QUALITY OF LIFE IN PREGNANT WITH HEART DISEASE

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ABSTRACT: The objective of this cross-sectional, descriptive and exploratory study was to describe the perceptions of pregnant women with heart disease concerning their quality of life. Ferrans and Powers Quality of Life Index was applied to 42 patients from the second trimester of pregnancy on, between January 2008 and March 2009. Descriptive statistics, analysis of variance and Student's t test were used. The Quality of Life Index median total score was relatively high (23.9), while the socioeconomic domain was the most compromised (22.9). An association between unplanned pregnancies and the socioeconomic domain was observed (p=0.065). These patients' quality of life can be regarded as good, but unplanned pregnancies contributed to worsening scores in the socioeconomic domain. High-risk pregnancies did not affect quality of life because a pregnancy is linked to meanings such as happiness, satisfaction and personal fulfillment.

DESCRIPTORS: Quality of life. Pregnancy. Heart diseases. Nursing.

QUALIDADE DE VIDA EM GESTANTES COM CARDIOPATIA

RESUMO: Pesquisa descritiva, exploratória, de corte transversal, que teve como objetivo descrever a percepção de qualidade de vida em gestantes com cardiopatia. O Índice de Qualidade de Vida de Ferrans e Powers foi aplicado em 42 pacientes, a partir do segundo trimestre de gestação, entre janeiro de 2008 e março de 2009. Usaram-se estatística descritiva, análise de variância e teste t de *Student*. A mediana do escore total de qualidade de vida foi relativamente alta (23,9) e o domínio socioeconômico, o mais comprometido (22,9). Tendência entre gravidez não planejada e domínio socioeconômico foi observada (p=0,065). A qualidade de vida destas pacientes pode ser considerada boa, mas quando a gravidez não foi planejada contribuiu para piorar a dimensão socioeconômica. A gestação de alto risco não afetou a qualidade de vida, uma vez que a mesma está atrelada a significados de felicidade, satisfação e realização pessoal.

DESCRITORES: Qualidade de vida. Gestação. Cardiopatias. Enfermagem.

CALIDAD DE VIDA EN GESTANTES CON CARDIOPATÍA

RESUMEN: Investigación descriptiva, exploratoria y transversal con objeto de describir la calidad de vida percibida en gestantes con cardiopatía. El Índice de Calidad de Vida de Ferrans y Powers fue aplicado en 42 pacientes, a partir del segundo trimestre de embarazo, entre enero del 2008 y marzo del 2009. Fueron usados la estadística descriptiva, análisis de variancia y test t de *Student*. La mediana del score total de calidad de vida fue relativamente alta (23,9) y el dominio socioeconómico el más comprometido (22,9). Fue observada tendencia entre embarazo no planeado y dominio socioeconómico (p=0,065). La calidad de vida de estos pacientes puede ser considerada buena pero, cuando el embarazo no fue planeado, contribuye para empeorar la dimensión socioeconómica. El embarazo de alto riesgo no influenció la calidad de vida, ya que la misma estuvo vinculada a significados de felicidad, satisfacción y realización personal.

DESCRIPTORES: Calidad de vida. Gestación. Cardiopatías. Enfermería.

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INTRODUCTION

Association between heart disease and pregnancy is a known potential obstetrical and fetal risk factor during pregnancy and childbirth. Additionally, heart disease is considered to be the main indirect cause of maternal mortality worldwide.1 In Brazil, the incidence of heart disease during pregnancy has reached a rate of 4.2%, which is eightfold the international rate.2 Such a high percentage is attributed to the high incidence of rheumatic diseases in women of a reproductive age.3 Rheumatic disease is considered the main etiological determinant of valvular heart disease4, and the healing of the inflammatory process that affects all segments of the heart during outbreaks of rheumatic fever causes deformation of the heart valves.5-6

The cardiovascular changes associated with pregnancy and the postpartum period can lead to severe clinical deterioration in these patients and often to the initial diagnosis of valvular disease. In this period, the volume of circulating blood increases by 30% to 50%, with a corresponding increase in cardiac output. Conjointly, systemic vascular resistance is substantially reduced and blood pressure is decreased. These changes begin in the first trimester and reach a peak between the 20th and the 24th gestational weeks, with an additional increase in the immediate post-partum period.⁸

Because pregnancy is a biological process that has social, economic, emotional, psychological and sexual consequences for women, little attention has been given to the quality of life of pregnant women with heart disease. In this context, nurses play an important role in improving the quality of life of these individuals as they incorporate the principle of integrality as a dimension of the care process.

In general, studies address quality of life during pregnancy in healthy women or other health issues during pregnancy. ¹⁰⁻¹² As to heart disease, the focus has been directed toward clinical outcomes in pregnancy. ¹³⁻¹⁵ Nevertheless, it is assumed that the hemodynamic changes and limitations imposed on daily activities during pregnancy may impact a pregnant woman's quality of life. This is a subjective concept, however, as the evaluation of quality of life depends on individual perspectives. ¹⁶

In fact, a study conducted with pregnant adolescents reported that little change was observed in relation to the participants' perceptions concerning quality of life.¹⁷ And another study conducted with 202 pregnant women assisted by a low-risk prenatal service showed that the highest quality of life score was attributed to the domain of general health conditions.¹⁸

This study's objective was to describe the perceived quality of life of pregnant with heart disease during pregnancy.

METHODS

This descriptive, exploratory and cross-sectional study was conducted in a public hospital providing specialized cardiac care in the city of São Paulo-SP, Brazil. This facility is accredited to provide high-complex care to patients covered by the Unified Health System, medical insurance and health plans, in addition to providing private service. This facility also stands out for its teaching and research activities.

The non-probabilistic sample was composed of 42 patients cared for in a specialized outpatient clinic from January 2008 to March 2009. Inclusion criteria were patients with heart disease and gestational age of 24 weeks or more who provided consent to participate in the study.

A two-part questionnaire was used to collect data. The first part addressed the participants' socio-demographic data and the second part included the Ferrans and Powers Quality of Life Index (QLI), translated and validated for the Portuguese language.¹⁹

This instrument contains 33 items to which the participants attribute ratings on an increasing scale of satisfaction and importance ranging from one to six. In the first part, the scale ranges from "very dissatisfied" (1) to "very satisfied" (6), and in the second part, it ranges from "not important" (1) to "very important" (6).

The QLI items comprise four quality-of-life dimensions (sub-scales), according to the authors' conceptual model: health/functioning (13 items), socioeconomic (eight items), psychological/spiritual (seven items) and family (five items). Each item in the first part of the instrument, which evaluates satisfaction, corresponds to the same subject addressed in the second part, which assesses importance.²⁰ The variation allowed for the total score and in each domain ranges from 0 to 30; the higher the score, the better one's quality of life.¹⁹

The researchers individually interviewed the participants, that is, companions were not al-

lowed to participate, after medical consultations took place on the premises of hospital's outpatient unit where the study was performed.

The study was approved by the Ethics Research Committee at the Sao Paulo State University School of Medicine Hospital (Protocol n. 1030/06). The patients participated voluntarily and signed informed consent forms. Data confidentiality was maintained in accordance with Resolution 196/96, National Health Council of Ministry of Health, which regulates research with human subjects in Brazil.²¹

Initially, all the variables were descriptively analyzed. The quantitative variables were analyzed using minimum and maximum values, mean, median and standard deviations. The absolute and relative frequencies were calculated for the qualitative variables.

The quality of life scores were expressed as medians and interquartile ranges. In order to evaluate the relationship between some items and the QLI mean score, analysis of variance was used. The comparison between the quantitative variables and the mean of the QLI was evaluated by Student's *t* test. Statistical analysis was performed using SPSS 15.0 (SPSS Inc. USA), and values p<0.05 were considered to be statistically significant.

RESULTS

In relation to socio-demographic characteristics, the pregnant women were predominantly young: 38% were aged between 22 and 26 years old (Table 1). The highest age was 39 years old, with a mean of 28.6 years (±SD 5.63). Most of the participants (42.9%) had from zero to seven years of schooling. Only one participant graduated from college, thus the sample was characterized as having a low educational level.

In regard to marital status, 21 (50.0%) participants reported having a partner, that is, they were either married or cohabitate. Additionally, more than half of the respondents (52.4%) already had children.

A total of 23 (54.8%) participants had formal jobs. Of these, 14 (33.3%) had jobs classified as non-specialized manual labor, that is, activities that do not require previous experience. They were housekeepers, day-cleaners, and cleaning aides, saleswomen, among others. A smaller number of women (3; 7.2%), performed specialized manual activities that required technical training, such as production aides, manicurists, and craftswomen.

Another six (14.3%) had jobs that were characterized as non-manual, as they required knowledge and technical skills, in addition to observation, concentration, and the ability to think abstractly. These included nurses, prosthodontists, beauticians, nursing technicians, and secretaries.

Table 1 - Distribution of the socio-demographic variables of the interviewed pregnant women. São Paulo-SP, Brazil, 2008

Age (years) 17–21 3 7.2 22–26 16 38.0 27–31 7 16.7 32–36 11 26.1 ≥37 5 12.0 Mean (SD) 28.6 (±5.63) Year of schooling 20–7 18 42.9 8–10 9 21.4 14 33.3 15+ 1 2.4 Marital status With a partner 21 50.0 20 Without a partner 21 50.0 50.0 Children 22 52.4 No 21 47.6 Professional activity Yes 23 54.8 No 19 45.2 Type of work Non-specialized manual labor 14 33.3 Specialized manual labor 3 7.2 Non-manual/technical positions 6 14.3 Status concerning work 0n leave 11 26.2 Active 12 28.6			0/
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Status concerning work On leave 11 26.2 Active 12 28.6 Homemaker 19 45.2 Income monthly(US\$) Mean 654.84	Specialized manual labor	3	7.2
On leave 11 26.2 Active 12 28.6 Homemaker 19 45.2 Income monthly(US\$) Mean 654.84	Non-manual/technical positions	6	14.3
Active 12 28.6 Homemaker 19 45.2 Income monthly(US\$) Mean 654.84	Status concerning work		
Homemaker 19 45.2 Income monthly(US\$) Mean 654.84	On leave	11	26.2
Income monthly(US\$) Mean 654.84	Active	12	28.6
Mean 654.84	Homemaker	19	45.2
Mean 654.84	Income monthly(US\$)		
SD ± 520.61		654.84	
	SD	± 520.61	

We observed that almost half of the respondents with a formal job were on sick leave (26.2%). The income mean and variance, US\$ 654.84 (±520.61), show the large economic variability in the sample.

Table 2 shows that 11 (26.2%) pregnant women had suffered miscarriages prior to the current pregnancy and 28 (66.7%) did not plan their pregnancy. Additionally, 33 (78.6%) women had

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previous pregnancies and almost half had more than one pregnancy. Another important piece of information is that most of the pregnant women (76.2%) did not participate in family planning groups, which could have contributed to reduce the rates of unplanned pregnancies. The mean gestational stage was 27.4 weeks.

We observed that 18 (42.9%) pregnant women had rheumatic fever as their predominant base pathology, which was followed by congestive heart failure (19,0%). Congenital heart diseases (9.5%), valvular stenosis (9.5%), and arrhythmias (7.1%) were less frequently reported.

Table 2 - Clinical and obstetric variables of the studied pregnant women. São Paulo-SP, Brazil, 2008

Variable	n	%
Prior pregnancy		
Yes	33	78.6
No	9	21.4
Number of prior pregnancies		
=1	17	51.5
≥2	16	48.5
Prior miscarriages		
Yes	11	26.2
No	31	73.8
Participation in family planning groups		
Yes	10	23.8
No	32	76.2
Pregnancy planning		
Yes	14	33.3
No	28	66.7
Etiology of heart disease		
Rheumatic fever	18	42.9
Congestive heart failure	8	19.0
Congenital heart diseases	4	9.5
Valvular stenosis	4	9.5
Arrhythmia	3	7.1
Chagas disease	1	2.4
Mitral valve prolapse	1	2.4
Intracardiac neoplasia	1	2.4
Non-specific chest pain	1	2.4
Takayasu's arteritis	1	2.4
Pregnancy age (weeks)		
Mean (SD)	27.4 (±4.05)	

The median score for the total quality of life index was relatively high (23.9), while the socioeconomic domain was the most compromised

(22.9), followed by the health and functioning (23.2) domains. Note that the family domain was better evaluated by 25% of the interviewees (Table 3).

Table 3 - Medians, quartiles (25th and 75th percentiles), mean and standard deviation for the Quality of Life Index scores in pregnant with heart disease. São Paulo-SP, Brazil, 2008

Domains	Medians	Percentile 25 and 75	Mean (SD)
Total Health/functioning	23.9 23.2	19.9 - 25.8 19.5 - 25.1	23.2 (±3.82) 22.3 (±4.57)
Socioeconomic	22.9	17.6 - 25.1	20.8 (±5.56)
Psychological/spiritual	27.4	23.1 - 28.5	25.6 (±4.52)
Family	28.5	24.3 - 30.0	27.2 (±3.48)

Table 4 shows a tendency toward a smaller average for the socioeconomic domains when pregnancy was not planned, though the tendency

is not statistically significant. No statistical significance was observed in relation to the remaining domains.

Table 4 - Descriptive statistics concerning the scores of the Quality of Life Index domains in relation to pregnancy planning. São Paulo-SP, Brazil, 2008

Prognancy planning			Domains		
Pregnancy planning -	Health	Socioeconomic	Psychological/Spiritual	Family	TQLI
Yes (n=14)	23.9±4.97	22.0±4.80	27.4±1.89	28.5±2.69	24.7±3.46
No (n=28)	21.5±4.21	20.3±5.89	24.7±5.17	26.5±3.69	22.4±3.82
p*	0.103	0.065	0.360	0.089	0.078

^{*} Student's t test.

DISCUSSION

In relation to socio-demographic characteristics, pregnant women from 22 to 26 years old with incomplete primary school predominated. A significant association between the mothers' lower educational level and low-weight birth infants were observed in a study conducted in the state of São Paulo, Brazil. A possible explanation is that these women may gain less weight during pregnancy and delay prenatal care due to their low socioeconomic status.²² Educational level is also associated with optimism, pessimism and health-related quality of life during pregnancy.²³

In regard to the etiology of their heart disease, rheumatic fever remains the main complication. This result is corroborated by a study that analyzed one thousand cases of pregnant women with heart disease cared for in the outpatient clinic of a tertiary hospital specializing in heart disease.²⁴

Another piece of information to be considered in this study refers to the evaluation of the perception of pregnant women with heart disease concerning quality of life, given their clinical and obstetrical complexity. Health aspects, as well as

psychological and social aspects, can influence the quality of life of women experiencing such a peculiar and special time in their lives.

In general, the women reported relatively good quality of life. Among the four domains of QLI, the family and psychological/spiritual domains were the ones that obtained the best evaluation, while the socioeconomic domain obtained the worst evaluation.

The evaluation of quality of life is admittedly a complex task because it is a subjective concept concerning which a consensus has yet to be reached. The very definition of quality of life adopted by the World Health Organization (WHO) is complex and presents the positive and negative facets of life in addition to the multidimensionality of the concept when dealing with the interrelationships between the environment and an individual's physiopsychological aspects, degree of independence, social relationships and personal beliefs.²⁵

Additionally, one must take into account that this interrelationship exists within a certain cultural context, namely the value system in which - 816 - Meneguin S, Xavier CL

individuals live in relation to their objectives, concerns, expectations and standards. ²⁶⁻²⁷ Therefore, any quality of life measure requires achieving an exact translation of this set of elements into an index or score that reflects the perception of diverse individuals in different circumstances of their lives. ²⁸

In fact, a study addressing the quality of life of pregnant women with type 1 Diabetes *Mellitus* and gestational diabetes reported that the general perception of health held by the studied participants worsened as their pregnancy progressed.¹²

Although quality of life was considered to be relatively good by this study's patients, the tendency observed in the socioeconomic domain among those with unplanned pregnancies may lead to the inference that quality of life is also related to socioeconomic factors. Despite the fact that our sample was composed predominantly of women without a formal job, the situation of family economic dependence must be taken into account in this context. The financial hardships resulting from an unplanned pregnancy are probably an obstacle for these women to provide the conditions they deem ideal for raising their children. Additionally, in a society where women contribute to the family's income in many ways, the fact of having a child without planning, as shown in this study, can lead to significant outcomes for one's personal and professional lives.

Thus, one of the issues indicated in this study concerns not only these women's lack of information, but also their lack of education, since merely advising them on aspects related to sexual physiology and contraceptive practices is insufficient to prevent the resulting consequences. The means providing such information should be open and sensitized to the psychosocial complexity of these women's universe, thus giving a particular meaning to pregnancy.²⁹

Each woman is unique with personal idealizations and meanings she assigns to the experiences of pregnancy and motherhood; such idealizations and meanings are constructed based on a person's socio-cultural and family contexts. ¹⁸ For women with heart disease, a pregnancy is a basis that can support and consolidate their female identity and fulfill the social role maternity represents. On the other hand, the non-consolidation of such a role is a factor that leads to the frustration of one's dreams and fantasies. ³⁰ For this reason, many women with heart diseases probably desire pregnancy despite its high risk.

Based on the premise that maternity is a process of transformation in a woman's life, it becomes complex when the woman experiences problems and limitations arising from a heart condition combined with maternity.

A study conducted with hospitalized pregnant women in the third trimester, 11 with heart disease and nine with diabetes, showed that the experience of having a health condition is often filled with suffering and difficult to endure due to the discomfort caused by treatment or limitations that may result from a disease and are imposed upon one's social life. Therefore, the management of a pregnancy in these circumstances requires the construction of integral and humanized care based on considerate care and guidance so that women feel supported and able to make conscious choices concerning pregnancy in the future.

The importance of contraception for these women is based on the premise that heart disease is the main non-obstetric cause of maternal death in pregnancy. Furthermore, an early diagnosis associated with proper treatment enables an increased number of cardiopathic women to plan for conception,² though one should keep in mind that even when properly advised, women often unconsciously wish to become pregnant despite medical contra-indications.

This attitude may be associated with an intimate need to adhere to the female procreation role, which, to these women, seems to integrate them into their model of an ideal woman. To them, pregnancy creates the possibility of overcoming obstacles,²⁹ and for this reason, a pregnancy may not be planned but nonetheless desired.

Therefore, health care professionals working in family planning programs should consider and also value the subjective, cultural and psychosocial aspects involved in high-risk pregnancies as much as the physiopathological elements involved. Having children and the choice of the most suitable contraceptive method are decisions that every woman is entitled to make freely with appropriate information, without discrimination, coercion or violence.³²

However, some limitations in this study must be acknowledged. The lack of studies on the quality of life of pregnant patients with heart diseases hindered the comparison of our results. But, on the other hand, it showed that further investigations will certainly be conducted in this field.

CONCLUSION

The study's findings revealed that these patients' quality of life was relatively good, contrary to the expectations that the peculiar physiological changes in the second trimester of pregnancy would negatively interfere with their perception of their quality of life. When pregnancy was unplanned, however, it contributed to worsening their socioeconomic status. A high-risk pregnancy did not affect these patients' quality of life since it was linked to happiness, satisfaction and personal fulfillment.

Such a fact shows the importance of providing integral nursing care, based on the redefinition of knowledge and practice, valuing the patients' subjectivity and uniqueness as essential elements. Due to the limited number of studies addressing this topic, we propose future studies including a larger number of pregnant women in order to increase possibilities of generalization.

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