

Original Research Article

ASSESSING THE MULTIDIMENSIONAL IMPACT OF PRETERM BIRTH ON FAMILIES IN NORTH KERALA: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: The care of a preterm child often changes the mother's physical and cognitive functioning. **Objective:** 1. To estimate the effect of preterm birth on family in terms of Impact on Family Scale (IOFS). 2. To determine the various social and medical factors that affect the quality of life of primary caregivers.

Materials and Methods: This cross-sectional study was conducted in a Neonatal Unit & OPD at a tertiary care teaching hospital in North Kerala. 126 Parents of preterm babies admitted to the NICU during the study period of 18 months were eligible except those with psychiatric illnesses and babies with congenital anomalies. Data were collected through interviews at six months postpartum using a questionnaire that included sociodemographic data and the 27-item Impact on Family Scale (IOFS) to measure financial, social, personal, and mastery impact. Medical details were obtained from records. Descriptive statistics, pearson correlation, independent sample t test and ANOVA were the statistical test used.

Results: The mean age of mothers was 27.4 years (± 5.2 years) and all the respondents were females. The mean IOFS score was 53.74 with social impact scoring highest followed by personal, financial, and mastery impact. Professional parents and families with higher income had significantly higher total IOFS scores indicating greater impact. Higher IOFS scores were also associated with babies of lower gestational age and birth weight, longer hospital stays, delays in initiation of KMC /NNS, and those with morbidities or requiring resuscitation.

Conclusion: These findings urge the need for holistic support to alleviate the burden and promote resilience in families affected by preterm birth.

Keywords: Pre-term birth, impact of family scale, neonatal unit, caregiver burden, cross-sectional.

INTRODUCTION

The birth of a child is usually anticipated with great joy, marking a transformative journey into motherhood. However it also brings profound changes in the physical, socio-emotional, cognitive functioning and behavior of mothers. They must adapt to the needs of a new baby often resulting in tiredness and loss of identity. Preterm birth, defined

as giving birth before 37 full weeks of pregnancy, remains a significant global public health issue. The World Health Organization (WHO) estimates that 13.4 million babies, or about one in ten live births, were born prematurely worldwide in 2020 .1 Preterm delivery accounts for roughly 35% of newborn deaths globally and is a major cause of neonatal mortality and long-term health problems.2 India has one of the highest rates of premature births, with an estimated 3.5 million preterm deliveries each year.3 Survival

rates have improved thanks to better neonatal intensive care, but these gains often lead to greater financial, emotional, and physical pressure on families.^[4]

With improving survival rates among premature and critically ill infants, who are at heightened risk of morbidity, the intensity of parent's responsibilities for newborn care expands.^[5] Preterm birth poses a dual challenge with its primary consequence being the precarious medical and neurophysiological state of the newborn. For instance, when compared to normal birth weight infants, low birth weight infants (LBWI) experience difficulty with feeding and growth, respiratory complications, rehospitalization, and neurocognitive challenges apart from other comorbidities.^[6] They are at increased risk of sensory and motor impairment, delay in cognitive development and behavioral problems.^[7] In addition to obstetric complications and the medical health conditions of the baby, other secondary factors like income, education, profession, and social support also influence the maternal health in the postpartum period. This puts them at increased risk for poor physical and mental health as well as negative feelings about their baby in the early months.^[8] Several studies have found that there is a heightened risk of anxiety, depression and post-traumatic stress disorder and diminished wellbeing among parents of preterm infants.^[9,10] These negative effects have been observed to endure for a substantial duration, resulting in family dysfunction which in turn poses a risk for later developmental difficulties in babies.^[11] Successful adaptation to the maternal role enhances self-confidence and satisfaction among mothers in caring for their children. When mothers embrace their maternal role, they are better equipped to care for their children.^[12,13] Identifying the factors influencing maternal role adaptation can enhance the quality of postnatal care and deepen the understanding of women's responses to such circumstances. While numerous studies,^[14,15] have examined the stress level of post-natal mothers in baby care there remains a gap in literature specifically addressing the impact of preterm birth on mothers in terms of various domains like financial, social, personal, and mastering ability despite the considerable influence of these factors on caregivers. Although the neonatal mortality rate in Kerala, one of India's most health-advanced states, is lower than the national average, preterm birth still presents difficulties.^[16] North Kerala provides a unique context for comprehending how families manage the stress of preterm birth because of its diverse urban-rural population and strong family-centered culture. Despite relatively high levels of literacy and healthcare access, regional and socioeconomic differences in neonatal outcomes still exist.^[17] Gaining knowledge about how families in this area cope with the complex effects of preterm birth can help improve family-centered neonatal care and psychosocial support networks. Although preterm delivery's psychosocial effects are gaining more

attention globally, not much research has been done in India, particularly in Kerala, to look at the complex effects on families. Most existing research focuses on medical outcomes or newborn survival rather than family well-being.^[18]

Our study addresses a gap in research, as only few studies,^[19,20] have explored caregiver burden in preterm care, especially in regions like ours, where economic and social support systems might significantly influence the challenges faced by caregivers. This article explores how preterm birth impacts various aspects of mother's lives, including financial, social, personal, and mastering abilities. Additionally, it investigates the multifaceted impact of preterm birth examining the various social and medical factors that affect the quality of life of primary caregivers.

Objectives: This study was conducted with the **Aim**

to assess the impact of preterm on caregivers.

The primary objective was to estimate the effect of preterm birth on family in terms of Impact on Family Scale (IOFS).

Secondary objective was to determine the various social and medical factors associated with the impact of preterm births primary caregivers

Hypothesis

Null hypothesis: There is no association between various medical and social factors with the impact of preterm births on care givers

Alternate hypothesis: there is association between various medical and social factors with the impact of preterm births on care givers.

MATERIALS AND METHODS

This cross-sectional study was conducted in the Neonatal Unit & OPD at a tertiary care teaching hospital in North Kerala. The study was performed from October 2021 to April 2023 (18 months). Parents of preterm babies born ≤ 34 weeks admitted in the NICU were eligible for the study. The study excluded parents with preexisting psychiatric symptoms and babies with congenital anomalies. Based on a previous study,¹⁰ the mean total impact score for the extremely low birth weight (ELBW) group of 25.30, and S.D of 6.11; the relative error (D) is taken as 5% of the mean score, and the sample size obtained is 119. The objectives and procedure of the study were explained and informed written consent was obtained from the participants. Data were collected by interviewing mothers at six months postpartum. Eligible parents were interviewed, and the data collected were sociodemographic data like education and occupation of both the parents, family income, family type and parity; and medical factors like gestational age, birth weight, kangaroo mother care, NICU admission, resuscitation, morbidities, maternal anxiety and depression, APGAR score and duration of hospital stay, NICU stay, full feed day, respiratory support were also collected. These factors

were related to preterm delivery may creating impact on the family, so these factors were included in the study. Medical details were obtained from hospital records.

The sample size was calculated using the formula $N = 4SD^2 / D^2$. Based on a previous study,²¹ the mean total impact score for the extremely low birth weight (ELBW) group of 25.30, and S.D of 6.11; the relative error (D) is taken as 5% of the mean score, and the sample size obtained is 119.

Data on impact of preterm delivery on family on various aspects like financial impact, social impact and personal impact were collected by administering the family scale questionnaire measuring four impact domains. IOFS - Impact on family scale was developed in 1980 designed to assess the impact of pediatric illness on the family. The scale comprises a 27-item Each item requires parents to indicate their level of agreement on a 4-point Likert scale. The subscales include financial impact (4 points), social (15 points), personal (5 points), and mastery (3 points), totaling a possible score of 108. Score of range 0 to 108 can be obtained. For each question, the parents can choose between 'strongly agree', 'agree', 'disagree', and 'strongly disagree'. Financial burden assesses economic consequences, social impact measures disruption of social interaction, personal strain evaluates psychological burden and mastery gauges coping strategies. The total IOFS score is obtained by summing scores from all items, with a higher score indicating a greater impact.²² Ethical clearance was obtained from the Institutional Ethics Committee (IEC) MESMCH/MESIRB/03(A)/Nov-2021/ PAED1. The confidentiality of data and the privacy of the participants were strictly maintained. By the participants. Mean plus or minus 2 SD was calculated for all the scores. The score below mean-2SD was considered to have low impact due to preterm birth and score greater than mean + 2SD was considered to have huge impact and score between mean $\pm$ 2SD was considered to have moderate impact. Depression and anxiety were assessed using hospital anxiety and depression scale. This has 7 questions for depression and 7 questions for anxiety. They are four point likert scale with scoring for each question ranging from 0 to 3. The total score ranges from 0 to 21 for both anxiety and depression. Higher the score higher is the chance of depression and anxiety. Scoring interpretations are as follows for both anxiety and depression.

0 -7 = normal

8 - 10 = borderline abnormal

11 - 21 = abnormal.

Statistical Analysis: Data were analysed using necessary statistical tools and techniques. Data was analysed using SPSS 26.0 (SPSS Inc., Chicago, IL) and the level of significance was set at $p < 0.05$ with 95% CI. Dependent variable in the present study is impact scores on various aspects due to preterm delivery. Socio-demographic factors and medical factors were independent variables. The normality of the variables was tested with the Shapiro-Wilkinson

test. Descriptive statistics included mean, frequency, and percentage. Inferential statistics included comparisons of the mean IOFS scores by socio-demographic attributes and medical factors using ANOVA followed by Bonferroni Posthoc test if there are more than two groups and independent sample t test was used if there are two different groups. Pearson test was used for the correlation test.

RESULTS

The analysis included mothers of 126 preterm newborns ≤ 34 weeks. 63 (50%) babies were ≤ 32 weeks. 15(12%) were very preterm (28-32week) and 6(5%) were extreme preterm babies(≤ 28 week). The mean age of parents was 27.4 years (± 5.2 years) for the mother and 34.8 years (± 4.9 years) for the father. The mean birth weight was 1500g (± 370 g). 50 (40%) babies had a birth weight below 1500 grams, 32(25%) babies required resuscitation & 76 (60%) babies had major medical morbidities like RDS, Shock, and significant jaundice. 84 (67%) babies had prolonged hospital stay for more than two weeks. The majority of mothers 107 (85%) and fathers 109 (86.5%) attained education at the school level. The majority of mothers were homemakers 118 (93.7%) and fathers 73(57.9%) were unskilled workers, 106 (84%) of families have income below 20000, 88 (69.8%) belong to joint family and 38 (30.2%) were nuclear families. [Table 1]

The mean score across all domains was 53.74 with a range of 93 to 17. Among the four domains, the social domain had the highest score 31.65 followed by personal 10.87, financial 7.51, and mastery impact 3.71. [Table 2]

Table 3 shows the association between various socioeconomic factors and IOFS score. It is important to note that the parents who were professionals had significantly higher total IOFS scores ($p < 0.05$) with the most affected domain being social and personal. The mean scores of the financial burden domain vary significantly with the mother's occupation ($p = 0.006$) and family income ($p = 0.02$). However, the type of family (nuclear vs. joint) and parent's educational status did not significantly impact IOFS domains or the total score (p value - 0.75 and 0.37 respectively for mother and father's education 0).

We further analysed the effect of various medical factors on IOFS domains. The IOFS score does increase significantly with decrease in gestational age and birth weight, with financial ($p = 0.008$, < 0.00) and social($p = 0.02$, < 0.00) factors scoring significantly higher impact. Similarly, other factors like prolonged duration of hospitalisation (≥ 14 days), delay in initiation of Kangaroo Mother Care/Non Nutritive Sucking (KMC/NNS) by more than a week and those with associated morbidities also had significantly higher IOFS scores with the financial domain being the most affected part. Furthermore, the necessity for resuscitation demonstrated a substantial impact on IOFS scores. Infants requiring resuscitation exhibited

a higher score (60.32) compared to those who did not required resuscitation (51.59) ($p=0.002$). These results highlight the relationship between the neonatal factor and their influence on family well-being indicating that shorter gestational age, lower birthweight, longer hospitalisation, delay in initiation of KMC/NNS and the babies with morbidities correspond to increased burden or negative impact on families as indicated by elevated IOFS score. Table 8 shows the correlation of preterm birth impact scores with various neonatal parameters and maternal anxiety and depression scores ($n=126$). APGAR score, length, head circumference were all negatively correlated with the impact scores (p value

is ≤ 0.001 .) when they increase the impact of preterm birth on family was less. Except mastery score all the other scores were significantly correlated. NICU stay duration, total days on respiratory support, full feeds day, birth weight regain day, anxiety and depression were all positively correlated with the impact scores. Increase in these parameters cause increase in the family impact due to preterm delivery. Except total days on respiratory support all other parameters were significantly associated with total impact score (p value = <0.001 for anxiety, depression, and duration of NICU stay, p value – 0.002 for duration of full feed day and birth weight regained day).

Table 1: Sociodemographic attribute of the families

		Frequency	Percentage
Mothers education	School level	107	85
	Graduate & above	19	15
Fathers education	School level	109	86.5
	Graduate level & above	17	13.5
Mothers occupation	Homemaker	118	93.7
	Employed	8	6.3
Fathers occupation	Unskilled	73	57.9
	Skilled	45	35.7
	Professional	8	6.3
Family income	<20,000	106	84.1
	≥ 20000	20	15.9
Joint/nuclear family	Nuclear family	38	30.2
	Joint family	88	69.8
Parity	Primiparous	40	31.7
	Multiparous	86	68.3
Type of delivery	Vaginal delivery	32	25.4
	LSCS	94	74.6
Comorbidity	Present	96	76.2
	Absent	30	23.8

Table 2: Summary of IOFS score

	No. Of items	Mean score	Minimum	Maximum
Financial impact	4	7.51(4.27)	4	16
Social impact	15	31.65(8.14)	2	54
Personal impact	5	10.87(4.66)	6	20
Mastery impact	3	3.71(1.55)	3	12
Total score	27	53.74(12.01)	17	93
Anova P value		0.0001		

Table 3: Socioeconomic influence on IOFS

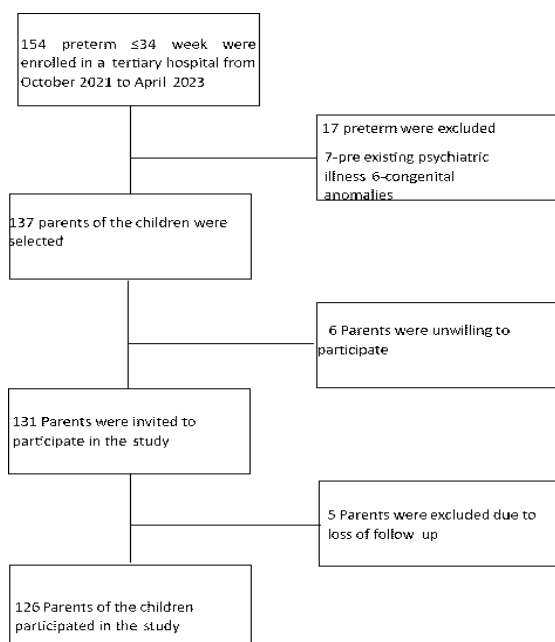
		Financial Mean p-value		Mean	Social p-value	Personal Mean p-value		Mastery Mean. p-value		Total IOFS score Mean p-value	
Mothers education	School level	7.74	0.69	30.61	0.34	4.71	0.97	1.98	0.37	53.13	0.75
	Graduate	7.41		32.19		4.66		1.33		54.00	
Fathers education	School level	7.58	0.81	30.45	0.04	10.87	0.98	3.95	0.03	52.84	0.37
	Graduate	7.40		33.48		10.88		3.34		55.10	
Mother occupation	Home maker	7.24	0.006	31.19	0.01	10.71	0.01	3.74	0.39	52.87	0.007
	Employed	11.50		38.50		13.25		3.25		66.50	
Father occupation	Unskilled	7.15	0.425	29.48	0.001	9.78	0.006	3.41	0.014	49.82	0.001
	Skilled	7.82		34.07		12.22		4.24		58.36	
	Professional	9.00		37.88		13.25		3.38		63.50	
Family income	<20000	7.13	0.02	30.66	0.001	10.42	0.01	3.7	0.26	51.98	0.001
	≥ 20000	9.50		36.90		13.30		3.35		63.05	
Type of family	Nuclear	7.16	0.54	32.76	0.31	11.89	0.10	3.97	0.20	55.79	0.28
	Joint	7.66		31.17		10.43		3.59		52.85	
parity	primi	7.550	0.940	32.150	0.841	10.650	0.716	3.850	0.480	54.200	0.802
	multi	7.488		31.419		10.977		3.640		53.523	

Table 4: Medical factors and IOFS

		Mean	Financial p-value	Mean	Social p-value	Personal Mean p-value		Mastery Mean. p-value		Total IOFS score Mean p-value	
Gestational age	≤28week	13.00	0.0001	39.0	0.016	17.0	0.004	3.83	0.21	13.00	0.0001
	28-30week	10.80		35.1		11.7		3.13		10.80	
	30-32week	7.07		31.7		9.81		3.51		7.07	
	32-34week	6.48		30.0		10.8		3.97		6.48	
Birth weight	<1500grams	9.22	0.00	34.58	0.00	11.56	0.12	3.66	0.76	59.02	0.00
	≥1500grams	6.00		29.07		10.27		3.75		49.09	
Hospital stay duration	<14days	5.67	0.00	29.11	0.00	9.67	0.001	3.67	0.69	48.12	0.00
	≥ 14days	10.00		35.04		12.51		3.78		61.33	
NNS/KMC	<7days	6.33	0.000	30.84	0.100	10.53	0.201	3.72	0.925	51.42	0.005
	≥7days	10.15		33.44		11.69		3.69		58.97	
Resuscitation	No resuscitation	6.72	0.0001	30.75	0.029	10.44	0.069	3.68	0.782	51.59	0.002
	Required resuscitation	9.94		34.42		12.19		3.77		60.32	
Nicu morbidities	No morbidities	5.72	0.00	29.06	0.003	10.28	0.24	3.86	0.37	48.92	0.002
	With morbidities	8.68		33.36		11.26		3.61		56.91	

Table 5: Correlation of preterm birth impact scores with various neonatal parameters and maternal anxiety and depression scores (n=126)

		IOFS : Financial	social total	personal	mastery	Total score
APGAR @ 5 min	Pearson Correlation	-.466**	-.246**	-.283**	-.184*	-.400**
	Sig. (2-tailed)	.000	.005	.001	.039	.000
Length	Pearson Correlation	-.344**	-.285**	-.137	.132	-.301**
	Sig. (2-tailed)	.000	.001	.127	.140	.001
Head circumference	Pearson Correlation	-.331**	-.289**	-.228*	.059	-.337**
	Sig. (2-tailed)	.000	.001	.010	.511	.000
NICU stay duration	Pearson Correlation	.478**	.319**	.265**	.007	.420**
	Sig. (2-tailed)	.000	.000	.003	.937	.000
Total days on respiratory support	Pearson Correlation	.175*	.126	.083	-.087	.144
	Sig. (2-tailed)	.050	.160	.356	.334	.107
Full feeds day	Pearson Correlation	.349**	.220*	.126	.024	.278**
	Sig. (2-tailed)	.000	.014	.161	.788	.002
Birth weight regained day	Pearson Correlation	.292**	.246**	.137	-.023	.275**
	Sig. (2-tailed)	.001	.005	.127	.796	.002
HADS Score Anxiety	Pearson Correlation	.197*	.273**	.456**	.378**	.412**
	Sig. (2-tailed)	.027	.002	.000	.000	.000
HADS Depression	Pearson Correlation	.222*	.239**	.402**	.454**	.390**
	Sig. (2-tailed)	.013	.007	.000	.000	.000
**. Correlation is significant at the 0.01 level (2-tailed).						
*. Correlation is significant at the 0.05 level (2-tailed).						



DISCUSSION

The present study explored the impact of preterm birth on various domains of a mother's life like financial, social, personal, and mastering ability and the influence of socioeconomic and medical factors on these domains as measured by the impact on family scale score.

The mean IOFS score in our study (53.74) indicates a moderate overall impact, with the social domain being the most affected, followed by personal and financial domains. Notably, social problems emerged as profound influencers of family well-being. Mothers experience social isolation, inability to plan day-to-day activities, limited opportunity to socialize with friends and family and increased job stress. There are studies with similar findings where families of premature infants have a lienation and social isolation which has a profound impact on parental emotions.^[23] This suggests that the family burden extends beyond direct medical expenses and includes emotional strain, social role disruption, and altered family functioning.

Parents who were professionals with higher incomes tended to score higher on the IOFS, particularly in social and personal domains indicating heightened impact levels. They feel additional pressure to excel in both their careers and caregiving roles leading to increased stress when confronting the challenges of caring for preterm infants, greater health awareness and higher perceived loss of control .24,25,26 In such a study although parents may not share equal responsibility for childcare the presence of the husband may buffer the impact of child care and provide a built-in backup of social support for the mother .27 However in the present study primary caregivers were only available as mothers probably due to economic dynamics and cultural norms prevailing in the study area . Numerous studies

revealed financial burdens in the forms of unpaid time off work, increased out-of-pocket expenses for outpatient services and medications, increased bills and debt were associated with higher impact .28,29 While improved income and professional status often provide a sense of control, the unpredictability of preterm birth can erode this sense, leading to increased burden. Their awareness, expectations and access to health-related content may also have played a role. In the current study, the availability of government medical insurance might have provided financial protection and support to families from lower socioeconomic status thereby decreasing the financial impact of preterm birth on them. However, indirect non-medical costs (travel, food, lost wages) likely remain unmeasured contributors. Conversely, the lack of significant impact of mother's education, father's education, and type of family on IOFS domains indicates that these factors may play a less critical role in shaping the caregiving experience for preterm infants. The lack of significant impact of the type of family on IOFS scores can be attributed to several potential factors. Both nuclear and joint families may experience similar levels of stress and burden due to the critical nature of preterm caregiving that necessitates similar levels of involvement and support, regardless of family structure. In a nuclear family, external support networks such as friends, extended family, or professional caregivers may step in to provide necessary assistance. Additionally, cultural factors and the adaptability of families to their caregiving roles might play a role. Petit et al have observed in their study that the quality of mother-infant interaction and the traumatic reaction of the mother are independent of the external support experienced by the mother.^[30]

On the medical front, the scores were higher among mothers of infants with lower gestational age and lower birth weight. There are studies where preterm birth and upbringing of an LBWI are associated with long-term impact on the family.^[31,32] High scores were associated with longer duration of hospitalisation, delayed initiation of KMC/NNS, babies with morbidities and those required resuscitation. They incur more treatment costs and experience delayed bonding opportunities exacerbating the impact on the families. This finding aligns with Reetha M's research and other studies which highlighted that mothers of infants facing life-threatening health issues requiring prolonged hospitalisation and dependency on technology for survival experienced clinically relevant anxiety and stress during the newborn period.^[33,34] These results reinforce an intuitive but important finding: the severity of neonatal illness directly amplifies family burden, especially in the financial and social domains. The correlation analysis further strengthens this by demonstrating that objective clinical markers (e.g., longer NICU stay, late feeding milestones) are aligned with greater family distress.

The present study found that the social impact exceeded financial impact, possibly reflecting cultural norms where mothers are primary caregivers and are socially isolated during prolonged hospitalization periods. This may also explain why mastery scores — reflecting coping confidence — were the lowest domain, indicating limited caregiver preparedness for prolonged neonatal stress.

While the present study offers valuable insights, it also has limitations. The scale used to find the impact of preterm delivery filled the subjective responses and it was not objective. Since it was a cross-sectional study it was not possible to elicit the long term effects of pre-term delivery. Mothers were the only responders and fathers were not included in the study, but however this study forms the base for long term multicentric studies with large sample size in future.

CONCLUSION

This study shows that preterm birth significantly affects family well-being. The social and personal aspects carry the heaviest burden, especially for families with very fragile infants. Financial and emotional stress increases due to factors like low income and professional jobs. Meanwhile, traditional support systems, such as extended family, do not appear to help much. These results highlight the need for, Routine psychosocial screening for families with high-risk preterm infants. Support networks specifically aimed at helping women who are the main caregivers. Regulations for both medical and non-medical costs. Structured early intervention programs that match clinical risks. Further long-term and multi-site research is necessary to understand the changing effects on families over time. This research can help shape ongoing support programs.

Ethical Clearance: Institutional Ethics Committee (IEC) ****/03(A)/Nov-2021/PAED1dated 22November 2021

Contributors: ** conceived the study; *** developed study protocol; ****: implemented the study; ****: supervised implementation; **: contributed to data collection and analysis; ****: contributed to data interpretation; ****: wrote the initial draft while ****: edited the final manuscript. All authors have reviewed the manuscript and approve the submitted version.

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