Acceptability of a Parental Early Warning Tool for Parents of Infants

with Complex Congenital Heart Disease: A Qualitative Feasibility

Study

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Acceptability of a parental early warning tool

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Abstract

Aim To explore the acceptability and feasibility of a parental early warning tool, called the Congenital Heart Assessment Tool (CHAT), for parents going home with their infant between first and second stage of surgery for complex congenital heart disease.

Background Home monitoring programmes were developed to aid early recognition of deterioration in fragile infants between first and second surgical stage. However, this necessitates good discharge preparation to enable parents to develop appropriate knowledge and understanding of signs of deterioration to look for and who to contact.

Design This was a longitudinal qualitative feasibility study, within a constructivist paradigm. Parents were taught how to use the CHAT before taking their infant home and asked to participate in semi-structured interviews at four timepoints: before discharge [T0]; two weeks after discharge [T1], eight weeks after discharge [T2] and after stage two surgery [T3]. Interviews were transcribed verbatim and thematically analysed.

Setting One tertiary children's cardiac centre in the UK

Subjects Twelve parents of eight infants who were discharged following first stage cardiac surgery for complex congenital heart disease, between August 2013 and February 2015

Results: Four main themes emerged: 1) parental preparation and vigilance; 2) usability; 3) mastery; 4) reassurance and support.

Conclusions: The study highlighted the benefit of appropriately preparing parents before discharge, using the CHAT, to enable identification of normal infant behaviour and to detect signs of clinical deterioration. The study also demonstrated the importance of providing parents with information about when and who to call for management advice and support.

Introduction

In the UK, congenital heart disease (CHD) occurs in approximately 6 per 1,000 births¹.

About half of the 5,000 babies born with CHD every year in the UK, have life-

threatening conditions requiring surgery and life-long follow-up². Improvements in

surgical, medical and nursing care have resulted in a significant increase in survival

rates over recent years³; however, the first year of life remains a critical time for infants

with complex CHD¹ with mortality after discharge estimated to be 3-5%⁴. To reduce

inter-stage mortality, home monitoring programmes have been implemented in many

centres⁵⁻⁹, however, effective assessment of the infant by parents is necessary. This is only achievable if parents fully understand their infant's CHD and the signs of deterioration to look out for¹⁰⁻¹²; are adequately prepared prior to discharge for their transition from hospital to home^{10,13} and know who to contact for appropriate advice and support^{4,10,12}. In response to this need, an early warning tool, the Congenital Heart Assessment Tool (CHAT)¹⁰, was developed using the principles of paediatric early warning scores (PEWS)¹⁴⁻¹⁶ in 2012 by a group of clinicians, parents and CHD charity members.

The CHAT, based on a traffic light system is divided into three columns: green (low risk), amber (intermediate risk) and red (high risk) and can be individualised by including the Consultant's preferred parameters (e.g. oxygen saturations). Parents are taught to assess their infant's activity level, skin colour, breathing, circulation, feeding and weight and to decide actions based on the information in each of the three columns (See Table 1). A CHAT assessment of *green* indicates that parents can 'carry on as normal'; any sign in *amber* triggers a phone call to the ward to discuss management; any sign in the *red* column indicates the infant is seriously ill and parents are advised to **phone for an ambulance (call 999) immediately¹⁰.**

Congenital Heart Assessment Tool Parent's Traffic Light System					
	Green – Iow risk	Amber – Intermediate	Red- High Risk		
		Risk A –if any of these signs are present ring for advice from Ward (name ward) If in doubt call 999	R – if any of these signs are present call for an ambulance on 999		
Baby's Skin Colour	Your baby's usual colour of skin, tongue, especially lips and nails	Bluer or paler than usual, or mottled	Very pale/bluer, very mottled		
Baby's Activity	Behaves normally e.g. Content/smiles Stays awake or awakens quickly (as normal) Normal crying easily resolved by e.g. feeding, comfort, nappy change etc	Quieter than normal, not feeding as normal Sleeping more than normal Responding less during normal activity Slightly irritable	Not responding to normal activity Does not wake or if roused does not stay awake Weak, high-pitched or continuous cry or no crying at all		
Baby's breathing	Usual breathing (rate, rhythm and effort) for your baby	More breathless, faster rate, working harder to breath, noisier breathing than normal Sucking in skin below ribs more than normal Nasal flaring Oxygen saturation range (add individual details)	Very breathless Struggling to breath Exhausted Very noisy breathing (Grunting) Very fast breathing or very slow breathing severe 'sucking in skin' below ribs		
Baby's circulation	Your baby's usual colour and warmth of hands and feet	More sweaty or clammy than usual Cooler hands and feet than usual and not 'pinking back up' Eyes, hand, feet and/or tummy puffier/more swollen than normal	Very cold, sweaty or clammy hands and feet Unresponsive Very puffy/ very swollen eyes, hands, feet or tummy		
Baby's Feeding	Baby feeding normally and regularly wet nappies Discharge feeding regime: (add details)	Any diarrhoea or vomiting Vomit after medications Poor feeding or struggling to feed (e.g. reduced time on breast) Not keeping feeds	Completely off feeds – not feeding at all Dry nappies Very sunken 'soft spot'		

Table 1 Congenital Heart Assessment Tool (CHAT)

		down Nappies less wet than normal More constipated than normal or change from normal bowel movements Slightly sunken 'soft spot'	
Other	None of the amber or red signs. Baby is following their own 'normal' growth line	Weight – increased or decreased Add in individualised weight range	Significant weight increase or decrease, outside weight range given
Parent Response	Good Carry on as usual	Having seen changes in your baby's condition you must now ring Ward (Name ward) Phone number: to discuss these signs and what to do next	Your baby is seriously ill phone an ambulance (999) immediately

A traffic light system for parents to use at home, when assessing their infant's clinical condition, following first stage cardiac surgery for functionally univentricular heart or systemic shunt dependent lesion. Reprinted with permission¹⁰

Parent preparation before discharge ensures understanding of how to assess their infant daily or at any other time if their infant's condition had changed¹⁰, interpret the significance of the signs by using the CHAT; and record findings in a diary. Findings about the number of daily CHAT recordings, how warning signs were presented and the acceptability and feasibility of the CHAT for parents are presented in this manuscript.

Design

This longitudinal study was part of a mixed methods feasibility study¹⁰.A dialectical perspective¹⁷, in which both qualitative and quantitative data collection methods work

together, was the best stance due to the underpinning epistemological assumptions of the study (interpretivism, constructivism and positivism), guiding each of the integral components. However, the interpretivist and constructivist paradigms were the dominant assumptions. Constructivist theory implies that humans try to make sense of the world that they are in; therefore, constructivism within the study explored the way parents independently made sense of their situations. Conversely, constructionism is socially constructed and considered the impact of culture and parents' social worlds (including the 'world' of being a parent of an infant with CHD) on the way they created and conveyed meaning¹⁸.

The study was undertaken at one UK specialist children's cardiac centre. Ethical approval was obtained from the National Research Ethics Committee West Midlands and Coventry University.

Sampling strategy

Parents were eligible to participate if their infant had undergone the first stage of cardiac surgery for complex CHD [functionally univentricular heart and systemic shunt dependent lesions] during the recruitment timeframe (August 2013 until February 2015); if they could read and understand English and could give informed consent. Screening was undertaken by the research nurse (RN) in association with the clinical team daily (table 2). Eligible parents received an invitation letter and a Participant Information Leaflet and were given a minimum of 24 hours to consider their participation, before written consent was obtained.

Table 2 Screening and recruitment

Screening	Numb	er	
Screened: infants had complex surgery during the recruitment phase	80		
Deceased: post operatively; before discharge planning took place	14		
Ineligible: poor English requiring translation; or not discharged between	19		
the two surgeries			
Refused: lived too far away; 'too much going on'; child fostered; other	15		
social issues			
Missed: missed during study suspension*; missed as discharged over	19		
the weekend			
Recruited:	13	(46.4%	of
	familie	S	
	approa	ached)	

*Due to staffing issues the study had to be suspended for 3months

Data collection, processing and analysis

Parents were randomised, using computer generated randomisation, to one of three groups after consent was obtained. Group A parents were asked to measure and document their infant's oxygen saturations (Sp02) and weight daily, assess their infants using the CHAT tool and document this in their daily diary. Group B parents were asked to use the CHAT daily and document; and Group C parents had standard discharge care, without the equipment or CHAT. Unique identifier numbers ensured anonymity. Baseline birth and medical information (table 3) and parental demographics (table 4) were collected by the RN. Semi-structured interviews were conducted by the first author

with parents in all three groups, at four timepoints: before discharge (T0); two weeks after discharge (T1); eight weeks after discharge (T2) and after stage two surgery (T3). Interviews at T0 were conducted face to face, to establish rapport with the family, subsequent interviews were conducted over the telephone. Couples were offered the opportunity to be interviewed either together or individually; T0 interviews were conducted individually for two couples, due to one father's work commitments and one father declining further interviews.

Time of Diagnosis	Number of responses (n=8)
Antenatal	8 (100%)
Female	6 (75%)
Male	2 (25%)
Gestation (weeks)	
<37 weeks	2 (25%)
>37 weeks	6 (75%)
Birth weight (Kg)	
<3Kg	4 (50%)
3.1-3.5Kg	3 (37.5%)
4.1-4.5Kg	1 (12.5%)
Diagnosis	
Hypoplastic Left Heart Syndrome	6 (75%)
Functionally univentricular heart	1 (12.5%)
Tetralogy of Fallot	1 (12.5%)
Other non-cardiac defects	3 (37.5%)
Genetic abnormality	2 (25%)
Specialist Hospital Admission Route	
Retrieval team	8 (100%)
Pre-operative management	
Mechanical ventilation	5 (62.5%)
Prostaglandin infusion	8 (100%)
Inotropic support	4 (50%)
Treated acidosis	5 (62.5%)

Table 3 Infant's Birth and Medical Information (Groups A and B)

Table 4 Parents' Demographics

Parent Demographics at time of surgery (Groups A and B)		
Parent's Age <21 21-25 26-30 31-40	Mother (n=7) 1 1 2 3	Father (not available)
Employment Employed for wages Self-employed A homemaker Maternity/paternity leave	Mother 0 1 7 0	Father 5 1 1 1
Deprivation Index Score** 0-5,000 (highest deprivation - top 20%) 5,000 – 10,000 10,000-15,000 20,000-25,000 (lowest deprivation – lowest 20%)	3 1 3 1	
Distance from Specialist Cardiac Hospital <20 miles 20-30 miles 30-40 miles 50-100 miles >100 miles	(n=8) 2 1 2 2 2 1	
<u>Ethnicity</u> White – British White - European Black or Black British British Asian	Mother 6 0 2 0	Father 4 1 2 1

**The postcode deprivation index (index of multiple deprivation) was calculated online in 2013; where a score of 1 was the most highly deprived area. This provided information about possible

socioeconomic factors that might have impacted on the parents' experience.

An interview schedule (table 5) guided discovery of parents' experiences whilst allowing free description, follow up questions and probes. Interviews were audio recorded and

transcribed verbatim. The Principal Investigator used the six phased thematic approach of Braun & Clarke¹⁹ to analyse the data. The analysis was subsequently reviewed by the research team and any disagreements resolved by consensus. QRS NVivo10 software was used for data management.

Table 5 Interview questions

Parents were asked a range of questions at each time point relating to their experience of being in the study and using the CHAT tool. Please can you tell me how you feel about being involved in the project? Do you have any particular concerns or worries about being in the project? Can you describe the preparation you had before discharge? Did you feel adequately prepared for going home? Can you tell me what you were told about the CHAT tool? How did you feel about using it? Can you describe your experience of using the CHAT tool? (Prompts included asking how they used it, when, why, how they felt) Thinking back to when you first went home, is there anything that you now think you should have been told but were not told? How do you feel about recognising clinical deterioration in your baby using CHAT Any other comments?

Criteria were employed to address trustworthiness²⁰ including triangulation with other data collected in the feasibility study; maintaining an audit trail; keeping field notes and reflective notes. Only staff at the study centre had access to additional personal data. The PI only had access to parents' first names and telephone numbers. Data were retained in accordance with Coventry University's policy on Academic Integrity.

Findings

Eighty infants were screened during the recruitment period, of whom 47 were eligible for participation (Table 2) with parents of 13 infants recruited (Group A =5; Group B = 4, Group C=4). Parents of 8 infants (8 mothers, 4 fathers) from Groups A (n=4) and B (n=4) took part in the interviews and were asked about the CHAT. Other interview findings are presented elsewhere²¹. The data set reported here included 22 interviews, lasting from 9.49 - 59.29 minutes, totaling 486.44 hours. Not all parents completed all four interviews due to their infant being readmitted to hospital, not being contactable, or not returning calls. The time from discharge to readmission (T0 to T3) varied amongst participants, ranging from 62-228 days (median = 151; mean = 145.6; S.D. = 61.6), but all infants survived the first two stages of surgery.

CHAT Recordings:

Six families documented the CHAT measurements in their daily diary (see Table 6). None of the families recorded their CHAT assessment every day, because of *'increasing confidence over time'*, *'being too busy with their infant's normal care'* and *'feeling burdened'*.

Group	Green (days)	Amber (days)	Red (days)	Time between stage 1 & 2 surgery (days)	Time at home (days)	Total diary entries (days)	Interview completion
A (1)	30	0	1	32	31	31(100%)	Mother T0, T1, T3
A (2)	13	1	0	197	174	14 (8%)	Mother all Father T1
A (3)	53	0	0	251	200	53 (26.5%)	Mother all Father all
A (4)	0	0	0	154		0	Mother T1, T3
B (1)	40	2	0	136	123	42 (34%)	Mother all Father all
B (2)	14	1	0	190	164	15 (9%)	Mother T0, T1, T2
B (3)	84	3	0	120	102	87 (85%)	Mother all Father all
B (4)	0	0	0	93		0	Mother T1

<u>Table 6</u> Number of daily measurements recorded in the daily diary and interview completion (Groups A, B)

Ward staff were asked to document calls from parents during the study, information was not recorded for all CHAT triggers in the ward documentation but was available in interview transcripts (see Table 7).

Table 7 CHAT Triggers (Group A, B) and Recorded Contact with Health Care

Professionals (Group A, B, C)

Participant	Number of contacts made	Contact with	Reason	Advice	Outcome		
A (1)	1	Phoned 999	Triggered red on CHAT, struggling to breath	Admitted to local hospital	Discharged the next day		
		OPA SpO2 dropp	PA SpO2 dropped admitted to the ward and kept in until stage 2				
A (2)	1	Ward	Vomiting and sticky eyes	Bathe eyes and observe feeding Attend GP	GP no medication given, advised to clean with sterile water		
		Admitted to ward	following MRI, Disc	charged			
A (3)	1	Ward	Advice re NGT (documented in interview transcript, not CHAT diary)	Not documented	Not documented		
A (4)	0	0	0	0	0		
В (1)	3	Routine OPA	Triggered amber on CHAT but was booked for OPA that day anyway	Seen by Dr	No medical concerns		
			than normal and pale				
		Went to GP	Amber trigger on CHAT	Seen by GP	No medical concerns		
			Subcostal recession				
		Routine OPA for ECHO	Amber trigger on CHAT but booked in for OPA anyway	Seen by Dr	No medical concerns		

			less, sleeping more			
		Planned admission for cardiac catheterisation, kept in for Stage 2				
B (2)	1	Ward	Amber triggered Nappy	Not documented	Not documented	
B (3)	3	Ward	Amber trigger on CHAT	Contact GP if worsens		
			Sunken fontanelle			
		Ward	Amber triggered on a few things	Contact local hospital	Admitted to local hospital	
			Increased respiratory effort, feeding reduced		overnight	
		Took straight to local A & E	Didn't use CHAT	Kept in overnight		
			Bronchiolitis			
B (4)	No information rec	corded in daily diary and only pre-discharge interview				
C (1)	0					
C (2)	4	2x Ward	Called for advice	Not documented		
			(interview transcript)			
		Attended local PAU	Vomiting	Observation on unit for 8 hours	discharged	
		Called 999	Choking, sick, blue	ED for 2 hours	Discharged home	
C (3)	Was not discharge	d home				
C (4)	1	Ward	Called for advice (interview transcript)	Not documented		

Interviews:

Four themes emerged from the interviews: 1) parental preparation and vigilance; 2) usability; 3) mastery; 4) reassurance and support.

1) Parental preparation and vigilance

Before discharge all parents perceived that being taught how to use the CHAT helped them to prepare for going home and to be vigilant; one father said it has "given us the main tools to survive with; if something happens I'll know what I need to do". Another parent (mother) said: "I feel good, because I know, because I'm with [infant] everyday, [have been looking at the CHAT everyday whilst in hospital] I know when [infant]'s poorly, I know when [infant]'s in green, when [infant]'s in amber and when to call 999". Another mother commented "it's good [CHAT] it's prepared us a lot for things that we wouldn't have been prepared for if we weren't in the programme".

Some parents felt that the CHAT gave them the confidence to make the right decision "If we didn't have it [CHAT] we'd have to be making our own judgement [it] could probably not be the right one". At T1, all but one of the parents felt that they were well prepared and that they were gaining confidence in recognising signs of deterioration by using the CHAT. One mother said "I'm not very confident with it but ... [RN] said she'd just go through what I'd done and make sure I'm on track". Conversely, another mother said that "It's really helpful because it tells you what to look for in green, amber and red. If I didn't have the CHAT to look at when [infant] was poorly the other night, I would have gone running straight into hospital; I wouldn't have known what to tell the doctor when I phoned up [the CHAT triggered Amber]. It's really helpful. It's helping me to describe what I'm seeing"

2) Usability

After discharge, most parents began to perceive an increase in confidence in terms of recognising what were normal signs for their infant. One mother explained "*it* [CHAT] is easy to use but I'll be honest I don't use it every day sometimes I forget, but if there's a problem with her it's the first thing I pick up, I don't really use it when everything's fine anyway".

In addition to feeling that they were well prepared for discharge, most parents' comments at T1, focused on the ease of using the CHAT at home. One father said "*I* enjoy the CHAT and *I* enjoy the diary thing, *I* think that's very good and *I'm* really appreciative of it because it does put you at ease knowing that you've got everything written in the diary as well". Another father explained "it's pretty straightforward with what signs you've got to look for and you know what to do if you see the signs so, yeah, it's pretty helpful". Conversely his wife described feeling unsure of how to use the CHAT (quote above),but was overwhelmed with the transition of going home and had arranged to receive further training from the RN at the outpatient's appointment the following week. At the final interview this mother evaluated the CHAT saying: "Reading through the coloured chart helped me to decide whether to get help or not, so I did find it useful from that point of view. There were just a couple of times that I phoned through. Having that to refer to just to double check things, it did help. [The CHAT] was easy enough to use, I wouldn't say there was anything to change. It seemed to work".

3) Mastery

All parents used the CHAT daily when they were first discharged, to assess their infant. However, over time some parents gained mastery in terms of knowing what was normal for their infant and recognising when something was different. At this point these parents stopped using the CHAT and recording daily and began using it only when something changed. For example, one mother explained: "we did [use the CHAT] when we first came out because we were nervous and we needed it to help usnow we feel confident enough that we know the signs to check for and the traffic light system ourselves and kind of know where it would be in the book". One mother explained how (at T2) the tool was just there to 'give them a boost'. They felt that the tool was a 'really big help' when they were first discharged and because they used the CHAT daily at the start they felt reassured that they were doing the right things "but now it's made us more confident because we've had that chart to start off with and to reassure us if we were doing the right thing or not".

Conversely, for some parents, continuing daily assessment helped them to feel more confident throughout their time at home with their infant, as this quote (at T2) demonstrates: *"I go through it every day and check [infant] against it. I think it helps me to pinpoint what's right and wrong. It definitely makes me [feel more confident] if I didn't have it as a backup I'd be panicking about everything and I'd be constantly ringing the hospital."*

4) Reassurance and support

Parents also described how the CHAT had reassured them to articulate their concerns at the appropriate time and to the appropriate person. One father said "*you look at her and you go through all of them CHATs and you go right ok yes, if I have any worries I go to amber and then you can ring somebody up to talk to somebody*".

Being able to talk to the specialist team directly for an amber trigger reduced pressure on parents, reducing the need to provide an explanation of their infant's cardiac condition to someone that did not understand. Parents perceived this as a positive aspect of support. One mother said: *"it does give you a lot of reassurance, obviously being able to phone the ward when it is in an amber state, having them reassure you and tell you what to do, it's very helpful. Because obviously if that's the case like an amber alert I would normally phone 111 the NHS service and then you'd have to explain what the condition is and not having to go through all of that, it again alleviates some of the pressure".*

Discussion

This study reports on the feasibility of the CHAT, which we believe is the first tool to be developed specifically for parents of fragile babies going home with their infant after the first stage of complex cardiac surgery. The main finding was a parental perception that early assessment of their infant was feasible using the CHAT, despite parents not documenting the results for the whole of their stay at home between stage 1 and 2 of

surgery. The CHAT was described as useful in preparing them for discharge; easy to use at home and reassuring. None of the parents gave any negative comments about the CHAT. Parents also perceived that the CHAT had increased their confidence in looking after their infant at home. Several families described how they felt informed by learning how to use the CHAT before discharge. Additionally, following an amber or red trigger of CHAT, parents felt able to make early decisions regarding accessing advice and treatment and articulating their concerns to health care professionals. These findings suggest that parents benefited from a greater understanding of their infant's condition before going home, by being taught signs of deterioration to look out for using the CHAT; being given a checklist and a formalised route to seek professional help. Parents also commented on the fact that their increasing confidence meant that they knew what was normal (green) and no longer needed to use the CHAT on a daily basis, but had the tool available to refer to if their infant's signs changed.

The CHAT was developed to enhance communication, using the principles of a traffic light system²⁶ and meeting the recommendations of other studies^{4,22-25}. The CHAT has contributed to practice by creating an effective discharge information and preparation tool to ensure that parents have the appropriate knowledge, understanding and skills to care for their fragile infant at home. However, mechanisms for sharing information with professionals outside the tertiary centre need improving²⁷ primary care and local community teams need individualised information, with expected clinical parameters, upon which to make decisions. Parental dissatisfaction with the information that they receive has been previously identified,²²⁻²⁵ indicating the need for standardised and

structured handover documentation to reduce the deficits in communication and information transfer at discharge⁴. Furthermore, for discharge preparation to be successful, professionals working within the *congenital heart network*²⁸, need appropriate skills and knowledge about complex CHD to teach parents about their infant's condition and how to spot signs of deterioration. This study also found that professionals need to be more effective at documenting telephone calls with families and the advice given, to ensure effective ongoing management of parents' concerns and their infant's condition.

An important issue preventing participation in the study was parents' psychological functioning. Some particularly anxious parents expressed feeling emotionally unable to take part; professionals need to consider the psychological impact of having a fragile infant and the affect on understanding during discharge preparation and vigilance at home. Another factor impacting on recruitment was the limited understanding of written and spoken English language for some parents. Ethnicity has previously been linked to adverse outcomes for infants with CHD²⁹. However, a more recent UK study⁴ found that the group labelled 'other' (including Far East, Middle East and North Africa) were at greater risk, perhaps reflecting contemporary migration changes. Future studies need to consider the varied population and language requirements of parents whose infants require cardiac surgery in the UK and address the cultural and language implications of translating the tool into other languages.

Conclusion

This study demonstrated that the CHAT was accessible and feasible for this group of parents. It enhanced discharge education by enabling greater confidence in knowing the signs of deterioration to look for, whilst reassuring and supporting them in contacting the relevant specialist team for advice. Further evaluation of the CHAT and its effectiveness is currently underway with a larger sample. A nationally standardised discharge package, including CHAT for parents of infants with a functionally univentricular heart, is currently being developed in the UK. Furthermore, the CHAT could be beneficial for local and community teams, who may have limited expertise in neonatal cardiac surgery and require guidance regarding specialist advice.

What is already known on this topic:

- Infants requiring complex cardiac surgery in the early neonatal period are vulnerable to sudden deterioration between the first and second stage of surgery
- Formal home monitoring of oxygen saturations and weight can help identify 'at risk' infants, however availability of home monitoring programmes is variable across the UK
- It is essential that parents can recognise signs of deterioration promptly to initiate timely decisions and early intervention by specialist health care professionals

What this study adds

• Use of a structured assessment tool, including assessment of their infant's activity and behaviour, can assist parents to identify signs of deterioration

- Pre-discharge preparation using a traffic light system can assist parents to gain confidence in their ability to assess their infant for signs of deterioration
- A structured tool can empower parents to clearly articulate their infant's needs and their concerns in a timely manner to the appropriate health care professionals

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