guide for the application of the *ECCIID-AVC*, in which there were questions directed to each item of the scale so that the interviewer had criteria to assess, based on the caregiver’s report, if he/she performed the activity correctly and autonomously. For example, in the item related to the preparation of food, the question was directed to identify whether or not the caregiver prepared the meal according to the prescribed or guided diet.<sup>(10,16)</sup>

For statistical analysis, we used the software Statistical Package for the Social Sciences (SPSS) version 21.0. The continuous variables were described as mean and standard deviation, or median and interquartile range. The categorical variables were presented as frequencies and proportions. The study was approved by the Research Ethics Committee under numbers

160580 and 17152. All respondents agreed to participate in the research by signing the Informed Consent Form or consent by telephone contact.

## Results

There was a predominance of female caregivers (82.6%) with a mean age of  $50 \pm 13$  years old (Table 1). More than half of the sample (71.6%) was married or lived with partners, 38.4% were employed and had an average of 9.6 years of study. As for the degree of kinship between the caregiver and the older adult, most of them were children (56.3%), who lived with the older person (73.7%). The average age of the older adult was  $72.8 \pm 10.2$  years old.

The median hours per week of care provided to the older person reported by the caregivers was 142.5. This weekly care period involves

physical care for the older person, care management, and emotional, instrumental, and financial support. Within this weekly workload, 78.9% of caregivers received help from other family members and friends, with a median of 70 hours per week. Among the caregivers, 101 (53.1%) had some expense taken from their income, and 97 (51%) received financial assistance from someone else. Most of the older adults, 166 (87.4%), had their income, with an average of 1.3 minimum wages.

The median time of care provided by caregivers to the older person was 5 months. Also, the median length of stay for the older person was 11 days and the median time between hospital discharge and the interview was 136 days. According to the mRankin scale applied at the time of hospital discharge of the older person, 130 (68.4%) caregivers cared for older people with moderate to severe disability, and most of them (172.5%) were cases of older people after an ischemic stroke.

**Table 1. Sociodemographic characteristics and information related to the care provided by 190 informal caregivers of the older adults after a stroke**

Sociodemographic characteristics	Descriptive statistics
Female; n (%)	157 (82.6)
Age (years old); mean $\pm$ SD	50 $\pm$ 13
Marital Status; n (%)	
Single/never married	36 (18.9)
Married/living with a partner	136 (71.6)
Divorced/Separated	15 (7.9)
Widow	3 (1.6)
Education level (years); mean $\pm$ SD	9,6 $\pm$ 3,9
Occupation; n (%)	
Employed	73 (38.4)
Unemployed	36 (18.9)
Housewife	36 (18.9)
Retired	43 (22.6)
Student	1 (0.5)
Not informed	1 (0.5)

**Table 1. Sociodemographic characteristics and information related to the care provided by 190 informal caregivers of the older adults after a stroke (Cont)**

Sociodemographic characteristics	Descriptive statistics
<b>Information related to the care provided</b>	
Degree of kinship; n (%)	
Children	107 (56.3)
Partner	54 (28.4)
Grandchildren	7 (3.7)
Siblings	5 (2.6)
Other	17 (8.9)
Hours/week dedicated to caring for the older person; median (Q1-Q3)	142.5 (60-168)
Receive assistance from other people to assist in the provision of care; median (Q1-Q3)	150 (78.9)
Hours/week when receiving help from other people; median (Q1-Q3)	70 (28-168)
Time in which the older person is cared for (months); median (Q1-Q3)	5 (2-10)
Length of hospitalization of the older person (days); median (Q1-Q3)	11 (7-17)
mRankin; n (%)	
Slight disability (2)	60 (31.6)
Moderate disability (3)	41 (21.6)
Moderately severe disability (4)	51 (26.8)
Severe disability (5)	38 (20)
Stroke type; n (%)	
Ischemic	172 (90.5)
Hemorrhagic	15 (7.9)
Transient ischemic attack	3 (1.6)

Regarding care activities (Table 2), more than 89% of caregivers performed all the necessary activities related to oral preparation, control, and diet intake. Of the 190 caregivers, only 15 (7.9%) provided care for the older person who received a diet through an enteral tube. Of these 15 caregivers, two caregivers did not perform the introduction of water if the tube became obstructed during the administration of the diet and medication, but all performed the washing of the tube with water after administration of the diet and medication.

The main activities performed by the caregivers were to provide materials and/or support necessary to facilitate feeding (99%), to dressing (98.4%), and administration of medication (96.2%). The skin care

activity of the older adult was developed by 66.3% of the caregivers and 63.1% stimulated the movement of the affected body member of the older adult to get the food and utensils. Regarding care with the transfer of the older person, 17.4% of caregivers did not need to perform it, as the older person was independent in this activity. Of the 157 caregivers who needed to transfer the older adult, 53.5% had difficulty and reported making the transfer of the older person without paying attention to their own posture. This difficulty was also present in the activity of positioning the older adult because, of the 134 caregivers who needed to position them, 43.3% also reported not paying attention to their own posture. The total average of the response options of the caregivers in the *ECCI/D-AVC* was  $2.56 \pm 0.42$ .

**Table 2. ECCIID-AVC: Care activities and difficulties faced by 190 informal caregivers of dependent older people after stroke**

ECCIID-AVC items	NA* n (%)	Need to perform the activity n (%)	Does not demon- strate (0) / Dem- onstrates partially (1) n (%)†	Demonstrates (2)/ Demonstrates completely (3) n (%)†
1- Prepare meals in accord with the pre-scribed or guided diet plan.	10 (5.3)	180 (94.7)	19 (10.6)	161 (89.4)
2- Prepare meals adequately.	6 (3.2)	184 (96.8)	12 (6.5)	172 (93.5)
3- Place food and utensil on the side on which the elderly person shows greater dependence to stimulate the affected member.	33 (17.4)	157 (82.6)	58 (36.9)	99 (63.1)
4- Provide support and/or materials necessary to facilitate feeding.	3 (1.6)	187 (98.4)	2 (1)	185 (99)
5- Control food ingestion.	1 (0.5)	189 (99.5)	8 (4.2)	181 (95.8)
6- Monitor swallowing.	5 (2.6)	185 (97.4)	8 (4.3)	177 (95.7)
7- Aid in the administration of medication as per the medical prescription.	6 (3.2)	184 (96.8)	7 (3.8)	177 (96.2)
8- Flush the tube with water if it becomes obstructed during the administration of diet and medication.	175(92.1)	15 (7.9)	2 (13.3)	13 (86.7)
9- Flush the tube with water after administering the diet and medication.	175(92.1)	15 (7.9)	0	15 (100)
10- Hydrate the skin.	9 (4.7)	181 (95.3)	60 (33.1)	121 (66.9)
11- Prepare hygiene material.	11 (5.8)	179 (94.2)	9 (5)	170 (95)
12- Provide support and/or materials necessary to facilitate personal hygiene.	11 (5.8)	179 (94.2)	7 (3.9)	172 (96.1)
13- Assist while bathing.	21 (11.1)	169 (88.9)	27 (16)	142 (84)
14- Assist with oral hygiene.	41 (21.6)	149 (78.4)	13 (8.7)	136 (91.3)
15- Maintain a neat appearance.	7 (3.7)	183(96.3)	4 (2.2)	179 (97.8)
16- Ensure privacy while using the toilet, when changing diapers and bathing.	6 (3.2)	184 (96.8)	13 (7)	171 (93)
17- Provide support and/or materials necessary to facilitate urinary and intestinal toilet routines.	21 (11.1)	169 (88.9)	10 (5.9)	159 (94.1)
18- Assist in toilet wiping and changing diapers.	44 (23.2)	146 (76.8)	13 (8.9)	133 (91.9)
19- Provide support and/or materials necessary to facilitate dressing.	5 (2.6)	185 (97.4)	3 (1.6)	182 (98.4)
20- Assist the person while dressing.	14 (7.4)	176 (92.6)	8 (4.5)	168 (95.6)
21- Assess the elderly person's capacity to transfer themselves from one place to another.	12 (6.3)	178 (93.7)	5 (2.8)	173 (97.2)



**Table 2. ECCIID-AVC: Care activities and difficulties faced by 190 informal caregivers of dependent older people after stroke (Cont)**

ECCIID-AVC items	NA* n (%)	Need to perform the activity n (%)	Does not demonstrate (0) / Demonstrates partially (1) n (%) <sup>†</sup>	Demonstrates (2)/ Demonstrates completely (3) n (%) <sup>†</sup>
22- Explain to the elderly person about the right way to transfer themselves from one place to another.	21 (11.1)	169 (88.9)	8 (4.7)	161 (95.3)
23- Provide support and/or materials necessary for the elderly person to transfer themselves from one place to another.	21 (11.1)	169 (88.9)	11 (6.5)	158 (93.5)
24- Assist the elderly person to transfer themselves from one place to another.	33 (17.4)	157 (82.6)	17 (10.8)	140 (89.2)
25- Employ the correct posture when transferring an elderly person from one place to another.	33 (17.4)	157 (82.6)	84 (53.5)	73 (46.5)
26- Provide support and/or materials necessary to position the elderly patient.	47 (24.7)	143 (75.3)	6 (4.2)	137 (95.8)
27- Assess the need to change the body position of the elderly person.	56 (29.5)	134 (70.5)	10 (7.5)	124 (92.5)
28- Employ the correct posture to position each part of the elderly person's body correctly.	56 (29.5)	134 (70.5)	58 (43.3)	76 (56.7)
29- Change the body position of the elderly person when they are laying down.	90 (47.4)	100 (52.6)	16 (16)	84 (84)

\*NA= not applicable. <sup>†</sup>proportions calculated on the number of caregivers who needed to perform the activity.

## Discussion

The results of this study show that care remains an activity performed predominantly by women, reinforcing information present in national and international studies regarding the role of women in care.<sup>(16-19)</sup> There is a need for special attention and encouragement for the self-care of women caregivers, since activities with the older person reduce their free time, bringing complications to their social life and even compromising their health.<sup>(20)</sup> The average age of informal caregivers was similar to others studies with caregivers of

older people after stroke and dependent older people in general.<sup>(17,21)</sup> The demographic transition occurring in Brazil results in an increase in the older population, consequently, the number of older people caring for other older people increases.<sup>(22)</sup> Nevertheless, the support structures remain fragile and support networks are disorganized.<sup>(22)</sup>

Most caregivers were married, similar to other national studies.<sup>(17,19)</sup> Also, 38.4% of caregivers had jobs, differing from other national research.<sup>(17,19)</sup> Maintaining a healthy and active relationship with the spouse, reconciling employment and care activities becomes a difficult task. Some caregivers even abandon their jobs, putting their self-care in



second place. With the precariousness of their relationships, many prioritize care activities for the older person.<sup>(23)</sup> The average education level of caregivers was similar to the national average,<sup>(1)</sup> however, it was lower than the average found in other studies developed in the same region.<sup>(21,24)</sup> Thus, nursing professionals play a fundamental role in finding strategies to educate informal caregivers according to their ability to understand, paying attention to their level of education.<sup>(2)</sup>

More than half of the responsibilities of caring for the older adult after a stroke were assumed by their children, which is similar to the findings of other studies with informal caregivers of older people after stroke and with caregivers of dependent older people in general.<sup>(18,19,21)</sup> Responsibility of children due to the duty to care for older parents is a subject discussed and investigated in recent years. In Brazilian culture, filial duty is defined as respect or devotion to parents, in which children feel the duty to repay the care dedicated by parents when they were children.<sup>(24)</sup> A study pointed out that the care provided by children, in most cases, is attributed to the fact that older people are unable to provide care for their spouses due to their disabilities.<sup>(21)</sup> The care of the older person after a stroke requires a long process of rehabilitation and effort from the caregiver and the care recipient.

In this study, most caregivers lived with the older person. This can be considered as a way to guarantee comprehensive care to patients with a functional disability after a stroke.<sup>(17)</sup> On the other hand, it requires great dedication. The median time of care for the older adult was five months, a period considered short to become able to care for a dependent older person after a stroke. Caregivers who provide care for a long time are more informed, as they learn from the daily care demands.<sup>(25)</sup> The median hours per week reported by caregivers as dedicated to caring for the older adult was 142.5 hours, above the median found in another study in the same region with relatives of dependent older people in

general.<sup>(21)</sup> The high number of hours per week dedicated to the provision of care was because the caregiver reports being available full time to care for the older person, in tasks that include physical, emotional, and financial support. Such data are justified because the stroke is a disabling disease, with the caregiver having the function of providing care and/or managing care.<sup>(18)</sup>

More than half of the caregivers had some expense taken from their income, plus financial assistance from another person, due to the care of the older person after a stroke caused costs from spending on medication, adaptations at home, special diet, thickener, diapers, which is not always available in the public health system. Therefore, stroke generates costs both for the health system with hospitalization and rehabilitation and for the older person and their family at home.<sup>(23)</sup> Many caregivers need to withdraw part of their income to meet the basic care demands and providing a home for the whole family, often causing financial burden and impacts on the caregiver's quality of life.<sup>(18)</sup> Most older people had their income, around a minimum wage, showing low income as observed in another local study.<sup>(21)</sup>

Because stroke is a disabling disease, many older people return to their homes in need of different types of care. In the study, 68.4% of the older adults had moderate to severe disability, requiring the caregiver to perform more complex activities. Thus, the transition of care and hospital discharge planning must be carried out by nurses, aiming at guiding and preparing family caregivers to provide adequate conditions to meet the care demands of dependent older people, seeking to identify them and intervene according to the needs of each caregiver.

The hospitalization period of the older adults in this study had a median of 11 days, higher than the average length of stay due to stroke in Brazil, 7.5 days, from November 2016 to November 2017.<sup>(1)</sup> The median time of care for the older participants was 5 months. We believe that this period may

have influenced the study's caregivers to acquire the ability to care since the average score of the caregivers in the *ECCI/D-AVC* was 2.56 ( $\pm$  0.42), varying from "demonstrates" (2) "demonstrates completely" (3). Although unknown, there is a time for learning to provide care, which involves the development of knowledge and skills, and psychological and relational aspects,<sup>(26)</sup> expressed in everyday life.

The caregiver often learns to deal with the care activities of a dependent older person through attempts and errors during day-to-day care at home.<sup>(27)</sup> However, this strategy can result in negative consequences for the care recipient. Each caregiver has also a demand for tasks according to the needs of the older adult. Thus, there is no established quantitative limit of activities they need to perform, but they must have the ability to perform them, exercise them safely and understand what they are doing. The informal caregiver should perform care while still in the hospital, supported by a multi-professional team, so that the caregiver learns and can perform these care activities adequately at home. This practice involves the planning of hospital discharge and the transition of care, from hospital to home, and the monitoring at home in a systematic way until it is assessed whether the caregiver has the autonomy to provide care.

The caregivers in this study showed to prepare the meal, paying attention to the recommended care at the time of hospital discharge regarding consistency (examples: pasty, mild, or normal) and the preparation of the diet. However, 36.9% of caregivers did not seek to stimulate motor skills on the side of the body of greater dependence on the older person during meals. This is a fundamental care for the rehabilitation of patients with hemiparesis after stroke and which should be reinforced in hospital discharge planning.<sup>(7)</sup> There was a low number of caregivers who performed feeding tube diets due to the few older people using it. Returning to the home with a feeding tube diet implies several changes in the life of the family, the individual, and the caregiver, requiring

adequate guidance for those who will provide this care.<sup>(28)</sup> Only 15 of the 190 caregivers provided care for the older adult with a feeding tube diet and two of them had difficulty in performing this activity, ignoring basic care regarding the feeding tube diet, such as the use of water to unblock it. Likewise, findings from a Brazilian study report that obstruction of the tube is one of the main difficulties exposed by caregivers of dependent older people who return home.<sup>(29)</sup> Moreover, we highlight that activities which require knowledge and skills from the caregiver, such as handling the tube and preparing the diet, both orally and through the tube, are fundamental activities that must be addressed by the multi-professional team even when the older person is hospitalized. This action involves guidance and the observation of whether the caregiver can perform the activity with autonomy.

Most caregivers helped with the administration of medication according to the medical prescription, paying attention to the dose, times, route of administration, and storage, being a positive finding in the prevention of a new stroke and the recovery of the older person. A study with family caregivers of dependent older people identified that the care with medications represented one of the main activities with difficulties to be carried out at home.<sup>(27)</sup> Such difficulties refer to the lack of information and knowledge of the family members regarding their performance, especially regarding the identification and storage of medications, the expiration date, and changes in the prescribed doses.<sup>(27)</sup>

We found that, in the skin care activities, most caregivers performed the position rotation, hydrate the skin, and changed the diaper frequently. Patients with neurological disorders are more dependent on care, such as changing the position, hydrating the skin, nutritional assessment, and frequent intimate hygiene, and the lack of this care exposes the older person to a greater risk for the occurrence of pressure injuries.<sup>(7,30)</sup> The dressing was among the main activities that caregivers demonstrated the ability to perform. In the care of the older adult after a stroke, this activity requires skill, as

it demands that caregivers pay attention to the use of comfortable clothing, start to wear it for the body member with the greatest dependence and, to undress, for the healthy body member.<sup>(7)</sup> Study-related to needs of family caregivers in caring for the dependent older person at home identified that caregivers lacked knowledge of how to perform the activity of dressing properly.<sup>(27)</sup> Although dressing is a less complex care activity, nurses must guide caregivers so that it is properly developed.

Regarding the activities of care with personal hygiene, eliminations, oral hygiene, and bed/shower bath, most of the caregivers were capable of carrying them out. These activities were facilitated by home adaptations that caregivers made and by having a bath chair, which facilitates the displacement of the older person. This finding differs from another study in which one of the main difficulties for family caregivers was the lack of equipment to provide home care.<sup>(27)</sup>

The transfer and positioning activities were performed by most of the caregivers in this study. However, most of them did not use adequate posture to perform the transfer and positioning, which is the main difficulty presented by caregivers. The inadequate posture of the caregiver to transfer the older person harms the health of the caregiver by performing the care with force and inadequate posture and also harms the older person. In this sense, we highlight the need for interventions performed by nursing professionals, together with the multidisciplinary team, to prevent musculoskeletal injuries in informal caregivers, which is associated with caring and promotes the well-being of both the caregiver and the older adult.<sup>(31)</sup>

As a stroke is a sudden disease, family members are often not prepared to care for a dependent older person, requiring the support of a formal health care network. In this perspective, the multi-professional teams of the primary health care units must provide training and support for these caregivers, especially in the initial phase of

returning home. Since 2011, the Brazilian Ministry of Health has implemented a new modality of health care, substituting or complementing the existing ones, called Home Care, provided by primary health care (with support from the *Núcleo de Apoio à Saúde da Família* - NASF) or by home care services, according to the complexity of care. Home Care is characterized by a set of promotion, prevention, treatment, and rehabilitation actions provided at home, with guaranteed continuity of care.<sup>(32)</sup> Older people with more complex or even basic needs could be accompanied by this type of service in the home. However, the home care service must be improved and expanded so that all informal caregivers and the older adults after a stroke can count on this resource. It is necessary to increase the number of professionals in the primary health care teams so that it is possible to take care of the population's care demands.

The Brazilian Unified Health System and the Brazilian Unified Social Assistance System also need to implement other forms of formal care such as daycare centers. This would enable to reduce the burden on the caregiver's number of hours, as well as provide assistance to the older person according to their needs, reducing the risk of complications and hospital readmissions. For the most dependent older adults, home care can be an alternative to provide training and adequate support to informal caregivers in the provision of care at home or to enable institutionalization in cases of fragile families.

This investigation had limitations such as a non-probabilistic sample, containing only caregivers of older people from two specific hospitals in the south of Brazil, not allowing the results to be generalized to other regions of the country. Although the *ECCIID-AVC* was developed to be used in the outpatient and home context, we decided to apply it in this study, only in the outpatient context. Considering the country's socio-cultural diversity, we recommend new observational studies using *ECCIID-AVC* in other contexts and Brazilian regions. Another limitation

found was the impossibility of comparison with other studies that used the same scale, since to date, there are no published studies that have used *ECCIID-AVC* in the national context.

This study contributes to the scientific knowledge of health professionals, especially nurses, as care managers and educators - both in hospital and outpatient settings, as well as at home - as they know what are the difficulties faced by informal caregivers. It also allows the elaboration of interventions aimed at teaching caregivers to develop these tasks in an appropriate way. This was the first study conducted in Brazil that used a specific scale for informal caregivers of older people after stroke with good reliability and validity (*ECCIID-AVC*), bringing results that encourage the planning of interventions for this population.

We conclude that most caregivers performed all essential care activities for dependent older people after stroke present in *ECCIID-AVC*, referring to oral feeding, medications, skin care, personal hygiene, bathing, eliminations, clothing, transfer, and positioning. However, most of the caregivers had difficulties in the transferring and positioning activities of the older adult due to

the lack of guidance as to the proper posture to perform such activities.

Once again, we highlight the nurse's responsibility for identifying problems and developing interventions aimed at the needs of caregivers to direct them at all levels of health care. For an adequate transition of care, health professionals who work in different settings must assess and support the family and the older person in the demands of day-to-day care, paying attention to their needs. Consequently, there is an implication for the health system, regarding the need to expand social and health policies and programs that provide information and support appropriate to the needs of caregivers and the older person after stroke. Thus, health professionals should advocate for the expansion and articulation of the health care network, providing the necessary support to caregivers, both in planning discharge and in returning to the home of the dependent older person after a stroke.

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# Humanized Care from the Perception of Oncology Patients from Southern Chile

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## Humanized Care from the Perception of Oncology Patients from Southern Chile

### Abstract

**Objective.** This work sought to determine the perception of behaviors of humanized nursing care and its relation with sociodemographic and clinical variables in patients hospitalized in a Hemato-Oncology Department.

**Methods.** Analytic cross-sectional study conducted with 51 patients hospitalized in the Hemato-Oncology Unit at Hospital Base Valdivia, Chile. A survey containing sociodemographic and clinical information was applied together with the questionnaire on *Perception of Behaviors of Humanized Nursing Care 3<sup>rd</sup> version* -PBHNC 3v (32 items distributed in the categories: Qualities of nursing work, Openness to nurse-patient communication, and Willingness to care). **Results.** Of the participants, 51% were women, with mean age of  $46.5 \pm 16.6$  years; 54.9% were diagnosed with Lymphoma and 78.4% were in the treatment induction stage. In 30 of the 32 items of the instrument, > 90% of the participants evaluated

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compliance with the behavior of caring at level of “always”. By categories, it was observed that for “Willingness to care” there was significantly lower score among patients from 18 to 49 years of age ( $p=0.0455$ ). For the category “Openness to nurse-patient communication” lower median score existed in patients with Myeloma ( $p=0.0043$ ) and in patients in the Remission-Consolidation stage ( $p=0.0084$ ). Days of hospitalization were associated significantly with the category “Willingness to care”, being lower with 16 days and more ( $p=0.0242$ ). **Conclusion.** High frequency was observed of humanized-care behaviors and small differences in their assessment that were associated with demographic factors like age, and clinical factors, like diagnosis, treatment stage, and days of hospitalization.

**Descriptors:** humanization of assistance; oncology nursing; nurse-patient relations; health education.

## Cuidado humanizado desde la percepción de pacientes oncológicos del sur de Chile

### Resumen

**Objetivo.** Determinar la percepción de comportamientos de cuidados humanizados de enfermería y su relación con variables sociodemográficas y clínicas en pacientes hospitalizados en una Unidad de Hemato-Oncología. **Métodos.** Estudio transversal analítico realizado con la participación de 51 pacientes hospitalizados en la Unidad de Hemato-Oncología del Hospital Base Valdivia, Chile. Se aplicó un formulario que contenía información sociodemográfica, clínica y el instrumento *Percepción de Comportamientos de Cuidados Humanizados de Enfermería 3ª versión* -PCHÉ 3v (32 ítems distribuidos en las categorías: Cualidades del hacer de enfermería, Apertura a la comunicación enfermera(o)-paciente y Disposición para la atención). **Resultados.** De los participantes, 51% fueron mujeres, con una edad media de  $46.5 \pm 16.6$  años. Un 54.9% presentó diagnóstico de Linfoma y 78.4% estaba en etapa de Inducción del tratamiento. En 30 de los 32 ítems del instrumento, sobre 90% de los participantes evaluaron el cumplimiento del comportamiento de cuidado en nivel “siempre”. Por categorías se observó que para “Disposición para la atención” hubo significativa menor puntuación entre los pacientes de 18 a 49 años ( $p=0.0455$ ). Para la categoría “Apertura a la comunicación enfermera(o)-paciente” existió menor puntaje mediano en pacientes con Mieloma ( $p=0.0043$ ) y en los pacientes en etapa de Remisión-Consolidación ( $p=0.0084$ ). Los días de hospitalización se asociaron significativamente con la categoría “Disposición para la atención”, siendo menor con 16 días y más ( $p=0.0242$ ). **Conclusión.** Hubo alta

frecuencia de comportamientos de cuidados humanizados y pequeñas diferencias en su valoración que se asociaron con factores demográficos como la edad y a factores clínicos como el diagnóstico, la etapa de tratamiento y los días de hospitalización.

**Descriptor:** humanización de la atención; enfermería oncológica; relaciones enfermero-paciente; educación en salud.

## Cuidado humanizado a partir da percepção de pacientes com câncer no sul do Chile

### Resumo

**Objetivo.** Verificar a percepção dos comportamentos de cuidado humanizado de enfermagem e sua relação com variáveis sociodemográficas e clínicas em pacientes internados em uma Unidade de Hemato-Oncologia. **Métodos.** Estudo transversal analítico realizado com a participação de 51 pacientes internados na Unidade de Hemato-Oncologia da Base Hospitalar de Valdivia, Chile. Foi aplicado um formulário que continha informações sociodemográficas e clínicas e o instrumento Percepção de Comportamentos da Assistência Humanizada de Enfermagem 3ª versão -PCHÉ 3v (32 itens distribuídos nas categorias: Qualidades do trabalho de enfermagem, Abertura à comunicação do enfermeiro (a) - Paciente e Disponibilidade para o cuidado). **Resultados.** Dos participantes, 51% eram mulheres, com média de idade de  $46.5 \pm 16.6$  anos. 54.9% apresentavam diagnóstico de Linfoma e 78.4% encontravam-se na fase de indução do tratamento. Em 30 dos 32 itens do instrumento, mais de 90% dos participantes avaliaram a adesão ao comportamento de cuidado no nível “sempre”. Por categorias, observou-se que para “Disponibilidade para o cuidado” houve significativamente menor pontuação entre os pacientes de 18 a 49 anos ( $p=0.0455$ ). Na categoria “Abertura à comunicação enfermeiro-paciente” houve menor pontuação mediana nos pacientes com Mieloma ( $p=0.0043$ ) e nos pacientes em fase de Remissão-Consolidação ( $p=0.0084$ ). Os dias de internação estiveram significativamente associados à categoria “Disponibilidade para o atendimento”, sendo menos com 16 dias e mais ( $p=0.0242$ ). **Conclusão.** Observou-se alta frequência de comportamentos de cuidado humanizado e pequenas diferenças na avaliação que estiveram associadas a fatores demográficos como idade e a fatores clínicos como diagnóstico, fase do tratamento e dias de internação.

**Descritores:** humanização da assistência; enfermagem oncológica; relações enfermeiro-paciente; educação em saúde.

## Introduction

The care and wellbeing of people receiving health care seeks to be the focus of every health system. Given this, it is imperative that these be delivered by humanized systems, that is, that these involve closely the ethical commitment and caring for people. This is based on the fact that said ethical treatment, worthy and of quality, is deserved by every person and within the health environment; this setting is understood as a right, a transversal human good and a fundamental axis in society.<sup>(1)</sup> The human and therapeutic relation between patients and professionals who provide care comprises a social phenomenon that is the core of treatment success within the health-disease process,<sup>(2)</sup> and which has implications, among other aspects, on adherence to treatment, always mediated by qualities like respect, empathy, and motivation.<sup>(3,4)</sup>

Health care has become sophisticated due to progress in knowledge and technology, which – undoubtedly – has contributed to better health management, but also has generated fragmentation within care, finding patients who perceive distant care, and manifest feeling vulnerable in front of professionals with mostly technical and procedural aptitudes than with a human attitude.<sup>(5)</sup> Humanization in caring has been proposed and highlighted for some years by Jean Watson, principally because the rational dimension of nursing, that is, the affective transpersonal relationship, stands in the foreground. The patient-nurse meeting can evolve to a moment of care, depending on the conscience, authenticity, and intentionality of the professional. A relationship of transpersonal care transforms the nurse and the patient alike, or in other words, it is characterized by mutuality and reciprocity. Additionally, the nurse's commitment seeks to help the patient to find meaning in their life and health experiences.<sup>(6)</sup>

Human care, then, includes the presence and dialogue between the care provider and the patient, and this real presence is part of the concept of environment in care. This environment provides an atmosphere that facilitates communication at individual and collective levels and is not limited to physical domain measurements.<sup>(7)</sup> Moreover, the association and humanist-scientific interaction constitute the essence of the nursing discipline, hence, it is fundamental for nursing professionals to focus on what needs to be done, from humanized care, which increases quality and user satisfaction, thus, having better resolution of their care demands, and covering integrally and globally the users' needs.<sup>(8)</sup> The wear and vulnerability of patients with diseases of poor prognosis and with high lethality in the often limited term, make it necessary to emphasize care for these patients and their families as human beings and to efficiently and closely develop humanized care. In this sense, cancer patients are subjected to multiple factors that impact directly on their health-disease process, which condition explicit needs of humanized care that include the

emotional, spiritual, social, and affective needs of a patient considered severely sick.<sup>(9)</sup>

Due to the foregoing, this work focused on delving into the experience of humanized care, so far studied mostly from the depersonalization of health professionals, or vulnerability of patients,<sup>(10)</sup> and looking for some factors that could be related with this experience. Consequently, the objective was to determine the perception of behaviors of humanized nursing care and its relation with the sociodemographic and clinical variables of patients hospitalized in a Hemato-Oncology Department of a high-complexity hospital from southern Chile, who were subjected to rigorous care at technical level, and furthermore are vulnerable patients by being closely linked to a high mortality scenario.

## Methods

Analytical cross-sectional study conducted with 51 patients from the Hemato-Oncology Department at Hospital Base Valdivia, a high-complexity establishment in the city of Valdivia, Los Ríos region, southern Chile, during the fourth trimester of 2019. This hospital constitutes a regional and supra-regional reference center for hemato-oncological disorders and radiotherapy of the country's Extreme South Macro Zone. The study worked with target population and not with a sample, given that the statistics of hospital discharges for the fourth quarter of the previous year (2018) were reviewed, which were 52 patients. Consequently, all potential participants of the fieldwork period were invited (October to December 2019).

The inclusion criteria established were being  $\geq$  18 years of age, hospital stay for  $>$  48 h, and having signed the informed consent to participate. The exclusion criteria considered any condition that implied neurological compromise or cognitive alteration, which would impede answering the questionnaire. The instruments used included

a questionnaire created for this study, to obtain information from the sociodemographic and clinical setting. The study also applied the instrument Perception about Behaviors of Humanized Nursing Care 3rd version (PBHNC V3) THAT permits evaluating the characteristics of humanized nursing care in hospital scenarios. The adaptation, validity, and measurement of the reliability of the PBHNC v3 instrument was carried out by González in Colombia,<sup>(11)</sup> and among its psychometric tests highlights 0.98 content validity (face validity = 0.78) and internal consistency of 0.96. The instrument has 32 items designed directionally, grouped into three categories: i) Qualities of nursing work that include seven items; ii) Openness to nurse-patient communication that contains eight items; iii) Willingness to care, which encompasses the remaining 17 items. Each item is structured as a four-point Likert scale, with levels associated with the score, like: 1 never, 2 sometimes, 3 almost always, and 4 always. Thus, the instrument has a score range from 32 to 128. In Chile, the transcultural adaptation and validation of the same instrument was conducted by experts, but with a limited population ( $n = 60$ ),<sup>(12)</sup> and, therefore, it may suffer from validity limitations. Nevertheless, this experience permitted recognizing that the questionnaire is applicable to the Chilean context. This work opted for applying the original version validated in Colombia after receiving authorization from the authors.

This study performed a descriptive statistical analysis and of association of the study variables, with calculation of mean, medians, mode and standard deviation to determine the perception of humanized care (global and by categories) provided nursing professionals to patients hospitalized in the unit described. The analysis began with an exploratory data evaluation to detect inconsistent or lost data. Thereafter, the descriptive analysis was developed from measures of central tendency and dispersion for the quantitative variables, like age, days of hospitalization, global score and score by categories, among others. Meanwhile, the qualitative, nominal and categorical variables (sex, diagnosis, treatment stage, etc.) are presented

using absolute and relative frequency distribution. To describe pertinently the quantitative variables and then, determine the adequate association analysis techniques, the fit of the quantitative variables to the normal distribution was evaluated by graphic evaluation (histogram) and the Shapiro-Wilk test. Thus, means and their standard deviation (SD) are described, and medians with the interquartile range (IQR). The analysis of association compared the median scores of the global PBHNC, and scores by categories, according to categorical sociodemographic and clinical variables, using the Mann-Whitney U test or the Kruskal-Wallis test, as corresponded. A level of statistical significance ( $\alpha$ ) of 0.05 was established. All the data were registered on a chart in Microsoft Office Excel 2016 (Microsoft Corporation, Redmond, WA, USA), and then exported to the Stata v.13 statistical package (College Station, TX, StataCorp LP 2013).

In the development of the study, the ethical aspects were protected with the evaluation and approval

of the protocol by the Human Research Ethics Committees from the Valdivia Health Services, 2019 (Ord. N°354), respecting the principles and norms of the bioethics of human research.

## Results

Regarding the sociodemographic profile, 51% of the group studied were women, with mean age of  $46.5 \pm 16.6$  years, 54.9% within the age range between 18 and 49 years; 47.1% came from the Region of Los Ríos, mostly from the urban area (72.5%). In all, 92.2% had a support network during their hospitalization period. Furthermore, with respect to the clinical profile, it was found that 54.9% were admitted due to diagnosis of Lymphoma, 78.4% was in the induction stage of their treatment, with a median of 15 days of hospitalization, and 68.6% de los patients had no previous hospitalizations (Table 1).

**Table 1. Sociodemographic and clinical profile of the patients (n = 51)**

Variable	Value
Sex; <i>n</i> (%)	
Male	25 (49)
Female	26 (51)
Age, years; Mean (SD)	46.5 (16.6)
Age range <i>n</i> (%)	
18-49	28 (54.9)
50 and more	23 (45.1)
Region; <i>n</i> (%)	
Los Lagos	20 (39.2)
Los Ríos	24 (47.1)
Other	7 (13.7)
Area; <i>n</i> (%)	
Urban	37 (72.5)
Rural	14 (27.5)
Has support network; <i>n</i> (%)	47 (92.2)
Diagnosis; <i>n</i> (%)	
Lymphoma	28 (54.9)
Leukemia	15 (29.4)
Myeloma	8 (15.7)
Treatment stage; <i>n</i> (%)	
Induction	40 (78.4)
Remission-Consolidation	11 (21.6)
Hospital stay, days; Median [IQR]	15 [6-31]
Days of hospitalization; <i>n</i> (%)	
< 7	13 (25.5)
7-15	13 (25.5)
16-30	12 (23.5)
31 and more	13 (25.5)
Previous hospitalizations; <i>n</i> (%)	16 (31.4)

SD: standard deviation; IQR: Interquartile range.

Regarding the perception of humanized care and the assessment by patients of each category of the PBHNC v3, it was observed that the global score ranged between 94 and 128 with a median

value of 128. By categories, the median values were: Qualities of nursing work 28, Openness to nurse-patient communication 32 and Willingness to care 68 (Table 2).

**Table 2. Descriptive statistics of the PBHNC 3v scores, global and by categories in patients from the Hemato-Oncology Unit at HBV (n = 51)**

PBHNC v3	Items	Median	IQR	Minimum	Maximum
Global score	32	128	126-128	94	128
<i>Categories</i>					
Qualities of nursing work	7	28	28-28	23	28
Openness to nurse-patient communication	8	32	31-31	21	32
Willingness to care	17	68	67-68	44	68

IQR: Interquartile range.

Additionally, it is highlighted that only two items were evaluated with less than 90% of the maximum value, with these being item 12 from the category of Openness to nurse-patient communication (“They indicate their name and position before

performing the procedures”), (76.5%) and item 13 from the category of Willingness to care (“They dedicate the time required for your care”), (86.3%). Besides, 18 items were evaluated entirely with the valuation of Always or Almost always (Table 3).

**Table 3. Distribution of patients (n = 51) according to the PBHNC 3v evaluation.**

Category/related items	Always (4)		Almost always (3)		Sometimes (2)		Never (1)	
	n	%	n	%	n	%	n	%
<b>Qualities of nursing work</b>								
1. They make you feel like a person	48	94.1	3	5.9	0	0	0	0
2. You are treated kindly	51	100	0	0	0	0	0	0
6. They make you feel well cared for when they talk to you	47	92.2	4	7.8	0	0	0	0
7. They make you feel calm when they are with you	51	100	0	0	0	0	0	0
8. They generate confidence when caring for you	50	98.0	1	2	0	0	0	0
15. They explain the care using a slow tone of voice	48	94.1	3	5.9	0	0	0	0
17. They show respect for your beliefs and values	48	94.1	2	3.9	1	2	0	0
<b>Openness to nurse-patient communication</b>								
4. They look in your eyes when talking to you	48	94.1	3	5.9	0	0	0	0
5. They take time to clarify your concerns	46	90.2	4	7.8	1	2	0	0
9. They facilitate dialogue	46	90.2	3	5.9	2	3.9	0	0
10. They explain the procedures previously	47	92.2	2	3.9	1	2	1	2
11. They answer your questions with security and clarity	47	92.2	4	7.8	0	0	0	0
12. They state their name and position before performing the procedures	39	76.5	7	13.7	5	9.8	0	0



**Table 3. Distribution of patients (n = 51) according to the PBHNC 3v evaluation. (Cont)**

Category/related items	Always (4)		Almost always (3)		Sometimes (2)		Never (1)	
	n	%	n	%	n	%	n	%
14. They provide indications about your care when you require it or according to your health situation	47	92.2	4	7.8	0	0	0	0
19. They provide you with sufficient and timely information so that you can make decisions about your health situation	48	94.1	3	5.9	0	0	0	0
<b>Willingness to care</b>								
3. They show interest in providing you with comfort during your hospitalization	50	98	1	2	0	0	0	0
13. They dedicate the time required for your care	44	86.3	6	11.7	1	2	0	0
16. They call you by your name	49	96.1	1	2	1	2	0	0
18. They care for your basic needs (hygiene, food, urinary and bowel evacuation) in a timely manner	50	98	1	2	0	0	0	0
20. They tell you that they are looking out for you	48	94.1	3	5.9	0	0	0	0
21. They allow you to express your feelings about the disease and treatment	46	90.2	3	5.9	2	3.9	0	0
22. They respond promptly to your call	47	92.2	3	5.9	1	2	0	0
23. They identify your physical, psychological, and spiritual needs	46	90.2	4	7.8	1	2	0	0
24. They listen to you attentively	47	92.2	3	5.9	1	2	0	0
25. They inquire and show concern for your mood	46	90.2	2	3.9	2	3.9	1	2
26. They provide you with warm and delicate care	48	94.1	2	3.9	1	2	0	0
27. They help you to manage physical pain	49	96.1	1	2	1	2	0	0
28. They demonstrate that they are responsible with your care	48	94.1	3	5.9	0	0	0	0
29. They respect your decisions	49	96.1	2	3.9	0	0	0	0
30. They tell you that when you need something, you can call them	51	100	0	0	0	0	0	0
31. They respect your intimacy	50	98	1	2	0	0	0	0
32. Medications prescribed by the physician are administered on time	50	98	1	2	0	0	0	0

Upon analyzing the relation of the perception of humanized care and the sociodemographic variables, it was proven that sex, area, support network, and region had no statistically significant differences regarding the PBHNC 3v global score and its categories. The age range had no statistically

significant differences in the categories of Qualities of nursing work and Openness to nurse-patient communication. However, in Willingness to care significant association was established, detecting lower scores in participants between 18 and 49 years of age (Table 4).

**Table 4. Global PBHNC 3v score and by categories (median and [interquartile range]), according to sociodemographic variables**

Variables	Global PBHNC score	Qualities of nursing work	Openness to nurse-patient communication	Willingness to care
Sex	$p=0.1210^*$	$p=0.9762^*$	$p=0.1535^*$	$p=0.2858^*$
Male ( $n = 25$ )	127 [125-128]	28 [28-28]	32 [31-32]	68 [67-68]
Female ( $n = 26$ )	128 [127-128]	28 [28-28]	32 [32-32]	68 [68-68]
Area	$p=0.4075^*$	$p=0.2781^*$	$p=0.5273^*$	$p=0.6003^*$
Urban ( $n = 37$ )	127 [127-128]	28 [28-28]	32 [31-32]	68 [67-68]
Rural ( $n = 14$ )	128 [126-128]	28 [28-28]	32 [31-32]	68 [68-68]
Support network	$p=0.2680^*$	$p=0.3755^*$	$p=0.5236^*$	$p=0.2118^*$
Yes ( $n = 47$ )	128 [126-128]	28 [28-28]	32 [31-32]	68 [67-68]
No ( $n = 4$ )	128 [127.5-128]	28 [28-28]	32 [31.5-32]	68 [68-68]
Age range	$p=0.3585^*$	$p=0.8693^*$	$p=0.9734^*$	$p=0.0455^*$
18-49 ( $n = 28$ )	127 [126-128]	28 [28-28]	32 [31-32]	68 [66.5-68]
50 and more ( $n = 23$ )	128 [127-128]	28 [28-28]	32 [31-32]	68 [68-68]
Region	$p=0.1440^\dagger$	$p=0.0796^\dagger$	$p=0.1927^\dagger$	$p=0.3902^\dagger$
Los Lagos ( $n = 20$ )	127.5 [127-128]	28 [28-28]	32 [31-32]	68 [67.5-68]
Los Ríos ( $n = 24$ )	128 [127-128]	28 [28-28]	32 [31.5-32]	68 [67.5-68]
Other ( $n = 7$ )	125 [98-128]	28 [26-28]	31 [24-32]	68 [54-68]

\*Mann-Whitney U test;  $^\dagger$ Kruskal-Wallis H test

With respect to the relation with clinical variables, it was noted that the diagnosis and treatment stage had no significant differences in the categories of Qualities of nursing work and Willingness to care but did indeed in Openness to nurse-patient communication and the PBHNC global score. There was a lower score in patients with Myeloma and subjects in the Remission-

Consolidation stage. Additionally, the variable of days of hospitalization was significantly associated with the category of Willingness to care, which had lower scores in those with 16 days and more. Lastly, the variable previous hospitalizations had no significant differences in relation with the global score and the categories of the PBHNC 3v instrument (Table 5).

**Table 5. Global score and by categories of the PBHNC v3 (median and [interquartile range]) and the clinical variables**

Variables	Global PBHNC score	Qualities of nursing work	Openness to nurse-patient communication	Willingness to care
Diagnosis	$p = 0.0118^\dagger$	$p = 0.4618^\dagger$	$p = 0.0043^\dagger$	$p = 0.1997^\dagger$
Lymphoma ( $n = 28$ )	128 [127-128]	28 [28-28]	32 [32-32]	68 [68-68]
Leukemia ( $n = 15$ )	128 [124-128]	28 [28-28]	32 [30-32]	68 [67-68]
Myeloma ( $n = 8$ )	125 [111.5-127]	28 [27-28]	30 [26.5-31.5]	67.5 [60-68]
Treatment stage	$p = 0.0144^\dagger$	$p = 0.1579^\dagger$	$p = 0.0084^\dagger$	$p = 0.0707^\dagger$
Induction ( $n = 40$ )	128 [127-128]	28 [28-28]	32 [31-32]	68 [68-68]
Remission-Consolidation ( $n = 11$ )	125 [109-128]	28 [26-28]	31 [26-32]	68 [57-68]
Days of hospitalization	$p = 0.3242^*$	$p = 0.0895^*$	$p = 0.5282^*$	$p = 0.0242^*$
$\leq 15$ ( $n = 26$ )	128 [127-128]	28 [28-28]	32 [31-32]	68 [68-68]
16 and more ( $n = 25$ )	128 [124-128]	28 [28-28]	32 [30-32]	68 [66-68]
Previous hospitalizations	$p = 0.9647^*$	$p = 0.5853^*$	$p = 0.7657^*$	$p = 0.5963^*$
No ( $n = 35$ )	128 [126-128]	28 [28-28]	32 [31-32]	68 [67-68]
Yes ( $n = 16$ )	127.5 [126.5-128]	28 [28-28]	32 [30.5-32]	68 [67.5-68]

\*Mann-Whitney U test;  $^\dagger$ Kruskal-Wallis H test

## Discussion

This study permitted establishing the perception of behaviors of humanized nursing care by patients hospitalized in a Hemato-Oncology Unit, highlighting the high score assigned to said care. In addition, it has been found that some sociodemographic and clinical variables are related with the patient's perception. In agreement with our findings, results within a similar Chilean context underscore that 86% of the patients hospitalized considered that they "always" received humanized care.<sup>(13)</sup> This same idea is held in other contexts, given that in Peru, more recently, perception was reported at excellent level in 84% of the patients from different hospitalization services<sup>(14)</sup> and in Colombia, 72% provided the same score.<sup>(15)</sup> Meanwhile, Mexico recently reported that 67% of the participants from

the context of surgical hospitalization, perceived the behavior of humanized care as favorable.<sup>(16)</sup> Nevertheless, another Colombian experience reported that only a little more than half of the patients studied (54.5%) considered that they "always" perceive the humanized-care behavior.<sup>(17)</sup>

From the point of view of sociodemographic factors, our work found no association with the patients' sex, while age was associated with the perception of humanized care in the settings included in the category of Willingness to care, where lower score was observed in individuals < 50 years of age. This coincides, in part, with that reported by Echevarría,<sup>(14)</sup> who found association of the quality of humanized care with the variables of sex and age.

From the clinical point of view, days of hospitalization were among the factors associated significantly with the category of Willingness

to care of the humanized-care behavior, but no relation existed with prior hospitalization. In the Colombian experience, neither days of hospitalization or the antecedent of prior hospitalization was related with the humanized-care behavior.<sup>(17)</sup> Within the same clinical context, in patients in the Remission-Consolidation stage lower frequency was evidenced in some behaviors of nursing care linked to humanized care within the setting of Openness to nurse-patient communication. Empirical observation permits supposing that this perception is given, in the first instance, by greater exposure to care and higher time of hospitalization in such a way that the care received, and the dialectical relationship established with the nursing professional is made more critical.

Whatever the scenario may be, always providing humanized care permits improving the quality of the existence of people, given that working with human sensitivity permits modifying and/or enhance positive conducts that impact upon a disease process, and confirm that the essence of nursing, that of caring, is significant and impacts upon the person when it is humanized because professionals are guided by values that will always look for the maximum wellbeing of others.

As concluded by Beltrán,<sup>(18)</sup> from a phenomenological study in cancer patients, humanized care is framed – finally – in the nurse-patient interaction, which implies demonstrating willingness and interest in the subject of care beyond the technical, considering ethical aspects and values of care and, lastly, having communications skills to establish a significant dialogic relationship

with other, considering the individual characteristics and those of the environment.

**Limitations and strengths.** Some limitations in this work must be considered to interpret and value its findings and scope. We could recognize that, although the study recruited all the patients from a period, the non-probabilistic nature of the selection limits – in part – the work's external validity. Moreover, we are unaware if a seasonal behavior may exist in user perception, given that the selection of the subjects occurred during a limited amount of time. Finally, the instrument applied to assess humanized care, although widely used, does not have rigorous validation in the Chilean context and although it has been already applied in our own setting, it must be recognized that the validity of the measurement could also be affected.

Notwithstanding the aforementioned, this work has strengths, like having collected the data in standard manner by the only researcher and that the analysis performed complied with the methodological rigor required giving the pertinent statistical treatment.

**Conclusion.** Nursing care, aimed at providing services in humanized manner, is recognized favorably by patients. Oncology departments require suitable professionals that show skills in distinct environments of clinical performance, integrating procedural and technical aspects and those aimed at emotional support, the capacity to prioritize the care demands and the disposition to communication. This requires identify potential sociodemographic and clinical factors that could necessitate greater emphasis in the dialectical nurse-patient relationship.

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# Effect of Educational Interventions to Reduce Readmissions due to Heart Failure Decompensation in Adults: a Systematic Review and Meta-analysis

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Systematic Review



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## Effect of Educational Interventions to Reduce Readmissions due to Heart Failure Decompensation in Adults: a Systematic Review and Meta-analysis

### Abstract

**Objective.** To estimate the combined effect of educational interventions (EI) on decreased readmissions and time of hospital stay in adults with heart failure, compared with usual care. **Methods.** Systematic review (SR) and meta-analysis (MA) of randomized controlled trials that followed the recommendations of the PRISMA statement. The protocol was registered on PROSPERO (CRD42019139321). Searches were made from inception until July 2019 in the databases of PubMed/Medline, Embase, Cochrane CENTRAL, Lilacs, Web of Science, and Scopus. The MA was conducted through the random effects model. The effect measure used for the dichotomous outcomes was relative risk (RR) and for continuous outcomes the mean difference (MD) was used, with 95% confidence intervals (CI). Heterogeneity

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was evaluated through the inconsistency statistic ( $I^2$ ). **Results.** Of 2369 studies identified, 45 were included in the SR and 43 in the MA. The MA of studies with follow-up at six months showed a decrease in readmissions of 30% (RR: 0.70; 95% CI: 0.58 to 0.84;  $I^2$ : 0%) and the 12-month follow-up evidenced a reduction of 33% (RR: 0.67; 95% CI: 0.58 to 0.76;  $I^2$ : 52%); both analyses in favor of the EI group. Regarding the time of hospital stay, a reduction was found of approximately two days in patients who received the EI (MD: -1.98; 95% CI: -3.27 to -0.69;  $I^2$ : 7%). **Conclusion.** The findings support the benefits of EI to reduce readmissions and days of hospital stay in adult patients with heart failure.

**Descriptors:** heart failure; patient readmission; patient education as topic; self-care; systematic review.

## Efecto de intervenciones educativas para reducir readmisiones debido a descompensación de falla cardiaca en adultos: una revisión sistemática y meta-análisis

### Resumen

**Objetivo.** Estimar el efecto combinado de las intervenciones educativas (IE) en la disminución de readmisiones y tiempo de estancia hospitalaria en adultos con falla cardiaca comparado con el cuidado usual. **Métodos.** Revisión Sistemática (RS) y meta-análisis (MA) de ensayos clínicos aleatorizados que siguieron las recomendaciones de la declaración PRISMA. El protocolo se registró en PROSPERO (CRD42019139321). Se realizaron búsquedas desde el inicio hasta julio de 2019, en las bases de datos PubMed/Medline, Embase, Cochrane CENTRAL, Lilacs, Web of Science y Scopus. El MA se realizó mediante modelo de efectos aleatorios. La medida de efecto utilizada para los desenlaces dicotómicos fue el riesgo relativo (RR) y para desenlaces continuos se usó la diferencia de medias (DM), con sus intervalos de confianza (IC) del 95%. La heterogeneidad se evaluó mediante el estadístico de inconsistencia ( $I^2$ ). **Resultados.** De 2369 estudios identificados, 45 se incluyeron en la RS y 43 en el MA. El MA de estudios con seguimiento a seis meses mostró una disminución en las readmisiones de 30% (RR: 0.70; IC 95%: 0.58 a 0.84;  $I^2$ : 0%) y el seguimiento a doce meses evidenció una reducción de 33% (RR: 0.67; IC 95%: 0.58 a 0.76;  $I^2$ : 52%), ambos análisis a favor del grupo de IE. Referente al tiempo de estancia hospitalaria, se encontró una reducción de aproximadamente dos días

en los pacientes que recibieron las IE (DM: -1.98; IC 95%: -3.27 a -0.69; I<sup>2</sup>: 7%). **Conclusión.** Los hallazgos soportan los beneficios de las IE para la disminución de readmisiones y días de estancia hospitalaria en pacientes adultos con falla cardíaca.

**Descriptor:** insuficiencia cardíaca; readmisión del paciente; educación del paciente como asunto; autocuidado; revisión sistemática.

## Efeito de intervenções educacionais para reduzir as readmissões devido à descompensação da insuficiência cardíaca em adultos: uma revisão sistemática e meta-análise

### Resumo

**Objetivo.** Estimar o efeito combinado de intervenções educacionais (IE) na redução de readmissões e tempo de internação em adultos com insuficiência cardíaca, em comparação com o cuidado usual. **Métodos.** Revisão sistemática (RS) e meta-análise (MA) de ensaios clínicos randomizados que seguiu as recomendações da declaração PRISMA. O protocolo foi registrado no PROSPERO (CRD42019139321). Foram realizadas buscas desde o início até julho de 2019, nas bases de dados PubMed/Medline, Embase, Cochrane CENTRAL, Lilacs, Web of Science e Scopus. A MA foi realizada usando um modelo de efeitos aleatórios. A medida de efeito utilizada para desfechos dicotômicos foi o risco relativo (RR) e para desfechos contínuos foi usada a diferença de médias (DM), com seus intervalos de confiança (IC) de 95%. A heterogeneidade foi avaliada por meio da estatística de inconsistência (I<sup>2</sup>). **Resultados.** De 2369 estudos identificados, 45 foram incluídos na RS e 43 na MA. A MA dos estudos com seguimento de seis meses mostrou uma diminuição nas readmissões de 30% (RR: 0.70; IC 95%: 0.58 a 0.84; I<sup>2</sup>: 0%) e o seguimento de doze meses mostrou uma redução de 33 % (RR: 0.67; IC 95%: 0.58 a 0.76; I<sup>2</sup>: 52%), ambas as análises em favor do grupo de IE. Em relação ao tempo de internação, foi observada uma redução de aproximadamente dois dias nos pacientes que receberam as IE (DM: -1.98; IC 95%: -3.27 a -0.69; I<sup>2</sup>: 7%). **Conclusão.** Os achados evidenciam os benefícios das IE para a redução de readmissões e dias de internação em pacientes adultos com insuficiência cardíaca.

**Descritores:** insuficiência cardíaca; readmissão do paciente; educação de pacientes como assunto; autocuidado; revisão sistemática.

# Introduction

**H**ear failure (HF) is part of the group of cardiovascular diseases. Defining this disease is complex, given that it involves different processes and its etiology is also varied, which is why it is referred to as a “syndrome”. Simply stated, it may be understood as “state in which the heart is not capable to pump the amount of blood necessary to fulfil the needs of the organism”.<sup>(1)</sup> Moreover, due to its high morbidity and mortality figures,<sup>(2,3)</sup> currently, HF is considered a public health problem, besides implying a high cost for governments and health systems. Evidence shows that the prevalence of HF increases gradually with age and it is estimated to affect 10% of elderly adults, becoming the first cause of hospitalization in this population.<sup>(4)</sup>

In relation with the socioeconomic burden due to HF, some European and South American countries show high costs for health services,<sup>(3,5,6)</sup> which has become a great concern for the governments and health institutions. Another one of the serious problems of HF is the increase of readmissions of patients due to the decompensation of the disease.<sup>(4)</sup> Within this context, over time, specialized units have been created with programs of multidisciplinary approach for the integral management of patients with HF.<sup>(3)</sup> Among these programs, education of patients is crucial to improve the clinical outcomes of patients. Health education is one of the professional roles of nursing. Nurses must have the ability to evaluate the patients’ individual needs for education and be able to improve their self-care practices that contribute to the reduction of readmissions.<sup>(2)</sup> Educational interventions can vary in their intensity, methodology, or strategy. The effect sought with these interventions is to achieve a greater number of patients with HF aware of their disease and of the importance of self-care habits for their health. This, in turn, favors better control of the disease and reduction of the different complications and costs associated with HF.<sup>(5,6)</sup>

Due to the aforementioned, up-to-date syntheses are required of the literature that evidences the effect the educational interventions have on reducing readmissions due to decompensation of the HF syndrome. Although primary studies exist to address this problem, it is important to group systematically every evidence to permit greater comprehension of the phenomenon and generate new results that contribute to the recovery of individuals who endure this disease. Hence, the objective of this study was to estimate the combined effect of the educational interventions on reducing hospital readmissions and time of hospital stay in adults with HF, compared with usual care.

## Methods

**Design and registry of the protocol.** This was a systematic review (SR) and meta-analysis (MA) of randomized controlled trials (RCTs) that followed the recommendations of the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement <sup>(7)</sup> and of the Cochrane Handbook <sup>(8)</sup> for SR of intervention studies. The protocol was registered in the International Prospective Register of Systematic Reviews (PROSPERO) with code CRD42019139321.

**Source of data and search strategy.** The information was collected from the following electronic databases: PubMed/Medline, Embase, Lilacs, Cochrane CENTRAL, Scopus, and Web of Science. Searches were made from inception until July 2019, using MeSH terms and entry terms for PubMed/Medline, emtree terms for Embase and descriptors for the other databases. Likewise, the following filters were used for the search strategy: randomized controlled trials, studies in humans and English, Portuguese, Spanish languages. To identify additional studies, search was made in other sources that included the review of references of the studies included, SR published, and the network of primary registries of RCTs recognized by the World Health Organization.

The following search strategy was used for PubMed/Medline: *((Heart failure[MeSH Terms]) OR (Cardiac Failure)) OR (Heart Decompensation)) OR (Decompensation, Heart)) OR (Congestive heart failure)) OR (Heart Failure, Congestive)) ) AND (Knowledge[MeSH Terms]) AND (Self-care[MeSH Terms])) OR (Care, Self)) OR (Self-care behaviors[MeSH Terms]) OR (Self-management[MeSH Terms]) OR (Management, Self)) OR (Self-efficacy[MeSH Terms]) OR (Efficacy, Self)) OR (Self Concept[MeSH Terms]) OR (Self-confidence)) OR (Confidence, Self)) AND (Education[MeSH Terms]) AND (Patient education[MeSH Terms])*

*) ) OR (Education, Patient)) ) OR (Education of Patients) ) AND (Education, nursing [MeSH Terms])) ) OR (Nursing Education)) OR (Educations, Nursing)) OR (Nursing Educations)) AND (Health education[MeSH Terms])) OR (Education, Health)) AND (Standard of Care).*

**Eligibility criteria of the studies.** This SR and MA included experimental studies or RCTs-type intervention studies. The following PICO (population, intervention, comparator, outcomes) research question was used to consider the eligibility of the studies, P: adult patients with HF in any stage of the disease; I: educational interventions; C: usual or standard care, and O: reduced readmissions and time of hospital stay due to decompensation of the HF.

**Data extraction.** Identification and selection of the studies was performed independently by two reviewers, who were young undergraduate researchers with prior training and certification in SR and MA. Disagreements were solved through the intervention of a third reviewer, senior researcher with PhD formation and experience in SR and MA. Articles duplicated in several databases were considered only once. The Mendeley reference manager was used to store references and eliminate duplicate studies.

**Outcomes.** The principal outcome was the decrease of hospital readmissions due to decompensation of the HF and the secondary outcome was the decrease of days of hospital stay.

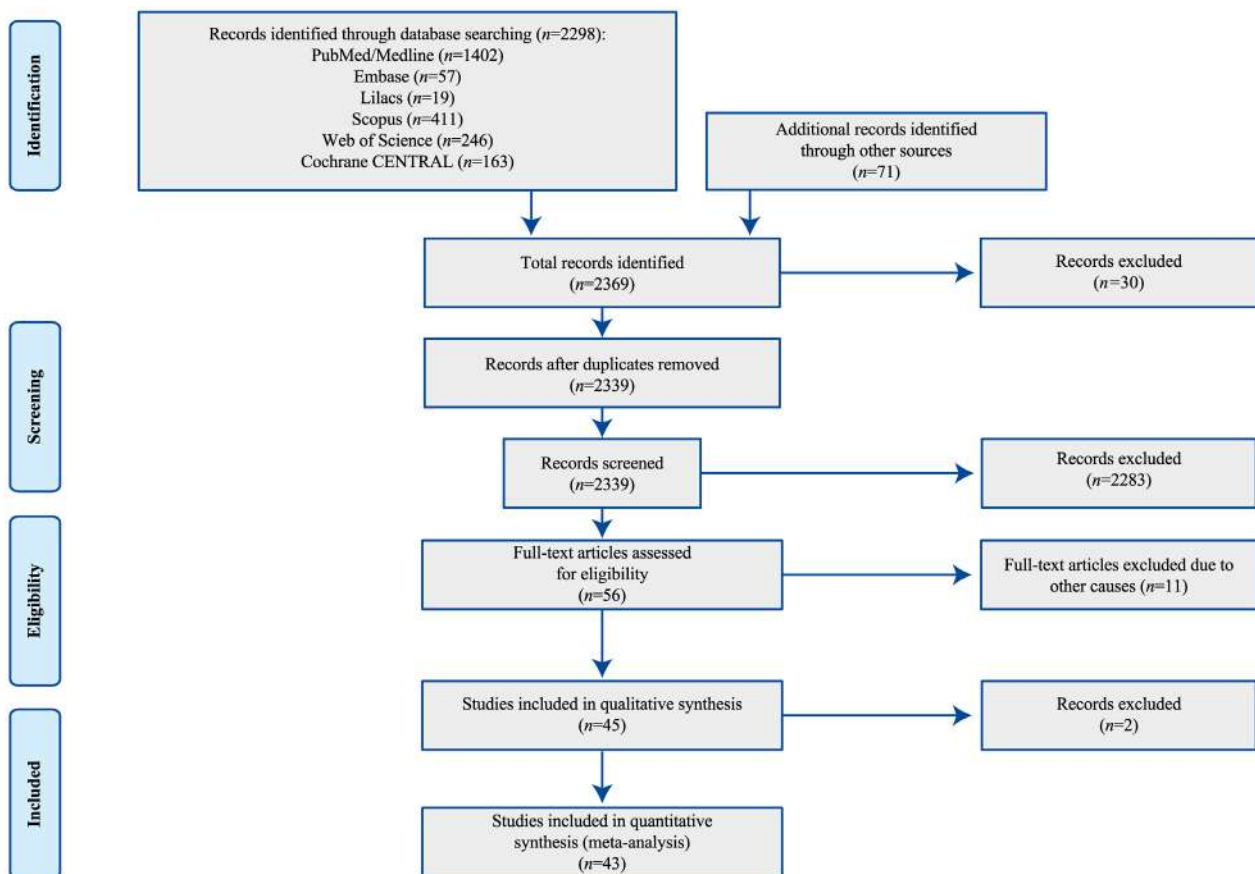
**Evaluation of the risk of study bias.** The risk of bias (RoB 1) tool from the Cochrane Collaboration <sup>(9)</sup> was used to evaluate the risk of bias in RCTs. The following parameters were evaluated: random sequence generation and allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective reporting of results and other sources of bias.

**Data analysis.** Estimation of the grouped effect was conducted with the Review Manager (RevMan 5.4) software from the Cochrane Collaboration.

The dichotomous results are presented and compared by using relative risk (RR) through the Mantel-Haenszel method and for continuous results the mean difference (MD) is presented through the inverse-variance weighted; both with their respective 95% confidence intervals (CI). Likewise, to quantify the heterogeneity of the studies included, the inconsistency ( $I^2$ ) statistic was used and the graphic presentation of the MA results used the forest plot. To evaluate publication bias or bias due to missing results, the Stata 16.0 software was used, through the Egger test and the funnel plot.

## Identification and selection of the studies

The work identified 2369 studies, of which 45 studies were included in the SR and data from 43 studies were included in the MA. Two studies were excluded from the MA because the data on readmissions corresponded to follow-up times different from the other studies and, hence, it was not possible to meta-analyze. The flow diagram for the selection and exclusion of studies is shown in Figure 1.



**Figure 1. PRISMA flow diagram for the studies selection**

### Characteristics of studies included

The general description of the studies is shown in Table 1, which contains the author, year of

publication, country, a brief description of the intervention, time of follow-up, and most relevant results for the research.

**Table 1. Characteristics of the included studies**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Aldamiz-Echevarría <i>et al.</i> , 2007 (10)	Spain	279	Educational program on basic data of HF and its treatment.	3, 6 and 12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 55 Control: 57 <b>Days of hospital stay+</b> Intervention: 8.5 (6.4) Control: 8.4 (11.6)
Atienza <i>et al.</i> , 2004 (11)	Spain	338	Education before discharge on knowledge of the disease and its management. Home visits.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 61 Control: 122
Blue <i>et al.</i> , 2001 (12)	Scotland	165	Education through home visits and telecare on knowledge and treatment of HF. Educational brochure. Instruments for self-monitoring.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 12 Control: 26 <b>Days of hospital stay+</b> Intervention: 3.43 (12.2) Control: 7.46 (16.6)
Boyd <i>et al.</i> , 2018 (13)	United States	200	Education prior to discharge on HF. Brochure and video.	1, 3 and 12 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 8 Control: 10 <b>Readmissions* at 12 months</b> Intervention: 8 Control: 14
Brian <i>et al.</i> , 2009 (14)	United States	749	Education on HF. Brochure and telephone follow-up.	1 month	Standard care	<b>Readmissions* at 1 month</b> Intervention: 55 Control: 76
Brotos <i>et al.</i> , 2009 (15)	Spain	283	Pre-discharge education on HF with brochure. Home visits for one year. Phone follow-up every 15 days.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 52 Control: 62
Cañon-Montañez <i>et al.</i> , 2013 (16)	Colombia	116	Education on HF and its management. Face to face and phone education.	1 and 2 months	Standard care (phone call)	<b>Readmissions* at 2 months</b> Intervention: 11 Control: 5 <b>Days of hospital stay at 2 months</b> Intervention: 6.27 (5.93) Control: 11 (11)

**Table 1. Characteristics of the included studies (Cont)**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Cui <i>et al.</i> , 2019 (17)	China	96	Structured education in HF for one hour upon admission, and one hour before discharge. Phone or face-to-face consultation every 4 weeks.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 5 Control: 13
Davis <i>et al.</i> , 2012 (18)	United States	125	Education during hospitalization. Phone call after discharge. Video with recorded sessions. Supplies to aid self-care.	1 month	Standard care	<b>Readmissions* at 1 month</b> Intervention: 14 Control: 12
De Souza <i>et al.</i> , 2014 (19)	Brazil	252	Home visits to educate on HF. Phone calls to reinforce education.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 20 Control: 30
DeBusk <i>et al.</i> , 2004 (20)	United States	462	Education with a videotape. Telephone counseling and printed educational materials.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 76 Control: 86
Delaney <i>et al.</i> , 2013 (21)	United States	100	Telemonitoring. Brochure with information on HF and its management.	3 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 3 Control: 7
Dewalt <i>et al.</i> , 2006 (22)	United States	127	Education on HF and warning signs. Phone calls for reinforcement of the education. Educational brochure.	6 and 12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 18 Control: 20
Domingues <i>et al.</i> , 2011 (23)	Brazil	120	Phone calls after hospital discharge to educate and evaluate signs of decompensation of HF.	3 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 20 Control: 23 <b>Readmissions* at 12 months</b> Intervention: 22 Control: 42 <b>Days of hospital stay at 12 months+</b> Intervention: 4.1 (6.4) Control: 7.6 (12.1)
Doughty <i>et al.</i> , 2002 (24)	New Zealand	197	Educational brochure on HF and its management. Home visits.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 36 Control: 65
Dracup <i>et al.</i> , 2014 (25)	United States	614	Face-to-face education session delivered by a nurse focusing on self-care. Phone calls.	3, 12 and 24 months	Standard care	<b>Readmissions* at 24 months</b> Intervention: 63 Control: 64
Ducharme <i>et al.</i> , 2005 (26)	Canada	230	Visits to the HF clinic to provide education in the management of the disease. Phone calls every month. Educational brochure.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 45 Control: 66



**Table 1. Characteristics of the included studies (Cont)**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Gómez-López <i>et al.</i> , 2012 (27)	Spain	208	Follow-up in the HF clinic after discharge. Phone call after discharge to reinforce education. Home visit.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 11 Control: 14 <b>Days of hospital stay at 12 months+</b> Intervention: 6.7 (13.5) Control: 10.7 (22.2)
González-Guerrero <i>et al.</i> , 2014 (28)	Spain	116	Flyer with information about the disease. Follow-up call within 48 hours. Reinforcement of education after 10 days. Visits to the geriatric center to reinforce education.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 14 Control: 18 <b>Days of hospital stay at 12 months+</b> Intervention: 16.8 (18.2) Control: 20.6 (23.5)
Hägglund <i>et al.</i> , 2015 (29)	Sweden	72	Educational sessions at home through a tablet about HF and its management.	3 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 7 Control: 11
Holland <i>et al.</i> , 2007 (30)	United Kingdom	399	Home visit after discharge to educate on HF and its management. Follow-up visit to reinforce education.	3 and 6 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 12 Control: 9 <b>Readmissions* at 6 months</b> Intervention: 1 Control: 1
Jaarsma <i>et al.</i> , 1999 (31)	Netherlands	174	Education about HF, treatment and management during hospitalization. Phone call and home visit.	1, 3 and 9 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 18 Control: 23 <b>Days of hospital stay at 3 months+</b> Intervention: 3 (7) Control: 4.1 (10)
Jaarsma <i>et al.</i> , 2011 (32)	Netherlands	1049	Home visit after discharge and every 6 months to receive education on HF. Additional home visits (basic group). Monthly contact with the nurse, additional visits and telephone follow-up (intensive group).	18 months	Standard care	<b>Readmissions* at 18 months</b> Intervention: 134 Control: 120
Jerant <i>et al.</i> , 2001 (33)	United States	37	Two home visits after discharge. Phone calls. Telecare.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 1 Control: 4
Kato <i>et al.</i> , 2016 (34)	Japan	38	Education and advice on knowledge about HF and self-care.	24 months	Standard care	<b>Readmissions* at 24 months</b> Intervention: 2 Control: 7

**Table 1. Characteristics of the included studies (Cont)**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Kimmelstiel <i>et al.</i> , 2004 (35)	United States	200	Home visit. Manual with information on HF.	3 and 6 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 15 Control: 24 <b>Days of hospital stay at months+</b> Intervention: 4.3 (10.2) Control: 7.8 (19.7)
Koelling <i>et al.</i> , 2005 (36)	United States	223	Education prior to discharge on the management of HF. Information brochure. Application of self-care questionnaires.	1, 3 and 6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 16 Control: 33 <b>Days of hospital stay at 6 months+</b> Intervention: 13.1 (36) Control: 17.1 (37)
Krumholz <i>et al.</i> , 2002 (37)	United States	88	Sequential education on HF and its management. Educational brochure. Home visits. Telemonitoring to reinforce education.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 22 Control: 42 <b>Days of hospital stay at 12 months+</b> Intervention: 4.1 (6.4) Control: 7.6 (12.1)
Leventhal <i>et al.</i> , 2011 (38)	Switzerland	42	Home visit to provide HF education. Phone calls to reinforce education. Educational kit with self-care procedures.	3, 6, 9 and 12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 1 Control: 2
Mau <i>et al.</i> , 2017 (39)	United States	150	Educational modules on HF and its treatment.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 5 Control: 18
Melin <i>et al.</i> , 2018 (40)	Sweden	72	Education of self-care practices and management of HF.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 14 Control: 16
Naylor <i>et al.</i> , 2004 (41)	United States	239	Daily education during the hospitalization period. Home visits to reinforce education about HF and its management.	3, 6 and 12 months - 2, 6, 12, 26, 52 weeks	Standard care	<b>Readmissions* at 12 months</b> Intervention: 40 Control: 72 <b>Days of hospital stay at 12 months+</b> Intervention: 11.1 (7.2) Control: 14.5 (13.4)
Negarandeh <i>et al.</i> , 2019 (42)	Iran	80	Telemonitoring with HF education.	1 and 3 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 7 Control: 14
Otsu <i>et al.</i> , 2011 (43)	Japan	102	Educational program in HF clinic about the disease and its management.	3, 6, 9 and 12 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 1 Control: 1

**Table 1. Characteristics of the included studies (Cont)**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Ramachandran <i>et al.</i> , 2007 (44)	India	50	Education on HF, management and treatment. Reinforcement of education by phone calls. Patient education manual. Follow-up in the HF clinic.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 6 Control: 4
Rodríguez-Gázquez <i>et al.</i> , 2012 (45)	Colombia	63	Educational program in nursing (educational meetings, home visits, telenursing and a printed book) in the improvement of self-care behaviors.	9 months	Standard care	<b>Readmissions* at 9 months</b> Intervention: 30 Control: 24
Ruschel <i>et al.</i> , 2018 (46)	Brazil	252	Home visits and phone calls. Education on HF and self-care practices.	6 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 30 Control: 30
Sethares <i>et al.</i> , 2004 (47)	United States	70	Education about HF during hospitalization. Reinforcement education after discharge.	3 months	Standard care	<b>Readmissions* at 3 months</b> Intervention: 6 Control: 12
Stewart <i>et al.</i> , 2015 (48)	Australia and New Zealand	624	Home visit after discharge. Education on HF and its management. Personalized care plan.	1 and 36 months	Standard care	<b>Readmissions* at 36 months</b> Intervention: 17 Control: 17
Tomita <i>et al.</i> , 2009 (49)	United States	40	Information online about HF and its management.	6 and 12 months	Standard care	<b>Days of hospital stay at 6 months+</b> Intervention: 1 (2.45) Control: 0.84 (1.89) <b>Days of hospital stay at 12 months+</b> Intervention: 1.23 (2.55) Control: 2.42 (5.07)
Tsuchihashi-Makaya <i>et al.</i> , 2013 (50)	Japan	164	Pre-discharge education on HF and its management. Educational brochure. Home visits once a week for two months. Monthly telephone follow-up for six months.	2, 6 and 12 months	Standard care	<b>Readmissions* at 6 months</b> Intervention: 6 Control: 15 <b>Readmissions* at 12 months</b> Intervention: 6 Control: 9
Wakefield <i>et al.</i> , 2008 (51)	United States	148	Follow-up after discharge. Phone calls to provide HF education.	3, 6 and 12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 21 Control: 29
Wierzchowiecki <i>et al.</i> , 2006 (52)	Poland	160	Education and follow-up in the HF clinic. Phone calls for educational reinforcement.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 13 Control: 25

**Table 1. Characteristics of the included studies (Cont)**

First author, year	Country	Sample size	Intervention group	Follow-up	Control group	Main outcomes
Wright <i>et al.</i> , 2003 (53)	New Zealand	197	Clinical review after discharge. Home visits every 6 weeks to educate on HF, treatment and management.	12 months	Standard care	<b>Readmissions* at 12 months</b> Intervention: 46 Control: 18 <b>Days of hospital stay at 12 months+</b> Intervention: 9.4 (13.6) Control: 14.9 (18.8)
Yu <i>et al.</i> , 2015 (54)	China	178	Education before discharge about HF. Home visits and phone calls for educational reinforcement.	6 weeks, 3 and 9 months	Standard care	<b>Readmissions* at 6 weeks - 3 months - 9 months</b> Intervention: 7 - 12 - 6 Control: 10 - 7 - 3

HF: heart failure; \* Data presented as number of patients readmitted due to decompensation of HF; + Data presented as mean (standard deviation).

Table 1 shows that this SR included 9688 adult patients with HF. The studies were published between 1999 and 2019. The investigations were conducted in 16 countries, with the highest number of these in the United States and Spain (16 and 5, respectively). The follow-up of the studies included was carried out during different periods, comprised between the first month after the intervention and at 36 months. Studies with follow-up at 3, 6 and 12 months were predominant.

With respect to the educational interventions, these were diverse; however, common strategies were found in the studies included, like: education during hospitalization, telephone follow-up, home visits to reinforce the education, visits to HF clinics, and delivery of printed or digital educational material (brochures, videos or manuals) for consultation by the patients. The education centered on knowledge of the disease, warning signs, diet, and self-care practices.

Regarding the comparison with the control group, it was found that in general, the usual care was

perceived as the clinical care by the cardiologist and a single control visit in the outpatient care service.

### Analysis of the risk of bias of the studies included

The evaluation of the risk of bias of the studies is presented in Table 2. According with the parameters evaluated by the RoB 1 tool,<sup>(9)</sup> it was obtained that all the studies performed an adequate random sequence generation; allocation concealment was optimal in 65.1% of the studies included. Due to the nature of the educational interventions, in the studies it was not possible to conduct blinding of the patients and of the staff who offered the interventions. In relation blinding of outcome assessment, only 48.8% low risk was presented for this domain. In all, 93% of the studies described clearly the losses presented during the follow-up and if the data analysis was carried out through intention of treatment, which reduced the risk of bias due to incomplete results. Finally, regarding the risk of selective reporting of the results, it was found that 97.7% described the results proposed since the beginning (Table 2).

**Table 2. Assessment of risk of bias among included studies**

Studies	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Aldamiz-Echevarría <i>et al.</i> , 2007 (10)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Atienza <i>et al.</i> , 2004 (11)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Blue <i>et al.</i> , 2001 (12)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Boyd <i>et al.</i> , 2018 (13)	Low risk	Low risk	Low risk	High risk	Low risk	Low risk
Brian <i>et al.</i> , 2009 (14)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Brotans <i>et al.</i> , 2009 (15)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Cañon-Montañez <i>et al.</i> , 2013 (16)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Cui <i>et al.</i> , 2019 (17)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Davis <i>et al.</i> , 2012 (18)	Low risk	Unclear risk	Low risk	Low risk	Low risk	Low risk
De Souza <i>et al.</i> , 2014 (19)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
DeBusk <i>et al.</i> , 2004 (20)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Delaney <i>et al.</i> , 2013 (21)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Dewalt <i>et al.</i> , 2006 (22)	Low risk	Low risk	Low risk	High risk	Low risk	Low risk
Domingues <i>et al.</i> , 2011 (23)	Low risk	Unclear risk	Low risk	Unclear risk	Unclear risk	Low risk
Doughty <i>et al.</i> , 2002 (24)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Dracup <i>et al.</i> , 2014 (25)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Ducharme <i>et al.</i> , 2005 (26)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Gámez-López <i>et al.</i> , 2012 (27)	Low risk	Unclear risk	Low risk	Low risk	Unclear risk	Low risk
González-Guerrero <i>et al.</i> , 2014 (28)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Hägglund <i>et al.</i> , 2015 (29)	Low risk	Unclear risk	Low risk	Unclear risk	Low risk	Low risk
Holland <i>et al.</i> , 2007 (30)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Jaarsma <i>et al.</i> , 1999 (31)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Jaarsma <i>et al.</i> , 2011 (32)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Jerant <i>et al.</i> , 2001(33)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Kato <i>et al.</i> , 2016 (34)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Kimmelstiel <i>et al.</i> , 2004 (35)	Low risk	High risk	Low risk	Low risk	Low risk	Low risk
Koelling <i>et al.</i> , 2005 (36)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Krumholz <i>et al.</i> , 2002 (37)	Low risk	Unclear risk	Low risk	Unclear risk	Low risk	Unclear risk
Leventhal <i>et al.</i> , 2011 (38)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk

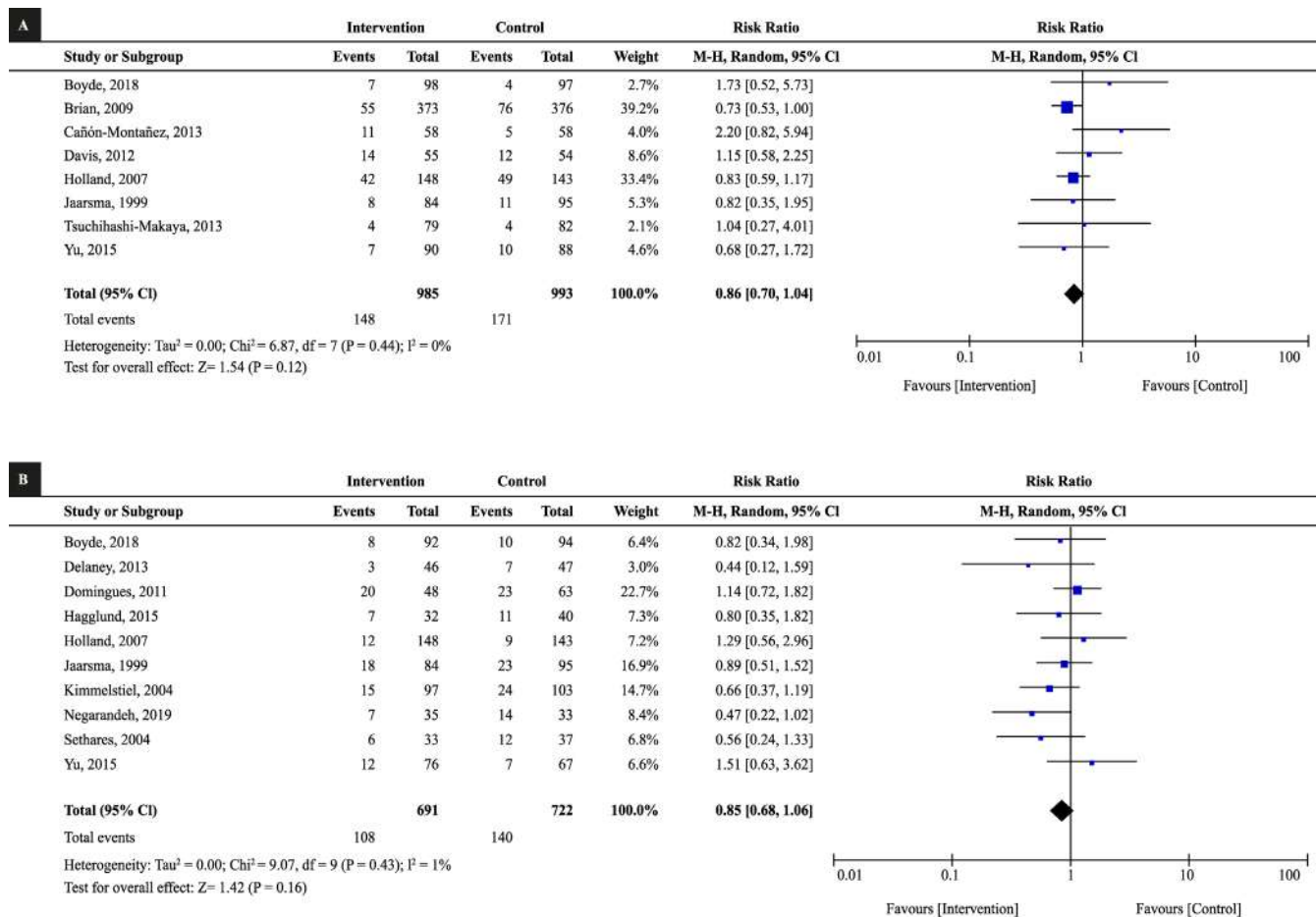
**Table 2. Assessment of risk of bias among included studies (Cont)**

Studies	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting
Mau <i>et al.</i> , 2017 (39)	Low risk	High risk	Low risk	Unclear risk	Low risk	Low risk
Melin <i>et al.</i> , 2018 (40)	Low risk	High risk	Low risk	Low risk	Low risk	Low risk
Naylor <i>et al.</i> , 2004 (41)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Negarandeh <i>et al.</i> , 2019 (42)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Otsu <i>et al.</i> , 2011 (43)	Low risk	Unclear risk	Low risk	High risk	Low risk	Low risk
Ramachandran <i>et al.</i> , 2007 (44)	Low risk	Low risk	Low risk	High risk	Low risk	Low risk
Rodríguez-Gázquez <i>et al.</i> , 2012 (45)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Ruschel <i>et al.</i> , 2018 (46)	Low risk	Unclear risk	Low risk	Low risk	Low risk	Low risk
Sethares <i>et al.</i> , 2004 (47)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Stewart <i>et al.</i> , 2015 (48)	Low risk	Low risk	Low risk	Low risk	Low risk	Low risk
Tomita <i>et al.</i> , 2009 (49)	Low risk	Unclear risk	Low risk	Unclear risk	Low risk	Low risk
Tsuchihashi Makaya <i>et al.</i> 2013 (50)	Low risk	Unclear risk	Low risk	Unclear risk	Low risk	Low risk
Walkefield <i>et al.</i> , 2008 (51)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk
Wierzchowiecki <i>et al.</i> , 2006 (52)	Low risk	Unclear risk	Low risk	Unclear risk	Unclear risk	Low risk
Wright <i>et al.</i> , 2003 (53)	Low risk	Unclear risk	Low risk	Unclear risk	Low risk	Low risk
Yu <i>et al.</i> , 2015 (54)	Low risk	Low risk	Low risk	Unclear risk	Low risk	Low risk

## Meta-analysis

The work included the results from 43 studies and analyzed hospital readmissions, during different follow-up periods, *i.e.*, 6 weeks, 1 month, 2, 3, 6, 9, 12, and 24 months. Upon evaluating the combined

effect, no statistically significant results were obtained in studies with follow-up <3 months nor at three months (Figure 2). Significant results were also not found at nine months (RR: 0.98, 95% CI: 0.64 to 1.54,  $I^2$ : 61%), as well as at 24 months (RR: 0.72, 95% CI: 0.24 to 2.17,  $I^2$ : 62%).

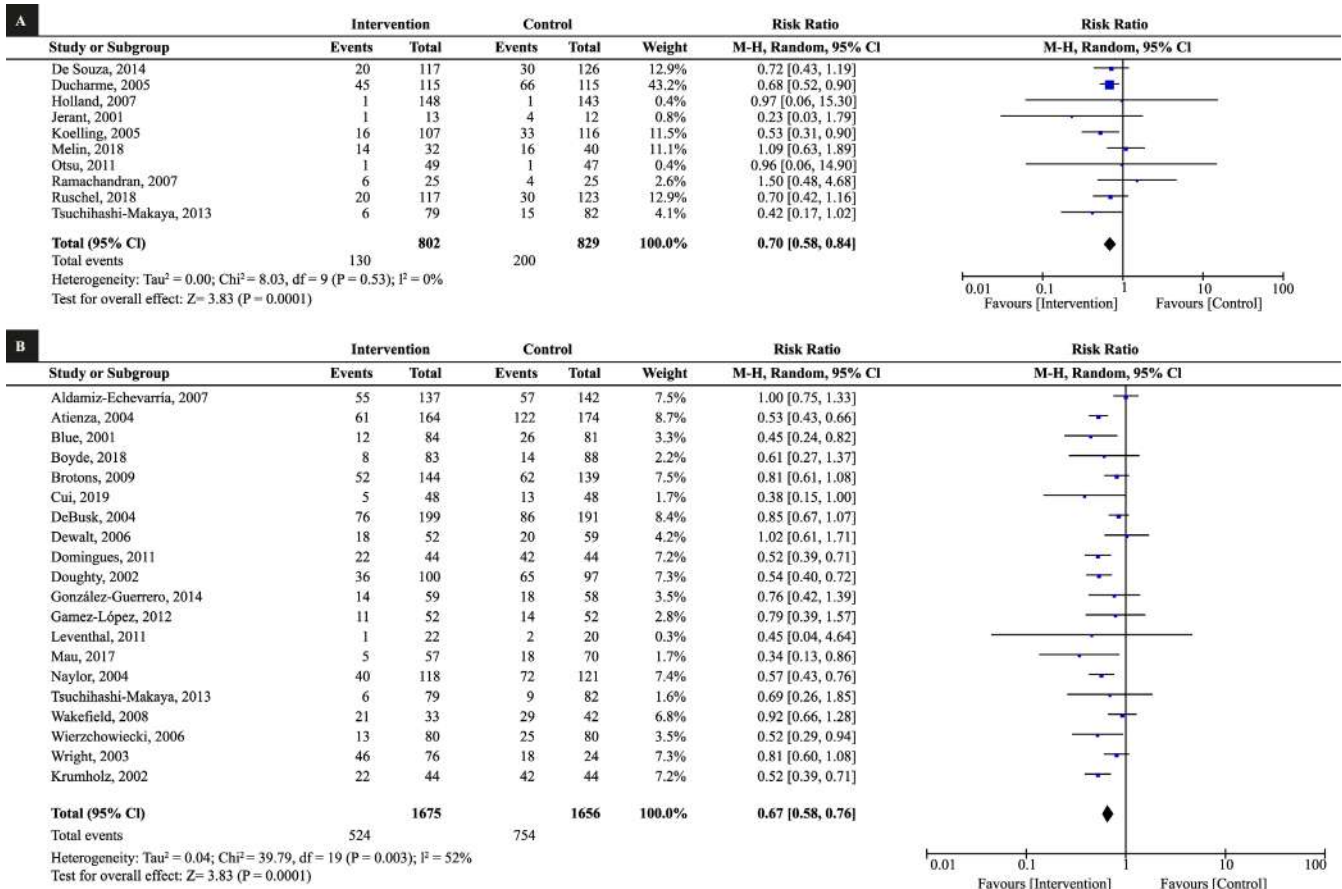


**Figure 2. Meta-analysis of the effect of the educational interventions on reducing readmissions due to heart failure. (A) Follow-up <3 months, (B) Follow-up at 3 months**

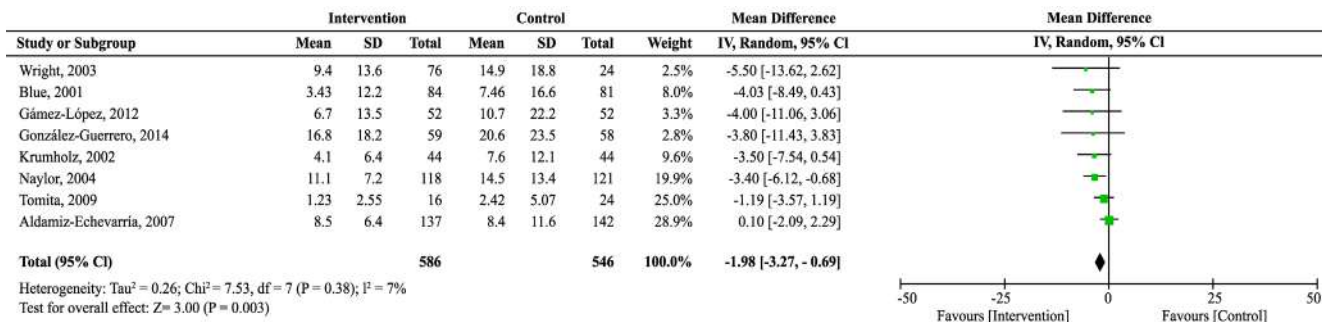
The MA of studies with follow-up at six months showed a 30% decrease in readmissions (RR: 0.70; 95% CI: 0.58 to 0.84; I<sup>2</sup>: 0%) and the 12-month

follow-up evidenced 33% reduction (RR: 0.67; 95% CI: 0.58 to 0.76; I<sup>2</sup>: 52%); both analyses in favor of the group of educational interventions (Figure 3).

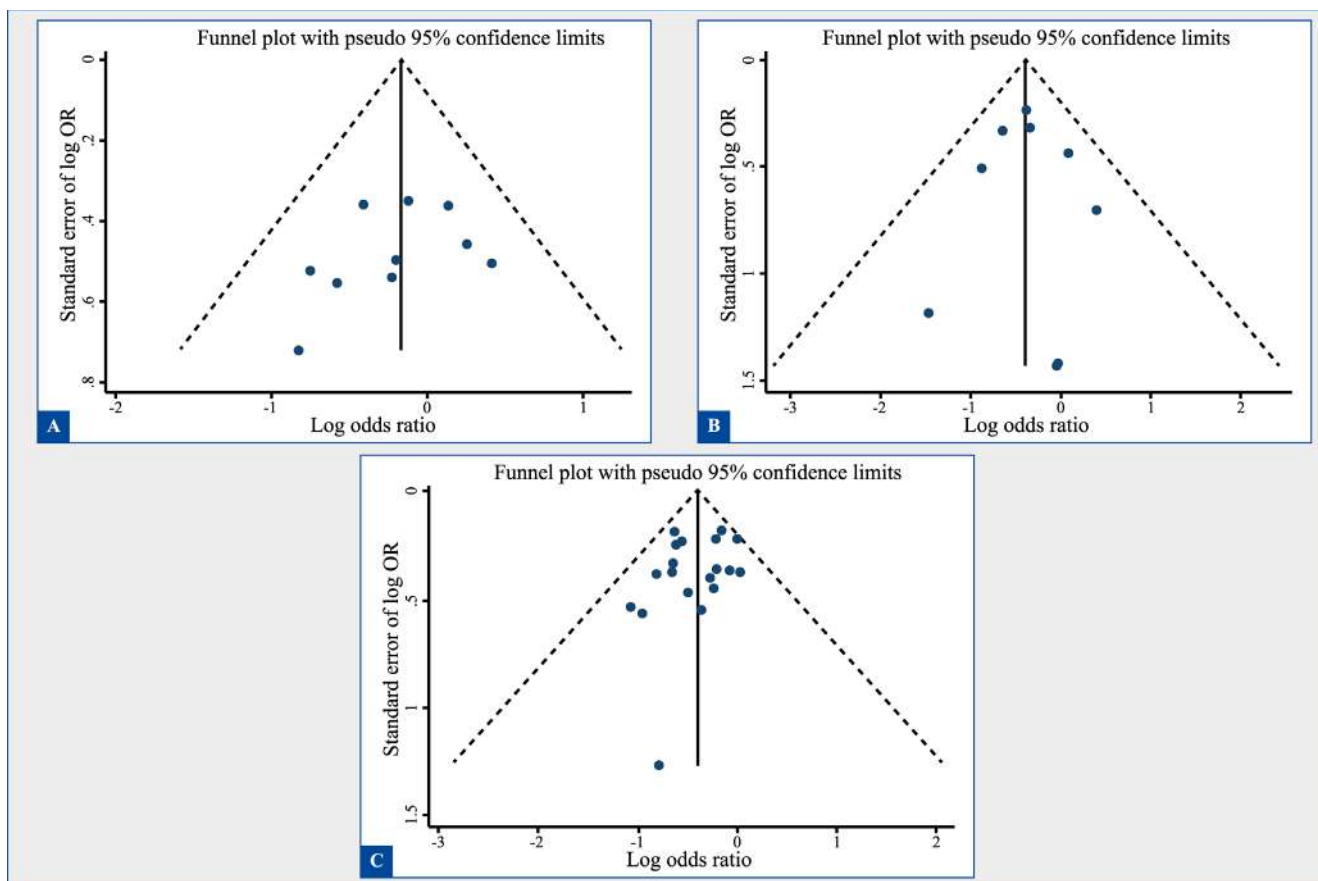




**Figure 3. Meta-analysis of the effect of educational interventions on reducing readmissions due to heart failure. (A) Follow-up at 6 months, (B) Follow-up at 12 months**



**Figure 4. Meta-analysis of the effect of educational interventions on reducing days of hospital stay due to heart failure at 12 months of follow-up**



**Figure 5. Funnel plot to analyze publication bias or bias due to missing results during three follow-up times. (A) 3 months, (B) 6 months, (C) 12 months**

For the secondary outcome, days of hospital stay, no favorable effect was found of the educational interventions during the follow-up at three months (MD: -1.71; 95% CI: -3.87 to -0.46; I<sup>2</sup>: 0%) and six months (MD: 0.07; 95% CI: -1.33 to 1.45; I<sup>2</sup>: 0%). Nevertheless, the MA with follow-up at 12 months (Figure 4) evidenced a reduction of approximately two days in patients who received the educational interventions (MD: -1.98; 95% CI: -3.27 to -0.69; I<sup>2</sup>: 7%).

### Evaluation of publication bias or bias due to missing results

Figure 5 shows funnel plot graphics to evaluate publication bias under analysis of 10 or more studies (three months, six months, and twelve months of follow-up). For the three times of follow-up, it is possible to observe generally a funnel shape that indicates that the studies are distributed uniformly on both sides of the average, which suggests lack of publication bias. The Egger statistical test also indicated absence of publication bias (3 months,  $p = 0.30$ ; 6 months,  $p = 0.87$ , and 12 months,  $p = 0.26$ ).

## Discussion

This up-to-date synthesis of the evidence shows the favorable combined effect of educational interventions during prolonged follow-up times (six and twelve months) to reduce readmissions and time of hospital stay in adults with HF. These results are coherent with other SR and MA conducted prior to this study.<sup>(55-57)</sup> In addition, the results found reinforce the importance of education for patients and of the multidisciplinary management of the HF syndrome. Similarly, these educational strategies become an alternative of effective intervention to improve the clinical outcomes of patients and which can be useful to reduce costs associated with health services due to HF decompensation. Within this context, a 2017 SR<sup>(55)</sup> concluded that educational interventions,

especially those guided by nurses, have positive effects on decreasing readmissions due to HF.

Two of its studies, which are also part of this SR<sup>(38,42)</sup> evidenced 50% reduction in readmissions when patients were subjected to educational interventions. In addition, an MA from 2019,<sup>(56)</sup> that included seven of the RCTs from this study, demonstrates a reduction in hospital readmissions due to HF in follow-up from 6 to 12 months of 27% (RR: 0.73; 95% CI: 0.61 to 0.88; I<sup>2</sup>: 0%) and a general 22% reduction, which groups all the follow-up times. The previously stated, reaffirms the results obtained in this study and gives value to educational interventions as a low-cost strategy to improve the clinical response of patients with HF.

Likewise, another MA from 2019,<sup>(57)</sup> obtained similar data. The researchers showed reduction of readmissions at 12 months of 36% (RR: 0.64; 95% CI: 0.53 to 0.78; I<sup>2</sup>: 51%). Moreover, this study also evidenced a decrease of approximately two days in hospital stay of adult patients with HF at 12-month follow-up and favorable for the educational interventions. However, no evidence was found of other SR or MA that have evaluated the effect of educational interventions for this result, becoming a significant contribution of this SR and which opens an important path to study this clinical outcome.<sup>(57)</sup> These results of the evidence can be a starting point to restructure nursing care and management programs for adults with HF. A proactive scenario is proposed in which patients after their discharge continue being a priority and responsibility for health institutions to avoid new readmissions. The findings of studies with prolonged follow-up times show that companionship and active monitoring of patients by a multidisciplinary team generate a positive impact on the clinical outcomes of patients.<sup>(56,57)</sup>

Another relevant aspect of this SR is that the educational interventions from the studies selected were variables on frequency, duration, methodology and personnel in charge of conducting them. Nevertheless, it is worth highlighting that a vast number of them were carried out by the nursing

staff experienced in the cardiovascular area, which reinforces the importance of the nurses' educator role as an effective strategy in reducing hospital readmissions and maintaining the quality of life of patients with HF. The aforementioned is based on nurses being the professionals called on to provide primary care in patients with chronic diseases.<sup>(58,59)</sup>

Also, it is important to mention although the study followed the methodological recommendations by the Cochrane Collaboration, this SR and MA had some limitations. First, lack of information is highlighted on the blinding of outcome assessment in some studies. Second, no additional analyses or meta-regressions were performed to explain possible sources of heterogeneity during some follow-up times  $I^2$  values > 60%. Lastly, this SR and MA did not use the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) methodology to evaluate the degrees of recommendation of the studies selected. Nonetheless, the evaluation of the risk of bias de los RCTs showed that most of the studies included had low risk of bias for the principal domains of the Cochrane RoB 1 tool.

In conclusion, this study demonstrates the protective effect of the educational interventions in adult patients with HF, compared with usual care, to reduce readmissions and days of hospital stay due to decompensation of the disease. Additionally, the results can be useful to reaffirm the need to implement in the clinical practice these intervention strategies during broad follow-up periods and which approach the patient during the transition from hospital to the home. Finally, the importance of participation of nurses in the multidisciplinary teams for the therapeutic approach of adult patients with HF is evident.

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# Conceptions of patient safety through the prism of social representations of intensive care nurses

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## Conceptions of patient safety through the prism of social representations of intensive care nurses

### Abstract

**Objective.** To analyze the concepts of patient safety from the perspective of the social representations of intensive care nurses. **Methods.** An exploratory, qualitative and quantitative study, based on the Theory of Social Representations, was conducted in a large hospital in northeastern Brazil, with 20 intensive care nurses. Data collection took place in 2019, using the techniques of free word association test and semi-structured interview. The lexicons apprehended in the test were processed by the *OpenEvoc* software, by prototypical analysis of the evocations, and for the interview data, thematic content analysis was used. **Results.** In the composition of the central nucleus, the elements of surveillance, knowledge, identification, communication, and quality stood out, and in the constitution of the peripheral system of the social representations of



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intensive care nurses permeate care, attention, attitudes, and normative aspects. The triangulation of the findings outlined three thematic categories: Central dimensions of critical patient safety; Attitudinal dimensions for patient safety in intensive care; Normative dimensions linked to the safe handling of the patient in the ICU. **Conclusion.** The social representations of intensive care nurses reveal that the critical patient's conceptions of security involve effective surveillance and communication, promotion of a safe environment based on risk prevention, use of guides and protocols, teamwork, and the sense of responsibility and commitment to individuality of being cared for, elements that for this social group, are the differential for assertive and safe care.

**Descriptors:** patient safety; intensive care units; nurses.

## Concepciones de seguridad del paciente a través del prisma de las representaciones sociales de las enfermeras intensivistas

### Resumen

**Objetivo.** Analizar los conceptos de seguridad del paciente desde la perspectiva de las representaciones sociales de los enfermeros de cuidados intensivos.

**Métodos.** Estudio exploratorio, cualitativo y cuantitativo, basado en la Teoría de las Representaciones Sociales, realizado en un hospital del noreste de Brasil, con 20 enfermeras de cuidados intensivos. La recolección de datos se realizó en 2019, utilizando las técnicas de prueba de asociación de palabras libre y entrevista semiestructurada. Los léxicos aprehendidos en la prueba se procesaron por el software *OpenEvoc*, mediante análisis prototípico de las evocaciones. Para los datos de la entrevista se utilizó análisis de contenido temático.

**Resultados.** En la composición del núcleo central se destacaron los elementos de vigilancia, conocimiento, identificación, comunicación y calidad. De otro lado, en la constitución del sistema periférico de las representaciones sociales de las enfermeras de la UCI permean los cuidados, la atención, las actitudes y los aspectos normativos. La triangulación de los hallazgos describió tres categorías temáticas: Dimensiones centrales de la seguridad del paciente crítico; Dimensiones actitudinales para la seguridad del paciente en cuidados intensivos; y Dimensiones normativas vinculadas al manejo seguro del paciente en UCI. **Conclusión.** Las representaciones sociales de los enfermeros de UCI revelan que las concepciones de seguridad del paciente crítico implican una vigilancia y comunicación efectiva,

la promoción de un ambiente seguro basado en la prevención de riesgos, el uso de guías y protocolos, el trabajo en equipo y el sentido de responsabilidad y compromiso con la individualidad del ser cuidado, elementos que para este grupo hacen la diferencia de un cuidado asertivo y seguro.

**Descriptor:** seguridad del paciente; unidades de cuidado intensivo; enfermeras y enfermeros.

## Concepções de segurança do paciente pelo prisma das representações sociais de enfermeiros intensivistas

### Resumo

**Objetivo.** Analisar as concepções de segurança do paciente pelo prisma das representações sociais de enfermeiros intensivistas. **Métodos.** Estudo exploratório, quali-quantitativo, fundamentado na Teoria das Representações Sociais, realizado em um hospital de grande porte do nordeste brasileiro, com 20 enfermeiros intensivistas. A coleta de dados ocorreu em 2019, sendo utilizadas as técnicas de teste de associação livre de palavras e entrevista semiestruturada. Os léxicos apreendidos no teste foram processados pelo software *OpenEvoc* por análise prototípica das evocações, e para os dados da entrevista, utilizou-se a análise de conteúdo temática. **Resultados.** Na composição do núcleo central destacaram-se os elementos vigilância, conhecimento, identificação, comunicação e qualidade, e na constituição do sistema periférico das representações sociais de enfermeiros intensivistas permeiam cuidado, atenção, atitudes e aspectos normativos. A triangulação dos achados delineou três categorias temáticas: Dimensões centrais da segurança do paciente crítico; Dimensões atitudinais para segurança do paciente na terapia intensiva; Dimensões normativas atreladas ao manejo seguro do paciente na UTI. **Conclusão.** As representações sociais de enfermeiros intensivistas revelam que as concepções de segurança do paciente crítico perpassam pela vigilância e comunicação efetiva, promoção de ambiente seguro tendo como base a prevenção de risco, uso de guias e protocolos, trabalho em equipe, e pelo sentido de responsabilidade e compromisso com a individualidade do ser cuidado, elementos que para este grupo social, são o diferencial para o cuidado assertivo e seguro.

**Descritores:** Segurança do paciente; unidades de terapia intensiva; enfermeiras y enfermeiros.

# Introduction

**H**ealth care organizations and services have shown growing concern for patient safety, and this phenomenon has been widely discussed to ensure and ensure that the care provided proceeds efficiently, free from harm and practices.<sup>(1)</sup> In Brazil, the landmark of attention to patient safety was the implementation of the National Patient Safety Program on April 1, 2013, demarcating actions, protocols, and guidelines for safe practices to be adopted as premises fundamental in this area.<sup>(2)</sup> This movement for safe care is essential in all health settings; however, in the Intensive Care Units (ICU) where complex care is imperative, with a diversity of technologies necessary for the care of critical patients, the patient safety dimension becomes a multi-professional challenge, especially for nurses who are on the front line of care. The intensive care nurses are responsible for a large part of the care actions and are in a privileged position to reduce the possibility of an incident, detect complications early, and perform the necessary steps to minimize damage.<sup>(3)</sup> Thus, not only these professionals but the entire multidisciplinary team must have the skills to act assertively in favor of reliable practices and the quality of care provided.

In these scenarios, the influence of the clinical conditions of critically ill patients on adverse events is frequent, that is, occurrences with the potential to cause damage, given the patient's instability, the need for risky interventions, and invasive procedures. Thus, critical patients are particularly more vulnerable to risks and complications from non-assertive behaviors.<sup>(4)</sup> In this sense, considering the peculiar characteristics described in the ICU context, with anchoring to hard technologies, meeting a different patient severity profile of the other services, multiple demands of processes and activities, it is important to get closer to the new dimensions of knowledge about patient safety, such as those in the area of the social representation, considering that safety is a theme permeated by subjectivity and relationships established in the daily work that can trigger behaviors and attitudes that influence professional practice but are liable to reframing.<sup>(5)</sup> However, knowing the social imaginary, that is, the senses, meanings, knowledge, values, and knowledge socially elaborated by intensive care nurses, access their social representations, their ideas, concepts, concepts, understanding, and attitudes towards the phenomenon of patient safety.

Social representations are concepts of everyday life from collective interaction without restricting individual perceptions. They are equivalent in our society to myths, traditional belief systems, that is, to the contemporary version of common sense.<sup>(6)</sup> Given these considerations, we understand that patient safety investigations favor management decision-making and interventions, modify care practices and organizational culture. Therefore, we outline the

following research objective: to analyze patient safety concepts from the perspective of the social representation of intensive care nurses.

## Methods

This is exploratory research with a qualitative and quantitative approach, based on the theoretical and methodological contribution of the Theory of Social Representations,<sup>(7)</sup> product of the master's thesis developed in 2019, in the Professional Master's Program in Nursing of the Health Department of the *Universidade Estadual de Feira de Santana*, Bahia (Brazil), entitled "Social Representations of Intensive Care Nurses on Patient Safety."<sup>(8)</sup> To ensure ethical rigor, this research was developed only after approval by the Research Ethics Committee with human beings, Opinion 3,239,115/2019. Participation in the research was conditioned to the acceptance and signing of the Informed Consent Form by the participants after being aware of the theme, justification, objectives, benefits, and risks of the research, following the ethical precepts of research with human beings.<sup>(9,10)</sup> We adopted methodological rigor, following the guidelines of the qualitative research checklist, Consolidated Criteria For Reporting Qualitative Research (CORE-Q),<sup>(11)</sup> in all stages.

The research scenario was a large private hospital, located in the northeastern region of Brazil, which has a general and specialized ICU. The approach to the field occurred through the dissemination and presentation of the research project at the institution in a meeting with the entire clinical staff and individual formalization through a printed invitation delivered to each potential participant in the study. On the occasion, the interviewer approached the field and highlighted the possibilities of reaching research interventions for the studied reality. Twenty intensive care nurses participated in the research, defined by inclusion/exclusion criteria, refusal, and data saturation. We

selected nurses who had a minimum of six months of service, who worked in general ICU and direct care for the patient, we excluded and coordinators for carrying out activities related to management, professionals who were on maternity/health leave or vacation during the data collection period. There was a refusal to participate and three nurses were not interviewed, due to the end of data saturation collection, which occurred when the essence of the testimonies did not point to new information, and those obtained ensured quantity, relevance, and consistency of content to meet the proposed objective of the research.

Data collection took place using the following techniques: Free Words Association Test (FWAT) and semi-structured interviews. FWAT, as a projective technique, helped to identify the content implicit in the construction of the object for the social context under study, allowing to obtain evidence of its representations.<sup>(12)</sup> The research participant was presented with the expression "patient safety", who acted as an inductive term corresponding to the representation phenomenon that is being investigated, asking him to evoke five words or expressions and to subsequently perform the hierarchy of the evoked terms in increasing order of importance to assign values from the most important to the least important.

After the application of the FWAT, we carried out a semi-structured interview, seeking to deepen knowledge about the social and collective imaginary, that is, the reality experienced, and to access other latent elements of social representations. As a comprehensive collection technique, the interview privileged social interaction covered the subjective field of ideas and meanings through the individuals' spontaneity and interaction.<sup>(13)</sup> We collected the research data between June and August 2019, with the consent of the service, in a private room, with an average duration of 15 minutes. The collection instruments were previously tested and included objective data referring to the characterization of the participants and subjective questions

that sought to meet the research objective. The contents of the FWAT and the interviews were recorded and transcribed *ipsis litteris*, returned to the participants for corrections, with no need for repetition and/or exclusion of content, and then submitted to analysis.

For the data collected at FWAT, a prototypical analysis of evocations was carried out using the OpenEvoc software,<sup>(14)</sup> which enabled the survey of the first social representations of what could be considered as central or peripheral elements, based on the hierarchy of Frequency and Average Order of Evocations (AOE) revealed in a table of four squares. This type of analysis has its validity based on the assessment of the salience of the representational elements quantitatively, when crossing Frequency and AOE, and the central elements of the representation are the most salient, being more present in the discourse. However, the salience is data that can also be found in peripheral elements.<sup>(15)</sup>

Considering the importance of multi-methodological analysis in studies of social representations, and aiming at a greater understanding, the empirical material produced by the interview followed the steps of thematic content analysis, allowing for an objective, systematic description of the manifest content of the communication.<sup>(16)</sup> In this process, three thematic groups were identified that outlined three analytical categories: Central dimensions of critical patient safety; Attitudinal dimensions for patient safety in intensive care; Normative dimensions linked to the safe handling of patients in the ICU, which reveal the concepts of patient safety through the prism of the social representations of intensive care nurses. We ensured the anonymity of the interviewees and

the contents of the speeches were named by vasoactive drugs (gluconate, quelicin, nipride, ancoron, bicarbonate, diprivan, dobutamine, dopamine), considering the amount of occurrence of AE related to the drug cycle in the health scenarios.

## Results

In the composition of the researched group, the age of the 20 participants ranged from 28 to 53 years old, with a predominance of females. We observed a long variation of time of training/graduation in nursing (ranged between 4 and 30 years), length of experience in the ICU (ranged from 2 to 29 years), and the time of work at the institution researched (ranging from 10 months to 28 years). As for complementary training, except for one nurse, all had postgraduate degrees in the area of expertise, either by specialization or by a residency in intensive care. Most had a single work contract, as a dependent worker contract, with a workload of 44 hours per week.

The prototypical analysis of evocations based on the content learned in FWAT, in response to the expression “patient safety”, apprehended 100 lexicons evoked by intensive care nurses, 61 of these were different and 16 were identified by the OpenEvoc software as the most important and made part of the composition of the schematic representation. The construction of the table of four houses was performed through the calculation and combined analysis of the Average Order of Evocations (generated around 3.1) and the average frequency of words (generated around 4), as shown in Table 1.

**Table 1. Social representations of 20 intensive care nurses on patient safety**

Central Core Elements 1 <sup>st</sup> Quadrant			Elements of the Peripheral System (1 <sup>st</sup> periphery) 2 <sup>nd</sup> Quadrant		
Lexicons	Frequency ≥ 4	AOE < 3.1	Lexicons	Frequency ≥ 4	AOE ≥ 3.1
Surveillance	6	2	Care	7	3.14
Knowledge	4	1	Attention	7	3.29
Identification	4	1.75			
Communication	4	2.5			
Quality	4	2.75			

Core Elements 3 <sup>rd</sup> Quadrant			Elements of the Peripheral System (2 <sup>nd</sup> periphery) 4 <sup>th</sup> Quadrant		
Lexicons	Frequency < 4	AOE < 3.1	Lexicons	Frequency < 4	AOE ≥ 3.1
Responsibility	3	2	Team	2	3.5
Visibility	2	2	Planning	2	3.5
Commitment	2	2.5	Devices	2	4
Assistance	2	3	Individuality	2	4.5
Protocols	2	3			

\* OME (Average Order of Evocations).

The processing established by the OpenEvoc software indicated that the set of words in the 1<sup>st</sup> quadrant is the likely central nucleus, as they presented higher citation frequencies readily evoked, suggesting greater meaning for the researched social group and, consequently, characterize the ontological meaning of the representation. In that quadrant, the terms “vigilance and knowledge” are highlighted. The word “surveillance” was evoked 6 times (with AOE = 2), that is, the term was quoted twice in the first, second, and third positions in the order of the evocation rangmot, and indicates an attitudinal dimension towards patient safety. However, the lexicon “knowledge” has a greater degree of salience, that is, greater importance given by the group, since this term was promptly evoked every time in the first position (AOE = 1), denoting

the elements of greater representativeness for the nurses. In this perspective, still composing the representations of the central nucleus, there are the terms “identification”, “communication” and “quality”, which occupied an equal position considering the frequency of evocations, although with differentiated AOE. The grouping of words from the central nucleus has associated characteristics and indicates a typical way of thinking of the researched group, constituting and reflecting the consensual basis that is shared collectively.

In the 2<sup>nd</sup> quadrant of the schematic representation, there are the transition elements of the social representations that make up the first periphery. They represent the highest frequency of quotes later evoked and reinforce the ideas of



the probable central nucleus. The terms “care” and “attention” seem to inductively refer to the essence of the intensive care nurse’s work process, promoting an association between concrete reality and the central nucleus, based on the integration between what is lived collectively and individual experiences.

In the 3<sup>rd</sup> quadrant there are the lexicons with the lowest frequency of citations, but readily evoked, which complement and discuss the central nucleus and the other peripheral elements and at the same time, represent tension in the object, as they may indicate changes or transitions in social representations. The terms “responsibility and commitment” denote attitudinal dimensions inherent in the work of assisting lives in situations of narrow limits between normality and abnormalities, associated with the complexity of the intensive care work process.

Returning to the table of four squares, we find that the lexicons “team”, “planning”, “devices” and “individuality”, which make up the 4<sup>th</sup> quadrant or second periphery, obtained the lowest frequencies of quotes evoked late. Therefore, they are the most distant elements of the central system and may suggest perceptions or individual experiences of the group regarding patient safety. From the representational structure presented in Table 1, safe intensive care is based on the dimensions: imagery (imaginary that sustain the representation), knowledge (refers to an acceptable basis for intensive care and the social cognitive self-reconstruction of this phenomenon in extreme situations), attitudinal (the attitudes that offer representation dynamics), and the normative (the pre-conceived constructions about representation, coming from common sense, but which are passive of reinterpretations).

The understanding of these dimensions and elements considered structuring was revealed by the contents of the speeches and outlined nuclei, categories, and thematic units:

### **Thematic nucleus 1. Surveillance, communication, identification, attention, devices, knowledge, and quality**

**Category:** *Central dimensions of critical patient safety*

**Thematic units:** *Security is the surveillance of people at the bedside, communication between shift changes, [...] attention to patient identification, attention to devices, the bed rail, fixations (Gluconate); It is to evaluate the individual not only with his illness but with everything around him, all with the knowledge that I think is paramount [...] (Quelicin); Safety is the pillar of our profession today, which will give quality to our service. (Bicarbonate).*

### **Thematic nucleus 2. Care, visibility, responsibility, commitment, and individuality**

**Category:** *Attitudinal dimensions for patient safety in intensive care*

**Thematic units:** *You try to make the most of that environment that is safe to provide your care, everything you can guarantee to prevent risks, risk of falling, risk of phlebitis, risk of various risks [...] (Nipride); I check everything, check if all risks and measures are prescribed for the patient (Ancoron); [...] it is the perception that will bring the commitment to individuality, the individuality that I say is the detail, that each patient is individual, there are different details of each one that will bring this to our safety (Bicarbonate).*

### **Thematic nucleus 3. Assistance, planning, and protocols**

**Category:** *Normative dimensions linked to the safe handling of patients in the ICU*

**Thematic units:** *[...] we have steps and work routines for almost all the procedures we do, and in case of doubt, you have the option to consult (Diprivan); [...] every time I feel insecure about some action I have to do, I go to the protocol (Dobutamine); Patient safety, it is part of the team’s work process, how does the team do this work, [...] if there is a synchrony of communication between all teams (Dopamine).*

## Discussion

The category “central dimensions of critical patient safety” points out the collective imagination that supports the representation of the researched social group, involving perceptions attributed by intensive care nurses to the safety of clinically unstable individuals, based on continuous surveillance, effective communication, attention during intensive clinical and device management, that is, it reflects the conceptual basis of intensive care and, consequently, the quality of care offered.

In this sense, the element “surveillance”, accessed from the inductive term “patient safety”, represents the product of the activity of construction of reality, derived from information, values, attitudes, and impressions of daily practice.<sup>(6)</sup> Such a fact is justified by the observation that the ICU’s main objective is to promote continuous and rigorous monitoring in the face of hemodynamic, ventilatory, fluid-electrolyte balance, management of vasopressor and sedative drugs, among other monitoring.<sup>(17)</sup> The representations learned to suggest that safe care should direct attention to the weaknesses in patient identification, prevention of falls and unintentional or iatrogenic exit of devices, elements of daily practice that can generate harm to patients and increase costs to organizations. The excerpt of the discourse that brings “knowledge as primordial” signals the importance of the scientific domain and the ability to evaluate the environment-disease-patient context as essential elements to guarantee safety.

Following the content of the speech and being part of the semantic universe of the central nucleus, the term “knowledge”, the act of perceiving or understanding through reason and or experience,<sup>(13)</sup> interacts with the element “care” of the first periphery, denoting connection between them. In this sense, nurses, when experiencing critical care, work with multitasking and with the automatism that the activities require. However, they need to exercise critical observation in

the face of the situations experienced and use scientificity in directing their assistance.<sup>(3)</sup>

The apprehension of the category in the reflective analysis also reports patient safety to the quality dimension of the intensive nursing service. Similarly, the element “quality” was chosen at FAWT for the composition of the central nucleus, suggesting representativeness for the social group, despite the adversities of being a health field nuanced by hard technologies, an exhaustive and uninterrupted work process, risks inherent to procedures invasive, which can influence, compromise, or even distance the reach of excellence in daily work. However, the central dimensions presented reinforce the structure of nurses’ social representations about assertive care, highlighting the meanings of professional practice and the daily socio-cognitive reconstructions of these professionals because of the understanding of patient safety, originated in the constructions, opinions, attitudes, values, feelings and collective experiences of the group.

The category “attitudinal dimensions for patient safety in intensive care”, originated from lexicons of the contrast zone and the peripheral system that offer dynamics to representations, that is, elements that reflect attitudes and actions for the safety of the critical patient’s patient. The movement to build a safe environment for the provision of intensive care, portraying the work process and the flow of activities that are attentive to patient safety, was observed in the speeches that point to critical care based on patient knowledge and risk reduction. In this perspective, social representations signal the act of prevention as an effective barrier to avoid damage associated with health care and the potential risks that can be avoided through actions and attitudes aimed at complying with prescribed measures, verifications, and checking.

Patient safety is related to changes in the work process, that is, the way the human being produces and reproduces his existence, interfering in the way

that the nurse performs his daily work.<sup>(17)</sup> Thus, the actions of conferences, checking described in the content of the discourse, if on the one hand demonstrate objectification, through the creation of superimposed barriers to minimize the risk of errors, exchange of patients and adverse events, on the other, they denote subjective implications, such as responsibility and commitment to the other. This subjective dimension reveals congruence with the constituent elements of the contrast zone of the representational structure, directs to a more critical look at the “patient safety” object, and reflects a positive safety culture because it signals ideas, meanings, feelings, from the lexicons: responsibility (duty, obligation), commitment (commitment, accountability), assistance (handling, surveillance, providing care).

The individuality was another meaning apprehended regarding the attitudinal dimension, observation of the particularities and singularities of the person being cared for. In this sense, we can infer that the assistance to the critical patient is marked by the application of greater knowledge by the nurse, who constantly directs his attention in the search for objective and subjective information from the client and objective data from the machinery. However, in the face of technological action, what is observed in daily practice is that care is based on the observations coming from the equipment to the detriment of individual observations.<sup>(18)</sup>

The complexity of the critical patient with its pluralities and demands, the hard technology used require the purposeful management of multiple resources and equipment. However, meeting the individualities and respecting the individual’s diversity are shown to be inseparable mechanisms to care security.<sup>(4)</sup> It reflects the nurses’ behavior, initiative, way of acting, that is, they portray attitudes, actions, daily work movements for patient safety.

The category “normative dimensions linked to the safe handling of patients in the ICU” reports preconceived constructions about the

phenomenon under study, coming from common sense and representations linked to the work process. Similar to the content of the speeches, the “protocols” recognized by the researched group since the prototypical analysis, composing the contrast zone of the representational structure, were identified as devices/instruments that help to define, standardize and review the way of processing direct attention the health. Thus, they seem to direct the work, record the care performed, helping to solve or prevent a problem.<sup>(19)</sup>

These apprehensions reveal an organizational culture focused on safe care, because of the familiarity with which the intensivist nurses surveyed demonstrate by consulting the protocols in situations of doubt, insecurity, and the knowledge of this instrument as a risk management tool, as a guide for compliance with organized flows and work routines.

Teamwork and its interface with safety bring representations that suggest the alignment of communication between all peers responsible for assistance, being important for the assertive management of conducts. Although the lexicon “team” is considered an intermediate element in the structure of social representation based on FWAT due to its lower frequency of citation that is late evoked, denotes the perception by the group of multidisciplinary interdependence and the importance of group work for patient safety. Thus, it is necessary to perceive teamwork based on a transdisciplinary proposal that must be characterized by the intensity of exchanges between people and daily integrations, which are crystallized from intentionality and elements of communication.<sup>(20)</sup> However, for the product to be multidisciplinary integration, assertive communications must occur. In this sense, critical moments of threat to patient safety occur precisely due to the low integration of the parts and communication failures in interactions poorly established by the multi-professional team,<sup>(21)</sup> with effective communication being a challenge for critical care units.

Thus, the category “Normative dimensions linked to the safe handling of patients in the ICU” indicates that the focus on patient safety and the improvement of the quality of health care, in general, requires a systemic view to understand the process between professionals/organizations/sectors, compliance with routines and protocols to create an integrated, adequate and timely network to achieve the best results in a transdisciplinary way.

We concluded that the representations apprehended in the implicit and latent contents reveal that the concepts of patient safety include working in the search for actions, tools, methodologies, solutions, and strategies that

aim to identify, make visible, prevent, reduce or mitigate risks, and then, minimize and/or eliminate the occurrence of AE and make complex care safe.

Also, despite the number of intensive care nurses interviewed, which can be considered a limitation of the study, the concepts presented by the researched group indicate a movement for assertive care. However, the observance and investment by health managers and multidisciplinary teams in daily practices that reflect the safe management of critical patients are still incipient. This highlights the potential of the result of this study, which may provoke new itineraries, reflections, training, and reframings regarding safety in these care scenarios.

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# Implementing Peer Tutoring for the Development of Empathy in Nursing Education

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## Implementing Peer Tutoring for the Development of Empathy in Nursing Education

### Abstract

**Objective.** This research sets out the effects of a training method based on peer tutoring, aimed at developing empathy among nursing students at the University of Barcelona (Spain). **Methods.** After initial training, students are matched in pairs with similar level of empathy, exchanging the role of tutor and tutee in every session, during 12 sessions. Before the session, the tutor prepares the activities to work with his or her tutee, following this structure: exploration of prior knowledge, explanation, practical activities, feedback, and reflection. Jefferson Scale of Empathy was administered as pre-test and post-test to 76 nursing students, 40 in the intervention group, and 36 in the comparison group. Following a mixed-methods sequential explanatory design, a quantitative study (a quasi-experimental design with a comparison group) was combined with a qualitative study (interaction

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analysis of the 12 videotaped sessions). **Results.** The results revealed statistically significant improvements in empathy in the intervention group. Subsequent analysis of the peer tutoring interaction highlighted the specific actions that had resulted in these improvements and generated a context in which the tutee was able to understand complex concepts, while enabling both students to participate, reflect and discuss. **Conclusion.** Peer tutoring is an effective method for the development of empathy in nursing students.

**Descriptors:** education, nursing; empathy; learning; peer group; psychology; students, nursing.

## Implementación de tutoría entre iguales para el desarrollo de la empatía en la educación de enfermería

### Resumen

**Objetivo.** Esta investigación evaluó los efectos de un método de formación basado en la tutoría entre iguales, destinado al desarrollo de la empatía en estudiantes de enfermería de la universidad de Barcelona (España). **Métodos.** Después de la formación inicial, los estudiantes son emparejados con compañeros con un nivel similar de empatía, intercambiando el papel de tutor y tutorado en cada sesión, durante 12 sesiones. Antes de cada sesión, el tutor prepara las actividades para trabajar con su tutorado, siguiendo esta estructura: exploración de conocimientos previos, explicación, actividades prácticas, retroalimentación y reflexión. Se administró la Escala de Empatía de Jefferson, en forma de pre y postest a 76 estudiantes de enfermería: 40 en el grupo de intervención y 36 en el grupo de comparación. Siguiendo el método mixto de diseño explicativo secuencial, se combinó un estudio cuantitativo (un diseño cuasiexperimental con grupo de comparación) con un estudio cualitativo (análisis de interacción de las 12 sesiones grabadas en video). **Resultados.** Los resultados revelaron mejoras estadísticamente significativas en la empatía en el grupo de intervención. El análisis posterior de la interacción en las parejas de tutoría entre iguales puso de relieve las acciones específicas que habían dado lugar a estas mejoras y generando un contexto en el que el tutorado era capaz de entender conceptos complejos, al tiempo que permitía a ambos estudiantes participar, reflexionar y discutir. **Conclusión.** La tutoría entre



iguales es un método eficaz para el desarrollo de la empatía en los estudiantes de enfermería.

**Descriptor:** educación en enfermería; empatía; aprendizaje; grupo paritario; psicología; estudiantes de enfermería.

## Implementação de tutoria entre pares para o desenvolvimento da empatia na educação de enfermagem

### Resumo

**Objetivo.** Esta pesquisa avaliou os efeitos de um método de treinamento baseado em tutoria entre pares, com o objetivo de desenvolver empatia em estudantes de enfermagem da Universidade de Barcelona (Espanha). **Métodos.** Após a formação inicial, os alunos são colocados em pares com pares com um nível de empatia semelhante, trocando o papel de tutor e estudante em cada sessão, durante 12 sessões. Antes de cada sessão, o tutor prepara as atividades para trabalhar com o seu estudante, seguindo esta estrutura: exploração dos conhecimentos anteriores, explicação, atividades práticas, feedback e reflexão. A Escala de Empatia de Jefferson foi administrada em forma de pré e pós-teste a 76 estudantes de enfermagem: 40 no grupo de intervenção e 36 no grupo de comparação. Seguindo o método misto de desenho explicativo sequencial, um estudo quantitativo (um desenho quase experimental com um grupo de comparação) foi combinado com um estudo qualitativo (análise de interação das 12 sessões gravadas em vídeo). **Resultados.** Os resultados revelaram melhorias estatisticamente significativas na empatia no grupo de intervenção. A análise subsequente da interação nos pares de tutoria de pares destacou as ações específicas que levaram a essas melhorias e gerou um contexto em que o estudante foi capaz de compreender conceitos complexos, permitindo que ambos os alunos participassem, refletissem e discutissem. **Conclusão.** A tutoria entre pares é um método eficaz para desenvolver empatia em estudantes de enfermagem.

**Descritores:** educação em enfermagem; empatia; aprendizagem; grupo associado; psicología; estudantes de enfermagem.

# Introduction

Empathy is a complex, cross-dimensional interpersonal skill. It is particularly essential for nursing professionals to help them care for patients and their families in a holistic manner and establish a therapeutic relationship.<sup>(1)</sup> Despite the difficulty to define the concept, many studies coincide in describing empathy as the skill to put oneself in the patient's shoes, while retaining one's own point of view, and ensuring that the patient knows that his/her point of view has been understood.<sup>(2)</sup> In the sphere of healthcare, considering empathy as a multi-dimensional element, Hojat<sup>(3)</sup> defines it as a predominantly cognitive attribute (rather than an emotional one), involving the comprehension (rather than the feeling) of patients' experiences, concerns, and perspectives, combined with the skill to convey this comprehension to them. Empathy therefore constitutes a basic element in the therapeutic relationship between the patient and the professional healthcare, beneficial both for patients and their families, as well as for nursing staff themselves and the health institution as a whole. Studies have demonstrated that patients that are cared for by highly empathetic nursing staff show reduced levels of anxiety and depression, lower hostility towards healthcare professionals and increased degree of satisfaction with the care received.<sup>(4)</sup>

For nursing professionals, the contact with the patient's suffering, tackling difficult and stressful emotional situations, overwork and lack of social support make them vulnerable to burnout and anxiety.<sup>(5)</sup> Furthermore, if the nursing staff has institutional and social support, they are less likely to be susceptible to burnout, anxiety, depression, and hostility.<sup>(6)</sup> The complex nature of empathy as a multi-dimensional concept makes it difficult to gauge.<sup>(7)</sup> Most studies measure it using quantitative methods such as the Jefferson Scale, given its wide acceptance among the scientific community, its extensive use in different health specialities, and its translation into different languages.<sup>(3)</sup>

Even though it is widely recognised that empathy should be further developed in healthcare professionals, during initial training there are few deliberate education opportunities with effective methods to develop empathy.<sup>(8)</sup> However, empathy can be developed through different types of activities, based on active methodologies –for example, experiential activities using real or simulated patients,<sup>(9)</sup> or peer tutoring.<sup>(10)</sup> In a formal training context, peer tutoring is described as a peer learning method based on the creation of pairs, with an asymmetric relationship (the role of tutor and tutee and their respective tasks) and a common and shared objective, which is the acquisition or improvement of some curricular competence, through structured interactions planned by the teacher.<sup>(11)</sup> Peer tutoring meta-analyses present numerous positive effects,<sup>(12,13)</sup> as well as being a potentially useful and effective methodology to improve cognitive, social, and communicative skills.<sup>(14)</sup>

Peer tutoring may involve fixed roles (the tutor and tutee always play the same role), or reciprocal ones (the tutor and tutee interchange their roles).<sup>(11)</sup> In this study, a reciprocal role type is proposed to give each student the chance to perform both roles.

In the field of nursing education, peer learning is presented as an educational model highly suitable for clinical placements, due to the increasing number of students and a limited number of preceptors.<sup>(15)</sup> Research on recent practices that use peer learning in clinical practice education shows positive effects on nursing students' self-efficacy<sup>(16)</sup> and professional competence.<sup>(17)</sup> Irvine *et al.*<sup>(18)</sup> carried out a review of 29 studies, between the years 1990 and 2017, and reported benefits of peer teaching in creating a safe supportive learning environment, learners viewing near-peer teachers as effective role models, and increased confidence experienced by learner and teacher. The reviewed studies mainly focused on cognition with little emphasis on metacognition or affective behaviours, and lacked training provided to tutors or peer teachers. The authors concluded that it is imperative that faculty embed near-peer teaching into the curriculum, but more studies are needed in order to provide definitive evidence supporting this pedagogical approach and a theoretical framework for its implementation, particularly from educational psychology. Given the importance of empathy as an integral part of the skillset required for nursing staff, and the need to find ways of developing it during the initial training period of these professionals, the objective of this study is to design a pedagogic project based on peer tutoring and explore its potential to develop empathy both in terms of positive aspects and areas of improvement, with a view to incorporating it into initial nursing staff training.

## Methods

This objective is summarised as a hypothesis and three questions. The hypothesis is that the students participating in the project will self-

report a greater degree of empathy, obtaining statistically substantial differences in the Jefferson Scale (Spanish version JSPE-S questionnaire,<sup>(19)</sup> between the pretest and posttest, while the comparison group is not expected to reveal any statistically significant changes. In order to explain the possible quantitative changes, the qualitative work, focused on analysing the process, aims to reveal which elements in the interaction contribute to the development of empathy in students. To do this, three questions are formulated: (1) In the first part of the peer tutoring session, where the tutor explains basic concepts to the student, what actions of the pair help or hinder the development of conceptual knowledge of empathy and why?; (2) In the second part of the peer tutoring session, where the different activities designed are put into practice, what actions of the pair help or hinder the emotional development of empathy and why?, and (3) In the final part of the peer tutoring session, where there is joint and individual reflection on what has been learned and undertaken, which aspects help raise awareness of the development of empathy itself and why?

**Research Design.** This research opts for a mixed-methods sequential explanatory design,<sup>(20)</sup> combining a quantitative study (a quasi-experimental design with a comparison group); and a qualitative study (an analysis of the data extracted from the interactions between each pair of students) to explain the quantitative changes detected.<sup>(21)</sup>

**Sample.** The sample consists of 76 third-grade nursing students in clinical internships at the University of Barcelona. To preserve the ecological validity of the study, two groups of students from equivalent degrees, consisting of 40 and 36 students, were randomly assigned as comparison or intervention group. The 40-student class became the intervention group and the 36-student class was set as comparison group.

**Intervention: Training Programme and Procedure.** Prior to the sessions, an initial training session is held, explaining the programme and what peer

tutoring entails, and students are administered an initial assessment using the JSPE-S test. Based on the scores, the pairs are formed, having the student with the highest empathy score paired with the student with the second highest score, and so on consecutively. Therefore, a similar level of skill is guaranteed among the two members of the pair, which –as indicated by extant literature– is essential for the use of reciprocal peer tutoring, in which the roles of tutor and tutee alternate.

<sup>(11)</sup> The programme is designed based on the systematic review of actions favouring empathy development and consists of six one-hour sessions of reciprocal peer tutoring in two sessions per week.<sup>(2,22)</sup> Working in pairs, the students are given two different dossiers (one for student A and one for student B) specifying what needs to be done throughout the session guided by an activity clock. This dossier contains the materials (in the form of text or audio-visual resources) that tutors need to prepare prior to the session. Student A acts as the tutor during the first hour, and B during the second hour, to give them both the chance to perform each role.

Sessions are structured by means of an activity clock: graphical structure that serves as a guideline so that students learn a work routine in each session and can be increasingly more autonomous when controlling each activity's timeline. Each session has the following time frames: 'Prior Training' (5 minutes): the tutor explores what his/her tutee knows about the subject before the session begins; 'Explanation' (10 minutes): tutor uses the teaching material he/she has prepared to explain what he/she knows to the tutee; 'Practical Session' (30 minutes): tutor guides the activities using role play, visualisation and video analysis, and written activities; 'Feedback between Pairs' (5 minutes); and 'Reflection and End of Session' (10 minutes): the pairs answer the Self-assessment questions from the dossiers. An example of a practical activity is to share a personal experience of emotional significance that created an internal conflict. The tutor explains the experience while the tutee listens to him/her

and asks questions if necessary. Then the tutee must explain the situation as if it had happened to him/her. This enables the tutee to perform an activity of reflection based on empathy towards the partner. In the case of videos and role plays, several aspects that are essential for building an empathic therapeutic relationship are analysed, such as appropriate use of verbal and non-verbal communication, developing a good relationship or understanding, and the professional's implication with the patient.<sup>(23)</sup> The randomly assigned comparison group is provided with the same learning content, not through peer tutoring but in a teacher-centred explanation for the whole group of students.

**Instruments.** To quantitatively measure empathy the Spanish version of the Jefferson Scale of Physician Empathy for Healthcare Science Students - JSPE-S-<sup>(19)</sup> was used (internal consistency of 0.74). This self-questionnaire is comprised of 20 items and a Likert scale of seven categories, where 1 means completely disagree and 7 completely agree. A high score on the JSPE-S suggests a higher degree of self-perceived empathy. The theoretical structure of the questionnaire is based on 3 dimensions: *perspective taking* (point of view that makes the professional unbiased when actively listening to the patient's concerns and offering empathic responses); *compassionate care or treatment* (the human connection based on care between patient and healthcare professional); and *skill to put oneself in the patient's shoes* (ability to perceive and understand others' feelings, entering into the others' subjective world).

Concerning the qualitative study, to analyse the pair interaction during the project sessions and answer the first three research questions, a category system based on extant literature but situated *ad hoc* was created. The procedure was performed as follows. After recording all the sessions (240 hours), an initial observer created the category system analysing 25% of total time recorded (60 hours). To verify reliability

and validity, two previously trained researchers individually coded these videos. The level of coincidence between them reached a value of 0.8 in Pearson coefficient, which indicates that the category system is reliable. The category system is comprised of 16 dimensions, which are in turn subdivided into factors evaluated with a binary answer (Yes/No). The evaluation of each factor is gradual and cumulative, that is, the higher the factor evaluated with a Yes, the better the student's preparation and explanation offered to the tutee. The dimensions and factors drawn up to analyse the degree of empathy are split into the 3 segments that make up the peer tutoring session that will be analysed: conceptual approximation, comprised of 8 dimensions and 30 factors; the practice, comprised of 5 dimensions and 19 factors; and finally, the reflection, comprised of 3 dimensions and 13 factors.

**Data analysis.** For the quantitative data, we opted for analysis of variance (ANOVA) for repeated measures, with the purpose of studying the variation over time of both groups regarding the dimensions studied (perspective taking,

compassionate care and putting oneself in the patient's position). Qualitative data were gathered by means of video recording the 6 peer tutoring sessions from 10 pairs –20 students–. Video tapes were analysed by means of the Atlas.Ti software.

**Ethical Issues.** This study does not involve any conflict of interests or ethical conflict, and all students' names were anonymised to ensure confidentiality. Explicit consent from each of the students was required and they signed a document to authorise data collection for research purposes in an anonymous and voluntary manner.

## Results

### Quasi-experimental Study Results

First, the homogeneity of both groups was analysed by means of Student's t-test for independent samples, comparing the different pretest scores between intervention and comparison group, presented in Table 1.

**Table 1. Scores by student t test for independent samples of each dimension between Comparison and intervention groups pre-test**

Dimensions	<i>t</i>	<i>gl</i>	<i>p-value (2-tailed)</i>	<i>Difference between means</i>	<i>Typical error of the difference</i>
Perspective taking	2.129	74	0.037	3.164	1.486
Compassionate care	2.587	74	0.012	2.786	1.077
Putting oneself in the patient's shoes	0.661	74	0.511	0.389	0.589

The results indicate that, except for the "Putting oneself in the patient's shoes" score, there are statistically significant differences for both the dimensions "Perspective taking" and "Compassionate care". This means that groups

are not homogeneous because they are part of different pre-test situations, which is not a problem because the study aimed to analyse the variation of different groups even though their initial scores are different. The results obtained with ANOVA

regarding the “Perspective taking” dimension in the pre-test-/post-test from the intervention group and the comparison group are presented in Table 2.

The results obtained reveal statistically significant differences between intervention and comparison groups ( $p=0.001$ ). There is an increase in intervention group scores, unlike the non-variation in comparison group. In relation to the dimension “Compassionate care”, the scores variation over time is statistically different between both groups ( $p=0.004$ ). There is an increase in the intervention group scores, but not in the comparison group scores. As regards “Putting oneself in the patient’s shoes” dimension, there are no differences over time between both groups ( $p=0.432$ ). Taking

the total scores of the tests, results show that the variation over time is statistically significant between both groups ( $p<0.0005$ ); the total score decreased in comparison group and increased significantly in intervention group.-

These results show that both groups have different pretest scores, with a higher mean in the comparison group (119.14) than in the intervention group (112.8). However, the variation over time of both groups is different; intervention group obtains a higher mean in the posttest (118.58), with an increase of more than 5.78 points from the pretest, while the comparison group shows a lower posttest mean (116.08) with a decrease of 3.06 points from the pretest.

**Table 2. Evolution of dimensions of the Scale of Physician Empathy for Healthcare Science Students over time in the comparison and intervention groups**

Dimension	n	Pre-test		Post-test	
		mean	S.D.	mean	S.D.
Perspective Taking*					
Comparison Group	36	60.89	6.02	60.69	6.38
Intervention Group	40	57.73	6.84	62.30	5.36
Compassionate Care†					
Comparison group	36	43.61	4.795	41.28	4.82
Intervention group	40	40.82	4.590	41.98	4.95
Putting oneself in the patient's shoes‡					
Comparison Group	36	43.61	4.795	41.28	4.82
Intervention Group	40	40.82	4.590	41.98	4.95
Total scale					
Comparison Group	36	119.14	10.81	116.08	11.09
Intervention Group	40	112.80	11.33	118.58	10.59

Time\*group interactions (Huynh-Feldt correction): \*:  $F= 1.91$ ;  $p=0.001$ ; †:  $F= 8.675$ ;  $p=0.004$ ; ‡:  $F= 0.623$ ;  $p=0.432$ ; §:  $F= 15.350$ ;  $p<0.005$

## Results of the Interaction Analysis using the Dimensions System

The category system designed to analyse the interaction of the video-taped pairs has 16 dimensions, subdivided into factors that are evaluated using a dichotomous response (Yes/No). The category system is divided into 3 segments that configure the peer tutoring session: the conceptual approach (with 8 dimensions and 30 factors); the practical session (5 dimensions and 19 factors); and finally, the reflection (3 dimensions and 13 factors). For

each factor, frequencies and percentages are obtained. Results are presented following the three questions.

### A) In the conceptual approach segment, which actions in the pair help or hinder the development of the conceptual understanding of empathy?

To answer the first question, the first 15 minutes of all conceptual understanding sessions were analysed ('Prior Training' and 'Explanatory Part'), assessing the pair interaction based on the first eight dimensions created for the analysis. Results are summarized in Table 3.

**Table 3. Results of Conceptual Approach Segment (20 pairs of students, 12 sessions)**

Dimension / Factors	f	%
1. Preparation of sessions		
1.1 The tutor did not bring the materials	1	1.2
1.2 The tutor brought the materials	56	70
1.3 The tutor brought the materials with underlining	14	17.5
1.4 The tutor brought the materials with underlining and notes on the underlined parts	9	11.2
2. Use of materials during the session		
2.1 The tutor used the extra material provided such as further information	29	36.2
2.2 The tutor created synthesis material (charts, graphs, material in notebooks or paper)	50	62.5
2.3 The tutor created teaching material (additional material such as photos, other documents or resources)	1	1.2
3. Conceptual understanding by the tutor		
3.1 Incorrect comprehension of the concepts	1	1.2
3.2 Correct comprehension of the concepts but in a literal way	5	6.2
3.3 Correct and appropriate comprehension (using own words) of the concepts without using examples	14	17.5
3.4 Correct and appropriate comprehension using examples	60	75
4. Action taken by the tutor to detect tutee's prior knowledge		
4.1 No questions asked to detect prior knowledge	5	6.2
4.2 The tutor asked the student without subsequently giving an answer	15	18.7
4.3 The tutor asked questions and provided answers	3	3.7
4.4 The tutor asked questions and gave feedback to the tutor	16	20
4.5 The tutor asked questions, assessed the response and helped prompt the tutee's prior knowledge (giving clues, examples)	41	51.2
5. Building on knowledge through pedagogical guidance		
5.1 The tutor transmitted information	41	51.2



**Table 3. Results of Conceptual Approach Segment  
(20 pairs of students, 12 sessions) (Cont)**

Dimension / Factors	f	%
5.2 The tutor used the tutee's prior knowledge and improved on it	30	37.5
5.3 The tutor recognised the tutee's prior knowledge and together they built on the framework/ idea/ concept	9	11.2
5.4 The tutor and the tutee built new knowledge based on their prior knowledge	0	0
6. Tutor's verification of tutees' knowledge		
6.1 No questions asked on understanding	22	27.5
6.2 The tutee was the one asking questions and the tutor simply answered them	28	35
6.3 Both tutor and tutee asked questions on their understanding	15	18.7
6.4 The tutor asked questions on the tutee's understanding	15	18.7
7. Guiding the interaction		
7.1 The tutor did not guide the interaction	5	6.2
7.2 The tutor guided the interaction during the conversation but did not anticipate the structure of the activity during the session	54	67.5
7.3 The tutor guided the interaction, anticipated the structure of the activity during the session, and guided the conversation	13	16.2
7.4 The tutor guided the interaction by providing guidelines on the activity during the session by recapitulating and concluding different blocks	8	10
8. The tutor stimulates and maintains the tutee's interest		
8.1 The tutor did not stimulate any interest in the tutee	3	3.7
8.2 The tutor stimulated the interest of the tutee in the task	11	13.7
8.3 The tutor stimulated the interest of the tutee and maintained it	66	82.5

Based on these results, it was considered that students were able to understand not only the concept but also what being empathetic and establishing a therapeutic relationship entails. Furthermore, tutors were able to formulate questions, assess the answers, and help prompt the tutees' prior knowledge (by giving clues or examples). It was also considered that they were able to synthesise and tell information to their peers in their own words –which indicated that their understanding had been fully interiorised. However, it seems that some actions from the tutors have room for improvement, especially

those related to stimulating their tutee's prior knowledge, avoiding transmission of information without rebuilding it with their tutees or checking the progressive understanding of the concepts, and guiding the session.

**B) In the practical activity, which of the pair's actions help or hinder the emotional development of empathy?**

The following 30 minutes of all practical sessions were analysed by examining pair interaction, based on the 5 dimensions created for the analysis. The results are shown in Table 4.

**Table 4. Results of practical session (20 pairs of students, 12 sessions)**

Dimension / Factors	f	%
9. Tutor's involvement in the practical activity		
9.1 The tutor showed little collaboration and prevented the practical activity from being performed correctly	0	0
9.2 The tutor showed little collaboration and made it difficult to perform the practical activity	1	1.2
9.3 The tutor showed little collaboration but completed the practical activity together with the tutee	2	2.5
9.4 The tutor collaborated when the tutee asked for help, and completed the practical activity correctly	8	10
9.5 The tutor collaborated during the practical activity, helping where the tutee required, and allowing the practical activity to be performed correctly	69	86.2
10. Helpfulness: explanation		
10.1 The tutor did not explain the concepts	6	7.5
10.2 The tutor provided explanations when the tutee asked for them	17	21.2
10.3 The tutor provided explanations without the tutee asking for them	57	71.2
11. Helpfulness: questions		
11.1 No interrogation or questions	17	21.2
11.2 Only the tutee asked questions	14	17.5
11.3 The tutor asked questions to the tutee	2	2.5
11.4 The tutor asked questions to the tutee and provided feedback	47	58.7
12. Guidance provided in practical activity		
12.1 The tutee explained the activity to the tutor	4	5
12.2 The tutor did not explain the activity, both tutee and tutor waited for the teacher to explain the activity	58	72.5
12.3 The tutor explained the activity to the tutee, but the tutor did not provide guidance during the activity	5	6.2
12.4 The tutor explained the activity to be done to the tutee and guided the activity considering the objectives proposed in the dossier	13	16.2
13. Objectives specified in the dossier		
13.1 The tutor did not consider the objectives that needed to be reached	2	2.5
13.2 The tutor considered some of the objectives that needed to be reached and the tutee reached them	18	22.5
13.3 The tutor considered the objectives that needed to be reached and the tutee reached them	60	75

It seems that the tutors did consider the objectives of the activity to help the tutees meet them. Tutors also prompted their tutees by asking questions and offering feedback, and generally collaborated throughout the practical session by helping their tutees.

**C) In the segment of reflection, which elements favoured their awareness on empathy development itself?**

The final 15 minutes, defined as the 'reflection segment' (feedback plus reflection) were analysed by examining pair interaction, based on the three final dimensions designed. The results, summarized in Table 5, show that students were able to create environments, generate time for reflection and expression, and actively listen to the respective points of view, which are all essential for the practice of empathy.

**Table 5. Results on Reflection Segment  
(20 pairs of students, 12 sessions)**

Dimension /Factors	F	%
14. Mutual understanding of the questions on reflection		
14.1 Tutee responded to questions on reflection and tutor gave his/her point of view, but no common reflection was made	2	2.5
14.2 Tutor reformulated questions to the tutee to understand his/her point of view and/or to delve into the answers given by the tutee	10	12.5
14.3 Tutor and tutee listened to and understood each other and gave each other time to think and explain their point of view	68	85
15. Reflection on meaning of concepts		
15.1 No assimilation of concepts was shown	2	2.5
15.2 Tutor and tutee understood and discussed the concepts following the conceptual approach and practical activity	15	18.7
15.3 Tutor and tutee understood and discussed the concepts learnt and justified them or gave examples	45	56.2
15.4 Tutor and tutee were able to reconstruct the meaning of the concept	12	15
15.5 Tutor and tutee were able to construct the meaning of the concept by changing the initial ideas	6	7.5
16. Self-assessment as a part of reflection		
16.1 No self-assessment was carried out	30	37.5
16.2 Self-assessment was carried out individually	12	15
16.3 Tutor assessed tutee	1	1.2
16.4 Tutee assessed tutor	7	8.7
16.5 Tutor and tutee assessed each other mutually	30	37.5

But not all the tutors' actions are in good direction. Results indicate that their reflections on the meaning of the concepts were limited to discussion, indicating that it was correct but superficial. Students' self-assessment could also be improved to include mutual assessment more frequently.

## Discussion

Given the need to help nursing students develop their empathy, a peer-tutoring intervention has been designed to generate favourable social exchange spaces. The results of the quasi-

experimental study show statistically significant improvements in the intervention group which did not occur in the comparison group, especially in the "Perspective Taking" and "Compassionate Care" dimensions. This suggests that this peer tutoring intervention can be effective in promoting social experiences that enhance empathy. The result reinforces the idea that empathy, as a complex social skill, can be developed through teaching methods based on cooperation.<sup>(10)</sup>

The analysis of pair interaction in the peer tutoring sessions that consist of three segments –conceptual approach, practical activity and self-reflection– can help us better account for the quantitative results. The reported improvement

in the “Perspective taking” and “Compassionate Care” dimensions may be due to the creation of an environment that enabled students (in both roles, tutors and tutees) to understand complex concepts, fostered a high level of participation, and provided opportunities for joint reflection and discussion. It seems that peer tutoring was effective given that tutors developed their conceptual learning of empathy by means of preparing materials for the session and using them to explain and question their tutees, which is known as learning by teaching.<sup>(24)</sup> However, results could probably be better in all dimensions, provided that tutors are encouraged to explain in their own words, adjust the explanations to the interest and characteristics of their tutees and ask and answer deep questions.<sup>(25)</sup> Nevertheless, it seems that tutees also increased their learning through the help received, which was personalised and adjusted by their tutor.

However, some actions were identified to have hindered the conceptual development of empathy, and these have been highlighted as elements to be improved on. For instance, it is important to help tutors in using tutees’ prior knowledge to build new knowledge, in ensuring the effective comprehension of what has been explained, and in guiding the session. The qualitative analysis of the interaction in the final segment of the peer tutoring session (self-reflection) seems to indicate actions that must be rectified to improve the dimension referring to “Putting oneself in the patient’s shoes”. Even though the tutor involves the tutee in the activity, they do not appear to sufficiently lead the activity but instead wait for

the teacher’s help. This problem has also been detected in peer tutoring practices in contexts where the teacher’s role is very relevant, and students are not used to offering pedagogical help.<sup>(11)</sup> One possible solution to help solve this problem might involve offering more autonomy to the pairs of students, which appears to be highly linked to the opportunities available to reflect on their own actions, through self-assessment. The results suggest that it is also necessary to help pairs develop quality self-assessment practices.

This study is limited by the small, non-probabilistic sample and by the specific cultural context where it was carried out. However, both limitations offer lines of future work: improving how students are assigned to intervention or comparison group, and increasing the number of students, the type of subjects and especially cultural and geographic contexts. Empathy is a cross-dimensional skill that all students from the healthcare sector should develop, as a key tool to care for patients and their families. That is why this peer tutoring programme has been created. However, not only is empathy important for nursing students, but also for any citizen in the 21<sup>st</sup> century. Thus, the project reported in this article lays the foundation stone to adopt an expanded, innovative standpoint that leads to an evidence-based empathy training programme that could be adjusted and applied in any university, but also implemented in primary and secondary education.

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# Quality of Professional Life and Burnout of the Nursing Staff at an Intensive Care Unit in Venezuela

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Original article



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## Quality of Professional Life and Burnout of the Nursing Staff at an Intensive Care Unit in Venezuela

### Abstract

**Objective.** To determine the relationship between the level of quality of professional life and the characteristics of the burnout syndrome of the nursing staff in the intensive care unit. **Methods.** An analytic cross-sectional study was conducted in the intensive care unit of a public hospital in Mérida (Venezuela), with the participation of 40 nurses from a total population of 43. The Professional Quality of Life of 35 items (QoPL-35) and Maslach Burnout Inventory scales were used. **Results.** Of the participants, 67.5% were professionals and 32.5% were residents, < 41 years of age (75%) and of female sex (90%). The professional quality of life was regular (median = 213), the intrinsic motivation dimension was the best scored (median = 76), followed by that of workload (median = 68) and that of directive support (median = 65). The prevalence of high burnout syndrome was 22.5%; emotional exhaustion affected

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75.5% of the participants and 37.5% had low personal achievement. The level of professional quality of life was related with the severity of the burnout syndrome ( $p=0.04$ ). **Conclusion.** The professional quality of life of the nurses in the ICU studied was regular and is associated with a higher risk of suffering severe burnout syndrome.

**Descriptors:** quality of life; nursing staff; intensive care units; burnout, psychological; cross-sectional studies.

## Calidad de Vida Profesional y Burnout del personal de enfermería de una Unidad de Cuidados Intensivos en Venezuela

### Resumen

**Objetivo.** Determinar la relación entre el nivel de Calidad de Vida Profesional –CVP- y las características del síndrome de Burnout del personal de enfermería en la Unidad de Cuidados Intensivos –UCI-. **Métodos.** Se realizó un estudio de corte transversal analítico en la UCI de un hospital público en Mérida (Venezuela), participaron 40 enfermeros de una población total de 43. Se emplearon las escalas Calidad de Vida Profesional de 35 ítems CVP-35 (Quality of Professional Life Questionnaire QoPL-35, en inglés) y *Maslach Burnout Inventory*. **Resultados.** De los participantes 67.5% eran profesionales y 32.5% eran residentes, menores de 41 años (75%) y de sexo femenino (90%). La calidad de vida profesional fue regular (mediana=213), la dimensión motivación intrínseca fue la mejor valorada (mediana=76), seguida de la de carga de trabajo (mediana=68) y la de apoyo directivo (mediana=65). La prevalencia del síndrome de Burnout alto fue de 22.5%; el agotamiento emocional afectó al 75.5% de los participantes y 37.5% tenía baja realización personal. El nivel de Calidad de Vida Profesional se relacionó con la severidad del Síndrome de Burnout ( $p=0.04$ ). **Conclusión.** La CVP de los enfermeros en la UCI estudiada es regular y se asocia a un mayor riesgo de sufrir un síndrome de Burnout severo.

**Descritores:** calidad de vida; personal de enfermería; unidades de cuidados intensivos; agotamiento psicológico; estudios transversales.

## Qualidade de vida profissional e Burnout da equipe de enfermagem de uma unidade de terapia intensiva na Venezuela

### Resumo

**Objetivo.** Verificar a relação entre o nível de qualidade de vida profissional e as características da Síndrome de Burnout da equipe de enfermagem em unidade de terapia intensiva. **Métodos.** Um estudo transversal analítico foi realizado na Unidade de Terapia Intensiva de um hospital público em Mérida (Venezuela), 40 enfermeiras participaram de uma população total de 43. As escalas de Qualidade de Vida Profissional de 35 itens CVP-35 (Quality of Professional Life QoPL-35, em inglês) e Maslach Burnout foram usados. Inventário. **Resultados.** Dos participantes, 67.5% eram profissionais e 32.5% residentes, menores de 41 anos (75%) e do sexo feminino (90%). A qualidade de vida profissional foi razoável (mediana = 213), a dimensão motivação intrínseca foi a mais valorizada (mediana = 76), seguida da carga de trabalho (mediana = 68) e suporte gerencial (mediana = 65). A prevalência de síndrome de Burnout alto foi de 22.5%, exaustão emocional afetou 75.5% dos participantes e 37.5% apresentaram baixa realização pessoal. O nível de Qualidade de Vida Profissional esteve relacionado à gravidade da Síndrome de Burnout ( $p=0.04$ ). **Conclusão.** A qualidade de vida profissional dos enfermeiros da UTI estudada é regular e está associada a um maior risco de sofrer de síndrome de Burnout grave

**Descritores:** qualidade de vida; recursos humanos de enfermagem; unidades de terapia intensiva; esgotamento psicológico; estudos transversais.

## Introduction

**P**rofessional quality of life (QoPL) is the emotional state resulting from the interaction between the demands of work and the resources (personal and institutional) available to satisfy them.<sup>(1)</sup> A Good QoPL is the feeling of job wellbeing product of the harmony among work exigencies, the capacities to comply with the tasks assigned, and the benefits obtained in exchange for the effort invested, which permit workers their optimal development, satisfy their needs and improve their life condition.<sup>(2)</sup> Thus, the perception of QoPL involves the interaction of multiple factors; personal, social, emotional, family, and institutional that condition the relations workers establish with their work environment, determining their motivation, satisfaction, and performance,<sup>(1,2)</sup> in this sense, QoPL is comprised of three structural dimensions: workload (excessive amount of work or pressure to conduct it), intrinsic motivation (emotional factors that condition conduct in the search for personal growth) and directive support (administrative support by the institution).<sup>(3)</sup>

In areas dedicated to caring and direct interaction with people, like health institutions, it is vital to comprehend the behavior of the QoPL and its influence on the quality of services provided to patients, with emphasis on the nursing staff who, besides being the most numerous component of the health staff, due to their work dynamics are prone to emotional burnout, perceiving low QoPL, and job dissatisfaction.<sup>(4,5)</sup> In special areas and of great demand. Like the intensive care unit (ICU), the nursing staff faces particular situations and of emotional stress, like constant contact with the death and suffering of patients, besides the frequent association of a high workload, strenuous work days, excessive hours on call, job inequity, scarce directive support, little recognition of the effort and inadequate financial remuneration; conditions that potentiate the susceptibility of perceiving low QoPL, cause physical and emotional discomfort with increased incidence of diseases related with work, like the burnout syndrome (BS).<sup>(5,6)</sup>

The BS is an occupational disease<sup>(6)</sup> consequence of exposure to high and sustained levels of stress capable of overcoming the individual's protection mechanisms of adaptation and resilience, triggering emotional fatigue (feeling emotionally exhausted), dejection, tiredness, irritability, anxiety, depression and development of negative feelings, and aversion to work. The BS is composed of three dimensions: emotional exhaustion (perception of depleting energies, anxiety, and irritability when thinking about the work), depersonalization (loss of empathy with the patients and appearance of cynicism with dehumanized treatment), and lack of personal achievement (sense of not achieving goals, feeling of stagnation); the presence of emotional exhaustion and depersonalization with low personal achievement determine the presence of the BS and determine its severity.<sup>(2)</sup>

In the nursing staff working in the ICU, it is common to find the association of low QoPL and higher severity of BS, a phenomenon that has negative consequences, like increased frequency of errors related with caring, deterioration of interpersonal relations, anxiety, emotional isolation, greater rate of resignations, diminished quality of care of patients, physical exhaustion, insomnia, depression, cynical treatment of patients, diminished job performance, lack of motivation, increased work absenteeism, consumption of alcohol and tobacco;<sup>(7)</sup> situations that compromise the safety of critically ill patients, deteriorate operations in the ICU and represent a risk to the health of nurses and patients.<sup>(2,6)</sup>

In view of the severe sequelae that accompany a low QoPL and the BS, and of the relationship that exists between both conditions, it is necessary for health institutions to have up-to-date information about their characteristics to design timely strategies to maintain optimal levels of QoPL and avoid the development of the BS.<sup>(4-6)</sup> The objective of this study was to determine the level of professional quality of life and characteristics of the burnout syndrome of nurses in an ICU in Mérida (Venezuela).

## Methods

A cross-sectional study was conducted in the intensive care unit at the *Instituto Autónomo Hospital Universitario de Los Andes* in Mérida-Venezuela from July to September 2019, with participation by 40 of the 43 nurses who constituted the total population, including professionals with academic degrees in intensive care (specialists, Master's, diploma courses) and graduate nursing degree students in intensive care (residents). The inclusion criteria had to do with having at least three months of continuous work in the unit at the moment of the study, performing

functions related with direct care of critically ill patients. Three nurses were excluded; two were in administrative assignments and one manifested the desire to not participate.

Prior to collecting the study information, a brief induction was made on the theme; informed consent was requested for participation and a 15-day limit was established to deliver an administrative form answered anonymously, containing: (1) sociodemographic data; (2) the Spanish version of the Quality Professional of Life Questionnaire (QoPL-35) instrument or Quality of Professional of Life (QoPL-35) questionnaire,<sup>(8)</sup> which was used to determine the professional quality of life of the nursing staff. This questionnaire is made up of 35 questions in a Likert scale from 1 to 10 (nothing = 1; much = 10), and evaluates three dimensions: workload (11 items), directive support (13 items), and intrinsic motivation (10 items). The sum of the scores of the 35 items is interpreted in three categories: good (246 to 350 points), regular (140 to 245 points), and poor (35 to 139 points); this questionnaire has an independent question destined to knowing the perceived professional quality of life (subjective appraisal) by each individual in a scale from 1 to 10 and interpreted through the categories: nothing = 1-2, somewhat or regular = 3-4-5, a lot = 6-7-8 and much = 9-10;<sup>(8)</sup> (3) The Maslach Burnout Inventory (MBI) instrument<sup>(9)</sup> to establish the behavior of the burnout syndrome, which is a questionnaire with 22 questions grouped into three dimensions: emotional exhaustion (9 items), depersonalization (5 items), and personal achievement (8 items). It evaluates the frequency with which specific work events are perceived through Likert-type response options (never = 0; sometimes per year or less = 1, sometimes per month or less = 2, a few times per month or less = 3, sometimes per week = 4, a few times per week or less = 5, and daily = 6), according to the score obtained, three categories were established for each dimension (Table 1).

**Table 1. Classification according to the score from each dimension from the MBI instrument<sup>(9)</sup>**

Dimension	Low	Medium	High
Emotional exhaustion	≤ 17	18 to 29	≥ 30
Depersonalization	≤ 5	6 to 11	≥ 12
Personal achievement	≥ 40	34 to 39	≤ 33

The severity of the BS is established according to the severity of the dimensions that compose its fundamental nucleus (emotional exhaustion and low personal achievement). However, for the instrument's authors, work and specially that related with direct care of patients represents in itself a risk for developing BS; which is why no category exists that excludes it in its entirety, considering that all the nurses have at least a low level of such.<sup>(9)</sup>

The quantitative data are shown through medians, interquartile range, and maximum and minimum values; qualitative data are presented in frequency tables. To establish the level of each dimension from the QoPL-35 questionnaire, a division was carried out in tertiles establishing three categories: high, medium, and low for each of them. The statistical relations were determined (bivariate analyses) through the chi squared test, considering significant a  $p$  value  $\leq 0.05$ . The statistical analyses were performed with the SPSS program version 21 (IBM Corporation,

New York, US). This study was approved by the ethics committee and competent authorities at *Instituto Autónomo Hospital Universitario de Los Andes*.

## Results

Of the 40 participants, the mean age was 35.5 years (range from 24 to 70 years), highlighting two age groups; those < 30 years of age (37.5%) and those from 31 to 40 years of age (37.5%); the female sex represented 90% of the sample; 47.5% manifested being single; 40% had no economic dependents; and 57.5% had – at the time of the survey – less than 5 years of work experience in ICU. It is highlighted that 67.5% are professionals with degrees in intensive care, 57.5% reported having only one job (in the institution where the study was conducted), and the majority of the nurses (55%) work by alternating day and night shifts (Table 2).

**Table 2. Sociodemographic characteristics of 40 nurses working in ICU**

Characteristic	Number	Percentage
Age group in years		
≤ 30	15	37.5
31 to 40	15	37.5
41 to 50	4	10
≥ 51	6	15
Sex		
Female	36	90
Male	4	10
Marital status		
Single	19	47.5
Married	11	27.5
Steady relationship	6	15
Divorced	4	10
Economic dependents*		
0	16	40
1	14	35
2	6	15
3 or more	4	10
Years of professional practice		
≤ 5	23	57.5
6 – 10	6	15
11 – 15	4	10
≥ 16	7	17.5
Academic level		
Professionals	27	67.5
Residents	13	32.5
Number of jobs		
1	23	57.5
2 or more	17	42.5
Shift		
Day	6	15
Night	12	30
Both	22	55

\* Economic dependents: Persons who lack economic autonomy and depend on others for their support.



The professional quality of life of the 40 participants is regular (median = 213), the dimension of intrinsic motivation was the best scored (median = 79), followed by the dimensions of workload (median

= 68) and directive support (median = 65). The perceived professional quality of life (independent question) obtained a median = 5 that is within the category of somewhat or regular (Table 3).

**Table 3. Descriptive measures of the scores for the total and the dimensions from the QoPL-35 Questionnaire of 40 nurses working in ICU**

Scale / Dimensions	Median	Quartile 1	Quartile 3	Minimum	Maximum
Total	213	190	240	152	288
Directive support	65	52	77	26	100
Workload	68	56	80	38	110
Intrinsic motivation	79	68	86	50	94
Perceived professional quality of life	5	4	8	2	10

Through the division by tertiles of the dimensions of the QoPL-35, it was established that only 40% of the participants perceive high directive

support, 37.5% considered being exposed to high workload, and 70% has between medium and high intrinsic motivation. (Table 4).

**Table 4. Division by tertiles of the dimensions from the QoPL-35 Questionnaire of 40 nurses working in ICU**

Dimensions	Number	Percentage
Directive support		
Low	13	32.5
Medium	11	27.5
High	16	40
Workload		
Low	13	32.5
Medium	12	30
High	15	37.5
Intrinsic motivation		
Low	12	30
Medium	14	35
High	14	35

Through the Maslach Burnout Inventory instrument, it was determined that 22.5% of the nurses have high burnout syndrome, 65% medium, and 12.5% low. Emotional exhaustion

affects 77.5% of the participants, 37.5% has low personal achievement, and only 15% manifests high degree of depersonalization. (Table 5).

**Table 5. Burnout syndrome according to dimensions and total from the Maslach Burnout Inventory instrument in 40 nurses working in ICU**

Dimensions from the MBI	Number	Percentage
Low	5	12.5
Medium	26	65
High	9	22.5
Emotional exhaustion		
Low	9	22.5
Medium	23	57.5
High	8	20
Depersonalization		
Low	25	62.5
Medium	9	22.5
High	6	15
Personal achievement		
Low	15	37.5
Medium	14	35
High	11	27.5

Significant statistical association exists between some sociodemographic characteristics and the dimensions of the QoPL-35 questionnaire; thus, it is evident that intrinsic motivation is higher in participants with 1 to 2 economic dependents; nurses with > 10 years of professional practice in ICU perceive greater workload, professionals

have greater intrinsic motivation and perceive higher directive support than the residents, however, they have a higher workload (Table 6). Likewise, nurses < 41 years of age have better perceived professional quality of life (independent question) than those from the other age groups ( $p = 0.002$ ).

**Table 6. Dimensions of the QoPL-35 Questionnaire according to sociodemographic characteristics in 40 nurses working in ICU**

Characteristic	QoPL-35 Dimension			p - value
	Low n (%)	Medium n (%)	High n (%)	
<b>Economic dependents</b>		<b>Intrinsic motivation</b>		0.045
0 (n = 16)	4 (25)	9 (56.3)	3 (18.7)	
1 (n = 14)	3 (21.4)	4 (28.6)	7 (50)	
2 (n = 6)	2 (33.3)	0	4 (66.7)	
3 or more (n = 4)	3 (75)	1 (25)	0	
<b>Years of professional practice</b>		<b>Workload</b>		0.034
≤ 5 (n = 23)	11 (47.8)	3 (13)	9 (39.2)	
6 – 10 (n = 6)	0	5 (83.3)	1 (16.7)	
11 – 15 (n = 4)	1 (25)	1 (25)	2 (50)	
≥ 16 (n = 7)	1 (14.3)	3 (42.8)	3 (42.8)	
<b>Academic level</b>		<b>Intrinsic motivation</b>		0.043
Professionals (n = 27)	9 (33.3)	6 (22.2)	12 (44.4)	
Residents (n = 13)	3 (23.1)	8 (61.5)	2 (15.4)	
<b>Academic level</b>		<b>Workload</b>		0.024
Professionals (n = 27)	5 (18.5)	10 (37)	12 (44.5)	
Residents (n = 13)	8 (61.5)	2 (15.4)	3 (23.1)	
<b>Academic level</b>		<b>Directive support</b>		0.025
Professionals (n = 27)	5 (18.5)	9 (33.3)	13 (48.2)	
Residents (n = 13)	8 (61.5)	2 (15.4)	3 (23.1)	

Medium and high BS prevalence is higher in participants > 41 years of age, with 11 or more years of professional practice and with regular professional

quality of life; in contrast, younger nurses, less time of professional exercise, and good QoPL tend to have lower severity of the BS (Table 7).

**Table 7. Prevalence of the burnout syndrome according to sociodemographic characteristics in 40 nurses working in ICU**

Characteristic	Burnout syndrome			p - value
	Low	Medium	High	
<b>Age (years)</b>				0.048
≤ 30 (n = 15)	2 (13.3)	8 (53.3)	5 (33.3)	
31 to 40 (n = 15)	3 (20)	11 (73.3)	1 (6.7)	
41 to 50 (n = 4)	0	2 (50)	2 (50)	
≥ 51 (n = 6)	0	5 (83.3)	1 (16.7)	
<b>Years of professional practice</b>				0.038
≤ 5 (n = 23)	3 (13)	15 (65.2)	5 (21.7)	
6 – 10 (n = 6)	2 (33.3)	3 (50)	1 (16.7)	
11 – 15 (n = 4)	0	3 (75)	1 (25)	
≥ 16 (n = 7)	0	5 (71.4)	2 (28.6)	
<b>Professional quality of life (QoPL)</b>				0.040
Good (n = 12)	5 (41.7)	6 (50)	1 (8.3)	
Regular (n = 28)	0	20 (71.4)	8 (28.6)	
Poor (n = 0)	0	0	0	

Moreover, it was determined that significant relations exist among the dimensions that compose both instruments; lower directive support indicates higher emotional burnout ( $p=0.015$ ) and with greater workload, lower personal achievement is perceived ( $p=0.009$ ).

## Discussion

In the ICU, the nursing staff is exposed to high and sustained levels of stress, mental, physical, and emotional exigencies that predispose them to physical wear, job dissatisfaction, emotional burnout, low QoPL, and development of the BS with negative effect in their performance, health and quality of the care provided to patients.<sup>(5,10)</sup> This research evidences regular professional quality of life with the following behavior: high intrinsic motivation, medium workload and medium to low

directive support, findings that agree with Canova-Barrios *et al.*,<sup>(3)</sup> and Fernández-Araque *et al.*,<sup>(11)</sup> a situation also found by Monroe *et al.*,<sup>(12)</sup> who also associated lack of directive support with the development of low QoPL, emotional exhaustion and job dissatisfaction in ICU.

The diagnosis of high BS has a prevalence of 22.5%, far surpassing the findings by Maticorena-Quevedo *et al.*,<sup>(13)</sup> and Salgado-Roa *et al.*,<sup>(2)</sup> with results of 2.1% and 10% in the nursing staff working in ICUs in Peru and Chile, respectively, findings also above those by Van der Heijden *et al.*,<sup>(14)</sup> who additionally concludes that a strong relationship exists between the prevalence of the BS and greater occurrence of adverse effects associated with care. Of the dimensions that make up the BS, emotional burnout has the highest influence and affects 77.5% of the participants. These results are equivalent to those by Vega *et al.*,<sup>(15)</sup> where emotional burnout was the principal

determinant for the development of the BS and had a 65% prevalence; in the same way as Monsalve-Reyes *et al.*,<sup>(16)</sup> depersonalization has little presence in this study; however, 37.5% perceive low personal achievement; a condition associated with depression and anxiety product of a sense of stagnation and which is capable of triggering emotional burnout and conditioning the subsequent appearance of cynicism or dehumanized treatment.<sup>(17)</sup>

Significant statistical associations exist between the sociodemographic characteristics and the dimensions that structure the QoPL-35; thus, similar to the findings by Fernandez-Araque *et al.*,<sup>(11)</sup> the staff < 41 years of age manifests lower perceived professional quality of life than those of higher age and the staff with more time of professional exercise perceives greater workload. As in Jang *et al.*,<sup>(18)</sup> professionals with degrees in intensive care perceive better directive support and have better intrinsic motivation than the residents; in their research, this behavior was attributed to greater experience, confidence, skills and communication abilities acquired during the professionalization. At the same time, and in keeping with the study by Galindo *et al.*,<sup>(19)</sup> professionals perceive greater workload than the students, associating this result with the extra responsibility of surveillance and advice to the students. Finally, as in Lee *et al.*,<sup>(20)</sup> the participants with economic dependents reported higher intrinsic motivation.

This research demonstrated a significant statistical relation among the severity of the BS, age, and time of professional practice; participants in the age group of 41 or more years and with > 10 years of professional practice have a higher prevalence of medium and high burnout syndrome, these results differ from Mefoh *et al.*,<sup>(21)</sup> and Molero-Jurado *et al.*,<sup>(22)</sup> who found higher severity of the

BS in young individuals who have less protection mechanisms against stress and are more prone to suffering its negative effects. In turn, as described by Roberts *et al.*,<sup>(23)</sup> and Kwak *et al.*,<sup>(24)</sup> a lower QoPL indicates higher presence of emotional burnout, job dissatisfaction, and high BS.

As a limitation, it must be stated that this was a study in a single hospital center and of cross-sectional design, making it difficult to extrapolate the results to other ICUs in the country. However, these results offer valuable and relevant information from the administrative point of view upon identifying points susceptible to intervention to improve the QoPL and diminish the BS prevalence and avoid its unwanted effects.

This research permits concluding that the QoPL of the nursing staff in the ICU studied is regular, high intrinsic motivation of the staff exists, workload is high, and 60% of the nurses perceive that directive support is from low to medium. The different dimensions that compose the QoPL have different behaviors related with age, time of professional exercise in ICU, number of economic dependents, and academic level. The high BS prevalence is significantly above that described in other research from the region; emotional exhaustion affects 77.5% of the participants and 37.5% has low personal achievement, however, depersonalization remains in low levels. It was demonstrated that the regular level of QoPL is related with higher severity of the BS.

According to the authors' knowledge, when conducting this study, no evidence was documented on the professional quality of life of the nursing staff in an ICU in Venezuela, which is why their behavior and association with the BS was totally unknown.

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# Grieves and struggles of family caregivers providing care for bedridden elderly patients affected by chronic degenerative diseases

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## Grieves and struggles of family caregivers providing care for bedridden elderly patients affected by chronic degenerative diseases

### Abstract

**Objective.** To understand grieves and struggles of family caregivers providing care for bedridden elderly patients affected by chronic degenerative diseases. **Methods.** This cross-sectional study was developed following the guidelines of the clinical-qualitative method. The sample was composed of 10 female family caregivers of bedridden elderly patients affected by chronic degenerative diseases in a city in the interior of Minas Gerais, Brazil. The sample size was determined by data saturation. The instruments used included semi-structured interviews and a field diary. The audio-recorded interviews were transcribed verbatim and submitted to content analysis. The field diary provided contributions to the organization of categories, conferring a more accurate context. **Results.** The participants

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experienced two types of grief, one for the loss of a “healthy family member” and the other for the “announced death” of this person. Additionally, the participants faced two main struggles: overcoming (objective and subjective) fatigue and becoming fully capable of performing their roles. **Conclusion.** The family caregivers of bedridden elderly patients affected by chronic degenerative diseases experience grieves and struggles that should be taken into account from the beginning of the care process through mental health actions intended to meet their needs.

**Descriptors:** caregivers; home nursing; aged; family health; qualitative research.

## Duelos y luchas de cuidadores familiares de ancianos postrados en cama debido a enfermedades crónicas y degenerativas

### Resumen

**Objetivo.** Comprender los duelos y las luchas que experimentan cuidadores familiares de ancianos postrados en cama debido a enfermedades crónicas y degenerativas.

**Métodos.** El estudio tuvo un carácter transversal y se desarrolló de acuerdo con las directrices del método clínico-cualitativo. La muestra estuvo conformada por 10 cuidadoras familiares de ancianos postrados en cama debido a enfermedades crónicas y degenerativas de una ciudad del interior del Estado de Minas Gerais en Brasil. La muestra se cerró por saturación. Los instrumentos utilizados fueron un guión de entrevista semiestructurada y un diario de campo. Las transcripciones literales y textuales de las grabaciones de audio de las entrevistas se sometieron a un análisis de contenido. Las notas del diario de campo proporcionaron aportaciones adicionales al proceso de organización de las categorías, dándoles un contexto más preciso. **Resultados.** Se constató que las participantes vivenciaban básicamente dos duelos, uno por la muerte del “familiar saludable” y otro por la “muerte anunciada” del mismo. Además, se comprobó que las participantes se enfrentaron a dos batallas principales: una para superar el cansancio – en sus vertientes objetiva y subjetiva – y otra para volverse plenamente aptas para la función que desempeñaban.

**Conclusión.** Las cuidadoras familiares de ancianos postrados en cama debido a enfermedades crónicas y degenerativas vivencian duelos y luchas que deben ser

tenidos en cuenta desde el inicio del proceso de cuidado mediante acciones de salud mental dirigidas a sus necesidades.

**Descriptor:** cuidadores; atención domiciliar de salud; anciano; salud de familia; investigación cualitativa.

## Lutos e lutas de cuidadoras familiares de pessoas idosas acamadas devido a doenças crônico-degenerativas

### Resumo

**Objetivo.** Compreender lutos e lutas vivenciados por cuidadores(as) familiares de pessoas idosas acamadas devido a doenças crônico-degenerativas. **Métodos.** O estudo possui caráter transversal e foi desenvolvido em consonância com as diretrizes do método clínico-qualitativo. A amostra foi constituída por 10 cuidadoras familiares de pessoas idosas acamadas devido a doenças crônico-degenerativas de uma cidade do interior do Estado de Minas Gerais, no Brasil. O fechamento amostral se deu por saturação. Os instrumentos utilizados foram um roteiro de entrevista semiestruturado e um diário de campo. As transcrições literais e integrais das gravações em áudio das entrevistas foram submetidas à análise de conteúdo. As anotações do diário de campo forneceram aportes adicionais para o processo de organização de categorias, conferindo-lhes um contexto mais acurado.

**Resultados.** Constatou-se que as participantes vivenciavam basicamente dois lutos, sendo um pela perda do “familiar saudável” e outro pela “morte anunciada” do mesmo. Ademais, verificou-se que as participantes enfrentavam duas batalhas principais: uma para superar o cansaço – em suas vertentes objetiva e subjetiva – e outra para se tornarem plenamente aptas para a função que desempenhavam.

**Conclusão.** As cuidadoras familiares de pessoas idosas acamadas devido a doenças crônico-degenerativas vivenciam lutos e lutas que devem ser levados em conta desde o início do processo de cuidado, por meio de ações de saúde mental dirigidas às suas necessidades.

**Descritores:** cuidadores; assistência domiciliar; idoso; saúde da família; pesquisa qualitativa.

## Introduction

The expression “family caregiver” refers to someone who provides unpaid and usually intuitive assistance to a sick family member, promoting his/her wellbeing.<sup>(1,2)</sup> Because this function is generally performed at home, living together is often necessary, especially when care is provided to elderly patients affected by chronic degenerative diseases and/or bedridden.<sup>(3)</sup> The reason is that the dependency and frailty of older individuals intensify in these conditions. On the other hand, cohabitation may lead family caregivers to neglect their own needs.<sup>(2)</sup>

Many studies worldwide have addressed the experiences of family caregivers from different perspectives, considering that a better understanding of this phenomenon can be instrumental in devising health actions at either the individual or collective level.<sup>(4-6)</sup> Most of these studies explore the grief triggered by the imminent death of patients in advanced stages of illness<sup>(7,8)</sup> or by their deaths.<sup>(9,10)</sup> However, few studies address family caregivers during the care process, especially emphasizing anticipatory grief.<sup>(11)</sup> Hence, there is an important gap in the scientific literature, considering that grief encompasses a set of responses raised by a significant loss, not necessarily caused by death, and anticipatory grief is triggered by the progressive threat of loss.<sup>(12)</sup> Another evident gap is that studies seldom address coping strategies adopted by family caregivers to facilitate the care provided to bedridden elderly patients affected by chronic degenerative diseases.<sup>(13-15)</sup>

Even though the term “struggle” is not part of the technical terminology in the health field, family caregivers in many Brazilian regions – especially in the interior of Minas Gerais – use this term to refer to these coping strategies. So, it is associated with a wide range of care tasks that demand unconditional availability, including from an emotional point of view. Given the previous discussion, this study aims to understand grieves and struggles experienced by family caregivers providing care to bedridden elderly patients affected by chronic degenerative diseases. It is an excerpt of a larger study and was implemented *a posteriori* to highlight specific findings, which, in our view, required further investigation.

## Methods

This cross-sectional study was developed following the guidelines of the clinical-qualitative method, which is intended to clarify experiences that concern the health-disease-care *continuum* from the perspective of patients, family members, or health workers.<sup>(16)</sup> The sample was composed of 10

female family caregivers who met the following criteria: (1) were providing care for at least six months to a bedridden elderly patient with a chronic degenerative disease, and (2) were at least 18 years old.

It was not intentional to include only female family caregivers. Data saturation determined the sample size; thus, the recruitment of participants ceased when the authors identified that data were redundant and already met the study's objectives.<sup>(17)</sup> The instruments used included a semi-structured interview and a field diary. Both are tools recurrently used in qualitative studies, and field diaries are usually adopted to facilitate access to data that complement information provided in the interviews.

Considering the objectives of the study from which this excerpt originates, the semi-structured interview was composed of 32 questions distributed into four axes. The first axis was composed of nine questions concerning how the family caregiver was chosen (e.g., "How was it determined who would be the family caregiver?"). The second axis included 10 questions addressing the care tasks (e.g., "What are your main responsibilities as a family caregiver?"). The third axis included 6 questions that investigated how the family caregiver performed his/her roles (e.g., "What are the difficulties and facilities you experience in the care process?"). Finally, the fourth axis encompassed 7 questions addressing the family caregivers' self-care (e.g., "What do you do to take care of your own health?").

A semi-structured interview script was used to encourage the participants to verbally express their feelings and thoughts regarding the topic under study.<sup>(18)</sup> A field diary was used by the primary author (a psychologist experienced with home visits and interviews who worked in a primary health care service at the time) to record her impressions regarding the participants' contexts.<sup>(19)</sup> The participants were recruited from the list of a public home care service – predominantly

aimed at elderly patients – located in a medium-sized city in the interior of Minas Gerais, Brazil. Those who met the inclusion criteria were invited by telephone to participate in the study. All the potential participants contacted were eligible, and none of them refused. Note that 30 individuals were listed; however, as the sample size was determined by saturation rather than exhaustion, we do not know how many of these individuals would be actually eligible. Therefore, we cannot accurately determine the number of individuals in the target population, considering that not all those assisted by the service were bedridden due to chronic degenerative diseases.

After the participants signed a free and informed consent form, the interviews were held in person, according to the participants' convenient date and time, between October and December 2018. Considering the guidelines for clinical-qualitative studies, interviews preferably take place in the natural setting of care.<sup>(16)</sup> Hence, data collection was conducted in the homes where the participants performed their family caregiver role in all cases. Note that the author responsible for collecting data did not previously know any of the participants. Also, the participants chose the room they deemed to be the most appropriate to provide the interview and whether they wanted to be accompanied by other people or not.

These aspects were somewhat heterogeneous because participants 1 and 2 opted to be interviewed in the patients' bedroom, while the remaining participants chose other rooms. Participants 3 and 4 chose to be accompanied by formal caregivers, participants 5 and 7 chose to be accompanied by their sisters, and participant 8 chose her granddaughter. There were no verbal or non-verbal expressions that embarrassed the participants. To reduce eventual biases, the companions also received clarification regarding the target population. Additionally, when the author responsible for data collecting was alone with the participants, she offered the possibility of an additional interview without any companions if

the participants desired to review or detail any of the information provided. None of the participants requested an additional interview.

The interviews were audio-recorded and lasted 40 minutes on average, and only one interview was conducted with each of the participants. The author responsible for data collection took note in the field diary of observations and reflections regarding the participants' non-verbal behavior and the home environment. The field diary was filled out immediately after the interviews to avoid potential embarrassment. Data collection was based on current ethical guidelines regulating research with human subjects in Brazil (Resolution CNS No. 466/2012). The study was approved by the Institutional Review Board at the university to which the authors are affiliated (Opinion Report CEP No. 2.798.042).

The *corpus* of analysis was mainly composed of verbatim transcriptions of the audio-recorded interviews. This material was submitted to content analysis, as proposed by Bardin.<sup>(20)</sup> According to Bardin, content analysis is intended to determine latent aspects of communications so that the process starts with fluctuating readings and culminates with the organization of categories that emerge from the coding process and result in significant results. Notes in the field diary provided additional contributions to the organization of categories, resulting in a more accurate context.

All the authors collaborated with the content analysis. The primary and fourth authors independently performed the fluctuating readings and organized preliminary categories based on relevance criterion and using the field diary as an additional resource. The preliminary categories were then refined, a process conducted by the primary and fourth authors throughout meetings. The second and third authors reviewed the categories and suggested some adjustments. After the primary and fourth authors reformulated specific aspects, the second and third authors reviewed the categories and validated them.

## Results

Most participants were married, presented a low level of education, and were the daughters of the elderly patient receiving care. Some disparities were found regarding the participants' age ( $M=67.7$  years) and how long they are providing care ( $M=8.3$  years). This information is presented in Table 1. Note that participant 7 did not live with the elderly patient to whom she provides care, and only participant 9 reconciled her family caregiver role with a paid job, a job she sporadically performed outside the home. Most of the elderly patients were men ( $n=6$ ) and presented complications and sequelae of neurological diseases, especially Alzheimer's ( $n=6$ ).

**Table 1. Characterization of the participants according to age, marital status, education, kinship, and duration of care**

Participants	Characteristics
1	55 years old / divorced / incomplete middle school / daughter / 10 years
2	82 years old / married / incomplete middle school / wife / 14 years
3	86 years old / married / incomplete middle school / wife / 10 years
4	86 years old / married / middle school / wife / 9 years
5	79 years old / widowed / college education / mother / 20 years
6	56 years old / single / middle school / daughter / 5 years
7	62 years old / married / middle school / daughter / 4 years
8	55 years old / divorced / incomplete college education / daughter / 3 years
9	54 years old / divorced / incomplete middle school / daughter / 7 years
10	62 years old / widowed / middle school / daughter / 1 year

Content analysis, according to the study's objective, led to the emergence of two categories. The first category, called "Grieves," sheds light on the participants' experiences considering losses caused or accentuated at different spheres due to their family caregiver role. The second category, called "Struggles," refers to the efforts required to overcome daily difficulties the participants had to face since they became family caregivers, considering repetitive and continuous care demands.

The first category revealed that the grief for the loss of a "healthy family member" was more prominent. From the participants' perspectives, their elderly patient, after became ill, and especially after became bedridden, were no longer the same person. This grief process appears as a procedural phenomenon. It begins with the illness and intensifies with the emergence of complications and sequelae, negatively impacting the family dynamics. Note that this impact occurs at different levels, and changing social roles is only one of them.

One example illustrating this situation refers to one of the participants who improvised a rope

system on the patient's bed to allow him to sit up by himself. This system was noted in the field diary: "The patient sits there holding strings. As a statue, he seemed to sit on a swing that does not swing". In Report 1, this participant explains how she rearranged the home environment, which suggests that care demands presented by a bedridden elderly patient may impose a need to reorganize the home, revealing transformations that occur in the context of affective relationships and social roles as a result of the loss of a "healthy family member".

*Report 1: It's been three years since I put these strings here. I looked at the window and thought: 'if only I tied some strings, he'd be able to sit by himself'. So I cut some strings and tied them here. Then, he had difficulties getting on the bed. So I thought: 'I'm going to put another string there'. Now, whenever he wants to sit, he uses the strings. (Participant 2)*

Another situation observed in the research field, in another participant's home, support this line of reasoning, which led to the following observation recorded on the field diary: "The scene of illness is wide open at the house's door. You can see



from the street the bedridden patient in his bedroom. From the outside you can see that there is someone ill at home". Report 2 refers to this situation and clarifies that the house was rearranged to confer more comfort to the patient. The patient started occupying one room at the house's entrance, which used to be a living room. His wife's bedroom remained in the same place, at the back of the house.

Report 2: *It used to be a living room [...], so we installed it [a larger window] there, arranged a single bed for him [...] and used that [a recently built access ramp] to take him outside.* (Participant 10)

It is worth noting that, as showed by Reports 3, 4, and 5, the participants occasionally expressed grief for the patients' progressive worsening clinical conditions, and as a consequence, sensed his/her finitude. Therefore, it seems reasonable to state that the results concerning the first category reveal that the participants also experienced grief for the "announced death", though more discreetly, than the grief for the loss of a "healthy family member".

Report 3: *He [patient] is quiet, speechless, doesn't talk, doesn't walk [...] He doesn't know anyone who enters there; he's on oxygen [...].* (Participant 3)

Report 4: *He [patient] used to swallow well, used to eat very well, now he doesn't want anything.* (Participant 5)

Report 5: *Because he still walked when he got sick. He was able to walk before he fell out of bed. So, it's over for three years now.* (Participant 4)

The second category showed that the participants' experiences as family caregivers were permeated by two significant struggles. One of which refers to the need to overcome the fatigue caused by their functions. The author responsible for data

collection noted that most of the participants showed signs of exhaustion. The following entry in the field diary refers to a specific case: "During the interview, the participant kept her eyes sad and showed signs of tiredness". Apparently, the participants' fatigue resulted from two reasons. As shown by Reports 6, 7, and 8, one of which was an objective reason and concerned the care tasks under their responsibility.

Report 6: *You get really tired [...]. Sometimes you have to wake up in the middle of the night [to care for the patient]. I put my mobile to wake me up, so I go and take a look at her, you know, to see if she's choking, you have to keep an eye on that. I sleep beside her. We sleep in the same room. I divorced my husband five years ago, and since then, I sleep with her.* (Participant 1)

Report 7: *In my free time, I just want to rest. I'm usually tired [for providing care to the patient] in my free time.* (Participant 2)

Report 8: *It's tiresome, you know? [to provide care]. Sometimes, you spend the night without sleep a wink. It's a struggle.* (Participant 6)

The second reason for the participants' tiredness, as we inferred, was subjective and related to the complex and gradual process of reconstructing their personal and professional identities, determined by the complete abandonment of their previous social roles, with which they apparently became involved after they became family caregivers. They suggested that their lives were completely changed, and they needed to reinvent themselves after it. Reports 9, 10, and 11 are emblematic in this sense.

Report 9: *I didn't live here, I lived abroad, in another city, another country. But then my mother needed me to come back, and I did. It was a radical change.* (Participant 9)

Report 10: *I was an assistant secretary. I got on leave in September, and it's been two years. I got*

*on leave to help and take care of my mother, I got on leave ahead of time, you know? (Participant 7)*

Report 11: *I used to do handcrafts, now I don't anymore... (Participant 8)*

However, this process of identity reformulation has positive aspects as well, considering that most of the participants developed personal resources that started to be used to favor adaptation to the new context caused by the illness of the elderly patient to whom they provide care. As a consequence, they experienced a comforting sense of accomplishment. Some of them clearly stated that their role “is not easy” but “it’s gratifying”.

To conclude the second category, we point out that the participants apparently fought another fight, attempting to acquire the skills and competencies necessary to play their family caregiver role, mainly to deal with critical situations, as shown in Report 12. After all, these situations clearly revealed the participants’ limitations – mainly originated from a lack of technical training – regarding the performance of care tasks, consequently raising insecurities. However, as noted by Report 13, what made this struggle particularly challenging, at least for some of the participants, was a fear that the person receiving care would, at some point, require the use of intracorporeal devices.

Report 12: *We are not perfect [...] I do my best when she feels sick [...], but I feel insecure. Sometimes I freak out when she [patient] feels sick. (Participant 6)*

Report 13: *I'm afraid that she might need a tube because I have no practice. A breathing tube... Because they [physicians] say that it may get to this point, you know? (Participant 1)*

## Discussion

First, we need to clarify that the participants’ profile is in line with the profile of family caregivers reported

by other studies conducted in Brazil concerning sex, kinship, and educational level.<sup>(21,22)</sup> Regarding the results more directly related to the study’s objective, note that the grief experienced for the loss of a “healthy family member” was the most evident among the participants. In some cases, this loss was revealed by the need to rearrange the home, which leads us to suggest that the grief related to the loss of a “healthy family member” may be synthesized by the loss of the place – concrete and symbolic – that these individuals previously occupied within the family.

In this sense, as defended by other authors,<sup>(22)</sup> the results highlight that relationships of reciprocity become relationships of dependence in the families in which the presence of a family caregiver is necessary. Perhaps this transformation is a facet of the grief for the loss of a “healthy family member”, and more subtly, of the grief for the patient’s “announced death”. After all, the death associated with chronic degenerative diseases usually occurs after long-term care provided at home and is preceded by many signs and symptoms.<sup>(12)</sup>

According to the participants’ reports, the grief for an “announced death” suggests anticipatory grief, because it concerns a situation in which death is very likely; however, one cannot estimate when it will actually occur.<sup>(12)</sup> This is a highly relevant finding, since some authors still doubt the possibility of anticipatory grief occur in family caregivers of patients who are not yet in advanced stage of illness.<sup>(23)</sup> Additionally, this grief expressed by the participants indicates that seeing the finitude of the elderly patient to whom they provide care caused them suffering. Equivalent findings are reported by previous studies,<sup>(5,24)</sup> revealing that considering one’s future at the long term triggers intense emotional mobilization among family caregivers.

This study also shows that the participants had to deal with the fatigue caused by the role they played in their routine lives, which, in our view, accrued

from both the care provided *per se*, but also from the process of reconstructing their personal and professional identities; a process initiated when they became family caregivers. However, we note that this reconstruction process also entails a positive facet despite the burdensome negative aspects. The family caregivers composing other studies' samples,<sup>(11,21)</sup> also reported specific beneficial changes in their lives resulting from providing care.

Furthermore, the participants endeavored to acquire the skills and competencies necessary to perform care tasks, representing part of their struggles. One integrative review<sup>(2)</sup> suggests that one factor that makes the transition to the family caregiver role so challenging is precisely the need to learn many procedures. However, the results found here concerning this specific aspect differed because they highlight the experiences of some of the participants who were afraid of being unable to provide care in the future for not being qualified to handle intracorporeal devices.

Therefore, the conclusion is that as family caregivers of bedridden elderly patients affected by chronic degenerative diseases, the participants experienced two types of grief, one for the loss of

a "healthy family member" and another for the "announced death" of this patient. Note that the first grief stood out and encompassed the loss of the place the patient previously occupied in the family. Additionally, the participants also faced two main struggles: overcoming their objective and subjective fatigue and becoming skillful to perform their roles. These results support the practice of health workers as they reinforce the importance of implementing mental health actions for family caregivers since the beginning of the care process and highlight their need for a support network within and outside the family.

This study's results also pose some questions that deserve to be further explored in the future. Specifically, multi-center, longitudinal studies are recommended to identify potential variations in how anticipatory grief is manifested during the care process. Note that this study has some limitations determined by its cross-sectional nature, in which a phenomenon was described – the experience of family caregivers performing their role within the home context – as spontaneously manifested at a given point in time. Another limitation refers to the fact that the participants were recruited from a single public home care service.

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# Experiences of Parents of Preterm Children Hospitalized Regarding Restrictions to Interact with Their Children Imposed Because of the COVID-19 Pandemic

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## Experiences of Parents of Preterm Children Hospitalized Regarding Restrictions to Interact with Their Children Imposed Because of the COVID-19 Pandemic

### Abstract

**Objective.** To describe the experiences of parents of hospitalized preterm children regarding the restrictions implemented in the neonatal intensive care unit -NICU- during the COVID-19 pandemic. **Methods.** Qualitative study. Semi-structured interviews were conducted between April and October 2020 with 12 parents of preterm children, whose children were hospitalized and discharged from NICU during the pandemic. The analysis was performed with tools from grounded theory through open and axial coding. **Results.** The study identified four categories regarding the experience: 1) needing information: refers to the need for clear and close information to compensate for the physical distance; 2)



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limiting the interaction with the children: expressed as a painful situation, which minimizes opportunities for learning to care at home for their preterm child; 3) the pandemic: adding to the fears: in which the virus appears as a new threat for the children, who are vulnerable given their premature condition; and 4) limiting social support after discharge: identifies that the parents had less family and professional support for care after discharge during times of pandemic. **Conclusion.** Parents of preterm children lived a difficult experience that became complex within the context of the pandemic. The experiences of parents of preterm children during times of COVID-19 indicate that restrictions to enter neonatal units to prevent the virus transmission limited the interaction with the preterm child and with the health staff and increased the needs for information.

**Descriptors:** pandemics; coronavirus infections; neonatal nursing; infant, premature; parents; intensive care units, neonatal; family nursing

## Experiencias de los padres de niños prematuros hospitalizados en torno a las restricciones impuestas por la pandemia para la interacción con su hijo

### Resumen

**Objetivo.** Describir las experiencias de padres de niños prematuros hospitalizados frente a las restricciones implementadas en la Unidad de Cuidado Intensivo Neonatal -UCIN- durante la pandemia por la COVID-19. **Métodos.** Estudio cualitativo. Se realizaron entrevistas semiestructuradas entre abril y octubre de 2020 a 12 padres de niños prematuros; los niños estuvieron hospitalizados y dados de alta en UCIN durante la pandemia. El análisis se realizó con herramientas de la teoría fundamentada mediante codificación abierta y axial. **Resultados.** Se identificaron cuatro categorías en torno a la experiencia: 1) Necesitando información: se refiere a la necesidad de información clara y cercana para compensar la distancia física; 2) limitando la interacción con los hijos: se expresa como una situación dolorosa, que minimiza las oportunidades de aprendizaje para el cuidado de su hijo prematuro en casa; 3) La pandemia: sumando a los miedos, en la que el virus aparece como una nueva amenaza para los hijos, quienes son vulnerables dada su condición de prematuridad; y 4) Limitando el apoyo social después del alta: se identifica que los padres tuvieron menos apoyo familiar y profesional para el cuidado después del alta en tiempos de pandemia. **Conclusión.** Los padres de los niños prematuros vivieron una experiencia difícil que se complejizó en el contexto de la pandemia. Sus experiencias, en tiempos de COVID 19, indican que las restricciones de ingreso a



las unidades neonatales para prevenir la transmisión del virus limitaron la interacción con el hijo prematuro y con el personal de salud e incrementaron las necesidades de información.

**Descriptor:** pandemias; infecciones por coronavirus; enfermería neonatal; recién nacido prematuro; padres; unidades de cuidados intensivos neonatal; enfermería de la familia.

## Experiências de pais de bebês prematuros hospitalizadas em relação às restrições de interação com seus filhos impostas pela pandemia

### Resumo

**Objetivo.** Descrever as experiências de pais de crianças prematuras hospitalizadas frente às restrições implantadas na Unidade de Terapia Intensiva Neonatal -UCIN- durante a pandemia do COVID-19. **Métodos.** Estudo qualitativo. Entrevistas semiestruturadas foram realizadas entre abril e outubro de 2020 com 12 pais de crianças prematuras, cujos filhos foram hospitalizados e receberam alta da UTIN durante a pandemia. A análise foi realizada com ferramentas da teoria fundamentada por meio de codificação aberta e axial. **Resultados.** Quatro categorias foram identificadas em torno da experiência: 1) Necessidade de informação: refere-se à necessidade de informações claras e próximas para compensar a distância física; 2) limitação da interação com os filhos: expressa-se como uma situação dolorosa, que minimiza as oportunidades de aprendizagem para cuidar do filho prematuro em casa; 3) A pandemia: agravando os medos: em que o vírus surge como uma nova ameaça às crianças, vulneráveis pela prematuridade; e 4) Limitação do suporte social após a alta: identifica-se que os pais tiveram menos apoio familiar e profissional para o cuidado após a alta em momentos de pandemia. **Conclusão.** Os pais das crianças prematuras tiveram uma experiência difícil que se tornou mais complexa no contexto da pandemia. As experiências de pais de bebês prematuros na época do COVID 19 indicam que as restrições de admissão em unidades neonatais para prevenir a transmissão do vírus limitaram a interação com o bebê prematuro e com o pessoal de saúde e aumentaram as necessidades de informação.

**Descritores:** pandemias; infecções por coronavirus; enfermagem neonatal; recém-nascido prematuro; pais; unidades de terapia intensiva neonatal; enfermagem familiar.

## Introduction

The COVID-19 pandemic, which demanded important adjustments in the health care of preterm children hospitalized in Neonatal Intensive Care Units (NICU), aimed at limiting exposure to the virus and preventing infection due to this cause. In general, children born prior to 37 weeks of gestation have greater predisposition to infectious diseases due to their immunological immaturity. Furthermore, although in the case of infection through the new coronavirus, this immaturity seems to avoid uncontrolled immune response and favor a favorable clinical course,<sup>(1)</sup> the need is without question to implement measures in neonatal units to protect preterm children and avoid their infection.

Infection through the new coronavirus has had a strong impact on the lives, health, and wellbeing of people throughout the world, where, according to data from the World Health Organization,<sup>(2)</sup> by 12 April 2021, COVID-19 had infected over 136-million people and caused nearly 2.9-million deaths, with the region of the Americas being the most affected. Colombia, by this same date, has reported over 2.5-million people infected and 65,889 people dead due to this cause.<sup>(2)</sup> This situation has led to entry restrictions to families to health institutions to avoid possibilities of infection and, particularly, in the NICUs, these restrictions limited possibilities of accompaniment, contact, and interaction by the parents with their children.

Although the incidence of COVID-19 in premature children is low and the expression of disease is predominantly slight,<sup>(3)</sup> it is necessary to implement strategies to prevent transmission to preterm children in NICUs, which also contributes to preventing the infection in the parents and the health staff in these care settings. The principal adjustments in neonatal care settings have had to do with restrictions for accompaniment by the parents of their children in neonatal units. These measures that, although necessary, generate great concern, given that it has been described that close companionship during hospitalization brings important benefits at physical and emotional levels for the parents and their children.<sup>(4-7)</sup> After years of promoting in Colombia the opening of the neonatal units to the parents and of working to favor their prolonged permanence during their children's hospitalization, the COVID-19 pandemic, almost unexpectedly, demanded an opposing attitude, whose effects are yet unknown. Given the scarce information on the theme and considering the importance of knowing the experiences of the parents within this context, this article sought to describe the experiences of parents of preterm children hospitalized in the neonatal intensive care unit, regarding restrictions implemented during the COVID-19 pandemic.

## Methods

A qualitative study was conducted, using tools from grounded theory to analyze the data. This study is part of a broader research that seeks to describe the experiences of parents of preterm children regarding birth, hospitalization, and transition to the home. During the field work, the COVID-19 pandemic was declared, which permitted identifying the experiences of the parents with regards to the restrictions adopted in the neonatal unit, which were expressed cross-sectionally during the trajectory with their children and became a core of analysis, which identified categories that gained strength, growing in density and depth. Of the number of participants in the principal study, 12 parents lived the experience of having a preterm child hospitalized in an NICU during the COVID-19 pandemic; with this number, it was possible to identify properties and establish the saturation of the categories identified. None of the parents refused to participate in the study.

The inclusion criteria were: parents of children born before 37 weeks of gestation, whose children had been hospitalized in NICU, who were currently at home, and who had been discharged from the hospital not over three months. The study excluded parents whose children had some health problem at the time of the interview. Semi-structured interviews were conducted between April and October 2020, lasting between 30 and 80 minutes, through video calls or phone calls, given restrictions for social contact due to the pandemic. During the interviews, no other family member was present. A snowball convenience sampling was carried out, that is, a father or mother was contacted, which referenced another with the same experience and so forth, obtaining information related with study phenomenon.

The principal researcher established a telephone relationship with the participants to invite them to participate in the study and schedule the interview, at which time she introduced herself to the father

or mother, indicating her credentials as nurse and nursing PhD student, in addition to informing about the objective of the study and the reasons to conduct the research, given her interests as a nurse from the area of neonatal care, in generating contributions to the quality of life of the parents and their preterm children. The interviews were carried out by the principal researcher who is a nurse specialized in neonatal nursing, Master's and Nursing PhD student, with formation and research and professional experience in the area. The number of interviews was determined through theoretical saturation, understood as the point at which no new properties, dimensions or relationships emerge during the analysis and at which response is given to the study objectives.

The general study had a guide that was subjected to a pilot study to evaluate the pertinence and clarity of the questions in the context. During the research process, new questions emerged on par with the theoretical sampling, which permitted delving into some themes. The interviews were recorded and transcribed textually, within 48 hours after they were conducted; thereafter, this was returned to each participant via WhatsApp or E-mail, inviting them to make contributions or corrections according to what they considered. It was not necessary to conduct new interviews of the participants, given that the encompassed the themes proposed in the interview. The interaction with the participants permitted identifying emotions, reactions, and feelings that were registered in field notes.

The data analysis was carried out through line-by-line open encoding, identifying incidents to assign codes; this process was performed by the principal researcher and was contrasted with the analysis by another researcher in the study. An analysis matrix was carried out in which the codes were entered, giving way to the categories and subcategories. Diagrams were used as visual representations of the analytic scheme, which facilitated the interpretative process and identification of the points that needed development. Also, axial coding took place, which

made the data comprehensible, by reducing its constitutive elements, relating the categories with their subcategories to form more complete descriptions through constant comparison of the data. No software was used for the analysis.

Credibility, auditability, and transferability criteria were conserved; the entire process was crossed by the reflexivity of the researchers.<sup>(8)</sup> In function of the credibility, verifications were made during the interviews through oral synthesis or repetitions to ensure that the interpretations by the researcher were consistent with the declarations by the participants. In addition, the interviews were returned and keeping open the possibility of making contributions during the process. Auditability was achieved through the constant comparison of different views toward the object of study in the coding and categorization among the researchers. Transferability or applicability, as possibility of extending the study results to other

populations will depend on how much the results fit another context; the readers will determine if they can transfer the findings to different contexts.

The study was supported by the research ethics committee in the Faculty of Nursing at Universidad de Antioquia minute # CEI-FE 2020-02. Informed consent was read and audio recorded, given that it was not possible to have face-to-face contact with the participants due to restrictions from the pandemic.

## Results

Twelve parents participated who had their children hospitalized in NICU during the pandemic, in different health institutions. The principal characteristics of the participants are shown in Table 1.

**Table 1. Characterization of parents participating in the study and of their children**

Information about the parents					Information about the children				
Code	Sex	Age	Schooling	Residence	Weeks of gestation	Multiple birth	Weight at birth in grams	Days of hospital stay	Days after discharge *
<b>P1</b>	F	29	University	Urban	28	No	1180	83	15
<b>P2</b>	F	20	University student	Urban	28	No	1005	48	39
<b>P3</b>	F	24	University	Urban	34	No	1830	39	32
<b>P4</b>	M	34	Complete primary	Urban	34	No	1830	39	32
<b>P5</b>	F	29	Complete secondary	Urban	31	No	1420	32	15
<b>P6</b>	F	35	Incomplete secondary	Urban	34	No	2135	16	90
<b>P7</b>	F	30	Technical	Urban	26	No	900	69	120

**Table 1. Characterization of parents participating in the study and of their children (Cont)**

Information about the parents					Information about the children				
<b>P8</b>	F	32	Technical	Rural	32	Yes	Son 1: 1920 Son 2: 1580	48	44
<b>P9</b>	M	52	Complete secondary	Rural	31	No	1775	34	15
<b>P10</b>	F	35	University	Urban	30	No	1056	59	30
<b>P11</b>	F	25	Complete secondary	Urban	26	No	840	60	28
<b>P12</b>	M	25	Technical	Urban	32	Yes	Daughter 1: 1610 Daughter 2: 1614 Daughter 3: 1200	Daughter 1: 17 Daughter 2: 19 Daughter 3: 34	Daughter 1: 29 Daughter 2: 31 Daughter 3: 1

\* At the time of the interview

Amid the diversity of the social characteristics of the participants, common experiences were found that broadened comprehension of the phenomenon. The results confirm that the experience of having a preterm child is complex for the parents and which is much more within the context of the pandemic. The following categories emerged: 1) *Needing information*, 2) *limiting the interaction with the child* 3), *the pandemic: adding to the fears* and 4) *limiting social support after discharge*.

### First category. **Needing information**

Preterm birth and hospitalization in the neonatal unit are critical and unexpected events for the parents, which are removed from the ideal imagined about their child's birth. Uncertainty is common in parents and information is one of the greatest needs during the experience. The category

needing information has as subcategories: "needing general information about the child" and "needing information about the pandemic".

The subcategory **needing general information about the child** reveals – in the first place – those parents need more than ever close and constant information because they cannot accompany permanently their children due to entry restrictions. The measures adopted varied from one institution to another and in all cases limited the time of their remaining in the unit, thus, increasing the needs for information. In this regard, the parents stated: *There was much restriction, it was only one hour in the morning and one hour in the afternoon (P08). Because of the pandemic, it was by beds, one day was for the mothers of children in even-numbered beds and the next for those in odd-numbered beds (P12)*. Under these circumstances, the

parents received information via telephone and WhatsApp that, although not replacing the need to be near their child, helped them and gave them relief. With greater information, the parents felt better with respect to the situation. One account indicated: *With the pandemic, every day they sent me a report on the status, they reported via WhatsApp; that information was like the daily bread, like the day's most important meal, like the day's biggest blessing* (P10).

Information from the health staff about the status of their children gained special sense during times of pandemic. The parents described the need for information as urgent because it was a way of connecting with their children's reality, which permitted bridging the painful physical distance. This general information the parents needed had to do with the status of their children, progress in the process, treatments and other aspects related with their care. But the parents indicated needing detailed, close, and personalized information; given that in some cases they identified that the information did not respond to their expectations: *When calling, the information was very mechanical; they would tell me: they are calm, ate well, are well, are asleep. I know it by memory and because you don't have the tools to know if that was so, then you said thank you, they are in your hands* (P12).

The pandemic required creating additional communication channels to keep the parents abreast of the daily evolution of their children. This is how the nursing staff resorted to alternatives, like photographs, which were appreciated positively by the parents. In this respect, one of the mothers expressed: *in the photograph from the first day the she had a bunch of devices, I was overcome by seeing her with so many things, I worried; but little by little, in the pictures, I started seeing they were removing the implements she had attached and it gave me come calm.* (P10). Moreover, the subcategory **needing information about the pandemic** indicates that besides information about their children, the parents need to know

about the pandemic and particularly about the reasons for the restrictions. Given the adequate information about the reasons for limiting their entry, the parents accepted and appreciated these types of controls: *They explained to us what they were doing, it was for the good of the babies, to care for them, they tested me twice, as a requirement* (P11).

The parents stated that separating from their children was painful and difficult to assume, but information gave them some tranquility and helped them to accept the situation: *They would explain that is was to care for the children. I hurt you, but when they explained it that way, you accepted it and calmed down* (P10). Parents of preterm children during times of pandemic need clear, close, and constant information from the health staff about their children, but also need to be guided about the need to limit their entry and contact with their children, to facilitate accepting the circumstances. Video calls, daily telephone reports, photographs and videos were of great importance for the parents.

## Second category. Limiting the interaction with the children

In general, parents of hospitalized preterm children had the need to be near their children. Even in the intensive care setting, when the children's physiological instability did not permit direct interaction, the parents felt relief when seeing their children in an incubator and knowing first-hand the events related with their health. During the pandemic, limitations for the interaction were expressed in two subcategories: "living the physical separation" and "limiting opportunities of preparation for caring".

**Living the physical separation** is a subcategory that indicates that the closeness of the parents with their children in the neonatal unit is an emotional need, which is why the separation is a painful event. The start of the quarantine increased the emotional burden, pain, and stress of the parents. On this theme, some testimonies



were: *that weekend of the quarantine that we could not go to see her, oh, I cried and was very stressed! Knowing it would be three days without seeing her, you can't imagine what one feels!* (P5). *There were two days that I did not go, the weekend when the quarantine started; for me, it was the longest weekend in history* (P2). During the quarantine, interaction was limited and although they got daily information, seeing their children from afar had for them great value: *I could see her from far away, through the glass I managed to see how she was and through the glass I would say hi and tell her: my princess, I am here to leave you the milk and that I loved her a lot* (P10).

The neonatal unit favors contact and active participation in the care when the child's conditions so permit. Direct interaction by the fathers with their children permits their developing their paternal role, receiving support and direct information from the health staff, and learning about caring for their child. In some units, the adjustments included restricting the father's entrance, only the mothers entered with assignment of days and schedules. Upon not having possibilities to accompany directly their children, the fathers were active through phone calls. One father expressed: *The role I assumed was that of staying in telephone contact with them, given that I could not be there, so I kept working, but calling in the morning and at night* (P12).

Except for the pandemic, paternal participation is promoted in all the care activities within the unit, but in spite of their disposition and interest, the reality of COVID-19 annulled – in some cases – the possibilities of participation by the fathers during hospitalization, permitting entry only to the mothers. In other cases, although the fathers could enter the unit with restricted schedules, they experienced logistic limitations to be with their children and only the mothers assumed this companionship. Some testimonies in this regard were: *we come from a village, with that of the*

*pandemic and work, I would tell him: why are you going to come if you can only stay for only one hour* (P7). *Given that he had to work, he had to return and I stayed alone, he saw her again when we arrived here* (P10). This aspect bears special relevance because mutual support is of great importance within the process and it is expected that both parents receive information and develop skills to care for their child.

The subcategory **limiting the opportunities to learn about caring for the premature child** indicates that because of the limited permanence in the neonatal unit, the fathers had less opportunities to learn and develop confidence to care for their child. The care preterm children receive at home is determinant for their health and wellbeing, due to that, the skills of the parents for caring is a criterion for discharge. Within the context of the pandemic, the preparation for the discharge was carried out in the settings of basic care, when the discharge was imminent, in contrast with the habitual conditions in which the parents tend to initiate the preparation process since the admission. The fathers recognize that with greater accompaniment time there are greater opportunities to gain confidence for care: *I went some times and paid attention to see how to handle him, I managed to practice two times* (P9). *Before giving her to me, she was in basic care and those last days they allowed me to enter, the nurses guided me; but as a mother you must be there more, so that when you leave, you leave secure* (P10). The processes of accompaniment are fundamental in aspects as sensitive as breastfeeding. This is a process in which the mothers need a lot of support from the nursing staff, given that it is a complex experience due to prematurity of their children. The pandemic also generated limitations at this level: *I got her to breastfeed two days before the lockdown began and then I could not breastfeed her* (P5).

One of the specific cares of preterm children is skin-to-skin contact through the kangaroo care method. This process starts during the



hospitalization and, upon discharge, it is expected that both parents have gained skills and confidence. Due to the restrictions, some fathers did not have the possibility of “kangarooing” (carrying the premature child in vertical position between the mother’s breasts or the father’s chest with the face lateralized and the upper and lower limbs in frog position, guaranteeing direct skin-to-skin contact), during hospitalization: *The kangaroo care was after they gave him to me and got out of there; there, I could not kangaroo care* (P09). One of the biggest immediate effects of the pandemic in parents of preterm children, was the limited interaction with their fathers. This aspect causes great concern because contact and permanence of the fathers with their children is a condition that favors the development of skills for caring in the fathers and the paternal bond, aspects that are determinant in the continuity of the care of the children.

### Third category. The pandemic: adding to the fears

The parents of preterm children experienced fears related with the risks of the immaturity of their children and with the uncertainty regarding their evolution and survival. This is how the parents who participated in the study described an experience burdened with fears, in which the pandemic was one more of these. Fears due to COVID 19 were expressed in two subcategories: “fear of infection” and “fear of going home with their child amid the pandemic”. **Fear of infection** is added to the emotional burden and to the fears of the parents. The COVID- 19 pandemic appears as a new possible cause of death for their children: *The pandemic is another thing that stirs a lot of fear, the fear was also that, losing one of the babies* (P8).

Seeing their children is the biggest craving for the parents, but the fear of being a possible source of infection confronted them with a painful experience. One mother indicated: *this was very scary, you being in a clinic and having to go to*

*your baby with the fear that perhaps you are bringing the virus, it is very hard* (P11). The parents confronted themselves regarding the risks of accompanying their children and the fear of infecting them confronted them with a personal dilemma: *It places you between a rock and a hard place because you have to take a risk and go out to the street without knowing if you will be infected and if you do you go and see your child and even if you wash your hands and where protective clothing, you are exposing the child too much* (P1).

The subcategory **fear of going home amid the pandemic** has to do in the first place with the recognition the parents have with respect to the importance of the follow up of their children after discharge, which is why they fear the pandemic will impede adequate follow up: *I was afraid because the kangaroo plan was closed because of the pandemic, so I was worried about the check up and the daily weight monitoring* (P10). Additionally, fears emerged about the daily life imposed by the quarantine. The parents recognize the possibility of negative health events of their children once they are at home and fear not being able to consult in timely manner: *my fear was that during the quarantine there was no transportation, I would go out and would see no taxis, or buses or anything. Then, I would say, I know I have to rush to the hospital if this or that happens, but if something does happen, what can I do if I have no transportation available* (P7).

The discharge tends to be a moment desired by the parents because it represents the closure of the most-critical phase of the process, but it was accompanied by the fear of infection of the virus, as shown by the testimony: *I felt joy and at the same time not too happy by this pandemic situation because going from here to there to take them to medical check-ups, you are risking yourself and the baby, that worried me* (P9). In contrast, for some parents, the discharge during the pandemic represented a relief because the situation added too much stress to the hospitalization process.

*The discharge was a chance to rest, this virus, this contingency and this lockdown, but I was already home with my son (P5).*

The pandemic was an additional factor that added to the difficult experience the parents lived, as they so stated: *There were many things, this quarantine, I separated from the other child from whom I had not been separated for so long; it was too many things, it is very hard (P08).* Fear was a common feeling in the parents during the pandemic, which accentuated the complexity of the experience, where a high emotional burden exists related with fears due to the vulnerability of their children.

#### **Fourth category. Limiting support after discharge**

At home, the parents acquired new dynamics and made adjustments for the care of their children. Limitations for the follow up of their children and for the support from relatives or people close to them to care for the child were aspects generated due to the pandemic and are identified in the subcategories “limiting the follow up” and “limiting social support after discharge”. In the subcategory **limiting the follow up**, it is important to consider that after discharge, the parents tend to attend the kangaroo program to monitor their children according to their specific needs, which permits – among other aspects – assessing and enhancing their skills for care. This program is of vital importance to guarantee the wellbeing of preterm children.

The contingency due to the pandemic generated changes in the program by making the experience more complex: *due to the quarantine, the kangaroo plan has been via telephone, the pediatrician came the first two weeks and now it is once a week via telephone, everything has been quite complex (P1).* *I did not have a kangaroo plan, it was the kangaroo method we practiced here, as they had taught us (P8).* *Due to the pandemic, I could not be seen in the*

*kangaroo plan, so the pediatrician sees her every month (P10).* In other cases, the fathers and their children did attend the kangaroo plan, but also faced entry restrictions. Only the mother could go in; the father could only enter to receive the medical information: *I was in the kangaroo plan only when the pediatrician was talking, but not during breastfeeding and the exercises because of the pandemic (P12).* In spite of the restrictions, the participants expressed their interest in active paternal participation in the kangaroo program: *I would have liked for the father to enter because he is very interested in his baby and wanted to know everything (P11).* For some fathers, who could not accompany their children during the care process, receiving direct information was an opportunity they appreciate and are grateful for, reaffirming the importance of personal interaction with the health staff and the need for information: *In the kangaroo plan, they said: dad, you cannot enter, I said: I want to know. The pediatrician finally let me enter and fortunately explained many things and I thank him for that (P12).*

Regarding the subcategory **limiting social support after discharge**, it is important to recognize that in the transition to the home the parents face a difficult reality, given that caring for a preterm child is highly demanding. Parents need help from people nearby, but the pandemic limited this possibility. Fear of infection appears as a threat to their children. Restricting the entrance to outside people was part of the measures adopted to protect their children at home: *When we got home, completely isolated, with nobody seeing or touching the baby, because we knew she could get sick (P4).* Preterm children must be protected from possible respiratory infections, but within the COVID-19 context, recommendations in this sense increased, while increasing fears in the parents: *We would not let anybody come over; we stayed in the house because of the pandemic (P10).*

Limiting contact also reduced the possibilities for help. The pandemic and the fears it generated

in the parents diminished the openness and disposition to receive support. Some testimonies were: with *the pandemic you are afraid of possibly infecting them, so no, nobody is going to come here* (P16). *One day, an aunt offered to help me, but I told her no, that I was very afraid because you don't know what symptoms she may have* (P11). The parents limited their going out, reportedly only going to appointments related with their children's health, to avoid exposing them: *we do not go out for anything, the only one who goes out is the father to work* (P1). Some parents reported receiving telephone support from their families: *the support was mostly from my mother-in-law via telephone because – due to the pandemic – we are not receiving anybody* (P10). The parents who received support, got it from very close individuals: *My sister, she was with me, she would help me* (P03). *My mother always helped me* (P05).

The risk of prematurity does not end with the hospitalization and the challenges the parents experience after the discharge are quite complex. The transition to the home supposes important challenges, which is why limitations in the follow up and in social support become a concern, whose effects in the children and their parents are still unknown.

## Discussion

Prevention of COVID-19 infection in neonatal units is a priority and amid the measures adopted with this purpose, restrictions against physical contact marked the experience of the parents; the effects of these measures upon the health and wellbeing of the children and their parents in the short and long term are still unknown. The birth of a preterm child, their hospitalization in the neonatal unit, and the transition to the home are complex phenomena in which the parents face a hard reality, burdened with pain, uncertainty, fear, anxiety, stress and guilt.<sup>(9,10)</sup> The complexities

of these phenomena were accentuated during times of pandemic. The parents experienced a marked need for information, which also has been described in studies that have inquired about the needs of the parents of preterm children.<sup>(10,11)</sup>

It is fitting to recognize that, in the specific case of the parents interviewed, the need for information went beyond, converting it into a form of connection with the reality of their children. Besides information about their children, the parents need support, accompaniment, and a channel to solve their concerns. Virtual media permit human interaction, where it is possible to respond to these needs. It has been identified that strategies involving the use of information and communication technologies are useful in this purpose.<sup>(12)</sup> Furthermore, it has been documented that telephone support can help to solve their concerns in the process<sup>(13)</sup> and, with such, becomes an opportunity to strengthen preparation processes for the discharge.

Separation of the preterm children and their parents has negative effects at the physical and emotional levels and in the mental health of the parents and children.<sup>(14)</sup> The presence of the parents facilitates to the nursing staff the direct transference of information about the child's care, but also permits establishing a relationship of trust,<sup>(15)</sup> provide support, and identify the needs and possibilities of each parent to assume effectively the care of their children, which is determinant for the child's health after discharge. Due to this, the virtual media used during the pandemic must be a means of emotional support and an educational setting that complements the limited spaces that allow the physical presence of the parents, which becomes a challenge for the nursing staff.

During the pandemic, personal interaction was limited and telephone information, videos, and virtual resources, in spite of their usefulness within this context, do not substitute the personal interaction. Although efforts in this sense were

of great importance and the health staff created possible communication channels amongst the circumstances, it is currently necessary to integrate theory and evidence<sup>(16,17)</sup> to guarantee involvement by the family, humanized care, and successful transition to the home amid the current possibilities.

One of the frameworks that must guide the strategies de acompañamiento and support for parents of preterm children during the pandemic is that of family-centered care. This model, broadly disseminated globally and whose principles are applied in the different contexts of neonatal care, promotes the implication of parents in caring for their children, favors family bonding and empowerment to achieve more humanized care.<sup>(7)</sup> Although the pandemic supposes new logics in the interaction by both parents with their children, it is important to consider that these principles continue tracing the path of caring for preterm children, given that evidence exists of the positive health effects and wellbeing of preterm children and their families.<sup>(15)</sup> In this care focus, it is necessary to recognize that the presence of both parents is fundamental. Within this atypical context, it is urgent to consider that the adjustments made in the neonatal units cannot exclude the fathers; by doing so, it generates a reversal whose impact upon the child's health and satisfaction by the fathers may be considerable. Limited interaction by the fathers with their children impacts negatively on their skills for care at home, which is why it is necessary – even during times of pandemic – to favor the male co-responsibility and promote the effective participation of the men in the paternity.<sup>(18)</sup>

Given that, currently, the physical presence by both parents in the neonatal unit is limited because of COVID-19, it is necessary to consider the urgency to compensate this distance through alternative communication means, like phone calls and video calls, not only as ways of transmitting information about their child's health status, but also as a possible means to establish a therapeutic relationship that can provide care

to aid and support and in which each father and mother can be assessed to start nursing interventions according with their specific needs, in function of their wellbeing and that of their children. These means also permit evaluating and potentiating social and family support networks to guide them toward the possibility of receiving help from significant persons, conserving the security and protection measures required by the current circumstances.

Moreover, today more than ever, it is necessary to strengthen the application of disciplinary theories that guide the care of preterm children and their families in phenomena as complex as, for example, development of the paternal role, the parental link and bond, adaptation, the transition by the parents of preterm children, and social support. Knowledge by nursing and its integration to the practice permits responding to the challenges imposed by the times of pandemic.

In turn, the disciplinary theory must also guide research amid the pandemic, during which new and complex questions emerge in the different care scenarios.<sup>(17)</sup> The results of the present study reaffirm that virtual media have become a valid, possible, and safe strategy during times of pandemic, which complement face-to-face activities, which, although limited by the need to prevent COVID-19 infection, are necessary and irreplaceable. The fathers need the interaction with their children to develop skills to care at home, which is a multidimensional phenomenon that not only has to do with knowledge and abilities, but also with confidence, social support, the bond, and development of the parental role, aspects that cannot be ignored amid the contingency and which – on the contrary – must be re-dimensioned under these circumstances, which has been described as one of the biggest challenges for the health staff in the neonatal units.<sup>(19)</sup>

**Conclusion.** The experiences of parents of preterm children during times of the COVID-19

pandemic indicate that entry restrictions to neonatal units to prevent the virus transmission limited interaction with the preterm child and with the health staff and increased the needs for information. After discharge, the pandemic diminished the opportunities of follow up and social support. All these aspects are sensitive in the experience of parents of preterm children and the effects of these restrictions are still unknown, which is why it is necessary to conduct studies that permit knowing their effects on the health

and development of the children, as well as on the wellbeing of the parents.

The study recommends guiding strategies to accompany preterm children, considering the principles of development-centered care involving both parents. Virtual media must complement and optimize live settings, which cannot be substituted and are necessary particularly in the development of skills for caring of preterm children at home.

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# Effectiveness of application of a manual for improvement of alarms management by nurses in Intensive Care Units

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## Effectiveness of application of a manual for improvement of alarms management by nurses in Intensive Care Units

### Abstract

**Objective.** To evaluate the effects of application of a manual on the improvement of alarms management in Intensive Care Units (ICU). **Methods.** This quasi-experimental study evaluated the effectiveness of the introduction into of a manual for alarm management and control in the ICU of a hospital in southeastern Iran. The intervention was a 4-hour workshop was on topics related to the adverse effects of alarms, standardization of ECG, oxygen saturation and blood pressure monitoring systems, and the use of ventilators and infusion pumps. Data were collected thorough 200 hours of observation of 60 ICU nurses (100 hours' pre-intervention and 100 hours' post-intervention). Response time, type of response, customization of alarm settings for each patient, the person responding to an alarm, and the cause of the alarm



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were analyzed. Alarms were classified into three types: false, true and technical. **Results.** The results showed a statistically significant difference between the pre- and post-intervention frequency of alarm types, frequency of monitoring parameters, customized monitoring settings for patients, and individuals who responded to alarms. The percentage of effective interventions was significantly higher for all parameters after the intervention (46.9%) than before the intervention (38.9%). **Conclusion.** The employment of a manual for management of alarms from electronic equipment in ICUs can increase the frequency of appropriate responses to alarms in these units.

**Descriptors:** clinical alarms; monitoring; intensive care units; observation; nurses.

## Efectividad de la aplicación de un manual para la gestión de alarmas en enfermeros de Unidades de Cuidados Intensivos

### Resumen

**Objetivo.** Evaluar los efectos de la aplicación de un manual en el mejoramiento de la gestión de las alarmas en enfermeros las Unidades de Cuidados Intensivos -UCI-. **Métodos.** Estudio cuasi- experimental en el que se evaluó la efectividad de la introducción de un manual en la práctica para la prevención y el control de alarmas en una UCI de un hospital del sudeste de Irán. Se realizó un taller de 4 horas de duración que incluía temas relacionados con los efectos adversos de las alarmas, la estandarización en los sistemas de monitoreo de ECG, saturación de oxígeno y presión arterial, y del uso de ventiladores y de bombas de infusión. Se realizaron 200 horas de observación a 60 enfermeras de la UCI (100 horas antes y 100 horas después de la intervención). Se analizó el tiempo de respuesta, el tipo de respuesta, la personalización de los ajustes de la alarma para cada paciente, la persona que responde a una alarma y la causa de la alarma. Las alarmas se clasificaron en tres tipos: falsas, verdaderas y técnicas. **Resultados.** Los hallazgos mostraron diferencias estadísticamente significativas entre la frecuencia de los tipos de alarma antes y después de la intervención, la frecuencia de los parámetros de monitorización, los ajustes de monitorización personalizados para los pacientes y las personas que responden a las alarmas. El porcentaje de intervenciones efectivas para el total de parámetros fue significativamente mayor después de la intervención (46.9%) que antes de la misma (38.9%). **Conclusión.** Los resultados del estudio

muestran que el empleo del manual para la gestión de las alarmas de los equipos electrónicos en una UCI puede aumentar la frecuencia de respuestas adecuadas de los enfermeros de estos servicios.

**Descriptorios:** alarmas clínicas; monitoreo; unidades de cuidados intensivos; observación; enfermeras y enfermeros.

## Eficácia da aplicação de manual para gerenciamento de alarmes em enfermeiros de Unidades de Terapia Intensiva

### Resumo

**Objetivo.** Avaliar os efeitos da aplicação de um manual na melhoria do gerenciamento de alarmes em enfermeiros de Unidades de Terapia Intensiva -UTI-. **Métodos.** Estudo quase-experimental no qual foi avaliada a eficácia da introdução na prática de um manual para prevenção e controle de alarmes em uma UTI de hospital no sudeste do Irã. Foi realizado um workshop de 4 horas que incluiu tópicos relacionados aos efeitos adversos dos alarmes, padronização dos sistemas de monitoração de ECG, saturação de oxigênio e pressão arterial e uso de ventiladores e bombas de infusão. Foram realizadas 200 horas de observação em 60 enfermeiras de UTI (100 horas antes e 100 horas após a intervenção). O tempo de resposta, o tipo de resposta, a personalização das configurações de alarme para cada paciente, a pessoa que responde a um alarme e a causa do alarme foram analisados. Os alarmes foram classificados em três tipos: falso, verdadeiro e técnico. **Resultados.** Os resultados mostraram diferenças estatisticamente significativas entre a frequência dos tipos de alarme antes e depois da intervenção, a frequência dos parâmetros de monitoração, configurações de monitoração personalizadas para pacientes e pessoas que respondem aos alarmes. O percentual de intervenções eficazes para todos os parâmetros foi significativamente maior após a intervenção (46,9%) do que antes (38,9%). **Conclusão.** Os resultados do estudo mostram que a utilização do manual para gerenciamento de alarmes de equipamentos eletrônicos em UTIs pode aumentar a frequência de respostas adequadas aos alarmes nos enfermeiros desses serviços.

**Descriptorios:** alarmes clínicos; monitoramento; unidades de terapia intensiva; observação; enfermeira e enfermeiros.

# Introduction

Excluding the noises made by human interventions in clinical environments, almost 80% of the noise in intensive care units is due to electronic alarms. Because of their physiological impact, alarms lead to alarm fatigue.<sup>(1-3)</sup> Alarm fatigue is defined as incompetence at identifying or prioritizing alarms which, in turn, leads to inappropriate responses to alarms.<sup>(4)</sup> There are two reasons for alarm fatigue: becoming desensitized to alarms due to emotional overload and indifference to responses and confusion caused by alarms which results in distrust in accuracy of alarms.<sup>(5)</sup> Alarm fatigue not only increases emotional burden in healthcare personnel who are overexposed to alarms,<sup>(6,7)</sup> but also causes considerable stress to patients and healthcare providers.<sup>(8,9)</sup> Moreover, alarm fatigue can lead to delayed responses to alarms, readjustment of alarms to ranges which are unsafe for patients and eventually switching alarms silent or off.<sup>(9)</sup> As a growing problem with dire consequences, alarm fatigue was ranked by Emergency Care Research Institute (ECRI) as the top hazard among the 10 threats of technology in healthcare in 2012.<sup>(10)</sup> Alarm fatigue is a human error responsible for a large number of fatalities in hospitals. According to Food and Drug Administration, between 2002 and 2004, 237 deaths were caused by negligence of clinical alarms.<sup>(11,12)</sup> In a survey conducted by Federal Drug Administration over 4 months in 2010, 73 alarm-related deaths were investigated 33 of which were attributed to physiologic monitors.<sup>(13)</sup>

The purpose of clinical alarms is to enhance patients' safety and alert doctors and nurses to aberrations in patients' conditions. Also, when a patient's condition gets worse or a machine fails to function properly, alarms alert doctors and nurses.<sup>(12)</sup> It is a fact that nurses are the best monitors of patients and physiologic monitors are simply for further assurance of the doctors and nurses who use them; however, the issue of false positive alarms remains a serious unsolved problem with many grave consequences.<sup>(14)</sup> False alarms are cry wolves which lead nurses to ignore alarms or respond to repetitive alarms with delay. Furthermore, alarms can prevent nurses from planning effectively and performing their tasks properly and distract them in other ways.<sup>(14)</sup> Studies show that the majority of alarms are false.<sup>(3,14)</sup> The results of 371 hours of monitoring in a study showed that 1762 alarms (99.4%) were false alarms.<sup>(15)</sup> In their study, Graham and Cvach have recorded 942 alarms per day or 1 critical alarm every 92 seconds, while other researchers report 6 to 16 alarms per hour.<sup>(16)</sup> Delay settings on SpO<sub>2</sub> (peripheral capillary oxygen saturation) alarm systems up to 15 seconds or 19 seconds,<sup>(17)</sup> can reduce the frequency of alarms to 50% or 70% respectively; thus, in the case of lack of oxygen saturation in short periods, the number of alarms is decreased.<sup>(10)</sup> Setting alarm ranges according to each patient's condition can also reduce the frequency of alarms, thus decreasing alarm fatigue.<sup>(17)</sup>

Considering the results of studies regarding the consequences of alarm fatigue and given the fact that, so far, few studies have addressed alarm fatigue management, the present study is an attempt at exploring the effects of development and introduction of a manual for alarm management for intensive care unit nurses.

## Methods

This study was approved by the Research Ethics Committee of Shiraz University of Medical Sciences located in Southwest of Iran (IR.SUMS.REC.1393.S7362), data were collected in 2017. The present study is a quasi-experimental work of research conducted in two stages: development of a manual for management of alarms from clinical equipment and introduction of the manual. Since a nurse's response to an alarm is an occurrence which may happen at any time in a hospital unit and is not considered a unique event, i.e. a nurse's response to an alarm is independent of the changes specific to a period, in the present study, considering the nature of the behavior under study, the researchers employed the methods of observation and time sampling.<sup>(18)</sup> The sample consisted of 200 hours of observation in an intensive care unit—100 hours before the intervention and 100 hours after the intervention. Accordingly, the nurses' responses to alarms were observed during different days and shifts (morning, evening and night) for 6.5 hours per shift.

To perform the observation, two of the researchers who were completely familiar with intensive care units would randomly select a shift every day and record the nurses' responses to alarms. For one month, data were collected from morning, afternoon, and evening shifts by the two researchers using a checklist. The study population consisted of all the practicing nurses in the general intensive care unit of the largest hospital in the south of Iran. Sampling was based on the census method and the subjects who met

the inclusion criteria of the study and filled out the informed consent form were included. The inclusion criteria were to be a permanent nursing staff member in the intensive care unit, to not have participated in a similar work of research, and to be willing to participate. The exclusion criterion was failing to attend one of the education sessions (none of the nurses were excluded).

**Data Collection.** The researchers developed the monitoring system alarms data collection form based on a literature review and the results of previous studies. The data collection form includes items about type of monitoring parameter, type of alarm, response time to alarm (the time lapse between the moment an alarm starts and the moment a response is made to it), type of response, personalization of alarm settings for each patient, the individual who responds to an alarm, and cause of alarm. Alarms were classified into three types: false, true, and technical. A false alarm is one which is detected and recorded by the monitoring system as a physiologic occurrence, while actually nothing has occurred. A true alarm is a correct detection of a deviation in parameter settings recorded by the monitoring system. A technical alarm is defined as an alarm which informs nurses of a problem in the functioning of a monitoring system, e.g. disconnection of a machine from the power supply and disconnection of the pipes and other gears attached to patients. The equipment dealt with in the present study were the entire vital signs monitoring systems, cardiac monitoring systems, ventilators and syringe pumps. To increase the validity of the findings, the data collected from the first 30 hours of observations were excluded and the data obtained during the following 200 hours of observations were analyzed. To test the reliability of a data collection form (in order to reduce the possibility of errors and increase consistency in the collection of data), the observers are required to be in the same environment and record the same event simultaneously. Accordingly, the two researchers who were responsible for data collection in the present study were placed in a

simulated environment where they were shown the same video of patient monitoring systems and answered the questions on the form about the alarms. Subsequently, SPSS v. 21 was used to measure the consistency between the data collected on the two forms. The consistency was found to be 0.88.

The manual for alarm management in intensive care units was developed as a protocol by three intensive care specialists, an intensive care unit head nurse and two experienced staff members, and the research team during three two-hour focus group sessions. The manual includes sections on introduction to alarms, the consequences of

alarms, and methods of controlling and preventing alarms. The manual was introduced to the ICU personnel over a six-session workshop (Table 1). Lasting for 4 hours, each session was directed by experienced professors in the field of intensive care. After the introduction of the manual for alarm management, the ICU personnel were asked to adjust themselves to the instructions they had received for two weeks. In the first week of the initiation, the personnel's inquiries were dealt with; in the second week, the personnel were allowed to use the manual on their own. Next, as of the fifteenth day, data were collected again in the intensive care unit using the monitoring system alarms data collection form.

**Table 1. Content of the workshops**

Session	Goal	Content
1	Introduction to alarms and their adverse effects	Discussing the role of alarms in the safety of patients Discussing the methods of controlling and preventing alarms
2	Standardization of ECG monitoring systems	A review of the content of the previous session Empowerment of the personnel by educating them in how to properly prepare the skin for ECG electrodes, daily replacement of electrodes, and modification of alarm parameters and thresholds of ECG monitors, among others
3	Standardization of SpO <sub>2</sub> and blood pressure monitoring systems	A review of the content of the previous session Modification of delay and threshold settings in SpO <sub>2</sub> monitoring systems Modification of threshold settings in blood pressure monitoring systems
4	Empowerment and education of personnel in using ventilators	A review of the content of the previous session Modification of settings of a ventilator, including respiratory rate, tidal volume, positive end-expiratory pressure, and respiratory tract pressure
5	Standardization of syringe pumps and infusion pumps	A review of the content of the previous session Modification of threshold settings in syringe pumps and infusion pumps Introduction to alarm types of syringe pumps and infusion pumps
6	Starting an inter-professional team	A review of the content of the previous session Creating an inter-professional team in the hospital which oversees alarm-related issues, including policy development and introduction of new methods

Abbreviations: SPO<sub>2</sub>, Peripheral capillary oxygen saturation; ECG, Electrocardiography

Data Analysis. The collected data were analyzed using SPSS v. 21. The central indexes and the distribution of the data were measured using descriptive statistics, including mean, standard

deviation, frequency, and percentage based on the type of variable (quantitative or qualitative). In order to assess the efficacy of the interventions, the researchers employed the statistical tests of paired

sample t-test, independent t-test, and Chi-square. The assumption that the variables were normal was tested using Kolmogorov–Smirnov test; if the assumption was disproved, nonparametric tests, including Mann-Whitney test, Wilcoxon test, Fisher’s exact test, McNemar test, and sign test would be used. The significance level for the tests was set at 0.05 and the confidence interval for the calculation of point estimations was 95%.

## Results

In the present study, 60 nurses with the average age of  $34.36 \pm 6.42$  years and work experience of  $9.69 \pm 7.44$  years participated. 63.3% of the

participants were female and 36.7% were male. 83.4% had a bachelor’s degree and 16.6% had a master’s degree. Also, 26.6% of the participants were permanent employees, 36.6% were fixed-term employees, 16.6% were contractual employees, and 20% were trainees. The results showed a significant reduction (53.8%) in the frequency of false alarms following the intervention. Also, the results of the Chi-square test showed a statistically significant difference between the pre- and post-intervention alarm types ( $p < 0.001$ ). As only one technical alarm was observed and because such alarms are in fact true alarms, the number of technical alarms was considered together with the true alarms and the tests were conducted between the two groups of false and true alarms (Table 2).

**Table 2. Frequency distribution of the types of alarms before and after the intervention**

Type of alarm	Before	After	Percentage change
	n (%)	n (%)	
False	552 (79.5)	255 (48.9)	-53.8
True*	141 (20.4)	262 (50.1)	85.81
Technical	1 (0.1)	5 (1)	4
Total	694	522	$p < 0.001$

\* Technical and true alarms were merged due to the small number of technical alarms, these alarms were combined with the true alarms in statistical calculations.

The results of Fisher’s exact test showed a statistically significant difference between the pre- and post-intervention frequency distribution of monitoring parameters ( $p < 0.001$ ). The highest and lowest impacts of the introduction

of the manual belonged to RR (Respiratory Rate) monitoring (with a 64.7% reduction in frequency of alarms) and NIBP monitoring (with a 19.8% reduction in frequency of alarms) respectively (overall  $p < 0.05$ ) (Table 3).



**Table 3. Frequency distribution of monitoring parameters before and after the intervention**

Type of parameter	Type of alarm	Before <i>n</i> (%)	After <i>n</i> (%)	<i>p</i> -value
<b>SPO<sub>2</sub></b>	False	228 (32.85)	110 (21.7)	<0.001
	True	37 (5.33)	89 (17.4)	
<b>NIBP</b>	False	51(7.34)	29 (5.55)	0.037
	True	40 (5.76)	44 (8.42)	
<b>ECG</b>	False	140 (20.17)	66 (12.64)	<0.001
	True	26 (3.74)	58 (11.11)	
<b>Ventilator</b>	False	14 (2.01)	40 (7.66)	0.005
	True	33 (4.75)	31 (5.93)	
<b>RR</b>	False	107 (15.41)	6 (1.14)	<0.001
	True	5 (0.72)	27 (5.17)	
<b>S.P</b>	False	12 (1.72)	4 (0.76)	0.01
	True	1 (0.14)	5 (0.95)	
<b>Total</b>	False	552 (79.5)	255 (48.9)	<0.001
	True	142 (20.5)	267 (51.1)	

Abbreviations: SPO<sub>2</sub>, Peripheral capillary oxygen saturation; NIBP, Non Invasive Blood Pressure; ECG, Electrocardiography; RR, Respiratory Rate; S.P, Syringe pump

The results of Fisher's exact test showed that the difference between the pre- and post-intervention types of response to alarms was not—statistically significant. The most and least effective responses to alarms after the intervention belonged to SpO<sub>2</sub> (16.47%) and

syringe pumps (0.5) was significant for the total of parameters. However, the percentage of effective interventions was significantly higher for all parameters after the intervention (46.9%) than before the intervention (38.9%) with a *p*-value of 0.005 (Table 4).

**Table 4. A comparison between pre- and post-intervention types of response to alarms**

Type of parameter	Type of response	Before <i>n</i> (%)	After <i>n</i> (%)	<i>p</i> -value
SPO <sub>2</sub>	Effective	95 (13.68)	86 (16.47)	0.17
	Ineffective	170 (24.49)	116 (22.22)	
NIBP	Effective	53 (7.63)	50 (9.58)	0.24
	Ineffective	40 (5.76)	26 (26)	
ECG	Effective	75 (10.8)	68 (13.5)	0.12
	Ineffective	91 (13.11)	57 (10.92)	
Ventilator	Effective	33 (4.75)	30 (5.75)	0.73
	Ineffective	13 (1.87)	10 (1.91)	
RR	Effective	9 (1.29)	8 (1.55)	0.44
	Ineffective	102 (14.69)	61 (11.7)	
S.P	Effective	5 (0.72)	3 (0.5)	0.71
	Ineffective	8 (1.15)	7 (1.35)	
Total	Effective	270 (38.9)	245 (46.93)	0.005
	Ineffective	424 (61.1)	277 (53.07)	

Abbreviations: SPO<sub>2</sub>, Peripheral capillary oxygen saturation; NIBP, Non Invasive Blood Pressure; ECG, Electrocardiography; RR, Respiratory Rate; S.P, Syringe pump

Even though the results of Wilcoxon test indicated a statistically significant difference ( $p$ -value=0.001) between the pre- and post-intervention personalized monitoring system settings for each patient, the majority of the alarms and parameters

(85.8%) remained without personalized settings. The greatest and smallest numbers of personalized settings for monitoring each patient as implemented by the nurses belonged to SpO<sub>2</sub> monitoring and ventilators respectively (Table 5).

**Table 5. A comparison between pre- and post-intervention personalized monitoring settings for each patient**

Type of parameter	Before <i>n</i> (%)	After <i>n</i> (%)	<i>p</i> -value
SPO <sub>2</sub>	0 (0)	26 (5)	<0.001
NIBP	0 (0)	23 (4.4)	<0.001
HR	0 (0)	13 (2.5)	<0.001
Ventilator	0 (0)	12 (2.3)	0.001
None	694 (100)	448 (85.8)	<0.001
Total	694	522	

Abbreviations: SPO<sub>2</sub>, Peripheral capillary oxygen saturation; NIBP, Non Invasive Blood Pressure; HR, Heart Rate; S.P, Syringe pump

Based on the results of Fisher's exact test, there was a statistically difference between the pre- and post-intervention types of individual who responded to alarms. Before the intervention, the nurses responded to 43.1% of the alarms, while after the intervention, they responded to 62.1% of the alarms. In other words, in the post-intervention

stage, the nurses were more responsive to the alarms from the patients' monitoring systems. Besides the nurses, the personnel consisted of the doctors, medical equipment technicians, and the cleaning staff. In the present study, the doctors were never seen to respond to an alarm in any way (Table 6).

**Table 6. Frequency of pre- and post-intervention types of individual who responded to alarms**

Type of parameter	Responding individual	Before n (%)	After n (%)	p-value
SPO <sub>2</sub>	Nurse	110 (15.8)	130 (24.9)	<0.001
	Nursing assistant	31 (4.4)	11 (2.1)	
	Others*	21 (3)	3 (0.5)	
	No response	103 (14.9)	58 (11.1)	
NIBP	Nurse	61 (7.8)	63 (12)	0.01
	Nursing assistant	8 (1.2)	1 (0.2)	
	Others	4 (0.6)	0 (0)	
	No response	18 (2.6)	12 (2.3)	
ECG	Nurse	74 (10.7)	78 (14.9)	0.008
	Nursing assistant	24 (3.5)	6 (1.1)	
	Others	1 (0.1)	0 (0)	
	No response	67 (9.7)	41 (7.9)	
Ventilator	Nurse	34 (4.9)	34 (6.5)	0.15
	Nursing assistant	3 (0.4)	1 (0.2)	
	Others	2 (0.3)	0 (0)	
	No response	8 (1.2)	5 (1)	
RR	Nurse	10 (1.4)	11 (2.1)	0.15
	Nursing assistant	2 (0.3)	0 (0)	
	Others	0 (0)	0 (0)	
	No response	100 (14.4)	58 (11.1)	
S.P	Nurse	10 (1.4)	8 (1.5)	0.86
	Nursing assistant	0 (0)	0 (0)	
	Others	1 (0.1)	1 (0.2)	
	No response	2 (0.3)	1 (0.2)	

\* The groups of others, nursing assistant, and no response were merged. Abbreviations: SPO<sub>2</sub>, Peripheral capillary oxygen saturation; NIBP, Non Invasive Blood Pressure; ECG, Electrocardiography; RR, Respiratory Rate; S.P, Syringe pump

## Discussion

In this study, 1216 alarms were recorded over 200 hours of observation, with the mean of 6.08 alarms per hour. Of the 1216 recorded alarms, 66.3% were false alarms, 33.1% were true alarms, and 0.4% were technical alarms. In their study, Graham *et al.* recorded 1 clinically significant alarm every 92 seconds.<sup>(16)</sup> Baillargeon reports that of the 174 alarms recorded in her study, 44.8% were false alarms, 47.7% were true alarms, and 7.4% were technical alarms.<sup>(6)</sup> In the study of Inokuchi *et al.* only 6.4% of the 11591 recorded alarms were found to be clinically significant; 93.6% were false alarms and 0.02% were technical alarms.<sup>(19)</sup> The findings of the present study are consistent with those of the studies of Graham *et al.*, and Inokuchi *et al.* but do not agree with the results of Baillargeon's study, which may be due to the shorter time span of Baillargeon's study or the fact that her study was conducted in an internal unit where telemetry monitoring was used.

Before the introduction of the educational intervention, 694 alarms were recorded, 79.5% of which were false alarms, 20.3% were true alarms, and 0.1% were technical alarms. After the intervention, of the 522 recorded alarms, 48.9% were false alarms, 50.2% were true alarms, and 1% were technical alarms. The 53.8% reduction in the occurrence of false alarms after the intervention can be attributed to the education which the nurses received in the workshops. Graham *et al.* report a 43% posttest reduction in the frequency of physiologic alarms.<sup>(16)</sup> In their study of the effect of daily replacement of ECG electrodes on the alarms of electrocardiogram monitors in CCU (Coronary Care Unit) and MPCU (Medical Progressive Care Unit), Cvach *et al.* report that the total number of daily alarms per bed decreased by 47% in MPCU and by 44% in CCU. Moreover, the number of technical alarms in MPCU and CCU decreased by 34% and 45% respectively; the number of audio

alarms in MPCU and CCU decreased by 52% and 46% respectively; finally, the number of alert alarms in MPCU and CCU decreased by 47% and 46% respectively. However, the frequency of high-priority (critical) alarms did not change.<sup>(13)</sup> The results of the studies of Graham *et al.*, and Cvach *et al.* are consistent—the greater reduction in the post-intervention number of false alarms in the study of Cvach *et al.* can be due to the fact that they included the entire monitoring systems in their study.

The results of this study showed that the difference between the pre-intervention response time ( $51.9 \pm 67.21$  seconds) and the post-intervention response time ( $30.8 \pm 15.09$  seconds) is statistically significant. In Baillargeon's study, alarm response time ranges between 1 minute and 20 seconds and 10 minutes, with the mean being 7.01 minutes<sup>(6)</sup> which is far more than the response time in the present study. In the present study, before the intervention, the longest response time was for SPO<sub>2</sub> monitoring (17.3 minutes). After the intervention, the longest response time, at 1.6 minutes, was for ECG (Electrocardiography), RR, and SPO<sub>2</sub> monitoring.

Of the 1216 alarms recorded in the present study, 38.4% were for SPO<sub>2</sub>, 23.9% were for ECG, 14.8% were for RR, 13.7% were for NIBP, 7.2% were for ventilator, and 1.9% were for syringe pump monitoring systems. The difference between the pre- and post-intervention frequency distributions of monitoring parameters was not statistically significant ( $p$ -value=0.92). In other words, even though the number of false alarms (as the primary source of alarm fatigue in nurses) decreased as a result of the educational interventions, the change in the frequency of monitoring parameters after the intervention was not statistically significant, which can be attributed to the higher frequency of true alarms from monitoring parameters in the post-intervention stage. However, in their study conducted at the Johns Hopkins Hospital, Taenzer *et al.* report a 63% reduction in the number of alarms after lowering the threshold of

SPO<sub>2</sub> monitor.<sup>(20)</sup> In the study of Cvach *et al.* the frequency of alarms related to arrhythmia and RR electrodes dropped in CCU and MPCU by 74% and 60% respectively for arrhythmia and by 65% and 36% for RR.<sup>(13)</sup>

According to the results of the present study, 59.53% of the alarms occurred during the morning shifts. The majority of the alarms were recorded during the morning shifts. The increased workload of nurses in the morning, the execution of many of the clinical procedures in the morning, doctors' rounds, and the presence of patients' visitors during morning visiting hours can account for the higher frequency of alarms in morning shifts. The findings of our study show a statistically significant difference between the nurses' pre- and post-intervention types of response to alarms: 42.35% of the alarms were responded to effectively and 57.65% received ineffective responses. Before the intervention, 38.9% of the alarms were responded to effectively and 61.1% were responded to ineffectively, while after the intervention, 46.93% of the alarms were responded to effectively and 53.06% were responded to ineffectively. Effective responses were those in which the type of alarm was checked, the signs were interpreted by a nurse and, subsequently, steps were taken to deal with the cause of the alarm or the doctors were informed. Ineffective responses were characterized by silencing alarms, delay in responding to alarms, ignoring alarms or deactivating them without investigating the cause of the alarm. According to Harris *et al.* the number of false and nuisance alarms is a determining factor in clinical alarm response time.<sup>(21)</sup> Jennings reports that when the frequency of nuisance alarms is high, the medical staff is more likely to ignore relevant alarms.<sup>(22)</sup> Similarly, Graham *et al.* state that positive false alarms or nuisance alarms can result in delayed response time or reduce the likelihood of nurses' responding to alarms.<sup>(16)</sup>

In this study, before the intervention, none of the alarms were personalized by the nurses for the monitoring of patients and all the alarms were on

default settings. However, after the intervention and the visual and practical education on the use of monitors in the workshops, the situation improved: of the 522 alarms recorded in the post-intervention stage, 14.17% of them made the nurses examine the sensitivity range of the monitors and alter them if necessary. Even though the difference between the pre- and post-intervention personalization of settings for the monitoring of each patient was statistically significant ( $p$ -value=0.001), a large number (85.8%) of alarms and parameters remained unchanged. These findings are consistent with the results of the study of Graham *et al.*: they found that modification of the default settings of monitors and informing nurses about the significance of personalization of monitor parameters can help reduce excess alarms.<sup>(16)</sup>

Based on the findings of this study, 51.23% of the alarms were responded to by nurses, 7.15% were responded to by nursing assistants, and 2.71% were responded to by others, including patients' visitors and the cleaning staff. 38.89% of the alarms were never responded to. It was also noticed that the cleaning staff occasionally silenced alarms that went off while they were cleaning the rooms and equipment. Before the intervention, 43.1% of the alarms were responded to by the nurses, while after the educational intervention, the nurses responded to 62.1% of the alarms. The results of the statistical tests show a significant difference ( $p$ -value=0.007) between the pre- and post-intervention frequency of responders to alarms: the nurses became more responsive. Even though the responsiveness of the nurses in charge of checking the clinical conditions of patients and the monitoring parameters improved in the present study after the intervention, the number of alarms which did not receive a response was still high (33.5%).

**Limitations.** One of the limitations of the study was its use of the observation method for data collection: changes in the observers' behavior, perception errors, and environmental factors

can adversely affect the reliability of the data. To reduce the impact of such factors, the researchers excluded the results of the first 5 observations. Also, to minimize the impact of the observers' presence, the researchers wore the same uniform as the personnel, established a friendly relationship with the personnel, and entered and exited the intensive care unit at the same time as the personnel.

**Conclusion.** According to the results of the field observations, aside from nurses who are considered the primary responders to alarms, other

individuals, including the cleaning staff and even patients' visitors, occasionally respond to alarms. Application of the manual for management of alarms in intensive care units can prove useful in decreasing the number of alarms and, consequently, their negative consequences. Considering the broadness of the issue of alarm fatigue and its serious consequences for both patients and nurses, it is suggested that alarm fatigue be measured in nurses and the necessary steps, including educational workshops and classes, be taken to deal with this issue.





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# Professional and ethical values in Nursing practice: An Indian Perspective

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## Professional and ethical values in Nursing practice: An Indian Perspective

### Abstract

**Objective.** This study was carried out to examine professional and ethical values related to the profession from nurses' perspectives. **Methods.** This was a cross-sectional survey carried out among 124 randomly selected nurses working at a tertiary care hospital in South India. The data was collected using Nursing Professional Values scale (NPVS-3). This tool consisted of 28 items to assess nurses' professional values in three domains namely; Caring (10 items), activism (10 items), and professionalism (8 items). The maximum range of scores is 28–140. The higher the score, the stronger the nurse's professional value orientation. **Results.** The mean total score of the Professional Value scale was high (121.07±15.32). The mean score of the participants was higher in the caring domain (44.02±5.75) than activism (42.19±6.33) and professionalism domains (34.86±4.27). Pearson correlational analysis revealed that nurses with less



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experience had greater mean professional values score than nurses with higher experience ( $p < 0.01$ ). **Conclusion.** The present study showed that nurses have high professional and ethical values, although they perceive that the most important values are those related to direct patient care. Continuing education programs should be designed so that nurses understand that nonclinical professional values are also equally important in promoting the nursing profession.

**Descriptors:** ethics, nursing; professionalism; social values; cross-sectional studies; India.

## Valores profesionales y éticos en la práctica de la enfermería: Una perspectiva india

### Resumen

**Objetivo.** Este estudio se llevó a cabo para evaluar los valores profesionales y éticos relacionados con la profesión desde la perspectiva de los enfermeros. **Métodos.** Se trata de un estudio transversal realizado entre 124 enfermeras seleccionadas aleatoriamente quienes trabajan en un hospital de atención terciaria del sur de la India. Los datos se recogieron utilizando la escala de valores profesionales de enfermería (NPVS-3). Este instrumento consta de 28 ítems con respuesta tipo Likert de 1-5 que evalúa los valores profesionales de los enfermeros en tres dominios: cuidado (10 ítems), activismo (10 ítems) y profesionalismo (8 ítems). El rango máximo de las puntuaciones es de 28 a 140, cuanto mayor sea la puntuación, mayor será la orientación hacia los valores profesionales de enfermería. **Resultados.** La puntuación media total de la escala de valores profesionales fue alta ( $121.07 \pm 15.32$ ). La puntuación media de los participantes fue más alta en el dominio de cuidado ( $44.02 \pm 5.75$ ) que en el del activismo ( $42.19 \pm 6.33$ ) y en el de profesionalismo ( $34.86 \pm 4.27$ ). El análisis correlacional de Pearson reveló que las enfermeras con menos experiencia tenían una mayor puntuación media en valores profesionales que las enfermeras con mayor experiencia ( $p < 0.01$ ). **Conclusión.** El presente estudio mostró que las enfermeras tienen altos valores profesionales y éticos, aunque perciben que los valores más importantes son los relacionados con el cuidado directo al paciente. Deben diseñarse programas de formación continua para que las enfermeras comprendan que los valores

profesionales no clínicos también son igualmente importantes para promover la profesión de enfermería

**Descriptor:** ética en enfermería; profesionalismo; valores sociales; estudios transversales; India.

## Valores profissionais e éticos na prática de enfermagem: uma perspectiva indiana

### Resumo

**Objetivo.** Este estudo foi realizado com o objetivo de avaliar os valores profissionais e éticos relacionados à profissão na perspectiva dos enfermeiros. **Métodos.** Este é um estudo transversal de 124 enfermeiras selecionadas aleatoriamente que trabalham em um hospital terciário no sul da Índia. Os dados foram coletados por meio da Nursing Professional Values Scale (NPVS-3). Esse instrumento é composto por 28 itens com resposta do tipo Likert de 1 a 5 que avaliam os valores profissionais do enfermeiro em três domínios: cuidado (10 itens), ativismo (10 itens) e profissionalismo (8 itens). A faixa máxima de pontuação é de 28 a 140, quanto maior a pontuação, maior a orientação para os valores do profissional de enfermagem. **Resultados.** A pontuação média total da escala de valores profissionais foi elevada ( $121.07 \pm 15.32$ ). A pontuação média dos participantes foi maior no domínio cuidar ( $44.02 \pm 5.75$ ) do que no ativismo ( $42.19 \pm 6.33$ ) e no domínio profissionalismo ( $34.86 \pm 4.27$ ). A análise correlacional de Pearson revelou que enfermeiras menos experientes tiveram uma pontuação média mais alta em valores profissionais do que enfermeiras mais experientes ( $p < 0.01$ ). **Conclusão.** O presente estudo mostrou que os enfermeiros possuem elevados valores profissionais e éticos, embora percebam que os valores mais importantes são aqueles relacionados ao cuidado direto ao paciente. Os programas de educação continuada devem ser planejados de forma que os enfermeiros entendam que os valores profissionais não clínicos também são igualmente importantes na promoção da profissão de enfermagem.

**Descritores:** ética em enfermagem; profissionalismo; valores sociais; estudos transversais; Índia.

## Introduction

**N**ursing is one of the most trusted professions which is rooted in professional ethics and values.<sup>(1)</sup> Professional nursing values are defined as important professional nursing principles of human dignity, integrity, altruism, and justice that serve as a framework for standards, professional practice, and evaluation.<sup>(2)</sup> Values play a key role in any profession including the nursing profession. Professional values are articulated in the code of ethics. In India, every newly registered nurse is expected to adhere to the code of ethics and code of professional conduct for nurses developed by Indian Nursing council.

Ethics and professional values enlighten the nurses in providing quality of care to their clients. Furthermore, professional values not only influence individuals' principles, behavior standards but also enable them in the creation of an ethical framework.<sup>(3,4)</sup> Weis and Schank argued that professional values are standards for behaviors that are recognized by professional groups and individuals, and are used to evaluate the integrity of the individual or organization.<sup>(5)</sup> However, according to the International Council of Nurses, the core nursing professional values include caring, activism, professionalism, trust, and justice.<sup>(6)</sup>

Published evidence report that professional values are vital components in nursing practice and nursing professionals need to be aware of these values as code of ethics to provide high-quality patient care.<sup>(6,7)</sup> Besides, professional values promote nurse's ethical competency and their ability to manage ethical concerns. However, a majority of nurses were unaware of professional values and their relation to ethical issues.<sup>(8)</sup> Also, the code of ethics guides professional behaviors including the quality of professional care, patient safety, and the norms of the profession, and these values are crucial to professional practice and essential for developing and sustaining a professional identity.<sup>(9)</sup> Earlier research demonstrated that professional values among clinical nurses were high.<sup>(7,10)</sup> Further, most of the studies also have examined the nursing students' views on the importance of professional values.<sup>(8,11)</sup> In India, very few studies have examined awareness of ethical principles among nurses.<sup>(12,13)</sup> However, research that focused on ethical and professional values among Indian nurses was limited. Therefore it is critical it is critical to investigate nurses' knowledge of professional and ethical values and the integration of these values in their practice. Therefore, the present study was aimed to examine professional and ethical values related to the nursing profession from the perspective of nurses working in a tertiary care center.

## Methods

This was a cross-sectional survey carried out from November to December 2019 among nurses working at tertiary care hospital in South India. The sample was selected randomly using (random number table) nurses' attendance register. The study criteria for nurses included having experience of more than one year and being directly involved in patient care. There were 156 nurses who were eligible to participate in this study and were invited for the same. Of the invited participants, nurses who were on leave ( $n=13$ ), refused to participate ( $n=8$ ) and few incomplete questionnaires ( $n=11$ ) were excluded from the study. Therefore, the final sample size comprised of the present study was 124 nurses with 79% response rate.

The data was collected using a two-part questionnaire; the first part included demographic variables such as age, gender, religion, professional qualification, and professional experience and the second part included the Nursing Professional Values Scale-3 (NPVS-3) developed by Weis and Schank.<sup>(14)</sup> This tool consisted of 28 items to assess nurses' professional values in three domains namely; Caring (10 items), activism(10 items), and professionalism (8 items). This was a Likert-scale rated from 1 (not important) to 5 (most important). The maximum range of scores is 28–140. The higher the score, the stronger the nurse's professional value orientation. The Cronbach's alphas are stated to be 0.942, with the subscale scores ranging from 0.70 to 0.85. Thus, the tool is considered valid and reliable.<sup>(14)</sup> In the present study, the reliability of the tool ( $r=0.86$ ) was established through test-retest method among 20 nurses.

**Data collection procedure.** The English version of the NPVS-3 questionnaire was piloted among a small group ( $n=20$ ) of nurses and found it was feasible. The researchers obtained permission from the Head of Department of Nursing and informed Nursing tutors and In-charge nurses

about the study and requested a feasible time to administer the questionnaire among the selected nurses. Then the researchers met the nurses individually in their clinical postings and invited them to participate in the study. The questionnaires were distributed among the participants and collected back immediately. The primary researcher was available during the data collection to clarify the doubts of the participants if any. It took approximately 20-30 minutes to complete the questionnaires.

**Ethical considerations.** This study was approved by the Ethics committee at the College of Nursing and permission was obtained from the administrators of the hospital where the study was conducted. The nurses were informed of the study's aims and procedures and obtained written informed consent from the volunteered participants. Data collection tools contained no identifying information to ensure the confidentiality of the participants.

**Statistical analysis.** The data were analyzed using appropriate statistical software (SPSS 21 version) and results were presented in the form of tables. Descriptive statistics such as frequency, percentage, mean and standard deviation were performed. Inferential statistics such as Independent t-test and ANOVA were used to examine the correlation of professional values' mean score with demographic variables of age, gender, religion, professional qualification, and professional experience. Pearson's correlation coefficient was performed to investigate the correlation of the nursing professional values' total score with the participants' age. The level of significance was fixed at 0.05 level.

## Results

A total of 124 nurses have completed the NPVS-3 questionnaire. The mean age of the participants was 31.2years (7.06 SD). Most

of the sample were females (70.2%), Hindus (54%) and graduates (75.8%) (Table 1). The majority of the participants had 6-15 years of experience in caring for the patients. According to Table 2 in NPVS-3 statements of nursing professional values, the statements “Respect the inherent dignity, values, and human rights of all individuals”, “Safeguard patient’s right to confidentiality and privacy” “Protect health and safety of the individuals” “Protect moral and legal rights of the patients” and “Accept responsibility

and accountability for own practice” received the highest scores, while the statements “Engage in consultation and collaboration to provide optimal care”, “Take actions to influence legislatures and other policymakers to improve health care” “Participate in nursing research and/or implement research findings appropriate to practice” “Act as a patient advocate” “Confront practitioners with questionable or inappropriate practice” gained the lowest importance as the mean score was lesser.

**Table 1. Relationship between nurses’ demographic characteristics and professional values**

Variables	Frequency n (%)	Mean scores (SD)	p-value
Age			0.14
<25	32 (25.8)	125.34 (16.54)	
26-35	58 (46.8)	118.71 (14.40)	
>36	34 (27.4)	121.09 (15.25)	
Gender			0.37
Male	37 (29.8)	122.95 (14.95)	
Female	87 (70.2)	120.28 (15.50)	
Religion			0.89
Hindu	67 (54.0)	121.25 (15.25)	
Christian/others	57 (46.0)	120.86 (15.55)	
Professional qualification			0.98
GNM (Diploma in Nursing)	10 (8.1)	120.50 (13.98)	
BSc	94 (75.8)	121.23 (16.07)	
MSc	20 (16.1)	120.60 (12.77)	
Professional Experience (years)			0.01
<5	53 (42.7)	125.15 (15.34)	
6-15	54 (43.5)	116.44 (14.97)	
16-25	17 (13.7)	123.06 (12.93)	

**Table 2. Mean scores of Professional Values Scale (NPVS-3) statements**

No	Statement	Mean (SD)
27	Engage in consultation and collaboration to provide optimal care	4.05 (0.98)
26	Take actions to influence legislatures and other policy makers to improve health care	4.05 (0.88)
17	Participate in nursing research and/or implement research findings appropriate to practice	4.15 (0.94)
16	Act as patient advocate	4.15 (0.98)
20	Confront practitioners with questionable or inappropriate practice	4.21 (0.83)
5	Participate in peer review	4.23 (0.75)
13	Assume responsibility for meeting health needs for diverse populations	4.24 (0.79)
11	Recognize the role of professional nursing associations in shaping health policy	4.26 (0.86)
25	Promote mutual peer support and collegial interactions to ensure quality care and professional satisfaction	4.26 (0.76)
28	Recognize professional boundaries	4.26 (0.84)
23	Actively promote health of the populations	4.27 (0.76)
21	Protect rights of participants in research	4.27 (0.83)
12	Establish collaborative partnerships to reduce health care disparities	4.28 (0.85)
24	Participate in professional efforts and collegial interactions to ensure quality care and professional satisfaction	4.29 (0.78)
22	Practice guided by principles of fidelity and respect	4.29 (0.89)
07	Promote and maintain standards where planned learning activities for students takes place	4.34 (0.77)
10	Advance the profession through active involvement in health-related activities	4.36 (0.83)
18	Provide care without bias or prejudice to patients and populations	4.36 (0.76)
06	Establish standards as a guide for practice	4.36 (0.74)
08	Initiate actions to improve environment of practice	4.41 (0.78)
01	Engage in on-going self-evaluation	4.45 (0.69)
04	Assume responsibility for personal well-being	4.46 (0.69)
09	Seek additional education to update knowledge and skills to maintain competency	4.46 (0.73)
15	Protect moral and legal rights of the patients	4.47 (0.76)
14	Accept responsibility and accountability for own practice	4.48 (0.73)
03	Protect health and safety of the individuals	4.56 (0.64)
19	Safeguard patient's right to confidentiality and privacy	4.57 (0.68)
02	Respect the inherent dignity, values, and human rights of all individuals	4.65 (0.57)

The mean score of the participants was higher in the caring domain ( $44.02 \pm 5.75$ ) than activism ( $42.19 \pm 6.33$ ) and professionalism domains ( $34.86 \pm 4.27$ ). These findings indicate that the participants perceived the professional values directly related to patient care as the

most important. The mean total score of the professional values from the nurses' perspectives was high ( $121.07 \pm 15.32$ ) and suggests that 86% of the nurses in this study were aware of professional values in the nursing profession (Table 3).



**Table 3. Subdimensions of Nursing Professional Values Scale (NPVS-3)**

Domains of the scale	Range	Minimum Score	Maximum Score	Mean (SD)
Caring (10 items)	10 to 50	26	50	44.02 (5.75)
Activism (10 items)	10 to 50	26	50	42.19 (6.33)
Professionalism (8 items)	8 to 40	25	40	34.86 (4.27)
Total (28 items)	28 to 140	85	140	121.07 (15.32)

In this study, the mean professional value scores of age, gender, religion, and professional qualifications were not significantly different. However, a statistically significant difference observed between nurses' professional experience and professional values scores. Nurses with

less experience had greater mean professional values score than nurses with higher experience ( $p < 0.01$ ). Pearson's correlational analysis revealed a positive relationship between caring, activism, and professionalism dimensions ( $p < 0.001$ ) (Table 4).

**Table 4. Correlation between age and subdimensions of Nursing Professional Values Scale (NPVS-3)**

Domains of the scale	Age	Caring	Activism
Caring	-0.074 0.41		
Activism	-0.031 0.73	0.816 0.001	
Professionalism	-0.014 0.87	0.813 0.001	0.817 0.001

## Discussion

This was the first study that explored the importance of professional and ethical values from the nurses' perspective from Indian settings. The higher mean score of the professional values scale indicates that nurses in this study

hold strong professional values in their practice. However, most of the participants perceived the professional values in the caring domain were most important than values stated in activism and professionalism domains. The fundamental responsibility of nurses is to provide safe, ethical, and quality of care. This can be achieved when the patients are treated with dignity, respect, and care and in this study, nurses rated high to the

item “*Respect the inherent dignity, values, and human rights of all individuals*” with a mean score of 4.65(SD, 0.57).<sup>(15)</sup>

In line with previous research,<sup>(16)</sup> nurses in the present study rated caring domain items as most important professional values. These items include; “*Safeguard patient’s right to confidentiality and privacy*” “*Protect health and safety of the individuals*” “*Protect moral and legal rights of the patients*” and “*Accept responsibility and accountability for own practice*”. These findings can be attributed to the fact that nurses mainly consider the values that are directly related to their professional practice.<sup>(17)</sup> Furthermore, it can also be argued that nurses are involved in offering patient care even with significant changes in the health care system.<sup>(5)</sup> On the other hand, the items under activism and professionalism domains were low rated. The low rated items include; “*Engage in consultation and collaboration to provide optimal care*”, “*Take actions to influence legislatures and other policymakers to improve health care*” “*Participate in nursing research and/or implement research findings appropriate to practice*” “*Act as a patient advocate*” “*Confront practitioners with questionable or inappropriate practice*”. Similar findings were observed in other studies.<sup>(7,18)</sup> These findings could be due to nurses often are not actively involved in policymaking. Further, nurses may believe that these are non-clinical activities in the nursing practice. The mean value “*Participate in nursing research and/or implement research findings appropriate to practice*” was low as nurses are busy in providing patient care or maybe having negative perceptions such as ‘difficult to understand the concepts of research.’<sup>(19)</sup> Most importantly, nurses are expected to be ethical and patients rely on nurses to be advocates for them.<sup>(20)</sup> Therefore, nurse administrators need to consider these areas to improve professional values through CNE or in-service educational programs.

In this study, the mean total score of the professional values from the nurses’ perspective was high (121.07 ± 15.32) which suggests 86%

of the nurses hold strong professional values. These results were consistent with findings of other studies conducted among nurses and the total mean score on professional values scale ranged 100.01 to 165.41.<sup>(16,21,22)</sup> These differences could be due to the attitudes and beliefs of nurses from various countries. Therefore, future studies should focus on the influence of culture on professional values among nurses.

Caring referred to as the core of nurses’ professional values.<sup>(23)</sup> Similarly, most of the nurses in this study felt that the items in the caring domain as the main and most important professional values while the item ‘act as patient advocate’ received the lowest score of 4.15±0.98. However, the mean score of the participants was higher in the caring domain than activism and professionalism domains. These findings indicate that the participants perceived the professional values directly related to patient care as the most important. Similar findings were observed in earlier studies.<sup>(16,18)</sup> Rabia S. Allari also stated that nursing issues outside the nurse-client relationship such as public policy, environment, professional nursing organizations, and research, and professional organizing were perceived as less important by nurses. Thus, it is an urgent concern to create awareness among nurses about the need to view the professional values under professionalism and activism domains as equally important to the caring domain to propel the profession to influence healthcare reform.

In this study, nurses with less experience had a greater mean professional value score than nurses with higher experience ( $p < 0.01$ ). These results were supported by findings in other studies carried out among nurses.<sup>(24)</sup> On the contrary, Poorchangizi *et al.* demonstrated that nurses with more experience have obtained higher scores of professional values. Similar to earlier research,<sup>(25)</sup> this study also indicates no statistically significant correlation between professional values scores and demographic variables ( $p > 0.05$ ). However, these findings were dissimilar to a study carried out among

nurses from a developed country.<sup>(26)</sup> Probably, these findings could be due to cultural differences.

**Limitations.** The present study has certain limitations such as the sample was selected from a single setting, a cross-sectional survey design, and the data was collected using self-reported questionnaires. Therefore, there may be a possibility of bias and exaggeration of scores. Due to these reasons generalization of the findings was limited. Further, the NPVS-3 scale measured the importance of professional values from the nurses' perspective, but it did not assess the application of these values in nursing practice. Future studies should focus on mixed methods designs to understand nurses' views on ethical and professional values and ethical challenges they encounter while incorporating these values into professional practice. Despite these limitations, the findings would be helpful for nurse educators and administrators to develop continuous educational programs to improve

nurses' awareness and understanding of the importance of professional values and improve the quality of care.

**Conclusion.** The present study shows that nurses hold high professional and ethical values which were prioritized from the nurses' perspective as caring, activism and, professionalism, respectively. Most of the nurses perceived the professional values related to direct patient care are most important. On the other hand, professional values related to nurses engaging in 'consultation and collaboration', 'policy-making', and 'evidence-based practice' were perceived by nurses as less important. Therefore, nurse administrators need to emphasize the less-important professional values in designing continuous education programs to improve nurses' understanding that non-clinical professional values also are equally important to promote the nursing profession.

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# Father's participation in prenatal care and childbirth: contributions of nurses' interventions


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## Father's participation in prenatal and childbirth: contributions of nurses' interventions

### Abstract

**Objective.** To describe the discourse of men about participation in prenatal care and childbirth/birth of their children from the contributions made by nurses. **Methods.** This is an exploratory study, with a qualitative approach, carried out in the wards of a public hospital/maternity hospital in a city in the Northeast, Brazil. Fifty men participated in the study. Data collection with an individual interview, guided by semi-structured script. The data were recorded, transcribed in full, systematized, categorized, and organized by the Collective Subject Discourse method analyzed under the framework of Gender and Masculinities. **Result.** It was evident in the collective discourse of men that how fatherhood is understood is in transformation, and that the father's participation in the pregnancy and parturition context is under construction. The study showed the change in behavior of men, as well as the



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expression of new models of masculinities, about the exercise of assisted parenthood motivated by nurses. **Conclusion.** Nurses' contributions represented necessary elements for greater adherence and male involvement and revealed a possibility to re-signify male identity from the reconstruction of the idea of fatherhood, in the context of pregnancy and parturition.

**Descriptors:** paternity; nursing; prenatal care; obstetric labor; parturition.

## La participación del padre en la atención prenatal y en el parto: contribuciones de las intervenciones de las enfermeras

### Resumen

**Objetivo.** Describir el discurso de los hombres sobre la participación en la atención prenatal y el parto/nacimiento de sus hijos a partir de las contribuciones realizadas por las enfermeras. **Métodos.** Estudio exploratorio, con un enfoque cualitativo, llevado a cabo en las salas de un hospital público/hospital de maternidad en una ciudad en el noreste de Brasil. Cincuenta hombres participaron en el estudio. Para la recolección de la información se utilizó la entrevista individual con guión semiestructurado. Los datos se registraron y transcribieron en su totalidad. También, se sistematizaron, categorizaron y organizaron por el método del Discurso del sujeto colectivo analizado en el marco de Género y Masculinidades. **Resultados.** Se evidenció en el discurso colectivo de los hombres que la forma en que se entiende la paternidad está en transformación y que la participación del padre en el contexto del embarazo y el parto está en construcción. Los hombres revelaron que pueden ser conscientes del autocuidado y se pueden empoderar en el manejo de su familia, asegurando la construcción de una nueva identidad masculina en la sociedad contemporánea. **Conclusión.** Los aportes de las enfermeras representaron elementos necesarios para una mayor adherencia



y participación masculina y revelaron la posibilidad de resignificar la identidad masculina a partir de la reconstrucción de la idea de paternidad en el contexto del embarazo y el parto.

**Descriptor:** paternidad; enfermería; atención prenatal; trabajo de parto; parto.

## Participação do pai no pré-natal e parto: contribuições das intervenções de enfermeiras

### Resumo

**Objetivo.** Descrever o discurso de homens sobre a participação no pré-natal e parto/nascimento de seus filhos a partir das contribuições promovidas por enfermeiras.

**Métodos.** Trata-se de estudo exploratório, com abordagem qualitativa, realizado nas enfermarias de um hospital/maternidade público de uma cidade do Nordeste, Brasil. Participaram do estudo 50 homens. Coleta de dados com entrevista individual, orientada por roteiro semiestruturado. Os dados foram gravados, transcritos na íntegra, sistematizados, categorizados e organizados pelo método do Discurso do Sujeito Coletivo analisados sob referencial de Gênero e Masculinidades. **Resultados.**

Evidenciou-se no discurso coletivo de homens que a forma como a paternidade é entendida está em transformação, e que a participação do pai no contexto gravídico e de parturição encontra-se em construção. O estudo evidenciou a mudança de comportamento dos homens, bem como a expressão de novos modelos de masculinidades, no tocante ao exercício da paternidade assistida motivado por enfermeiras. **Conclusão.** As contribuições de enfermeiras representaram elementos necessários para maior adesão e envolvimento masculino e revelaram uma possibilidade para resignificar a identidade masculina a partir da reconstrução do ideário da paternidade, no contexto gravídico e de parturição.

**Descritores:** paternidade; enfermagem; cuidado pré-natal; trabalho de parto; parto.

# Introduction

Pregnancy is a unique and complex period of intense physical, psychological, and social changes in the life of the pregnant woman and the future father. This phase leads to new expectations, feelings, doubts, typical and singular of pregnancy, childbirth, and postpartum, making it necessary to support this woman so that she feels more secure and confident.<sup>(1)</sup> For parents, pregnancy is a critical period in the emotional development of man, sometimes generating growth, fulfillment, preparation, maturation of the role, sometimes frustration and disruption.<sup>(2)</sup>

The culture of gender distinction and the division of roles between the genders following the logic of a society in which patriarchy operates is clear and has always been present in a society in which paternal and maternal functions were traditionally distinct. Women have been assigned the role of caring for the home and children, men are assigned the fixed position of family provider. Thus, the father had the distant authority, he was not involved in the care and upbringing of his children, leaving mothers as an affective reference for children. The changes in the sexual division of labor and the male participation in the care performed with the children are other important milestones to be considered. We observed that the advances have occurred in a limited way, which has repercussions on obstacles in achieving gender equality, especially in the domestic context, given that, asymmetrically, women have continued to be responsible for most of the activities related to social and physical reproduction of the family constitution.<sup>(3)</sup>

Even in the face of this national panorama, we need to recognize the emergence of changes in the construction of social roles, including the configuration of paternity. Examples of these new conformations and paternal arrangements have been observed, such as the growth of single-parent male families, called patrifocal families, in which parents live with their children without the presence of a spouse and/or other relatives.<sup>(4)</sup> Given this current conjuncture, we need to prepare the man for the pregnancy-puerperal period, given the complexity of skills and knowledge necessary of caring, protecting, developing affectivity and socializing with the child. Becoming a father is a permanent construction, and its degree of success can compromise the exercise of the parental role and have implications for the health and well-being of the family. Thus, the father's participation in prenatal care and childbirth helps not only to form a bond with the child but also in the role as a partner, transmitting security and support to the woman.<sup>(5)</sup>

As a possibility to provide theoretical support capable of explaining the phenomena and promoting directions for the development of professional practices, we need to use theories of gender and masculinities, as proposed by Joan Scott<sup>(6)</sup> and Raewyn Connell.<sup>(7)</sup> The assumptions provided in the theoretical

constructs are a contributory lens for thinking about the elaboration of strategies for planning and programming actions in health services.

In this way, sex/gender systems can be understood as a set of practices, symbols, representations, norms, and social values that support society to elaborate their configurations, often based on anatomy physiological sexual differentiation, making questions such as sexuality and reproduction. In this context, the concept of gender is essential because it starts from a relational analytical perspective in which the masculine and the feminine are thought of not as entities but as interdependent constructions in their relational dimension to suppress asymmetries of power.<sup>(6)</sup> The constructs of the concept of masculinity have moved in this perspective and have allowed us to identify that there is centrality in patriarchy in the configuration of hegemonic masculinity, which in large part has despised the figure of the man who is careful with himself and in turn with his children.<sup>(7)</sup> Connell has thought of gender as a global perspective to analyze hierarchies, norms, marginalities, and colonialities present in masculinities that are imposed on some men categories.

Conducting studies focused on the male perspective is considered relevant because the greater involvement and participation of men in all areas of sexual and reproductive health care is an international recommendation. Given the problem, the study aimed to describe the discourse of men about the participation in prenatal care and childbirth/birth of their children from the contributions made by nurses.

## Methods

This is an exploratory study, with a qualitative approach, carried out in the wards of a public hospital/maternity hospital in a city in the Northeast, Brazil. The study participants were 50 men who met the following inclusion criteria:

having accompanied their partners during or after childbirth, including the prenatal period, and being 18 years old or older. We excluded from the study those who had any mental impairment that prevented the interviews. Data collection was carried out through semi-structured interviews. The physical space for conducting the interviews was defined at the maternity hospital, in a private room, to guarantee the individuality of the participants and the confidentiality of the information provided. Each interview lasted an average of 30 minutes.

To carry out the interviews, operational strategies of approaching men were made, through conversation circles in the sector and welcoming and listening actions through the performance of situation rooms while waiting for the service and the distribution of printed information on fatherhood. The interviews had as a guiding question: "Tell me about the contributions made by nurses for their participation in prenatal care and childbirth/birth of their children" The criterion used to determine the size of the study sample was data saturation, that is, the moment in which the search for new subjects does not add new information to the investigation. The collected data were recorded, transcribed in full, systematized, and categorized using the NVIVO® 11 software, and organized by the Discourse of the Collective Subject (DCS) method.

The DCS is a category of exposure of the results of qualitative research, having testimonies as raw material, in the form of one or more synthesis speeches written in the first person of the singular. It is a resource that aims to express the thinking of a collective. This method consists of pointing out, from each answer, the key expressions, which are the central ideas of the discursive content expressed by the interviewees.<sup>(9)</sup> The data configured through the DCS were analyzed based on the references of gender and masculinities, from the perspective of Scott<sup>(7)</sup> and Connell,<sup>(8)</sup> respectively.

The DCS uses four methodological figures called Key Expressions, Central Ideas, Anchoring, and

the Discourse of the Collective Subject. After transcribing the interviews, we identified the Key Expressions and Central Ideas, which represent a synthesis made by the researchers of the discourse emitted by the participant and reveal what people think. Anchoring is a statement that contains a value, a theory, an ideology, an explicit belief in the discourse that is professed by the individual. After identifying the Central Ideas and Anchoring, those that had a similar or even complementary meaning were grouped into categories. These categories were designed to best express all the Central Ideas and Anchorings with the same meaning, for the Discourse of the Collective Subject construction.<sup>(8)</sup>

All research participants were informed about the purpose of the study and the ethical precepts that guide it and signed the Informed Consent Form. This study was approved by the Research Ethics Committee of Faculdade Nobre de Feira de Santana.

## Results

The collective discourse points out that men recognized the importance of assuming fatherhood and exercising responsibility for the pregnancy and care of their children, developed strategies for prenatal consultations and tried to maintain periodicity and adherence, attributing the success achieved the performance of the nurse. They also revealed that, through their participation in prenatal care, they had the opportunity to monitor the baby's growth more closely, by listening to the fetal heartbeats and touching their companions' bellies. Men reported feeling safer when participating in prenatal care and highlighted the nurse's work in conducting information and guidance as a relevant factor for the performance of paternal care. They revealed that they had the opportunity to access the health system more broadly, carrying out laboratory tests, updating the vaccination calendar, as

a result of coming to prenatal consultations, expressed in the collective discourse.

### Central Idea Synthesis: Sensitization and insertion in prenatal and pre-childbirth

*In the prenatal period, I followed most of the consultations, I went whenever I could. There were days when I couldn't stay for the entire consultation, but even so, I attended it. I used overtime and exchanges on workdays and shifts, just to be able to attend. It all started when the nurse sent me an invitation given by my wife so that I could go to the appointments. She kept encouraging me and I started to go. I started to realize that this was my responsibility, to assume the role of the father from the beginning, after all the son is also mine and all this the nurse said to me. I felt important and therefore I made every effort to be present, programming myself to be with my wife, after all, she needed me and I think my son also knew that I was around, through my voice, because they say that they recognize it. I believe that my presence also motivated my wife to make all consultations and examinations. It was a very good experience, and quite different, as I learned about everything that happened about the pregnancy, her, and the baby's health. I got to hear his little heart at the time of the exam and follow the whole process and the child's development and this reduced the fear, calmed me, and made me safer. I learned what to do in a few moments, as I had a lot of doubts, and the information that the nurse was giving me clarified. I also had exam guides, I took courage and did it to see if everything was fine with me and I also had all the vaccinations. When it came time to take my wife to the hospital, I was more prepared, and it was certainly due to my participation in prenatal care. It's almost like training to be a father [laughs]. (DCS of men who experienced prenatal care and childbirth for their sons and daughters).*

The speech revealed the men's lack of knowledge regarding the law of the companion, and the right to participate in childbirth. However, due to the

nurse's performance, they were disseminated and expanded, as evidenced.

### **Central Idea Synthesis: Dissemination of knowledge about the Law of the companion**

*I had never heard of the law of the companion. At the hospital, they told me nothing, but I had already been informed by the unit's nurse when I attended prenatal consultations with my wife. It is very important, as it is a way to be able to reassure the woman more when the baby's birth is happening and also power is reassuring the rest of the family, as she already knows that someone known is present. The problem is that it is a right that not everyone respects. Everything is beautiful on paper, but in practice, it hasn't happened. It is a pity that it does not work because it is very important for the woman and also for the father, it is a good experience for both of them and for that to happen it is necessary to know about our rights.* (DCS of men who experienced prenatal care and childbirth for their sons and daughters).

The following speech points out that men were unaware of the possibility of participating in childbirth with their partners, although they had been informed during prenatal consultations. Even so, these men could not accompany the childbirth and birth of their sons and daughters, but they were able to embrace and bring them closer to the hospital:

### **Central Idea Synthesis: Dissemination of knowledge about the right to participate in childbirth**

*At first, I thought that the follow-up was for her not to be alone in the hospital, but I didn't know that I could participate directly in the delivery, I knew all of that during prenatal care. But unfortunately, I was not able to participate, someone else in my family was the one who attended because the hospital did not allow parents to enter. All for the sake of bureaucracy.*

*The hospital nurse said she was not allowed to let me in and commented that there were other pregnant women at the scene and the men could not be at the scene. According to her, this was a hospital policy. I was waiting at the reception. I was in agony, waiting for news, and along with me, several parents were waiting outside. The situation only eased when the nurse brought me the news of the birth and told me that she would soon bring my son so that I could at least see what he was like.* (DCS of men who experienced prenatal care and childbirth for their sons and daughters).

The discourse shows the male contribution during childbirth, from the perspective of men, as a way of providing happiness and security for the couple, and helping women through motivation and demonstration of affection.

### **Central Idea Synthesis: Male empowerment to care during childbirth**

*Just being there saying something, holding her hand should be a relief. I think that would make her more courageous. I'm sure it would calm my wife down. When she was afraid, she would see me and be better, because I would give support and security, tranquility, and calm down, for her to feel more confident. After all, it is a moment of great anxiety, especially for her. I would give moral support, with words of encouragement, love, affection, I would say that no harm would happen to her because I would apply everything, I learned in those months participating in prenatal care. It motivated and would ask for patience. I would value her as the mother of a being who is about to come into the world. It would encourage her to give birth, make her think only of having the baby, and not worry about anything else. She had high blood pressure during childbirth, because of the nervousness, I think that if she were calmer, it might not have happened. It is also my wish to accompany my son's first care, to ensure that no stranger touches him, as this is also her concern. But today I am more relaxed and more secure*



*after all the information I had from the nurse. As a father, we have to accompany, and this is a happy moment for the couple. I will always be his father regardless of whether I saw the birth or not, but I would certainly be a different father if I were in that room. I can't explain it, but I think it would make me feel good.* (DCS of men who experienced prenatal care and childbirth for their sons and daughters).

## Discussion

Despite pregnancy, childbirth, and the puerperium is considered an essentially feminine event, the struggle for humanization favored male participation in this scenario, showing the expression of models favorable to the exercise of assisted fatherhood and responsibility for maternal and child development. In this context, this study showed behavioral changes in men, and new models of masculinities capable of contributing to the reaffirmation and valorization of paternity, family empowerment, and greater satisfaction with the gestational process.

The construction of masculinity in Brazil is directly influenced by social, political, economic, and cultural conditions, in which the stimulus for care is incipient and marked by great challenges, showing vulnerabilities in different perspectives that involve recognition and parental responsibility, and changes in gender roles and the formation of family arrangements.<sup>(9,10)</sup>

In the analysis of speeches, the paternal interest and motivation for prenatal training and participation in childbirth were found, resulting in the development of different strategies for adherence and maintenance of the periodicity of follow-up. This conception shows that regardless of gender differences, men demonstrated an egalitarian stance towards their partners and a greater awareness of the relevance of their family attribution and accountability. The analytical approach to gender promotes the

horizontality of parental care, showing that the subsets are interconnected and evoking symbolic representations in the existing connections and the understanding of roles. Thus, paternity becomes a favorable moment for male incorporation from the gestational process to the consolidation of equitable relationships in the domestic routine.<sup>(9)</sup>

In this investigation, male participation in prenatal care was described as a unique opportunity to monitor fetal development, resulting in greater involvement in consultations and self-evaluation, and maternal satisfaction. This perception was also identified in another study that, when analyzing in the scientific evidence the contributions of the paternal organism during the prenatal consultations, we observed potentialities for the formation of support and support networks for women, the establishment of family bonds, the promotion of maternal-fetal health and well-being.<sup>(11)</sup>

The prenatal period is considered in the literature as a propellant for the development of the paternal identity, in which the monitoring of the gestational process promotes the physical and psychological adjustment necessary to face the new role and profound reflections on the parental model that the parents want for the future of the child.<sup>(12)</sup> The collective discourse also revealed that, during the evaluations, the men were sure about the maternal-fetal health conditions, by monitoring the auscultation of the fetal heartbeats and techniques to check the uterine height. Therefore, this process allows for a better understanding of the changes that have occurred with the woman, obtaining information and reducing the insecurity and anxiety resulting from doubts in the development of care.<sup>(5)</sup> Thus, paternal participation in childbirth and puerperium can be determined by the different experiences lived during prenatal care, in which the monitoring of procedures such as ultrasound and fetal movements are positive because they influence the acceptance of pregnancy, the recognition of paternity, and the strengthening of bonds.<sup>(12)</sup>

The international literature also described male involvement in maternal health services, including prenatal education as a favorable strategy for fulfilling supportive roles, leading to the development of safe maternity practices, and the preparation for childbirth, and the identification, treatment, and prevention of maternal-fetal complications.<sup>(13)</sup> The paternal insertion in prenatal care promotes access to nursing consultations, meeting their demands and how to perform exams and immunization, a proposal widely recommended by the Ministry of Health, based on encouraging the implementation of male prenatal care. The political strategy called “male prenatal care” aims to encourage the father to make frequent visits to health services in a preventive manner, developing a greater emotional bond between him, his partner, and the child, and track infectious diseases, and expand access to health services.<sup>(14)</sup>

The greater adherence to the monitoring and performance of paternal care was attributed to the nurse who represented a necessary instrument for conducting information and guidance.

Nursing care in this context constitutes a fundamental element for maternal and fetal health, constituting an important information resource, capable of favoring the reception and paternal valorization and leading to the development of actions and strategies that prioritize health promotion, disease prevention, and the humanization of care. Therefore, it is possible to have a paternal presence in the gestational dynamics, which can result in the foundation of care in elements of quality, efficacy, and safety.<sup>(15)</sup>

Among the benefits, we highlight the presence of difficulties constantly faced by the father, which can reflect effectively in the monitoring. Thus, the incompatibility between the opening hours of health services and work was significant and constituted a major challenge to be overcome. Male representation as a financial provider for the

family means that the request for paternity leave to work may lead to feelings of vulnerability as it involves high costs, in this case, the financial impact or loss of work.<sup>(16)</sup> In this perspective, the articulation in health that gives rise to the guarantee of labor rights, as a way of guaranteeing men the right to parenting, similar to mothering and without impediments, implications, or losses in the labor and financial dynamics.

Based on this understanding, we found that men have not been assigned the role of caregivers, whereas their institutions and other workspaces do not prioritize the moment of the childbirth of their children, nor do they ensure enforcement of rights, as a public policy in force in the country.

In the Brazilian scenario, the presence of a companion during childbirth and the puerperium is one of the fundamental rights of women, is regulated by Law 11,108 of 2005, which considers support for parturient women as conduct associated with better maternal and neonatal outcomes.<sup>(14)</sup> However, the lack of knowledge by men about the rights and regulations proposed by the Law of the Companion is evident, showing that even though they were informed about the validity during the gestational period, their right to participate in childbirth was not effective in the hospital environment, making monitoring impossible from birth.

Although the social constructions of patriarchal symbols place men in a position of distancing from the exercise of fatherhood, awareness strategies have been developed during the actions performed by nurses who seek the male approach to a field considered exclusive to women.<sup>(17)</sup> In this sense, the current panorama reveals the existence of barriers in the application and full implementation of these strategies, possibly of a social and cultural nature that generates behaviors in health professionals that are resistant to new interventions, as they use speeches based on “experience” loaded with the absence of empathy concerning the presence of these new subjects, accompanying labor and childbirth.<sup>(10)</sup>



Despite the achievements of parents with their role as a partner, the characteristics of paternity leave that existed since its formulation, demonstrate participation as an adjunct, revealing the risk of reinforcing the hierarchical stereotype that places men and women in a situation of vulnerability.<sup>(18)</sup> In this sense, the speech pointed out fragile knowledge about the participants during the delivery of their sons and daughters, but they got enlarged during the prenatal consultations. Institutional restrictions and barriers conditioning gender differences prevented men from accompanying their partners during childbirth, having at that moment to rely on the support of other family members, with a predilection for females.

In the hospital environment, men were unable to enter internal facilities, in which the presence of other pregnant women was the justification for enabling their remain in the sector. Although they did not have the governability to allow parents to enter the delivery rooms, the strategies developed by nurses promoted the approach, welcoming and strengthened the bond through the parents' previous meeting with the babies. The sex-gender system printed in institutional norms, calls attention to the understanding of gender not as a constitutive element of social relations based on perceived differences, but as a primary way of signifying power relationships, in which power is articulated. To distance men from this process is to put them on the margins of protagonism and significant opportunities to acquire contributions from the caregiver and responsible parenthood.<sup>(19)</sup>

The presence of a partner in the delivery room is described as an action capable of promoting maternal comfort, involving the emission of words of encouragement, demonstration of love, affection, and protection, ensuring motivation and empowerment for fatherly exercise. In this sense, men expressed concern with the complications that could exist during delivery

and the fear that something might happen to the baby, showing willingness and to accompany the first care. Therefore, the father can experience myths and fantasies about what is happening during childbirth, or about what may happen in the inpatient units, when the right to participate in this area is not presented, leading to the development of emotional relationships, to the negative experience about the parturitive process, to the removal of that experience, to the lesser autonomy and the paternal empowerment.<sup>(19)</sup>

Such an active, sensitive, and enlightening posture by the professionals in the promotion of present, participatory, caring, and responsible fatherhood, can contribute to overcoming the denial of the paternal process, maturing and reflections on the role of being a father, strengthening bonds that structure the family as a referenced microsystem.<sup>(9)</sup> The limitation of the study refers to the only context adopted for investigation. Future research is necessary considering different levels of health care that can contribute to accountability, autonomy, empowerment, and paternal appreciation during pregnancy, childbirth, and the puerperium.

Thus, we conclude that despite the limitations in public policies, working conditions, and paternity rights, paternal participation in the context of pregnancy and childbirth was significant and is under construction. The nurse represented a necessary element for greater adherence and male involvement in this process.

Thus, this study showed the change in behavior of men, and the expression of new models of masculinities, revealing that men can be aware of self-care and empowered in the management of their family, and guaranteeing the construction of a new male identity in contemporary society. Finally, the results revealed a possibility to resignify male identity from the reconstruction of the ideals of fatherhood.

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