

A Statewide Study of Knowledge and Attitudes Regarding Health Care Transition

Abstract

This article presents the results of a survey of interagency transition council members that assessed familiarity with health care transition (HCT) and the inclusion of HCT-related goals in individual educational plans (IEPs). School personnel, agency representatives, and family members completed a total of 187 surveys. Results of the study indicate respondents had limited knowledge of HCT and HCT related issues were often not addressed through school-based transition activities. Respondents, however, reported a high level of interest in learning more about the issue of HCT. Implications of this research include the need to provide additional training to school and agency representatives regarding the importance of expanding current educational transition practices to include HCT.

Introduction

How do I manage my health care needs so that I can work or attend college? How do I advocate for my health care needs in the workplace? How will I pay for my medications and doctors' appointments? These are just a few of the health care-related questions that adolescents with disabilities and special health care needs (SHCN) need to be asking themselves as they prepare for adulthood. Unfortunately, adolescents and their families often don't raise these questions before the young person¹ reaches adulthood. This can result in an abrupt, poorly planned or unsatisfactory transition to adult-oriented health care or to less than optimal health care that can have a negative impact on all aspects of the young adult's life.

The transfer from pediatric to adult-oriented medicine is one of the many transitions that students must accomplish on their way to adulthood. However, for students with disabilities and SHCN, access to quality adult-oriented medical care and the ability to manage their own health care needs, plays a fundamental role in building their capacity to successfully carry out mandated transition activities (IDEA, 2004) and other responsibilities that come with adulthood. Transition to adulthood represents a critical "turning point" in the life course; suboptimal transition experiences including those related to health care may affect the future ability of these young people to optimize their quality of life (Halfon & Hochstein, 2002).

Need for Health Care Transition

In the United States, almost 9.4 million children (ages 0 – 17) have SHCN (Centers for Disease Control, 2001; McPherson et al., 2004); and approximately 500,000 turn 18 annually (Newacheck & Taylor, 1992). Children with SHCN are defined as, "those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" and includes those with a broad range of chronic health conditions such as asthma, cystic fibrosis, spina bifida, epilepsy, hemophilia, sickle cell disease, and cancer (McPherson, et al. 1998, p.138). The large and growing number of young adults who have SHCN and disabilities is the result of medical advances over the past 25 years. A generation ago, most children born with chronic health conditions and congenital disorders did not reach adulthood. Today, more than 90% reach their 21 birthdays (Blum, 1995; Gortmaker, Perrin, Weitzman & Homer, 1993). But reaching adulthood also presents many problems maintaining access to health care as these young people age out of the pediatric health care system.

Many healthy young adults between the ages of 18 and 24 do not have a regular source of medical care, with percentages of 35% for men and 19% for women observed during the 2003 National Health Interview Survey (Centers for Disease Control and Prevention, 2004). There are many reasons for this lack of a regular source of health care but the loss of health insurance as a result of aging out of programs for children or of family provided health insurance is often a contributing factor (Collins, Schoen, Tenney, Doty & Ho, 2004; Fishman, 2001; White, 2002). Collins, et al. reported that 44% of all 19-29 year olds did not have health insurance at some time during the year 2001. Young adults' general good health, combined with lack of access, allows a large number of healthy young adults to drop out of the health care system for a time when discharged from their pediatric providers. However, young adults with disabilities and SHCN do not have the option of "dropping out" (Reiss & Gibson, 2006)

¹ Health care transition is important for all young people. This article specifically addresses the health care transition needs of young people with disabilities and special health care needs. References to young people, students or adolescents refer to those with disabilities and special health care needs unless otherwise noted.

Interruptions in access to health care can pose serious and/or life-threatening consequences for young people with disabilities or SHCN. Their success in adulthood is dependent, in part, on being able to access medical care that helps them be as healthy and functional as possible and that supports them in the process of acquiring the knowledge, skills and experiences they need to carry out adult roles and responsibilities. For these young people, continuous health care, and a smooth and appropriately timed transfer to adult-oriented care is imperative (Viner, 1999).

Expanding Transition Services

When school-based professionals think about transition planning, they are concerned with preparing students for a broad range of adult roles and responsibilities including worker, consumer, community member, family member, and friend (Brolin & Lloyd, 2004; Greene & Kochhar-Bryant, 2003; Halpern, 1994). Despite the fact that school is an appropriate environment for learning to be self-sufficient in managing day-to-day health care needs, education-based transition does not typically encompass health care roles.

Educational transition services have focused on helping the student to become a fully functioning adult in the community. Best practices in education for guiding the student through the transition process and preparing them for specified adult roles have been researched and disseminated (Brolin & Lloyd, 2004; Greene & Kochhar-Bryant, 2003; Kohler, 1993; Patton, 1999; Patton, 2004; Sitlington, Clark & Kolstoe, 2000). These practices can be generally classified as either (a) providing support for youth and young adults or (b) assisting students and young adults to acquire needed skills and competencies (Repetto, Webb, Neubert, & Curran, in press).

In contrast, the medical community's interest in transition focuses almost exclusively on health care, as reflected in the following, broadly accepted definition of HCT: "the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (Blum et al., 1993, p.570). Not only must young adults assume an increased level of responsibility for their own health care, they must do so within the adult-oriented health care system, which is organized and provides care in ways that are significantly different from pediatrics (Rosen, 1995; Reiss & Gibson, 2002; Reiss, Gibson & Walker, 2005).

Health care transition has been described as a multi-staged developmental process that requires both skill development on the part of the young person as well as changes within existing medical systems (Reiss, Gibson & Walker, 2005). Forbes, et al. (2001) in their extensive review of the HCT literature identified transition-related practices as focusing on: (a) youth and family education and preparation, (b) practitioner-focused clinical education and training and (c) systems development.

Integration of Education and Health Care Transition Services

The educational and health care approaches to transition share an orientation of providing support both through system change and through skill development. Considering the needs of adolescents and the shared and interdependent goals of independence and full participation in community life, it makes good sense to consider how these parallel transition services can be integrated to foster the success of young people with disabilities and SHCN. An excellent example of this type of integration is seen in the results of a survey conducted by Heller and Tumlin (2004). This study found "the overwhelming majority" of school nurses and special education teachers who participated in their survey were willing to teach students to perform health care procedures and to include these procedures as official goals and objectives on the student's IEP. Unfortunately this type of collaboration is not often observed in real life or discussed in the educational or medical literature.

The transition from pediatric to adult-oriented health care is important for a significant and steadily growing number of students. Therefore, we believe that HCT is an issue that should be integrated into the transition programs and services offered by school districts. Before this could happen it was necessary to understand what obstacles needed to be overcome and what efforts were needed to develop workable strategies that would help school districts incorporate HCT into existing transition programs. To accomplish this, we surveyed members of transition councils throughout Florida to gauge their current level of knowledge about HCT practices and the perceived importance of HCT in the overall transition process.

Methods

Survey Development

Survey questions were developed as a result of a review of the literature and the consideration of questions specifically relevant to the work of interagency transition councils and the content of Transition IEPs (i.e., the “Florida” term used to describe IEPs developed for students 14 and older). The investigators organized the survey questions into four sections: Demographics, Knowledge of HCT, Attitudes Toward HCT and HCT Related Behaviors. Questions were reviewed by experts in survey development and transition content. Cognitive testing was completed on the final draft of the survey at a statewide meeting attended by interagency transition council members including (a) family members, (b) school personnel, and (c) agency representatives. Feedback on the survey indicated that the structure of the survey was appropriate and the content of questions was well understood by respondents. However, it was noted that the response categories used for some of the questions might make summarizing results difficult. As a result of this input, revisions and enhancements of the survey instrument were made, and a final version was developed. The final version of the survey contained 8 multiple-choice questions and 6 Likert Scale questions which asked participants to rate frequency of behaviors, responsibility and barriers across multiple items.

Survey Implementation

Members of interagency transition councils participating in *Project CONNECT* (The Transition Center at the University of Florida, 2005) from across the state of Florida were surveyed to ascertain their knowledge, attitudes and behaviors regarding the incorporation of HCT related issues into school-based transition planning. *Project CONNECT* is a statewide interagency initiative, funded through the Florida Department of Education, Bureau of Exceptional Education and Student Services, designed to assist local interagency transition councils to (a) form new and/or revitalize existing interagency councils to improve interagency collaboration in transition planning, (b) provide technical assistance and advice in support of progressive educational transition activities, and (c) identify transition best practices through enhancing community partnerships (The Transition Center at the University of Florida). The interagency councils are composed of education personnel, agency representatives, community partners, students and their family members and others. These councils are generally associated with individual school districts, however, in some instances multiple school districts, often smaller and/or more rural ones, work together through the same *Project CONNECT* interagency council.

Each *Project CONNECT* council is managed locally by one or two coordinator(s). Coordinators were contacted to elicit their support in the administration of the survey. Directions for the survey procedure, written copies of the survey, and a form requesting

additional meeting demographic information were disseminated to coordinators within a nine-week period either at an annual *Project CONNECT* conference or by mail. Coordinators distributed surveys during a regularly scheduled interagency council meeting held during the spring of 2005. Completed surveys along with additional meeting demographic information were returned for tabulation and analysis. Survey data was compiled into a database where it was prepared for analysis. The University of Florida Institutional Review Board approved the survey.

Results

At the time of the survey, the state of Florida had a total of 32 *Project CONNECT* councils. Twenty-three project interagency councils (72%) participated in the study by returning completed survey forms. Responding councils included districts of all sizes, large (7), medium (9), small (3), and mixed (4).

A total of 187 surveys with signed consent forms were returned and used in the analysis presented below. Seventeen percent (32) of the responses were from men, and 83% (153) of the responses were from women. *Project CONNECT* coordinators were asked to provide the total number of individuals present at the meeting where the survey was distributed. This information was returned by 14 of the 23 interagency councils. The response rate for the 14 councils where total attendance was known was 62%.

Respondents were classified as belonging to one of four participant groups that make up *Project CONNECT* interagency councils: *School Personnel*, *Agency Representatives*, *Parent/Family Member*, and *Student Representatives*. *School Personnel* (n=83, 44%) included teachers, administrators, school-based therapists, and school-based health personnel. *Agency Representatives* (n=72, 39%) included individuals from community-based agencies and organizations (such as Vocational Rehabilitation, Centers for Independent Living, Agency for Persons with Disabilities, Division of Blind Services, etc.) that provide support to individuals with disabilities. *Parent/Family members* (n=4, 2%) included individuals who identified themselves as parents or other family members of a young person in a school served by the *Project CONNECT* council. Although the survey was to include student members of the *Project CONNECT* councils, no students were in attendance at the meetings where the survey was administered. A category of *Other* (n=28, 15%) was also constructed for individuals who could not be categorized (such as District Administrator or Behavior Analyst with no affiliation indicated). Responses were totaled for each response group and presented in aggregate. The small number of responses from parents and the heterogeneity of the *Other* category limited comparison of these groups with the agency and school personnel groups.

Knowledge of Health Care Transition

Knowledge of HCT was the focus of the first part of the survey. Respondents were provided with the generally accepted definition of HCT (as previously stated) and then asked to rate their knowledge as *Never Heard Of*, *Know a Little*, *Know Something* or *Know a Great Deal*. The distribution of the responses was similar across respondent groups. Sixteen percent (n=29) of all respondents reported they *Never Heard Of* HCT. Forty-one percent (n=76) reported *Knowing a Little*, 38% (n=69) *Knowing Something* and 5% (n=10) *Knowing a Great Deal* about HCT. Forty-nine percent (n=41) of school personnel and 64% (n=46) of agency representatives *Never Heard of* or *Knew Little* of HCT.

Respondents were asked to identify their personal experience with HCT. Ninety-one respondents or almost half of those who completed the survey reported they had no

experience with HCT. Those respondents who did have transition experience were asked to identify the types of experience they had. Most identified only one type of experience. Thirty-nine respondents reported hearing about someone who transitioned from pediatric to adult-oriented health care. Thirty-one had served on a committee or work group that addressed HCT issues and 26 respondents had observed a student transition. Personal experience with transition was limited, as only eight respondents had a family member experience HCT, and six responded affirmatively to the statement “*I have experienced health care transition.*”

Respondents were asked to categorize the level of their knowledge about the changes in access to health insurance coverage that are associated with becoming an adult. Twenty-four (n=44) of the respondents were *Unaware*, 23% (n=43) *Knew Very Little*, 43% (n=80) *Knew Something* and 9% (n=17) *Knew a Great Deal*. Of the four respondent groups, *Agency Representatives* had the highest percentage of respondents who reported either *Knowing Something* (51%, n=36) or *Knowing a Great Deal* (10%, n=7) about changes in health insurance. The three other respondent groups reported less knowledge of age-related changes in access to health insurance. Fifty-one percent (n=42) of School Personnel reported being *Unaware* or

Knowing Very Little on this topic.

Respondents were asked, based on their experience, how often HCT issues were addressed in Transition IEPs. Percentages across respondent groups were again generally very similar. Almost one-third (n=56) of the respondents reported that they do not participate in Transition IEP meetings and, therefore, did not have the personal experience needed to answer this question. Of those respondents who did participate in developing Transition IEPs, 8% (n=15) reported HCT was *Never*, 25% (n=45), *Rarely*, 23% (n=42) *Sometimes*, 9% (n=16) *Often*, and 5% (n=9) *Almost Always* included in Transition IEPs.

Those respondents who participated in Transition IEP meetings were then asked to rate how often HCT should be included in IEPs. No respondents indicated that HCT should *Never* be addressed in a Transition IEP and 61 (47%) of these respondents thought it should be included *Nearly Always*. Thirty-one percent (n=41) thought HCT should be included *Often*, 20% (n=26) *Sometimes* and 2% (n=3) *Rarely*. Agency representatives were most supportive of addressing HCT issues, with the highest proportion of respondents (66%, n=29) indicating it should *Nearly Always* be included in Transition IEPs.

The 131 respondents who participated in Transition IEP meetings rated how often 16 HCT-related goals were included in Transition IEPs. As part of the analysis, the rating categories *Often* and *Nearly Always* and *Never* and *Rarely* were collapsed to create a three-point frequency scale. The goal areas reported as being most often included in Transition IEPs were:

- Identifying and accessing agencies other than school systems that can help achieve educational and vocational goals (65%)
- Self-determination and goal setting (60%)
- Independence with self-care (59%)
- Interpersonal communication skills (58%)
- Use of transportation systems or services (34%)
- Completion of job application and/or job interview (34%)

The goals that most frequently received a rating of *Never* or *Rarely* were:

- Complete health forms and communicate effectively with health care providers (84%)

- Knowledge of insurance coverage and how to use health insurance benefits (81%)
- Maintenance of a personal health record (77%)
- Overall general health, including sex education and family planning (74%)
- Knowledge of when and how to access urgent medical care (71%)

Attitudes Towards Health Care Transition

All respondents to the survey were asked, “How important is it to include health related goals, issues, tasks and concerns in Transition IEPs?” Respondents overwhelmingly agreed (n=172, 94%) that inclusion of health care was *Very Important*. Eighty-three percent (n=153) of respondents also felt that it was *Very Important* that young adults with disabilities and SHCN receive their health care from adult-oriented providers.

Respondents were asked to indicate how responsible different individuals/professionals were for facilitating the HCT process using the scale *Not At All Responsible*, *Somewhat Responsible* and *Have a Primary Responsibility*. Parents were identified as *Have a Primary Responsibility* by 85% of the respondents. Students and Transition IEP teams were identified as *Have a Primary Responsibility* by 59% and 46% of the respondents, respectively. Those most frequently identified as being *Somewhat Responsible* included Family Advocacy and Support Agencies (62%), School Based Health Care Providers (60%), Therapists (55%), Children’s Medical Services (CMS) (55%), Pediatric Providers (54%) and Transition IEP teams (50%). Although there is consistent agreement that the parents and the student have primary transition responsibility, respondents also felt that school personnel, as well as other health care providers, share some responsibility for the transition process.

Health Care Transition Related Behaviors

Parents were seen by 87% of the respondents as having a primary responsibility for developing HCT-related goals and activities for Transition IEPs. This was followed by 70% for Transition IEP teams and 66% for students. School-based health care providers (55%), CMS (51%) and Vocational Rehabilitation (VR) (51%) were also seen as having responsibility for developing goals.

When asked to rate the participation of various health care providers on the Transition IEP team, respondents observed that speech therapists (51%), occupational therapists (49%) and physical therapists (48%) *Often* or *Nearly Always* participated in Transition IEPs. VR counselors were seen as participating *Often* or *Nearly Always* by 35% of the respondents. On the other hand, physicians were seen as *Never* or *Rarely* participating by 88% of the respondents and CMS as *Never* or *Rarely* participating by 72% of the respondents.

When asked what type of information might be most helpful, all suggested items listed on the survey were positively rated. Items are presented in order of ranked percentage, providing a checklist identifying age-related HCT knowledge, skills, and behaviors (84%), written examples of HCT-related goals and interventions (79%), summary of federal or state guidance/rules regarding inclusion of health issues in Transition IEPs (70%), videos that raise awareness of health as a transition issue (66%), written materials that raise awareness of health as a transition issue (61%) and online materials that raise awareness of health as a transition issue (57%).

Barriers to the Inclusion of Health Care Transition

Respondents were asked to rate barriers to the inclusion of HCT in Transition IEPs. Items rated as a *Significant Barrier* to HCT by at least half of the respondents were lack of awareness of the HCT process (72%, n=124), lack of knowledge/information about HCT (64%, n=109), lack of funding (54%, n=87), lack of perceived mandate to include health issues (51%, n=88) and perception that health issues are a low priority for Transition IEPs (50%, n=85).

Items rated as a *Moderate Barriers* to HCT by about half the respondents were family does not perceive importance of including health issues (50%, n=84), lack of examples/tools (50%, n=83), student does not perceive importance of including health issues (51%, n=87), school does not perceive importance of including health issues (49%, n=83) and school district policy and procedures (48%). It is of importance to note that only 16% of respondents felt that school district policies and procedures were *Significant Barriers* to the Inclusion of HCT.

Discussion

Our research confirms that HCT is not typically addressed in Transition IEPs. This survey has provided information about why HCT is not included in Transition IEPs and possible strategies to increase awareness of HCT. These strategies fall into two main categories (a) a need for additional knowledge and awareness, and (b) systems change that incorporates and acts upon this new information. We will discuss each category in this section along with implications for practice.

Knowledge

The results of this survey highlight the significant need for additional information and training for school system personnel, agency representatives and students and families in order for them to recognize the importance of planning for HCT and integrating HCT-related goals and activities within Transition IEPs. This lack of knowledge about HCT was most clearly reflected in the respondents' observation that goals related to health and health care were less likely to be included in Transition IEPs than goals that were more directly related to future success in school or employment. Additionally, many of the barriers to including HCT in Transition IEPs were seen by respondents as being related to a need for additional information.

Information needs to be offered that both raises the awareness level about HCT and convinces stakeholders of its importance in educational planning. This might be done through videos, written materials, online materials and presentations. Information to be disseminated is not limited to, but should include, (a) health care legislation, (b) school and state policies, (c) implementation guidelines and examples, and (d) differences between the pediatric and adult-oriented health care systems. An example of this type of training can be found at the Florida Developmental Disabilities, Inc. (Reiss, Gibson, & Miller, 2005) online health care transition web based training program for families of adolescents with developmental disabilities. Since this is a relatively new area, it is important to monitor the level of information needed because the range of knowledge goes from "never heard of it" to "knowing a great deal." Therefore, some stakeholders need to be made aware of HCT while others may be ready to implement HCT practices (Loucks-Horsley, 2006).

Beyond a working knowledge of HCT, self-determination skills are crucial to success. Respondents identified families as important initiators of activities that support HCT, and families and students are seen as primarily responsible for prompting the inclusion of HCT in Transition IEPs. Fostering self-determination skills (Field & Hoffman, 1994; Field & Hoffman,

1999) in students and family members will help them to take a proactive role in HCT addressing related issues.

When examining the results of this survey, it is also important to consider the effect of the relatively few parents (n=4) who participated in the survey. Although it is not possible from this survey to know whom parents in general perceive as being responsible for facilitating HCT planning, their response to this question would help to confirm or counter the belief held by school personnel and agency representatives that parents are primarily responsible. Another reason for this expectation may be related to the lack of knowledge reported by school and agency representatives about HCT and their belief that parents may be more informed. It will be important to understand stakeholders' expectations about roles and responsibilities as attempts are made to increase the inclusion of such goals in Transition IEPs.

Systems change

In addition to a need for increased knowledge, the survey documented that interagency transition councils support the idea of including HCT goals and activities in Transition IEPs. Perceived rates of inclusion in Transition IEPs were inversely related to how often the respondents believe HCT should be included. The differences in these responses reflect the support and need for the inclusion of health related transition goals.

The results of this study also identified a possible resource to assist in increasing awareness of HCT and facilitating its-inclusion in Transition IEPs. Although health care providers such as pediatricians and CMS staff were generally seen as infrequent participants in Transition IEP meetings, school-based health personnel and therapists appear to participate in Transition IEP meetings quite often. While this study does not provide specific information on therapist's or school health personnel's awareness or knowledge of HCT planning, their training in health care, along with additional HCT information, could make them an excellent resource for HCT within the context of Transition IEP development.

Respondents specifically noted that school system policies and procedures are not perceived as a major barrier to the inclusion of HCT in Transition IEPs. Members of transition interagency councils judged it to be appropriate to integrate HCT into Transition IEPs but indicated a need for additional information, training and tools in order to be able to add this information.

In addition to providing professional development activities, school districts can promote the inclusion of HCT in Transition IEPs by specifically addressing the importance of health care knowledge and skills in district IEP policies and procedures. Such an inclusion would indicate district level support to address this important topic. Along with policy changes, state and/or district education agencies need to provide school personnel, parents and youth with materials that would make it easier to incorporate HCT-into Transition IEPs. Such materials might include examples of HCT related goals and interventions and a listing of age-related HCT knowledge, skills, and behaviors. These materials may be adaptations of current interventions and goals such as those in HCT curricula (See Hess, Aman-Brousseau, Pollard, & Sansosti, 2005; Florida Department of Education, 2004).

Implications for Practice

Addressing HCT requires the expansion of current transition practices and the inclusion of a new set of stakeholders in interagency planning. An initial step encouraging this expansion might be a series of working meetings where educational and health care practitioners, along with families, identify issues and needs. The first step in these meetings

would be to build a knowledge base covering educational transition and HCT. Once the issues and needs are identified, a three prong approach could be taken (a) school based curriculum can be developed and evaluated to address specific skills needed to support HCT, (b) guidelines can be developed and implemented covering the inclusion of medical information in Transition IEPs and curriculum (e.g., legal implications, sample goals), and (c) systems can be developed and implemented to include medical personal in the Transition IEP process. In May of 2006 the Florida Developmental Disabilities Council, Inc. sponsored a Health Care Transition Forum, a first in a series of working meetings to bring educators, health care practitioners and families together to work on this issue. During this first meeting, areas of focus for future meetings were identified including school based curriculum, communication between school and health care professionals, and training for educational and medical personnel. Responses from participants were very favorable and there was a willingness to work across disciplines. Throughout this meeting a need for research-based practice was apparent.

This forum also pointed out the many areas where additional information is needed. Further research is needed to identify best practices to support families and young people with their medical independence in school environments as a way to prepare transitioning youth for life in the community. It will also be important to understand ways to address health independence yet balance safety and liability issues. Effective practices should be documented, evaluated and shared. Additional research questions should identify what applicable skills and knowledge are needed to navigate the American health care system and what the responsibility of the American education system is in imparting this information. Other questions may include issues such as: (a) What are the implications for practice of a universal health care information portfolio for all graduating seniors with and without disabilities? (b) What aspects of health care transition training are applicable to healthy students? and (c) What are the health outcomes of this training?

Conclusion

This study should be viewed as an affirmation that HCT is an additional area to be addressed in the transition planning process. It can be anticipated that, with ongoing medical improvements and medical care, more and more students with health issues will need HCT. The good news is that respondents in our study expressed an interest in learning more about this important topic. This study has not addressed possible needs for additional time or resources to expand Transition IEPs to include HCT. It will be necessary to ascertain if the expansion of education based transition incurs additional expenses. If so, discussions will need to be held among policy makers, administrators, and educators to determine ways to allot necessary resources to this important student service.

For the Transition IEP to fully address the needs of young people with disabilities and SHCN, it is important to raise awareness of HCT and conduct further research to identify guidelines and best practices that incorporate health independence into the school environment. Although this study specifically addressed students with disabilities, what is learned in this area may also be useful and relevant for young people without disabilities.

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