

Review

Esther Ravens*, Johanna Becker, Lars Pape and Gundula Ernst

Psychosocial benefit and adherence of adolescents with chronic diseases participating in transition programs: a systematic review

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Abstract: Chronically ill young people must transition to the adult health care service after their 18th birthday. The transition from child centred paediatric care to the adult health care service is not simply limited to the change from familiar structures to something unknown, but includes the entire process of growing up, of individuals becoming independent from their parents and taking responsibility for their own disease management. Young people are at particular risk of losing the connection to medical care during this phase and the transition of young people with chronic conditions is associated with a high risk of declining adherence and worsening health status. Studies suggest that transition programs might be helpful, yet there is no evidence as to whether risks can be reduced or which intervention components are particularly conducive to better outcome. This study aimed to identify transition-specific interventions and evaluate their effect on the improvement of psychosocial parameters, such as health related quality of life and adherence of patients. A systematic literature review was conducted. Electronic databases (Cochrane, Embase, Pubmed, Web of Science) were searched by two independent reviewers for intervention studies aiming to improve transition. Grey literature

was also searched. Studies were included if they evaluated transition-specific interventions aiming to improve psychosocial or adherence parameters of participants aged 12 years and older suffering from a chronic condition. Both controlled trials and studies with measurements before and after the intervention were included. The GRADE approach was used to assess the quality of evidence. The inclusion criteria was met by forty studies. Patients suffered from different chronic conditions, such as inflammatory bowel disease, type 1 diabetes or juvenile idiopathic arthritis. Transition interventions used several program components, such as transition coordinators, patient education programs or web-based interventions. Outcomes included quality of life, transition-specific knowledge, adherence and loss to follow up. Thirty-eight studies showed beneficial effects in the intervention group, respectively after intervention. The overall study quality was low. A large number of studies evaluating transition-specific interventions was included. Transition-specific interventions seem to have beneficial effects on psychosocial outcomes and adherence. The promotion of health literacy, appointment arrangement service and the use of technical elements (websites, SMS) seem to be particularly helpful in the transition process. As the patient population was diverse, the results can be transferred to other diseases. Even though the overall study quality was poor, it is possible to draw some conclusions. Future studies should aim to include large numbers of patients over extended periods of time in order to assess long-term outcomes.

***Corresponding author: Esther Ravens,** Institute of Medical Psychology, Hannover Medical School, Hannover, Germany; and Departement of Paediatric Nephrology, Hannover Medical School, Hannover, Germany, E-mail: Esther.L.Horn@stud.mh-hannover.de
Johanna Becker: Departement of Paediatric Nephrology, Hannover Medical School, Hannover, Germany; and Institute of Medical Psychology, Hannover Medical School, Hannover, Germany, E-mail: Johanna.Becker@stud.mh-hannover.de
Lars Pape: Departement of Paediatric Nephrology, Hannover Medical School, Hannover, Germany, E-mail: Lars.Pape@uk-essen.de. <https://orcid.org/0000-0002-3635-6418>
Gundula Ernst: Institute of Medical Psychology, Hannover Medical School, Hannover, Germany, E-mail: Ernst.Gundula@mh-hannover.de

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Introduction

With the advances in modern medicine, more and more chronically ill children and adolescents are reaching adulthood [1]. For example, children with cystic fibrosis or

congenital heart disease, who were previously only treated in paediatric departments, now regularly enter adulthood [2, 3]. In addition, the prevalence of other chronic diseases such as asthma or type 1 diabetes is increasing [4, 5]. Hence there is now a need for these patients to transition from the paediatric service to adult health care structures. Transition means the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child centred to adult health care service” [6]. Therefore, transition is not simply limited to the transfer from patient-centred paediatrics to adult care but includes the entire process of growing up and becoming independent. Transition covers not only the medical needs of young people, but also the educational, professional and psychosocial aspects of life. This time window is especially challenging for adolescents with a chronic disease and their need of ongoing care [7, 8]. In Germany alone, at least 15% of young people have special health care needs [9, 10]. Studies from other countries show similar figures [11, 12]. During the transitional period, up to 40% of patients lose the connection to specialised health care services [13]. Numerous studies have shown that the time of transition is often accompanied by decreasing adherence, increasing loss to follow up and the declining health status of patients [14–17]. Adolescents with complex diseases are particularly affected by these problems [18].

Although there are currently some approaches to improve transition [19, 20], there is a lack of generally applicable and cross-diagnostic standards and recommendations [21, 22]. In order to establish a transition-specific guideline, it is necessary to take into account previous scientific findings. Within the framework of evidence-based medicine, systematic reviews are essential to summarise and evaluate the results of previous research [23, 24]. Thus, they offer an up-to-date and comprehensive overview of the current state of science [25]. The purpose of this review is to identify transition-specific interventions and evaluate their effect on the improvement of patients’ psychosocial or adherence parameters. In addition, particularly helpful interventions will be identified.

Methods

Structure based on PRISMA

The established PRISMA checklist (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) and the PRISMA flow chart were used as a basis for the systematic literature research [24].

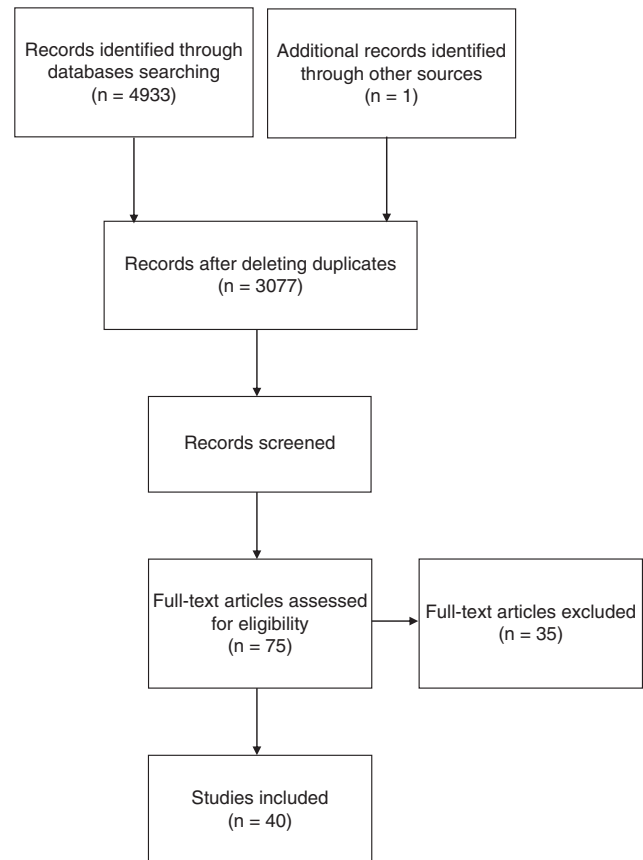


Figure 1: PRISMA Flowchart.

By using the PRISMA instrument, a well-founded scientific framework was provided for summarising individual studies into a systematic review. The PRISMA study flow chart is shown in Figure 1.

Inclusion criteria

The inclusion criteria for the systematic literature search were defined with regard to the study population, the intervention, the study design and the outcome parameters investigated (PICO-framework) [26] and are shown in Table 1.

Table 1: PICO framework defining inclusion criteria.

Can an intervention aimed to improve transition of care ameliorate psychosocial and behavioural outcomes of chronically ill young people?	
Population	12 years or older Somatic chronic diseases or health conditions
Intervention	Intervention aimed to improve transition of care
Comparison	Control group or comparison between two points of time (before and after intervention)
Outcome	Psychosocial or behavioural outcomes

Population

Studies were included if the participants were at least twelve years old and suffered from a chronic health condition or special health care need that led to a special need for medical care.

Psychiatric diseases or cognitive disabilities were not investigated.

Intervention

All included studies had to examine an intervention aimed at improving the transition from paediatric to adult health care services.

Comparison, study design

To clearly identify possible effects, randomised controlled trials (RCT), intervention studies with non-randomised control groups (NRCTs) and trials with measurements before and after the intervention (pre-post-comparison) were included.

Outcomes

All studies measuring psychosocial and behavioural outcome parameters as a dependent variable were included. Psychosocial outcomes include measurements such as Health related Quality of life (HrQoL), stress level or transition readiness, whereas behavioural outcomes relate to adherence and the behaviour regarding follow up. Studies that exclusively examined somatic outcomes such as morbidity or mortality were not included.

Electronic searches

Databases

Two independent reviewers (Johanna Becker, Esther Ravens) searched the international electronic databases Cochrane Library, Embase, Pubmed and Web of Science Core Collection.

Search strategy

Since there is a 2011 review with similar inclusion criteria covering older literature [27], only studies with an English title and abstract, published between June 2011 and October 2018 were considered.

In order to make the search in the individual databases generally valid, databases were searched using the same transition- and age-specific search terms. Alternative spellings and truncations were considered. The search strategy was adapted for each database with database-specific keywords. All search strategies are listed in the online supplement (Supplementary Tables 1–4).

Searching other resources

In addition, a so-called grey literature screening was carried out, meaning that the reference lists of relevant studies and reviews were also searched. Authors of unpublished studies were contacted.

Study selection

After the deletion of duplicates, all titles and abstracts identified by the search in electronic databases or other sources were screened. The full text was obtained for all potentially relevant studies and checked for inclusion by both reviewers. Differences in assessment were discussed between reviewers in order to reach a consensus. In case of ambiguities regarding individual studies, the respective authors were contacted. All studies excluded are listed with reason for exclusion in the online supplement (Supplementary Table 5).

Certainty of evidence

To assess the certainty of evidence, the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach [28] and a modified grading scale based on GRADE for better internal differentiation of studies with low to very low evidence quality was used.

GRADE

The GRADE process was developed for the classification of recommendation strengths within the framework of guidelines and systematic reviews. Based on various criteria, the quality of evidence is divided into four levels – high, moderate, low or very low [28]. Usually, outcomes are graded separately [29]. However, in this review it was decided to grade per study, as it was estimated that heterogeneous outcome measures would prevent outcome summaries of different studies.

Table 2: Modified grading scale.

Criteria	Possible score ^a
Randomised controlled trial	2
Controlled trial	1
No increased risk of selection bias	1
No increased risk of other biases	1
No indirectness of evidence	1
Precision based on sample size:	
n > 150 (or n > 40 if rare disease)	1
n > 100 (or n > 20 if rare disease)	1

^aFor each criterion met, the number of points indicated in the right column will be given (8 points in total). Rating: 1–2 points: very low quality; 3–4 points: low quality; 5–6 points: moderate quality; 7–8 points: high quality.

Modified grading scale

Since the results of former reviews indicate that transition studies often have a low quality of evidence, a modified grading scale was developed. The modified grading scale is based on GRADE, but allows better differentiation of the quality of evidence in the lower range. The modified grading scale divides the quality of evidence into eight levels, where one point corresponds to a very low evidence quality and eight points to a very high evidence quality. Table 2 provides an overview of the evaluation criteria of the modified grading scale.

Results

The search in the electronic databases and the grey literature screening identified 4933 records. After deletion of duplicates, the remaining 3077 titles and abstracts were screened for their relevance. The full text was obtained for 75 studies, of which 40 met the inclusion criteria.

Study design

Of the forty eligible studies, eight were RCTs and eighteen were controlled but not randomised. Of the studies without a randomised control group, six studies used a historical control group. Thirteen studies used comparisons between two points in time, pre- and post-transition. Three studies used a pre-post comparison in addition to the control group. One study compared different transition components and their associations with various outcomes.

Quality of evidence

When evaluating the studies with GRADE, ten studies achieved the quality level low, whereas thirty studies were

classified as very low. Using the modified grading scale, the quality level of nine studies was classified as very low, twenty studies reached a low-quality level, ten studies reached a moderate-quality level and one study reached a high-quality level. Consistency and selective reporting could not be analysed due to heterogeneity of study characteristics and small sample size.

Population

All forty studies together evaluated the outcomes of 3333 patients aged between 12 and 28 years.

Various diseases were examined, led by inflammatory bowel disease [30–36], type 1 diabetes [17, 34, 35, 37–43], juvenile idiopathic arthritis [44–46] and congenital heart disease [47–50]. Patients with cerebral palsy [37], cystic fibrosis [34, 35, 51–53], epilepsy [54, 55], sickle cell anaemia [56], liver transplant [57, 58], congenital adrenal hyperplasia [59], renal transplant [60, 61], haemophilia [62], warfarin therapy [63], chronic kidney disease [64], oesophageal atresia [65] and spina bifida [66] were also studied. One study examined children with diverse chronic diseases [67]. Apart from four studies investigating patients with various diseases [34, 35, 37, 67], all studies focused on patients with one disease.

Interventions

Most studies evaluated combined transition interventions with at least two program components. Two studies evaluated an intervention consisting of a single component: a web-based intervention was evaluated by Ammerlaan et al. [68] and a patient education program intervention by Schmidt and colleagues [35]. One study did not conduct its own transition intervention, but examined associations between intervention components and outcomes in patients from different programs [37]. The different intervention programs focused both on the patients and the service provision. Figure 2 provides an overview of the various intervention components and their success.

A multidisciplinary team (n = 15 studies) [17, 31, 36, 39, 40, 46, 47, 51, 53, 55, 58–60, 64, 69] or a transition coordinator (n = 14 studies) [38–41, 44, 45, 51, 54, 57, 60–62, 66, 69] were most frequently used in intervention components. A multidisciplinary team means that, in addition to doctors and nurses, professionals from at least one other discipline, such as psychologists or dietitians, were involved in the program. Transition coordinators work in specially created divisions covering a range of activities regarding the transition process. A transition coordinator most commonly had intensified patient

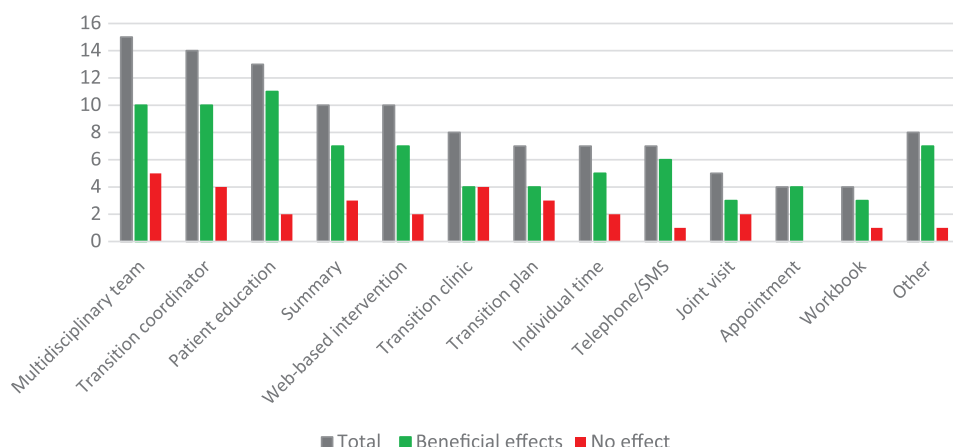


Figure 2: Number of studies that evaluated certain intervention components.

Total: total number of studies. Beneficial effects: Number of studies showing a significantly better outcome in the intervention group or in measurements after intervention compared to the control group or measurements before intervention. No effects: Number of studies showing no significant differences between groups or between measurements before and after intervention.

contact during the whole transition process and helped with making appointments or the provision of information. The program component patient education ($n = 13$ studies) [17, 35, 40, 48–51, 54, 63–65, 67, 69] includes not only transition or disease-specific knowledge education, but also training on transition-specific skills and competences. Patient education took place both individually and in groups depending on the study. Ten studies worked with a document summarising important patient information for the new treatment team [17, 33, 38, 43, 49, 54, 57, 60, 61, 63]. Nine studies worked with a web-based intervention, for example a special web-site access, chat rooms or online documentation systems for medical parameters, such as international normalised ratio (INR) or blood glucose level [17, 34, 40, 62, 63, 65, 67–69]. Eight institutions set up a transition clinic to which patients were transferred after paediatric care [31, 33, 36, 39, 46, 55, 61, 64]. These clinics often had more staff, longer appointments and treated only patients of transition age. Whenever a clinic planned a special sequence of events around the transition, this was summarised under a transition plan ($n = 7$ studies) [31, 43, 44, 46, 47, 51, 63]. The age of transition was individually determined by seven institutions [31, 38, 45, 46, 58, 63, 66]. The Transition Readiness Assessment Questionnaire (TRAQ) [49, 50, 52, 66] was a common method for determining age. Another seven studies observed the effect of a telephone or SMS service as an appointment reminder or alternative way of keeping contact [17, 34, 38, 41–43, 50]. Joint visits are appointments where, in addition to the paediatric team, the new adult treating team is also involved and these were conducted in five studies [31, 38, 51, 52, 59]. The first appointment at the new treatment institution was made for the

patients by a member of the paediatric team in four studies [17, 43, 45, 56]. Additionally, four studies used a workbook or alternative information material [45, 48, 49, 52].

All investigated components achieved positive rather than no results much more frequently, with the exception of the transition clinic. Out of eight studies investigating a transition clinic, four reached significantly positive results.

Outcomes

The forty studies included in the review investigated several outcomes relating to psychosocial and behavioural measurements. Psychosocial outcomes include HrQoL, well-being, disease-related self-management and -efficacy, patient activation, transition readiness and competence, transition or health-specific knowledge and independence, especially from parents. Behavioural outcomes refer to the adherence behaviour of patients. Medication adherence or the adherence to blood measurements (e.g. INR), follow up and a stable transfer fall under this heading. Jensen et al. defined a successful transfer as at least two visits at the new adult treatment site [45]. Psychosocial outcomes were analysed in twenty-eight studies (7863 patients) and adherence outcomes in eighteen studies (1708 patients).

Studies were considered successful if at least one patient-relevant outcome was significantly improved. None of the included studies showed a deterioration of the intervention group compared to the control group. Two studies showed a deterioration of outcomes in pre-post comparison [60, 63]. Annunziato et al. [60] showed a significant deterioration in medication adherence after

implementing a transition program consisting of a transfer summary, a transfer plan and a social worker for 22 renal transplant patients. Bauman and team [63] also implemented a transition summary and plan, but additionally included an online program and an individual transfer time. The study population comprised nineteen adolescents with different diseases requiring warfarin therapy. The adherence of INR blood measurement and documentation showed a significant decrease during the study period; all other measured outcomes remained constant.

Both studies examining transition competence showed improvements [35, 67]. Transition preparedness/readiness could be improved in 75% of the relevant studies [53, 62, 66]. The rate of loss to follow up or drop out could be improved in 40% of the studies investigating this outcome [43, 56, 58, 61]. Another 30% of these did not record a single patient lost to follow up [38, 53, 57]. One study showed a correlation of young age with non-attendance of medical appointments [59], whilst another study showed a correspondence between transition-specific knowledge and appointment perception [58]. Self-efficacy [34–36, 62] or the time span between appointments [47, 50] each showed improvements in 66% of the studies examining these outcomes. Of the studies investigating transition or health-specific knowledge, 63% showed positive results [48–50, 62, 65, 67, 69]. 50% of the studies examining well-being showed improvements [38, 40, 42]. Half of the studies surveying disease-related self-management [34, 49, 50, 62] showed significant improvements. Patient activation was improved in two out of four studies [34, 35, 54, 67].

Of both studies scrutinising adherence to blood measurement [17, 63], one showed a significant decrease [63]. The independence of patients [55] and the completion of transfer [45] could be improved in 33% of the studies examining these outcomes. 28% of the studies looking at medication adherence showed improvements [31, 57], whereas 14% demonstrated a decline [60]. HrQoL did not change in any study.

A detailed table with the characteristics of all studies, interventions, outcomes and grade rating can be found in the online supplement (Supplementary Table 6).

Discussion

The purpose of this review was to identify transition-specific interventions and to evaluate their effect on the psychosocial and adherence parameters of adolescents. To this end, forty studies examining a total of 3333 patients

could be included. Since these studies focused on various diseases and intervention components, the findings of the review are a valuable contribution to previous transition research. Compared to previous reviews [27, 70], more studies were identified, which underlines the increasing importance of the topic of transition.

A review published by Crowley et al. in 2011 [27] included ten studies, all focusing on type 1 diabetes. Due to the poor methodological quality of the studies under scrutiny, the significance of the review was limited. Furthermore, it is questionable whether the results can be transferred to other diseases. Campbell and co-workers [70] evaluated four RCTs in 2016. The review was able to show slight improvements in disease management, self-efficacy, transition or health-specific knowledge and transition readiness. In addition, it found that transition interventions may not lead to an improvement in quality of life or well-being. However, psychosocial factors in particular are of great importance for adolescents beginning to take long-term responsibility for their own health behaviours [71]. Skills such as self-efficacy, self-management and disease-specific knowledge enable adolescents to take control of their lives. A high degree of empowerment among adolescences can lead to an improvement in psychosocial outcomes such as HRQoL, well-being and independence, the foundation of a solid health status [72].

Both reviews had difficulties evaluating the results of single components of combined interventions. These findings are in line with our findings. Since most studies combined several components into one intervention, it is difficult to attribute effects to single components. However, it seems reasonable to combine several intervention components. The results also suggest that a promotion of health literacy, an appointment arrangement service and the use of technical elements such as websites or telephone/SMS interventions seem to be particularly beneficial to the transition process. Out of online programs and patient education, disease- or transition-specific knowledge and transition competence seem to be of especial benefit. Previous reviews come to a similar conclusion: both Crowley et al. [73] and Campbell and team [70] identified patient education to be particularly helpful. The Campbell results also suggest that interventions using technology may have a favourable effect on self-efficacy and self-management.

The success rate of the interventions differs widely across the heterogeneous outcomes. Transition competence, transition preparedness/readiness and loss to follow up responded very well to interventions. The outcomes adherence, transfer, independence and HRQoL could be

improved in less than half of the studies. These outcomes will need special attention in future research studies.

However, it must be said that in this review, success was defined as a significant improvement of one outcome parameter. Since the main danger of transition lies in the deterioration of health during the time of transfer, it would be worth considering whether the stabilisation of an outcome parameter could also be considered a success. For example, no deterioration was shown for HRQoL in any of the included studies, meaning that this particular outcome was successful in each study.

Furthermore, the initial value of HRQoL before intervention should also be included in the evaluation. Depending on the severity of disease, the DISABKIDS field study [74] describes the HRQoL of children and adolescents ranging from 67.2 to 80.4 points evaluated using the DISABKIDS Chronic Generic Measure. Compared with this, some included studies already showed above average values even before the intervention started [57, 67, 75], whereby a stabilisation of these values could be considered a great success.

Of course, the overall low study quality is a limitation of the results of this review. In addition to the low methodology quality of those studies included in the review, comparability is also limited due to differences in the length of observation periods and the collection of results. In most studies, the results were collected over a period of 6 months to 1 year, making it difficult to draw conclusions about long-term effects. Nevertheless, even short observation periods can assess whether an intervention has the potential to influence transition.

It is important to note that there are certain challenges when conducting transition interventions. Not only is the target population very diverse, but it is also difficult to find sufficiently large numbers of participating patients [41]. The blinding of the groups is usually neither possible nor useful and the observation periods for long-term health outcomes would be ideally life-long. In addition, there are those who consider RCTs on transition to be unethical, since the control group is denied access to a potentially helpful intervention [36, 76].

Despite these concerns, there were eight RCTs with relatively high study quality and several non-randomised trials with a moderate-quality level, which were included in the review. The outcomes of studies with lower quality were consistent with those from studies with high and moderate quality, indicating that low-quality studies might offer important contributions to knowledge in this context.

Due to the large diversity of examined diseases, it is possible to transfer the results to a wide spectrum

of patients and conditions. Therefore, the evidence provided by this review forms the basis for the development of future recommendations, providing the opportunity of establishing a transition-specific guideline with disease-crossing validity.

Conclusions

The evidence of this review suggests that transition interventions are beneficial to improve relevant patient outcomes. There are many intervention components which can be used individually or in combination. The promotion of health literacy, appointment arrangement services and the use of technical elements such as websites or telephone/SMS interventions seem to be particularly beneficial to the psychosocial outcomes of the transition process and help to improve adherence. Guidelines should be based on the results of the present review, but must also be supported by expert consensus, as there is a partial lack of solid evidence.

Future studies should aim to include larger numbers of patients over long periods of time to be able to assess long-term outcomes. In addition, it would be helpful for future evaluations to examine single intervention components separately. Currently, there are several ongoing high-quality studies with large numbers of patients, the results of which are awaited with anticipation.

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