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## The experiences of heart transplant recipients' spouses during the pre-transplant waiting period: Integrative review

**Aims and Objectives:** To explore the experiences of spouses of heart transplant recipients and to consider how an understanding of these experiences may inform nursing practice.

**Background.** There is a lack of knowledge about the experiences of spouses of heart transplant recipients during the pre-transplant wait. Evidence suggests that spousal support improves post-transplant outcomes of heart transplant recipients, therefore it is important to understand how nurses can improve spouses' psychological well-being during the pre-transplant wait.

**Design.** Integrative review.

**Method.** A search of six electronic databases between November and December 2015 and a hand search yielded 510 citations; nine studies met the review eligibility criteria. Inclusion criteria were applied to selected studies for review. Methodological quality of selected studies was evaluated, and data were extracted and compiled.

**Results.** Six themes were identified: uncertainty, thoughts about death, changes to lifestyle and priorities, loss of sense of self, quality of life, and learning to cope. Spouses experience high levels of stress caused by uncertainty about the patient's survival, increased responsibilities, and changes to their lifestyle.

**Conclusion.** The results reveal that the pre-transplant period is all-consuming for spouses of heart transplant recipients. The impact of the pre-transplant wait on spouses' well-being should be recognised by nurses and improvements must be made in support and education available to spouses during the pre-transplant period.

**Relevance for clinical practice.** There is a need for improved education about the transplant process, and reinforcement of positive coping strategies.

**Keywords:** Experiences, Spouse, Partner, Heart transplant, Pre-transplant, Waiting period, Review

### What does this paper contribute to the wider global clinical community?

- The stress of the pre-transplant period for spouses is often underestimated.

- The population of transplant recipient spouses is increasing worldwide, and nurses must be able to meet the needs of this growing population.
- Spousal support is crucial for post transplant outcomes. Therefore, maintaining the psychological well-being of spouses may result in better outcomes for heart transplant recipients.

## **Introduction**

Heart transplantation remains the treatment of choice for end-stage heart failure, despite advances in mechanical circulatory support, biventricular pacing, and stem cell therapies (Cheng & Slaughter 2014, Jabbour & Macdonald 2015). A total of 4,477 heart transplants were performed worldwide in 2013, from 252 centres. 90% of adult recipients required heart transplantation because of coronary artery disease or myopathy, with an additional 8% requiring transplant as a result of valvular dysfunction, congenital problems, or re-transplantation (International Society for Heart and Lung Transplantation 2015). At the end of December 2015, 250 patients were on the waiting list for a heart transplant in the United Kingdom alone (NHSBT 2016). The transplant process profoundly affects the lives of both the patient and their family, particularly the spouse or partner. Although the physical aspects of transplantation only affect the patient, the process undoubtedly impacts the partner's psychological well-being and quality of life as they learn to adapt and cope with the new situation (Bunzel *et al.* 1998).

## Background

For the candidate and their family, acceptance onto the heart transplant waiting list is often followed by a brief period of excitement and relief, which soon gives way to new concerns about the reality of the waiting period. The candidate and spouse may be required to relocate closer to the hospital, and some patients may even be in intensive care during the wait for transplantation (Jalowiec *et al.* 1994). The average waiting time for a non-urgent heart transplant is 1033 days, however waiting time is not fixed and may change as a result of deterioration in medical status (NHSBT 2016). Therefore, the pre-transplant waiting period is laden with uncertainty about whether a donor heart will become available in time, and concerns surrounding deterioration prior to transplantation (DiMartini *et al.* 2008). It is widely acknowledged that candidates experience considerable stress during the wait for transplant (Jalowiec *et al.* 1994). In addition to this stress, patients become more physically dependent on others during the pre-transplant period. Therefore relatives, most commonly the spouse, often take on the role of the patient's primary caregiver (Conway *et al.* 2013). Because of the interdependence of the marital relationship, spouses are often profoundly affected by their partners' illness (Coyne & Smith 1991). There is substantial evidence that chronic illness results in emotional and psychological distress to the spouse that may even be greater than that experienced by the patient (Bohachick & Anton 1990, Coyne & Smith 1991).

Research shows that it is essential to include relatives in the transplant care pathway to improve patient outcomes; spousal support in particular has been shown to greatly improve post-operative recovery (Rodrigue *et al.* 1997, Miyazaki *et al.* 2010). However, lifestyle changes and increased responsibilities as a result of their partner's illness can cause

considerable stress, and may hinder the ability of the spouse to care for the heart transplant recipient. Therefore, supporting the spouse and maintaining their psychological well-being is crucial during the pre-operative period. Although a considerable amount of research has been conducted into the impact of the pre-transplant period on patients, there has been relatively little research into the impact of the pre-transplant period on spouses of heart transplant candidates. To date, no systematic review on the spouses' experiences of heart transplant has been carried out. As the population of transplant recipient spouses increases worldwide, nursing must address the care needs of this group (McCurry & Thomas 2002). Integrating findings from research on the experiences of spouses will highlight how their experience differs from that of other family members, and will positively influence nursing care.

## **Aim**

The aim of the review was to explore the experiences of spouses of heart transplant recipients and to consider how an understanding of these experiences may inform nursing practice.

## **Methods**

### **Search Strategy**

A systematic approach to searching and critiquing was employed in order to minimize bias and omissions (Aveyard2014). To obtain relevant papers, 7 databases were searched (Applied Social Sciences Index and Abstracts (ASSIA), CINAHL, Embase, Medline, ProQuest

Nursing and Allied Health Source, and PsycINFO) between November and December 2015. Search terms were identified by exploring key words used in relevant literature, and identifying multiple synonyms and related words. A summary of the search terms used is included in Table 1. A mixture of keywords and Medical Subject Headings (MeSH) were used to search databases. Boolean operators were used to first expand, and then limit the search, and truncation was used to find all available endings of keywords. To ensure all relevant papers were located, no date restriction was set on the search, and studies of any design were included in the search. The literature search was limited to studies in the English language; additional inclusion and exclusion criteria are listed in Table 2.

### **Search outcome**

A total of 509 potentially relevant studies were identified through database searching (ASSIA = 4, CINAHL = 38, Embase = 227, Medline = 138, ProQuest = 75, PsycINFO = 27). A hand search of relevant journals yielded one further study. Studies were screened and assessed for eligibility using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Liberati *et al.* 2009). Figure 1 shows a full summary of the screening process. Of the 510 studies identified, 158 duplicates were removed. Therefore, the abstracts of 352 papers were screened against the inclusion criteria. Those that did not meet the inclusion criteria were excluded, and if it was unclear from the abstract alone whether a study was eligible, the full text was screened. A total of 26 full texts were examined, and nine papers were found to be suitable for inclusion in the review. Finally, an additional hand search of the reference lists of included studies was completed, but did not produce any additional studies of interest. An overview of included studies is provided in Table 3.

Both qualitative and quantitative studies were included in the review due to the limited amount of existing research found in this subject area. Additionally, combining quantitative and qualitative data allowed for a degree of comprehensiveness which could not be achieved by using either approach alone (Blake 1989).

### **Quality appraisal**

After relevant articles had been identified, their quality was determined. The studies were tabulated using the following headings: sample and setting, aim, design and data collection, data analysis, and limitations (See Table 3). Following tabulation, the methodology of each paper was critiqued.

Critical appraisal tools allow the reviewer to be objective, minimizing bias (Coughlan *et al.* 2007). The Critical Appraisal Skills Program (CASP) checklist was used to determine the quality of the selected qualitative papers as recommended by Ciliska *et al.* (2008). This tool uses eleven questions to examine the main areas of a study, allowing a judgment of overall quality to be made (Dale *et al.* 2011). The appraisal tool used should be appropriate to the study being appraised (Kuper *et al.* 2008). Therefore, a quantitative BestBETs (2012) tool was used to appraise quantitative papers.

### **Data Analysis**

Whittemore and Knafl (2005)'s 5 stage framework for Integrative reviews was used as a guide for data analysis. First, for the data reduction stage, similar data were extracted from all articles. Each study was read twice to identify topics for analysis. The data were compiled into a spreadsheet, reducing each source to one page with similar data extracted from each source. This organisation facilitated appraisal and comparison of articles. The studies were compared and contrasted, themes were noted, and patterns in the data were identified. Results were continually revised as new data were incorporated into the findings. Finally, verification occurred by comparing themes and patterns with the original data sources.

## **Results**

Finally nine relevant papers were selected for review. The studies were of varied design and quality. One paper was excluded due to an inappropriate sample: of the sample of relatives, only two were partners, and the researchers did not differentiate between the results obtained from partners and other relatives. The remaining papers were deemed to be of good quality, and were therefore all included in the review. One major area of weakness noted was the predominance of female participants among all studies, which limits the generalisability of results to male spouses. Additional limitations are shown in Table 3.

After analysis, six themes emerged from the data, which provided a framework for the reporting of results: uncertainty, thoughts about life and death, changes to lifestyle and priorities, loss of sense of self, quality of life, and coping strategies.

## Uncertainty

For spouses of heart transplant candidates, the pre-transplant wait is a time of uncertainty.

Collins *et al.* (1996a) studied stress levels in 28 spouses of heart transplant candidates during the wait for transplant. Results showed that on a scale of 0-3 (0= not stressful, 3=very stressful), the factors rated most stressful were all related to uncertainty: fear that the patient might die (M = 2.34); not knowing when the transplantation will take place (M = 2.28); not knowing if the transplantation will take place (M = 2.19); and not knowing if a donor heart will become available (M = 2.02).

Williams (1991) studied social and psychological processes of 16 spouses of heart transplant recipients during the pre-transplant period. Spouses reported that the uncertainty of the situation resulted in inability to plan for the future; this was found to be one of the most stressful aspects of waiting for the transplant (Williams 1991, Collins *et al.* 1996a). Lack of information was a common stressor; spouses expressed the need for better education about the transplantation process to diminish some uncertainty (Busé and Pieper 1990, McCurry & Thomas 2002). Mishel and Murdaugh (1987) conducted unstructured group interviews about the transplant process at support groups for relatives of heart transplant candidates. They found that during the pre-transplant stage, relatives are uninterested in listening to information about the post-transplant period. Of note, Mishel and Murdaugh's (1987) study did not focus solely on the spouses of heart transplant recipients; the sample consisted of a group of relatives, of which the majority were spouses. Although the researchers did not differentiate between results obtained from spouses and other relatives, the results were

judged to be valuable for providing an insight into the experiences of heart transplant recipients' spouses during the pre-transplant wait, and were therefore included in the review.

### **Thoughts about life and death**

Uncertainty surrounding the likelihood of the candidate's survival sparks thoughts about life and death. Anton *et al.* (2001) used a self-report questionnaire to assess spouses' adjustment to heart transplantation. 80% of spouses reported 'quite a bit' to 'extreme worry' about their partner's illness and other matters during the pre-transplant period. Busé and Pieper (1990) looked into the impact of the heart transplant process on the life, relationship and stress levels in 30 spouses of heart transplant recipients, and found that feelings concerning loss of a husband/wife impacted spouses' lives greatly in the pre-transplant period. On a scale of 1-7 (minimal-great impact), the mean score for 'impact of thoughts about death' on the spouses' life was 5.73.

McCurry and Thomas (2002) conducted in-depth interviews with 7 spouses about their experiences during the pre-transplant wait. Many spouses focused on the possibility of limited time left together, and described watching the candidate's health deteriorating. One spouse said "You see your spouse laying there dying inches by inches." (McCurry & Thomas 2002 p.189). Mishel and Murdaugh (1987), Busé and Pieper (1990), and McCurry and Thomas (2002) all found that the heightened awareness of death resulted in vigilance. One spouse said, "you listen to him breathe... making sure he's alright..." (McCurry & Thomas 2002 p.189).

Williams (1991) interviewed 16 spouses of heart transplant recipients, and found that spouses become increasingly attached to the candidate during the waiting period, due to the vulnerability of the patient. Spouses described reluctance to leave the candidates' side through fear of something happening in their absence. One spouse explained, "you just don't want to leave, you don't know if you're going to be told he's dead or dying. You just want to be there" (Williams 1991 p.131). Spouses also described increased need to express their love and appreciation for their partner, as time together might be limited (Williams 1991).

### **Changes to lifestyle and priorities**

Numerous changes affect spouses' lives during the pre-transplant wait. These changes are described in terms of giving up and taking on responsibilities, and changes to lifestyle.

Mishel and Murdaugh (1987) and Williams (1991) found that spouses changed their lifestyle in order to 'free themselves', so that they could dedicate all energy towards caring for their partner. This included actions such as quitting jobs, sacrificing proximity to family and friends, and relocating to increase the chance of the candidate receiving a heart. Nolan *et al.* (1992) studied the stressors perceived by families of heart transplant recipients using a 71-item checklist of possible stressors. The factor relatives rated as most stressful was 'increase in tasks or chores that don't get done' (Nolan *et al.* 1992). Similar to the study by Mishel and Murdaugh (1987), Nolan *et al.*'s (1992) sample consisted of 38 relatives of transplant recipients, 27 of whom were spouses, and therefore the results were judged to be representative of the experiences of heart transplant recipients' spouses during the pre-transplant wait. Mishel and Murdaugh (1987) also found that partners reassigned priorities

and transferred responsibilities to other people. Spouses reported taking over responsibilities which had previously belonged to their partner such as household tasks and paying bills (McCurry & Thomas 2002).

Collins *et al.* (1996a) found that on a scale of 0-3, the mean score for stressors related to responsibilities was 0.61, suggesting that responsibilities are not the most stressful factor for spouses during the pre-transplant wait. They reported that one of the least stressful factors was 'loss of job' with a mean score of 0.24. They also found, on the same scale, that socioeconomic stress, responsibility stress, and stressors related to the self were all higher in working spouses than non-working spouses. Anton *et al.* (2001) found that prior to transplant, time lost from work was a significant problem, and 80% of spouses indicated illness-related financial strain.

### **Quality of Life**

Collins *et al.* (1996b) assessed the quality of life of 28 spouses of heart transplant candidates. On a scale of 1-10, 50.6% of spouses rated their quality of life as good (8-10), 43.5% as fair (4-7), and 5.9% as poor (1-3). Additionally, participants were asked to rate the overall impact of the transplant experience on their life: 31% reported transplant experience had negative impact on life; 3% reported no impact; and 66% reported positive impact. They found that those reporting a negative impact of the transplant experience also reported more stressors related to the self. Collins *et al.* (1996a) found that spouses who had been waiting over 6 months for the transplant experienced more stress related to the self than those waiting less than 6 months. Stressors related to the self include: having little time for themselves;

being unable to sleep well; decline in social life; and change in lifestyle as a result of their partner's illness.

Spouses reported having little time for themselves, and little time for socialising. Busé and Pieper (1990) found that the amount of time spouses had available for themselves was greatly impacted during the pre-transplant period. On a scale of 1-7 (minimal to great impact), spouses reported a mean impact score of 5.40 for time available for self. Similarly, Anton *et al.* (2001) found that 61% of spouses reported a reduction in the amount of time spent socialising with family members outside the home, with 20% reporting that time spent socialising with family was completely eradicated. Additionally, spouses had little time for engaging in leisure activities: 31% reported little or no participation in social activities with family, and 35% reported little or no social activities with friends. Mishel and Murdaugh (1987) labelled the waiting period a time of 'immersion', during which relatives devoted all energy towards caring for the candidate. Williams (1991) also found that spouses' lives were immersed in the waiting period: "You don't have a life, it all belongs to the transplant" (Williams 1991 p127).

### **Loss of sense of self**

Mishel and Murdaugh (1987) found that partners lose their sense of self as a result of the intense union that develops with the candidate. Partners were unable to discuss their own feelings, and began replacing "I" as a personal pronoun with "we" when responding to interview questions. They found that personal experience was absent, and all activities and interests that remained were those which were shared by the patient and partner. McCurry

and Thomas (2002) also found that participants began to describe the experience using the word 'we' for example, 'when we first found out', and 'when we got the transplant' (McCurry & Thomas 2002 p187); this demonstrates how spouses live the whole experience alongside the patient.

### **Learning to cope**

To alleviate distress, partners engaged in a variety of coping strategies. Burker *et al.* (2005) studies coping strategies among spouses during the pre-transplant wait. They found that the most frequently used coping strategies were positive reinterpretation and planning, and less helpful behaviours such as behavioural disengagement and denial were used less frequently. Burker *et al.* (2005) also assessed coping strategies among spouses suffering from depression, finding that depressed spouses were more likely to use ineffective coping strategies than spouses who were not depressed. Nolan *et al.* (1992) found that the most frequently used coping strategies were: acquiring social support; mobilising family to accept help; and reframing. An inverse relationship was found between use of reframing and stress score (high, moderate, or low stress), which suggests that use of reframing may decrease stress levels. Mishel and Murdaugh (1987), McCurry and Thomas (2002), and Williams (1991) found that many spouses found it helpful to think of the process as being temporary: 'you have to just tell yourself it's just temporary; we have to go through it so in the end it'll be better.' (Williams 1991 p118).

### **Discussion**

This integrative review has found that the pre-transplant period is all-consuming for spouses of heart transplant recipients. The transplant dominates all thoughts, and demands all attention. A prominent finding was that the uncertainty about whether the patient would survive caused a great deal of distress for spouses. The success of the heart transplant process cannot be guaranteed, and therefore feelings of uncertainty can never be entirely dispelled. However, it seems that educating spouses about the transplant process may reduce distress caused by uncertainty to some extent.

Findings regarding QOL are inconclusive, with some studies reporting increased QOL, and others reporting a decrease. However, the results clearly demonstrate that spouses are willing to make great sacrifices to focus on maintaining the candidate's life until transplant. Family lifestyle changes, meaning spouses assume different roles and responsibilities. Some move home to be closer to the hospital, leaving behind family and friends. Furthermore, personal interests and social activities are abandoned at the expense of the spouses' own psychological well-being and quality of life.

Another major finding of this review is that throughout the pre-transplant period, spouses are consumed by thoughts about death. The results revealed that spouses become increasingly attached to the candidate, through fear of limited time left together. This results in constant monitoring of the patient's physical condition, and it becomes increasingly difficult to leave the patient's side. Among the studies reviewed, the majority of spouses were primary caregivers for the heart transplant recipient. This meant that the pre-transplant period was spent living with the sole purpose of caring for the candidate. The results suggest that spouses

may experience role engulfment; their identity becomes based on their role as caregiver, displacing other roles. The role engulfment that spouses experience may result in a loss of self. Loss of self is the loss of one's distinct individuality or loss of essence of oneself, and is common among primary caregivers (Pearlin & Skaff 1992). Loss of identity became apparent in the studies of Mishel and Murdaugh (1987) and McCurry and Thomas (2002), when spouses began speaking as though they were one with the patient, using "we", rather than "I" as a personal pronoun. Pearlin and Skaff (1992) studied loss of self in caregivers and found that spouses were more likely to experience self loss than adult children. This could be because the deterioration of a marital relationship inherently includes greater loss than the loss of a parent-child relationship. If the spouse and patient have a strong 'couple identity' then the significant change to the dynamic of the relationship could contribute to loss of identity.

To reduce anguish, spouses employed a range of coping strategies such as acquiring social support, positive reinterpretation, and planning. Burker *et al.* (2005) found that spouses who use maladaptive coping strategies are at higher risk of depression; of their sample, spouses who weren't depressed seldom engaged in maladaptive coping strategies. However, it is possible that social desirability and selection criteria for transplant play a role in spouses reporting of coping styles. To become a candidate for heart transplant, a patient must demonstrate stability and family support in order to deal with the rigour of the transplant process. Burker *et al.*'s (2005) study was completed at the same time as the transplant evaluation process, therefore spouses may have attempted to present themselves as being able to cope. Nolan *et al.* (1992) found that few candidates and spouses reported passive coping. This may reflect the selection criteria, as patients who passively deal with stress and lack

family support may not have been selected. Thus, it is possible that spouses of heart transplant candidates engage in more maladaptive coping strategies than they are willing to report. As negative coping strategies are difficult to detect, delivery of nursing interventions and education about coping strategies to all spouses prior to transplant may be beneficial in decreasing psychological distress. Nolan *et al.* (1992) found that many patients coped by keeping a sense of hope, and were very confident about their loved one's survival. Healthcare professionals must be honest when discussing the patient's condition, but care must be taken to maintain the family's hope at this time. Collins *et al.* (1996b) suggest a long waiting period for transplant may cause spouses to become drained and lose hope. It is not appropriate to assume that spouses who have been waiting for a long time are adapting well to the situation. It is important to provide the same level of support to patients and spouses regardless of waiting time, and care should be adapted to meet changing needs.

### **Relevance to clinical practice**

The results of this review suggest that better education about the transplant process may reduce distress caused by the uncertainty of the situation. Busé and Pieper (1990) and McCurry and Thomas (2002) found that education has a positive effect on spouses' lives pre- and post-transplant. This finding was somewhat contradictory from Allender *et al.* (1983) and Mishel and Murdaugh (1987) who found that patients and families on the waiting list paid very little attention to teaching about the transplant process. This difference could possibly be due to quality or timing of teaching that the participant received in each study. However, Molter (1979) and Benzein *et al.* (2006)'s studies into the needs of relatives of critically ill patients demonstrated the importance of healthcare professionals delivering clear information to relatives. Despite the recognition of the importance of education, it seems that education

requirements are often not met in families of critically ill patients (McKiernan & McCarthy, 2010). NICE (2009) recommend providing initial information about critical illness in order to reduce feelings of uncertainty. Nurses' frequent interaction with spouses of heart transplant recipients means that they are well placed to provide information and alleviate distress. Additionally, the stress of having a critically ill relative has been found to reduce the ability to absorb information (Hughes *et al.* 2005). To overcome these factors, assessment of understanding and repeated delivery of clear information by nurses will ensure understanding. Additionally, education should be delivered both verbally and in written formats to allow spouses to absorb information in their own time.

This review also reveals a need for healthcare professionals to recognise the conjoined experience. Spouses may not be going through the same physical experience as the candidate, but they go through the same psychological distress. In fact, Anton *et al.* (2001) found that both pre- and post-transplant, spouses experienced higher levels of psychological distress than patients. Additionally, spouses are more likely to blame themselves and feel guilty about letting others down. The results of this review suggest that spouses of heart transplant candidates require consistent professional support to improve quality of life and reduce distress. Research shows that psychological distress of relatives during the heart transplant process is recognised by the transplant team, but often underestimated (Luttik *et al.* 2005). As a result, caregivers may not receive the psychological and practical support they require. Research has demonstrated that spousal support is associated with better recovery and well-being of patients (Luttik *et al.* 2005). Therefore, it is crucial to protect spouses' psychological state both for their own well-being, and to improve patient outcomes.

## **Limitations**

A high proportion of female participants was noted among all studies, which could reflect a higher number of male heart transplant patients than females (International Society for Heart and Lung Transplantation 2015). This may have affected results as evidence demonstrates that there are gender-related differences in stress and coping strategies. In a systematic review of gender differences in psychiatric morbidity in caregivers, Schulz and Yee (2000) found that men tend to engage in behaviours that put them at lower risk for psychiatric morbidity. Additionally, evidence suggests that female caregivers experience higher amounts of caregiver burden than males (Pinquart & Sörensen 2006). Moreover, women are more susceptible to psychiatric morbidity than men as they respond to all stages of the stress process differently to men (Schulz & Yee, 2000). Therefore, the finding that spouses of heart transplant candidates experience high levels of psychological distress may be due to the fact that the majority of participants were females.

Time and resource restraints meant that only articles written in English were included, potentially limiting the cultural relevance of the findings as all retrieved papers were from the USA. This could also be a reflection of the high number of heart transplants performed in the USA annually in comparison with the rest of the world (International Society for Heart and Lung Transplantation 2015). This hinders the transferability of the results to other countries. Additionally, being a novice researcher, the identification, critique and synthesis of literature may not have been as thorough as that of a more experienced researcher (Aveyard 2010).

## **Conclusion**

This is the first review of the research regarding experiences of spouses of heart transplant recipients. The findings demonstrate the all-consuming nature of the pre-transplant period. Every aspect of the spouse's life is affected as they immerse themselves in sharing the candidate's life and suffering. Spouses change their lifestyle to accommodate the candidate's needs, which often results in spouses experiencing a loss of self. All energy is directed towards maintaining the candidate's health, regardless of the impact this has on the spouse's own well-being. The uncertainty of the pre-transplant period can be very distressing for spouses, and they employ a range of coping strategies in order to alleviate stress. Findings suggest that there is a requirement for education about the transplant process, and reinforcement of positive coping strategies. Additionally, nurses must recognise the distress caused by the pre-transplant wait and provide support through this stressful period.

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