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New ways of seeing and being: Evaluating an acceptance and mindfulness group for parents of young people with intellectual disabilities who display challenging behaviour.

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Abstract

The current study presents findings from an acceptance and commitment therapy based intervention for family carers of children who have an intellectual / developmental disability and display high levels of challenging behaviour. The Parent Wellbeing Workshops consist of 2 workshops incorporating acceptance and mindfulness based exercises and discussions. Semi-structured interviews were conducted with five family carers following attendance of the workshops. Participants found the workshops useful and reported that they were better able to cope with stress. They also described how they had incorporated mindfulness into their daily lives and how their practice had had positive effects on their own wellbeing and on those around them (e.g. their child). Implications of the findings are discussed with emphasis on how the workshops can be included within a Positive Behaviour Support framework. Future directions include a more robust quantitative evaluation, inclusion of follow up sessions, and the application of the workshops with other client groups and in other delivery formats.

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Introduction

Children and young people with intellectual / developmental disabilities are at increased risk of displaying behaviours that challenge (Emerson & Einfeld, 2010; Totsika et al. 2011a; Totsika et al. 2011b). These behaviours are known to have a negative impact on the wellbeing and quality of life of the individual (Allen, Hawkins & Cooper, 2006; Emerson & Einfeld 2011) but also on those who provide care and support. In particular, family carers are often found to experience stress and other emotional difficulties (Baker et al. 2003; Hastings, 2002).

The emotional wellbeing of family carers may be a critical factor in determining the success and implementation of interventions designed to support children who present with behaviour that challenges (e.g. Singh et al., 2014) and in preventing family breakdown. Mental health and emotional support for carers is increasingly recognised within the scope of Positive Behavioural Support (PBS; Gore et al, 2013; LGA & NHS England, 2014) as a model of best practice.

In recent years an emerging body of literature has suggested that mindfulness and acceptance based approaches may offer an effective way for family carers to cope or remain resilient when raising a child with complex needs. Jon Kabat-Zinn defines Mindfulness as “paying attention in a particular way: on purpose, in the present moment, and non-judgementally” (Kabat-Zinn, 1994). Both traits of mindfulness and acceptance have been found to mediate emotional wellbeing for family carers (Beer, Ward, & Moar, 2013; Lloyd, & Hastings, 2008). A variety of mindfulness-based interventions have been found to help reduce emotional difficulties for parents who have children with intellectual / developmental disabilities (e.g. Benn, Akiva, Arel, & Roeser, 2012; Ferraioli & Harris, 2013; Minor, Carlson, MacKenzie, Zernicke, & Jones, 2008; Neece, 2014) and without (e.g. Coatsworth, Duncan, Greenberg, & Nix, 2010; Duncan & Bardacke, 2010; Murrell & Scherbarth. 2006).

In the current study we provide a qualitative analysis of parent interviews that followed the piloting of a brief wellbeing intervention for parents who had a child with intellectual disability who displayed high rates of behaviour that challenges. The intervention was based on Acceptance Commitment Therapy (ACT – Hayes, Strosahl, & Wilson, 1999); a third-wave cognitive-behavioural model that includes mindfulness exercises alongside a variety of other components (i.e., cognitive diffusion, willingness, values-led behaviour change). A study by Blackledge and Hayes (2006) reported positive outcomes for parents of children with Autism who completed a 10 week ACT programme, and brief, workshop-based ACT interventions have been demonstrated to improve emotional wellbeing for paid carers who support people with behaviour that challenges (Noone & Hastings, 2011; Smith & Gore, 2012).

Despite evidence to support use of mindfulness and acceptance approaches with family carers there have been very few attempts to capture the experience of group members via a qualitative approach, In the only known example of using such an approach, Duncan, Coatsworth, and Greenberg (2009) used a focus group to evaluate the experiences of participants following attendance of a parenting program that had been adapted to include mindfulness based content. Participants reported positive changes in their parenting style and wellbeing, as well as positive

experiences of the program. There are, however, no known studies that have used a qualitative approach specifically within the field of intellectual/developmental disabilities. The experiential nature of mindfulness and acceptance approaches would suggest, however, that first-hand accounts via interview may be a particularly valuable way of investigating in greater detail how parents draw upon discussions and exercises and use these within their everyday lives. The present study therefore aims to evaluate an ACT based intervention for family carers of children with an intellectual / developmental disability using qualitative approach.

Methodology

Service

The Parent Wellbeing Workshops were run within the Intensive Therapeutic and Short Break Service (ITSBS) which has been described in detail in an earlier publication (Reid, Sholl, & Gore, 2013). The service aims to provide intensive support to children who are at risk of requiring a residential school as a result of behaviour that challenges. The ITSBS service model involves providing a 3-week short break to the child (either in a designated short break service or in their own home) which allows the family some restorative time and an opportunity to access therapeutic support and training which may have otherwise been difficult to attend. Whilst the child is receiving their short break, their behaviour is observed and assessed in order to devise an intervention plan and provide appropriate support. A PBS plan is then formulated in consultation with the child's family, support workers, and other stakeholders. The plan is implemented within the short break service and the family are trained and supported to continue the plan following the child's return home. At the same time, the family is offered support within a systemic framework in order to strengthen the family system and resolve any difficulties. This support can include one-to-one therapy sessions, family therapy, support for siblings, or group support. The Parent Wellbeing Workshops are offered as part of their systemic support to families.

Participants

Nine family carers whose child was currently receiving or had recently received support from the ITSBS were invited to attend the parent wellbeing workshops. Of these, seven family carers attended the workshops. Family carers were verbally informed of the evaluation by the first author and invited for interview following the workshops. Written consent was gained from five family carers to be interviewed. The interview was audio recorded.

All participants were female; two were married and the remainder were single parents. Three participants were of Asian ethnicity, one was white British, and one was mixed race. Three participants had more than one child, whilst for two the focal child was their only child.

The five focal children were aged between 9 and 14 years and all had an Autism Spectrum Disorder, a severe learning disability, and displayed challenging behaviour. Before input from the ITSBS, all of the children were at risk of placement in a residential school due to the severity of their challenging behaviour. At the time

of the interviews, four of the five children were placed in local special schools and all of the children were living at home with their families.

Intervention

The Parent Wellbeing Workshops were based on Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 1999) and consisted of two four-hour workshops held one week apart. They were facilitated by the first and third author and were held at the ITSBS. The workshops were structured around five key concepts of Acceptance and Commitment Therapy and used metaphors taken from the literature to illustrate each concept (as described by Smith & Gore, 2012). The five concepts were i) stress is normal, ii) how we use language and thoughts to problem solve, iii) the downside to living in our thoughts, iv) alternatives to living in our thoughts and v) being led by our values not by our thoughts. The workshops included a range of exercises and discussions surrounding these concepts which were designed to allow participants to experience mindfulness practice and consider ways to incorporate the practice into their lives.

Ethical Considerations

The project was categorised as a service evaluation by West London Mental Health NHS Trust. All participants gave informed consent before taking part in the evaluation and were aware that they could withdraw from the evaluation at any time. They were assured that both they and their child would remain anonymous and they gave consent to the results being written up for publication.

Interview Schedule

The first and second author collaborated to devise a semi-structured interview schedule for use in the evaluation. The schedule was designed to be open-ended and flexible in order to allow the interviewer to adapt the structure and order of the questions as necessary. The interview schedule contained questions about the following areas:

1. General information about whether the participant had attended any similar workshops before and whether they attended both of the sessions
2. What their experience and emotional wellbeing was before the workshops
3. Their experiences of the parent wellbeing workshops
4. Recommendations for future workshops

The interviews were conducted as soon as possible after the final workshop in order to capture participants' immediate experience of the workshops. They took place in a clinic setting and lasted a maximum of an hour and a half (the actual duration was variable due to the flexible nature of the interview). The interviews were conducted by the second author and recorded in order to aid transcription.

Analysis

Following transcription, a thematic analysis was conducted based on the six steps described by Braun and Clarke (2006) and corresponding with Boyatzis (1998).

Thematic analysis allows flexibility in data analysis and is able to provide a detailed account of a complex phenomenon (Braun & Clarke, 2006). It is also said to be of most use in the early stages of the research inquiry process, which is suitable for the current study (Boyatzis, 1998).

The first three authors independently read the transcripts and highlighted ideas and significant comments. They then met to elicit broad themes which reflected a consensus of the highlighted areas of the transcripts. The third author then extracted a potential set of themes based on these discussions which were verified by the first and second authors by re-reviewing all transcripts, identifying supporting quotes, and ensuring these were representative of the sample.

Results

Parents expressed a wide range of views about their experience of the mindfulness group and how this influenced several key aspects of their lives. The analysis yielded six central themes and several sub-themes (see Table 1).

Table 1: Overview of themes and sub-themes

| Themes | Sub-Themes |
|---------------------------------|--|
| 1. It mounts up/crunch point | |
| 2. Sweeping it under the carpet | <i>Avoidance-led strategies</i> |
| 3. A unique group | <i>Where do I fit?</i> |
| 4. New ways of seeing and being | <i>All in the same boat</i> |
| 5. Positive changes | <i>A different kind of support</i> |
| 6. Looking to the future | <i>A different perspective</i> |
| | <i>Making mindfulness my own</i> |
| | <i>Back on an even keel</i> |
| | <i>Values-led changes</i> |
| | <i>New ways of responding to same old situations</i> |
| | <i>Changes for others</i> |
| | <i>Personal practice</i> |

Theme 1: It Mounts Up/Crunch point

A narrative emerged about the struggles parents were facing prior to the group, which was characterised by the emotional and physical strain of caring for a child with significant behavioural challenges, and the level of isolation they experienced as a consequence. There was a sense that the situation for these parents had come to a head, or a *crunch point*, before taking part in the group.

Most of the parents talked about feeling isolated with the difficulties they experienced:

I had to literally have my house windows taken out ... just because of how he was and like I don't think people that don't have those kind of problems they don't understand. (P3)

Parents unanimously referred to the significant detrimental impact their situation was having on their emotional wellbeing:

...there were times before I used to get very down about it ... kind of being like a yo-yo, been through stages where I've been quite low. (P4)

My nerves were shot to pieces...it comes out in physical form. Terrible back ache, headache, not sleeping so I know I was very stressed out. (P5)

One parent captured the all-consuming nature of being the parent of a child with a significant learning disability who displays behaviour that challenges and the knock-on effect this brings to other areas of life:

like I've not got enough time to do anything like just to catch up on myself and you know the housework. Everything with him takes up a lot of time and anything that I can do when he's not there I've only got a small window to do it in and it mounts up.' (P5)

Theme 2: Sweeping it under the carpet

Parents reported a range of previous support and coping strategies: whilst a small number of the parents were engaging in constructive forms of support (e.g. counselling, yoga), the majority recognised that they were struggling to cope.

Avoidance-led strategies

The majority of parents had strove to *get on with it* and where possible avoid acknowledging difficult emotions:

... just to get on with it and sweep the reality of how difficult it is kind of under the carpet.... (P2)

I kind of just tend to get on with stuff I think I was just kind of blotting a lot of it out just working on autopilot. (P5)

Where do I fit?

Parents unanimously talked about a sense of not belonging; feeling ostracised by other parents due to their child's level of need or behaviour. This tended to leave parents feeling unable to speak out about their difficulties in a group, and reluctant to make use of the support:

You just feel like you're isolated. (P3)

I've been to meetings before where there's parents and it really didn't help me much. (P3)

There was a general consensus that previous outlets of support had often not worked but uncertainty about what an alternative might be:

I suppose in the back of my mind I'm always hoping there's a miracle somewhere that will solve all these problems and make it a bit easier on us. (P5)

Theme 3: A unique group

On reflection of previous experiences of support, parents emphasised the unique nature of the current group; placing a high value on meeting others in similar

situations. There was also a mix of prior exposure to mindfulness ideas, which influenced parents' expectations of the group.

All in the same boat

An important experience raised by all parents was the realisation that they were not alone, and that others shared similar experiences to them. This enabled a sense of cohesion to develop between group members:

I didn't feel alone ... we could just be ourselves.' (P2)

... you meet these people and you realise that "right they are also in the same boat". (P1)

... they're on the same page as you in a way because other people don't get it. (P3)

Meeting other parents with similar experiences also provided a story of resilience, allowing the parents to further develop a sense of hope:

In some ways it really gives you a lot of strength to know that there are others who are coping with this ... they're able to survive this so it really makes you feel strong like you can do that too. (P1)

[Hearing] stories that they told and the strength and they've never given up. (P2)

A different kind of support

The parents reflected on the nature of the group being unlike their previous experiences of support:

I thought it sounded really good that it was focusing on the parent. (P4)

One parent described how their experience of the group challenged their expectations of what a therapeutic group entails:

I didn't expect it to be like that I just thought it would just be somebody telling us how to look after ourselves. (P4)

Unlike previous groups, the parents' shared experiences enabled them to talk about previously hidden aspects of their parenting roles:

We could actually talk about the fact that some of our kids hit and punch ... we usually can't talk about [these things] anywhere else.' (P1)

Mixed assumptions and prior experiences of mindfulness were highlighted: a small number had prior interest in using mindfulness techniques, however, several talked about being sceptical about the *new* approach:

make us just sitting around in a circle and make us do meditation and tell us other ways to do it but it was very different. (P1)

I was a bit cynical about it but it really did work. (P3)

Theme 4: New ways of seeing and being

A key theme highlighted by the parents related to how the workshops had changed their perceptions and experiences. It can be separated into two clear sub-themes: seeing a different perspective of their difficulties and building new ideas into their lives.

A different perspective

The parents referred to the insights they had developed during the group and how this had supported a more mindful outlook. Most of the parents made specific references to metaphors introduced in the group:

... it makes it a lot tougher when you are in the quicksand... And you can either struggle and sink deeper or you can make peace with it. (P1)

There appeared to be some development of self-compassion and self-validation:

I remember initially sort of talking about what our daily life is like and how stressful it is and how impossible it is when you wrote it down... if [someone] were paid to do it sort of thing it would be really difficult to fit it all in. (P5)

... perhaps I shouldn't be too hard on myself and find time to get a break. (P2)

The parents recalled some of the mindfulness exercises in the group that stood out to them:

... we were asked to do that letter ... and I think I was able to focus a bit more on here and now than always looking you know going ahead 50 miles an hour, to be kind of aware. (P4)

Yet in some cases this reflected some ongoing confusion between mindfulness and relaxation:

The meditation relaxation sort of thing that was really good as well cause probably half of us don't relax you know not properly. (P3)

Making mindfulness my own

The second sub-theme pertinent to the parents was the idea of introducing mindfulness to their own lives. Although there appeared to be general consensus amongst the parents that they were eager to practice the exercises, some parents were struggling with this and acknowledged barriers to implementation:

... I've been so busy and to be honest I haven't followed up too much with the breathing. (P2)

Others had begun to approach their lives and parenting more mindfully and with acceptance:

I've been doing [mindfulness exercises] ... maybe a couple of times a week. (P3)

... even if it's not nice actually doing it and being present while you're doing it. (P4)

One parent had created their own metaphor to capture their experience of mindfulness and acceptance:

It's almost like a detoxification of the mind just like when you detox your body at first you feel really sick and some people throw up and do all that because your body is trying to cleanse itself. (P1)

Theme 5: Positive changes

The parents described a range of positive changes that had occurred following the group.

Back on an even keel

All the parents reflected on an enhanced emotional wellbeing, particularly in relation to a reduction in stress:

I feel a lot more at an even keel than too much up here or too much down there. (P2)

I don't get so stressed out and angry now. (P3)

Values-led changes

Prior to the group there was a general consensus amongst the parents that they did not have time for themselves. Following the group, several parents noted, small, yet significant changes in their actions that were more in line with their value of self-care:

... you never do much for yourself but then suddenly you're starting to think about yourself and think yeah I can do things. (P3)

to get back to my interests that I had (P1)

New ways of responding to same old situations

Unanimous amongst the parents was the realisation that their situations at home had not changed, yet their response to approaching their difficulties had:

Not struggling and not trying to escape it and rather just making peace with it I think that, I think it has helped me. (P 1)

... I was still facing the aggression but it wasn't affecting me emotionally as it did the other times. (P1)

There has been new problems that have arisen ... where it's been a bit more stressful but I think I have managed it a little bit better than I did before. (P4)

Changes for others

The changes noted by the parents were not only impacting on their emotional wellbeing and ability to manage difficult situations, but also had a positive influence on others:

It did really make me feel quite mindful about when I was doing things with my children and whatever I was doing even if I didn't enjoy it, to be present. (P4)

... interactions between me and my son a lot more positive and because I am a lot calmer because I am a lot happier. (P1)

Theme 6: Looking to the future

Personal practice

Through the interviews it became apparent that the group had provided a powerful tool to enable the parents to make changes:

I think this is a very very empowering technique simple as it might seem but it does do a lot and you know regular practice of that can literally change your life. (P1)

It's the only thing that I can do at the moment and the alternative is just to carry on being stressed. (P5)

There was a sense that the parents were beginning a new journey in discovering how to implement mindfulness and acceptance:

I think trying to be mindful I'm not 100% sure if I'm doing it all the time ... um I feel a little bit I think more confident. (P4)

I need to get better at ... my life has been just one big stress fest and that's all I'm used to so you gotta get into good habits. (P5)

Several parents expressed their continued investment in using mindfulness and acceptance, and were considering ways to expand their knowledge and experiences:

I do the meditation every day and uh but in addition to that I am looking out for every other way of thinking. (P1)

I'm hoping to go more deeper into it ... when you have a child with special needs you're always going to have problems. (P4)

Discussion

The Parent Wellbeing Workshops aim to provide support to family carers, whose child displays high levels of challenging behaviour, based on an ACT framework to enable family carers to promote and maintain their emotional wellbeing. The workshops are offered as part of a positive behaviour support (PBS) and systemic service model which aims to provide intensive clinical psychology support to the child and their family in order to prevent the child entering a residential school placement. The current study aimed to evaluate the workshops using semi-structured interviews to generate a detailed account of participants' experiences of the workshops and of drawing on acceptance and mindfulness practices within their daily lives.

Interviews were conducted with five family carers following attendance at the workshops. Family carers reported that they found the workshops useful and were able to incorporate mindfulness and acceptance into their daily lives. A number of important limitations must be considered before interpreting these results, however. Firstly, the sample size was relatively small and participants were all parents of children with severe intellectual / developmental disabilities who displayed high levels of challenging behaviour. This may limit the generalizability of the findings and it is not known whether these results are applicable to families who support children with less severe disabilities or behaviour difficulties.

Secondly, although the qualitative approach taken in this study allowed an in-depth examination of participants' experiences (which previous research has lacked), the absence of quantitative data to confirm participants' reports should be considered. The accounts given by participants suggest that the intervention did have a positive effect; however a more robust mixed methods evaluation of the intervention with a larger sample size and a waiting list control group is needed to confirm this.

Finally, this study does not examine which components of the intervention may account for the positive changes experienced by the participants. For example, it is not known to what extent the practice based exercises or the discussions supported participants to perceive their experiences differently. Whilst it is likely that a combination of elements was responsible for the outcomes described by participants, an analysis of the various components and delivery formats of the workshops would add to the knowledge base for supporting family carers with this approach.

Despite these limitations, the results of this study provide initial evidence for the effectiveness of the Parent Wellbeing Workshops. Participants reported generally poor wellbeing and high levels of stress prior to the workshops consistent with evidence which suggests that family carers of children with intellectual / developmental disabilities often experience high levels of stress and emotional difficulties (e.g. Baker et al., 2013; Hastings, 2002). Although they had mixed expectations of the workshops, all of the parents said that they found them useful and described positive changes following attendance at the workshops, including a new perception of their difficulties, the use of mindfulness in their daily lives, and an improved ability to cope with stress. These qualitative accounts confirm earlier findings of a significant reduction on quantitative stress measures following acceptance and mindfulness based interventions for family carers (Benn, Akiva, Arel, & Roeser, 2012; Farraioli & Harris, 2013; Minor et al., 2008; Neece, 2014) and an

increase in mindfulness and life satisfaction (Benn, Akiva, Arel, & Roeser, 2012; Neece, 2014).

Participants also reported that attendance at the workshops with other parents who had similar experiences was an important aspect of the workshops and they expressed a desire to continue or develop their meditation practices. Whilst some parents were confused about the difference between mindfulness and relaxation, most were able to describe mindfulness techniques and spoke of ways that they could fit these techniques into their daily lives. Many of these changes relate to key features of acceptance and commitment therapy (e.g. themes relating to a new perspective and self-compassion) (Hayes, Strasahl, & Wilson, 1999; Smith & Gore, 2012) and participants often described their experience using metaphors from the workshops. This suggests that the effectiveness of the intervention was due to more than social support alone, though this in and of itself was also highlighted as an important factor and is highlighted by previous research as important for family carer wellbeing and health (Dunst, Trivette, & Cross, 1986; Guralnick, Hammond, Veille, & Connor, 2008; Skok, Harvey, & Reddihough, 2006; Wei et al., 2012).

In addition to positive changes noted for the participants themselves, family carers also spoke of the impact of their attendance at the workshops on others (e.g. on their child). Participants felt that their improved ability to cope with stress and approach activities mindfully and with acceptance impacted positively on those around them. This is consistent with evidence suggesting that a mindfulness based support programme may influence outcomes for the child as well as the family carer (Neece, 2014). These findings fit with the values of a PBS approach (Gore et al., 2013; LGA & NHS England, 2014) to supporting individuals with intellectual / developmental disabilities and challenging behaviour, which places emphasis on a systems wide approach. In this way, the parent wellbeing workshops could usefully be incorporated into PBS plans (as they have been within the Ealing Intensive Therapeutic and Short Break Service; ITSBS) in order to provide support to the wider systems around an individual and improve quality of life for the individual themselves and their family.

The workshops were designed to be therapeutic in nature and place few demands on participant's time outside of the workshop (i.e. in relation to homework tasks). The facilitators felt that the extended sessions (lasting 4 hours each) were useful both logistically, as there was no need for participants to identify weekly slots to attend the sessions, and therapeutically, due to the opportunity to undertake extended practice and deeper discussion than would have been possible with short weekly sessions. The accessible and brief nature of the intervention ensures that it can be incorporated into routine clinical practice and places few time commitments on either the participants or the facilitators.

Longer term outcomes for group members are not yet known and the utility of monthly follow up sessions or refresher workshops could usefully be explored by future research. Follow up sessions could, for example, be scheduled monthly for six months following the initial intervention and directed largely by the participants themselves. In addition, periodic refresher workshops, during which facilitators guide participants through practice and help participants to overcome any issues with practicing at home, could be scheduled in order to help maintain the effects of the

intervention and help participants to incorporate mindfulness and acceptance into their way of life.

In addition, the application of the intervention with other client groups (e.g. family carers of children with less severe difficulties), in different services (e.g. in CAMHS settings), and utilising different formats (e.g. a full day workshop) would add to the evidence base for the intervention and improve understanding of the factors related to effectiveness. Finally, as mentioned previously, replications of the intervention on a larger scale, with more robust evaluation methods and a waiting list control group, are needed to support the conclusions from this study.

Conclusions

The importance of supporting the emotional wellbeing of family carers of children with intellectual / developmental disabilities is well evidenced. Mindfulness and acceptance based approaches have been shown to support family carer wellbeing by reducing stress, increasing mindfulness skills, and influencing outcomes for both the family carer and their child; however these approaches have not been evaluated qualitatively. As a result, little is known about participants' experiences of these interventions and their perception of the impact of the intervention on their daily lives.

The current study qualitatively evaluated an acceptance and mindfulness based intervention for family carers of children with intellectual / developmental disabilities who displayed high levels of challenging behaviour and were at risk of a residential school placement. Participants reported that they found the Parent Wellbeing Workshops useful and they felt that they were better able to cope with stress following attendance at the workshops. In addition, they described new perceptions of their difficulties and felt that they were able to incorporate mindfulness into their daily lives with positive effects on both their own wellbeing and on others around them. The importance of attending the sessions with other family carers was highlighted and participants expressed a desire to continue their practice both within additional group sessions and independently at home.

Future research should explore quantitative outcomes of the workshops for both the participant and their child given evidence and accounts of the impact of mindfulness and acceptance based approaches on others around the participant. In addition, longitudinal outcomes should be examined and the utility of refresher or follow up sessions should be assessed. Finally, the application of the workshops with other client groups (e.g. family carers of children with less severe difficulties) and in other delivery formats (e.g. a full day workshop rather than two shorter sessions) is needed.

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