

Quality of life of people with intestinal stomas

Qualidade de vida de pessoas com estomias intestinais de eliminação

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Abstract

Objectives: To evaluate the quality of life of people with intestinal stomas and verify its association with sociodemographic and clinical characteristics.

Methods: A cross-sectional descriptive study was carried out with 96 people registered in an ostomy program, with the use of the City of Hope-Quality of Life-Ostomy Questionnaire.

Results: The mean score of total QoL in this study was 6.2 ± 2.8 . The highest mean score was found in the spiritual well-being dimension $7.5 (\pm 1.9)$ and the lowest in the social well-being dimension $5.6 (\pm 2.1)$. Sociodemographic characteristics (per capita income, education level, religion) and clinical characteristics (length of use and adaptation to the stoma, length of time needed for ostomized people to feel comfortable, difficulty with self-care, and limitation to perform activities of daily living) were associated with total quality of life and its dimensions ($p < 0.05$).

Conclusion: Intestinal stomas interfere with quality of life, especially in physical and social dimensions.

Resumo

Objetivos: Objetivou-se avaliar a qualidade de vida de pessoas com estomias intestinais de eliminação e verificar sua associação com características sociodemográficas e clínicas.

Métodos: Trata-se de estudo descritivo e transversal realizado com 96 pessoas cadastradas em um Programa de estomizados, utilizando o *City of Hope - Quality of Life - Ostomy Questionnaire*.

Resultados: O escore médio de QV total deste estudo foi $6,2 \pm 2,8$. O maior escore médio foi encontrado no domínio Bem-estar espiritual $7,5 (\pm 1,9)$ e o menor no domínio Bem-estar social $5,6 (\pm 2,1)$. As características sociodemográficas (renda per capita, escolaridade, religião) e as características clínicas (permanência e adaptação à estomia, tempo de estomizado para sentir-se confortável, dificuldade para o autocuidado e limitação para realização de atividades diárias) associaram-se a qualidade de vida total e seus domínios ($p < 0,05$).

Conclusão: As estomias intestinais de eliminação interferem na qualidade de vida, principalmente nos âmbitos físico e social.

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Introduction

Intestinal stomas result from surgical interventions undertaken in the large intestine (colostomy) and small intestine (ileostomy). They consist of the exteriorization of an intestinal segment through the abdominal wall, creating an artificial opening for elimination of feces and flatus.

⁽¹⁾ In adults, the main causes of these types of stoma are colon and rectal cancer, traumas (injury by firearms or knives and car accidents), and inflammatory bowel diseases (ulcerative colitis and Crohn's disease).⁽²⁾

In the postoperative period, ostomized patients face changes in the anatomy of their bodies and daily habits of life, because the elimination of feces and flatus occurs by means of a stoma and without their control.⁽³⁾

These changes make the creation of intestinal stomas a traumatic and aggressive process that significantly reduce the quality of life (QoL) of ostomized patients.⁽⁴⁻⁶⁾

For the World Health Organization, QoL means "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".⁽⁷⁾

Brazilian studies have evaluated the QoL of ostomized people by means of generic instruments, including the WHOQOL-BREF.^(8,9) However, few studies used the City of Hope-Quality of Life-Ostomy Questionnaire (COH-QOL-OQ), which is a specific instrument for evaluation of QoL of ostomized people.^(6,10-12)

Studies of this sort are necessary because they will enable the identification of sociodemographic and clinical factors that influence QoL and the comparison of results with other studies, enabling the development of nursing interventions and public health policies to improve care for ostomized people.

Therefore, the aim of the present study was to evaluate the quality of life of people with intestinal stomas and verify its association with sociodemographic and clinical characteristics.

Methods

This was a cross-sectional descriptive study carried out in an outpatient unit in the capital city of Piauí, in the Northeast region of Brazil, which is reference in care for ostomized patients, from April to July 2013, after approval from the research ethics committee (Protocol nº. 12882613.1.0000.5214).

The population was made up of all people (n=635) registered in the ostomy program of the abovementioned outpatient unit, by June 2013. The convenience sample was made up of 96 patients who met the following inclusion criteria: being 18 years or older at the time of data collection, presenting conditions to participate in the study, having intestinal stomas undertaken for at least one month, living in the capital city of Piauí, and having agreed to participate in the study.

Participants were selected based on a survey of records of patients with intestinal stomas registered in the ostomy program of the outpatient unit, and by active search of those who received care from the service or were represented by their family or responsible for the collection equipment. Patients with intestinal stomas whose first contact was not carried out in the outpatient unit were contacted by telephone, by means of three attempts in different schedules. After selection, date and time were scheduled for the participants to be interviewed in the outpatient unit, according to their preference and availability. In the case of conditions that made it difficult for the participants to go to the unit, for example, advanced age and locomotion difficulties, and after request and authorization of the participants, the interviews were scheduled and carried out at their homes.

Instruments for sociodemographic and clinical characteristics based on variables associated with the literature^(8,9,13-15) and the COH-QOL-OQ,⁽¹⁰⁾ a specific instrument adapted and validated for the Portuguese language to evaluate the QoL of ostomized patients, were used for data collection. This instrument has 43 items divided into four subscales: physical well-being (items 1 to 11), psychological well-being (items 12 to 24), social well-being (items 25 to 36), and spiritual well-being (items 37 to 43). Each item was answered with the support of a

Likert 0-10 scale, in which 0 represented the worst result and 10 the best result. Before the creation of the database, items 1 to 12, 15, 18, 19, 22 to 30, 32 to 34, and 37 were reversed. The subscales were calculated by the sum of the scores in each item and, then, dividing the sum by the number of items of this subscale. The total QoL was obtained from the sum of the score in all items and dividing the sum by the total number of items, that is, 43.⁽¹⁶⁾

The data were analyzed with the Statistical Package for the Social Sciences 18 software (SPSS). The sociodemographic and clinical characteristics of people with intestinal stomas were analyzed by means of descriptive statistics, frequency, mean, and standard deviation. The association between sociodemographic and clinical characteristics and quality of life and its dimensions was evaluated by the parametric tests Student's t-test, ANOVA, and Pearson's correlation, and, with the violation of their assumptions, their equivalent nonparametric tests Mann-Whitney, Kruskal-Wallis, and Spearman's correlation coefficient were used. When a significant difference was detected in the ANOVA or Kruskal-Wallis tests, the Post Hoc and Mann-Whitney tests with the Bonferroni correction were respectively used. A significance level of $\alpha=0.05$ was adopted for all analyses.

Results

Education level, being older, having partners, and being catholic were the most important characteristics of the study sample (Table 1).

Eighty-one people (84.4%) had a colostomy and the most frequent complications after the creation of intestinal stomas were prolapse of the intestinal loop 10 (10.4%) and dermatitis 27 (28.1%). The mean length of stoma use was 53.9 months (standard deviation of 60.6) and the mean length of time needed to feel comfortable with the stoma was 214.0 days (standard deviation of 315.0). Thirty-eight (39.6%) people had a good adaptation to the stoma, 65 (67.7%) had difficulty with self-care, and 48 (50.0%) had limitations to perform activities of daily living.

Table 1. Sociodemographic characteristics of people with intestinal stomas (n=96)

Variables	n(%)	Standard Deviation
Gender		
Male	51(53.1)	
Female	45(46.9)	
Age (years)		59.7(18.6)
Marital status		
Married/stable union	46(47.9)	
Single	23(24.0)	
Widowed	17(17.7)	
Divorced	10(10.4)	
Religion		
Catholic	79(83.2)	
Evangelic	12(12.6)	
None	4(4.2)	
Education level		
Elementary school	37(38.5)	
High school	26(27.1)	
Illiterate	21(21.9)	
Higher education	12(12.5)	
Monthly household income (R\$)		1,789.9(2,036.2)
Per capita income (R\$)		582.2(679.2)

The mean score of total QoL was 6.2 (\pm 1.7). The highest mean score was found in the spiritual well-being dimension 7.5 (\pm 1.9) and the lowest in the social well-being dimension 5.6 (\pm 2.1). The psychological and physical well-being dimensions had mean scores of 6.2 (\pm 2.0) and 5.9 (\pm 1.9), respectively.

Per capita income was the only variable with a significant association; however, it was moderate with all dimensions of QoL, including total QoL. Education level also presented a significant association with the psychological well-being ($p=0.045$), spiritual well-being ($p=0.005$), and total QoL ($p=0.023$) dimensions, whereas religion was associated with the spiritual well-being dimension ($p=0.026$) (Table 2).

The variable length of stoma use presented a significant association with the physical well-being ($p=0.018$), psychological well-being ($p=0.009$), and total QoL ($p=0.010$) dimensions. Adaptation to the stoma was associated with the physical well-being ($p=0.031$), psychological well-being ($p=0.000$), social well-being ($p=0.018$), and total QoL ($p=0.001$) dimensions. People who had a good adaptation

Table 2. Association of sociodemographic characteristics of people with intestinal stomas with quality of life dimensions (n=96)

Variables	Physical well-being	Psychological well-being	Social well-being	Spiritual well-being	Total quality of life
Gender					
Male (SD)	5.73(1.91)	6.33(2.09)	5.77(2.05)	7.16(2.07)	6.16(1.78)
Female (SD)	5.96(2.03)	6.09(2.00)	5.41(2.12)	7.93(1.61)	6.17(1.59)
Test (p-value)	0.560 ¹ (0.577)	-0.586 ¹ (0.559)	-0.836 ¹ (0.405)	918.5 ² (0.092)	0.028 ³ (0.978)
Age (years)					
Test (p-value)	0.082 ² (0.425)	0.121 ² (0.241)	0.124 ² (0.230)	0.042 ² (0.685)	0.141 ² (0.169)
Marital status					
Married (SD)	5.79(2.08)	6.37(2.10)	5.50(2.26)	7.70(1.82)	6.19(1.81)
Single (SD)	5.87(2.03)	6.14(1.94)	5.35(1.91)	7.45(1.93)	6.06(1.53)
Widowed (SD)	5.98(1.73)	5.80(2.18)	6.26(1.68)	7.26(1.94)	6.21(1.63)
Divorced (SD)	5.76(1.83)	6.42(1.96)	5.47(2.44)	7.30(2.24)	6.13(1.72)
Test (p-value)	0.048 ³ (0.986)	0.353 ³ (0.787)	0.720 ³ (0.542)	0.804 ³ (0.849)	0.037 ³ (0.990)
Lives with other people at home					
Yes (SD)	5.79(2.01)	6.22(2.09)	5.66(2.12)	7.55(1.90)	6.17(1.74)
No (SD)	6.44(1.16)	6.23(1.62)	4.99(1.67)	7.16(1.90)	6.09(0.81)
Test (p-value)	-0.909 ¹ (0.366)	0.016 ¹ (0.987)	0.866 ¹ (0.389)	285.000 ² (0.374)	0.229 ¹ (0.822)
Religion					
Catholic (SD)	5.86(1.97)	6.21(1.99)	5.66(2.11)	7.62(1.89)	6.20(1.67)
Evangelic (SD)	5.93(1.71)	6.06(2.09)	5.15(1.78)	7.82(1.12)	6.06(1.52)
None (SD)	5.09(2.95)	6.35(3.42)	5.42(2.81)	4.43(1.60)	5.45(2.65)
Test (p-value)	0.302 ³ (0.740)	0.038 ³ (0.963)	0.313 ³ (0.732)	7.281 ⁴ (0.026)*	0.382 ³ (0.683)
Education level					
Illiterate (SD)	5.36(1.85)	5.39(1.83)	4.92(1.49)	6.50(1.75)	5.43(1.34)
Elementary school (SD)	5.48(1.91)	6.03(2.09)	5.51(2.11)	7.45(1.96)	5.97(1.71)
High school (SD)	6.68(2.14)	7.01(2.02)	6.04(2.22)	8.24(1.40)	6.86(1.69)
Higher education (SD)	5.93(1.42)	6.52(1.86)	6.11(2.45)	7.99(2.22)	6.50(1.63)
Test (p-value)	2.590 ³ (0.058)	2.795 ³ (0.045)*	1.415 ³ (0.243)	12.735 ⁴ (0.005)*	3.334 ³ (0.023)*
Monthly household income (R\$)					
Test (p-value)	0.083 ² (0.422)	0.142 ² (0.168)	0.122 ² (0.236)	0.156 ² (0.130)	0.154 ² (0.133)
Per capita income (R\$)					
Test (p-value)	0.242 ² (0.018)*	0.318 ² (0.002)*	0.267 ² (0.008)*	0.234 ² (0.022)*	0.332 ² (0.001)*

(SD): mean (standard deviation); ¹Student's t-test; ²Mann-Whitney; ³ANOVA; ⁴Kruskal-Wallis; ⁵Spearman's correlation coefficient; *Value of p<0.05

differed statistically from the others. The variable length of time ostomized presented a significant association with the psychological well-being ($r_s = 0.247$, $p=0.015$) and total QoL ($r_s = 0.228$, $p=0.025$) dimensions. A significant association was found between the length of time needed to feel comfortable and the physical well-being ($r_s = -0.301$, $p=0.005$), psychological well-being ($r_s = -0.261$, $p=0.016$), social well-being ($r_s = -0.265$, $p=0.015$), and total QoL ($r_s = -0.310$, $p=0.004$) dimensions. There was

also a significant association between difficulty with self-care and the physical well-being ($p=0.000$), psychological well-being ($p=0.000$), social well-being ($p=0.002$), and total QoL ($p=0.000$) dimensions. When analyzing the presence of limitation to perform activities of daily living, a significant association was found with the physical well-being ($p=0.000$), psychological well-being ($p=0.004$), social well-being ($p=0.000$), and total QoL ($p=0.000$) dimensions (Table 3).

Table 3. Association of clinical characteristics of people with intestinal stomas with quality of life dimensions (n=96)

Variables	Physical well-being	Psychological well-being	Social well-being	Spiritual well-being	Total quality of life
Type of stoma					
Colostomy (SD)	5.90(1.91)	6.26(1.98)	5.66(2.12)	7.41(1.87)	6.19(1.66)
Ileostomy (SD)	5.57(2.36)	6.30(2.35)	5.51(1.75)	8.45(1.14)	6.24(1.77)
Colostomy/ Ileostomy (SD)	4.82(0.90)	4.00(2.28)	3.83(2.83)	6.14(5.45)	4.51(2.60)
Test (p-value)	1.115 ⁴ (0.573)	2.065 ⁴ (0.356)	1.498 ⁴ (0.473)	2.690 ⁴ (0.261)	1.221 ⁴ (0.443)
Length of stoma					
Temporary (SD)	5.43(1.82)	5.74(1.93)	5.25(2.02)	7.34(1.89)	5.78(1.57)
Permanent (SD)	6.38(1.97)	6.81(1.91)	6.03(2.07)	7.88(1.77)	6.66(1.60)
Test (p-value)	-2.410 ¹ (0.018)*	-2.657 ¹ (0.009)*	-1.839 ¹ (0.069)	854.500 ² (0.119)	-2.641 ¹ (0.010)*
Complication with the stoma					
No (SD)	6.00(2.16)	6.24(1.69)	5.20(2.04)	6.83(1.66)	5.98(1.56)
Yes (SD)	5.82(1.95)	6.22(2.09)	5.65(2.09)	7.60(1.91)	6.18(1.70)
Test (p-value)	0.272 ¹ (0.786)	0.031 ¹ (0.976)	-0.641 ¹ (0.523)	305.500 ² (0.135)	-0.352 ¹ (0.726)
Complication with peristomal skin					
No (SD)	0.22(1.86)	0.24(2.00)	0.25(2.11)	0.21(1.78)	0.20(1.65)
Yes (SD)	0.42(2.19)	0.41(2.13)	0.37(1.96)	0.41(2.13)	0.33(1.72)
Test (p-value)	-0.741 ¹ (0.461)	-1.286 ¹ (0.202)	-1.486 ¹ (0.141)	771.500 ² (0.192)	-1.467 ¹ (0.146)
Adaptation to the stoma					
Excellent (SD)	7.00(2.04)	7.73(1.83)	6.31(2.44)	8.57(2.12)	7.31(1.77)
Good (SD)	6.50(1.83)	7.20(1.80)	6.43(2.03)	7.90(1.84)	6.92(1.52)
Regular (SD)	5.43(2.05)	5.48(1.97)	5.07(1.57)	7.63(1.33)	5.70(1.37)
Poor (SD)	5.13(1.61)	5.13(1.46)	4.94(1.76)	6.71(1.94)	5.33(1.29)
Very poor (SD)	5.31(2.05)	5.60(2.15)	4.91(2.29)	7.26(2.12)	5.61(1.68)
Test (p-value)	2.798 ³ (0.031)*	6.086 ³ (0.000)*	3.142 ³ (0.018)*	8.384 ⁴ (0.078)	5.069 ³ (0.001)*
Length of time ostomized (months)					
Test (p-value)	0.191 ⁵ (0.063)	0.247 ⁵ (0.015)*	0.198 ⁵ (0.054)	0.136 ⁵ (0.186)	0.228 ⁵ (0.025)*
Length of time needed to feel comfortable with the stoma (days)					
Test (p-value)	-0.301 ⁵ (0.005)*	-0.261 ⁵ (0.016)*	-0.265 ⁵ (0.015)*	-0.171 ⁵ (0.120)	-0.310 ⁵ (0.004)*
Difficulty with self-care					
No (SD)	6.31(1.84)	6.71(1.73)	6.04(2.01)	7.68(1.71)	6.58(1.45)
Yes (SD)	4.85(1.85)	5.19(2.28)	4.68(1.95)	7.18(2.23)	5.28(1.82)
Test (p-value)	-3.632 ¹ (0.000)*	-3.624 ¹ (0.000)*	-3.136 ¹ (0.002)*	886.000 ² (0.341)	-3.767 ¹ (0.000)*
Limitation to perform activities of daily living					
No (SD)	6.54(1.92)	6.82(1.95)	6.34(2.04)	7.63(1.84)	6.75(1.56)
Yes (SD)	5.13(1.75)	5.62(1.98)	4.86(1.87)	7.42(1.96)	5.57(1.61)
Test (p-value)	-3.767 ¹ (0.000)*	-2.990 ¹ (0.004)*	-3.685 ¹ (0.000)*	1078.000 ² (0.587)	-3.610 ¹ (0.000)*

(SD): mean (standard deviation); ¹Student's t test; ²Mann-Whitney; ³ANOVA; ⁴Kruskal-Wallis; ⁵Spearman's correlation coefficient; *value of p<0.05

Discussion

The inexistence of an updated database of ostomized people in the city of Teresina stands out as a limitation of the present study. However, this study is expected to encourage further research and contribute to the improvement in care provided to ostomized people, including the development of rehabilitation programs and promotion of QoL.

These data strengthen the need for multidisciplinary and holistic follow-up, from the perioperative

until the rehabilitation period, with a focus on ostomized patients and their families, with emphasis on the role of nurses in the establishment of a comprehensive and continuous care plan aimed at social reintegration, providing confrontation and adaptation strategies, and encouraging self-care according to perceptions of recovery and well-being of ostomized patients.

The mean score of total QoL of people with intestinal stomas in this study was 6.2 (\pm 2.8). Studies carried out in Iran and Brazil with adults that had also used the COH-QOL-OQ to evaluate the QoL

of ostomized people, found similar mean scores, with 7.48 (± 0.9) and 6.1 (± 1.4) respectively, and, in spite of the stoma creation, the total QoL obtained in these studies was considered moderate and good.^(6,11)

The spiritual well-being dimension presented the highest mean score of QoL and the social well-being dimension the lowest. This result is similar to that of another study carried out in Iran with ostomized people, in which the highest and lowest mean scores were also detected in the spiritual well-being and social well-being dimensions, respectively.⁽⁶⁾

Spiritual well-being is directly associated with an inner peace feeling, hope, and motivation to live, which favors the acceptance to changes imposed by the stoma on the new life condition.^(17,18) Religion is essential to restructure the new life condition, because it brings relief, confidence, and enables better adherence to the therapeutic treatment.⁽¹⁹⁻²⁶⁾ However, social isolation may occur due to loss of self-confidence and concern associated with privacy to empty the collection equipment, until problems with effluent leakage and flatus smell.^(6,23,24)

Per capita income was the only variable of the group of sociodemographic characteristics that was associated, although moderately, with all QoL dimensions, including total QoL. Other studies point out that low income may act as a negative factor for the reestablishment of QoL, because it limits access to medical care, self-care, housing, and food, affecting recovery and functional and psychological reestablishment of ostomized people.^(9,25,26)

With regard to clinical characteristics, the variable length of stoma use presented a significant association with the physical well-being ($p=0.018$), psychological well-being ($p=0.009$), and QoL ($p=0.010$) dimensions. Having a temporary stoma causes a feeling of anxiety for the closing of the stoma.⁽²⁷⁾ In this perspective, a study carried out in China showed that patients with lower length of time with the disease and length of stoma presented lower levels of acceptance of their clinical condition, thus affecting QoL.⁽²⁸⁾

Adaptation to the stoma was associated with the physical well-being ($p=0.031$), psychological well-being ($p=0.000$), social well-being ($p=0.018$),

and total QoL ($p=0.001$) dimensions. Although the main difficulty in adaptation of ostomized people is the adjustment to loss of control on the elimination of feces and flatus, there are other changes regarding clothes, sexuality, loss of confidence, independence, and dignity, in addition to difficulty to travel due to change of habits and privacy.^(14,29-31) The stoma is also associated with emotional problems and limitations, especially with isolation and depression, which interfere with the spontaneity to act, preventing an appropriate performance in the social and psychological dimensions.^(25,30)

The necessary length of time to feel comfortable with the stoma presented a significant association with the physical well-being ($r_s = -0.301$, $p=0.005$), psychological well-being ($r_s = -0.261$, $p=0.016$), social well-being ($r_s = -0.265$, $p=0.015$), and total QoL ($r_s = -0.310$, $p=0.004$) dimensions. This length of time may be long, because changes related to the stoma may last for at least five years after the surgery, with emphasis on physical, social, and financial impairment in the first six months.^(25,30) The progress to complete rehabilitation occurs when the ostomized person is able to manage changes associated with the use of the collection equipment and accept the loss of fecal continence. Therefore, the implementation of inclusive and irrigation technologies, for example, for people with descendant and sigmoid colostomies, may provide a wide choice of self-care management, improving body image, recovering continence in up to 12 hours, providing freedom and mitigating fear and nervousness caused by interpersonal relationships.⁽¹⁴⁾

Difficulty with self-care presented a significant association with the physical well-being ($p=0.000$), psychological well-being ($p=0.000$), social well-being ($p=0.002$), and total QoL ($p=0.000$) dimensions. This result corroborates another study carried out in the United States with adults, which shows that the presence of postoperative complications, such as fistulas, skin irritations, and protrusion of the stoma may determine a lower QoL in the long term, because they interfere with self-care.⁽²⁵⁾

Limitation to perform activities of daily living presented a significant association with the physi-

cal well-being ($p=0.000$), psychological well-being ($p=0.004$), social well-being ($p=0.000$), and total QV ($p=0.000$) dimensions. It is worth mentioning that the collection equipment causes restrictions to the daily life, especially limitations on sexuality, social life, activities of daily living, clothing, and food. In a previous study conducted in Brazil, adult and elderly women, for example, reported that the stoma caused restrictions on activities of daily living, especially regarding household tasks.⁽¹⁸⁾

Conclusion

Intestinal stomas interfere with QoL, especially in the physical and social dimensions. It was also observed that the perception of ostomized people on their QoL may be associated with a reduced number of sociodemographic factors compared with clinical factors. Improvement on physical, psychological, social, and spiritual QoL due to sociodemographic factors is associated with higher income; whereas having a religion positively affects QoL only in its spiritual dimension. A higher education level improves general, psychological, and spiritual QoL. Clinical factors associated with better adaptation, lower length of time to feel comfortable, absence of limitations to perform activities and difficulties with the stoma self-care presented a positive impact on general QoL in all dimensions, except the spiritual. Whereas clinical factors associated with higher length of stoma and its permanent aspect presented a positive impact on the general QoL and psychological dimension, only the latter presented a positive impact on the physical dimension. These may enable the development of public health policies for ostomized people and nursing interventions, such as, guiding of patients in the perioperative period on the stoma that will be created regarding the segment to be exteriorized, length of stoma, type of effluent, normal characteristics, demarcations, information about changes in elimination of feces and flatus, possible complications and impacts on body image, clothing, food, sexuality, interpersonal relationships, activities of daily living, and preparation for the stoma self-care.

Collaborations

Almeida MCV and Cezar-Vaz MR declare that they contributed to the conception, project, analysis and interpretation of data, writing of the article, relevant critical review of its intellectual content, and final approval of the version to be published.

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