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–Nursing Research and Education–

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Editorial

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Wildfires as a Public Health Problem: a Setting for Nursing in Disasters

R. Mauricio Barría P[1]

Descriptors: air pollutants; wildfires; disasters; global warming; public health; pulmonary disease, chronic obstructive; professional role; health personnel.

Descriptores: contaminantes atmosféricos; incendios forestales; desastres; calentamiento global; salud pública; enfermedad pulmonar obstructiva crónica; rol profesional; personal de salud.

Descritores: poluentes atmosféricos; incêndios florestais; desastres; aquecimento global; saúde pública; doença pulmonar obstrutiva crónica; papel profissional; pessoal de saúde.

Climate change and global warming are phenomena that are progressively affecting the planet. Temperature changes have been posing mayor threats for different domains of human society. One of these threats is related to health due extreme temperatures, and natural disasters. Thus, it is constituted as a global threat to biodiversity and the human population, since not only affects ecosystems equilibrium but increasing wildfires as consequence of increased

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temperatures and diminished precipitations. Moreover, wildfires have concentrated attention not only because of their ecological and environmental consequences but also for affecting production, economics, and health of people potentially exposed to environmental risks such fire, smoke, and others chemical products released from wood combustion process.

Wildfires have been steadily increased in recent decades, and are likely to continue according to the progress of climate change. Consequently, the impact of wildfire smoke on health will be increased in a near future.(1) Hence, it is to be expected that, knowing the increasing in frequency and intensity of extreme climate conditions, policies would be designed and implemented to prevent wildfires, along with public health strategies to coping smoke inhalation and to respond efficiently to their ravages.

Much of the understanding of the effects of wildfire smoke on health derives from studies on exposure to urban particles, principally fine particulate matter (PM2.5), derived from vehicular traffic and from other anthropogenic sources, like the use of fossil fuels for cooking and heating. There is already been reported an important burden to public health, in terms of frequency and economic cost of deaths and diseases related with these events.(2) Today, it is known that smoke from forest fires may increase dramatically the levels of PM2.5 with respect to periods when wildfires do not occur(3) and considering that PM2.5 originated from wildfires could have exceptionally high compositions or concentrations of specific chemicals that differ from that generated by other sources, it could also have a different response and outcomes on the exposed populations health. In this scenario, the knowledge gap on short- and long-term effects of exposure to wildfires will require multiple approaches and collaborative work to provide significant information on such exposure. For example, joint work among experts in monitoring air quality, wildfire smoke exposure modeling, toxicology, physiology, and epidemiology to seeking a better understanding in wildfires smoke impact on health.(4)

A review on the effects on health due to non-occupational exposure to wildfire smoke concluded that these fires have the potential of inducing an important burden to health, furthermore, proposing that because wildfires can occur with greater frequency and intensity due the effect of climate change, this burden may increase in the future.(3) Currently, sufficient evidence exists that the air contamination stemming from wildfires is associated consistently with respiratory effects, which can occur differently according to age and other sociodemographic factors.(5) A strong association exists between wildfires smoke exposure (PM2.5) and mortality due all causes, and respiratory morbidity. Specifically, association has been verified between this exposure and exacerbations of asthma and chronic obstructive pulmonary disease, bronchitis, and pneumonia.(6,7) Since the epidemiological data that linked exposure to smoke from wildfires with cardiovascular mortality and morbidity are mixed and inconclusive, further studies to establish its relation with cardiovascular morbidity and mortality in the population are needed.(3,6)

Although many countries have implemented policies and legislation to control environmental air contamination, including that in interior spaces, efforts to avoid and control wildfires and mitigate their consequences seem insufficient. Otherwise, key territorial factors envision that even if prevention policies exist, wildfires will continue occurring, hence, the focus should be on mitigating their effects.

From a public health approach, besides recognizing the consequences of this environmental exposure, it is important to differentiate who within the population are the individuals potentially most affected and the environments where increased risks to health may exist. This is how it is recognized that smoke from wildfires can have a significant impact on subgroups of vulnerable population that are more sensitive even with exposure to lower concentrations; among them, children and adolescents, individuals with respiratory or cardiovascular compromise, the elderly, pregnant women, and cigarette smokers.(8) Also, an impact exists on the safety of the population in zones surrounding the fires in roadways and air traffic due to reduced visibility in zones affected by wildfires. Identifying vulnerable communities to wildfires smoke exposure effects allow to prepare responses, increase resilience, and improve public health outcomes during fire activity. In this regard, tools have been designed to establish the population vulnerability like the Community Health Vulnerability Index based on factors known for increasing the risks of effects on health due to air contamination and wildfires smoke exposure. Thus, it has been possible to differentiate most vulnerable zones and communities and identify those with the potential to benefit most from mitigation strategies to minimize exposure to smoke and diminish the economic and health burden imposed on the population.(9) Similarly, the Center for Disease Prevention and Control (CDC) develops an on-line tool that uses short-term predictions and prognoses of the concentrations of wildfires smoke to integrate them with measurements of vulnerability at population level to identify groups at risk. To develop this tool, contribution was sought from all stakeholders involved from academic, federal, state, local, tribal, and territorial settings.(10)

Currently, we are witnessing global-scale disasters, which require countries with a shared policy with planetary reach. At to date of this article, the catastrophe in the Amazon has revealed the ecological and environmental scope, as well as the effect to human health by megafires, like that commented. Besides the direct deterioration of the affected zone, death of different species and destruction of their habitat, smoke could affect strongly global climate, modifying rain patterns and terrestrial radiation balance. This emergency recently moved leaders from seven countries in the Amazon to undersign the Leticia Pact that seeks a cooperation network upon disasters, articulating national systems on disaster prevention and response.(11)

In turn, at local level, policies aimed at preserving ecosystems to fires must also consider public health, requiring an intersector and comprehensive approach. For this, in addition to considering resources to fight wildfires, we must include prevention, territorial planning, and community work strategies.

As is other types of disasters, phases may be recognized in wildfires where nurses can act: mitigation, preparation, response, and recovery. Understanding these phases allow diminishing the effects of wildfires and increasing the community's resilience. Mitigation includes activities of health promotion, professional and public education on health effects due to wildfires, and the preparation for public health needs. Preparation refers to activities nurses carry out to help individuals, families, and communities to understand what they must do to protect their health and stay safe during a wildfire. Nurse responses to disasters consider the type of response needed, their professional roles, if dealing with a local disaster or not, their own preparation, and personal obligations. Finally, recovery seeks to help communities to return to functional levels as fast as possible –resilience-.(12)

In other scenario, have been proposed some interventions or actions that nurses must conduct from a clinical setting to avoid or minimize exposure to contamination during a wildfire and which look to: i) provide patients with knowledge and tools to avoid and/or manage wildfire smoke exposure; ii) minimize adverse effects of wildfire smoke exposure; iii) prepare and educate patients for future events of wildfire smoke.(8)

As it has been argued in this paper, wildfires have become more frequent and with greater severity. In response to this, planned and collaborative intersectoral interventions are required, among which are the actions of the health teams. The role of nursing in response to disasters has been evolved. Nowadays, training aimed to developing specialists and leaders to response efficiently and successfully these events are required, focusing care on vulnerable groups and communites during disaster response.

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Original article

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Influential Factors in Adherence to the Therapeutic Regime in Hypertension and Diabetes

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Influential Factors in Adherence to the Therapeutic Regime in Hypertension and Diabetes

Abstract

Objective. To determine the factors associated with adherence to the therapeutic regime in patients with hypertension and type 2 diabetes mellitus cared for in primary care centers. **Methods.** This was an analytical cross-sectional study, conducted with 500 patients from two institutions in Bucaramanga (Colombia). Adherence to the therapeutic regime was measured with the label of Nursing outcomes "Treatment Behavior: Illness or Injury" and the instrument "Factors that influence on adherence to pharmacological and non-pharmacological treatments" by Ortiz Suárez was used. **Results.** Factors affecting negatively adherence to the therapeutic regime were: belonging to the subsidized regime, never being able to read written information about the management of their disease, and never receiving information about benefits of the medications ordered by the physician. On the contrary,

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positive influence was noted by referring "never" to the following statements, which impacted positively on adherence: the diverse occupations you have in and out of the house hinder your following the treatment; when your symptoms improve, do you interrupt the treatment? previously, have you had difficulties in complying with your treatment and believe there are difficult-to-change customs about foods and exercises? **Conclusion.** Two socioeconomic factors and one related with the health system and staff affected negatively on adherence to the therapeutic regime, while four factors related with the therapy favored it. The factors identified could be used in the design of nursing interventions to improve adherence in this population.

Descriptors: treatment adherence and compliance; hypertension; diabetes mellitus, type 2; risk factors; cross-sectional studies.

Factores influyentes en la adherencia al régimen terapéutico en hipertensión y diabetes

Resumen

Objetivo. Determinar los factores asociados a la adherencia al régimen terapéutico en pacientes con hipertensión y diabetes mellitus tipo 2 en centros de atención primaria. **Métodos.** Estudio de corte transversal analítico, realizado en 500 pacientes de dos instituciones de Bucaramanga (Colombia). La adherencia al régimen terapéutico se midió con la etiqueta de Resultados de Enfermería "Conducta terapéutica: enfermedad o lesión" y se empleó el instrumento "Factores que influyen en la adherencia a tratamientos farmacológicos y no farmacológicos" de Ortiz Suárez. **Resultados.** Los factores que afectaron negativamente la adherencia al régimen terapéutico fueron: pertenecer al régimen subsidiado, nunca poder leer información escrita sobre el manejo de su enfermedad y nunca recibir información sobre beneficios de los medicamentos ordenados por el médico. Por el contrario, influyeron positivamente referir "nunca" a las siguientes afirmaciones, que impactaron positivamente la adherencia: las diversas ocupaciones que tiene dentro y fuera del hogar le dificultan seguir el tratamiento; cuando mejoran sus síntomas, ¿usted suspende el tratamiento?; anteriormente, ¿ha presentado dificultades para cumplir su tratamiento y cree que hay costumbres sobre alimentos y ejercicios difíciles de cambiar?. **Conclusión.** Dos factores socioeconómicos y uno relacionado con el sistema y equipo de salud afectaron negativamente la adherencia al régimen terapéutico, mientras que cuatro factores relacionados con la terapia la favorecieron. Los factores identificados podrían ser utilizados en el diseño de intervenciones para mejorar la adherencia en esta población.

Descriptores: cumplimiento y adherencia al tratamiento; hipertensión; diabetes mellitus tipo 2; factores de riesgo; estudios transversales.

Fatores influentes na aderência ao regime terapêutico em hipertensão e diabetes

Resumo

Objetivo. Determinar os fatores associados à aderência ao regime terapêutico em pacientes com hipertensão e diabetes mellitus tipo 2 atendidos nos centros de atenção primária. **Métodos.** Estudo de corte transversal analítico, realizado em 500 pacientes de duas instituições de Bucaramanga (Colômbia). A aderência ao regime terapêutico foi medida com a etiqueta de Resultados de Enfermagem "Conduta terapêutica: doença ou lesão" e se empregou o instrumento "Fatores que influem na aderência a tratamentos farmacológicos e não farmacológicos" de Ortiz Suárez. **Resultados.** Os fatores que afetaram negativamente a aderência ao regime terapêutico foram: pertencer ao regime subsidiado, nunca poder ler a informação escrita sobre o manejo da sua doença e nunca receber informação sobre benefícios dos medicamentos ordenados pelo médico. Pelo contrário, influíram positivamente referir "nunca" às seguintes afirmações, impacto positivamente a aderência: as diversidades ocupações que tem dentro e fora do lar lhe dificultam seguir o tratamento; quando melhoram seus sintomas, você suspende o tratamento; anteriormente há apresentado dificuldades para cumprir seu tratamento e acredita que há costumes sobre alimentos e exercícios difíceis de mudar. **Conclusão.** Dois fatores socioeconômicos e um relacionado com o sistema e equipamento de saúde, afetaram negativamente a aderência ao regime terapêutico, enquanto que quatro fatores relacionados com a terapia a favoreceram. Os fatores identificados poderiam ser utilizados no desenho de intervenções de enfermagem para melhorar a aderência nesta população.

Descritores: cooperação e adesão ao tratamento; hipertensão; diabetes mellitus tipo 2; fatores de risco; estudos transversais.

Introduction

The concept of therapeutic adherence was defined by the World Health Organization with a more inclusive vision, which highlights the diverse interdisciplinary recommendations that must be complied by patients with chronic disease and, additionally, evidences the patient's active participation during the disease process.(1) In this sense, it was agreed that therapeutic adherence corresponded to the "degree to which a person's behavior in relation with taking medications, following a dietary regime, or modifying life habits corresponds to recommendations agreed by a health care provider".(1) The low level of adherence to the therapeutic regime is well-known throughout the spectrum of chronic disease.(2) In developed countries, only 50% of the people who suffer from chronic disease comply with the prescribed treatment, while in developing countries this adherence may be lower because of the scarcity of resources and inequities in access to health services.(1,3)

Lack of adherence is attributed to multiple factors; according to the World Health Organization, five dimensions exist that constitute the Multidimensional Model of Adherence: health system and staff, therapy, disease, patient, and socioeconomic aspects.(1) Regarding arterial hypertension and type 2 diabetes mellitus (T2DM), non-adherence to the therapeutic regime constitutes a public health problem. In this respect, very variable figures have been reported of the prevalence of adherence to medications ranging between 24.1% and 92.7%(4) in patients with arterial hypertension and between 38.5% and 93.1%(5) in patients with T2DM. With non-pharmacological aspects, non-adherence is most common, thus, non-compliance frequencies have been found ranging between 33.2% and 25% in diabetic patients(6,7) and 68.8% in hypertensive patients,(8) while for dietary concerns, non-compliance has been reported between 88% and 44.8% in diabetic patients(6,7) and 30.9% in hypertensive patients.(8).

Bearing in mind the disease burden In arterial hypertension and T2DM and the low therapeutic adherence (on average 50%),(1) in the future it is expected that complications from these two pathologies to become the principal threats to public health resources globally(9). Research has been conducted to identify the factors associated to adherence to treatment,(10) however, most has focused on the aspect of pharmacological compliance, without measuring adherence to changes in lifestyle, like diet, physical activity, consumption of alcohol and tobacco, among others, of which evidence exists that its adhesion contributes to achieving the therapeutic objectives.(11,12) In this sense, the literature has indicated that nursing, as part of the health staff, plays a fundamental role in improving this problem, especially through education actions aimed at modifying lifestyles and understanding the disease.(13) Consequently, the aim of this study was to determine the factors associated with adherence to the therapeutic regime (pharmacological and non-pharmacological treatment) in patients with arterial hypertension and T2DM cared for in primary care centers in the city of Bucaramanga in Colombia.

Methods

Study design and population. An analytical cross-sectional study was conducted in 2013 in patients with medical diagnosis of arterial hypertension or T2DM belonging to cardiovascular risk programs from two primary care institutions, one of public nature from the city of Bucaramanga-Colombia. The inclusion criteria involved individuals over 18 years of age, totally independent of their care and actively attending cardiovascular risk programs. The study excluded pregnant women, individuals with altered mental sphere, with chronic or severe alterations, and with communication limitations. To calculate the sample size, the study took as reference an available population of 7,000 people, an expected adherence to the therapeutic regime of 50%, 95% confidence interval, a design effect of 1, and losses due to non-response rate of 20%, obtaining as a result a sample size of 438 people. Probabilistic sampling (simple random) was used for sample selection.

Measurements. The work assessed sociodemographic and clinical factors, like age, sex, marital status, socioeconomic level, distance between the place of residence and the health care center, social security regime, occupation, disease suffered, time registered with the cardiovascular risk program, number of hospitalizations within the last year, short-form Charlson Comorbidity Index,(14) risk of general cardiovascular disease at 10 years, according to Framingham,(15) and number of pills taken per day. This information was gathered by reviewing the participants' medical records and confirmed during the application of self-report instruments. Adherence to therapeutic regime was measured with the label Nursing Outcomes Classification "Treatment Behavior: Illness or Injury",(16) which evaluates compliance with the medication regime, diet and activity prescribed, supervision of the therapeutic effects and avoidance of behaviors that potentiate the pathology. This is a self-report instrument with dichotomy response scale (yes/no), comprised of 13 items grouped into five dimensions. Total scores vary from 0 to 13 points, indicating that higher scores mean greater adherence and vice versa. The construct validity and test-retest reproducibility of said instrument yielded as a result a total explained variance of 67.62%, Cronbach's alpha internal consistency of 0.60, and a test-retest reproducibility of 0.63. Factors related with adherence were measured with the instrument "Factors that influence on adherence to pharmacological and non-pharmacological treatments",(17) which evaluates factors related with the following aspects: (I) socioeconomic; (II) provider: health system and staff; (III) therapy, and (IV) patient. This instrument can be self-completed or completed with aid; it has a Likert-type response scale with three options (never / sometimes / always) and it is comprised of 24 items grouped into four dimensions that explain 45% of the variance and report a Cronbach's alpha of 0.60.

Statistical analysis. The total score of adherence to the therapeutic regime did not show normal distribution (Shapiro-Wilk test, p <0.001); thereafter, it was described with the median, first and third quartile. A bivariate analysis was performed between the total score of adherence to treatment (quadratic transformation) and the sociodemographic and clinical variables and factors influencing adherence to the therapeutic regime through linear regressions. A multivariate analysis was carried out, an automated stepwise backward regression methodology was used; the variables obtaining a value of p ≤0.20 in the bivariate analysis were included in the multiple linear model, variables with p ≤0.05 were retained in the model. No variable was considered as the main exposure. The original scale of the influential factors instrument has three response options (never/ sometimes / always); for this analysis, the categories sometimes and always were grouped as reference category and never as risk category. Once the model was determined, the multi-collinearity was evaluated with thee variance inflation factor (VIF), considering collinearity with VIF>10. Model specification was evaluated with linktest, indicating adequate specification with non-significant hatsq ($p \geq 0.05$). The assumptions of the linear model were assessed: linearity was evaluated with studentized residuals, the normality of the residuals was explored with the Q-Q-plot graphic, P-P plot and the Shapiro Wilk test; homoscedasticity with the Cook-Weisberg test, fulfilling all the assumptions of the linear model.

Ethical considerations. This study was approved by an institutional research ethics committee and was approved by the participating institutions. The research subjects provided a previously written informed consent. It also received written authorization by the author of the instrument "influential factors in adherence to pharmacological and non-pharmacological treatments" for use in this research.

Results

In all, 500 patients were studied (69.4% had arterial hypertension, 9.0% DM, and 21.6% had both pathologies). The median age of the population was 68 years of age (Q1=59 years; Q3=75) and 69.0% were women; 52.2% were married/common law; 58% were in the low socioeconomic level; 65% had primary education; 44.8% were housekeepers. The median of pills taken by patients per day was five pills (Q1=3; Q3=7 pills). Lack of comorbidity was identified in 90.0%, according to the Charlson index 12% and 48.47% had high and very high risk of cardiovascular disease at 10 years, according to Framingham.

The median of the total score of adherence to the therapeutic regime was 10 over a total of 13 points (Q1=9; Q3=11) (total score of adherence with quadratic transformation, mean of 99.5±37.5 points). The bivariate analysis with sociodemographic and clinical factors shows that having a low socioeconomic level and being in the subsidized health regime diminish the adherence score, while a greater time being registered in the cardiovascular risk program increases the level of adherence (Table 1).

The socioeconomic-type influential factors that do not favor adherence include not having the economic resources to travel to the consultation site, not being able to read written information about managing their disease, and not having support from their families or close friends to comply with their treatment; on the other hand, when people reported that changes in diet were not made difficult due to the high cost of foods recommended, this was associated with increased adherence. Regarding factors related with the health system and staff, when patients stated that the people caring for them never respond to their concerns and difficulties with respect to their treatment; this was associated with a decreased level of adherence. With regards to the influential factors related with the therapy, it was evident that the majority of the factors affect positively on adherence, and on factors related with the patient; people who never manifest interest for knowing about their health condition and how to care for themselves had lower adherence (Table 2).

Table 1. Sociodemographic and clinical factors of adherence to the therapeutic regime. Bivariate analysis (*n*=500)

Adherence to the therapeutic regime	β	95% CI	*p*-value
Age (years)	0.02	-0.27; 0.31	0.889
Sex			
Female	Reference		
Male	4.14	-2.98; 11.27	0.254
Marital status			
Single	Reference		
Married	8.14	-1.36; 17.65	0.093
Common law	-0.90	-13.22; 11.42	0.886
Divorced/Separated	-8.84	-23.74; 6.06	0.244
Widowed	3.36	-7.04; 13.77	0.525
Socioeconomic level			
Medium/high	Reference		
Low	-7.38	-14.04; -0.72	0.030
Distance from place of residence/care center (minutes)	0.07	-0.12; 0.26	0.473
Social security regime			
Contributive	Reference		
Subsidized	-16.29	-22.74; -9.84	0.001
Occupation			
Employed	Reference		
Independent	-5.32	-20.61; 9.97	0.495
Unemployed/laid off	-2.68	-18.01; 12.64	0.731
Pensioned/Retired	11.38	-3.43; 26.20	0.132
Home/Housekeeper	-1.96	-15.61; 11.68	0.778
Disease suffered			
Hypertension	Reference		
Diabetes mellitus	-9.55	-21.23; 2.12	0.109
Hypertension and diabetes mellitus	-0.59	-8.71; 7.53	0.886
Time registered in the cardiovascular risk program (months)	0.28	0.10; 0.47	0.003
Number of hospitalizations in the last year (times)	-1.27	-5.50; 2.96	0.556
Charlson index (Continuous)	-1.27	-5.85; 3.31	0.586
Risk of general cardiovascular disease at 10 years (Framingham)	-0.13	-0.50; 0.23	0.458
Number of pills/day	0.86	-0.47; 2.19	0.206

*The total score of adherence was used with a quadratic transformation.

Table 2. Influential factors (socioeconomic, provider, therapy and patient) in adherence to the therapeutic regime. Bivariate analysis (*n*=500)

Adherence to the therapeutic regime	β	95% CI	*p*-value
Socioeconomic			
Family has economic availability to meet basic needs (diet, health, housing, education).	-4.79	-24.14; 14.55	0.626
Can afford medications.	3.03	-4.48; 10.56	0.428
Has economic resources to travel to the consultation.	-10.32	-20.09; -0.54	0.039
Changes in the diet are difficult due to the high cost of the foods recommended.	8.47	1.78; 15.16	0.013
Can read written information on managing their disease.	-14.63	-21.50; -7.76	0.001
Have support from their families or close acquaintances to comply with their treatment.	-11.16	-19.39; -2.93	0.008
Provider: Health system and staff			
People caring for them respond to their concerns and difficulties with respect to their treatment.	-20.61	-39.28; -1.94	0.031
Are aware that their physicians control if they are following the treatment by the questions they make.	-12.20	-25.45; 1.05	0.071
Receives information about the benefits of the medications ordered by their physicians.	-5.40	-12.80; 2.00	0.152
Receives guidance on how to adjust schedules to the medications according to their daily activities.	-0.17	-9.99; 9.64	0.972
In case you failed in your treatment, would your physician and nurse understand your motives?	-5.70	-12.80; 1.39	0.115
The physician and nurse give you explanations with words you and your family understand.	-15.63	-33.30; 2.03	0.083
The physician and nurse have explained to you what results the treatment you are getting will have on your health.	0.46	-7.17; 8.11	0.905
Do you feel the physician and you coincide in the hope of improving with the treatment and the changes being made in your habits.	-7.21	-21.10; 6.66	0.308
The therapy			
The diverse occupations you have in and out of the house make it difficult to follow the treatment.	32.09	18.69; 45.48	0.001
The distances from your house or work to the consultations hinder compliance with the appointments.	6.53	-2.27; 15.34	0.146
Have doubts about how to take their medications, regarding the amount, schedules, and the relationship with foods.	15.83	4.71; 26.95	0.005
When your symptoms improve, do you interrupt the treatment?	20.81	10.15; 31.47	<0.001
Have you previously had difficulties to comply with your treatment?	21.22	10.66; 31.78	<0.001
Do you believe there are customs about foods and exercise that are difficult to change?	10.87	4.00; 17.75	0.002
The patients			
Are convinced the treatment is beneficial and that is why they continue with it.	-31.01	-67.98; 5.94	0.100
Are interested in knowing about their health condition and how to care for themselves.	-48.81	-91.35; -6.27	0.025
Believe it is important to follow their treatment to improve their health.	-22.95	-59.96; 14.05	0.224

The multivariate analysis found seven factors associated with adherence to the therapeutic regime; three of which affect negatively on adherence, two of them related with socioeconomic aspects: *belonging to the government subsidized regime* compared to the so-called contributive (private) regime and *never being able to read written information about managing their disease;* the third was related with the health system and staff: *not receiving information about the benefits of the medications ordered by the physician.* Finally, when patients state "never" to each of the following four statements, adherence is favored positively: *the diverse occupations in and out of the house hinder their following the treatment; when your symptoms improve, do you interrupt treatment; have you previously had difficulties to comply with your treatment; and do you believe there are customs about foods and exercise that are difficult to change* (Table 3).

Table 3. Influential factors (socioeconomic, provider, therapy, and patients) on adherence to the therapeutic regime. Multivariate analysis (*n*=500)

Adherence to the therapeutic regime	β	95% CI	*p*-value
Socioeconomic			
Social security (Subsidized vs. Contributive)	-15.43	-22.83; -8.03	<0.001
Can read written information about managing their disease	-8.16	-15.56; -0.76	0.031
Provider: Health system and staff			
Receives information about the benefits of the medications ordered by their physician	-8.72	-16.15; -1.29	0.022
The therapy			
The diverse occupations in and out of the house hinder their following the treatment	17.36	3.92; 30.79	0.011
When your symptoms improve, do you interrupt the treatment?	12.64	2.34; 22.94	0.016
Have you previously had difficulties to comply with your treatment?	19.52	8.86; 30.18	<0.001
Do you believe there are customs about foods and exercise that are difficult to change?	7.26	0.73; 13.80	0.029

Discussion

Non-adherence is a global phenomenon of serious consequences and it is present in almost every chronic disease. It is related with multiple aspects, among them socioeconomic, the health system and staff, therapy, the disease, and patients, which makes it complex to framework and intervene.(1) The principal findings of the study permit showing that factors related specifically with therapy affect the total score of adherence to the therapeutic regime, among them aspects concerning diverse occupations, antecedents of difficulties, interruption of treatment, and beliefs about eating habits and exercise; followed by socioeconomic factors and system factors, like the social security regime, not being able to read information about the disease, and not receiving information about the benefits of the medications ordered by the health providers.

This study showed that not being able to read written information about managing the disease and not receiving information about the benefits of the medications ordered by the physician were associated with low levels of adherence; these two aspects are highly related with the level of schooling and knowledge. For this study, the population was principally characterized by having a low (58.0%) and medium (41.4%) socioeconomic level, likewise, 11.0% was illiterate and 65.4% only had primary school education. These results agree with the findings described by Castaño-Castrillón *et al*.,(18) who, with 200 hypertensive patients cared for in different low-complexity healthcare centers in the city of Manizales – Colombia, measured adherence with the questionnaire by Martín-Bayarre-Grau (MBG) and found low levels of adherence associated with low educational level and low knowledge of the pathology. Also, Ghembaza *et al*.,(19) found a positive relationship between patients' knowledge about the complications of hypertension and adherence ($p<0.003$; OR=0.46) in a study conducted with 453 patients from a public primary care center in the department of Tlemcen in Algeria. Likewise, Rodríguez-Abt *et al*.,(20) in 2017, investigated the association between knowledge about hypertension and adherence to the treatment (MBG measure) in 340 hypertensive patients cared for in cardiology consultation in a National Hospital in Lima - Peru, and determined that patients with low knowledge of hypertension have 1.5 times more probability of having partial adherence to the treatment than patients with high knowledge. Multiple studies have evidenced the relationship between the level of knowledge and adherence to the treatment in both hypertension and diabetes mellitus.(7,21)

With respect to improving symptoms and interrupting the treatment, it was found that not interrupting the treatment, even if symptoms improve, favors adherence to the treatment. In this sense, a systematic review of qualitative research on the perspectives of hypertension and adherence to medications, which synthesized information from 59 articles (53 of them qualitative) and studies derived from 16 countries, evidenced that participants reduce or interrupt intentionally the treatment without consulting their treating physician; commonly, participants perceive that their blood pressure improves when symptoms diminish or when they are not stressed, and that the treatment is not necessary at that those moments.(22)

In addition, it was found that belonging to the subsidized regime is associated negatively with adherence to treatment, which may be because people belonging to this regime are of scarce economic resources, which hinders compliance with the therapeutic regime, for example, adoption of an appropriate diet according to their health condition, frequent follow-up visits with the treating physician, and the need to purchase medications when these are not readily dispensed by the health provider. In this respect, the scientific literature indicates that lack of economic resources do not favor adherence, given that, for example, patients stop taking medications due to their high costs and stop attending their appointments, among others.(5,7,21,22)
Other relevant aspects were related with stating "never" having had prior difficulties to comply with the treatment, or diverse occupations in and out of the house that hinder their following the treatment, which was associated positively with adherence. In that respect, some studies have reported that being busy keeps patients from taking their medications, engaging in exercise, or attending control appointments.(7,22) Likewise, it was found that if they never "believe that customs exist about foods and exercise that are difficult to change", this favors adherence positively. In this regard, it has been documented that the attitudes of the individuals, their sex, lack of motivation, beliefs, being busy, and the sense of self-care, among others, influence adherence significantly and, hence, on the adoption of healthy behavioral changes.(7, 23,24)

Among the strengths of this study, we highlight the measurement of adherence to treatment, pharmacological and non-pharmacological, in patients with arterial hypertension and T2DM. Most studies only evaluate adherence to pharmacological treatment. Similarly, the study highlights the size and probabilistic sample selection, which makes it representative and control selection bias. Further, the influential factors of adherence were studied framed within a model scientifically known and established by the World Health Organization (Multidimensional Model of Adherence). However, some limitations to be noted emerge, having considered only patients who were active in cardiovascular risk programs, which could represent a population with higher adherence with respect to those who are not active. In addition, as known, self-report instruments are easy and practical to use and some have been validated against objective measurement methods in elderly populations with hypertension and Parkinson's disease, nevertheless, they have the disadvantage of overestimating the measurement of adherence and it is likely that each method varies in its performance, according to the characteristics of the population studied.(10)

Regarding the implications of this study for the practice, for health services providers and for health professionals, it is important to know the factors that influence on the behavior of adherence of individuals with processes of chronic disease, like arterial hypertension and T2DM, given that these affect people's behaviors, leading them to not complying strictly with the therapeutic regime prescribed and, thereby, not complying with the therapeutic objectives. In this sense, nursing – as part of the health staff in primary care and within the current role highlighted by the Comprehensive Health Care Model in Colombia – can lead individual and collective actions to maintain health and diminish degrees of disability in people with these pathologies. Similarly, the influential factors identified in this study could be useful to design future studies of nursing intervention aimed at improving adherence to the therapeutic regime in this population, a key aspect in optimizing the use of resources, an action that is part of the responsibilities of nursing management. (25)

To conclude, this study identified the therapy, socioeconomic, and health system/health staff factors associated with measuring adherence to the therapeutic regime (pharmacological and non-pharmacological) in patients with arterial hypertension and T2DM; three of them affecting adherence negatively (subsidized social security regime, not being able to read written information about managing the disease, and not receiving information about the benefits of the medications ordered by the health providers) and four factors favoring adherence (not having diverse occupations, not interrupting treatment even if symptoms improve, not having antecedents of difficulties to comply with the treatment, and not believing that customs exist about foods and exercises that are difficult to change). The influential factors identified in this study could be useful to design future studies of nursing intervention aimed at improving adherence to the therapeutic regime in this population.

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Original article

Parental Competence in Parents of Children with Autism Spectrum Disorder: A Systematic Review

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Parental Competence in Parents of Children with Autism Spectrum Disorder: A Systematic Review

Abstract

Objective. This work aimed to define and assess the parental competence of parents with autistic children. **Methods.** This study was conducted through a systematic review. The search was done in databases, including Cochrane Library, PubMed, CINAHL, Science Direct, Wiley Scopus, Pro Quest, Web of Science, Elsevier, Google Scholar, and Ovid by using keywords, like "children, autism, parenting, competence, and scale" from 1974 to 2019. Inclusion criteria were that the article should be quantitative, qualitative, and mixed-method studies in nursing, psychology, and medicine; the full text of the article should be available and the article should be in English or Persian. **Results.** Competence among these parents was affected by more factors and they reported lower competence compared to other parents. Moreover, only two instruments were available to assess parenting

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competence, which were not designed for parents of autistic children. Variables and factors affecting parenting competence has not been examined well in parents of children with autism, and no specialized instrument is available to evaluate parenting competence in parents with autistic children either. **Conclusion.** Although parental competence has been known as the main element to improve the quality of care, it has been studied restrictively from the viewpoints of the parents of children with autism. Therefore, the development of this concept is highly essential for clinical application and investigating its outcomes support.

Descriptors: autistic disorder; child; parents; systematic review.

Competencia parental de padres de niños con trastorno del espectro autista: una revisión sistemática

Resumen

Objetivo. Evaluar la competencia parental de los padres con hijos autistas. **Métodos.** Revisión sistemática narrativa. La búsqueda se realizó en las bases de datos de la Biblioteca Cochrane, PubMed, CINAHL, Science Direct, Wiley Scopus, ProQuest, Web of Science, Elsevier, Google Scholar y Ovid, mediante el uso de las palabras clave "niños, autismo, crianza, competencia y escala". Los criterios de inclusión fueron: artículos originales o de revisión publicados entre 1974 a 2019; estudios cuantitativos, cualitativos o de métodos mixtos en las disciplinas de enfermería, psicología o medicina, y estar disponible en texto completo en inglés. **Resultados.** La competencia de los padres de niños con trastorno del espectro autista fue menor en comparación con padres de niños sin este trastorno. Existen dos escalas para la evaluación de la competencia parental, pero no se diseñaron para su evaluación en padres de niños autistas. Los factores que afectan la competencia parental tampoco se han examinado exclusivamente para estos padres. **Conclusión.** Aunque se sabe que la competencia de los padres es un elemento primordial para mejorar la calidad del cuidado del niño con autismo, el tema se ha estudiado de manera restrictiva. Es necesario el desarrollo de este concepto para la aplicación en la práctica clínica y para la investigación de sus resultados.

Descriptores: trastorno autístico; niño; padres; revisión sistemática.

Competência parental de pais de crianças com transtorno do espectro autista: uma revisão sistemática

Resumo

Objetivo. Avaliar a competência parental dos pais com filhos autistas. **Métodos.** Revisão sistemática narrativa. A busca se realizou nas bases de dados da Biblioteca Cochrane, PubMed, CINAHL, Science Direct, Wiley Scopus, ProQuest, Web of Science, Elsevier, Google Scholar e Ovid, mediante o uso das palavras clave "crianças, autismo, criança, competência e escala". Os critérios de inclusão foram: artigos originais ou de revisão, publicados entre 1974 a 2019, ser estudos quantitativos, qualitativos ou de métodos mistos, nas disciplinas de enfermagem, psicologia ou medicina, e estar disponível em texto completo em inglês. **Resultados.** A competência dos pais de crianças com transtorno do espectro autista foi menor em comparação com pais de crianças sem este transtorno. Existem duas escalas para a avaliação da competência parental, mas não foram desenhadas para sua avaliação em pais de crianças autistas. Os fatores que afetam a competência parental tampouco se hão examinado exclusivamente para estes pais. **Conclusão.** Embora se sabe que a competência dos pais é um elemento primordial para melhorar a qualidade do cuidado da criança com autismo, o tema se há estudado de maneira restritiva. É necessário o desenvolvimento deste conceito para a aplicação na prática clínica e para a investigação de sus resultados.

Descritores: transtorno autístico; criança; país; revisão sistemática.

Introduction

Autism is one of the most important developmental disorders, which severely affects both parents and children.(1) This disorder imposes great physical, mental, and social pressures on families, particularly parents,(2) and affects various dimensions of their lives.(3) These parents, especially mothers, try to adapt with the painful events and the care burden and seek support from various resources.(4) Hence, the healthcare providing is required to identify the needs and problems of these parents and help them to do their parenting roles well.(5) In order to identify the problems of parents of children with autism, in recent years many studies have focused on the assessment of stress level and compatibility strategies in parents of autistic children.(6) These studies, in fact, aimed to find strategies for reducing the impacts of these children on other family members, particularly mothers(7) The results of these studies indicated that such mothers had lower health status, higher levels of stress, and lower self-efficacy and parenting competence compared to mothers with healthy children as well as those with children suffering from other disorders.(8,9) Although some studies have examined parental self-efficacy among parents of children with autism, parental competence is more comprehensive and broader than parental self-efficacy.(10) Some studies have attempted to define the concept of parental competence in parents of children with normal growth and development,(11,12) however the systematic review revealed that this concept is not explained in the parents of children with autism; when parents face their children's severe conditions, their competence will be significantly affected by their children's sickness and other background factors.(13,14) Also according to several studies, parental competence in these parents are influenced by more factors than the normal children's parents.(13-15)

It is important that nurse's awareness of the effective factors in parenting competence among parents of autistic children that they can take basic steps in identifying the problems of these parents, promoting parenting competence and subsequently promote the quality of life of parents and the child with autism. In addition, definition, dimensions, and effective factors of parenting competence are not established well in such parents. The aim of the present study is to answer the question, which is to define and assess the parental competence of the parents with autistic children?

Methods

The present study is a comprehensive systematic review of the available literature on parental competence among parents of autistic children. The applied approach to systematic review is based on Cochrane's guideline which consists of topic selection, inclusion criteria, search strategy, selection of studies, evaluation of the quality of articles, data collection, analysis and conclusion.(16) The entire articles related to parental competence were published over the past forty years, from 1974 to 2019, and were checked electronically. The collected resources based on publication year, country of origin, type, research type and domains have been summarized in Table 1.

Table1. Summary of the collected resources

Variable	*n* (%)
Year of Publication	
1974-2000	11 (24.44)
2001-2010	27 (60.00)
2011-2019	7 (15.56)
Country of origin	
Iran	5 (11.11)
United States	11 (24.44)
Canada	7 (15.56)
United Kingdom	9 (20.00)
Australia / New Zealand	6 (13.33)
Others	7 (15.56)
Reference type	
Best practice implementation article	31 (68.88)
News brief	8 (17.78)
Commentary/letter to editor/editorial	5 (11.11)
Book/book review	1 (2.23)
Domain	
Clinical	35 (77.78)
Educational	6 (13.33)
Theoretical/conceptual	4 (8.89)
Research type	
Quantitative	30 (66.67)
Qualitative	10 (22.22)
Mixed	5 (11.11)

Inclusion criteria. The articles related to parental competence published between 1974 and 2017 were examined by the researchers. The following criteria were used for inclusion: 1) The article should be original and have the qualities of a review study; 2) The full text of the article should be available; 3) The article should be in English or Persian; 4) The keywords should be included in the title/abstract of the article.

Strategy. In the present study, the following databases were used for searching articles: Cochrane Library, PubMed, CINAHL, Science Direct, Wiley Scopus, Request, Web of Science, Elsevier, Google

Scholar, and Ovid. Research was performed using the search operators OR and AND. In addition, the keyword control “Mesh”, which is available in PubMed, was used to find words related to the subject of the study. The following keywords were used individually and in combination for the search: Competence, qualification, ability, authority, autism, children with autism, parents, caregiver, parenting competence, parents with autistic children, and parental competence scale.

Selection of articles. Initially, three of the researchers individually made a list of the titles and abstracts of all the articles collected from the databases. Subsequently, the articles which appeared on the list more than once were omitted. Next, the abstracts were carefully reviewed and irrelevant articles were omitted. The remaining articles were thoroughly examined and evaluated. Eventually, the articles which addressed the questions raised in the present study were included in the systematic review.

Selection of articles for analysis. 353 relevant articles were found in the databases: 67 articles from Web of Science, 15 articles from Cochrane Library, 72 articles from PubMed, 32 articles from Cinahl, 75 articles from Google Scholar, 25 articles from Ovid, 21 articles from Science Direct, 22 articles from Scopus, 13 articles from Elsevier, and 11 articles from ProQuest. After a review of the titles of the articles, 101 articles were omitted due to repetition. Subsequently, 252 Papers evaluated by the title and abstract according to the inclusion and exclusion criteria, 200 papers were omitted because they assessed other concept in parent’s children with autism and did not assesse parenting competence, also full text 52 of the retrieved papers were concisely assessed, excluded 7 articles such as full text written in non-English language. Finally, 45 articles remained to be thoroughly examined and reviewed.

Results

Out of the 350 articles selected in the first stage only 45 dealt with the definition of parenting competence and evaluation of this concept in parents with autistic children. Among these articles, 34 were quantitative and 11 were qualitative. Additionally, 11 articles concerned the definition of competence and parenting competence, 25 involved the effective factors in parenting competence, particularly in parents of autistic children, 6 had assessed parenting competence in such parents and 3 articles developed appropriate instruments for evaluation of parenting competence. There were high risks of bias in 31 studies (mainly due to the design), moderate risks in 2 studies and weak risks in 5 studies. (Figure 1)

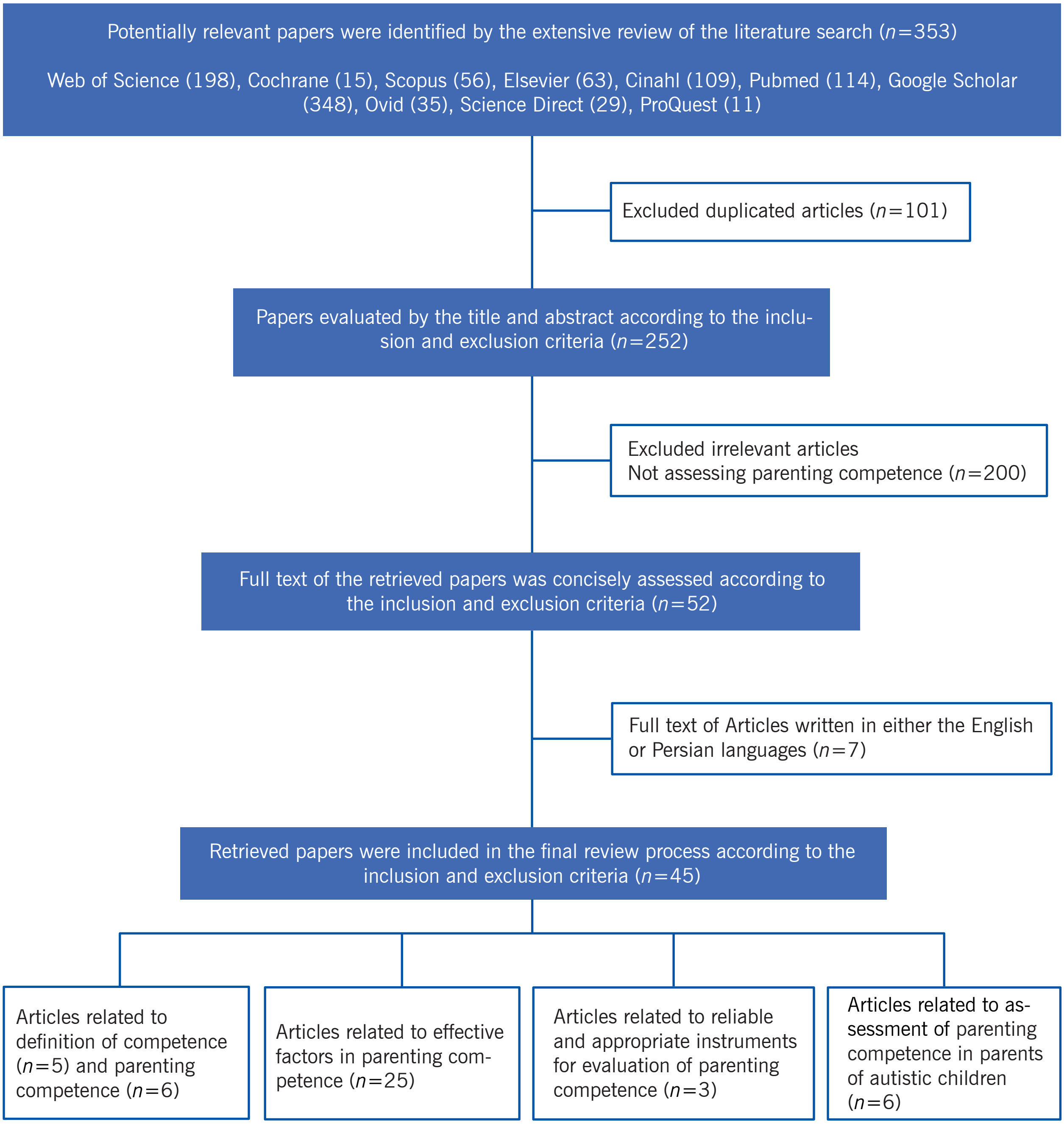

Figure 1. Flow diagram of the selection process for the study

What is the meaning of parenting competence?

Review of the literature indicated that competence is an expanded concept(17) with various meanings depending on backgrounds, conditions, domains, and individual characteristics.(18) Therefore, no global definition can be presented for competence.(17,18) Indeed, studies on assessment of parenting competence have provided various definitions for this concept.(11,19) For instance, Nair *et al*.(20) defined parenting competence as parents' ability to provide care without asking others for help. In addition, Montigny *et al*.(21) conducted a study on analysis of maternal self-efficacy and stated that competence and self-efficacy were inter-related but different. Shin *et al*.(11) also disclosed that maternal sensitivity was related to, but different from maternal competence.

From psychological point of view, competence is defined as sufficient knowledge and skills for successful and effective performance of tasks.(19,22) On the other hand, Pridham *et al*.(23) defined parenting competence as the knowledge, skills, problem solving ability, and activity for child care, with knowledge and skills being more important compared to other dimensions. Mercer(24,25) also defined maternal competence as the ability to perform maternal roles through interaction with microsystems, particularly the family. Mondell *et al*.,(26) too, defined parenting competence as self-efficacy, trust in interpersonal relationships, and compatibility with parental roles. However, no studies have been conducted on this concept in parents of autistic children.

What factors affect parenting competence in parents with autistic children?

The results of the studies demonstrated that parenting competence could vary depending on parents' and children's characteristics.(27) However, it was affected by interaction with professionals,(28) acquiring skills in child care,(28,29) ability to recognize the child's reactions,(29,30) parents' childhood experiences,(29) mental health,(29,31) age,(29,32) self-efficacy,(33,34) and parents' self-confidence.(23) Among these factors, parents' self-efficacy and self-confidence were two important predictors of parenting competence.(23,35,36)

The findings of the studies on parents with autistic children revealed that stress, depression, familial and social support, parents' mental and physical health, feeling of guilt due to child's disease, participation in care programs, and being supported by professionals were effective in self-efficacy and subsequently parental competence of parents with autistic children.(37,38) On the other hand, other studies indicated that parents' self-efficacy had an impact on their parenting behaviors. It is evident that parents' behaviors and competence could, in turn, affect children's social, emotional, and educational growth and development.(2,32,39) Accordingly, parents with higher self-efficacy showed more responsibility, kindness, sympathy, and attempt for developing appropriate behaviors in their children and, as a result, were more competent to take care of their children.(40-42)

What are appropriate and reliable instruments for the evaluation of parenting competence?

To evaluate each concept, it is essential that there be a valid instrument(43) Since self-efficacy is one of the main predictors of parenting competence,(23,35,36) parental self-efficacy questionnaires were used to assess parenting competence in most studies.(30,43,44) However, parenting competence is rather wider in comparison to parental self-efficacy(21) and cannot be judged by the mere assessment of self-efficacy. The findings revealed three main scales for the evaluation of parenting competence, namely Parenting Sense of Competence Scale, Sense of Competence Scale of the Parenting Stress Index and parental competence scale in parents of children with autism.(40,45,46) Gibaud-

Wallston *et al*.(40) designed Parenting Sense of Competence Scale in 1977. This scale contains two dimensions, namely self-efficacy, knowledge, and skills (8 items); and satisfaction, comfort, and worthiness (9 items). The items can be answered through a 6-point Likert scale ranging from completely agrees to completely disagree. It should be noted that all items receive equal scores, and higher scores represent higher competence and self-confidence. This scale was first used in 100 parents to 10-week-old neonates born through natural vaginal delivery. The reliability coefficient was reported to be 0.80 for the whole scale and 0.69 and 0.80 for self-efficacy and satisfaction dimensions, respectively.

Abidin *et al*.(45)designed Sense of Competence Scale of the Parenting Stress Index in 1990. This scale consists of 120 5-option questions including 101 main and 19 voluntary items. The items are further divided into three categories: childhood (6 items), parental (7 items), and life stress (1 item). Childhood scales include adaptability (11 items), receptivity (7 items), eagerness (9 items), creativity (5 items), inattention and hyperactivity (9 items), and empowerment (6 items). Besides, parental scales include depression (9 items), attachment (7 items), parental roles limitations (7 items), feeling of competence (13 items), social isolation (6 items), relationship with spouse (7 items), and parents' health (5 items). Finally, life stress as the voluntary scale contains 19 items. Scores higher than the 75th percentile represent more problems and higher stress levels.

Mohammadi *et al*.(2) designed mixed-method study that developed and psychometrically of parental competence scale in parents of children with autism in 2018. This scale has two dimensions including: adapting with the present situation (9 items) and excellence in care (16 items). The parental competence scale demonstrated acceptable psychometric properties. Therefore, this scale can be used for assessing parental competence in parents of children with autism.(46)

What instruments have been used to evaluate parental competence in parents of children with autism?

According to the results, seven articles had evaluated parenting competence in parents with autistic children using Parenting Sense of Competence Scale and Sense of Competence Scale of the Parenting Stress Index.(43,47-51) The findings of these studies indicated that autistic children's behavioral problems affected the parents' satisfaction regarding parental roles, self-efficacy, social interactions, fatigue, and parenting competence. However, none of these factors could predict parents' satisfaction level, self-efficacy, and parenting competence (Table 2).

Table 2. Studies conducted on evaluation of parenting competence in parents with autistic children

Reference	Description
43	**Scale:** Parenting Sense of Competence Scale (PSOC) **Authors, year:** Sarabi Jamab *et al*., 2011 **Sample characteristics:** 21 mothers of preschool children with autism (aged 3-7 years) **Components of the Measure:** 16 items; general measure **Psychometrics:** Cronbach's α=0.57 **Results:** Parents training caused no increase in their self-efficacy, satisfaction, and parenting competence.
47	**Scales:** The Parenting Stress Index (PSI) **Authors, year:** Baker-Ericzen *et al*., 2005 **Sample characteristics:** parents of 37 children with Autism Spectrum Disorders (ASD) and 23 typically developing children (TDC). **Components of the Measure:** 120 items; domain-specific measure; The Child Domain, The Parent domain. **Psychometrics:** Cronbach's α=0.92. **Results:** Parents with autistic children reported higher stress levels compared to those with normal children. Nevertheless, mothers with autistic children showed a significant reduction in their stress in relation to their children, not parenting stress. They also noted that children's social skills were the most important factor affecting their stress levels. However, no significant difference was observed in fathers' stress levels in child-related and parenting dimensions.
48	**Scale:** The World Health Organization Quality of Life Assessment-BREF self-administered instrument (WHOQOL-BREF) **Authors, year:** Dardas *et al*., 2014. **Sample characteristics:** 184 parents of children with Autistic Disorder. **Components of the Measure:** 26 items; domain-specific measure; (physical, psychological, social, and environmental health) and two individual items about an individual's overall perception of QOL and health. **Psychometrics:** Cronbach's α=0.67-0.93. **Results:** The results showed no significant difference between mothers and fathers with autistic children regarding physical, mental, social, and environmental health. Moreover, parents' quality of life was significantly associated with stress, adaptation strategies, and demographic features.
49	**Scale:** Parenting Sense of Competence Scale (PSOC) **Authors, year:** Giallo *et al*., 2011 **Sample characteristics:** 59 Parents of children with ASDs aged between 2 and 5 years **Components of the Measure:** 16 items; general measure. **Psychometrics:** Cronbach's α=0.75. **Results:** Mothers of autistic children reported higher fatigue levels compared to those with normal children. Additionally, mothers' fatigue was associated with age, occupation, and number of autistic children in the family. On the other hand, a significant relationship was found between parents' self-efficacy and fatigue, depression, anxiety, low-quality sleep, and need for social support. However, none of these factors could predict satisfaction level and self-efficacy in parents with autistic children.

Table 2. Studies conducted on evaluation of parenting competence in parents with autistic children (Cont.)

Reference	Description
50	**Scales:** Parenting Sense of Competence Scale (PSOC) **Authors, year:** Rezendes *et al*., 2011 **Sample characteristics:** 140 mothers of children between the ages of 3 and 16 with Autism Spectrum Disorders (ASDs) **Components of the Measure:** 16 items; general measure. **Psychometrics:** Cronbach's α=0.69. **Results:** Parenting stress was affected by the relationship between children's behavioral problems and parents' self-efficacy. On the other hand, parents' self-efficacy was associated with the relationship between parental stress and depression and anxiety. Accordingly, behavioral problems increased parents' stress levels, decreased their self-efficacy, and increased their anxiety and depression.
51	**Scales:** Parenting Sense of Competence Scale (PSOC) **Authors, year:** Rodriguez *et al*.,1992 **Sample characteristics:** Fathers of 20 autistic, 20 Down syndrome, and 20 developmentally normal children **Components of the Measure:** 16 items; general measure **Psychometrics:** Cronbach's α=0.69. **Results:** The results revealed a significant difference between the fathers of children with autism and Down syndrome and those with normal children regarding familial function and interpersonal relationships. On the other hand, fathers of children with autism and Down syndrome mentioned that they repeatedly used information seeking and fantasizing as defense mechanisms.

Discussion

The present study aims to define parenting competence and determine an appropriate instrument for its evaluation among parents with autistic children. The results indicated that competence was quite an expanded concept depending on backgrounds, conditions, and individual characteristics. Therefore, no global definition could be provided for this concept.(17,18) However, the results indicated that a few studies have explained parenting competence in parents with normal children(11,19-21,23-26) These studies have defined parenting competence as skills, knowledge, comfort, and satisfaction regarding the successful and effective performance of parenting roles.(19,22) However, parental competence is not defined for the parents of children with autism.

This study has also demonstrated that more factors affected parental competence in parents with autistic children, compared to those with normal children, because behavioral problems children with autism cause their parents to experiencing more.(23,52,53) Parents' stress, anxiety, depression and fatigue levels were increased by behavioral problems, whereas their self-efficacy was decreased.(40,54) Therefore, acquiring child care skills and the ability to recognize children's reactions play a critical role in promoting parenting competence.(29,30) Evidence has revealed self-efficacy, self-confidence, participation in care, and professional relations as predictors of parenting competence.(23,35,36) Accordingly, parents' self-efficacy affects their parental behaviors, and this improved behavior influences their parenting competence as well as their children's growth and development.(55) Indeed, parents' participation in child development programs plays a key role in the promotion of parenting competence, because the parents acquire skills for organizing children's behaviors and benefit from professional support.(56,57) Since self-efficacy is one of the main predictors of parenting competence, most studies had utilized parental self-efficacy questionnaires in order to assess parenting competence.(29,44)

The study results indicated that some studies involved designing instruments for the evaluation of parental self-efficacy in parents of children with other diseases. However, parenting competence has a far wider definition compared to parental self-efficacy.(21) Thus, parenting competence cannot be judged by the mere assessment of parents' self-efficacy, Therefore this study identified only three scales are available in this regards, namely Parenting Sense of Competence Scale, Sense of Competence Scale of the Parenting Stress Index and parental competence scale in parents of children with autism.(40,45,58) Parenting Sense of Competence Scale is a general instrument for determining parenting competence in parents with normal children.(59) Sense of Competence Scale of the Parenting Stress Index is one sub scale with 13 items for evaluating parenting competence.(59) Although this questionnaire is a reliable scale for assessing parental stress, it is not comprehensive enough to be utilized for the evaluation of parental competence.(45) Review of the related literature revealed that parental competence scale in parents of children with autism is only specialized instrument for the assessment of parenting competence in parents of children with autism. This scale was designed in 20019; therefore this scale has not been used by other authors.(57) Nonetheless, 7 articles were found to evaluate parental competence in parents of children with autism, in which they had used these two non-specialized instruments to determine parenting competence and self-efficacy in parents of children with autism. The results of these seven studies with those of the two non-specialized scales for the parents of children with autism revealed that parents' quality of life was significantly associated with stress, adaptation strategies, and demographic features, but it showed no significant difference between mothers and fathers of autistic children regarding physical, mental, and social health.(60)

One of the limitations of the present study was that the Literature about explaining the concept of parental competence of children with autism and its standard tools are few, the reason for its scarcity can be the absence of a comprehensive definition of the concept of parental competence and the lack of an appropriate scale for its measurement. Furthermore, most of the studies found on the subject were carried out in developed countries. Since the level of health care and services in developed countries is higher and social welfare is generally better compared to developing countries, the findings cannot be generalized to developing countries (such as Iran).

Conclusion. Although parental competence has been proposed as the main element in improving the quality of life among parents with autistic children, there have been few empirical studies and research; however, as parental competence is one of the key features among parents, it should be defined in parents with autistic children. An appropriate instrument should also be developed to evaluate parenting competence in such parents. The findings of the present study can develop the knowledge and attitude of researchers and healthcare providers regarding the evaluation of parenting competence of parents with autistic children and subsequently, improve families' and children's health status. Thus, based on our findings, it can be said that the development and definition of parental competence concept among parents of autistic children, as well as the promotion and development of assessing the parental competence will be an important aspect of nursing care and clinical performance. Therefore, the development of this concept is highly essential for clinical application and investigating its outcomes support. In order to understand parental competence of parents with autistic children, it is suggested that mixed research be used to define this concept, then development and psychometric scale for assessing parental competence of such parents in different cultures.

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State of Mental Health and Associated Factors in Nursing Students from Southeastern Iran

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Original article

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State of Mental Health and Associated Factors in Nursing Students from Southeastern Iran

Abstract

Objective. To evaluate the state of mental health and its relation with associated factors among nursing students. **Methods.** A cross-sectional study was conducted with 130 students from the Nursing and Midwifery College affiliated to the University of Medical Sciences of Shiraz (Iran). Data was collected through a document that included information on the demographic characteristics, the mean grades of the practical assignments and of the total (practical and theoretical assignments), and the Goldberg Health Questionnaire (GHQ-28) that measures symptoms grouped into four dimensions (somatic symptoms, anxiety and insomnia, social dysfunction, and depression). **Results.** Most of the participants (65.1%) were women; 5.3% were between 21 and 22 years of age, 84.5% were single, and 33.3% were in the sixth semester; 68.5% of

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the students had problems with mental health. By dimensions of the GHQ-28, it was found that 7.7% had somatic symptoms, 13.8% symptoms of anxiety and sleep disorders, 52.3% social dysfunction, and 6.2% depression. Males had a higher score of depression than females, and being single was related with higher scores of physical symptoms, anxiety and insomnia, and depression, compared with those who were married. An inverse relationship was found between the GHQ-28 average score and the semester, the grade in practical assignments, and the total grade for physical symptoms and anxiety and insomnia. **Conclusion.** There is a high proportion of nursing students with suspected mental health disorder. Some demographic and academic factors are related with the mental health of students and must be kept in mind by the institutions training future nurses.

Descriptors: students, nursing; mental health; depression; anxiety; sleep wake disorders; confounding factors (epidemiology); surveys and questionnaires.

Estado de salud mental y factores asociados en estudiantes de enfermería del suroeste de Irán

Resumen

Objetivo. Evaluar el estado de salud mental y su relación con factores asociados entre los estudiantes de enfermería. **Métodos.** Se realizó un estudio de corte transversal con 130 estudiantes del Colegio de Enfermería y Partería afiliado a la Universidad de Ciencias Médicas de Shiraz (Irán). Para la toma de los datos se empleó un formulario que incluía información sobre las características demográficas, los promedios de calificación de las asignaturas prácticas y del total (asignaturas prácticas más teóricas), y el Cuestionario de Salud Goldberg (GHQ-28) que mide síntomas agrupados en cuatro dimensiones (síntomas somáticos, ansiedad e insomnio, disfunción social, y depresión). **Resultados.** La mayoría de los participantes (65.1%) fueron mujeres; el 5.3% tenía entre 21 y 22 años; solteros, el 84.5% y el 33.3% estudiaba en el sexto semestre. El 68.5% de los estudiantes tenía problemas con la salud mental. Por dimensiones del GHQ-28, se encontró que el 7.7% tenía síntomas somáticos; 13.8%, síntomas de ansiedad y trastornos del sueño; 52.3%, disfunción social y 6.2% depresión. El sexo masculino tuvo mayor puntaje de depresión que las mujeres, y el estado civil soltero se relacionó con mayores puntajes de síntomas físicos, ansiedad e insomnio y depresión, comparado con los casados. Se encontró una relación inversa entre el promedio del puntaje del GHQ-28 y el semestre, la calificación en las asignaturas prácticas y la calificación total para síntomas físicos y ansiedad e insomnio. **Conclusión.** Es alta la proporción de estudiantes de enfermería con sospecha de trastorno de la salud mental. Algunos factores demográficos y académicos están relacionados con su salud mental y deben ser tenidos en cuenta por las instituciones formadoras de los futuros enfermeros.

Descriptores: estudiantes de enfermería; salud mental; depresión; ansiedad; trastornos del sueño-vigilia; factores de confusión (epidemiología); encuestas y cuestionarios.

Estado de saúde mental e fatores associados em estudantes de enfermagem do sudoeste do Irã

Resumo

Objetivo. Avaliar o estado de saúde mental e sua relação com fatores associados entre os estudantes de enfermagem. **Métodos.** Se realizou um estudo de corte transversal com 130 estudantes do Colégio de Enfermagem e Parteira afiliada à Universidade de Ciências Médicas de Shiraz (Irã). Para a toma dos dados se empregou um formulário que incluía informação sobre as características demográficas, as médias de qualificação das matérias práticas e do total (matérias práticas mais teóricas), e o Questionário de Saúde Goldberg (GHQ-28) que mede sintomas agrupados em quatro dimensões (sintomas somáticos, ansiedade e insônia, disfunção social, e depressão). **Resultados.** A maioria dos participantes (65.1%) eram mulheres; 5.3% tinham entre 21 e 22 anos, eram solteiros (84.5%) e o 33.3% estudavam no sexto semestre. 68.5% dos estudantes tinham problemas com a saúde mental. Por dimensões de GHQ-28, se encontrou que 7.7% tinham sintomas somáticos, 13.8% sintomas de ansiedade e transtornos do sono, 52.3% disfunção social e 6.2% depressão. O sexo masculino teve maior pontuação de depressão que as mulheres, e o estado civil solteiro se relacionou com maiores pontuações de sintomas físicos, ansiedade e insônia e depressão, comparado com os casados. Se encontrou uma relação inversa entre a média da pontuação de GHQ-28 e o semestre, a qualificação nas matérias práticas e a qualificação total para sintomas físicos e ansiedade e insônia. **Conclusão.** É alta a proporção de estudantes de enfermagem com suspeita de transtorno da saúde mental. Alguns fatores demográficos e acadêmicos estão relacionados com a saúde mental dos estudantes e devem ser tidos em conta pelas instituições formadoras dos futuros enfermeiros.

Descritores: estudantes de enfermagem; saúde mental; depressão; ansiedade; transtornos do sono-vigília; fatores de confusão (epidemiologia); inquéritos e questionários.

Introduction

Mental health is defined as a state of well-being in which individuals realize their own potential, can cope with normal stresses of life, can work productively and fruitfully, and are able to contribute to their community.(1) According to Kamau,(2) a person enjoying mental health is one who is away from anxiety and disability symptoms, can communicate well with others, and is able to face life's pressure. According to another theory, mental health is "the adaptation of individuals with their surrounding world to the extent that it causes happiness and useful and effective enjoyment completely".(3) Actually, a person with good mental health has a better function and quality of life, compared with others.(4) Mental health is a subject which has been studied vastly among students during recent years. Health problems are numerous and increase among students.(5) The importance of studying mental health in universities is valuable because it could have direct relation with the educational progress of students.(6) Student life, non-acquaintance with the new educational environment, remaining away from family, being uninterested with the educational field, incompatibility with others in the student life environment, socio-economic problems, and the lack of welfare facilities are among the causes creating mental problems and inconveniences and, finally, causes educational subsidence.(7,8)

The prevalence of mental disorder among students has been addressed by researchers. In the research carried out, this rate has been reported at 50.0% and 30.0% among students from universities in the USA and Europe, respectively.(8,9) According to such reports, 79.2% of students from African universities and 43.2% from Asian universities also have symptoms of mental disorder.(6,10) Also, according to a study conducted, the rate of depression disorder in students from Iranian universities is reported at 28.04%.(11) Considering the importance of the mental health of students, specially nursing students, due to the nature of this educational field and because they have direct contact with patients and their relatives and other health staff and that no research has been carried out in this respect among nursing students from Shiraz University and paying attention to the fact that, general health is such an index that should be measured in various individuals of a society during different periods of life; therefore, researchers decided to carry out a study to determine the mental health status among such students. This will be the first step to promote the level their mental health, so that students with this kind of problems would be identified for diagnosis and treatment and, in this way, complications in their mental health state and poor educational performance would be prevented.

Methods

A descriptive, cross-sectional study was conducted between 2016 and 2017. The variable of mental health of undergraduate nursing students was evaluated in this study. All undergraduate nursing students studying at the Nursing and Midwifery College affiliated to the Shiraz University of Medical Sciences comprised the research population and all accessible students who had propensity of participating in the study and signed the informed consent were evaluated. Of the 176 students selected, only 130 delivered the questionnaire completely filled out to the researchers. Data collecting tools consisted of demographic characteristics (sex, age, marriage status), academic characteristics (semester of study, training score and total average and Goldberg Health Questionnaire (GHQ-28) to measure general health. The training score means the grade of practical lessons and the average is the total average of theoretical and practical assignments. This questionnaire includes 28 multiple choice questions used by Goldberg and Hiler in 1972 to recognize the mild mental disorder.(12) The questions in this questionnaire include four levels, namely, "much lower than regular level with the score of zero", "lower than regular level with the score of one", "at the regular level with the score of two" and "more than regular level with the score of three" and its score range will be from 0 to 84. Each dimension consists of seven questions and the maximum score in each dimension is 21 and in total, there are 84 scores and the higher score specifies lower general health.(13) This tool included four sub-scales in social function, anxiety and sleep disorder, depression, and disorder in physical health. The cutoff point of 23.0 and 14.0 was considered to determine mental health disorder and for the sub-scale, respectively. The validity as well as reliability of the Persian version of questionnaire was confirmed in various studies.(14,15) The reliability coefficient for the whole GHQ was 0.96 and for the sub-scales of depression, anxiety, physical and social disorder, it was determined as 0.94, 0.90, 0.89, and 0.7, respectively.(16) Cronbach´s alpha in this research was calculated at 0.85. Data collected were analyzed by using SPSS version 23 software, with help from descriptive statistic tests, independent tests, Kruskal-Wallis H, Mann-Whitney U, and One Way Analysis of Variance. The statistical significance level for the tests was 0.05.

Results

In this study, most of the participants (65.1%) were women, with mean age ranging from 21 to 22 years (55.3%). Most of students (84.5%) were single and 33.3% of them were in the 6th semester. The maximum training score of the participants was 19.0 and the minimum was 15.5; the mean of the total average of all the students was 15.62±1.62. In this investigation, only 30.0% of students were healthy and 68.5% of them were suspected of suffering from mental health disorder (Table 1). By evaluating each questionnaire domain, it was specified that 7.7%, 13.8%, 52.3%, and 6.2% of the individuals suffered from disorders in the physical dimension, symptoms of anxiety and sleep disorder, disorder in social function, and symptoms of depression, respectively. The most prevalent disorder was observed in social function (Table 1).

Table 1. Frequency of healthy individuals and those suspected of suffering from mental health disorder (*n* = 130)

Mental Health	Healthy		Doubtful about disorder		Missing data	
	Number	Percentage	Number	Percentage	Number	Percentage
Total score of GH	39	30.0	89	68.5	2	1.5
Physical symptoms	116	89.2	10	7.7	4	3.1
Symptoms of anxiety and sleep disorder	108	83.1	18	13.8	4	3.1
Social Dysfunction	56	43.1	68	52.3	6	4.8
Symptoms of depression	119	91.5	8	6.2	3	2.3

Table 2 shows the average scores of the total and by domains of the GHQ-28, according to demographic variables. Males had higher average scores, exclusively in the domain of depression; and those who were single in the scale total and in the domains of physical symptoms, anxiety and insomnia, and depression. Age was not significantly related with the scale score in any domain or with the total.

Table 2. Mean and standard deviation of the scores of four domains of mental health according to demographic characteristics

Variables	Dimensions	Physical symptoms	Anxiety and Insomnia	Social dysfunction	Depression	Total scale
Sex	Male	5.88±3.77	6.88±4.79	13.39±3.48	5.37±5.50	30.50±10.34
	Female	6.96±4.53	7.01±5.86	13.06±3.89	2.79±3.98	29.34±10.55
	Test	t = 1.34 *p* = 0.18	t = 0.12 *p* = 0.90	Z = 0.33 *p* = 0.74	Z = 2.76 *p* = 0.006	t = 0.59 *p* = 0.55
Age	19-20	7.24±5.11	7.43±5.71	12.66±4.26	4.13±4.91	30.31±11.65
	21-22	6.77±4.04	6.74±5.59	13.37±3.53	3.47±4.62	29.77±10.22
	23-29	4.18±3.12	5.87±4.41	13.93±3.67	3.62±5.26	27.62±9.81
	Test	F = 2.98 *p* = 0.055	F = 0.47 *p* = 0.62	F = 0.72 *p* = 0.48	X^2 = 1.009 *p* = 0.63	F = 0.36 *p* = 0.69
Marriage Status	Single	6.94±4.48	7.36±5.58	12.95±3.91	4.18±4.87	30.79±10.79
	Married	4.38±2.06	4.50±4.42	14.63±2.11	1.52±1.02	23.57±5.60
	Test	F = 49.82 *p* <0.001	t = 2.067 *p* = 0.04	Z = -1.62 *p* = 0.105	Z = -3.89 *p* <0.001	t = 4.36 *p* = 0.001

For the academic variables, the average of the GHQ-28 noted that the significant and inverse relation between educational semester and the score of the depression domain could be mentioned as the other results of this research in such a way that students in higher semesters obtained a lower depression score. The training score showed a significant and also inverse relationship with the global score, as well as the score of physical symptoms and anxiety domains; meaning that those who had a better training scores obtained a lower score of mental health, physical symptoms, and anxiety. The total average score had a borderline statistical significance with the scores of the total scale and its domains (Table 3).

Table 3. Mean and standard deviation of the scores of four domains of mental health according to the educational semester, training score, and total average

Variables	Dimensions	Physical symptoms	Anxiety and insomnia	Social dysfunction	Depression	Total scale
Educational Semester	3	60.50±4.18	8.09±5.67	12.93±3.18	5.67±5.41	32.21±11.63
	4	7.55±4.88	7.39±6.08	13.14±4.60	3.40±5.05	30.85±10.96
	6	6.32±3.88	5.79±4.28	13.14±3.34	3.02±4.05	27.67±8.92
	7	5.47±4.24	7.00±6.47	13.66±3.94	2.27±3.02	28.11±10.23
	Test	F=1.01 *p*=0.38	F=1.17 *p*=0.32	X^2=0.82 *p*=0.84	X^2=8.11 *p*=0.04	F=1.45 *p*=0.23
Training score	11-14	8.38±4.38	9.19±5.60	12.20±4.06	5.28±5.61	33.92±11.65
	14.01-16	6.30±4.05	5.60±4.95	13.44±3.96	3.10±4.24	27.97±9.78
	16.01-20	5.86±3.82	6.05±4.98	12.97±3.03	3.76±4.97	28.31±9.59
	Test	F = 3.21 *p* = 0.044	F = 4.23 *p* = 0.017	X^2 = 2.40 *p* = 0.30	X^2 = 1.68 *p* = 0.43	F = 3.12 *p* = 0.048
Total average	11-14	6.30±3.63	6.91±4.89	14.31±3.02	5.21±5.71	31.08±9.85
	14.01-16	5.95±4.09	5.93±5.18	13.72±3.59	2.80±3.95	27.43±10.46
	16.01-20	6.77±4.24	7.30±5.50	12.50±3.73	3.28±3.97	29.86±9.12
	Test	F = 0.49 *p* = 0.61	F = 0.83 *p* = 0.43	X^2 = 5.63 *p* = 0.06	X^2 = 2.56 *p* = 0.27	F = 1.31 *p* = 0.27

Discussion

In this study, only 30.0% of students had good mental health and the total score average of mental health of the Shiraz nursing students was reported at 29.74±10.45. A study in China in this respect in 2012 showed the general health of students at 22.9%.(17) A study in Sweden reported the prevalence of depression disorder among first-year nursing students at 16.4%(18) and 24.0% of medical students from the USA were suffering from depression.(19) According to a five-year prospective study in England, it was specified that 66.2% of medical students were suffering from at least one of the indexes of general health status. Also, the general health status of first-year students was accounted as a criterion for anticipating their mental health status during the coming years.(20) Considering the rate of mental health obtained, using the psychological and therapeutic methods, it seems necessary to improve the general health status of nursing students.

The results show that social function disorder was the most prevalent (52.3%) problem of students, which is similar to previous studies;(20,21) thereby, more attention should be paid to studying the social function of students during student consultations. Students could be encouraged to have the best function, causing the support of their self-reliance by arranging the consultation and self-adjustment classes. Using the educational guides to support the social skills of students also seems necessary. The dimension of physical symptoms in the GHQ is an indication of the chance for individuals to suffer from physical illness.(22) In this study, the mean of 6.58±4.29 with 7.7% was obtained in this dimension. In this respect, Dalal and Bala(23) showed a mean of 23.7%.

In the depression domain, the lowest percentage (6.2%) with the mean of 3.66±4.69 was obtained. This dimension was mentioned as 2.7% in previous studies.(23) The American National Institute of Mental Health reported the rate of depression of students at 30.0%.(24) From the view point of the anxiety domain in our study, the rate of 13.8% with the mean of 6.96±5.49 was obtained. This index has been reported in other studies at 53.3%.(23) Suitable educational environment, good contact with professors and reciprocal understanding of students and professors could be effective in reducing such condition. Given that anxiety could affect other important aspects of life, causing disorder in the social function, paying attention to such is of great importance.

In this study the score of depression dimension of male students was higher than in female students. Most studies either did not obtain any statistical significant relation between women and men(25) or obtained significant statistical difference from the point of view of sex among students using alcohol, drugs, or tobacco.(26) It seems that, this lack of similarity is due to the existence of various reasons, like differentiating of cut-off point among sub-divisions in the present study, that nursing students were only the under study group while in the mentions studies.

The relation between marital status and the score of general health and sub-divisions of depression, physical symptoms, and anxiety was statistically significant in such a way that married people obtained better scores. In this respect, these findings were similar to research carried out in Mazandaran, Zahedan, Jiroft, and Iran University of Medical Sciences,(19,20) but are not similar to some studies.(24) This variation is likely due to the difference between the groups studied because none of the studies mentioned have been carried out with nursing students. The significant relation between semester of study and the score of the depression dimension could be mentioned as the other results of this research so that the students from higher semesters obtained a lower depression score. In this respect, the results of the study by Dalal and Bala showed that the general health of students from higher semesters is better than those in lower semesters.(23) Davidson also reported that anxiety among beginner students is more than that of seniors.(27) It seems that nursing students during the initial semesters, due to not being aquainted with the ward and with the nature of their educational field (most of the subjects are covered at the hospital and therapeutic centers), will adapt to the environment during the higher semesters and obtain better mental health.

The training score showed statistically significant relation with the score of mental health, as well as the score of the physical symptoms and anxiety sub-divisions, meaning that those who had better training scores obtained better scores in mental health, physical symptoms, and anxiety. In this respect, the results of this study were similar to the results from other studies.(21,23,25) In this study, the average score showed no statistically significant relation with the scores of mental health and its sub-divisions, but some of the studies mentioned showed reverse statistical relation between the mean score and the score of general health, meaning that higher mean score indicates lower score of general health so that the student's mental status was better.

The conclusion of this research reveals that cases suspected of general health disorder among students from Shiraz University of Medical Sciences are comparatively high. Although the GHQ-28 cannot prove the physical or mental problems of students definitely, it recognizes students exposed to risk to some extent. University students report educational-related and general stressors in Iran.(28) This study also found that some demographic and academic factors are related with the mental health of the students, this is why they should be kept in mind by institutions training future nurses.

The limitations of this research could also interfere in explaining the results; refusal by some students to answer some questions and the small sample size are among the limitations of this study. No motivation or desire to answer the research questionnaire is the current problem of such studies. It seems that carrying out longitudinal research with a large sample size and considering the interfering variables and controlling the confounding variables is the most suitable choice to reach better results. Therefore, more specific evaluations to study this disorder could also determine the cause of the increase in this index compared with other studies carried out. Of course, by recognizing such students and arranging consultation classes with psychologists and psychiatrists, the risk factors could be reduced in these students.

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Original article

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Perceived stress and resilience and their relationship with the use of mobile phone among nursing students

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Perceived Stress and Resilience and Their Relation with the Use of the Mobile Phone among Nursing Students

Abstract

Objective. The study sought to explore the relationship between levels of stress and resilience with the use of the mobile phone in nursing students. **Methods.** Cross-sectional study conducted with 102 nursing students from several Nursing schools in India who were invited to participate in the research. The data were gathered by using the following instruments: *Perceived Stress Scale* (PSS) by Cohen, *The Connor-Davidson Resilience scale* (CD-RISC), and *Mobile Phone Involvement Questionnaire* (MPIQ) by Walsh. **Results.** Most of the participants were women (94.1%), studying in the undergraduate (70.6%), with a mean age of 25.2 years. In all, 77.5% of the students had stress perception between moderate and high, 20.6% had high resilience capacity, and 25.5% were frequent mobile phone users. Perceived stress was

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correlated significantly and negatively with age and resilience capacity. Graduate students had greater capacity to recover than undergraduate students. **Conclusion.** This study indicates the negative relation of resilience capacity with stress and the use of mobile phones among nursing students. Hence, it is necessary for institutions preparing nurses to develop intervention strategies to enhance the resilience capacity, improve skills to manage stress, and healthy use of the mobile phone.

Descriptors: stress, physiological; resilience, psychological; students, nursing; cell phone use; cross-sectional studies; surveys and questionnaires.

Estrés y resilencia percibidos y su relación con el uso del teléfono móvil entre los estudiantes de enfermería

Resumen

Objetivo. Explorar la relación entre los niveles de estrés y resiliencia con el uso del teléfono móvil en estudiantes hindúes de enfermería. **Métodos.** Estudio de corte transversal realizado con 102 estudiantes de enfermería de varias escuelas de enfermería en la India a quienes se invitó a participar en la investigación. Los datos se recopilaron con la ayuda de los siguientes instrumentos: *Percibed Stress Scale* (PSS) de Cohen, *The Connor-Davidson Resilience scale* (CD-RISC) y *Mobile Phone Involvement Questionnaire* (MPIQ) de Walsh. **Resultados** La mayoría de los participantes fueron mujeres (94.1%), estudiaban pregrado (70.6%) y tenían un promedio de edad de 25.2 años. El 77.5% de los estudiantes tenía una percepción de estrés entre moderada y alta; el 20.6% tenía alta capacidad de resiliencia y el 25.5% eran usuarios frecuentes de teléfonos móviles. El estrés percibido se correlacionó significativamente y de manera negativa con la edad y la capacidad de resiliencia. Los estudiantes de posgrado tuvieron mayor capacidad de recuperación que los estudiantes de pregrado. **Conclusión.** El presente estudio indica la relación negativa de la capacidad de resiliencia con el estrés y el uso de teléfonos móviles entre los estudiantes hindúes de enfermería. Por lo tanto, es necesario que las instituciones formadoras de enfermeros desarrollen estrategias de intervención para fortalecer la capacidad de resiliencia, mejorando las habilidades para manejar el estrés y el uso saludable del teléfono móvil.

Descriptores: estrés fisiológico; resiliencia psicológica; estudiantes de enfermería; uso del teléfono celular; estudios transversales; encuestas y cuestionarios.

Estresse e resiliência percebidos e sua relação com o uso do telefone móbil entre os estudantes de enfermagem

Resumo

Objetivo. Explorar a relação entre os níveis de estresse e resiliência com o uso do telefone móbil em estudantes de enfermagem. **Métodos.** Estudo de corte transversal realizado com 102 estudantes de enfermagem de várias escolas de enfermagem na Índia que foram convidados a participar na investigação. Os dados se recopilaram utilizando os seguintes instrumentos: *Percibed Stress Scale* (PSS) de Cohen, *The Connor-Davidson Resilience scale* (CD-RISC) e *Mobile Phone Involvement Questionnaire* (MPIQ) de Walsh. **Resultados** A maioria dos participantes eram mulheres (94.1%), estudavam graduação (70.6%)e tinham uma média de idade de 25.2 anos. 77.5% dos estudantes tinham uma percepção de estresse entre moderada e alta, 20.6% tinha alta capacidade de resiliência e 25.5% eram usuários frequentes de telefones móbeis. O estresse percebido se correlacionou significativamente e de maneira negativa com a idade e a capacidade de resiliência. Os estudantes de pós-graduação tiveram maior capacidade de recuperação que os estudantes de graduação. **Conclusão.** O presente estudo indica a relação negativa da capacidade de resiliência com o estresse e o uso de telefones móbeis entre os estudantes de enfermagem. Por tanto, é necessário que as instituições formadoras de enfermeiros desenvolvem estratégias de intervenção para fortalecer a capacidade de resiliência, melhorando as habilidades para manejar o estresse e o uso saudável do telefone móbil.

Descritores: estresse fisiológico; resiliência psicológica; estudantes de enfermagem; uso do telefone celular; estudos transversais; inquéritos e questionários.

Introduction

Stress is an emerging issue in the present life. There are many factors that lead to stress among the nursing students. The effect of perceived stress on students' health depends on their coping abilities and resilience as well. Stress and mobile phone use has been found to have bi-directional interaction. For example, mobile phone can be used by some students as stress relieving gadget and similarly, students who use mobile phone excessively may be stressed because of constant connection with others. Psychological stress among the students especially those who are pursuing a professional degree, is one of the major factors that affect students' academic performance and satisfaction.(1) Research focusing on nurses has commonly found that this population reports high levels of stress.(2) Stress has been defined as 'a strain that accompanies a demand perceived to be either challenging (positive) or threatening (negative) and depending on the appraisal either adaptive or debilitating'.(3) Lazarus & Folkman in 1984 defined stress as a 'Particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her wellbeing'.(4) Stress is perceived when an individual feels an inability in managing the stressors either due to inadequate abilities or resources.(5) Previous literature has found perceived stress to be associated with self-efficacy, workload,(6) poorer physical, psychological, and social health.(1)

The sources of stressors reported among nursing students are: academic, clinical and personal sources.(7,8) Along with other personal problems, financial concerns and lack of free time play major role as stressors.(7) Work/life imbalance is a significant stressor for female nursing students with children.(9) The effect of perceived stress on students' health depends on their coping abilities. Resilience is a coping ability to keep on trying and bouncing back on adverse circumstances.(10) Resilience is related to positive emotions and these positive emotions during stressful experience have adaptive benefits in coping with stress.(11) Thus, the individual with good resilience tends to perceive less stress in a difficult environment and overcome the stressful situation easier than the one with less resilience.

High mobile phone use is associated with stress, sleep disturbances and symptoms of depression for the young adults,(12) and their vast effect on communication and interactions, it is important to study possible negative health effects of mobile phone exposure. The overall aim of this study was to investigate whether there are associations between psychosocial aspects of mobile phone use and mental health symptoms in a prospective cohort of young adults. Methods: The study group consisted of young adults 20-24 years old (*n* = 4156 whereas a significant cross-sectional association was found between problematic mobile phone use, psychological distress and academic performance among college students.(13) High mobile phone use can lead to stress, depression and anxiety or vice-versa. The studies mentioned so far have tried to identify the relationship of stress and resilience either individually or combined with other factors affecting mental health. Further, few studies have assessed the impact of mobile phone use on stress, sleep, self-esteem and depression.(12,13) But the present study is one of its kind which assesses the level of stress and resilience and their relationship with use of mobile phone among the nursing students.

The objectives of the study are 1) To explore level of stress, resilience and mobile phone use among nursing students. 2) To find out the relationship between those variables. 3) To find out association between the level of stress, resilience and mobile phone use with socio demographic variables, such as gender and education. The study also sought for implications for the academicians regarding the same.

Methods

This is a cross-sectional descriptive study based on convenience sampling. Undergraduate and postgraduate nursing students from various colleges of nursing in India who came for clinical experience were invited to participate in the study.

Sample. In 2017 when the study was being conducted, students from total 15 colleges had come to the said institute for clinical experience and out of them, 9 colleges were willing to take part in the study. All possible sample was considered for the study. However, post-hoc analysis for sample size calculation was done with known population mean and SD from previous study.(14) Fixing alpha at 0.05 and power at 80%, the sample size was estimated to be minimum 98. Hence, the questionnaires were distributed to 110 students (postgraduates=32 and undergraduates=78). However, 8 uncompleted questionnaires were discarded and the final sample comprised of 102 with 92.7% response rate.

Procedure. The study was approved by the Institute Ethics Committee. Participants were explained briefly about the study and asked if they would consider participating. Permission was obtained from the respective college Principals or teachers. Consenting participants were informed in details about the assessments. Informed consent was obtained from the participants. Both male and female students were included. Students who used substances in any form were excluded from the study. The details of current/lifetime use of any substance were elicited in the demographic data sheet. It helped in excluding students with substance use. It was an attempt to address the confounding variable in the current study on assessing the psychological correlates of mobile phone use. However, none of the participants had a history of current/lifetime use of any substance use.

Measures. 4 types of information sources were used: 1) Socio-demographic data sheet was used to find out the age, gender and education of the study participants; 2) *Perceived stress scale –PSS-* (15) is one of the most commonly used tools across different countries, cultures and population characteristics. It aims at accessing the degree to which situational changes in one's life are perceived as stressful. The 10-items version was used in this study. It has a good internal consistency with alpha coefficient of 0.85. Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress. Scores ranging from 0-13 is considered low stress, scores ranging from 14-26 as moderate stress and scores ranging from 27-40 as high perceived stress; 3) *Connor–Davidson Resilience Scale* (CD-RISC):(16) The CD-RISC is a 25-item scale that measures the ability to cope with stress and adversity. Studies reported the internal consistency for the CD-RISC scale as 0.89 and 0.92, respectively.(16,17) Based on quartile deviation, resilience is scored for this study as ≤ 61 low or less resilience, 62-79 moderate resilience and ≥ 80 high or good resilience; and 4) *Mobile Phone Involvement Questionnaire* (MPIQ;)(18) MPIQ is an 8-item measure of mobile phone involvement on a 7-point Likert scale with good construct validity. Cronbach's alpha shows acceptable reliability (α=0.81) for this questionnaire. Based on quartile deviation in this study, mobile phone use is considered low when score is ≤20, moderate if scores range from 20-35 and high when score is ≥36.

Statistical analysis. Data were analyzed using SPSS-22. Descriptive statistics such as frequency and percentage were used to describe the categorical variables and mean and SD were identified for the continuous variables. Rrelationship between the perceived stress, resilience and use of mobile phone was identified by using Pearson's correlation test and Chi-square was used for association between selected socio-demographic variables and the study variables.

Results

Majority of the 102 students were female (94.1%) and undergraduate (70.6%). Mean age of the participants was 25.3±4.8 years. About the test: resilience was higher (71±11.5), the perceived stress was moderate (18.6±5.9) and mobile phone use was moderate too (27.4±8.6).

Eighty percent students had moderate to high perceived stress, 20.6% had high resilience and 25.5% were frequent mobile phone users (Table 1).

Table 1. Distribution of subjects based on level of perceived stress, resilience and mobile phone use

Level Test	Low %	Moderate %	High %
Stress	22.5	67.7	9.8
Resilience	19.6	59.8	20.6
Mobile phone use	21.6	52.9	25.5

Table 2 shows that perceived stress was significantly negatively correlated with resilience (r=-0.196) and age (r=-0.295) and positively correlated with mobile phone use (r=0.216). Resilience was found to be significantly higher among the post graduate students than the undergraduates (F=10.4, p=0.002). No other study variable had significant association with socio demographic variables.

Table 2. Correlation between the variables of the research

Variables	MPIQ	PSS	Resilience
Age	-0.072	-0.295**	0.181
MPIQ		0.216*	-0.037
PSS			-0.196*

*$p<0.05$, **$p<0.01$

Discussion

This study provides the preliminary findings on the level of perceived stress, resilience and their relationship with the usage of mobile phone among nursing students. The present findings are corroborated with available literature among nursing profession. Nursing students are vulnerable to perceive more stress than other group of students. To be specific, they experience longer hours of study and associated lack of free time.(7) Studies documented moderate to high perceived stress among nursing students.(11,19) Eighty seven percent of the nursing students reported to have endured higher to much higher than average level of perceived stress.(1) Similar to the present study findings, the mean stress score was found to be 16.7±4.8 in a college student group which is little lower than the present study findings.(14) This emphasizes the fact that the nursing students experience more stress than the general college students. On the contrary, mean perceived stress score was seen to be 28.7±5.3 among nursing undergraduate students (n=282) in another study, which is alarming.(20) This discrepancy could be due to the use of different measures of perceived stress over studies.

The current findings that resilience is significantly negatively correlated with perceived stress is in line with previous studies from other parts of the country or from outside India. A significant negative relationship (r=-0.7) has been seen between perceived stress and resilience of the respondents.(11) Resilience score was significantly found to be negatively correlated (r=-0.31) with perceived stress.(1)

In this study, perceived stress is negatively correlated with age and resilience was found to be significantly higher among the post graduate students than the undergraduates (F=10.4). It could be attributed to the fact that higher the level of maturity, higher the resilience and higher the resilience, lower the perception of stress. This trend is in accord with previous research showing that resilience increases with life experience and age.(21) High use of mobile phone is positively correlated with perceived stress. Prior literature has also shown that high use of mobile phone is associated with high level of stress. Similar to the present study findings, one study found that there were cross-sectional associations between high mobile phone use and stress, sleep disturbances, and symptoms of depression among the young adults as well.(12) Significant cross-sectional association was also reported between problematic mobile phone use and psychological distress, lower self-esteem, gender, smartphone use, multiple chatting applications, committed relationship status and frequency of mobile phone use.(13)

Strength and limitation. The present study included students who came from many other states of India which may be representative of the country. Use of internationally standardized scale in the study and good response rate (92.7%) were main strength of the study. The study has also certain limitations such as cross sectional descriptive study, small sample size and the data was collected using self-reported questionnaires. As this study was conducted only with Indian nursing students, generalization of the findings in other countries has to be cautiously considered.

Recommendations. The preliminary study findings show that there is higher perceived stress among the group which is negatively correlated with resilience. Stress is also found to be related with the use of mobile phone. This initial trend shows that there are implications of stress on use of mobile phone where resilience can be considered as a protective factor, but the correlation is low that needs to be validated through large sample size. Hence the implications for the study are to raise awareness of mental health issues. These findings highlight the importance of stress management and life skill training program and promotion of healthy use of technology in the colleges or universities, where the students can avail themselves with the abilities of managing stress or coming back easily from adverse situations and where the mobile phone will be used only when necessary, not as a stress relieving gadget.

Conclusion. The present study indicates the negative relationship of resilience with stress and mobile phone use among the nursing students. Thus, the study highlights the need for developing psycho-educational module or brief-intervention to strengthen their resilience, enhancing the skills to manage stress as well healthy use of mobile phone. The study also paves the way for academicians and administrators of colleges of nursing or other institutes for providing facilities and opportunities to the students for managing their stress which in turn equip them for better patient care.

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Effect of Yoga on the Quality of Life of Nurses Working in Intensive Care Units. Randomized Controlled Clinical Trial

Original article

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Effect of Yoga on the Quality of Life of Nurses Working in Intensive Care Units. Randomized Controlled Clinical Trial

Abstract

Objective. The work, herein, sought to determine the effect of yoga on the quality of life of nurses working in intensive care units (ICU). **Methods.** This was a randomized controlled clinical trial of a preventive intervention of three weekly sessions of yoga exercises, which included aspects of meditation, breathing control, and slow body movements. The study selected 70 nurses working in ICU and assigned them to two groups: experimental (n = 35) and control (n = 35). The World Health Organization Quality of Life brief questionnaire (WHOQoL-Bref) was used to evaluate on four moments (baseline, one, two, six months after the start of the study); this scale has 26 items with Likert-type response options ranging from 1 to 5; higher total score indicates better quality of life. **Results.** The baseline score of quality of life in the

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experimental group was 62.3, which increased to 70.7 on the first month and continued improving in the evaluations on the second month (72.8) and sixth month (74.1), with this change being statistically significant. Instead, the control group showed no differences in scores of the different moments of evaluation (baseline = 62, first month = 61.9, second month = 62.4, and sixth month = 60.4). In the four domains of the WHOQoL-Bref (physical, psychological, social relationships, and environment), it was also noted that the experimental group obtained better scores over time compared with the control group. **Conclusion.** The intervention of yoga exercises was effective in improving the quality of life of nurses working in ICU.

Descriptors: yoga; exercise; meditation; nurses; quality of life; intensive care units; randomized controlled trial; surveys and questionnaires; encuestas y cuestionarios.

Efecto del yoga en la calidad de vida de las enfermeras que trabajan en Unidades de Cuidados Intensivos. Ensayo Clínico Controlado Aleatorizado

Resumen

Objetivo. Determinar el efecto del yoga en la calidad de vida de las enfermeras que trabajan en Unidades de Cuidados Intensivos (UCI). **Métodos.** Ensayo clínico controlado aleatorizado de una intervención preventiva de 3 sesiones semanales de ejercicios de yoga que incluyeron aspectos de meditación, control de la respiración, y movimientos corporales lentos. Se seleccionaron 70 enfermeras que trabajan en UCI y se asignaron aleatoriamente a dos grupos: experimental (*n*=35) y de control (*n*=35). El cuestionario de Calidad de Vida de la Organización Mundial de la Salud -WhoQol-Bref- se utilizó para la evaluación en cuatro momentos (basal, uno, dos y seis meses posinicio del estudio), esta escala tiene 26 items con opciones de respuesta tipo Likert de 1 a 5, a mayor puntaje total se considera que es mejor la calidad de vida. **Resultados.** La puntuación basal de calidad de vida en el grupo experimental fue de 62.3, la cual se incrementó a 70.7 en el primer mes y continuó mejorando en las evaluaciones del 2º mes (72.8) y 6º mes (74.1), cambio estadísticamente significativo. Por el contrario, en el grupo control no se encontraron diferencias en el puntaje en los diferentes momentos de evaluación (basal =62, primer mes =61.9, segundo mes =62.4 y sexto mes =60.4). En los cuatro dominios de WhoQol-Bref (físico, psicológico, relaciones sociales y ambiente), también se apreció que el grupo experimental obtuvo mejores puntajes en el tiempo comparado con el grupo control.

Conclusión. La intervención con ejercicios de yoga mejoró la calidad de vida de las enfermeras que trabajan en UCI.

Descriptores: yoga; ejercicio; meditación; enfermeras y enfermeros; calidad de vida; unidades de cuidados intensivos ensayo clínico controlado aleatorio; inquéritos e questionários.

Efeito da yoga na qualidade de vida das enfermeiras que trabalham em Unidades de Tratamentos Intensivos. Ensaio Clínico Controlado Aleatorizado

Resumo

Objetivo. Determinar o efeito da yoga na qualidade de vida das enfermeiras que trabalham em Unidades de Tratamentos Intensivos (UTI). **Métodos.** Ensaio clínico controlado aleatorizado de uma intervenção preventiva de 3 sessões semanais de exercícios de yoga, que incluíam aspectos de meditação, controle da respiração, e movimentos corporais lentos. Se selecionaram 70 enfermeiras que trabalham em UTI e se designaram aleatoriamente a dois grupos experimentais (*n*=35) e de controle (*n*=35). O questionário de Qualidade de Vida da Organização Mundial da Saúde -WhoQol-Bref- se utilizou para a avaliação em quatro momentos (basal, um, dois e seis meses pós início do estudo), esta escala tem 26 itens com opções de resposta tipo Likert de 1 a 5, a maior pontuação total se considera que é melhor a qualidade de vida. **Resultados.** A pontuação basal de qualidade de vida no grupo experimental foi de 62.3, a qual se incrementou a 70.7 no primeiro mês e continuou melhorando nas avaliações do 2º mês (72.8) e 6º mês (74.1), sendo este câmbio estatisticamente significativo. Em câmbio, no grupo controle não se encontraram diferenças na pontuação nos diferentes momentos de avaliação (basal =62, primeiro mês =61.9, segundo mês =62.4 e sexto mês =60.4). Nos quatro domínios de WhoQol-Bref (físico, psicológico, relações sociais e ambiente), também se apreciou que o grupo experimental obteve melhores pontuações no tempo comparado com o grupo de controle. **Conclusão.** A intervenção de exercícios de yoga foi efetiva no melhoramento da qualidade de vida das enfermeiras que trabalham nas UTIs.

Descritores: ioga; exercício; meditação; enfermeiras e enfermeiros; qualidade de vida; unidades de terapia intensiva; ensaio clínico controlado aleatório.

Introduction

From the world health point of view, the concept of quality of life is influenced by physical health, psychiatric manners, independency level, personality development, social relationships, and interaction with outstanding organizations in the environment. quality of life includes a range of mental and objective dimensions which interact with one another; hence, living a high quality of life leads to a positive feeling for individuals. quality of life can be described in terms of person's complete health welfare and consists of different dimensions like physical, intellectual, psychological, role performance, and social support welfare.(1)

Researchers believe that investigating quality of life and endeavoring for its improvement plays a great role in person's health and their social and individual lives.(2) Various factors like age, diseases, and social environment may have positive and negative effects on the quality of life. Meanwhile, one of the effective factors is job stresses.(3) Stress is a main problem in every society that involves individuals physically and mentally.(4) Although every occupation has its own sources of stress, in jobs encountering with people's health, this issue is of a higher importance. Medical team members, particularly, nurses are among the people who experience higher levels of professional stress.(2) Thus, their health and quality of life is strongly influenced by stress and risk of diseases like diabetes, cardiovascular, and other chronic diseases.(5) In addition, stress directly affects quality of life, job satisfaction, professional exhaustion, increase in medical faults, and therefore decreasing the quality of healthcare services for patients.(6) Nurses working in intensive care unit, due to conditions of their job, physical environment of the ward, type of patients, and their tense conditions, as well as their heavy duties experience more stresses.(7,8)

There are different strategies to control occupational stresses and therefore, improving the quality of life.(9,10) Matsumoto has divided the strategies of coping with stress into three groups of emotion focus, problem focus, and ineffectiveness.(11) In the emotion focus strategy, person does not make any effort to decrease and control stress, but he tries to calm himself and get rid of stress. In the problem focus strategy, the individual tries to decrease or control his occupational stress. Unfortunately, the majority of people use the ineffectiveness strategy. In this strategy the individuals neither solves the problem nor decreases it; he usually uses inefficient harmful strategies that cause negative outcomes to control stress.(12) Yoga is one of these strategies which has a significant role in controlling stress.(13) Yoga, actually is a set of movements that coordinate body and soul and create flexibility against negative pressures and increase ability to cope with stress.(14) Yoga has positive short-term and long-term effects on physical stress that consequently improves the quality of life.(15) Even though it has been tried to teach treatment to yoga team through different studies, there is not any study done directly to investigate the effects of yoga on the quality of life of nurses working in intensive care units (ICU).(16) Then, the researchers decided to investigate the effect of this strategy on the quality of nurses' lives working in ICU.

Methods

This clinical trial study was conducted in 2017. According to previous studies the sample size was 70 nurses working in intensive care units. After the approval of the study by the ethics committee of Shiraz University of Medical Sciences, the study was started. The eligibility criteria for participants were items like not using painkillers, having at least six months of job experience, and tendency to participate in the study. The criteria for exiting the study included participating in any of aerobics classes, meditation, and unwillingness to continue their cooperation with the research. In order to determine the quality of nurses lives, quality of life Who-QOL-Bref questionnaire was used whose reliability and validity have been admitted by Sharbaf *et al.*(17) This questionnaire consists of 26 questions. Grading is defined as one point for at all choices, five points for very much choices, and for questions 3, 4, and 26 which have negative connotations, it is contrariwise. Higher points represent higher quality of life. For conforming this questionnaire, grading to WHO 100-question complete questionnaire, each of the points will be multiplied by 4 in order to gain the main grade. Settings and locations where the data were collected were special sections of all Shiraz Medical Sciences Hospitals. Qualified people who were willing to participate in this research were registered until the list reached 70 people. The selected nurses were divided randomly into two equal case and control groups by using Simple Block Random sampling method.

In the introduction meeting, after receiving letters of satisfaction and explaining that entering and exiting this research is optional, first the nurse's quality of life was investigated in four physical (6 questions), psychological (7 questions), social relations (3 questions), and environmental (8 questions) before starting the classes. Then, the interference group participated in yoga classes for two months and twice a week. One, two, and six months after the classes were finished; the questionnaire completed by both interference and control groups and then, gathered.

In each session of yoga classes, three aspects of mind control, breathe control, and slow body movements were worked out. Yoga movements start as the participants lying down on their backs during which they practice concentrating on mind and breathe for fifteen minutes. In this condition, the individual's mind is turned rotatory in different parts and it is attempted to teach the individual how to control his mind. After that, and in this condition, four slow body movements are exercised. After doing each movement, the patient's mind is concentrated on the intended organ so that he can have a better perception of it after concentration. After each movement, the breathing and mind control practice was done on that organ. Afterwards, three slow movements are done in sitting condition and after each movement, psychological and mental attention is paid to that organ. Next, the person does four slow movements as he stands and after each movement, his psychological and mental attention is paid to the intended organ; at the end, the breath control is done. After that, the person is set in lying position again and his mind is being worked out on for fifteen minutes until he reaches a good feeling towards himself and the world around him.

For ethical considerations through the research process from start to the end, the researcher emphasized conscious satisfaction, nurses' anonymity, confidentiality of the information, the right to leave the participation at any optional time.

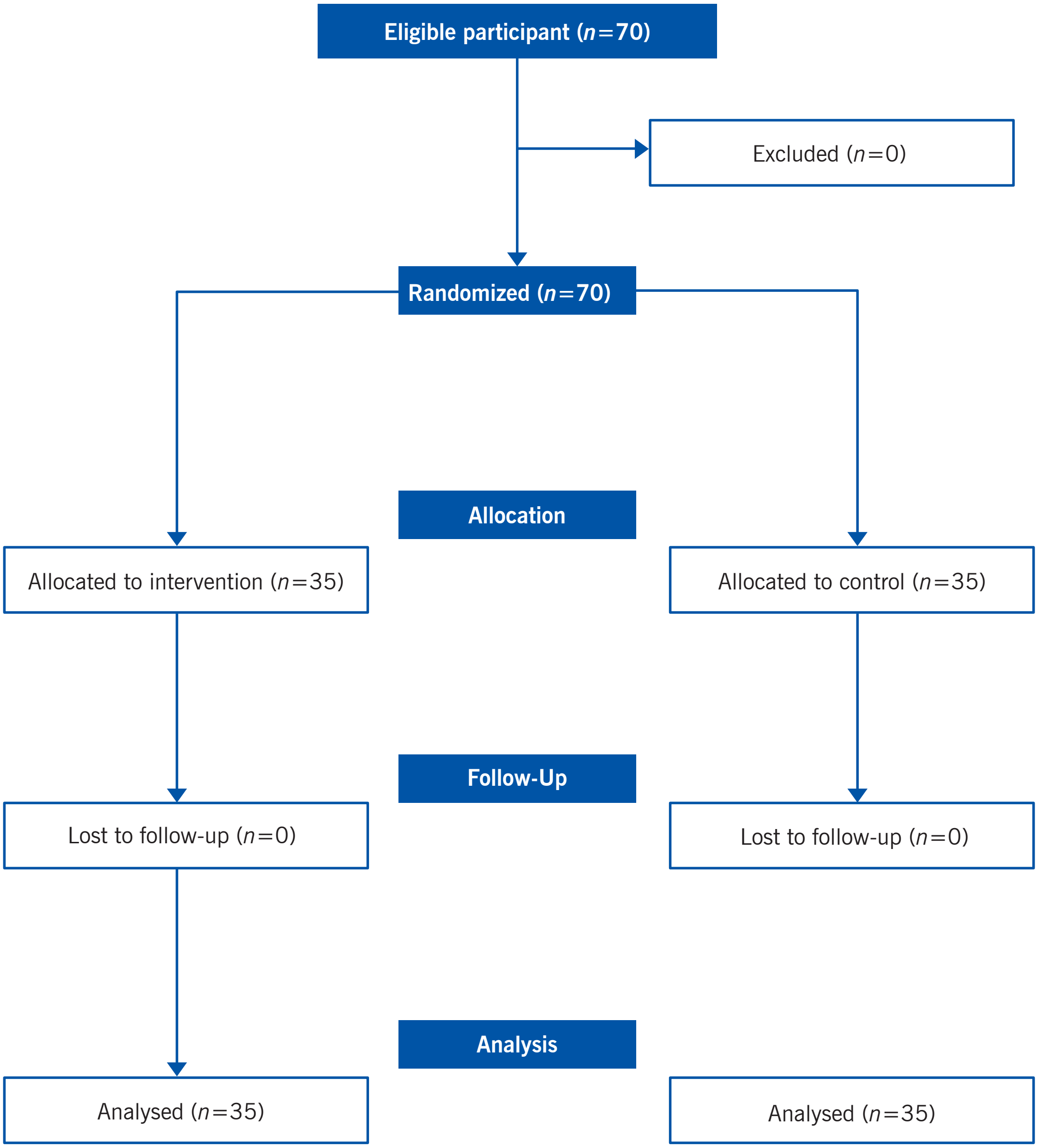

Figure 1. Flow Diagram of the study

Results

The average age of the experimental group is 30.5±5.14 years versus 29.3±5.1 years in the control group. The average of experience (in a year) for experimental group is 6.23±3.1 and in the control group, it is 5.9±2.8. The average of work time in the week for experimental group is 40.55 ± 2.2 and in control group, it is 38.41 ± 4.3. The amount of monthly salary for experimental group (in Tomans) is 1834600±61500 and in control group, it is 1822540 ± 51000. It has been determined that there is no meaningful statistical difference between experimental and control groups in terms of quantitative demographic information. Also, there is no meaningful statistical difference between the two experimental and control groups in terms of gender, marital status, number of children, shift conditions, and job satisfaction.

The results of how yoga classes influence the quality of intensive care unit nurses' lives are illustrated in Table 1. The global score of nurses' life qualities between groups before intervention has no meaningful statistical difference.

Table 1. Comparison of the intervention and control groups regarding the global and dimensions mean scores of WhoQOL - Bref by time

Dimension	Group	Time				Time by group p-value
		Before	One month	Two months	Six months	
Physical	Experimental	61.02±2.03	68.3±3.1	70.14±3.1	75.1±2.15	<0.001
	Control	62.3±2.9	61.1±3.04	62.1±2.3	59.3±1.52	
	Between group p-value	<0.05	<0.001	<0.001	<0.001	
Psychological	Experimental	62.2±3.1	70.01±2.6	73.3±3.0	73.2±1.88	<0.001
	Control	60.3±3.4	61.8±2.4	62.2±1.8	58.8±1.96	
	Between group *p*-value	<0.05	<0.001	<0.001	<0.001	
Social Relations	Experimental	63.01±2.2	71.2±2.9	72.6±2.8	73.8±1.95	<0.001
	Control	64.3±1.5	63.9±2.5	64.2±2.4	61.9±2.3	
	Between group *p*-value	<0.05	<0.001	<0.001	<0.001	
Environment	Experimental	62.9±2.05	73.04±2.1	75.5±2.4	74.05±2.00	<0.001
	Control	61.1±2.04	60.9±3.3	61.3±2.5	60.1±1.92	
	Between group *p*-value	<0.05	<0.001	<0.001	<0.001	
Global	Experimental	62.2±2.38	70.72±2.6	72.8±2.8	74.1±2.03	<0.001
	Control	62±2.46	61.9±2.8	62.4±2.2	60.4±1.9	
	Between group *p*-value	<0.05	<0.001	<0.001	<0.001	

As it is obvious, the average total score of nurses' quality of life in experimental group has increased meaningfully in 1 month and 2 months after interference comparing to that of prior intervention in the four dimensions of WHOQOL-BREF. Therefore, time was an effective factor for dimensions of this change, with respect to P-V which has become meaningful, it can be said that the changes process in experimental group comparing with this process in control group have a meaningful difference.

Discussion

There are several factors in every job that influence the job holder's quality of life. In the present study, the process of changes in nurses' general quality of life who work in intensive care units and in the time span of six months and earlier to the end of interferences showed the effectiveness of yoga exercises on the quality of their lives. Since there were not any significant differences between the two groups' biological variables, it can be said that changes in the general quality of service users' lives of yoga group were resulted from the interferences made more confidently. In similar researches also, the quality of different groups' lives has improved significantly by applying yoga interferences.(18,19) Lin(19) set to investigate the effect of 12 weeks of yoga exercises on controlling factors affecting quality of life like stress and strategies of coping with stress in mental health professionals that consequently showed positive effect of yoga training on these factors.

In this study, the comparison of two groups' averages before starting the interferences revealed that the condition of control group, in terms of general quality of life and its realms comparing to interference group, does not have any meaningful statistical differences. After eight weeks of training, total grade of quality of life and its realms in yoga group increased when compared to control group. In this investigation, and according to the findings, in four physical, psychological, social relations, and environment subscales, there has been a meaningful improvement in yoga group; and also there were more changes in this group than in the control group. This represents effectiveness of yoga program in augmenting nurses' quality of life. Although quality of life grade in the first month after trainings has improved remarkably, the changes in this group through two and six months later was not that much noteworthy. Considering that the yoga program for nurses was short-term, it seems that the reason lies in these trainings, not being long-lasting during their workdays.

In this study, meaningful statistical differences were seen between the two yoga and control groups in terms of physical, psychological, social relations, and environment subscales. A study by Tekur *et al.*(20) also admits this after a one month period of yoga exercises with the purpose of investigating the effect of yoga on physical, mental, emotional and intellectual dimensions and four physical, psychological, social relations, and environment subscales on the quality of life of patients suffering from chronic backache, a meaningful improvement was seen before and after interference. The findings of paired t-test in the study conducted by McDermott *et al.*(21) showed that after yoga trainings, the grade of quality of life in physical performance, physical role, general health status, and psychological role dimensions have had a great meaningful increase which corresponds with the findings of the present study.

In the study by Jyotsna *et al.*,(22) also yoga exercise were practiced with 49 patients suffering diabetes type 2 for six months, and results revealed that the average of body performance and role dimensions grew about 3 points that is statistically meaningful. Yoga can lead to increase in quality of life and the feeling of health in the whole body by adjusting automatic psychological, neural, immunity systems, enhancing body stability and resistance, and regulating immunity system.(23) Yoga exercises, in this study, resulted in improvements in physical and body dimensions. Because yoga body and breathing exercises enhances flexibility and muscular strength, improves circulation, oxygen absorption, and hormone system performance, and finally, it can boost both body performance and body role.(24) Evaluating the studies show that medical interferences concentrating on activity level (like yoga and progressive-resistive exercise) will have more positive effects on patients' abilities to do their daily works, and consequently on their quality of life.(25)

In the present study, a meaningful increase was seen in the average grades of psychological health and psychological role in yoga group comparing to control group. In the study by Jyotsna also, an increase in the average of two psychological health and psychological role after practicing the exercise has been reported.(22) These results adjust with that of other studies.(21,26). Due to the outstanding effect that yoga has in relaxing, people enjoy an endless calmness. Yoga is a set of exercises and body stretches that are accompanied by releasing psychological energies exercises. It emphasizes on the principle of balance between psychological and body powers as well as decreasing stress.(13) Therefore, it seems reasonable that after a period of yoga exercise, nurses' psychological health grade boosts. In this study, the effects of yoga on improving health, social relations, and environment's safety were positive and meaningful in a way that the grade of these two dimensions of quality of life in experimental group improved remarkably before interference up to six months after that. So, this finding adjusts with that of some researches so that it is said trainings led to this boost in social and environmental health dimensions.(27) Accordingly, yoga can be used as an effective, convenient, and inexpensive method to improve quality of life of these people.

Conclusion. The results of this study illustrated that yoga improve the quality of life of nurses working in Intensive Care Units. Considering the fact that nurses' job stresses grow every day and therefore, the expenses causing from them increase too, and also with respect to the advantages of yoga exercise like not containing any side effects, inexpensiveness, easy to do, availability, not being offensive, and applicability of exercise, it is very valuable, and, nurses can use yoga as an extracurricular activity.

Among the limitations of this research, we can name the selection of participants from the available and people who volunteered to take part in classes; so it cannot be considered as the representative of the whole society. This confines generalizing the results of this research to all nurses who work in intensive care units. It is suggested that appropriate yoga exercises be practiced in order to increase coping with job stress at home and medical centers by nurses so that continuing these exercises endures the effect of these exercises.

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Nurses' Moral Sensitivity Regarding the Terminally Ill

Original article

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Nurses' Moral Sensitivity Regarding the Terminally Ill

Abstract

Objective. The purpose, herein, was to determine the moral sensitivity of nurses when caring for terminally ill patients. **Methods.** Descriptive study conducted in the city of Cartagena (Colombia) with the participation of 118 nurses with minimum experience of six months in caring for the terminally ill in general hospitalization, caring for chronic patients, and intensive care units. The study used the 23-item questionnaire on Moral *Sensitivity in Nursing Care* – (*Sensibilidad Moral en el Cuidado Enfermero* -CuSMCE-23, in spanish) - by Campillo, which has six Likert-type response options (0 = total disagreement, to 5 = total agreement) and which has two dimensions: *Nurse values* (12 items) and *Care responses* (11 items). A higher score meant a higher degree of moral sensitivity. **Results.** It was found that 89.8% of the participants were women; 20.3% had a graduate degree; 39.8% had less

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than five years of care experience; 58.5% worked in a public institution – by type of service: 58.5% worked in general hospitalization; 32.2% in the intensive care unit; and 9.3% with chronic patients. The global moral sensitivity regarding the terminally ill in the study group was at 80%. By dimensions, while the *Values* dimension obtained 90%, the Care responses dimension only reached 70.4%, with the latter dimension showing difficulties in the items: 'Often, when I am with a patient, I talk about myself to be more comfortable' (27.1%), 'It is hard for me to accept certain decisions by the patients' (55.1%), and 'It is hard for me to identify concerns regarding the religious expression' (60.2%). **Conclusion.** Although the global levels of nurse's moral sensitivity regarding the terminally ill and of the dimension *Nurse Values* are high, the dimension of Care responses has limitations, especially in accepting the diversity of expressions presented by patients

Descriptors: nursing care, terminally ill, intensive care units; hospitalization; morals; ethics, nursing; surveys and questionnaires; cross-sectional studies.

Sensibilidad moral de la enfermera ante el enfermo terminal

Resumen

Objetivo. Determinar la sensibilidad moral de las enfermeras al cuidar pacientes terminales. **Métodos.** Estudio descriptivo realizado en la ciudad de Cartagena (Colombia) con la participación de 118 enfermeras con experiencia mínima de seis meses en cuidado al enfermo terminal en hospitalización general, cuidado al paciente crónico y trabajo en unidades de cuidados intensivos. Se utilizó el Cuestionario de 23 ítems *Sensibilidad Moral en el Cuidado Enfermero* (CuSMCE-23) de Campillo, el cual tiene seis opciones de respuesta tipo Likert (0 = desacuerdo total a 5 = acuerdo total) y dos dimensiones: *Valores enfermeros* (12 ítems) y *Respuestas de cuidado* (11 ítems). A mayor puntaje mayor grado de sensibilidad moral. **Resultados.** El 89.8% de los participantes fueron mujeres; el 20.3% había realizado un posgrado; el 39.8% tenía menos de 5 años de experiencia asistencial; el 58.5% laboraba en una institución pública. Por tipo de servicio: el 58.5% laboraba en hospitalización general; el 32.2%, en la Unidad de Cuidados Intensivos y 9.3%, en pacientes crónicos. La sensibilidad moral global ante el enfermo terminal en el grupo estudiado fue del 80%. Por dimensiones, mientras que en la dimensión Valores se obtuvo un 90%, en la de *Respuestas de cuidado* solo se alcanzó el 70.4%, teniendo esta última dimensión dificultades en los ítems: 'A menudo cuando estoy con el paciente hablo de mí misma para estar más cómoda' (27.1%), 'Me cuesta aceptar determinadas decisiones de los pacientes' (55.1%) y 'Me cuesta identificar inquietudes respecto a la expresión religiosa' (60.2%). **Conclusión.** Aunque el nivel global de sensibilidad moral de la enfermera ante el enfermo terminal y de la dimensión *Valores enfermeros* son altos, la dimensión Respuestas de cuidado presenta limitaciones, especialmente en la aceptación de la diversidad de expresiones que presentan los pacientes.

Descriptores: atención de enfermería; enfermo terminal; unidades de cuidados intensivos; hospitalización; principios morales; ética en enfermería; encuestas y cuestionarios; estudios transversales.

Sensibilidade moral da enfermeira frente ao doente terminal

Resumo

Objetivo. Determinar a sensibilidade moral das enfermeiras ao cuidar pacientes terminais. **Métodos.** Estudo descritivo realizado na cidade de Cartagena (Colômbia) com a participação de 118 enfermeiras com experiência mínima de seis meses em cuidado ao doente terminal em hospitalização geral, cuidado ao paciente crônico e unidades de tratamentos intensivos. Se utilizou o Questionário de 23 itens *Sensibilidade Moral no Cuidado Enfermeiro* (CuSMCE-23) de Campillo, o qual tem seis opções de resposta tipo Likert (0 = desacordo total a 5 = acordo total) e duas dimensões: *Valores enfermeiros* (12 itens) e *Respostas de cuidado* (11 itens). A maior pontuação maior grau de sensibilidade moral. **Resultados.** Se encontrou que 89.8% eram mulheres, 20.3% havia realizado uma pós-graduação, 39.8% tinha menos de 5 anos de experiência assistencial, 58.5% trabalhava numa instituição pública, por tipo de serviço: 58.5% trabalhava em hospitalização geral, 32.2% na Unidade de Tratamentos Intensivos e 9.3% em pacientes crônicos. A sensibilidade moral global frente ao doente terminal no grupo estudado foi de 80%. Por dimensões, enquanto que na dimensão Valores se obteve um 90%, na de *Respostas de cuidado* somente se alcançou 70.4%, tendo esta última dimensão dificuldades nos itens: 'Com frequência quando estou com o paciente falo de mim mesma para estar mais cômoda' (27.1%), 'É difícil aceitar determinadas decisões dos pacientes' (55.1%) e 'É difícil identificar inquietudes ao respeito à expressão religiosa' (60.2%). **Conclusão.** Embora o nível global de sensibilidade moral da enfermeira frente ao doente terminal e da dimensão Valores enfermeiros são altos, a dimensão *Respostas de cuidado* apresenta limitações, especialmente na aceitação da diversidade de expressões que apresentam os pacientes.

Descritores: cuidados de enfermagem; doente terminal; unidades de terapia intensiva; hospitalização; princípios morais; ética em enfermagem; inquéritos e questionário; estudos transversais.

Introduction

Human existence imposes the condition of finitude and with it disease and death may appear at any moment of life. In this sense, in Colombia, Legislation 1733 defines as terminally ill the "person with a disease of irreversible and progressive nature, not susceptible to curative treatment and of proven effectiveness, which permits modifying the prognosis of near death; or when the therapeutic resources used with curative purposes have ceased to be effective".(1)

Cases of patients with chronic noncommunicable diseases (CNCD) and terminally ill patients have increased in all regions of the world due to causes as diverse as increased life expectancy — which surpasses 80 years,(2) — tobacco use, sedentary lifestyle, harmful use of alcohol, and unhealthy diets.(3) In 2016, CNCD caused 71% of deaths in the world (40.5-million), 44% of which were due to cardiovascular disease, 22% due to cancer, 9% caused by respiratory diseases, and 4% due to diabetes.(4) Throughout the world, in 2017, 940 000 people died due to diseases related with HIV.(5) In Colombia, between 2005 and 2014, the principal causes of death in the general population were diseases of the circulatory system in 30.0% and neoplasm that caused 17.9 % of all deaths, with prevalence in adults between 27 and 59 years of age (71.2%) and people over 60 years of age (82.1%).(6) In the department of Bolívar, in 2014, the highest rate of mortality due to CNCD occurred due to ischemic heart disease, with 70.99 deaths in men and 45.47 deaths in women for every 100 000 inhabitants.(7)

The burden represented for the healthcare sector by said diseases in terminal stage increases the world's need for palliative care at global scale. Currently, it is estimated that 20.4-million people need these cares; 69% of them are adults over 60 years of age and 52% are of male gender. Europe concentrates the highest rates globally: approximately, for every 100 000 inhabitants, between 307.17 and 467.52 people require these cares, followed immediately by countries from the western Pacific region with between 281.64 and 307.16 people and those from the region of the Americas with between 272.66 and 281.64 people. The need for palliative care is concentrated at 38.4% in patients with cardiovascular disease, 34.0% in patients with cancer, and the rest due to pathologies, like HIV/AIDS, diabetes, and Alzheimer's, among other CNCD.(8) In terminal stage, the person endures numerous and diverse multifactor symptoms, which are changing and, often, cause the loss of their autonomy and quality of life, leading them to the maximum of their vulnerability. The care provided during this phase of the disease is no longer focused on the recovery of health, but on achieving the best quality of life possible for the patients and their families(8) and facilitating the construction of experiences that lead to a serene end of life.(9)

Regarding the terminally ill, nurses must have the moral sensitivity that allow them to be intuitive, perceiving and being alert to their needs to respond physically, emotionally, and professionally with moral attitudes and behaviors, like empathy, comprehension, and self-awareness,(10) which help them to understand the fragility of the people and to be aware of the implications of the moral decisions made in favor of the patient.(11) In nursing, moral sensitivity permits a nurse-patient relationship centered on trust and the availability to respond to individual needs, which enables or limits the patient's autonomy to protect them in their vulnerability.(11) A low degree of moral sensitivity may cause nurses to have difficulties in distinguishing between a situation of moral nature from another that is not, that the moral component goes unnoticed or the absence of adequate decision making in favor of the patient; above all, when patients do not accept their disease or the treatment.(12) In this sense, moral sensitivity stands out as an essential aspect to care and recognize dignity to the individual at the end of life, especially when said person has the autonomy to give up unnecessary medical treatments, without therapeutic proportionality, and which do not represent a dignified life.(1)

Factors determining moral sensitivity include gender, age, professional experience, and type of clinical practice.(13) Regarding gender, Lutzen(14) finds that women show greater subjectivity in their moral reasoning, prioritize the interpersonal relationship, individualize and particularize care, expressing greater moral sensitivity through actions that seek protection of the patient's vulnerability and decision making under the principle of integrality. Men manifest moral sensitivity with greater objectivity: assume moral actions from the obligatory, conceiving autonomy and rules in decision making as priority.(14) Perception, as condition present in moral sensitivity, permits nursing professionals –men or women- to give meaning to their intuition and observation of the care experience from a particular perspective of their values and beliefs; helping them to comprehend the moral dilemmas generated around the patient, as well as discerning about the decisions that must be made and their consequences.(11)

In relation with the perception of caring for the terminally ill, Souza *et al.*(15) describe that nurses participating in their study observed that terminally ill patients endured death with much pain when extraordinary measures were used in treating patients who were not recoverable, with indiscriminate use of advanced therapies that only prolongs the dying process. Bedregal and Zúñiga(16) found that the fear of death impacts upon the moral sensitivity, increasing uncertainty, anxiety, and the perception of this event as a dilemma, which hinders decision making. The purpose of caring for the terminally ill is to propitiate that the cease of biological life does not mean pain and despair, but for it to have a spiritual transcendence for patients and their families. From these considerations, the aim of this study was to determine the moral sensitivity of nurses who care for terminally ill patients.

Methodology

This was a quantitative study with descriptive design, with the participation of 118 nursing professionals from the services of general hospitalization, care for chronic patients, and intensive care and with at least six months of experience in caring for the terminally ill. The study was conducted in Cartagena (Colombia) during 2017, in five health institutions, one public and four private (two in tier II of care and three in tier III of care, which authorized through written communication the collection of the information. To select the participating institutions, the study kept in mind the hospital centers concentrating the highest number of terminally ill patients. Two research aides participated in collecting the information after receiving training on aspects inherent to this process. The research was estimated without risk;(18) nevertheless, the nurses working in the institutions selected were explained the study objectives and the possibility of withdrawing their participation if they so desired. Thereafter, they signed the informed consent and proceeded to fill out the sociodemographic survey and the Questionnaire on Moral Sensitivity in Nursing Care (*Sensibilidad Moral en el Cuidado Enfermero* -CuSMCE-23, in spanish).(17)

CuSMCE has 23 statements that evaluate the moral sensitivity of nurses in the dimensions of "values" (12 items) and "care responses" (11 items), with an internal consistency of 0.83 and Pearson's r coefficient of 0.86.(17) In this study, the Cronbach's alpha obtained was 0.77 and by dimensions it was 0.78 for values and 0.70 for care responses. Each item was evaluated in a Likert-type scale with six response options, where zero corresponds to "total disagreement", one means "considerable disagreement", two is "slight disagreement", three denotes "slight agreement", four is "considerable agreement", and five corresponds to "total agreement".(17) The data were grouped so that the response options "considerable agreement", "slight agreement", and "total agreement" are represented by the term "agree" and the options "total disagreement", "slight disagreement", and "considerable disagreement" are identified with the term "disagree". The data collected were analyzed in the SPSS statistical package, version 21.0. The global score of values of the instrument ranges between a minimum score of 0 and a maximum score of 115, for the dimension of values between 0 and 60 and the dimension of care responses between 0 and 55. Bearing in mind that the score exceeds 50% of the maximum score, it was considered that scores above 58 points indicate high degree of moral sensitivity; above 31 is interpreted as high degree for the dimension of values and for care responses a score >28.

Results

From the general characteristics of the 118 participating nurses, 89.8% were women; 85.6% were between 20 and 40 years of age; two in every 10 received graduate formation; six in every 10 had over five years in nursing care; and 58.5% work public hospitals in general hospitalization wards (Table 1).

Table 1. Sociodemographic characteristics of 118 nurses caring for the terminally ill

Characteristics	Frequency	%
Sex		
Female	106	89.8
Male	12	10.2
Age in years		
20-30	52	44.1
31-40	49	41.5
41 and more	17	14.4
Level of formation		
Undergraduate	94	79.7
Specialist	24	20.3

Table 1. Sociodemographic characteristics of 118 nurses caring for the terminally ill (Cont.)

Characteristics	Frequency	%
Work experience in years		
0-5	47	39.8
6-10	35	29.7
11-15	17	14.41
16-20	5	4.24
20 and more	14	11.86
Work area		
Chronics	11	9.3
Hospitalization	69	58.5
ICU	38	32.2
Institution		
Private	49	41.5
Public	69	58.5

The average moral sensitivity found in nurses participating in the study when confronted with a terminal patient was of 92±8.6 points (minimum = 73 and maximum = 110). Regarding the dimensions, in Values an average was found of 54±4.8 points (minimum = 41 and maximum = 60) and in *Care responses* an average was obtained of 38.7±6.1 points (minimum = 24 and maximum = 52). The global score obtained by the participants for moral sensitivity was of 80.0%; for the items contained in the dimension of *Values*, it was of 90.0% and for the Care responses it was of 70.4% (Table 2).

Upon evaluating the dimension of Values, it was found that 100% of the male and female nurses, regarding the terminally ill, agree that in the work setting, it is fundamental to show an attitude of support, establish a relationship of trust, help them to express their concerns to the physician, to realize that they are unique beings, to being attentive to the patients' expressions to perceive their needs and support them in times of suffering. Between 90% and 99.2% manifested agreement in expressing to the patient their availability as professionals, having the ability to perceive that which worries the patient, demonstrating sincere interest for the patient, and trying to reach a nurse-patient relationship based on honesty. In relation to having time to sit by the patients and listen to them, and feeling bothered when hearing that patients are referred to by their diagnosis had a value <86% (Table 2).

With respect to the dimension of *Care responses,* it was found that in front of the terminal patient, more than 84% of the participants stated agreement in having to address the person they are caring for in a calm and unhurried voice, demonstrating special interest in proving them comfort, helping them to identify their strengths and capabilities, and debating the patients' care concerns directly with the physicians implied. Between 60% and 72.0% of the nurses in the study considered that while they are caring for a patient, their head is someplace else; they believe that sometimes they impose their values; they minimize patients' feelings to avoid their being stressed; they sense difficulty to being available to listen to their feeling; they sense difficulty to identify concerns with respect to religious issues; and often when they are with the patient, they talk about themselves to feel more comfortable; for an average of 55.1% of the participants it is difficult to accept certain decisions by the patients (Table 2).

Table 2. Proportion of nurses caring for terminally ill patients who agree with the statements in the QuMSNC-23 scale (*n* = 118)

Dimension / items	Percentage
Dimension of Nurse Values	
For me, it is important as a nurse to express to the patient my availability as professional	99.2
In my work setting, I consider it fundamental to show the patient an attitude of support	100
In my work setting, I consider it fundamental to establish a relationship of trust with the patient	100
I believe that as a nurse, I must help patients express their concerns to the physician	100
I have a special interest in helping patients realize that each being is unique	100
I have the ability to perceive what worries the patient	98.4
I feel that I must assure patients that as caregiver I will be available to support them in times of suffering	100
Being attentive to the patients' expressions helps me to perceive their needs.	100
It bothers me to hear patients being referred to by their diagnosis.	85.7
It worries me not to have time to sit by the patients and listen to them	88.4
I feel I must show sincere interest for the patient	97.5
I need my relationship with patients to be based on honesty	97.5
Dimension subtotal	90.0
Dimension of Care Responses	
It is difficult for me to be willing to listen to the patient's feelings	67.8
It is hard for me to identify concerns regarding the religious expression	60.2
As a nurse, I think it is not my place to debate the patient's care concerns directly with the physicians implied	84.7
Sometimes, I believe I impose my values on patients	74.6
Often, when I am with a patient, I talk about myself to be more comfortable	27.1
I try to address patients in a calm and unhurried voice	96.6
Sometimes, I feel I must minimize the patients' feelings to avoid their being stressed	67.9
I think it is important to help patients to identify their strengths and capabilities	89
I have a special interest in providing comfort to the patients	95.8
Sometimes, I am caring for a patient, but feel my head is someplace else	78
It is hard for me to accept certain decisions by the patients	55.1
Dimension subtotal	70.4
Scale Total	80.0

Table 3 shows the total average and averages by dimensions of the CuSMCE-23 were only significantly different in the dimension of *Care responses* by type of institution, where the private institution had a higher score than the public. Generally, it may be stated that the moral sensitivity score was higher in women, increases with the person's age, is higher in nurses who only have an undergraduate degree, improves with years of work experience; by type of services, it is superior in chronic care, and by type of institution, the score is higher in private institutions.

Table 3. Average of the total score and by domains of the CuSMCE-23 scale according to variables of interest (*n*=118)

Characteristics	Total	Dimension	
		Values	Care Responses
Total	92.7±8.6	54.0±4.8	38.7±6.0
Sex			
Male	91.4±11.1	52.5±6.1	38.9±6.5
Female	92.8±8.3	54.2±4.6	38.6±6.0
p value	0.677	0.362	0.879
Age in years			
20-30	91.3±7.6	53.3±4.5	38.1±5.4
31-40	93.2±9.4	54.2±4.8	39.0±6.4
41 and more	95.3±8.9	55.9±4.9	39.4±6.8
p value	0.224	0.121	0.665
Level of formation			
Specialist	91.8±9.2	52.6±5.3	39.3±6.2
Undergraduate	92.9±8.5	54.4±4.6	38.5±6.0
p value	0.602	0.128	0.576
Work experience in years			
0-5	91.3±8.2	53.2±4.7	38.1±5.3
6-10	92.8±8.2	53.6±4.6	39.2±5.7
11-15	95.2±9.2	55.9±4.2	39.3±7.1
16 and more	93.6±9.7	55.2±5.4	38.4±7.2
p value	0.425	0.150	0.821
Work area			
General hospitalization	91.6±8.7	53.9±5.1	37.69±5.9
ICU	93.9±8.1	54.2±4.4	39.7±6.1
Chronic care	95.4±9.1	54.0±5.0	41.5±4.8
p value	0.219	0.955	0.57
Institution			
Public	91.5±8.9	53.9±5.1	37.6±6.0
Private	94.3±8.0	54.2±4.4	40.1±5.7
p value	0.079	0.691	0.028

Discussion

The moral sensitivity determined in the nurses participating in the study was of 92.7±8.6 points and corresponds to 80% of the study participants. In this regard, Tas Arslan,(19) in a study on moral sensitivity conducted with pediatric nurses, found a total median score of 95.89 ± 24.34, which determined that over half of the nurses consider themselves competent to recognize and solve ethical problems, supported on their own knowledge or on the participation from the members of the health staff. Dalla(12) found that primary-care nurses have moderate moral sensitivity and express it in the dimensions "interpersonal orientation", which centers on the construction of a relationship of trust with the patient, and on "professional knowledge" as base to elaborate ethical judgment in care. This author describes, additionally, that conflict and moral significance are the dimensions that denote lower level of moral sensitivity, reflected on the difficulty nurses have in experiencing moral conflicts, understanding them, and assigning them moral content.

With relation to the moral sensitivity and with the population studied not having the maximum degree of moral sensitivity (100%), it is necessary to reflect on which aspects influence positively or negatively on its presence. Park and Kjervik(20) showed in their study that moral sensitivity increases with ethical education, with higher-semester nursing students registering higher scores compared with first-year students. Thus, they conclude that if there is greater formation, reflection, and discussion around ethical themes in the students and the alumni professionals, an increase could be noted in their level of moral sensitivity in the care relations.

As in other studies,(12,13,17,21) the participants were mostly women and although no statistically significant difference was evidenced, they had higher results in total moral sensitivity and in the dimension of values, which is relevant to highlight because being a woman could be a determining factor in moral sensitivity, given that Lutzen(14) indicates a difference between the female and male genders in the way of establishing the physician-nurse-patient relationship and making decisions based on medical and nursing knowledge. Tas Arslan(19) reports that participating female nurses had holistic approaches and a higher moral sensitivity compared with male nurses. Gilligan,(22) in the theory of the ethics of care, expresses that the moral reasoning between men and women is different, arguing that men, generally, bear in mind impartiality I the moral action guided by judgment towards the just, the unjust, and the obligatory. Women, instead, tend to do it from the sphere of the particularity and protection of human fragility. Campillo.(17) differs from the idea expressed previously, given that her research studied the relation between moral sensitivity and gender and reached the conclusion that men and women respond equally when asked about their moral sensitivity in nursing care.

The participants in this study are mostly young adults between 20 and 40 years of age with professional experience under 10 years. In this respect, Lutzen,(11) in relation to age and professional experience, indicates that moral sensitivity increases with age, is developed by experiences, and is expressed differently in groups, that is, each person can conceive differently the importance of the relationship with the patient, respect to autonomy, and becoming aware of the moral consequences. Sayers,(23) however, considers that the biological age does not determine a professional's level of sensitivity or insensitivity, as do their life experiences and the development of their knowledge, which allow them to create moral conscience of themselves and of the rest. According to said study, nurses were unanimous when expressing that one became a "sensitive being" with experience and as their practice advanced. These findings lead to thinking that female nurses and young male nurses, with less experience in the professional exercise, could have difficulties distinguishing problems of moral nature from those that are not, as well as making ethical decisions when offering care, above all in the terminal disease context.

In this study, the score de moral sensitivity in nurses working in a private institution and in chronic care units was higher than that of those working in a public institution and in general hospitalization. The study by Molouk(24) reports ethical conflict when the institutional values that are part of the work environment are related with the nurses' values, Dalla(12,13) expresses the need to reflect about the organization, its sustainability, and conformation, given that nurses often make clinical decisions bearing in mind their personal principles and values, but these can lead to conflicts with the staff, the directors, and families of patients. The concern nurses show about the personal and organizational norms, expresses high ethical sensitivity in the safety and care of patients, and the relationships among coworkers. Within the setting of nursing care, the study of moral sensitivity can help to create and consolidate work teams and to generate environments and strategies that favor an ethical climate, which contribute to maintaining and increasing the quality of care, (17) which can be affected by high levels of work stress and anxiety(24) because a high level of moral sensitivity could help nurses to confront the situation and defend their autonomy and moral integrity.

The degree of moral sensitivity determined by the dimension of Values in the participating nurses corresponds to 90%, a higher finding than that published by Campillo,(17) who reported 75.7%. Most of the participants consider that moral sensitivity in caring for the terminally ill is based principally on values because, for them, being morally sensitive implies having professional availability, establishing interpersonal relationships of trust, supporting the patient —above all in times of suffering—, being attentive to their needs and, even, appropriate communication with the physician. A similar finding was obtained in another study(17) in which the items with higher score over moral sensitivity were, in their order: "in my work environment, I consider it fundamental to show the patient an attitude of support", "I believe that as a nurse, I must help patients to express their concerns to the physician", "in my work environment, I consider it fundamental to establish a relationship of trust with the patient", "for me, it is important – as a nurse – to express to the patient my availability as a professional", "I feel I must assure patients that, as a nurse, I will be available to support them in times of suffering", and "being attentive to patients' expressions helps me to perceive their needs".

According to that expressed by Campillo,(17) the moral sensitivity of nursing professionals in any care activity is evidenced through values of responsibility, honesty, and trust; this aspect coincides with the ideas by Watson,(25) who expresses that care must be based on a system of humanist-altruist values that grant nurses the possibility of giving and receiving, appreciating the whole diversity of life and their individuality. Elliott,(26) in turn, in a systematic review, found that respect, altruism, honesty, responsibility, compassion, commitment, trust, and social justice are values that give identity to the nursing professional. For the participants, particularity and individuality are significant in caring for the terminally ill, given that the majority considered it important to recognize that each being is unique and should not be subordinated to a medical diagnosis. This contrasts with that found by Campillo,(17) who reports a lower score in the items "I have a special interest in helping patients realize that each being is unique" and "it bothers me to hear patients being referred to by their diagnosis".

When caring for the terminally ill, nurses confront the vulnerability, needs of the patient and the different ethical dilemmas involving each particular situation; perceiving these and providing care responses evidences their degree of moral sensitivity.

This study found an average of 38.7, which corresponds to 70.4% of moral sensitivity —similar data to the 70.7% found in a study(17) about care responses. In research like this, most of the nurses agreed that in front of terminal patients it is necessary to show a calm attitude, provide comfort to the sick, and help them identify their strengths and capabilities. Likewise, they harmonize in that related aspects on being morally sensitive in nursing means having attitudes, like patience, active listening, observation, openness, and transparency, seeking comfort, tact, comprehension and promotion of self-esteem;(23) a peaceful end-of-life experience is achieved when nurses provide wellbeing by preventing, controlling, and relieving physical discomfort, facilitating rest, satisfaction, and preventing complications in patients.(9) At the end of life, it is necessary to seek a calm environment and an atmosphere of serenity and peace; for such, nurses will strengthen the family bond and that of friends, will meet the desires and preferences, and the needs for communication of patients and their families; likewise, nurses must support patients in their construction of sense, that is, help them to resignify death, what is left of life and plan it near death.(9)

Over half the nurses who participated in this study believe that sometimes they impose their values on the patient, it is difficult for them to identify concerns with respect to religious expressions (candles, fasting, or feeding practices) and accept certain decisions by the patients. In the study by Campillo,(17) nurses expressed difficulty in accepting and respecting expressions regarding the beliefs and values of the people. These care responses mediated by particular values and beliefs indicate that nurses would be upon an ethical conflict and of values with respect to those professed by the patient, given that many of the decisions made regarding care do not always agree with the patient's system of values.

Conclusion. The nurses participating in this study have high moral sensitivity to care for patients in terminal state. The dimension of values evidences the respect for the beliefs and values of the people and for their capacity to decide. The results obtained in the dimension of care responses show that the study participants have difficulties in accepting the diversity of expressions emerging while caring for patients. Within the setting of nursing care, this study of moral sensitivity indicates that strategies must be formulated to favor an ethical climate and which contribute to improve the quality of care, which can be affected by high levels of work stress and anxiety, given that a high level of moral sensitivity could help nurses to face the situation and defend their autonomy and moral integrity.

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Family orientation group as a strategy for care in chemical codependency

Original article

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Family orientation group as care strategy in chemical codependency

Abstract

Objective. To determine the importance of the family support group in the treatment of codependency, based in reports made by relatives of a therapeutic community for drug addicts. **Methods.** Study conducted in a therapeutic community for alcohol and other drug addicts in a city in the southern extreme of Brazil. This is a qualitative, exploratory and descriptive research with eight drug addict relatives. Data collection occurred through semi-structured interviews and the use of a field diary, focusing on the family orientation group as a space for the health promotion of family members of psychoactive substance users. **Results.** Through discursive analysis, it was found that the family orientation group constitutes an important tool of educational character, capable of responding to the family demands of chemical dependence, as well as rethinking and modifying attitudes and characteristic

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behaviors of co-dependence. **Conclusion.** The support group is fundamental as a care strategy for codependent families, and may act more effectively when professionals are trained to intervene in the phenomenon of codependency.

Descriptors: family; substance-related disorders; codependency (psychology); therapeutic community; family therapy; communication; qualitative research.

Grupo de orientación familiar como estrategia de cuidado en la codependencia química

Resumen

Objetivo. Conocer, a partir del relato de familiares de una comunidad terapéutica para dependientes químicos, la importancia del grupo de apoyo familiar en el tratamiento de la codependencia. **Métodos.** Este estudio se realizó en una comunidad terapéutica para consumidores de alcohol y otras sustancias en una ciudad del extremo sur en Brasil. Se trata de una investigación cualitativa, descriptiva, con la participación de ocho familiares de dependientes químicos. La recolección de datos se realizó con entrevista semiestructurada y con el uso del diario de campo, teniendo como foco el grupo de orientación familiar como un espacio para la promoción de la salud de familiares de usuarios de sustancias psicoactivas. **Resultados.** En el análisis discursivo, se constató que el Grupo de Orientación Familiar es una importante herramienta de carácter educativo, capaz de responder a las demandas familiares sobre la dependencia química, así como repensar y modificar actitudes y comportamientos característicos de la codependencia. **Conclusión.** El apoyo grupal es fundamental como estrategia de cuidado a las familias codependientes y puede ser aún más eficaz cuando los profesionales son capacitados para intervenir el fenómeno de la codependencia.

Descriptores: familia; trastornos relacionados con sustancias; codependencia (psicología); comunidad terapêutica; terapia familiar; comunicación; investigación cualitativa.

Grupo de orientação familiar como estratégia de cuidado na codependência química

Resumo

Objetivo. Conhecer, a partir do relato de familiares de uma comunidade terapêutica para dependentes químicos, a importância do grupo de apoio familiar no tratamento da codependência. **Métodos.** Trata-se de uma pesquisa qualitativa, exploratória e descritiva com oito familiares de dependentes químicos. A coleta de dados ocorreu por meio da entrevista semiestruturada e pelo uso do diário de campo, tendo como foco o grupo de orientação familiar como um espaço para a promoção da saúde de familiares de usuários de substância psicoativas. **Resultados**. Mediante análise discursiva, constatou-se que o Grupo de Orientação Familiar se constitui em uma importante ferramenta de caráter educativo, capaz de responder as demandas familiares da dependência química, bem como repensar e modificar atitudes e comportamentos característicos da codependência. **Conclusão.** O grupo de apoio é fundamental como uma estratégia de cuidado às famílias codependentes, podendo atuar de modo mais eficaz quando os profissionais são capacitados para intervirem no fenômeno da codependência.

Descritores: família; transtornos relacionados ao uso de substâncias; dependência mimética; comunidade terapêutica; terapia; familiar; comunicação; pesquisa qualitativa.

Introduction

Dependence on psychoactive substances is a phenomenon that affects not only the user, but also the family environment, causing changes in the routine and behavior of family members. Given the dysfunctional relationship that is established, many families are unable to disentangle themselves from the suffering caused by chemical dependency, becoming what we call codependents. Codependency is defined as a set of pathological patterns, behaviors and thoughts, characteristic of family members or people living directly with drug addicts, which lead to psychological distress.(1,2) Although there is no definition of codependency in the DSM-5 and ICD-10, the literature has shown us that chemical dependence may lead family members to illness.(3,4) Therefore, because it is a problem that translates into suffering for the codependent's life, it is important to consider that he / she also needs professional care, since it significantly changes his or her lifestyle, not only with regard to the interaction with the user, but also in relation to other people.(5)

Focusing on professional care on drug users only, fragments and hinders the effective treatment of chemical dependence. Codependents condition their lives around the drug user and, as a result, they no longer have a life of their own. In this context, the family that should be an important ally in the treatment of drug addicts, can no longer support and care them, since it is also suffering a pathological process, having unconsciously allowed the deepening of pathological and dysfunctional relationships. Therefore, by recognizing the family, as a social group that may be sick, highlights the need for social programs. Drug use by one of the family members invariably reveals the fragility of family dynamics. Such vulnerability shows the need to include this social group into treatment, not only as those who have socially defined roles and functions and who may not be able to perform them. The drug addict family must be inserted in the practice of care related to chemical dependence.(6) Despite the increase in the number of studies on this subject, initiatives that give recognition to this family member as an individual who also requires help are incipient, a fact that justifies an important knowledge gap, highlighting the need for greater scientific production on this subject.

The family has been using the health care network to counter the effect (physical and mental symptoms) of the dependent and not the cause (behavior towards the dependent). This behavior may reveal a disease and consequently compromise the quality of life of family members, a fact that justifies the relevance of the study. Health services, in turn, provide care to family members, focusing their approach on drug addicts; there is no actions directed to family members who are codependents. Thus, the family guidance group comes to promote health to those family members who are sick due to chemical dependency.

This study aims to know, from reports made by family members who are part of a therapeutic community for drug addicts, the importance of the family orientation group (FOG) in the treatment of codependency. This is a study whose approach seeks to characterize the FOG as an educational and participatory space, standing out as a key element for health promotion.

Methods

A qualitative, exploratory and descriptive study developed with relatives of drug addicts under treatment, in a therapeutic community of southern Brazil. The studied case describes the history lived by families, based on phenomena such as chemical dependence, composing facts, data and information, focusing on the author's final objective, which is to show these data and to evidence what they caused in family functioning over the course of time.

From the point of view of its purpose, the present study can be classified as exploratory, since studies that contemplate drug addicts do not consider the possibility of family illness. This gap justified the need to know the manifestations of codependency in family members of drug addicts. The research was developed in the FOG of a therapeutic community, which is responsible for the treatment of male drug addicts, over 18 years old. This community is located in the southern extreme of Brazil, in the municipality of Rio Grande / RS, which, according to data from the Brazilian Institute of Geography and Statistics, has a population of approximately 200 000.(7) It is a city port located between Lagoa Mirim, Lagoa dos Patos (the largest lagoon in Brazil) and the Atlantic Ocean. Its channel is the only link between the maritime and inland navigation routes of the state.

Following the authorization of the therapeutic community coordinator and the favorable opinion of the Rio Grande Federal University Research Ethics Committee, under the CAEE 52761515.0.0000.5324, a first approach was made in order to know the functioning of the FOG and to present the survey to family members.

In the study participated eight relatives of drug addicts, users of multiple drugs, who were previously identified as codependents, from the literature, the knowledge arising from the researcher's professional practice and the speeches identified during the group. The following inclusion criteria were used: family members of alcohol and other drug addicts, over 18 years old who were attending the therapeutic community family guidance group, who agreed to participate in the study and had characteristics of codependents, such as: denial, shame, guilt, fear, anger and low self-esteem.

Family members who did not maintain the minimum attendance frequency in 3 monthly meetings were excluded from the study due to the FOG being held once a week. Also were excluded participating family members under 18 years old, as well as those who did not show co-dependency characteristics. Interviews were started with those family members who manifested characteristics of codependency. The FOG during the observation period of the codependent participants had an average number of 31 relatives. During this period, the group addressed situations experienced with the chemical dependent family member, routine, emotional status, family perspectives and past life experiences.

From the reports involving these themes and the observations that the interviewer evaluated as pertinent, it occurred the identification / selection of the family member with codependency characteristics. Participation in the groups occurred during the months of May and June 2017, weekly from 19h to 21h. The type of bond between participants and drug addicts were: father, mother, daughter, sister, wife and paternal aunt. To preserve their identities, study participants were identified by the letter "F" (family member) followed by the interview sequential number. The study participants were asked to sign the informed consent form, after the researcher informed them about the objectives and methodology of the study, clarifying about their freedom to give up at any time, without personal consequences.

The techniques used were the semi-structured interview and field diaries records, which served to facilitate the identification of codependent families. For the semi-structured interview, a script consisting of twelve guiding questions was used. The script was related to the interviewee's perception of the situation experienced, feelings about the situation of chemical dependence of the family member and how family life has been affected since the problem arose. The interviews lasted an average of one hour and were recorded with the consent of the participant and took place in a private environment in order to allow an approach without external interventions. After transcribing the interviews, the data were subjected to discursive textual analysis, through rigorous reading, in-depth analysis and its deconstruction, highlighting the units of analysis.

Results

Regarding the characteristics of family members participating in this study, six were female and two male, aged between twenty-four and fifty-six years old. Family income ranged from one to five minimum wages. Most have incomplete elementary education and 50% of family members live with the drug addict.

Table 1. Sample of family members interviewed

Informant relative	Family bond with the dependent	Age	Family income (mínimum wage = R$ 937)	Educational level	Resides with the dependent
F1	Wife	24	2 minimum wages	Complete high school	Yes
F2	Mother	59	1 minimum wage	Incomplete elementary school	Yes
F3	Paternal aunt	67	3 minimum wages	Complete high school	Yes
F4	Mother	48	2 minimum wages	Incomplete elementary school	Yes
F5	Father	56	5 minimum wages	Incomplete elementary school	No
F6	Father	54	1.5 minimum wages	Incomplete elementary school	No
F7	Daughter	34	2 minimum wages	Complete high school	No
F8	Sister	33	2 minimum wages	Incomplete elementary school	No

In the data analysis process, the following category emerged: Importance of the family group as a care strategy for the codependent family member.

The results show that, from the moment the family members participate in the FOG, there is a change in their conduct. All family members who composed this research were emotionally dependent on their sons, daughters, wives, siblings. For the most part, they could not maintain their identity and autonomy and began to live the life of the drug addict. According to family members: *"the support group has helped a lot, we see a change. After I started attending the group I feel good. There is not much discussion at home today. Before that, it was from morning to night"* (F2).

Considered as a health-promoting and beneficial space for support seekers, F2 seems to have changed her behavior from the moment he discovered that her attention was focused solely on his son, who had been causing constant family quarrels with the support from FOG, F2 can discover new ways for building healthy relationships with the dependent family member. The conversation shows that over time, she noticed improvements in her mental health and some personal growth, which probably reflected in the quality of self-care, revealing the reorganization of family dynamics in order to break with the vicious cycle of a dysfunctional system.

To F3, the problem experienced by the family member, affects the other relatives and, therefore, need follow-up: *"I think that if everyone who lives at home attended the meetings, it would be better"* (F3 - paternal aunt). The statement presented, reinforces the idea that the behavior manifested towards the dependent may represent a disease and, consequently, compromise the quality of life of all family members.

When the family member seeks help to break the dysfunctional cycle, it is usually in the support services that they find it. However, they do not always seek to modify their behavior towards the dependent. It is observed in the statements below that family members seek the FOG as a "distress call", when they realize that chemical dependence has caused them suffering. F6 can reevaluate feelings, needs, reestablish limits that until then, he denied due to the dependence of the child. F7, rescued values that until then, he had lost in his role as a father. F8, by recognizing herself as a codependent, was able to better address his brother's drug addiction problem in a healthy and proactive manner: *"The group has helped us in what we need, for example, to get closer, talk more, learn more about our own family..."* (F6 - Father); *"My life before I became codependent on my mother was quiet, I was a happy person, I was not ashamed. Then I started to be ashamed, I didn't finish what I had to... If it wasn't for this group help, I wouldn´t feel as good and calm as I am now in this interview"* (F7 - Daughter); *"I consider myself a codependent because I am living his life, leading my brother's life. Certainly, the group helps us by learning how to help and to support my brother without harming me"* (F8 - Sister).

The codependent needs to realize and acknowledge that, its relationship with the drug addict is pathological, and that its efforts to help and protect him are doomed to failure, due to their inability to care because they are also ill. Therefore, it is clear that with the help of the group, the family member can identify the difficulties arising from living with the drug addict, admitting that the disease affected him, making him a codependent. Reports show the relevance of family participation in treatment, especially when someone becomes ill due to their family member.

Discussion

The results allow to infer how much families mobilize due to the problem, becoming affected with the behavior of the dependent family member.[8-10] Due to the conflicts experienced by chemical dependence, attempting to overcome these conflicts and seeking for family reorganization, it is that families may find in the family orientation group the care they need.[11,12] It should be noted that the problem experienced by a family member usually affects the other family members, shifting the perception sense of individuality; even if each one tries to maintain it, it is difficult to do so, due to the bond that permeates these relationships,[13] corroborating F3's statement.

In the process of illness, family members experience situations such as anguish, conflicts, fears, doubts. Therefore, they require a therapeutic space to be heard and helped.[4] That is why the treatment should be systematic, because if the family fails the drug user will fail as well. Because of this lack of support for families, many of them become codependent on drug addicts.

(14) Recognition of every individual's limitations is essential for the health restoration and the pursuit of quality of life. However, to obtain an effective result, professionals need to be able to address the phenomenon of codependency, taking into account the family's life history and the aspects involved, in order to better understand family functioning.(15,16) It is important to emphasize the fact that, when the codependent makes himself more available to others than to himself, creates a permissive profile that, in most cases, prevents the drug user from assuming responsibility for its actions. This difficulty recognizing the disease, and therefore the drug user does not seek treatment.(3)

As limitations of the study, it is worth mentioning that the research was conducted just at one location, not being explored in other units, such as the psychosocial care centers and other therapeutic communities provided with health professionals. However, the study drew attention to the rethinking of professional practices and nursing / health research, since family codependency is present in all spaces. Still, the focus is concentrated on the dependent.

The study sought to highlight the importance of the support group as a care strategy for codependent families. This may act more effectively when professionals are trained to intervene in the phenomenon of codependency. As indicative for the practice of nursing/health, the findings provide subsidies that may contribute to the elaboration of intervention strategies, subsidizing the identification of family codependency, the proposition of solutions and decision making, such as the creation of public policies directed to the researched profiles.

The support group is recognized as a protection space. Families achieved, throughout the meetings, to understand that their life was dependent on the drug user and so, they no longer lived their own life. The characteristics presented by the families, further reinforced how exposed and vulnerable they were to the dependent. Thus, when dealing with a disease that translates into suffering for the codependent's life, as for the addict, this study becomes relevant for the scientific community, still little explored in the academic environment and in health services.

The family uses health services, often to alleviate the physical and mental symptoms arising from the imbalance of the family system. However, health professionals need to be equipped to identify what leads families into this disease. Although health services offer attention directed to family members, their approach is still focused on the dependent, which justifies the importance of the study.

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Original article

Validity and Reliability of the Treatment Adherence Questionnaire for Patients with Hypertension

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Validity and Reliability of the Treatment Adherence Questionnaire for Patients with Hypertension

Abstract

Objective. To determine the validity and reliability of the Treatment Adherence Questionnaire for Patients with Hypertension (TAQPH), Spanish version, designed by Chunhua Ma *et al*. **Methods.** This study was carried out in the city of Ibagué (Colombia) and the test validation determined validity (face, content, and construct) and reliability. Face and content validity were conducted through expert judgment, using Fleiss' Kappa Coefficient statistical tests and modified Lawshe's content validity index. The construct validity and the reliability test had the participation of 220 people with diagnosis of primary hypertension. Reliability was calculated through Cronbach's alpha statistical test. **Results.** In the face validity, the instrument reported a Fleiss' Kappa index was 0.68 in comprehension, 0.76 in clarity, and 0.64

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Article linked to the research: Effect of the intervention "deploying my personal resources" on adherence in patients with primary hypertension.

Conflicts of interest: none.

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in accuracy, interpreted as a substantial agreement. The content validity index was satisfactory with 0.91; el exploratory factor analysis reported six factors with a total variance explained of 54%. Cronbach's alpha for the total scale was 0.74. **Conclusion.** The Spanish version of the TAQPH is a valid and reliable scale to evaluate adherence to treatment in patients with primary hypertension.

Descriptors: essential hypertension; treatment adherence and compliance; surveys and questionnaires; psychometrics; validation studies.

Validez y confiabilidad del cuestionario adherencia al tratamiento en pacientes con hipertensión arterial

Resumen

Objetivo: Determinar la validez y confiabilidad del cuestionario para medir la adherencia al tratamiento en pacientes con hipertensión arterial (*Treatment Adherence Questionnaire for Patients with Hypertension* - TAQPH), versión en español, diseñado por Chunhua Ma *et al*. **Métodos.** Estudio de validación de pruebas realizado en la ciudad de Ibagué (Colombia) en el que se determinó la validez (facial, de contenido y de constructo) y la confiabilidad. La validez facial y de contenido se efectuó mediante el juicio de expertos, utilizando las pruebas estadísticas de Coeficiente Kappa de Fleiss e índice de Lawshe modificado. En la validez de constructo y prueba de confiabilidad participaron 220 personas con diagnóstico de hipertensión arterial. La confiabilidad se calculó mediante la prueba estadística de alfa de Cronbach. **Resultados.** En la validez facial, el instrumento reportó un índice de Kappa de Fleiss de 0.68 en comprensión, 0.76 en claridad y 0.64 en precisión, interpretado como un acuerdo sustancial. El índice de validez de contenido fue satisfactorio con 0.91. El análisis factorial exploratorio reportó seis factores con una varianza total explicada de 54%. El alfa de Cronbach fue de 0.74 para la escala total. Conclusión. La versión en español del TAQPH es una escala válida y confiable para la evaluación de la adherencia al tratamiento en pacientes con hipertensión arterial.

Descriptores: hipertensión esencial; cumplimiento y adherencia al tratamiento; encuestas y cuestionarios; psicometría; estudios de validación.

Validez e confiabilidade do questionário aderência ao tratamento em pacientes com hipertensão arterial

Resumo

Objetivo: Determinar a validez e confiabilidade do questionário para medir a aderência ao tratamento em pacientes com hipertensão arterial (*Treatment Adherence Questionnaire for Patients with Hypertension* - TAQPH), versão em espanhol, desenhado por Chunhua Ma *et al*. **Métodos.** Estudo de validação de provas que se realizou na cidade de Ibagué (Colômbia) no qual se determinou a validez (facial, de conteúdo e de construto) e a confiabilidade. A validez facial e de conteúdo se efetuou mediante o juízo de especialistas, utilizando as provas estatísticas de Coeficiente Kappa de Fleiss e índice de Lawshe modificado. Na validez de construto e prova de confiabilidade participaram 220 pessoas com diagnóstico de hipertensão arterial. A confiabilidade se calculou mediante a prova estatística de alfa de Cronbach. **Resultados.** Na validez facial, o instrumento reportou um índice de Kappa de Fleiss de 0.68 em compreensão, 0.76 em claridade e 0.64 em precisão, interpretado como um acordo substancial. O índice de validez de conteúdo foi satisfatório com 0.91, a análise fatorial exploratório reportou seis fatores com uma variação total explicada de 54%. O alfa de Cronbach foi de 0.74 para a escala total. Conclusão. A versão em espanhol de TAQPH é uma escala válida e confiável para a avaliação da aderência ao tratamento em pacientes com hipertensão arterial.

Descritores: hipertensão esencial; cooperação e adesão ao tratamento; inquéritos e questionário; psicometria; estudos de validação.

Introduction

Among the group of chronic noncommunicable diseases characterized for being long lasting and of slow progression, we find cardiovascular diseases, attributable to risk factors among which there is primary hypertension.(1) Together, cardiovascular diseases represent the first cause of morbidity and mortality in the world and affect principally low- and medium-income countries,(2) causing disability and premature death, which leads to increased disease burden due to this group of diseases.

One of the indicators of success in the treatment of primary hypertension is adherence,(3) in spite of this, it is estimated that between 50% and 80% of the patients who receive antihypertensive drug treatment have low adherence,(4) approximately 10% omits a dosage of medication on a given day and nearly half of those diagnosed suspend the medication during the first year of treatment.(5) This situation can lead to inadequate control of the blood pressure, which in the future could cause cardiovascular complications, hospital readmissions, premature deaths due to disability, besides the costs implied for care in the health system.(6) Lack of adherence may take place when starting a new prescription, in the implementation of the treatment, or during the persistence and it is manifested by the difficulty to start the treatment, abandonment or incomplete compliance, non-attendance to consultations and interconsultations, lack of modification of lifestyles, and/or inadequate follow up of the recommendations, a situation that affects the course of the disease.(7).

To establish objectively the concordance between the therapeutic orientations and their execution by the individual, it is necessary to measure the degree of adherence to treatment; for such, different methods have been proposed, which are classified into direct and indirect, without any of them considered the gold standard.(8) Among the indirect methods, there are the questionnaires, like: the Medication Adherence Scale by Morisky *et al.*,(9) the Brief Medication Questionnaire,(10) the Hill-Bone Compliance to High Blood Pressure Therapy Scale,(11) the Martín-Bayarré-Grau Questionnaire,(12) the Maastricht Utrecht Adherence in Hypertension (MUAH),(13) the evaluation of the "Therapeutic Behavior: disease or lesion", which corresponds to a standardized classification of the patient's results established by the North American Nursing Diagnosis Association (NANDA), and the Compliance Scale of Hypertensive Patients;(14) however, some of these instruments measure exclusively adherence to pharmacological treatment,(9) while others center on facilitators or barriers to adherence, such as beliefs on the effects of the medications,(10) behavior related with sodium intake, compliance with treatment and medical appointments,(11) attitudes and therapeutic coping,(13) autonomy upon the treatment and participation by the patient,(12) lifestyle, attitude toward the disease, and responsibility in the treatment.(14) In spite of the availability of these instruments, none estimates adherence in terms of the pharmacological treatment and lifestyle, fundamental aspects in controlling primary hypertension, besides being included in the definition of adherence proposed the World Health Organization, which considers it as the measure in which the behavior of a person who takes medications, follows a diet and/or undergoes lifestyle changes corresponds with the recommendations agreed with a medical care provider.(15)

The Treatment Adherence Questionnaire for Patients with Hypertension (TAQPH), designed and validated by Nursing Dr. Chunhua Ma *et al.*,(16) measures adherence to pharmacological and non-pharmacological treatment. This 28-item instrument is originally composed of six factors (F1 – Medication = 9 items, F2 – Diet = 9 items, F3 – Stimulants = 3 items, F4 - Weight control = 2 items, F5 – Exercise = 2 items, F6 – Stress relief = 3 items) and has four Likert-type response options (1 = never, 2 = sometimes, 3 = most of the time, 4 = all the time), the score is the sum of the value obtained in each item, a higher score means better adherence. The evaluation of its factor validity showed that the six factors explain 62.5% of the total variance; besides, having criterion validity when compared with the Medication Adherence Scale by Morisky (r = 0.76) and with the General Self-efficacy Scale (r = 0.69) and high reliability (0.86). This questionnaire does not have a Spanish version and, given that a valid and reliable instrument was required adapted to the context in which it will be used, which is Colombia, this study was conducted to determine the validity and reliability of the TAQPH.

Methods

This study was conducted between March 2017 and April 2018 in the city of Ibagué in Tolima, Colombia. The development phase included the translation, linguistic and cultural adaptation, pilot test, and back-translation. The confirmation phase performed the face, content, and construct validity, along with the internal consistency evaluation.

First phase: Translation and cultural adaptation. A direct translation was carried out from English to Spanish by two official translators and a Colombian bilingual nurse (Spanish-English), different from the principal researcher with knowledge on the theme of adherence. This procedure focused on adaptation of meanings more than a textual or literal translation. Thereafter, the combination of translations was conducted along with the synthesis of a first version revised by a committee comprised of the principal researcher, a nurse with a Masters degree in cardiovascular care, and a linguist experienced in the production of written texts and knowledge of medical terminology, who were in charge of judging the semantic, idiomatic, conceptual and cultural equivalence. From the aforementioned, a second preliminary version was generated, which was applied to a group of 10 adult volunteers with different educational levels, to collect information regarding comprehension of the instructions and items, register the time needed to fill out the instrument and identify possible errors of content or form that were corrected prior to moving on to the following phase. Lastly, the back-translation was conducted by a third official translator after expert approval of the face and content validity; this was subsequently sent to the author for her final approval.

Second phase: Face validation. This was carried out by two groups: one made up of 20 patients, men and women, over 18 years of age, with diagnosis of primary hypertension, registered in a follow-up program for chronic patients, which were not included in the principal study and another made up of panel of four experts, selected for their academic formation with graduate degree or Masters in the health area and clinical experience over five years, who evaluated the instrument by considering three scoring criteria: comprehension, clarity, and accuracy. With the results, the Fleiss' Kappa index was calculated, which permitted determining agreement among observers correcting randomness. The results were interpreted according to that recommended by Landis and Koch,(17) who consider satisfactory those items obtaining values ranging between 0.61 and 0.80, recognized as substantial agreement.

Content validity. The same four experts who participated in the face validity participated in the content validity, evaluating each of the items with the following criteria: "essential", "useful but not essential", and "not necessary". With the data obtained, the Content Validity Ratio (CVR) was calculated, which was defined as the proportion of agreements in the essential category with respect to the total number of evaluators. Additionally, the Content Validity Index (CVI) of the whole instrument was calculated. The aforementioned is supported in the Lawshe model modified by Tristán(18) that establishes that CVR value ≥0.58 is sufficient to consider an item as acceptable, independent of the number of evaluators.

Construct validity. To apply the questionnaire, a type of convenience sampling was applied. The Gorsuch(19) proposal of five subjects per item was taken as reference for sample size selection. According to the aforementioned, the study opted for a calculated sample of 216 participants, considering seven people per item plus an additional 10% in case of losses, obtaining in the end the participation of 220 patients. Inclusion criteria were: men and women over 18 years of age, with diagnosis of primary hypertension, registered in a cardiovascular risk program, with more than six months of treatment. The study excluded patients with secondary hypertension and those who, besides having primary hypertension, were diagnosed with diabetes mellitus.

To verify the data fit prior to the exploratory factor analysis, Bartlett's sphericity tests were applied ($p<0.0001$), and the sampling adequacy measure with the Kaiser-Meyer-Olkin (KMO) index. Thereafter, an exploratory factor analysis was performed with the principal components extraction method and the Kaiser-Varimax rotation method; the analysis was forced to six factors in correspondence to those described by the instrument's author. Taking as reference that defined by Bandalos,(20) the criteria used to determine the amount of factors extracted in the instrument were own values >1 and with loads >0.30. The data were processed by using the SPSS statistical program, version 22.0. Lastly, the internal consistency was determined from Cronbach's alpha calculation, considering that a Cronbach's alpha of 0.70 or higher was adequate if the objective of the scale is for use in research.(21)

Ethical considerations. Throughout the development of the research process, ethical principles were complied; the study participants signed the informed consent after receiving information about the study objective and accepting voluntarily to participate in the research. Permission was obtained from the instrument's author to carry out the translation process, cultural adaptation, validity, and reliability from the internal consistency.

Results

Translation and cultural adaptation. It was found that all the questions of the instrument in English began with the modal verb "would", which gave for a conditional nature; with accompaniment by the instrument's author, it was clarified that the instrument sought to establish the behavior in relation with taking medications, monitoring the diet, and changes in lifestyle the person had had until the moment. Due to the aforementioned, it was established that the most adequate verbal tense to use in the Spanish version would be the perfect tense, given that it indicates an action in the past that continues in the present. At the end of this phase, a version was available adapted to the Colombian language and cultural context.

Face validity. In relation with the scale accuracy, the agreement index – measured through Fleiss' Kappa – reported for the instrument in general substantial agreement, summarized in values of comprehension 0.68, clarity 0.76, and accuracy 0.64. The evaluation made by the 20 individuals reached an agreement percentage of 98%; 96% for clarity; and 95% for accuracy. From these results, corresponding adjustments were performed, incorporating the recommendations made by the experts and the patients in terms of phrasing the items.

Content validity. The content validity kept in mind the judgment by experts or the evaluation panel. The results corresponding to CVR indicated that all the items could be acceptable, given that values obtained were >0.58, ranging between 0.75 and 1. The content validity index for the 28 items was of 0.91, a value considered acceptable and, as consequence of these findings, all the items were maintained.

Construct validity. Of the 220 subjects participating in this stage, the majority were women (72.3%); the mean age was 65.1 years, ranging between 50 and 82 years; nearly three out of every four (73.1%) patients had a maximum of secondary education; 42% were dedicated to household work; and 62% were married or in common-law relationships (Table 1).

Table 1. Sociodemographic characteristics of the 220 patients with primary hypertension

Characteristics	Values
Age; mean ± SD, range	65.1±7.4, 50-82
Sex; n (%)	
Female	159 (72.3)
Male	61 (27.7)
Level of schooling; n (%)	
Primary	63 (28.6)
Secondary	98 (44.5)
Technical or university	59 (26.8)
Occupation; n (%)	
Employed	37 (16.8)
Home	93 (42.3)
Pensioned	52 (23.6)
Independent worker	38 (17.3)
Marital status; n (%)	
Married or common-law	138 (62.7)
Single, divorced, or widow(er)	82 (37.3)

Prior to the factor analysis, Bartlett's sphericity test was conducted, reporting a chi-square value = 2171.3 (p <0.001); the Kaiser-Meyer-Olkin sampling adequacy measure was 0.74, which proved the general adequacy of the matrix and indicated that it was possible to perform the *factor analysis.* The anti-image matrix in the extraction through the principal components method and Varimax rotation showed that 54.5% of the total variance was contained in six factors (F1 = 16.0%, F2 = 31.2%, F3 = 38.0%, F4 = 44.6%, F5 = 50.0%, and F6 = 54.5%), making it satisfactory and sufficient to identify the dimensions that establish relations among the items that conform the instrument. The first factor had 8 items, the second 5 items, the third 6 items, the fourth 2 items, the fifth 3 items, and the sixth 4 items. The exploratory factor analysis showed reorganization of the items that would integrate each of the six components, as noted in Table 2.

Table 2. Rotated matrix of principal components of the items of the questionnaire to measure adherence in patients with primary hypertension

Item	F1	F2	F3	F4	F5	F6
1. Have you taken the medications according to the frequency indicated in the formula provided by the physician?	**0.680**	0.224	0.042	0.011	0.158	0.149
2. Have you taken the medications according to the dosage indicated by the physician?	**0.693**	0.064	0.136	0.015	0.109	0.071
3. Have you taken the medications according to the schedule indicated by the physician?	**0.425**	0.379	0.235	0.195	0.159	0.003
4. Have you taken the medications for a long period without interruptions, according to indications provided by the physician?	**0.684**	0.087	0.107	0.101	0.078	0.032
5. Have you taken the medications according to indications by the physician, without increasing or diminishing the dosage?	**0.656**	0.113	0.014	0.038	0.074	0.011
6. Have you continued taking the medications even if you don't have symptoms of hypertension?	**0.732**	0.092	0.106	0.050	0.208	0.035
7. Have you forgotten to take your medications?	0.254	**0.382**	0.014	0.001	0.299	0.089
8. Have you suspended the medications when you have felt that symptoms have improved?	**0.730**	0.051	0.051	0.059	0.048	0.018
9. Have kept using the medications in spite of feeling that the symptoms have worsened?	**0.809**	0.078	0.019	0.084	0.056	0.006
10. Have you complied with a low-salt diet?	0.063	**0.649**	0.117	0.181	0.074	0.074
11. Have you complied with a low-fat diet? Reducing consumption of fried preparations, sauces, dressings, sausages (cold cuts – Mortadella – fast foods in general)	0.069	**0.745**	0.225	0.017	0.072	0.092
12. Have you complied with a low-cholesterol diet? Reducing consumption of red meats, chicken skin, eggs, sauces (mayonnaise – tomato sauce – industrial vinaigrettes), oil, lard and butter).	0.038	**0.774**	0.234	0.014	0.049	0.091
13. Have you diminished consumption of sugar and sweets?	0.020	**0.645**	0.134	0.133	0.031	0.216
14. Have you increased consumption of fiber? Such as papaya, pineapple, soursop, peaches, pears, and apples; also cereals, like oats, quinoa and bran.	0.070	0.191	**0.661**	0.059	0.362	0.046
15. Have you increased consumption of fresh vegetables?	0.011	0.178	**0.761**	0.019	0.115	0.192
16. Have you increased consumption of fresh fruits?	0.002	0.170	**0.786**	0.078	0.288	0.123

Table 2. Rotated matrix of principal components of the items of the questionnaire to measure adherence in patients with primary hypertension (Cont.)

Item	F1	F2	F3	F4	F5	F6
17. Have you increased consumption of grains? Including beans, chickpeas, lentils, peas. Besides dry nuts, like peanuts and almonds.	0.505	0.381	**0.566**	0.364	0.332	0.182
18. Have you increased consumption of low-fat dairy products?	0.074	0.252	**0.516**	0.049	0.231	0.093
19. Have you diminished the consumption of coffee?	0.031	0.257	0.035	0.197	**0.412**	0.189
20. Have you limited consumption of alcoholic beverages?	0.181	0.119	0.085	0.182	**0.649**	0.138
21. Have you stopped smoking?	0.077	0.174	0.165	0.115	**0.581**	0.020
22. Have you performed physical exercise at least five times per week?	0.088	0.143	0.105	**0.904**	0.125	0.069
23. When performing physical exercise, have you dedicated at least 30 minutes to it?	0.071	0.128	0.069	**0.908**	0.094	0.072
24. Have you been able to control the amount of food you consume?	0.001	0.166	0.062	0.053	0.045	**0.623**
25. Have you maintained your body weight under control?	0.018	0.340	0.019	0.067	0.337	**0.574**
26. Have you set aside daily time for relaxation for yourself?	0.065	0.100	0.316	0.194	0.123	**0.635**
27. Have you recurred to some forms to relieve stress or tension?	0.126	0.005	**0.422**	0.385	0.234	0.318
28. Have you controlled yourself emotionally in light of sudden events?	0.031	0.111	0.085	0.228	0.253	**0.474**

The principal components matrix showed a grouping of the items into six factors, which does not coincide precisely with those defined by the instrument's author, hence, the proposal to rename each factor with a label according to the conceptual relationship among the items, thus: First: use and follow up of the pharmacological treatment; Second: follow up of diet restrictions; Third: follow up of a healthy diet; Fourth: capacity to perform physical exercise regularly; Fifth: control in the use of stimulant substances, and Sixth: management of stressful situations and control of body weight.

Reliability analysis. The instrument reported a Cronbach's alpha coefficient of 0.74, which indicates an acceptable level of the questionnaire's reliability.(22)

Discussion

This study describes the validity and reliability process, evaluated with the internal consistency of the TAQPH instrument, to measure adherence to pharmacological and non-pharmacological treatment (lifestyle), in patients with primary hypertension. The adapted version had modifications without affecting the instrument's original structure to maintain the semantic equivalence, a fact validated by its author. Face validity permitted evaluating the clarity, comprehension, and accuracy of each items in the instrument, obtaining substantial agreement among the experts. The content validity obtained an index of 0.91, a value considered adequate, showing the pertinence of each of the items in the conformation of the instrument, according to that defined by Lawshe and then modified by Tristán.(18)

It is highlighted that in the study evaluating psychometric properties by Ma *et al*.,(16) when performing the factor analysis through the principal components method and Varimax rotation, a six-factor solution was obtained, and of the 33 items that initially comprised the instrument; five were eliminated due to having factor loads <0.4, thus, the final version of the instrument is conformed by 28 items. To analyze the items integrating each of the instrument's factors, the study kept in mind the order and content of the questions of the final version published in English, which was compared with the results from this research.

Six factors were identified and renamed, thus: Factor 1 - Use and follow up of the pharmacological treatment, comprised by eight items (1, 2, 3, 4, 5, 6, 8, and 9); Factor 2 – Follow up of the diet restrictions, which grouped five items (7, 10, 11, 12, and 13), representing the actions performed by the individual to diminish or avoid consuming foods harmful to health, except for item 7 that corresponds originally to the dimension "medications"; Factor 3 – Follow up of a healthy diet, made up of six items (14, 15, 16, 17, 18, and 27) that reflect actions related with the consumption of an adequate diet for people with primary hypertension, except for item 27 that migrated from dimension 6 denominated by Ma *et al.*,(16) as "stress management"; Factor 4 – Capacity to perform physical exercise regularly, with items 22 and 23, had the particularity of presenting high correlation coefficients and maintaining the only two items that correspond conceptually and conform the dimension denominated by the author as "exercise"; Factor 5 - Control in the use of stimulant substances, grouped three items (19, 20, and 21) that correspond conceptually to the dimension denominated originally "stimulants; and, lastly, Factor 6 – Management of stressful situations and weight control was conformed by four items (24, 25, 26, and 28). In the original version, the six factors were related with "medication" (9 items), "diet" (9 items), "exercise" (2 items), "stimulants" (3 items), "weight control" (2 items), and "stress relief" (3 items). As noted, the dimension originally denominated as "diet" was divided in this study into two factors distributed in the second and third factors, which maintain theoretical coherence among the items that comprise them, except for item 7 that is related more with factor 1 "medications" and item 27 related more with factor 6 "stress relief".

The study by Dehghan *et al*.,(23) which validated the TAQPH instrument in Persian, obtained a six-factor instrument with a total of 25 items, given that items 4, 19, and 20 were eliminated because they did not report factor loads in any factor. In addition, they introduced the following denominations for each of the factors: "diminish the unsafe diet and weight control" (7 items), "medication" (5 items), "increase the safe diet" (5 items), "stimulation and exercise" (3 items), "avoid self-medication" (3 items), and "recover from stress" (3 items).

In this study, a detailed analysis of the parameters used to evaluate the internal structure of the TAQPH instrument found that the item-factor correlation coefficient was lower than that established by the instrument's author; however, a value of 0.30 tends to be considered an acceptable minimum.(20) Additionally, to evaluate the coefficients, aspects must be evaluated, like sample size and number of items; in general, with a higher number of subjects, the coefficients can be lower, although these should not be <0.30 to consider them as representative of a factor. With respect to the conformation of Factor 4 – Capacity to perform physical exercise regularly, although it had two items, it was maintained as independent factor, given that the underlying concept is the physical activity, which differentiated it from the other factors.

The total variance explained in this research was lower, considering that the six factors provided 54.51% of the total variance, compared with

62.54% reported in the original study conducted by Ma *et al*.,(16) and with the 60.3% reported by Dehghan *et al*.,(23) The internal consistency was estimated through Cronbach's alpha at 0.74, considered adequate,(21) against α = 0.86 reached in the study conducted by the instrument's author in its English version and the α = 0.80 obtained by Dehghan *et al.*,(23) that may be due to the variants in the cultural context and language.

Among the limitations of the study is that the sample was obtained from a single municipality in urban population and did not include patients from other regions or rural area, which must be kept in mind for the generalization of the results.

The conclusion, herein, is that the questionnaire to measure treatment adherence in patients with hypertension, in its Spanish version, is a valid and reliable instrument to measure the construct of adherence; the results show the strength of the instrument for its use by health professionals, both in the clinical setting and in research, to identify the degree of adherence and develop intervention strategies aimed at promoting and maintaining the health of individuals who endure this condition.

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Original article

Experience Lived by Iranian Patients with Irritable Bowel Syndrome: Transitory Crisis and Liberation

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Experience Lived by Iranian Patients with Irritable Bowel Syndrome: Transitory Crisis and Liberation

Abstract

Objective. Research on the nature of living with Irritable Bowel Syndrome. **Methods.** Qualitative study of the hermeneutical phenomenology, which conducted in-depth semi-structured interviews with people trained on the irritable bowel syndrome. The sampling was intentional type and open questions were used to collect data. The Thematic Analysis Method by Van Manen was used. **Results.** Two principal themes and five subthemes emerged in this research to determine the meaning of living with the irritable bowel syndrome: *Storm in corporality* (body with pain and affliction, tension and sequence of symptoms, and: distress during moments of life) and *Relief* (sense

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of liberation of the body symptoms, and moments with pleasure). **Conclusion.** The experience lived by patients with irritable bowel syndrome is of a transitory crisis and liberation.

Descriptors: irritable bowel síndrome; qualitative research; hermeneutics.

Experiencia vivida de pacientes iraníes con Síndrome de Intestino Irritable: crisis transitoria y liberación

Resumen

Objetivo. Conocer la experiencia de vivir con el Síndrome del Intestino Irritable. **Métodos.** Estudio cualitativo de la fenomenología hermenéutica en el que se realizaron entrevistas semiestructuradas en profundidad a personas con diagnóstico de síndrome del intestino irritable. El muestreo fue de tipo intencional y se utilizaron preguntas abiertas para recopilar los datos. Se empleó el método de análisis temático de Van Mennen. **Resultados.** Dos temas principales y cinco subtemas emergieron en la presente investigación para determinar el significado de vivir con este síndrome: *Tormenta en la corporalidad* (cuerpo con dolor y aflicción, tensión y secuencia de síntomas, y: angustia en los momentos de la vida) y *Alivio* (sensación de liberación de los síntomas corporales, y momentos con placer). **Conclusión.** La experiencia vivida de pacientes con síndrome del intestino irritable es de una crisis transitoria y de liberación.

Descriptores: síndrome del colon irritable; investigación cualitativa; hermenéutica.

Experiência vivida de pacientes iranianos com Síndrome de Intestino Irritável: crises transitórias e liberação

Objetivo. Investigar a natureza de viver com a Síndrome do Intestino Irritável. **Métodos.** Estudo qualitativo da fenomenologia hermenêutica na qual se realizaram entrevistas semiestruturadas em profundidade a pessoas com diagnóstico de síndrome do intestino irritável. A amostragem foi de tipo intencional e se utilizaram perguntas abertas para recopilar os dados. Se empregou o método de análises temático de Van Mennen. **Resultados.** Dois temas principais e cinco subtemas emergiram na presente investigação para determinar o significado de viver com a Síndrome do Intestino Irritável: *Tormenta na corporalidade* (corpo com dor e aflição, tensão e sequência de sintomas, e: angustia nos momentos da vida) e *Alívio* (sensação de liberação dos sintomas corporais, e momentos com prazer). **Conclusão.** A experiência vivida de pacientes com síndrome do intestino irritável é de uma crises transitórias e liberação.

Descritores: síndrome do intestino irritável; pesquisa qualitativa; hermenéutica.

Introduction

Irritable Bowel Syndrome (IBS) is the most prevalent chronic functional gastrointestinal disorder (FGID) which is diagnosed by the change in intestinal habits (Diarrhea or Constipation alone or both together) and the existence of symptoms like bloating (swelling) and abdominal pain.(1) The prevalence of this disorder is varied throughout the world according to the various diagnostic criteria. The highest rate between 9 to 22 percent occurs in Unites States of America and European countries and the lowest rate, i.e. 4.2 and 4.4 percent, occurs in India and Thailand, respectively.(2) The IBS prevalence in Tehran has been shown to be about 25 percent by "Rome II" criterion.(3) Its prevalence in adults over 35 years in Shiraz (Iran) has been 10.9 percent.(4) Studies have shown that 50 to 70 percent of patients with IBS who are in search for treatment suffer from psychiatric comorbidity.(5) Another study in Iran showed that the mean score of quality of life of patients with IBS and its components are lower compared with healthy people. In addition, their mean score of mental health is higher than that of the healthy people, and the physical symptoms, anxiety and depression among patients with IBS were also more severe.(6) The expenses resulting from this disorder have been estimated to be about 2.8 million Dollars in Iran.(7) Patients with IBS had the maximum drug usage in Iran and the period of their absence from work had been 2.26 days more compared with patients with other functional digestive disorders.(8)

The quantitative studies with positivism paradigm regarding the recommendations of the lifestyle, medicinal and educational interventions; dietary modification; eating habits; and also psychological intervention for such patients have contributed to relief from the effect of some aspects of this disorder on the living of sufferers to some extent.(9,10) Since quantitative measurements cannot often possess thoughts, feelings and experiences of people, the study of all aspects of life is possible via qualitative evaluation. The qualitative research focusing on human communications, feelings, thoughts, and understanding of individuals help the researchers to discover behaviors, feelings, and their experiences. Phenomenology as a research method is a rigorous, critical and systematic way to approach unknown phenomena. Its purpose is to comprehend the lived experience of certain phenomena, searching for meaning units of it.(11) In order to recognize the nature and meaning of life of patients with IBS, a review on qualitative studies was carried out. Based on this review, the patients state that the syndrome has influenced their daily performance, thoughts, feelings, and behaviors.(12) The physical and psychological effects,(13) socio-psychological consequences(14) and the experiences of changes in dietary programs(15) were also described by patients. In another study, patients expressed the methods of their adaptation with this disorder.(16) Most studies surveyed the experiences of patients with IBS and Inflammatory Bowel Disease (that has the organic cause) together or investigated a particular aspect of the experience of patients with IBS. In a few studies on the experience of patients with IBS in total, grounded theory(17) or descriptive phenomenology(18) was used. None of the mentioned studies has been carried out by hermeneutic phenomenology method which is a combination of description and interpretation. Also, no qualitative study regarding IBS has been conducted in Iran and other developing countries. It seems that, considering the existence of cultural, social, religious and believability background in our country, the knowledge of nurses for effective, comprehensive and holistic care of such patients is not sufficient. As a result, researchers followed this study with hermeneutic phenomenology approach in order to determine what the meaning of living with IBS is so as to perceive and extract their lived experiences about daily living.

Methods

The researcher selected educational clinics (Shahid Motahari and Shahid Faghihi) and Kowsar clinic of Shiraz University of Medical Sciences as the research setting. Considering the objectives of the study, the participants were selected by purposeful sampling method, description and interpretation of experience of patients from living with IBS and was continued till rich, deep, powerful and relative results were obtained. Participants in the research included 15 patients with IBS who agreed to take part in the study. The inclusion criteria were suffering from IBS for a period of one year as diagnosed by a gastroenterologist through Rome III criterion, adults over 20 years, speaking Persian easily, having rich experiences in this regard and making appropriate communication, being inclined to present their experience to the researcher, having no acute psychological and cognitive disease and lack of organic disease like Inflammatory Bowel Disease (IBD) including Crohn´s and Ulcerative Colitis.

Semi-structured deep interviews and taking note in place were used to collect and produce data. Expressing the purpose, assuring the participants regarding the confidentiality of information in all stages of the research, and obtaining informed consent from the participants, we carried out the interviews according to the guide questions after recording their demographic information by the researcher. Examples of the main questions of the current study included: “What does living with IBS look like?”, “What is the meaning of living with IBS?”, “What comes to your mind when we say IBS?”. The interviews lasted between 40 to 90 minutes. The total conversation was recorded after obtaining the patients’ permission. The recorded information was listened several times exactly after carrying out the interview at the possible shortest time. Thereafter, the interviews were written down word by word and analyzed.

During the process of collecting and recording data, the researcher has used the mentioned anecdote recorded by Navab and Hajibabaee(19) quoted from Van Mennen(20) in order to facilitate this process. In the current study, the Hermeneutic phenomenology with an emphasis on Van Mennen viewpoint and method was used to discover the experience of patients as to living with IBS. The academy of Van Mennen is a descriptive and interpretative academy. He believes that description and interpretation are inseparable from each other. In this study, the six Van Mennen methodological themes were used as the research structure, as follows: 1- Turning to the nature of the lived experience: in this stage, the researcher was interested in understanding the nature of living with IBS at the time of the clinical trial research; 2- Investigating lived experience: selecting the participants with lived experience with IBS as their integral part was performed at this stage. Participants in their descriptions showed the nature of living with IBS from their personal experiences, and these descriptions were recorded for later written transcription; 3- Reflecting on the essential themes which characterize the phenomenon: in this stage, using the thematic analysis with selective and holistic technique, there was an attempt to determine the main themes from descriptions of the patients from lived experience with IBS. Also, after reflecting on each transcript once while listening to the audio recordings, the themes emerged from the lived experiences with IBS. From the themes, the essence of living with IBS was approached; 4- Describing the phenomenon through the art of writing and rewriting: the researcher wrote the extracted essential themes from the interviews as the story several times for a rich description of the lived experience of IBS patients, 5- Maintaining a strong and oriented relationship with the phenomenon: this phenomenon in this stage was maintained considering the question of "What is the lived experience of IBS patients?"; and, 6- Balancing the research context by considering the parts and the whole: the researcher maintained the relationship between the parts and the whole in her mind.

In order to facilitate the analysis, we used MAX-Q version 7. The study of interviews as holistic resulted in creation of 17 descriptions from 17 interviews which had been carried out. Based on Van Mannen(20) viewpoint, in order to increase the criterion validity of the study, the interviews were guided with purposeful, original sampling in the direction of answering the main question of the research, i.e. "What is the meaning (nature) of living with IBS"?

The researcher was in contact with the participants during the interview process for a long time. In order to ensure the trustworthiness of the study, Lincoln and Guba(21) criterion was used. For the credibility of the research, the results were presented to participants and they expressed the coordination of results with perception during life with IBS. To meet this criterion, the experts' analysis and prolonged engagement were used. By doing some measures like member checking and experts' analysis, the dependability of the study was ensured. By thick and vivid descriptions in the text, effort was made to prepare the background for judgment and evaluation of the others regarding the transferability of the results. Preserving the careful documentations at all stages of the research, and also efforts to obtain the comments of professors of the department of Persian literature, psychiatric nursing and gastroenterologists in this regard helped the confirmability of the research.

The Research Ethics Committee of Shiraz University of Medical Sciences approved this study to be conducted (Issue: IR.SUMS.REC.1394.S137). Ongoing informed consent was obtained from the participants after written and verbal explanations were provided as the patients' consent was necessary for each stage of the research process. The participants were reassured about the confidentiality of the data. It was also emphasized that in case they no longer wished to participate or wanted to withdraw from the study at any time, there would be no effect on their treatment and care.

Results

Participants included 15 patients with an age range of between 21 to 73 years and mean age of 37.53 years; they were 10 women and 5 men. The time range of affliction with IBS was 1.5 to 30 years with a mean of 7.8 years. In Table 1, demographic characteristics of the participants are shown.

Table 1. Demographic characteristics of the participants in the study

	Sex	Age (years)	Marriage status	Education	Occupation	No. of children	Affection History (years)	Type of disorder
1	Male	35	Married	B.Sc.	Headmaster	2	15	Mixed
2	Female	30	Married	Diploma	House keeper	2	10	Mixed
3	Female	30	Married	M.Sc.	House keeper	2	10	Constipation
4	Male	39	Married	B.Sc.	Employee	1	8	Diarrhea
5	Female	41	Married	Associate degree	House keeper	0	5	Mixed
6	Male	27	Married	Under diploma	Worker	1	4	Diarrhea
7	Male	28	Single	Associate degree	Farmer	0	3	Mixed
8	Male	73	Single	Diploma	Retired nurse	0	30	Constipation
9	Female	42	Married	Under diploma	House keeper	1	3	Mixed
10	Female	36	Married	Under diploma	House keeper	1	6	Mixed
11	Female	40	Divorced	Under diploma	Employee	1	8	Constipation
12	Female	21	Single	Diploma	Tailor	0	2	Mixed
13	Female	36	Single	B.Sc.	House keeper	0	6	Diarrhea
14	Female	55	Widow	Diploma	House keeper	4	5	Constipation
15	Female	30	Married	B.Sc.	House keeper	1	1.5	Mixed

The appeared themes emerged from the data of this study were all around the lived experience of patients with IBS. These themes emerged from about 1500 thematic phrases, sentences or paragraphs from the interviews. Firstly, these phrases, sentences or paragraphs formed 8 themes and 25 sub-themes out of total interviews and then at a back and forth process and by merging these themes, lived experience of patients with IBS emerged in the form of 1 theme, 2 sub-themes and 5 sub-sub-themes. The emerged theme, relative sub-themes and sub-sub-themes of each one.

According to the descriptions of patients, the concept of living with IBS was the theme of "Transient and Crisis Liberation". This theme has been formed from sub-themes of "storm in corporeality" and "relief". In fact, patients with IBS experienced the "transient crisis and liberation" with feeling of storm in corporeality and relief. Participants in the current study faced the crisis in parts of their life, especially during the incidence of attacks of IBS. "Liberation" resembles the possibility of going beyond "current situation" to "other situation". These patients experienced the feeling of relief and comfort in some days of their life or at the time of ending the attacks. They have somehow tackled with symptoms of IBS with fluctuations, as a tide. This theme has been linked with the meaning of living with IBS to such an extent that one of the participants, stated that *When I was in a wedding party, I felt uncomfortable because of signs of my illness* *and I just wanted to go as soon as possible and get free* (P.4). This exemplification associates the theme of Transient Crisis and Liberation in the mind of any reader excellently.

Storm in the Corporeality

One of the sub-themes of transient crisis and liberation was the concept of storm in the corporeality. Meaning and purpose of storm in the corporeality was the severe bodily symptoms like hard wind or heavy rain so that these symptoms were accompanied with tension and this tension led to repetition of the signs. These patients also spend moments with pain and severity resulted from the annoying and frustrating symptoms. For example, the descriptions of the following participant reflect the concept of storm in the corporeality in the mind of any reader clearly. A woman said in this regard with a garbled face that, *the similarity of living with syndrome.... is like that, there is war and fracas in the body and earthquake is coming* (P.15). The experience of storm in the corporeality of patients with IBS meant "body in pain and affliction", "tension and symptom sequence" and "distress in the moments of life".

Body in Pain and Affliction. The statements mentioned from the participants that indicate the existence of resistant, intolerable, unpredictable and variable defecation signs plus comorbidity diseases with IBS illustrate the concept of "body in pain and affliction" Well. For example, a participant with a sullen face said that, by hearing the word IBS, its harassments come to his mind said that: its harassment means you feel heavy and pain in your abdomen; *it seems like stone, a disease whose pain is so resistant. In spite of the existence of so many physicians and treatment, it is inscrutable like a stone* (P.3).

Many participants mentioned the painful defecation as frequent excretion immediately after seeing or eating food or even by hearing the name of food. It is necessary to mention that all the participants in their descriptions suggested the feeling of having no complete discharge after each time of defecation. This is an indication of defecation with persecution and facing patient's body with pain and affliction. Participants variously mentioned the complications, symptoms or comorbidity with IBS which all indicate the cases like arthritis, depression, anxiety, intestinal prolapse and failure to control excretion, headache, sleep problems, bad smell of the mouth, sexual problems, fatigue, transpiration, faint position, falling down, and obsession. For example, a participant, regarding chronic fatigue syndrome stated that: *my body is weak; I get tired soon; I cannot do my works quickly and on time; and I get a headache. That's all due to the syndrome* (P.1). Some of the propounded psychological aspects by participants played a role in the formation of the concept of body in pain and affliction. For example, one of the participants said in this regard that: *I cry with happy music, too* (P.12). Some of participants explained their experience about sexual problems resulting from IBS. It is clear that all conditions accompanied with IBS, either physical or psychical, that were described by the participants in different ways indicate the existence of pain and affliction in the body of the patients with IBS which is somehow associated with the storm in corporeality. Another sub-sub-theme forming the theme "transient crisis and liberation" during lived experience with IBS was "tension and symptom sequence" which is quite related to the "storm in corporeality" sub-theme.

Tension and Symptom Sequence. Tension and symptom sequence was one of the sub-sub-themes which played a role in the formation of storm in corporeality. They explicitly mentioned their lived experience and tension with IBS in their statements as the cause of symptoms of IBS and also propounded the relative symptoms as stressors. Before any dialogue, we point to a story from a participant that reflects the tension and symptom sequence properly. *I never forget when we went to Esfahan during my pregnancy. They had a playful child. I had no way. I sat in the toilet for a long time. I could not stand up.*

It was not finished. I wound up with pain. Their child was repeatedly saying that ...Why does not my aunt come out. I was so embarrassed. That moment was painful and I became nervous. I cried. I was shedding tears involuntarily. This is a very bad feeling (tears were gathering in her eyes). I could not control the situation ... (P.3). Many participants mentioned in different ways the stressors of symptoms of IBS which were all indications of cases like nervous excitements resulting from family quarrels, hearing bad news in our journey, seeing the opposite sex during adolescence, occupational inconstancy of the spouse, and pregnancy. Most participants stated that as soon as they went out of house, the symptoms of IBS started. Some participants stated that they suffered from the attacks of IBS, 3 to 4 times per month and each time it lasted for two days.

Distress in the moments of life. Participants in the study who emphasized their expressions on "body in pain" and "tension and symptom sequence", experienced "distress in the moments of life too". All these cases faced the patient with IBS with "storm in corporeality". Participants pointed in different ways to the situations like having the possible worst situation at the time of fecal incontinency, feeling of explosion due to severe constipation and distension, displeasure from eating and moments of life, late elapsing of time in party and being harassed from the permanent mental engagement with IBS. All aforesaid cases played a considerable role in the formation of "distress in the moments of life". The participants in the study pointed to the mentioned cases with various interpretations that all are indications of feeling of distress in the moments of life.

Relief

It is estimated from descriptions of the participants that patients with IBS are faced with a problem in fulfilling their physiological basic requirement that is defecation. This fact encounters them with crisis. When this physiological requirement is fulfilled well, they have the feeling of freedom and liberation. According to the participants in the study, it could be said that the prettiness of days without IBS, enjoying the party and lack of attention to t time during privacy are related to the "moments with pleasure". All aforesaid cases lead to relief in the individual with IBS. The second sub-theme related to "transient crisis and liberation" was relief. This sub-theme referred to the meaning of "feeling of release from bodily symptoms" and "moments with pleasure".

Feeling of release from bodily symptoms. Patients mentioned the following cases about "feeling of release from bodily symptoms" in their experiences. Feeling calm and light was followed by complete evacuation of the digestive system, not being afraid of going everywhere and feeling of release and liberation at the time of lack of symptoms. A participant described the feeling of liberation as a flying butterfly at the time of lack of IBS: *Once I was looking at children's program on TV. Children were playing on grass field, opened their hands and butterflies were moving above their head. I felt that I was feeling relief and liberation like these children at those times when I was not suffering from the syndrome* (P.10).

Moments with pleasure. Moments with pleasure were such experiences that confront the patient with IBS with comfort. As mentioned, moments with pleasure means beautiful days without the symptoms of IBS, enjoying the party and eating and lack of attention to time in our privacy. A participant stated that: *The days when I am not faced with the syndrome, it seems that I am living like other human beings and I enjoy. O' God, the days that I do not have this problem are so beautiful* (P.5).

Many participants described the sympathy of relatives when symptoms appear as the factor of improvement of the symptoms and having moments with pleasure. A participant mentioned that moments with pleasure occur while I do not realize the passage of time. At some moments like loneliness, being at journey or lack of disorder attacks, the time is passed in such a way that the patient does not pay attention to its passage and enjoys those moments. Some participants enjoyed drinking herbal tea and had a good feeling from drinking effective distillates on the symptoms of IBS.

Discussion

The main theme "Transient Crisis and Liberation" emerged in the present study. Actually, the meaning of living with IBS has been "Transient Crisis and Liberation". Lämås *et al.*(22) showed in a study that Swedish middle-aged women described the lived experience with constipation under the title of "being alone at excruciating situation" in relation with "turbulence between feeling of torture and feeling of liberation and release" and "living with permanent tension and anxiety". This result is similar to the findings of the present study. In the current study, the theme "Transient Crisis and Liberation" that includes two sub-themes of "storm in corporeality" and "relief" describes the attacking nature and unpredictability of living with IBS.

The sub-theme "storm in corporeality" was related to the "body in pain", "tension and symptom sequence" and "distress in life moments". According to the statements of participants, this sub-theme expresses that sometimes the body of the patients with IBS suffers intolerable and resistant to treatment symptoms. They also sometimes face the same symptoms followed by the minimum tension whether physical, chemical, psycho-social, psycho-chemical and economical. Many of these patients suffer gradually from situations like chronic fatigue, arthritis, depression and anxiety, too. These cases are called co-morbidity diseases which all are indications of body in pain. All these cases cause tension in them and lead to the repetition of symptoms related to the disorder. Actually, tension and symptom sequence occurs. During these times, patients will not enjoy their moments of life and suffer from distress in those moments.

The body is the base of our perception. During sickness, the individuals' awareness of the world is disturbed and the body experiences the pain differently from what was expected. In one's daily life and during health, the body is normal, but at the time of sickness, it loses its piece and cannot be normal and there exists a deep feeling of losing the bodily overall coherence.(23) In this regard, Schneider and Fletcher(13) in Canada illustrated the negative effect of IBS /Inflammatory Bowel Disease (IBD) on the physical and psychological dimensions of life of 7 women aged 18-22 years and found similar results. The experience of the mentioned women was in the form of anxiety reaction that resulted from the attack of IBS. This attack acted as a stimulator of the cascade of physical and psychological effects and they mentioned the permanent and intolerable pain as physical effects. Considering the fact that in the current study the body has been also in pain, the results of the above mentioned study was similar to those of the current study. In this regard, participants in a research carried out by Bertram *et al.*(24) also acknowledged the attacking and unpredictability of the symptoms.

The comparison of the results of the current study with those of the research conducted by Farndale and Roberts in which the experience of patients with IBS regarding the effect of disorder on their daily life and its psycho-social consequences has been studied seems to be logical. The reason for such comparison was to find out the emotional effects of living with IBS. Such effects are being created as emotional cycle beginning from the fear of inaccurate diagnosing of disorder in patients. Fear results from tension in them followed by worsening of the symptoms and, recreation of fear.(14) Generally, any type of tension could lead to activation of IBS,(25) but continual and chronic stressors are of more importance compared with acute stressor incidents.(26) Participants in the current study also declared that any type of tension causes appearance of symptoms of IBS and then the symptoms resulted in tension. Such forward-backward movements lead to tension and symptom sequence. Also, accompanying the courses of IBS with tension-in such a way that tension caused the symptoms and symptoms in turn caused the tension-was among the descriptions of Swedish patients with IBS in Jacobson *et al*.'s study.(27) This point is similar to the results of our study. On the other hand, the lived experience with constipation among Swedish middle-aged women was described by Lamas et-al. as being alone with ex a devastating situation causing physical and psychological tensions for them. The physical discomforts included feeling of sickness, having colic and inflation, and tolerating severe and painful defecation. In this study, living with permanent tension and anxiety was among the themes emerging from the descriptions of patients with constipation(22) that is similar to the results of our study, too.

The participants of our study stated that they were suffering from the comorbidity of disorders with IBS like anxiety and depression which are two disorders related to tension,(28) so these disorders caused their body to be in pain. Other study also indicate the high repetition of these two disorders in patients with IBS.(29) Therefore, the effects of psychological aspect of this disorder should be considered by nurses and other health care providers. Participants in the current study described a part of the meaning of storm in corporeality as distress in moments of life. Jacobson *et al*.(27) studied the experiences of Swedish patients with long-term affliction with IBS in their daily life and showed that their experience was not definite cure and domination on IBS, but it was only improvement of the disorder. Patients were living with intermittent interaction between being good and illness. Researchers inferred the sub-sub-theme "tension and symptom sequence" from the descriptions of participants with phrases like feeling bad at moments of life which could be enjoyable;(27) this is similar to the results of the current study.

Two sub-sub themes of "feeling of release from bodily symptoms" and the "moments with pleasure" formed the "relief" sub-theme which includes the extensive meaning of descriptions of the participants regarding the under studied phenomenon. The perception of patients from "relief" not only included "feeling of release from bodily symptoms", but also consisted of "moments with pleasure" in relation to the beauty of days without IBS, the enjoyment of using herbal medicines, enjoying the party, lack of attention to time during privacy and the sympathy of relatives for improvement of symptoms of IBS. In the study of Bengtsson *et al.*(25) the perception of Swedish patients with IBS from the good quality of life was related to sub-themes of not having anxiety and pain, sense of peace and not having tension, feeling of fitness and comfort and liberation from symptoms of IBS.(30) In a research by Lämås *et al*.,(22) middle-aged female participants with constipation experienced feeling of liberation and having the best days at the time of having bowel movements. Lived time from the view point of Van Mannen(20) is our temporary way in the world.

Patients with IBS in the world with this disorder have had the feeling of comfort and liberation in the days without symptoms or at the moments of ending attacks. Patients of the current study described that in the toilet if the door is open before their entrance and also existence of good smell over there, they feel comfortable. Patients always wanted to be near the toilet and have private toilet so as to feel comfortable. These descriptions are similar to the results of the study of Faulkner(31) regarding the life of young adults with IBD. IBD consists of two Ulcerative Colitis and Crohn disease which occur due to organic reasons but produce digestive symptoms like IBS. However, "transient crisis and liberation" is a meaning of living with IBS that have been emphasized with similar terms both in this study as well as in the studies of developed countries. However, regarding the relative acceptance of views in other developing countries, the need for further studies is felt. There was no special limitation in this study.

To the best of our knowledge, this study is the first qualitative research in this regard in Iran. It is suggested that the future studies survey the experiences of nurses, physicians and families of such patients so as to obtain deeper insight regarding IBS.(32) Researchers hope that the results of this study could be a right foundation for the functioning of treatment-health teams, especially nurses, and become effective in decision making and orientation of measures related to the care of such patients. Although lack of generalizability of the results of qualitative research is the characteristic of such studies, it may be considered as one of the limitations of this type of research from the view point of those who give great importance to practical use of the results of research.

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Factors in the Transition from Legal to Illicit Drug Use in Young Adults from Northern Mexico

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Original article

Factors in the Transition from Legal to Illicit Drug Use in Young Adults from Northern Mexico

Abstract

Objective. This research sought to analyze the predictive effect of personal (personality traits), social (social support and social stigma) and community factors (characteristic of the neighborhood and exposure to consumption) on the transition of drug use in young adults. **Methods.** Case and control study. The cases were 70 individuals from 18 to 34 years of age who had already transitioned into illicit drug use and the controls were 210 legal drug usuers (tobacco or alcohol) in the same age range who had not had the transition. A data file was applied along with seven instruments that measured the transition and consumption variables. **Results.** Marihuana was the illicit drug of highest transition. It was shown that greater personality traits of neuroticism, extraversion, and

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openness to the experience meant higher probability of drug use transition; while greater personality traits of agreeableness and conscience meant lower probability for the transition. The characteristics of the neighborhood environment and exposure to the opportunity of consumption increase the probability of the drug use transition. Social support and social stigma influenced negatively upon the drug use transition. **Conclusion.** Personality traits, neighborhood characteristics, exposure to drug use, social support, and the social stigma of drug use are factors that intervene in the transition from legal to illicit drug use.

Descriptores: street drugs; drug users; risk factors; young adult; personality; social support; social stigma; residence characteristics; surveys and questionnaires; case-control studies.

Factores en la transición del consumo de drogas legales a ilegales en jóvenes del norte de México

Resumen

Objetivo. Analizar el efecto predictivo de factores personales (rasgos de personalidad), sociales (apoyo social y estigma social) y comunitarios (características del barrio y exposición al consumo) sobre la transición del consumo de drogas en jóvenes. **Métodos.** Estudio de casos y controles. Los casos fueron 70 personas de 18 a 34 años que habían transitado al consumo de drogas ilícitas y los controles fueron 210 personas de la misma edad consumidores de alguna droga lícita (tabaco o alcohol) que no han tenido transición. Se aplicó una cédula de datos y siete instrumentos que midieron las variables de transición y consumo. **Resultados.** La droga ilegal de mayor transición fue la marihuana. Se mostró que a mayores rasgos de personalidad de neuroticismo, extraversión y apertura a la experiencia fue más alta la probabilidad de la transición del consumo de drogas, por el contrario, a mayores rasgos de personalidad amabilidad y conciencia fue menor fue la probabilidad para la transición. Las características del entorno de barrio y la exposición a la oportunidad de consumo incrementan la probabilidad de la transición del consumo de drogas. El apoyo social y el estigma social influyeron negativamente en la transición del consumo de drogas. **Conclusión.** Los rasgos de personalidad, las características del barrio, la exposición al consumo de drogas, el apoyo social y el estigma social del consumo de drogas son factores que intervienen en la transición del consumo de drogas legales a ilegales.

Descriptores: drogas ilícitas; consumidores de drogas; factores de riesgo; adulto joven; personalidad; estigma social; apoyo social; características de la residencia; encuestas y cuestionarios; estudios de casos y controles.

Fatores na transição do consumo de drogas legais a ilegais em jovens do norte do México

Resumo

Objetivo. Analisar o efeito preditivo de fatores pessoais (características de personalidade), sociais (apoio social e estigma social) e comunitários (características do bairro e exposição ao consumo) sobre a transição do consumo de drogas em jovens. **Métodos.** Estudo de casos e controles. Os casos foram 70 pessoas de 18 a 34 anos que haviam transitado ao consumo de drogas ilícitas e os controles foram 210 pessoas da mesma idade consumidores de alguma droga lícita (tabaco ou álcool) que não hão tido transição. Se aplicou uma cédula de dados e sete instrumentos que mediram as variáveis de transição e consumo. **Resultados.** A droga ilegal de maior transição foi a maconha. Se mostrou que as de maiores características de personalidade de neuroticismo, extroversão e apertura à experiência foi mais alta a probabilidade da transição do consumo de drogas; enquanto que a maiores traços de personalidade amabilidade e consciência foi menor foi a probabilidade para a transição. As características do entorno de bairro e a exposição à oportunidade de consumo incrementam a probabilidade da transição do consumo de drogas. O apoio social e a estigma social influenciaram negativamente na transição do consumo de drogas. **Conclusão.** Os traços de personalidade, as características do bairro, a exposição ao consumo de drogas, o apoio social e a estigma social do consumo de drogas são fatores que intervém na transição do consumo de drogas legais a ilegais.

Descritores: drogas ilícitas; usuários de drogas; fatores de risco; adulto jovem; personalidade; estigma social; apoio social; arreglo de vivienda; inquéritos e questionários; estudos de casos e controles; apoio social.

Introduction

Illicit drug abuse constitutes an important risk for the health of individuals due to diverse chronic noncommunicable diseases and, hence, contributes significantly to premature mortality and affects the quality of life of people as it is related with accidents, violence, suicides, assaults, and fights.(1) Currently, a general trend exists of considering the predisposition for illicit drug use as the result of the interaction of personal, community, and social factors,(2) but the initial consumption of alcoholic beverages, tobacco, or illicit drugs considers personal decisions and voluntary behaviors, which is why this would be an interesting approach for prevention by nursing professionals. In that sense, some studies found a higher probability of experimenting with illicit drug use when legal drugs have been consumed previously,(3,4) denominating this phenomenon as the transition from one drug to another. However, these transitions between the consumption of legal to illicit drugs has still not been examined sufficiently.

Within the literature on the phenomenon of drug use, the word "transitions" refers to the passage of using one drug to another, for example from alcohol to tobacco; from alcohol to marihuana; from tobacco to cocaine, and from such to amphetamines.(5) Studies identify some personal and community factors that can influence as facilitators in the drug use transition, like exposure to the opportunity, context of the residence such as characteristics of poor quality of the neighborhood, availability of drugs, perception of lack of social support, dropping out from school, child abuse, family history of consumption and delinquency, consumer peers, low control in situations of consumption, and personality of the subjects.(6,7)

Due to the aforementioned, it is worth delving into the phenomenon of the transition from legal to illicit drug use, as well as into the predictive influence of some personal and community factors that can help to explain this phenomenon, which can constitute an important target of prevention efforts, given that the occurrence of the event over time helps to understand the value of prevention actions. In Mexico, cross-sectional studies have been conducted that explore, among other topics, the initiation in the use of drugs;(6,7) however, enough investigations are not reported that incorporate in their methodology the analysis of diverse factors that can be facilitators or inhibitors in the transition processes of consumption from one to another drug. This situation permits reflecting on the need to address this phenomenon under perspectives of the nursing discipline, which permit identifying more clearly what factors facilitated the transition from legal drug use to illicit drugs in young consumers. The aforementioned permits characterizing populations in greater risk of drug use to carry out preventive actions aimed at strengthening inhibitor factors of drug use.

Within the nursing discipline, there is the Transition Theory by Meleis,(8) which conceptualizes the influence of factors that can facilitate or inhibit transitions toward behaviors that generate health or disease. The aim of this study was to analyze the predictive effect of personal (personality traits), social (social support and social stigma), and community factors (characteristic of the quality of the neighborhood and exposure to the opportunity of consumption) on the nature of the transition from legal to illicit drug use in young adults in northern Mexico.

Methods

The study design was individual base analytic observational of cases and controls; with hypotheses derived from some proposals by Meleis' Transition Theory:(8) H1 - personality traits increase the risk of the transition of illicit drug use; H2 - the characteristics of the neighborhood environment and exposure to the opportunity of consumption increase the risk of the drug use transition; H3 - social support and social stigma influence upon the drug use transition.

The study population included individuals from 18 to 34 years of age, from the metropolitan area of Nuevo León, Mexico. The sample calculation was carried out through the nQuery Advisor software 7.0, for a logistic regression conditioned with 0.05 significance level, with bilateral alternative hypothesis, for 25% transition proportion, disparity rate ratio of 1.75, principal covariant ratio of 0.20, and 90% power. The final calculated sample size was of 280 subjects. The study considered 25% of the total simple as cases (n=70) and the remaining 75% (n=210) were controls.

The selection of the 70 cases was conducted among young adults who have transitioned from legal to illicit drug use, the search for and selection of the participants was through the snowball method and which accepted to participate in the study and signed the informed consent. For this study, the group of 210 controls was gathered from the search for young adults who did not use illicit drugs, but consumed some type of legal drug (tobacco or alcohol) at home, taking as reference the place of residence of each case.

To collect the data, a Personal Data file was used along with the History of Drug Use plus six instruments. The personal factor of personality trait used the Five-Factor Reduced NEO Personality Inventory (NEO FF-I), which measures five personality traits; neuroticism, extraversion, agreeableness, openness to the experience, and conscientiousness.(9) The social factors (social support and social stigma) used the Social Support Questionnaire(10) (MOS- Medical Outcomes Study) and the Stigma Internalization Scale.(11) The community factors (neighborhood characteristics and exposure to consumption) used the Neighborhood Short Form,(12) and the questionnaire on exposure to the opportunity of consumption.(13) The neighborhood characteristics scale measures quality characteristics, like safety, support, and pride. It should be mentioned that for each instrument the final scores were converted into indices taking values from 0 to 100, where a higher score means a greater factor measured. To measure drug use, the study used the Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST).(14)

This study was approved by Research and Ethics Committees at the Institution to which the authors belong. After obtaining the corresponding authorizations, the search was made for cases; if the subject wished to participate, a screening interview was conducted inquiring if their first drug consumed was a legal drug to verify their eligibility for the study. The process began by gathering information, reading and signing the informed consent, and requesting apart in a blank sheet – and with no possibility of relating it to the participant – their home address to take it as reference for the search for the participants in the control group; subsequently they were given the instruments to be answered. Thereafter, data was collected from the participants in the control group, it should be mentioned that this group was comprised from the reference of the places of residence of the participants in the case group. The place of residence was located and, using the clockwise method, continuous homes were visited to search for three controls per case that fulfilled or not the criterion of not being consumers of illicit drugs while being consumers of some legal drug. Once these were identified, information was gathered and their informed consent was read and signed.

The data obtained were processed through the Statistical Package for the Social Sciences (SPSS®), version 20.0 for Mac OSX. Descriptive statistics was used to obtain frequencies, proportions, measures of central tendency and of variability to describe the study population and the variables used within the model. The internal consistency of the instruments was determined through Cronbach's Alpha Reliability Coefficient. The Kolmogorov-Smirnov Goodness of Fit test was used with Lilliefors Correction to determine the normality in the distribution of continuous and numerical variables and, based on these results, non-parametric statistics and Logistic Regression Models were used.

Results

The mean age among the participants was of 21.4 years (SD=3.3); in relation to sex, 77.1% of the young adults were men and 22.9% women in both groups. Regarding academic level, it was found that the young adults with undergraduate degree represented the highest percentage in both groups (52.4% group without transition 52.9% group with transition), followed by high school level (36.2% and 30.0%, respectively). Seventy percent of the young adults from the control group answered that they lived with both parents and only 44.3% from the case group; 78% (95% CI 69%-88%) of the participants who have transitioned to illicit drug use reported having consumed marihuana, with this substance showing the highest consumption, followed by consumption of sedatives (20%, 95% CI 10%-30%) and consumption of amphetamines (11.4%, 95% CI 4%-19%).

Table 1 illustrates the Logistic Regression Models between the personality traits and the drug use transition to answer H1. The results show positive effects of the traits of neuroticism, extraversion, and openness to the experience; on the contrary, the personality traits of agreeableness and conscientiousness had negative effects on the transition from legal to illicit drug use. This means that higher personality traits of neuroticism, extraversion, and openness to the experience mean higher probability of the transition of illicit drug use, while a higher personality trait of agreeableness and conscientiousness means lower probability for the drug use transition (Figure 1).

According to H2, the results from Table 2 indicate that neighborhood characteristics and exposure to the opportunity of consumption have significant effect on the drug use transition with an explained variance of 17.9%. The results show negative effect of the neighborhood characteristics, while exposure to the opportunity of consumption had a positive effect on the drug use transition, that is, that a lower perception of neighborhood quality means a greater probability of the transition to drug use; however, the probability of the transition increases with higher exposure to opportunities of consumption (Figure 2).

To answer H3, which proposes that social support and social stigma influence on the transition from legal to illicit drug use, the results are shown in Table 3, finding that social support and social stigma showed significant negative effect on the drug use transition, with an explained variance of 13.2%. These results demonstrate that greater social support and higher perception of stigma on the drug use indicates lower probability for the transition of illicit drug use (Figure 3).

Table 1. Binary logistic regression model of personality traits on the drug use transition

Variables	β	*SE*	Wald	DF	OR	*p*-value	95% CI for OR	
							LL	UL
Neuroticism Constant	0.06 -3.91	0.008 0.439	58.69 79.70	1	1.06	0.001	1.04	1.08
Model 1	X^2=81.33, df=1, R^2=37.3%, p<0.001							
Extraversion Constant	0.05 -4.30	0.010 0.604	38.83 50.84	1	1.05	0.001	1.03	1.07
Model 2	X^2=42.09, df=1, R^2=20.7%, p<0.001							
Openness to the experience Constant	0.04 -3.53	0.008 0.514	28.19 47.05	1	1.04	0.001	1.02	1.06
Model 3	X^2=35.95, df=1, R^2=17.8%, p<0.001							
Agreeableness Constant	-0.08 3.96	0.011 0.650	59.54 37.22	1	0.916	0.001	0.89	0.93
Model 4	X^2=109.53, df=1, R^2=47.9%, p<0.001							
Conscientiousness Constant	-0.06 2.90	0.009 0.527	58.39 30.33	1	0.936	0.001	0.92	0.95
Model 5	X^2=84.42, df=1, R^2=38.5%, p<0.001							

Note: β = beta, SE = Standard error, DF = Degrees of freedom, OR = Odds ratio, *p* = Probability, CI = Confidence interval, LL = Lower limit, UL = Upper limit, R^2 = Determination coefficient.

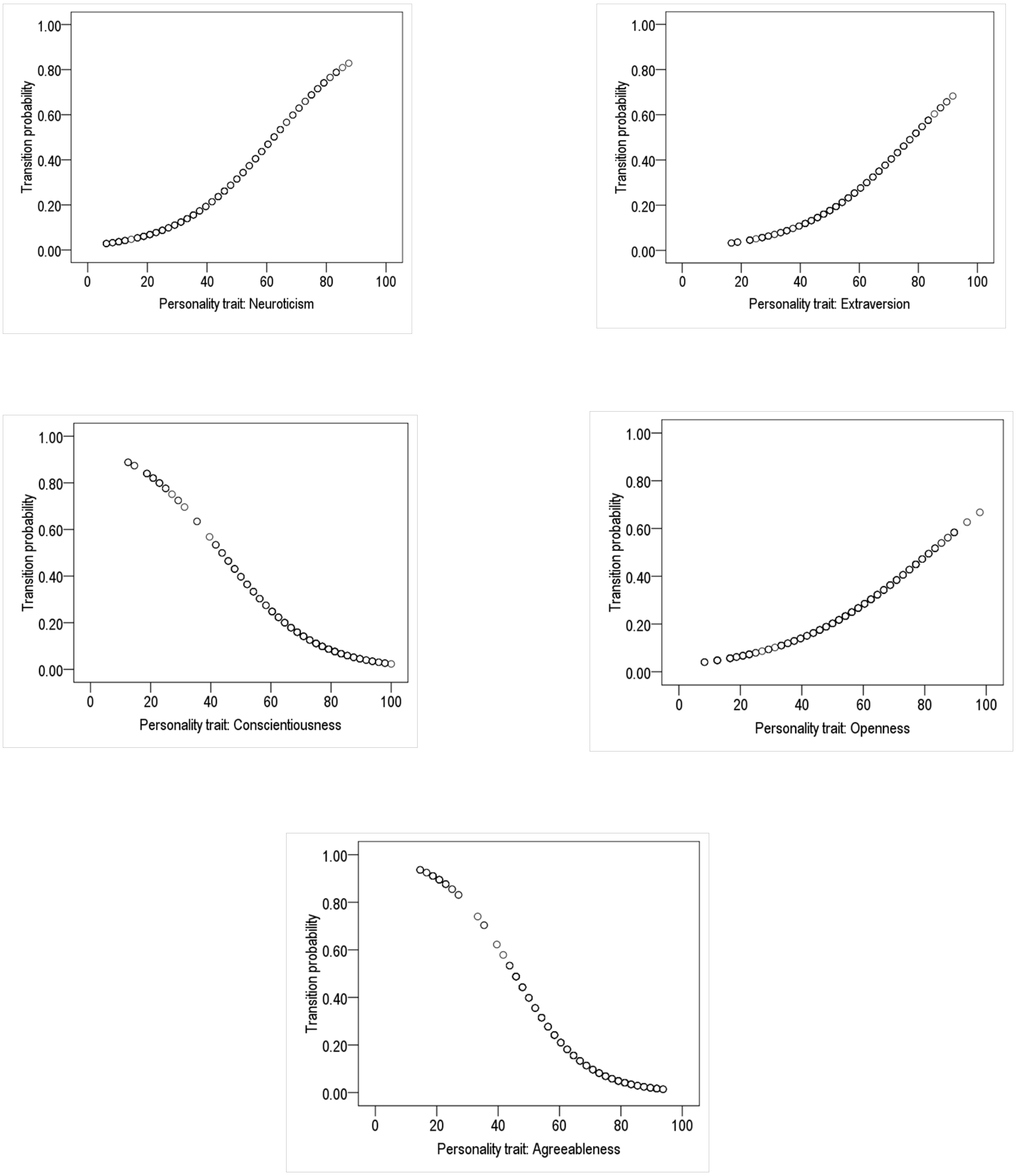

Figure 1. Effect of personality traits on the drug use transition

Table 2. Binary logistic regression model of neighborhood characteristics and exposure to the opportunity of consumption on the drug use transition

Variables	β	SE	Wald	DF	OR	*p*-value	95% CI for OR	
							LL	UL
Neighborhood characteristics	-0.020	0.009	4.45	1	0.98	0.035	0.96	0.99
Exposure to the opportunity of consumption	0.328	0.059	31.46	1	1.38	0.001	1.23	1.55
Constant	-1.49	0.385	15.09					
Model 1	X^2=36.07, df=2, R^2=17.9%, *p*<0.001							

Note: β = beta, *SE* = Standard error, *df* = Degrees of freedom, *OR* = Odds ratio, *p* = Probability, IC = Confidence interval, LL = Lower limit, UL = Upper limit, R^2 = Determination coefficient.

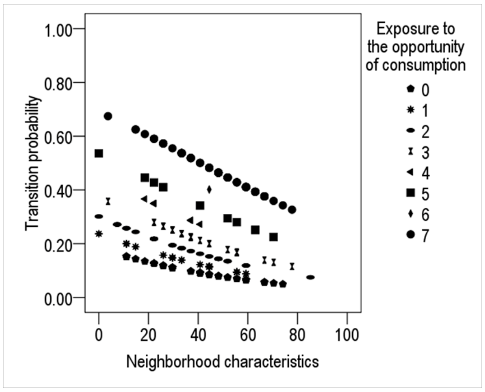

Figure 2. Effect of neighborhood characteristics and exposure opportunity on the drug use transition

Table 3. Binary logistic regression model del social support and social stigma on the drug use transition

Variables	β	SE	Wald	DF	OR	*p*-value	95% CI for OR	
							LL	UL
Social support	-0.023	0.007	11.84	1	0.977	0.001	0.96	0.99
Social stigma	-0.038	0.010	13.89	1	0.963	0.001	0.94	0.98
Constant	1.70	0.615	7.69					
Model 1	X^2=26.17, df=2, R^2=13.2%, *p*=0.001							

Note: β = beta, *SE* = Standard error, *df* = Degrees of freedom, *OR* = Odds ratio, *p* = Probability, IC = Confidence interval, LL = Lower limit, UL = Upper limit, R^2 = Determination coefficient.

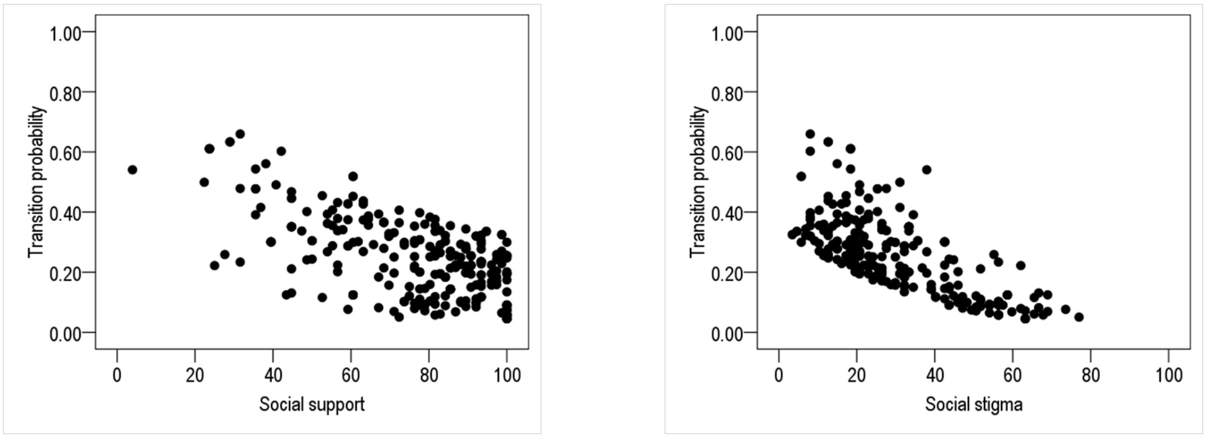

Figure 3. Effect of social support and social stigma on the drug use transition

Discussion

In this study, marihuana was the illicit drug of greater consumption among young adults who have transitioned from legal to illicit drug use. These data agree with official reports in Mexico for 2016 and 2017,(15) highlighting the prevalence of marihuana, which is quite above cocaine, inhalable substances, and hallucinogens. The aforementioned could be explained by the fact that it is the only substance with important growth in recent years, while the rest have had stable behavior. The literature(4-6) shows that marihuana is considered the entry way to the consumption of other illicit substances, denominated "hard drugs", particularly cocaine and methamphetamines. Besides, an explanation on the high prevalence of marihuana use is that many young adults perceive it as a drug of little or no danger; likewise, in recent years, its legalization has been discussed in diverse public, political, academic, social, and legal settings.(16)

Regarding H1, which claims that personality traits influence on the transition from legal to illicit drug use, our results support said hypothesis, showing positive effects of the traits of neuroticism, extraversion, and openness to the experience; on the contrary, agreeableness and conscientiousness had negative effects on the drug use transition. As with the results from other studies,(17,18) when the personality traits of neuroticism, extraversion, and openness to the experience are present in an individual's personality there is a higher probability for illicit drug use, while if the individual has higher personality traits of agreeableness and conscientiousness, the probability can be lower for the drug use transition to occur; this may be due to the harmful influence of lack of scrupulousness in substance abuse behaviors that reveal that lack of control of the behavior, increased impulsivity, and participation in risk behaviors found in the traits of neuroticism and extraversion, characterized by sociability, the need to have many friends, the taste for risk and a tendency to be aggressive, surely through social facilitation processes, and having a high number of friends engaged in behaviors outside the norm are associated with higher consumption during this evolutionary stage. Conversely, the trait of agreeableness is characterized by the capacity for altruism, compassion, and sensitivity with others; these characteristics are to a large measure why they do not show transition and agree with some authors.(19,20) In this sense, it is important for these personality traits to be indicators to bear in mind in the design of prevention programs that promote the development of these traits.

Hypothesis two proposes that the characteristics of the neighborhood environment and exposure to the opportunity of consumption increase the risk of the transition from legal drug use to illicit drug use. The findings permit supporting said hypothesis; according to the neighborhood characteristics, in this study a negative effect was shown, that is, a better perception of the quality in the neighborhood environment indicates lower probability of consumption. These data agree with the literature,(21,22) which indicate that unfavorable neighborhood conditions are a risk factor for the onset of drug use.

With respect to the number of opportunities to use drugs, the highest figures were reported by the young adults who have transitioned to illicit drug use, compared with those who have not transitioned. This is similar to another research(23) which found that exposure to the opportunity of consumption represents a higher risk with the use of drugs. In addition, said study indicates that exposure to the opportunity of consumption can be a cause on the initiation of illicit drug use due to the possibility that this represents of being in front of the substance and the ease of access to it without intentionally looking for it.

Hypothesis three proposes that social support and social stigma influence on the transition from legal to illicit drug use. Results permitted testing the study hypothesis, showing that social conditions, like social support and the perception of social stigma, are factors that inhibit the drug use transition. These results agree with other authors(24,25) that show that when the individual has higher perception of social support and greater perception of the stigma, which is understood as the stereotypes or negative physical, moral, or social prejudice that society implants in young adults who use drugs, there is lower probability to transition from illicit drug use. Social support from the family, peers, and from the environment can function as a protection factor due to the fact that by feeling as part of their environment, can serve to avoid the search for sensations through the drug use. Studies(24,26) have evidenced that inadequate social support in young adults has been related with maladaptive behaviors, including drug use, explaining that social support in function of the different sources of support predict the consumption of different substances. Thus, the results herein point to a protection relationship of social support mainly from the family. Thereby, the family becomes the core of the protection factors of social support against the transition of drug use. That is, the fact of feeling loved, esteemed, and protected by the family members is one of the principal resources the young person has to avoid getting involved or transitioning in the drug use.

Similarly, higher scores were reported of stigma in the young adults who had not transitioned to illicit drug use. This agrees with diverse studies, which indicate that stigmatization toward consumers of illicit drugs can be an isolation factor, besides they are subject to derogatory stereotypes or criminalization by society.(25,27) This can influence as a protection factor due to the public perception of the stigma in drug consumers, affect social and labor development, and – thus – avoid the rejection an illicit drug user may have. In spite of the results found, which reported that the perception of the stigma diminishes the transition to illicit drug use, studies(25,27) indicate that the stigmatization people who use drugs is marked with negative attributes that damage their social and mental development even when they have stopped consuming and are in rehabilitation, and this brings along a deficit in treatments or places for rehabilitation due to the lack of government support. In Mexico, programs have been developed to avoid discrimination in diverse vulnerable groups, like HIV patients, racial discrimination, among others; however, care for the group of drug users is scarce or null, and drug use is considered a public health problem, but more identified with security than with the individual consumers and their need for care. This may be because drug use is seen as an attitude related with a decision by each individual and not as a disease or ailment.

The prior results permit affirming that proposed in the Transitions Theory by Meleis, which indicates that transition conditions, like personal, community, and social factors or characteristics can facilitate or inhibit the experience of the transition from legal to illicit drug use. Meleis(8) indicates that transitions may be unhealthy and develop over a given time with responsibility to obtain a problematic result against the transition experienced, which will depend directly on the vulnerability presented by the person and on the facilitating or inhibiting conditions of the transition process, such as personal conditions, like beliefs, cultural attitudes, knowledge, and the community and social conditions in which the person is immersed. All of the aforementioned could harm or enhance the transition stage. According to Meleis,(8) these process patterns guide people to health or toward greater vulnerability, this permits nursing to evaluate patterns, like coping strategies to facilitate healthier results.

Nursing professionals are the principal caregivers of clients and families who undergo the transitions from legal to illicit drug use; in this sense, the role of nurses within primary care staff and specialized nurses can develop a leading role in actions regarding promotion of community health and in prevention to avoid the drug use transition in young populations from a multi-factor approach on addictions. Their contribution can be decisive in early detection, the initial approach, referral to specialized resources, and in the coordination and follow up from the different social and health teams, always from continuous communication with the user individual, bearing in mind individual needs and favoring the development of each patient. Nursing professionals, as professionals implied and called to lead these processes, must be capable of integrating the tools of the discipline to solve and avoid the transitions of the drug use.

It is important to recognize that this research has limitations. In the first place, by this being a case and control design, it is not possible to identify direct causality. This urges interpretation of the data with caution because the method was based on retrospective data; concerns are generated on the accuracy of the memory and it is important to consider using other types of designs for future research. Although the use of questionnaires is acceptable to collect information related with the use of substances, it is important to emphasize on the lack of biochemical or physiological indicators, so that the estimation of these variables is according to the answer provided by the participant.

The conclusion here is that the findings contribute to improving the understanding of some factors that intervene in the transition from legal to illicit drug use, such as personality traits, neighborhood characteristics, exposure to drug use, social support, and the social stigma of drug use, which could be useful to develop more effective interventions to prevent drug use. In future studies, it is important to consider a more detailed analysis of the quality and duration of the family relationships because they can be risk factors, as well as protection factors, necessitating their inclusion in future research and, thus, obtain a more complete picture of these relationships during adolescence and youth, to be taken into account in the design of interventions to prevent the transition from legal to illicit drug use. Additionally, we recommend replicating the study with longitudinal designs to broaden the data collection time and have more specific data. This is important because some of these factors are developed during early stages of life when information on these factors could be collected in more detail.

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Strategies of care for adolescent users of crack undergoing treatment

Original article

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Strategies of care for adolescent users of crack undergoing treatment

Abstract

Objective. To analyze the care strategies of the adolescent crack user under treatment. **Methods.** Study of qualitative approach of descriptive type. The participants were 20 professionals from *the Centro de Atenção Psicossocial Álcool e Drogas* (Center for Psychosocial Care Alcohol and Drugs) and 10 professionals from the *Centro de Atenção Psicossocial Infanto-juvenil* (Center for Child Psychosocial Care) in a municipality in the interior of Rio Grande do Sul (Brazil). Data collection occurred through semi-structured interviews and the data were submitted to Thematic Analysis. **Results.** It was identified the development of strategies in four scopes: attractive activities in specialized services, the building of bonds between the team and the adolescent, the inclusion of family in the care and the intersectoral work. **Conclusion.** Care

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strategies, directed to and that address the needs of adolescents, contribute to better adherence to treatment and social reintegration.

Descriptors: Adolescent; Crack Cocaine; Street Drugs; Mental Health; adolescent health services; qualitative research.

Estrategias de cuidado al adolescente usuario de crack en tratamiento

Resumen

Objetivo. Analizar las estrategias de cuidado del adolescente usuario de crack en tratamiento. **Métodos.** Estudio con abordaje cualitativo de tipo descriptivo. Los participantes fueron 20 profesionales de un Centro de Atención Psicosocial Alcohol y Drogas y 10 profesionales de un Centro de Atención Psicosocial Infanto-Juvenil de un municipio del interior de Rio Grande do Sul (Brasil). La recolección de la información se realizó mediante entrevistas semiestructuradas y los datos se sometieron a análisis temático. **Resultados.** Se identificó el desarrollo de estrategias en cuatro ámbitos: actividades atractivas en los servicios especializados, la construcción de vínculos entre el equipo de salud y el adolescente, la inclusión de la familia en el cuidado, y el trabajo intersectorial. **Conclusión.** Las estrategias de cuidado, direccionadas a cubrir las necesidades de los adolescentes, contribuyeron a una mejor adhesión al tratamiento y a la reinserción social.

Descriptores: Adolescente; Cocaína Crack; Drogas Ilícitas; Salud Mental; Servicios de Salud del adolescente; investigación cualitativa.

Estratégias de cuidado ao adolescente usuário de crack em tratamento

Resumen

Objetivo. Analisar as estratégias de cuidado do adolescente usuário de crack em tratamento. **Métodos.** Estudo com abordagem qualitativo de tipo descritivo. Os participantes foram 20 profissionais de um Centro de Atenção Psicossocial Álcool e Drogas e 10 profissionais de um Centro de Atenção Psicossocial Infanto-Juvenil de um município do interior do Rio Grande do Sul (Brasil). A recolecção da informação se realizou por meio de entrevistas semiestruturadas e os dados se submeteram a análise temática. **Resultados.** Se identificou o desenvolvimento de estratégias em quatro aspectos: atividades atrativas nos serviços especializados, a construção de vínculos entre a equipe de saúde e o adolescente, a inclusão da família no cuidado, e o trabalho inter-setorial. **Conclusão.** As estratégias de cuidado, direcionadas a cobrir as necessidades dos adolescentes, contribuíram a uma melhor adesão ao tratamento e à reinserção social.

Descritores: Adolescente; Cocaína Crack; Drogas Ilícitas; Saúde Mental; Serviços de Saúde do adolescente; pesquisa qualitativa.

Introduction

Adolescence is a fundamental stage in people's development, characterized by biological and psychosocial changes that affect all aspects of adolescent life. It is a vital phase that includes moments of choices, decisions, and experiences that often determine future development.(1) In this context, experiences of both licit and illicit drug use often arise, which may lead to abuse and dependence. One of these illicit drugs is crack, which began to circulate in Brazil approximately 30 years ago, covering an increasing number of adherents to its habit, including the adolescent public.(2) According to the *Pesquisa Nacional de Saúde do Escolar* (National Health Survey of the School Student) conducted by the *Instituto Brasileiro de Geografia e Estatística* (Brazilian Institute of Geography and Statistics) between 2012 and 2015, there was an increase in the percentage of 9th grade students, which equates to the starting year of highschool, who tried illicit drugs (marijuana, cocaine, crack, *cola, loló, lança-perfume*, ecstasy, among others), going from 7.3% to 9.0%. Of these, 5.5% used crack in the last 30 days prior to the survey.(3)

For this reason, crack consumption and its implications in adolescence has been a matter of concern in society due to clinical and social problems that happen in a precocious manner. In adolescent health, crack use can cause psychotic disorders, cognitive impairment, mood and behavioral changes, and cardiorespiratory problems.(4,5) In addition, adolescent crack users are exposed to situations of violence, criminality, and also dropping out from school, leaving them socially vulnerable as well.(5,6) Thus, the complexity of the consequences related to the abusive use of crack in adolescence and the social vulnerability to which many adolescents and young people are exposed, demands new ways of producing health, with priority for integrated actions within the scope of intersectoral public policies and networking aimed at efforts for prevention, treatment adherence and harm reduction.

The current global health strategy, which covers the period 2016-2030, includes adolescents as a priority target for actions, proposing an agenda aimed at guaranteeing health rights, for physical and mental well-being, and the promotion of healthy behavior, preparing them to develop their full potential in adulthood.(1) In Brazil, governmental actions in the area of drugs emphasize the construction of the *Rede de Atenção Psicossocial* (RAPS, Psychosocial Care Network) for people in psychological distress and with needs arising from the use of crack, alcohol and other drugs. The RAPS strengthens the conception of continuous care with guaranteed access and integration of the points of care, especially for children, adolescents and young people due to their vulnerable condition.(7) At RAPS, the referral services for specialized care for adolescent crack users are *Centros de Atenção Psicossocial* (Psychosocial Care Centers), in their child or adult mode, aimed at users of alcohol and other drugs. Adolescents in these services should be targeted for prevention, harm reduction, intersectoral actions, and social reintegration.(7)

Although treatment guidelines are established in the public sphere and the extent of the theme has grown, mental health services face difficulties in presenting resolute proposals to the adolescent user of crack, alcohol and other drugs. It is verifiable that beyond being incipient the installation of specialized services for this population, both the *Centro de Atenção Psicossocial Infanto-juvenil* (CAPSi, Child Psychosocial Care Center) and the *Centro de Atenção Psicossocial Álcool e Drogas* (CAPSad, Psychosocial Care Center for Alcohol and Drugs), there is a difficulty in the organizing of and planning of specific actions the demands of the adolescent substance user public.(8-10) Thus, by not having their specificities considered, the adolescent has poor adherence to the actions of the service, difficulty in linking teams and frequent relapses, constituting an important barrier to treatment.(9-11) This scenario highlights the need to understand the care strategies for adolescent crack users, favoring the organization of teams to offer actions that can assist in treatment adherence and social reintegration. Therefore, the article aims to analyze the care strategies of adolescent crack users undergoing treatment.

Methods

This is a descriptive study with a qualitative approach to data, linked to a broad research project entitled ‘(Des)*caminhos percorridos pelo adolescente usuário de crack na rede de atenção psicossocial: contribuição para a Enfermagem’* (or ‘(Mis) paths coursed by the adolescent crack user in the psychosocial care network: contribution to Nursing), developed at the *Centro de Atenção Psicossocial Álcool e Drogas* (CAPSad, Psychosocial Care Center for Alcohol and Drugs) and the Centro de *Atenção Psicossocial Infanto-juvenil* (CAPSi, Child Psychosocial Care Center) of a medium-sized municipality in the interior of Rio Grande do Sul (Brazil) that is part of the Crack Program, it is possible to win. The project was submitted to the *Comitê de Ética* (Research Ethics Committee) and approved following the *Certificado de Apresentação para Apreciação Ética* (Certificate of Presentation for Ethics Appreciation). In order to ensure ethical principles for research involving human subjects, participants were included in the study only after being advised about the study’s objectives and methodology and expressing their agreement to participate by signing the Free and Informed Consent Form. In addition, the anonymity of the participants was preserved by using the letter P succeeded from the interview number and service to which they belong.

Twenty CAPSad professionals and 10 CAPSi professionals participated in the study. The selection of participants was intentional, according to the inclusion criteria and research objectives. Namely, the inclusion criteria were: being a mid-level or higher worker who is part of the CAPSad or CAPSi multiprofessional team; have at least six months of experience in the service. Professionals on vacation or sick leave during the data collection period were excluded. The number of participants was defined by the data saturation defined when, in the researcher’s evaluation, a certain redundancy or repetition occurs, and it is not considered relevant to persist in the data collection. Data collection took place in the first half of 2017, through semi-structured interviews conducted by a single interviewer, questioning them about the care strategies offered to the adolescent crack user under treatment. In view to participants’ privacy, the interviews were conducted in rooms available at the services, respecting the functioning of CAPSad and CAPSi. In order to preserve the original content and increase the accuracy of the data obtained, the interviews were captured by an audio recorder and later transcribed in full. For the organization and processing of the data, the Nvivo 11 software was used, and subsequently analyzed and categorized according to the Thematic Analysis. From the organization and analysis of data emerged the following categories: Attractive Therapeutic Activities; Bond building; Inclusion of the family; and Intersectoral Work.

Results

From the data analysis, it was identified the development of strategies in four areas: attractive activities in specialized services, the building of bonds between the team and the adolescent, the inclusion of the family in the care and intersectoral work.

Attractive Therapeutic Activities

The adolescent public is considered more agitated, with more energy, showing greater adherence to activities performed outside the service, in community resources such as squares, libraries and events. In CAPS, stands out the therapeutic workshops of music and gym. In this sense, one identifies as a strategy the attractive therapeutic activities, directed to the needs of this audience: *Upon arrival, we make a nursing consultation, always asking: what does he like to do, because CAPS activities are not very targeted at teenagers, for example, they are not about painting, nor about making crafts. They still do, but that's unattractive. So we try to fit them into the music classes, the gym, which they like, to spend a lot of energy. [...] There are teenagers who need the street, so there have to be street activities. We use a lot of street resources, because there is the square, the library. Whatever is an event that we can participate we take them. This is not easy, activities need a change all the time* (P7 CAPS AD). *The teenager comes with a whirlwind of things along, so the team needs to have the profile to work with them. They have much more energy, much more agitation, need to have much more activities, need to have specific activities that compensate, have verbal handling that is 24 hours* (P18 CAPS AD). *[...] or because of abstinence, tolerance, they end up not having as much focus on the proposed activities so they have to have a bigger unfolding, more to offer, more variety of activities because really the focus is not so long and the whole question the impulse to leave the place, to be stuck* (P4 CAPS i).

Thus, it is necessary to broaden the menu of activities offering modalities such as: internet access, video games, sports in multi-sport courts, socialization activities in the community and pedagogical accompaniment: *To improve care would be necessary other modalities and activities such as access to internet and video games, to keep the teenager in service. In addition, spaces would be indispensable for sports, such as sports courts* (P9 CAPS AD). *We're dealing with teenagers and they have a lot of energy, not only energy for being a teenager, but this whole lust that comes with substance use, so keep them indoors, just television, just play, just handle verbal is not enough, they need sports, they need pedagogical accompaniment. They can't stay closed, the world is out there waiting for them. This treatment can not be totally closed here between four walls, this treatment will be part of a walk in a square, to take in a historic center, rescue what he lost* (P17 CAPS AD).

Bond building

Care for adolescent crack users requires the building of bonds, so that the team develops strategies to establish trust, management and patience, respecting the adolescent's moments: *In care they are very suspicious, so you need to gain their trust* (P14 CAPS AD). *You have to have management, you have to have patience, you can't just come and go, you have to have a bond [...]. It's a building job, bond establishing. He has to realize that he has a bond with this team and that he can trust that team because only then can we get him to go to the host unit* (P16 CAPS AD). *The bond with the team facilitates the identification of social needs and adherence to treatment, and the turnover of professionals can* *interfere in this process: [...] here we work with the user, we work with bond and, unfortunately, they come and go. So today he comes and talks to me, tomorrow is you. This is very bad, this whole turnover. Teenagers have ties with us and soon we change, they have a lot of losses and that is also very bad* (P7 CAPS AD). *[...] We discover things like this little by little, as you go, they get confidence* (P9 CAPS i).

Family Inclusion

The care for the adolescent crack user involves the inclusion of the family member, since the adolescent is underage, and especially because the focus of the problem is often found in the family. The participation of the family member is seen as one of the necessary aspects for the progress in treatment and the family group as an important therapeutic device of care: *We try to locate family members and always involve the family member because they are underage* (P19 CAPS AD). *In UAI there are two days of visit, and what we see, that the family puts them inside the UAI [...]. So if we don't do this strong, well-done work with this family, we can't see progress* (P7 CAPS AD). *[...] the whole family issue has to be worked out [...]. This is very related to the lack of family structure with drug use, so I think the conduct of the team has to be differentiated* (P6 CAPS i). *Also interesting is the teen-only family group that is run by a social worker. There is that family group there because it is no use treating only the teenager, often the problem is there in the family* (P2 CAPS i).

Intersectoral work

Adolescent crack users are in vulnerable environments, exposed to conflicting family relationships and street life. Thus, it is necessary to work in intersectoral network through dialogue and joint actions between health, social assistance, tutelage council, the judiciary sector and partnerships with community devices aiming at offering possibilities of social reintegration: *I think it has to be much further, because Only the CAPS and the Childcare Unit will never meet all the demand, it has to be an intersectoral work. These teenagers, mostly, have broken families, sometimes have no father, no mother, or only mother, sometimes parents are users, sometimes traffickers, sometimes they're living on the street, so they demand from other sectors* (P8 CAPS AD). *I think one thing that we have been focusing a lot and that is very difficult is the intersectoral partnerships, so to get courses, workshops, gymnastics, pilates, box, computer course, training course, internships, that kind of thing, you should prepare them better and that you could really offer them new prospects for reintegration* (P18 CAPS AD). *I think it is the services that sit and talk, the RAPS points of attention that all work with children and youth [...], and thus it has to be intersectoral including, not only RAPS. Intersectoral, because we will work together with the council, we will work together with the judiciary, we will work together with CRAS, many times we will work with a teenager who is using marijuana, for example, but the mother and the father so using heavier drugs more periodically then, you have to work with the network if you don't work with the network and then so when I say work with the non-model network alone. Then the damage reduction or CAPSad be the articulator, but they have support from other services as well [...]* (P5 CAPS i).

Discussion

Adolescents and young people constitute a population group that requires new modes of health care. The health problems evidenced in this phase are largely due to habits and behaviors that, in certain situations, make them vulnerable. In this context, attention to adolescents should be guided by comprehensiveness, impressing a look at the different aspects of adolescent life and their specificities, which requires reorganization and planning of actions directed to this audience.(12) In this study, care strategies for adolescent crack users within the scope of RAPS include the development of dynamic therapeutic activities involving music, sports, the use of the internet and video games, and especially insertion activities in community spaces. These activities are considered more attractive for maintenance treatment.

Games and music are also identified in another study as potent therapeutic resources in the treatment of adolescent psychoactive substance users.(11) These strategies make it possible to work in a playful and attractive way on aspects related to cognition, social interaction, expression of feelings, simulations of real life situations and exposure to situations of vulnerability. In addition, the study underscores the importance of specific actions and strategies that consider the socioeconomic and cultural context, aiming to assist adolescents in establishing and empowering the protagonism of their lives. Practices involving playfulness, fantasy, communication and imagination are also means to clarify doubts and provide guidance on the relationship of pleasure and suffering caused by drug use. It is identified that these activities are most effective when built in groups, because young people, by making analogy of biographical situations and sharing experiences, can better work with their own issues.(13) The organization of the service in a way that is more attractive to adolescents goes through a construction process, and it is first necessary to be closer to the reality of young people in order to comprehend in a broader way the reality in which they are inserted, and thus develop strategies that can develop critical thinking and reflection on the problems experienced.(10)

It is identified in the present study that the organization of the service to offer such activities is still a challenge, and CAPS needs to advance in this aspect. The activities traditionally performed in specialized mental health services do not meet the needs of this public. These data corroborate research that points to a deficit in relation to the *organization of Centros de Atenção Psicossocial* (Psychosocial Care Centers) to attract adolescents, which may reflect on the follow-up of therapy and treatment losses.(8,9) It is noteworthy that the *Política Nacional de Saúde Mental* (National Mental Health Policy) signals the structuring and strengthening of specialized services in the mental health network aiming at an organization and qualification of the actions provided. However, in addition to the more attractive environment for this audience, it is necessary to consider the singularities of each adolescent, prioritizing a different attention in the construction of each therapeutic plan. Thus, therapeutic activities that are attractive to adolescents should be dynamic and targeted, which arouses their interest and motivation. We highlight activities such as music, sports, use of new technologies, and above all, activities performed outside CAPS, in the community, in spaces of socialization, leisure and culture. In this sense, it is important to know the needs and community resources, integrating actions in the territory of life of adolescents.

The bond construction as another care strategy requires management, patience and establishment of trusting relationships to adhere to the proposed strategies and social reintegration. Researchers point out that bonding between the adolescent and the team is one of the main factors in adherence to treatment, favoring commitment to therapeutic activities and changes in behavior regarding drug use.(14) In caring for adolescent crack users, bonding develops respect for choices, encourages participation in treatment, and moments of listening without prejudice and judgment so that adolescents perceive, in the service, a place of inclusion and acceptance of their needs beyond drug use. Many adolescent drug users face taboos and prejudices until they come to health services for help, so it is important for staff to adopt a cordial, understanding attitude to build trust. This mode of attention aims to break with the traditional logic of attention, which is still very much present in practice, where it is observed the imposition of norms and behaviors that place the adolescent in a position of inferiority and passivity, removing not only freedom of choice but also the responsibility for their actions.(15)

However, it is worth noting that the construction of the bond as a therapeutic resource is a complex process that requires, in addition to technical skills, the organization of the service provided to it, as well as the reduction of the turnover of professionals in mental health services, a factor that already highlighted in previous research.(16) Inclusion of the family in treatment was also identified as a care strategy for adolescent crack users within the scope of RAPS. The present study demonstrates that the progress in therapy is related to the inclusion of the family member in the treatment, since it is within the family structure that many problems are found, which may be related to drug abuse and, therefore, need understanding. and approach in this area.

Adolescent drug use may be related to the exposure of children and adolescents to many problems that permeate a disrupted family environment. In this regard, the research highlights the lack of coexistence or lack of dialogue with parents or guardians, the use of drugs in the family, facilitated access to drugs in this environment and experiences of aggression in the family environment.(17,18) In this sense, the use of crack in adolescence is not an isolated problem, but related to different factors, in which the family context has an important influence. This aspect alerts to the situation of family members and highlights the reflection of weaknesses in family dynamics in the life and illness of their members.(19) It is not uncommon for RAPS professionals to serve members of the same family in different mental health services and witness the perpetuation of the consequences of a problematic family context across different generations.

Families' difficulties in dealing with the problems of adolescent drug abusers are mainly related to a scarce support network in the community that gives them proper support. This fragility makes it difficult for the family members to be co-responsible for adolescent care and generates a feeling of powerlessness and helplessness in the family, which often causes the family member to seek institutionalization in shelters or psychiatric hospitals, an option that has not been effective.(8) Given this situation, it is not up to professionals to judge or blame families, but rather to include them as a target of care and partners in the treatment of adolescent crack users. Family support is fundamental for physical and social restoration, as well as for continued treatment.(20,21) On the other hand, the family integration deficit, with discussions, discrimination and fights, stimulates the use of alcohol and other drugs, distorting and destroying the self-confidence and self-esteem of the members.(21) The inclusion of the family member in the treatment becomes relevant due to the weaknesses identified in this context that require understanding and assistance. Thus, we suggest strategies that aim to strengthen the role of the family and family relationships such as family group activities and individual family care in specialized services. Therefore, it is the responsibility of the services and public policies to promote family care and conditions for their participation and partnership in care, even if the difficulties may be great. It is necessary to know the family's experiences, feelings, and parents' experience regarding the use of crack and other drugs. This strategy helps to overcome anxieties and doubts so that they are encouraged and empowered to act in the process of social reintegration of their children.(18)

Intersectoral work was also identified as one of the demands of adolescent crack users, constituting an important strategy for comprehensive care and action on social vulnerabilities in which many adolescents are inserted. Sectors such as health, social assistance, guardianship council, the judiciary and community devices should compose this partnership, through dialogue and joint actions, aiming at offering possibilities of social reintegration. This finding is in line with other studies that highlight the intersectoral articulation as one of the possibilities to broaden the action on the needs of adolescent crack users and overcome the difficulties faced in caring for this public.(18,19)

The political and institutional field stresses the need for an intersectoral and multidisciplinary approach in the care of adolescent crack users, with development not only of clinical actions, but also related to family, community, school, housing, culture, drug trafficking and violence, emphasizing the harm reduction strategy as the axis of actions in the SUS. Despite the recognition of the necessary articulation in an intersectoral network, what is currently observed are sectoral or institutional actions that contribute little to the management of the phenomenon of drug use in adolescence. In general, it is clear that the health, social assistance, school and judiciary sectors interfere at different levels and situations, with a delegation of responsibilities that sometimes falls on one sector, sometimes on the other.(5,23)

The results of this sectorial work are visible as new data point to the increase in crack consumption in adolescence and to the difficulties in the treatment and rehabilitation of users and their families who deal daily with the problem.(18,22) According to the participants of this study, intersectoral networking involves spaces for sharing, dialogue between the different actors that are part of the care of children and youth, having as articulators of the network CAPSad and Harm Reduction. In this conception, partnerships with social devices in the territory are also essential, with the offer of courses, training, therapeutic workshops, internships, sports, as a way to offer different perspectives of social reintegration through an intersectoral practice.

These data corroborate the research that highlights the partnerships in the territory as essential for network design, giving an intersectoral practice on health needs. However, the study points out that these resources are little explored, requiring greater involvement of professionals, including partnerships, funds and interests in the implementation and maintenance of these spaces.(24) In this sense, it is understood that the intersectoral network in the care of adolescent crack users is a task under construction, requiring the involvement of professionals, management support, material resources and qualified human resources in order to expand the possibilities of its implementation, producing more significant results in the social reintegration of adolescent crack users. From the above, it is considered that the health network, through strategies directed to adolescents can help them in the process of treatment and social reintegration, preventing them social and health damage in their current phase and in adulthood.

The results of the present study allow us to conclude that the care provided to adolescent crack users under treatment involves the development of strategies in four areas: attractive activities in specialized services, the building of bonds between the team and the adolescent, the inclusion of the family in care, and intersectoral work. These care strategies directed to the needs of adolescents contribute to a better adherence to treatment in the Psychosocial Care Centers and to their social reintegration.

In the present study we sought to deepen the most outstanding demands at the present time by workers of specialized services. However, it is understood that there are different demands for care when considering this theme regarding adolescents and drug use, such as the prevention demands that may be the target of future studies.

As a limitation of the study, it is pointed out that it was performed in two services that make up the RAPS, not covering other emblematic services in the care of adolescents who use crack, alcohol and other drugs. For this reason, it is recommended that new research include the analysis of other services and sectors such as guardianship council, education and justice that are directly involved in the care of young people using crack, contributing to the knowledge of new practices that address the complexity of care of this audience.

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