



CLOSENESS AND LIFE SATISFACTION AFTER SIX YEARS FOR PERSONS WITH STROKE AND SPOUSES

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Objective: To explore long-term experiences of satisfaction with life in persons with stroke and spouses.

Design: This prospective cohort-study collected data on life satisfaction 1 and 6 years after stroke using the Life Satisfaction Checklist; focusing on "Life as a whole" and the domain "Closeness" ("Family life", "Partner relationship", "Sexual life"). Open-ended questions were added to illustrate changes in daily life.

Subjects: A total of 72 stroke participants (24 singles, 48 married) and 24 spouses. Most of the stroke participants were men with a mild stroke. Median age for persons with stroke and spouses was 65 years.

Results: All groups (singles/married stroke participants, spouses) experienced changes in satisfaction regarding "Closeness", and most often these changes were perceived as negative. The item "Sexual life" had the lowest proportion of satisfied participants. After 6 years, 58% of singles and 78% of married stroke participants were satisfied with "Life as a whole". The proportion of satisfied spouses was 41%.

Conclusion: For the vast majority of people who have had a stroke and their spouses, long-term satisfaction with aspects of "Closeness" decline. The results suggest a need to develop, evaluate and implement programmes that support satisfaction with the different aspects of "Closeness".

Key words: stroke; stroke rehabilitation; satisfaction; personal satisfaction; sexuality.

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To suffer a stroke is demanding for individuals and their close family, even when the stroke is classified as mild (1–3). Impairments will often lead to unwanted activity limitations and/or maladaptation, or difficulties in interaction with others. Important tasks for stroke rehabilitation include intervention strategies that support the patient and spouse/family to re-orientate themselves towards their new life situation. That is, a life in which one can experience oneself as a person in health with capacity, within the environment,

LAY ABSTRACT

The aim of this study was to explore long-term experiences of satisfaction with life in persons with stroke and spouses. Data were collected 1 and 6 years after stroke; focusing on "Life as a whole" and the domain "Closeness" ("Family life", "Partner relationship", "Sexual life"). A total of 72 persons with stroke (24 singles, 48 married) and 24 spouses participated. Most of the stroke participants were men. All groups (singles/married stroke participants, spouses) experienced changes in satisfaction regarding "Closeness" and most of these perceived as negative. "Sexual life" had the lowest proportion of satisfied participants. After 6 years, 58% of singles, 78% of married stroke participants and 41% of spouses were satisfied with "Life as a whole". In conclusion, for the majority of people with stroke and their spouses, long-term satisfaction with aspects of "Closeness" declines. The results suggest a need to develop, evaluate and implement programmes that support satisfaction with the different aspects of "Closeness".

to act and respond in ways that support ones' goals and aspirations (4, 5); thus, being able to achieve satisfaction with life as a whole. Focusing on life satisfaction, a concept characterized by the contentment a person derives from a certain domain of life or from life as a whole, can be one strategy in rehabilitation (5).

Most studies on satisfaction with life after stroke are performed within 1 year, and longer follow-ups and longitudinal studies are quite uncommon. Findings show that, after a year, people affected by stroke report their overall life satisfaction to be between 40% (6) and 50% (1, 7). With time, life satisfaction may improve, as reported in a 3-year follow-up investigation of persons with stroke by Boosman et al. (8). However, studies with longer follow-ups are scarce, but are needed to better understand life satisfaction after stroke.

Experienced satisfaction with aspects of intimacy, i.e. family life, partner relationship and sexual life, a domain labelled "Closeness" (9), has been found to be closely associated with overall life satisfaction. Several studies have found that the impact of stroke on these 3 domains of life is problematic and distressing (2, 3). The majority of both affected patients and spouses regard family life and sexual life as unsatisfactory (2). There are, however, large variations; for example, negative impact regarding family life has been reported to vary between 5% and 54%.

In general, spouses are found to report lower levels of satisfaction with life irrespective of years since stroke (10, 11). The lived experiences of spouses of persons with stroke have been highlighted and have often been found to be stressful, demanding and even a burden (12, 13), while studies on life after stroke for single persons are rare. However, in a prospective study, Wise et al. (14) found marital status to be the strongest predictor of social integration following mild stroke, thus leaving the single person more vulnerable. Furthermore, in a review study McGrath et al. (15) have stressed the importance of including singles in future studies.

Thus, in the short term women and men affected by stroke, and their spouses, seem to be at risk of a dissatisfying life with a depleting “Closeness” domain (i.e. aspects of intimacy: family life, partner relationship, sexual life). However, less is known about the long-term experiences. Therefore, this study explores 6 years’ experiences of overall life satisfaction and aspects of “Closeness” in single and married people who have had a stroke and, when applicable, their spouses.

METHODS

Participants and procedures

Data were collected from the 1-year and 6-year follow-up of a prospective cohort study of the rehabilitation process after stroke, Life After Stroke phase 1 (LAS-1). Detailed description of LAS-1 has been reported elsewhere (16). In short, all patients with a stroke diagnosis who were admitted to Karolinska University Hospital in Stockholm, Sweden, between 2006 and 2007 were eligible for inclusion in LAS-1. At baseline, 349 patients were consecutively included, of whom 121 were

followed up at 6 years (Fig. 1). When included, the patients were asked to identify a significant other, e.g. a partner, child, or friend, who would consider participating in the study. Data from persons with stroke and their significant others were collected by research assistants (with experiences in stroke rehabilitation) during home visits; using structured interviews, tests and questionnaires. The interviews started with open-ended questions, thus the research assistants were not aware of the test results. At the 6-year follow-up 166 were deceased, 44 declined to participate, and 18 could not be found. This study was a subgroup analysis of LAS-1 and included all persons with stroke and their spouses (if available) who had taken part in the 1-year and 6-year follow-ups and who had answered a questionnaire on life satisfaction on both occasions. All participants had the same marital status and spouse on both occasions. Marital status was defined as those who had a steady partner relationship, “married stroke participant”, and those without a partner, “single stroke participant”.

Ethics

All participants received oral and written information about the study and informed consent was obtained. The Regional Ethical Review Board in Stockholm approved the study (no. 2012/428-32).

Data collection

Data on experienced life satisfaction were collected using the Life Satisfaction Checklist (LiSat-11) (9). The questionnaire is commonly used to assess life satisfaction after stroke and has been found to be reliable (17). It is a self-report generic questionnaire that assesses life satisfaction with the global item “Life as a whole” and 10 domain-specific items. Answering alternatives range from 1 (very dissatisfied) to 6 (very satisfied). In the present study, the overall item “Life as a whole” and the domain “Closeness”, reflecting aspects of intimacy, (“Family life”, “Partner relationship” and “Sexual life”) were included and analysed as recommended (9) by dichotomizing the answers into *not satisfied* (alternatives 1–4) and *satisfied* (alternatives 5 and 6). Notably, these items are not exclusively for those having a family life and/or partner relation. Thus, single people were also asked to judge their satisfaction within these areas of life.

Data on gender, age (all participants) and work status (persons with stroke) were collected during interviews. The Barthel Index (BI) (18) was used to categorize stroke severity at stroke onset. The BI includes 10 personal care and mobility activities with a score range of 0–100, where a higher score reflects a greater degree of independence. A score ≤ 14 was classified as a severe stroke, 15–49 as moderate, and ≥ 50 as mild (19). The BI has shown good agreement with other measures of stroke severity (19).

Open-ended questions were used to collect data from persons who had had stroke. These questions addressed how they managed their daily activities after the stroke and what strategies they used to handle problems as the result of the stroke. The questions were framed as follows: “(1a) How do you think your daily activities work for you today? (1b) Is there anything that has changed (mention 3 examples of activities that have become harder to perform)? (2) Do you have any thoughts about how this (activities that have changed) might work better, such as how you could solve the problem?” A similar open-ended question was used to collect data from spouses. The question addressed how their partner’s stroke changed their daily life.

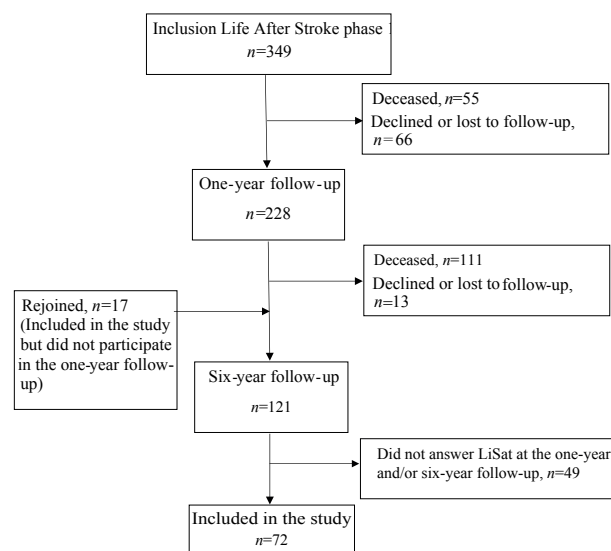


Fig. 1. Flow-chart of included stroke participants and spouses.

The question was framed as follows: “What are the 3 greatest changes in your everyday life after your partner’s stroke?” The participants answered the questions orally and these were written down by the research assistant.

Statistical analysis

Descriptive statistics were used to present the results; proportions of satisfied within the domain “Closeness” and “Life as a whole” based on the LiSat-11 for single stroke participants, married stroke participants and spouses. Selected answers to the open-ended questions are quoted to further illustrate the results from the LiSat.

RESULTS

This study includes 72 persons (24 singles and 48 married) who had had stroke who answered the LiSat-11 at the 1-year and 6-year follow-ups. Moreover, 24 spouses answered the questionnaire during the 2 follow-up occasions. Data on gender, age, children at home, work status and stroke severity in persons who had had stroke are shown in Table I. The majority were men, the median age at stroke onset was 65 years (range 25–86 years) and the majority were not working. According to the BI, 88% had a mild stroke. Most spouses were women (88%) with a mean age of 65 years (range 31–87 years). All married participants had the same spouse at both follow-ups. The median age of all 349 participants in the original LAS-I study group at stroke onset was 74 years (range 24–95 years), 54% were men, 61% had a mild stroke, and 76% had a spouse.

Life satisfaction in people affected by stroke

Experiences of satisfaction with “Life as a whole” and the “Closeness” domain are shown in Fig. 2. At the 1-year follow-up approximately 60% reported being

satisfied with “Life as a whole”; singles being slightly more satisfied. At the 6-year follow-up the opposite pattern was found, as 78% of those married experienced “Life as a whole” as satisfactory in contrast to 58% of the single participants.

Being satisfied with “Life as a whole” was expressed: *“I’ve figured it out; I ask for help if there’s something I need. I’ve learned to ask for help more. I accept that that’s the way it is”* (6-year follow-up, married woman). However, being unsatisfied with “Life as a whole” was also expressed: *“It’s no fun to be alone, not fun, no one to share things with”* (6-year follow-up, single woman).

A great majority was satisfied with the domain “Family life” at 1 year, but at the 6-year follow-up the proportions who were satisfied were lower, both for married and single participants (Fig. 2).

When answering the open-ended question about changes 1 man who was satisfied referred to “Family life”: *“Take breaks; trying to solve the problem as soon as it arises is a given. Always think through solutions beforehand. Requires more thought before the activity. My wife handles activities that require standing on a stool or a ladder.”* (1-year follow-up, married man). A married woman said the following: *“I am clumsier ... can’t play piano. I try to help my girls, but I don’t play myself”* (6-year follow-up, married woman).

Satisfaction with “Partner relationship” was markedly higher for participants who had a spouse compared with singles. However, among the latter, half were satisfied, with a slight increase at 6 years (58%). In the married group decreases were noted at 6 years.

On both follow-ups the domain “Sexual life” had the lowest number of satisfied participants (range 32% and 50%, see Fig. 2). However, after 6 years married participants affected by stroke reported slightly lower, and singles slightly higher, sexual satisfaction.

With respect to low satisfaction within “Family life” and “Partner relationship” the participants described their present life situation as follows: *“I’m not very active. I find it lonely at home”* (6-year follow-up, single man), and *“The mental part has changed, contact between people. A little difficult to establish contact”* (6-year follow-up, single woman), *“I feel more reserved”* (6-year follow-up, married man) and *“I don’t meet with friends as often. Phone calls are difficult”* (6-year follow-up, single man). None of the participants, spontaneously, answered the open-ended question related to “Sexual life”.

Life satisfaction in spouses

At the 1-year follow-up 58% of the spouses expressed satisfaction with “Life as a whole”. However, this satisfaction decreased to 41% at the 6-year follow-up.

Table I. Sociodemographic and stroke severity data on persons with stroke

	Persons with stroke without spouse n = 24	Persons with stroke with spouse n = 48
Sex, n (%)		
Women	16 (67)	12 (25)
Men	8 (33)	36 (75)
Age, median, years (range) ^a	66 (25–86)	63 (29–85)
Children at home, n (%) ^b		
Yes	1 (5) ^c	18 (39) ^c
No	21 (95)	28 (61)
Working, n (%) ^b		
Yes	3 (27)	20 (69)
No	7 (73)	9 (31)
Stroke severity, n (%) ^a		
Mild	21 (88)	42 (88)
Moderate	2 (8)	3 (6)
Severe	1 (4)	3 (6)

^aAt baseline.

^bAt 1 year for those of working age (<65 years).

^cMissing value, n = 2.

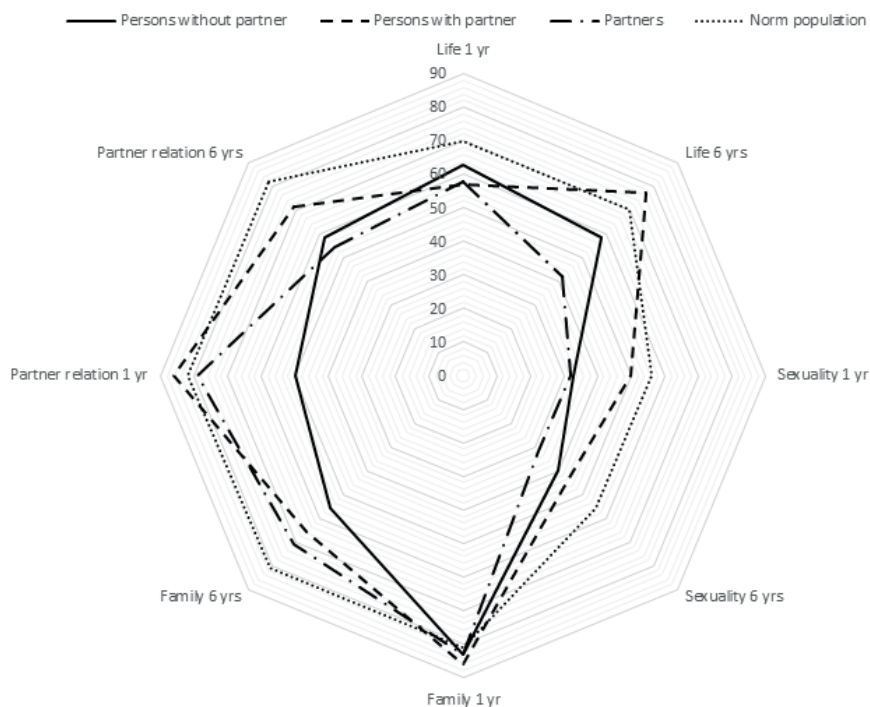


Fig. 2. Experiences of satisfaction with “life as a whole”, “sexual life”, “family life” and “partner relationship” in stroke participants without partner, stroke participants with partner and spouses 1 year and 6 years after stroke. Included are data from the general population.

One unsatisfied spouse made this observation: “*Because my husband can’t drive a car after the stroke, all the shopping, drop-offs and pick-ups are on me. My husband can’t work anymore, which means I have financial responsibility for the family. My husband sits there; he can’t work, doesn’t drive a car.*” (6-year follow-up, woman).

At the 1-year follow-up approximately 80% of the spouses were satisfied with both their “Family life” and “Partner relationship” (Fig. 2). However, at the 6-year follow-up the percentage of satisfied spouses was lower; especially regarding satisfaction with “Partner relationship” where just above 50% reported being satisfied.

At the 1-year follow-up difficulties were expressed: “*He has a hard time showing emotion*” (1-year follow-up, woman), and “*There are problems with daily socialising – to understand/converse*” (1-year follow-up, woman) and “*Spouse’s mood swings and major misunderstandings between us*” (1-year follow-up, woman). Notably, some expressed positive experiences: “*Our relationship has almost become stronger and our gratitude at not having been physically affected is infinite. We love each other and care about each other in a new way.*” (1-year follow-up, woman), and “*Greater insight into life’s vulnerability and the meaning of good relationships within the family*” (1-year follow-up, woman).

At the 6-year follow-up the spouses expressed negative aspects: “*He’s shut in at home. Family life is adapted based on him. Everything revolves around him.*” (6-year follow-up, woman), and “*My husband is more irritated, easily stressed and has increased susceptibility to alcohol. This leads to more conflicts, and small and large talks about many things we once agreed on.*” (6-year follow-up, woman), and “*I have almost total responsibility for the household; I buy the food, take out the recycling, clean, do the laundry and so on.*” (6-year follow-up, woman).

The domain “Sexual life” had the lowest proportions of satisfied spouses, with less than 33% being satisfied on both follow-up occasions.

DISCUSSION

This study explored overall life satisfaction and, in particular, the 3 items of “Closeness”, i.e. “Family life”, “Partner relationship” and “Sexual life”, at 1 and 6 years after stroke. The findings showed that married stroke participants and single stroke participants experienced changes in satisfaction regarding all 3 items of “Closeness”, most often of a negative character. The same pattern was found among spouses. The results revealed that 6 years after stroke the levels of satisfaction in stroke participants and spouses were far below those of the general population (9). However, there

was 1 exception: married participants who had had a stroke reported “Life as a whole” at the 6-year follow-up to be more satisfying than the general population (78% and 70%, respectively). Hence, for this group the influence of time since stroke seemed to favour a more positive view on “Life as a whole”. This pattern, of spouses being less satisfied, has previously been found in a study of couples (20). A much lower level of life satisfaction, similar to the level among single participants in the present study has been found at 4–6 years after a severe stroke (21). Altogether, a somewhat higher prevalence of satisfied participants was found in the present 1-year follow-up in comparison with other follow-up studies within the same time-frame (1, 6). The present results that reveal low satisfaction with “Life as a whole” in spouses, both at 1 and 6 years, concur with results from previous studies (10, 11, 22).

Large differences in prevalence of problematic or distressing family life after stroke have been reported in a review by Daniel et al. (2). These variations may be explained by, for example, methodological variation, such as the time from stroke to follow-up. In the present study the same methodology was used for 1-year and 6-year follow-ups. Both single and married participants who had had a stroke reported high levels of satisfaction with “Family life” 1 year after stroke; comparable with a nationally representative sample (9). However, after 6 years markedly fewer were satisfied. This dissatisfaction was particularly evident in singles, although they had a small increase in satisfaction with “Partner relationship” at the late follow-up. At the 1-year follow-up married participants had high and comparable levels with the general population with respect to satisfaction with “Partner relationship”, but this satisfaction deteriorated markedly at the 6-year follow-up. Achten et al. (20) have, in agreement with others (23), found significantly lower satisfaction with partner relationship in spouses than in those affected. One explanation for this difference might be that the stroke participants idealize the spouse or the relationship; referred to as marital aggrandizement by O’Rourke & Cappeliez (24). Feelings of gratitude towards the spouse could be another explanation for the gap between the couples’ satisfaction.

Negative changes in family roles and partner roles are commonly reported both among those who have had a stroke and their spouses (12, 15, 25–30) and can be an important explanation for the low levels of satisfaction with “Family life” and “Partner relationship” 6 years after stroke. Unwanted role changes within a partner relationship, e.g. going from being a partner to being a care-giver (3, 12, 15, 25, 29) may create ambivalence, or avoidance of a mutual sexual life. Thus, not surprisingly “Sexual life” was reported

as the least satisfying in all 3 groups of participants. This finding agrees with results from 3-year follow-up studies post-stroke (8, 20).

It is well-known that sexual dysfunctions and sexual problems are very common after stroke (25, 31, 32) due to complex bio-psycho-social factors. Notably, decreased sexual desire and sexual dysfunctions often concur within partnerships (33). Furthermore, changes in sexual repertoires and role identity in intimate relationships and fear of having a new stroke during sexual activities have been reported (25, 32). Nevertheless, in a previous qualitative study we found that changes in sexual life could be a positive experience as long as 6 years after stroke (34). The participants attributed the positive change to feelings of increased intimacy, different active strategies and an open communication between spouses. Experiencing a deeper relationship and caring for each other in new ways were mentioned by a few spouses at the 1-year follow-up in the present study, and we interpret this as a positive partner relationship, which could support a fulfilling sexual life and vice versa: a rewarding sexual life can support an intimate partner relationship. Albeit in this population none of the spouses had any positive statement at the 6-year follow-up and this, together with the very low proportion of satisfied spouses, once again points to the importance of including the needs of spouses in stroke rehabilitation.

Being dissatisfied with “Life as a whole” and the domain of “Closeness” were further shown when all 3 groups of participants commented on factors leading to changes in life after stroke and the most pertinent characteristic was interpreted as feelings of loneliness. Similarly Boosman et al. (8) found socially active post-stroke participants to be more satisfied with life than inactive participants. In a qualitative study Martinsen et al. (26) have shown the vulnerable situation for persons with stroke, in particular singles. In light of the present results, and in accordance with McGrath et al. (15), it seems important to include spouses when addressing post-stroke recovery, as the spouses are at risk of a life in an unsatisfying partner relationship.

Low levels of satisfaction are interpreted here as aspiration/achievement gaps (5) regarding activities and roles within the domain “Closeness”. These gaps can lead to problems and/or distress; resulting in low levels of satisfaction for the majority of both persons who have had a stroke as well as their spouses. In addition to the medical examination and treatment an adequate case-history, through inter-professional collaboration, is necessary for identification of problems as well as resources (individual, familial and social network) that could be added to the rehabilitation plan. We propose that, by exploring new ways to reach previous goals,

or to reorient oneself in the domain of “Closeness”, the burden of stroke might be reduced. However, this demands acknowledgement of the process of adaptation, a process that most often necessitates support, adequate treatment and long follow-ups. We agree with Kitzmüller et al. (35), who underline the importance of professional family support to increase communication skills and handle changes in relationship roles; including provision of support for sexual health after stroke.

An overall strength of this study is its long follow-up period and the use of the same methodology on both occasions. In addition, strengths include using data from both single and married stroke participants, as well as spouses, and data collection performed during home visits (i.e. a place where participants can relax and feel safe). A limitation is the small sample and the few male spouses, which might affect the external validity of the findings. Furthermore, due to the small sample no inferential statistics were performed. Thus, leading to caution regarding interpretation and generalization of the results. However, since studies on experiences on overall life satisfaction and aspects of “Closeness” after stroke are scarce, in particular in the long-term, our results contribute important new knowledge. In addition, it should be acknowledged that most participants with stroke were homogeneous regarding the severity of stroke (i.e. these were mild strokes) and the mean age at stroke onset was 65 years, whereas the mean age for stroke in the general Swedish population is 75 years (36). No qualitative analysis of the answers to the open-ended questions was conducted. Instead, answers that illustrated the results on LiSat were selected.

Clinical relevance

The negative long-term changes in life satisfaction in the domain “Closeness” both for persons who have had a stroke and their spouses emphasize the importance of interventions that support “Family life”, “Partner relationship” and “Sexual life”. Moreover, the relatively large differences in perception of satisfaction between married stroke participants and spouses should be noted. In clinical practice, this is an important finding, as the impact on everyday life can affect intrapersonal and interpersonal areas of life including social circumstances; the discrepancies in satisfaction can create and maintain unnecessary difficulties. Thus, it seems important to open up discussions and to raise the issue of satisfaction within the domain “Closeness” both early on and in the long-term after a stroke (32, 35, 37–39). In spite of the relatively small sample the results support the need for inter-professional rehabilitation teams and interventions, ranging from peer-group supportive programmes to individual, couple or family psychoth-

erapy. Furthermore, development of educational programmes for healthcare professionals covering aspects of “Closeness” seems important (37–39).

The long-term deterioration in experienced life satisfaction, overall and domain-specific, after stroke also has implications in research on life satisfaction/quality of life. As pointed out by Daniel et al. (2) there is a need for improved study methodology that makes comparable conclusions possible. New interventions will require gaining knowledge, not only on risk factors, but also salutogenic factors; knowledge that can be gained through long follow-ups. In addition, we propose that extra attention to be paid to both single people who had had a stroke and to the interplay within a partner relationship where one person had had a stroke.

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