

# Sudden Infant Dead: Reaction to Bereavement in Siblings and Mothers

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## Abstract

**Background:** This study aims to determine if surviving siblings of children who died from Sudden Infant Dead Syndrome (SIDS) had behavioural or psychological problems and if their mothers had suffered from alexithymia.

**Methods:** We have enrolled 39 families (58 children). The "Mourning Group" (MG) consisted in 16 families (28 children) with following characteristics: 1) having an infant die from SIDS; 2) having at least one surviving child aged 6 to 18 years; 3) at least 8 years of mourning. The control group (CG) consisted of 23 families (30 children) free from any kind of mourning experiences. We used CBCL 6-18 questionnaire to assess behavioural and psychological problems on siblings, and TAS-20 in order to measure alexithymia in mothers.

**Results:** Children in the MG compared with children in the CG presented a significantly higher score in CBCL on "social problems", whilst reported a significantly lower score on "social competencies". Mothers in the MG compared with mothers in the CG presented significantly lower scores in the externally oriented thinking (subscale F3 of TAS). A positive significant correlation emerged between time of bereavement and difficulty in identifying feelings (subscale F1).

**Conclusions:** Our study confirms the presence of social difficulties in siblings born in families that experienced SIDS and shows that most of the mothers had long lasting difficulties in identifying their feelings.

**Keywords:** SIDS; Bereavement; Alexithymia; Psychology; Siblings

## Background

Sudden Infant Death Syndrome (SIDS) is defined as the sudden, unexpected death of an infant under one year of age, with onset of the fatal episode apparently occurring during sleep that remains unexplained after a thorough investigation, including performance of a complete autopsy, examination of the death scene, review of the circumstances of death and the clinical history [1].

The incidence of SIDS is difficult to assess because it varies over time, among countries (for instance, in the USA, SIDS remains the leading cause of postneonatal mortality where 2353 babies died from SIDS in 2008, about 0.6/1000 live-births) [2] and between different ethnic groups [3]. Moreover, in many cases an autopsy is not performed due to the lack of consent by parents [4].

As regards Italy, the incidence of SIDS could be estimated between 0.2 and 0.4 per 1000 [5]. A large number of mechanisms have been proposed: thermal stress, rebreathing of expired gases, infection/inflammation airway obstruction, QT interval prolongation at ECG [6]. Also risk factors: co-sleeping [7] genetic factors [8] smoking [9] prone sleeping position [10].

There are many reasons why SIDS may have a particularly severe effect on surviving family members. First its suddenness allows no time for either parents or children to prepare for the loss although it has been described that "anticipatory mourning" can significantly reduce the impact of death in the families of children with prolonged illnesses [11]. Secondly, the legal procedures involved in cot death, the arrival of the police and the investigation by a coroner may exacerbate shame, guilt and anger by interfering with necessary grief work, most notably, the task of arriving at a meaningful and acceptable account of the death [12]. Finally, medical uncertainty about the aetiology of SIDS can cause extreme anguish for remaining family members that may manifest anger or bewilderment [13]. Whilst each of these factors are usually thought as affecting parents after cot death, they are also likely to affect

siblings, either directly or indirectly, by affecting parents' behaviour and consequently the children's experience [14].

Typical reactions in surviving siblings include sense of guilt, anger, anxiety and sadness which frequently lead to behavioural and physical symptoms [15]; these reactions are similar to the mourning of the adult [16]. Previous studies have shown that bereaved siblings had prolonged and significantly elevated non-specific behavioural problems, such as depression, aggression, social withdrawal and sexual problems [17] and there was a wide variety of other problems reported, from social withdrawal to aggression towards peers. Others have reported bed wetting, clinging to mother, tantrums, rejection of the mother, fear of going to bed, sleep disturbances, nightmares and searching for the baby [18].

Some studies have focused on the impact of the loss of an infant on parents: Miller and Rahe [19] described that the death of a child is the heaviest stress that a woman can experience in her life; Rogers et al. [20] have recorded the presence of depression and health problems in bereaved parents up to 35 years after the event; Arnold et al. [21] described that in two thirds of the mothers of their sample, the pain has persisted for nearly 62 years after the death of the child. According to these studies, we wanted to explore the outcome of mourning in

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mothers at a distance of at least 8 years after the event.

SIDS is a peculiar entity in that the self-condemning reactions of the surviving family go far beyond the death itself. Parents should be helped in understanding that SIDS is a disease, although the mechanism of death is still not known, and that it is neither preventable nor predictable. Surviving siblings should not be excluded from the mourning process and should be reassured about their good health and blamelessness in causing the death. If parents defer having another child until the grief process is complete, the psychological environment for subsequent children will be healthier [22].

It is possible that mothers develop some defence mechanisms as a result of mourning, including a possible form of alexithymia definable as a state of deficiency in understanding, processing or describing emotions and in distinguish between emotive personal experiences and physiological activation of emotions, externally oriented cognitive style and social conventionality [23]. In fact some research associates the construct of alexithymia with reactions of grief caused by bereavement [24], furthermore associated with poor outcome in psychotherapy [25]. This study aims to determine if surviving siblings of children who died from SIDS had behavioural or psychological problems after at least 8 years of mourning and if their mothers have suffered from alexithymia.

## Methods

### Participants

The study was designed considering a study group of mothers and children with a brother/sister dead from SIDS and a control group of mothers and children not in mourning, combined in demographic terms, with the previous group.

Families in the "mourning group" (MG) were recruited through the "Semi per la SIDS" (Seeds for SIDS) Association in Florence (Italy), using 3 criteria for inclusion:

1. The families had an infant die from SIDS ascertained with the post-mortem examination.
2. At least 8 years of mourning have passed (to verify long term psychological outcome of bereavement).
3. The families had at least one surviving child who, at the time of data collection, was between 6 and 18 years of age.

Twenty families with an infant dead from SIDS were contacted by phone or by mail to receive their consent to participate and to request additional information on family history and bereavements; 16 of them agreed to participate to the research (28 children). Families of the Control Group (CG) were recruited from schools of the same geographic area; Twenty-nine families with siblings of similar age of the study group were contacted and interviewed by phone to ascertain no history of recent familiar bereavements; 23 of them agreed to participate to the research (30 children).

### Instruments

We used the following instruments:

- 1) TAS-20, Toronto Alexithymia Scale [26], parental questionnaire utilized to measure alexithymia administered to mothers.

It consists of 3 subscales: F1 – difficulty in identifying feelings; F2 - difficulty in communicating feelings to others; F3 - externally oriented thinking (operational thinking).

The subject is asked to answer 20 questions using a 5-point Likert

scale (1 = strongly disagree and 5 = strongly agree). The total score (TAS-20) is the sum of all responses and a score greater than 61 indicates alexithymia, a score of 52 to 60 possible alexithymia and less than 52 no alexithymia.

- 2) CBCL- Child Behaviour Checklist 6-18 [27]. It is designed to assess in a standardized format the behavioural problems and social competencies of children as reported by parents. From questionnaire scoring it is possible to obtain a profile of the skills of the child, the syndromic and general scales and of the DSM IV [28] oriented scales.

Responses to the items were recorded into a software (ADM, Assessment Data Manager), that computes the scores and creates the profile of the child's behaviour as perceived by the parent.

In the evaluation of each scale, developed by ADM software, t scores, T-score and percentile are displayed. The raw score (total score) indicates the sum of the responses given by the parent on the frequency of the items considered significant for each scale. The T-score represents the conversion of the raw score into a standardized score for age. For summary scales (internalizing problems, externalizing and total) a T-score  $\geq 63$  is considered clinically significant whereas a score between 60 and 63 is considered borderline. For the syndromic scales and the DSM-oriented scales a T-score  $\geq 70$  falls within the clinical range, while between 65 and 70 is a borderline score.

All questionnaires were completed by mothers, who were more active in the association "SEMI PER LA SIDS" (Seeds for SIDS) than fathers.

We wanted to verify differences between the two groups in terms of CBCL and TAS-20 scores considering also family socio-demographic data, mother's age, siblings gender, age of siblings, time of birth of siblings (before or after the loss) and length of time from the loss.

### Statistics

Given the non-parametric nature of the data, Mann-Whitney U test was used to compare the results for each test between the study group and control group. Chi square test was performed to compare qualitative parameters, such as gender differences. Pearson's R was used to evaluate correlations between scores of CBCL questionnaire, TAS scales and time from bereavement.

Given the TAS-20 coding in Likert scales, we used an ANOVA model of analysis [29] to test if a class of mother's age influences F3 scores. We coded age as class 1: 33-38 years old; class 2: 39-44 years old; class 3: 45-50 years old; class 4: >50 years old. Data were analyzed using STATISTICS for Windows.

### Results

The MG consisted of 16 mothers, mean age 45.56 years (SD = 4.7), and 28 children including 19 females and 9 males with mean age 12.03 (SD = 3.48) years. Fourteen children were born after the SIDS loss. Mean time since bereavement is 12.68 years (Table 1).

The CG consisted of 23 mothers mean age 45.23 years (SD = 4.39) and 30 children (18 females and 12 males), mean age 12.36 years (SD = 3.49) recruited from schools of the same city areas of the MG group. No differences were found for age and gender of the children and for age of the mothers ( $p > 0.05$ ) between the groups.

Differences between the MG and CG mothers in TAS scores are shown in Table 2.

No differences were found in the total scores of the TAS-20 and both in F1 and F2 subscale. Mothers in the MG obtained significantly lower scores in the externally oriented thinking (operational thinking) F3 subscale ( $p = 0.001$ ).

More deeply, by means of a post-hoc test (Tukey), we observed that the differences for the F3 sub-scale are due to the strong effect of the

differences between MG mothers aged 45-50 years compared to CG mothers with class of age 3 (45-50 years old), Mean MG = 30.57 sd 4.03; Mean CG = 39.01 sd 12.51; ( $p= 0.03$ ).

Mothers who had been mourning for more than 15 years, showed significantly higher scores in F1 scale of TAS-20. (Mean 16.50 SD 6.56;

| MOTHERS |                 |                      | CHILDREN |        |                     |  |                            |                         |
|---------|-----------------|----------------------|----------|--------|---------------------|--|----------------------------|-------------------------|
| ID      | age (years old) | Years since mourning | ID       | Gender | Year of birth       | mourning (days / months of a child's life) | Born prior to the mourning | Born after the mourning |
| 1       | 44              | 12                   | 1        | (F)    | 1996                |  | •                          |                         |
|         |                 |                      |          |        | 1998                | 42 days                                    |                            |                         |
| 2       | 55              | 17                   | 2        | (M)    | 2001                |  |                            | •                       |
|         |                 |                      |          |        | 1993                | 5 months                                   |                            |                         |
| 3       | 43              | 12                   | 3        | (F)    | 1998                |  |                            | •                       |
|         |                 |                      | 4        | (F)    | 1994                |  | •                          |                         |
| 4       | 37              | 11                   |          |        | 1998                | 40 days                                    |                            |                         |
|         |                 |                      |          |        | 1999                | 42 days                                    |                            |                         |
|         |                 |                      | 5        | (M)    | 2000                |  |                            | •                       |
| 5       | 46              | 12                   | 6        | (F)    | 2002                |  |                            | •                       |
|         |                 |                      | 7        | (F)    | 1995                |  | •                          |                         |
| 6       | 41              | 8                    |          |        | 1998                | 3 months                                   |                            |                         |
|         |                 |                      | 8        | (F)    | 2000                |  |                            | •                       |
| 7       | 52              | 16                   | 9        | (M)    | 1997                |  | •                          |                         |
|         |                 |                      | 10       | (F)    | 2000                |  | •                          |                         |
| 8       | 47              | 12                   |          |        | 2002                | 5 months                                   |                            |                         |
|         |                 |                      | 11       | (F)    | 1992                |  | •                          |                         |
| 9       | 43              | 13                   |          |        | 1994                | 14 months                                  |                            |                         |
|         |                 |                      | 12       | (F)    | 1996                |  | •                          |                         |
| 10      | 44              | 13                   |          |        | 1998                | 2 months                                   |                            |                         |
|         |                 |                      | 13       | (M)    | 2002                |  |                            | •                       |
|         |                 |                      | 14       | (F)    | 1996                |  | •                          |                         |
|         |                 |                      |          |        | 1997                | 16 months                                  |                            |                         |
|         |                 |                      | 15       | (F)    | 1999                |  | 5° month of pregnancy      |                         |
| 11      | 45              | 13                   | 16       | (M)    | 2001                |  |                            | •                       |
|         |                 |                      | 17       | (F)    | 2002                |  |                            | •                       |
| 12      | 52              | 16                   | 18       | (F)    | 2003                |  |                            | •                       |
|         |                 |                      | 19       | (F)    | 1992                |  | •                          |                         |
| 13      | 46              | 10                   |          |        | 1997                | 36 hours                                   |                            |                         |
|         |                 |                      | 20       | (F)    | 1993                |  | •                          |                         |
| 14      | 50              | 11                   |          |        | 1997                | 2 months                                   |                            |                         |
|         |                 |                      | 21       | (M)    | 1999                |  |                            | •                       |
| 15      | 42              | 11                   |          |        | 1994                | 2 months                                   |                            |                         |
|         |                 |                      | 22       | (F)    | 1995                |  |                            | •                       |
| 16      | 42              | 16                   | 23       | (M)    | 1993                |  | •                          |                         |
|         |                 |                      |          |        | 2000                | 45 days                                    |                            |                         |
| 17      | 46              | 10                   | 24       | (M)    | 2001 <sup>(1)</sup> |  |                            | •                       |
|         |                 |                      | 25       | (F)    | 2001 <sup>(1)</sup> |  |                            | •                       |
| 18      | 50              | 11                   | 26       | (F)    | 1997                |  | •                          |                         |
|         |                 |                      |          |        | 2000                | 2 months                                   |                            |                         |
| 19      | 42              | 11                   |          |        | 2000                | 4 months                                   |                            |                         |
|         |                 |                      | 27       | (F)    | 2003                |  |                            | •                       |
| 20      | 42              | 16                   | 28       | (M)    | 1995                |  | •                          |                         |
|         |                 |                      |          |        | 1999                | 1 months                                   |                            |                         |

<sup>1</sup>Twins

**Age (years old):** age of the mothers included in the study

**Years since mourning:** number of years that are elapsed since the mourning

**Children:** Children belonging to families in mourning

**Year of birth:** year of birth of all the children of mothers in mourning, including those included in the study, those who were not included because they fall outside the age range useful for the CBCL test's administration and children died because of SIDS.

**M:** Male; **F:** Female

**Table 1:** Characteristics of Mourning Group.

| Subscale of TAS-20                                      | Mourning group (N=16) | Control group (N=23) | Mann-Whitney U | p-value |
|---|-----------------------|----------------------|----------------|---------|
| F1 (difficulty identifying feelings)                    | 12.06 ± 4.55          | 11.61 ± 6.02         | 151.000        | 0.341   |
| F2 (difficulty in communicating feelings to others)     | 8.81 ± 2.34           | 9.48 ± 4.5           | 179.500        | 0.897   |
| F3 (externally oriented thinking, operational thinking) | 11.94 ± 3.41          | 17.26 ± 4.51         | 64.000         | 0.001   |
| Total TAS   | 32.81 ± 6.46          | 38.35 ± 11.16        | 138.000        | 0.189   |

Table 2: Differences between Mourning Group and Control Group in TAS-20.

|  | Mourning group (N=28) | Control group (N=30) | Mann-Whitney U | p-value |
|--|-----------------------|----------------------|----------------|---------|
| Age  | 12.03 ± 3.48          | 12.67 ± 3.55         | 324.500        | 0.135   |
| Social Activities                          | 7.30 ± 2.22           | 8.5 ± 1.87           | 272.500        | 0.021   |
| School                                     | 5.2 ± 0.68            | 5.32 ± 0.44          | 413.500        | 0.915   |
| Total Competence                           | 21.2 ± 3.74           | 21.68 ± 3.49         | 363.500        | 0.378   |
| Anxious / Depressed                        | 4 ± 3.96              | 3.03 ± 2.77          | 375.000        | 0.480   |
| Withdraw / Depressed                       | 2.36 ± 2.51           | 1.63 ± 1.83          | 367.500        | 0.403   |
| Somatic Complaints                         | 2.36 ± 3.56           | 1.10 ± 1.32          | 378.500        | 0.499   |
| Social Problems                            | 2.14 ± 2.63           | 0.93 ± 1.34          | 294.000        | 0.039   |
| Thought Problems                           | 1.89 ± 2.44           | 0.90 ± 1.21          | 324.000        | 0.111   |
| Attention Problems                         | 3.32 ± 2.88           | 2.53 ± 2.58          | 357.500        | 0.325   |
| Rule-Breaking Behaviour                    | 1.57 ± 2.44           | 1.03 ± 1.24          | 410.500        | 0.874   |
| Aggressive Behaviour                       | 4.54 ± 4.34           | 3.47 ± 3.87          | 334.000        | 0.176   |
| Internalizing Problems                     | 8.71 ± 8.68           | 5.77 ± 4.94          | 350.000        | 0.274   |
| Externalizing Problems                     | 6.11 ± 6.43           | 4.50 ± 4.83          | 349.500        | 0.270   |
| Total Problems                             | 24.68 ± 21.92         | 17.53 ± 14.30        | 340.000        | 0.213   |
| Affective Problems                         | 2.46 ± 2.69           | 1.73 ± 1.82          | 354.500        | 0.298   |
| Anxiety Problems                           | 1.93 ± 2.03           | 1.93 ± 1.74          | 404.000        | 0.799   |
| Somatic Problems                           | 1.57 ± 2.57           | 0.77 ± 1.25          | 366.500        | 0.365   |
| Attention Deficit / Hyperactivity Problems | 2.39 ± 2.63           | 2.10 ± 2.56          | 392.500        | 0.661   |
| Oppositional Defiant Problems              | 2.14 ± 1.71           | 1.70 ± 1.86          | 338.000        | 0.191   |
| Conduct Problems                           | 1.39 ± 2.45           | 0.90 ± 1.21          | 406.500        | 0.815   |
| Sluggish Cognitive Tempo                   | 1.04 ± 1.14           | 0.80 ± 1.03          | 371.000        | 0.414   |
| Obsessive-Compulsive Problems              | 1.61 ± 2.06           | 1.57 ± 1.48          | 381.000        | 0.530   |
| Post-traumatic Stress Problems             | 5.14 ± 4.28           | 3.77 ± 2.86          | 359.000        | 0.339   |

Table 3: CBCL differences between Mourning Group and Control Group.

p < 0.02).

Children in the MG as compared to children in the control group, present a significantly lower score in CBCL social activities, whilst reporting a significantly higher score on social problems (Table 3). We did not find any difference in scores depending on whether a child was born before or after the SIDS event.

## Discussion

Based on previous studies [17], which detect the presence of many issues (such as social problems, depression, aggression and sexual problems) close to the mourning for SIDS, our study wanted to assess whether any of these problems persisted over time.

Our study, compared with the only other study conducted with the CBCL present in Literature [17], confirms a significant difference to Social problems, as reported by mothers, in children of the mourning group, while other issues are not considered such as depression, aggression, and sexual problems.

This difference in results may be due to the fact that, in the previous study, subjects examined had an infant die of SIDS within the 18 months prior to data-collection (September 1987 to March 1989) while in our sample, the time since bereavement was significantly higher. Since mothers are considered an essential part of the support group for parents, it is possible that our subjects have been able to process the mourning and re-establish homeostasis within their families.

In Hutton study [17] CBCL 4-18 was used and the average age

of 38 siblings in the bereaved group was six years. These children were compared with 40 children matched on age. A semi-structured interview was administered to the families by the counsellor of the Sudden Infant Death Research foundation (SIDRI) in Melbourne, Australia, where topics covered included: how the surviving children felt about the baby prior to the death; both parents discussed the death with the child; the child's degree of involvement in post-death activities, the baby's funeral; the parents own intentions with regard of having more children, and last, reaction to the death. The aim of this interview was partly therapeutic. Variables for analysis were funeral attendance, subsequent baby status and whether or not the family had moved house. All of these factors had been mentioned as potentially important variables to explain the distress of bereaved siblings in earlier discussions.

In our study, however, we used CBCL 6-18 and the average age of 28 siblings in the MG was 12.03 years.

As reported by mothers, our study confirmed that children of families in mourning for SIDS have more social problems and participate in fewer social activities compared to the control group.

The average score of almost all the different scales of the CBCL for group mourning, is greater than the scores of the comparison group. This difference does not seem statistically significant, except, as noted above, the scale of social problems and social competencies.

The scoring of the questionnaires shows that in 7 children of the bereavement group, there may be several areas within the clinical

range. A staircase that seems particularly relevant is the internalizing problems scale; in fact, 6 of these children reached the scores (T-score) ranging from 65 to 84, and the threshold for clinical significance is a T-score greater than 63.

Compared to other scales, it can be observed a number of scores within clinical range, in particular in 3 brothers, in those scales in addition to the above internalizing problems there are other problems such as: somatic problems, externalizing problems, anxiety, post traumatic stress, emotional problems, deficit attention hyperactivity disorder, anxiety / depression, withdrawal / depression, thought and conduct problems.

Two children in the control group, with 64 and 65 T-scores on the scale of internalizing problems were found instead. It is necessary to point out that one of those children's mother received a positive score for alexithymia (67), it is possible that this trait may have influenced her perception about her child's conduct.

It's necessary to consider the item free of CBCL: "What worries you more than your son?" mothers of the control group did not exhibit any particular concerns in relation to their children, in particular they either didn't answer this item or they expressly wrote that there is nothing in particular that may be bothering. Other concerns expressed are general (i.e. adolescence, school), about physical ailments (i.e. myopia) or on aspects that can be considered strengths of the child as well as areas of concern for mothers (i.e. sensitivity, extreme trust in others, stubbornness).

All mothers of the mourning commentators expressed concern regarding their children. It's interesting that almost all the mothers had the same concerns: namely, hypersensitivity, difficulty expressing emotions, self-confidence, emotion, shyness, fear of new situations, low self-esteem. From this description it is possible to understand the reason of the choice of high scores in the scale of internalizing problems and significantly higher in the scale of social problems than the control group.

In fact, the mothers of the bereaved group describe their children as reserved and closed up, many of them also confirm that their child complains of feeling lonely.

The TAS-20, in contrast to our expectations, did not show a significant difference between the two groups, exception of the F3 subscale "externally oriented thinking", where the control group scored higher. This significant difference seems to be determined more by mothers aged from 45 to 50 years and those who had been mourning for more than 15 years showed higher scores in the subscale F1 (difficulty Identifying feelings) of the TAS-20.

A weakness of our study could be that it wasn't possible to examine the subjects close to the traumatic event, so it is difficult to ensure if there are other problems behind mourning, detected by the CBCL. For these reasons it would be interesting to replicate a longitudinal study with a new sample, examining the same group of subjects close to the mourning and once again after some time. So, this should make it possible to verify the spontaneous variation of issues related to the mourning. It would also be interesting to include a further control group consisting of bereaved families with the opportunity to receive psychological treatment and to evaluate the effectiveness of any treatment by estimating the desirable improvement of issues related to the mourning.

## Conclusion

Compared to the initial research hypothesis, our study showed that

children of families in mourning for SIDS have more social problems and participate in fewer social activities compared to the control group as reported by mothers.

We can provide two different interpretations of these results: first, it may simply be true that children of families in mourning for SIDS show more social problems and participate in fewer social activities. Alternatively, it might be argued that the difference between children in the bereaved and control groups is a consequence of significantly greater distortions in the bereaved parents' perceptions of their children.

More than the initial research hypothesis, in contrast to our expectations, none of the mothers in the MG was positive with alexithymia, but the mothers who had been mourning for a long time (15 years or more) showed higher scores in the difficulty of identifying feelings (subscale F1). Even this result may be interpreted according to different hypothesis: first, mothers' commitment in the association and the long time from the bereavement may bring them in touch with themselves and with their emotions, helping them to the mourning process their pain and turning into practical help for others, although contradictory and difficult to identify feelings remain in them when remembering the bereavement. Second, mothers who have been mourning for a long time, may actually have more difficulty in identifying their feelings and could avoid this through the commitment in the Association.

Moreover, about the CBCL's data, it is possible to assume that the concerns of bereaved mothers about their surviving children can be a projection of the difficulties that they themselves have had in the elaboration of mourning and in being able to talk about their feelings about it. The significant difference observed at the level of social problems in children, concerning many mothers, is that their child frequently complains of feeling alone, maybe due to the fact that they themselves report feeling alone. In fact, many mothers have lived in a time of mourning in which attention to SIDS was not yet sufficiently widespread and have found themselves faced with this event with their own resources.

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