



Parent perspectives and psychosocial needs 2 years following child critical injury: A qualitative inquiry

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ABSTRACT

Introduction: To provide effective care and promote wellbeing and positive outcomes for parents and families following paediatric critical injury there is a need to understand parent experiences and psychosocial support needs. This study explores parent experiences two years following their child's critical injury.

Methods: This multi-centre study used an interpretive qualitative design. Parent participants were recruited from four paediatric hospitals in Australia. Semi-structured interviews were audio recorded and transcribed verbatim. Qualitative data were thematically analysed and managed using NVivo 11.

Results: Twenty-two parents participated. Three themes were identified through analysis: Recovering from child injury; Managing the emotional impact of child injury; Being resilient and finding ways to adapt.

Conclusions: A long-term dedicated trauma family support role is required to ensure continuity of care, integration of support and early targeted intervention to prevent long-term adverse outcomes for critically injured children and their families. Early and ongoing psychosocial intervention would help strengthen parental adaptation and address families' psychosocial support needs following child injury.

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Introduction

Traumatic injury is a leading cause of death of children and adolescents worldwide [1]. Each day the lives of more than 2000 families are changed irrevocably by the loss of a child to unintentional injury [2]. Most injuries of children are caused by falls and road traffic collisions [3,4]. In Australia, childhood injury is a major public health problem, with injury hospitalisation rates not reducing in over a decade [3,5]. Even when critically injured children survive their injuries, they often face long-term health consequences, such as physical disability and reduced health-related

quality of life [6,7]. These sequelae of critical injury impact not only the child but also their parents and other family members [8].

Children are dependent on their parents to meet their physical, emotional and social needs, however child injury can be highly stressful for parents and may impact their ability to effectively meet these needs [9]. When injury has an ongoing impact on child wellbeing and functioning and they require long-term care and treatment, parental stress can persist over time. Parents' psychosocial (i.e., mental, emotional, and social) health and wellbeing can be substantially affected. Evidence indicates that parents of injured children are at a higher risk of mental health conditions, such as depression, anxiety, acute stress disorder (ASD) and post-traumatic stress disorder (PTSD) [10–13]. A systematic review by Woolf et al. [11] found that within the first three months following a seri-

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ous illness (e.g. diabetes requiring intensive care unit admission), or injury in their child, 12–63% of parents experienced ASD and 8–68% experienced PTSD. Parents with the highest prevalence of PTSD were those of children hospitalised following road or burn injury. These effects were not limited to the initial period immediately following injury and can persist over time. Wade et al. [14], followed families over an extended period (on average 4 years) and found that families of children with severe traumatic brain injury experienced high levels of stress associated with the child's recovery for several years following the injury.

Understanding the factors involved in positive parental adaptation following a child's critical injury is important for prevention of future adverse mental and physical health outcomes for parents, and for effectively addressing parent and family psychosocial needs. Resilience, or the process of positive adaptation following adversity, involves dynamic interaction between personal characteristics and resources such as self-mastery and optimism, and available external resources, such as social support and effective healthcare [15]. While there is emerging evidence of resilience of parents of an injured child in the initial year following injury, there is no literature on parent resilience at longer-term follow-up [16]. A consensus meeting of European trauma experts on quality of life after injury [17] indicated the assessment of long-term outcomes should take place at least two years post-injury. There are few studies on parents' experiences and wellbeing and factors influencing their emotional wellbeing following their child's injury [9,18–20] and even fewer studies on parent experiences two or more years following their child's injury [14].

Aim and questions

The overall aim of the study was to explore parent experiences and psychosocial support needs two years following their child's critical injury. Research questions were, two years following child injury:

- (1) What are parents' experiences of having a critically injured child?
- (2) What are parents' psychosocial and practical support needs?
- (3) What psychosocial factors helped or hindered parents and the family to recover?

Methods

This multi-centre study examined the experiences and support needs of parents of critically injured children 0–12 years of age, two years following the child's injury. An interpretive qualitative design with thematic analysis was used to explore parents' experience after a child's critical injury and hospitalisation. Collection and analysis of data were inductively approached, as this is a suitable method for studies investigating how people make meaning of a situation [21]. Ethics approval was gained prior to study commencement: HREC/13/SCHN/404; HREC/14/QRCH/149; and 34,089 A.

Setting and participants

A purposive sampling technique was used to recruit parent participants from four paediatric hospitals in three Australia states (New South Wales, Victoria and Queensland). Eligibility criteria were: (1) aged over 18 years of age; (2) able to speak, read and write English; (3) had a critically injured and hospitalised child 0–12 years with an Injury Severity Score > 15 [22] and/or requiring admission to the intensive care unit.

Data collection

Telephone interviews were conducted with participants and audio-recorded with consent. A semi-structured interview guide was utilised and covered four main areas:

- (1) Child's recovery – the child's physical and emotional recovery;
- (2) Needs – parent and family psychosocial needs, including how these were met and by whom;
- (3) Impact – how the injury impacted the child, parent and family, e.g. how life had changed, what had been challenging and what had been helpful; and
- (4) Resilience – what resilience meant to parents and how they managed the impacts of injury.

To allow for a fuller understanding of the meaning they made of their experience, parents were also encouraged to discuss any issues important to them at any point in the interview [23].

Data analysis

Interviews were transcribed verbatim and analysed using thematic analysis. Data were managed using the QSR International qualitative data software NVivo 11™. The thematic analytic process involved data familiarisation where transcripts were read multiple times and each transcript was initially coded against the research questions. Detailed analytic memos were kept during the coding process. Codes were collated and then patterns across data identified, with initial themes developed. These were reviewed and discussed by three researchers until consensus was reached and final themes were defined and described [24].

Results

Parent and injured child characteristics

Twenty-two parents participated in the study. Of the parents who provided demographic information, 89.5% were partnered or married and 84.2% had two or more children. The majority (89.5%) of parents were born in Australia and less than half (42.1%) had completed a university degree (Table 1). These 22 participants were parents of 18 children who were critically injured and hospitalised. The majority of children (61.1%) were female with a median age of 8 years (Table 2). Three themes were identified through analysis: Recovering from child injury; Managing the emotional impact of injury; and Being resilient and finding ways to adapt.

Recovering from child injury

A child's recovery from injury involved both physical and emotional recovery. Parents identified that for most children, their emotional recovery from injury was closely associated with their physical recovery, that is, where children regained function and had fully recuperated from their physical injury; they also experienced positive emotional recovery. Two years following injury, the majority of parents reported that their child/children had fully recovered physically ($n = 16$) and emotionally ($n = 13$) and required no further treatment or support from healthcare services. Parents described life for their child and family as having 'returned to normal', being 'back on track', or 'as if the injury had never happened':

'She's doing everything that all the other kids do, if not more. Like she'll sit down and she enjoys puzzles, she interacts with all the kids, her speech is excellent, she likes learning new things. I haven't noticed anything that's really held her back from progressing like any other three year old' (Mother, 1 year old girl, head injury)

Table 1
Parent characteristics.

| Characteristics | n (%) |
|---|-------------|
| Gender (n = 22) | |
| Male | 10 (45.5) |
| Female | 12 (54.5) |
| Age (n = 22) | |
| Age range male | 24–53 years |
| Mean age male | 42 years |
| Age range female | 32–51 years |
| Mean age female | 41.4 years |
| State of residence (n = 22) | |
| New South Wales | 4 (18.2) |
| Queensland | 9 (40.9) |
| Victoria | 9 (40.9) |
| Marital status (n = 19) | |
| Single | 1 (5.3) |
| Partnered or married | 17 (89.5) |
| Separated or divorced | 1 (5.3) |
| Number of dependent children (under 18 years) (n = 19) | |
| 1 | 3 (15.8) |
| 2 | 9 (47.4) |
| 3 | 7 (36.8) |
| Country of birth (n = 19) | |
| Australia | 17 (89.5) |
| Other country | 2 (10.5) |
| Level of highest education (n = 19) | |
| Year 10 | 1 (5.3) |
| Year 12 | 2 (10.5) |
| College/TAFE | 8 (42.1) |
| University | 8 (42.1) |
| Employment (n = 19) | |
| Paid employment | 16 (84.2) |
| Unknown | 3 (15.8) |
| Gross weekly household income (AUD) (n = 19) | |
| \$1–649 | 1 (5.3) |
| \$650–1699 | 10 (52.6) |
| \$1700–3999 | 8 (42.1) |

Table 2
Child characteristics.

| Characteristic (n = 18) | n (%) |
|-----------------------------------|--------------------------------------|
| Age | Range: 1–12 years Mean: 8.2 years |
| Injury Severity Score | Range: 4–38 Mean: 21.1 |
| ICU stay | |
| Yes | 15 (83.3) |
| No | 3 (16.7) |
| Gender | |
| Male | 7 (38.9) |
| Female | 11 (61.1) |
| Type of Injury* | |
| Head injury | 10 (55.6) |
| Spinal injury | 5 (27.8) |
| Limb fractures | 5 (27.8) |
| Multiple intra-abdominal injuries | 3 (16.7) |
| Lung/airway injury | 2 (11.1) |
| Facial injury | 1 (5.6) |
| Neck injury | 1 (5.6) |
| Rib fractures | 1 (5.6) |

* Some children sustained more than one type of injury.

However, a third of children had either ongoing functional ($n = 4$), emotional ($n = 1$) or both functional and emotional ($n = 1$) problems due to their injuries. Some continued to experience physical problems (e.g. bladder and bowel problems, loss of manual dexterity), while others may have recovered physically but not emotionally. Children who experienced continuing emotional issues in relation to their injury were reported to have PTSD (officially diagnosed), difficulty managing and expressing emotions, panic attacks, anxiety, depression, anger, sleeping problems and personality changes:

'It's changed her personality [she's] more reclusive, more in-bound, certainly less happy because of [her limited mobility]' (Father, 10 year old girl, spinal column and limb fractures)

Physical recovery was particularly challenging for a couple of children who sustained a head injury. Two years following injury, these children continued to have ongoing issues including problems processing information, difficulty with working memory, and challenges regulating their feelings. This presented as tantrums, crying and angry outbursts. A father explained how his son struggled to keep up with online conversations, which impacted on his friendships:

'He's always a minute behind the conversation... he'll bring something up that was talked about a minute or two before.... It's in his processing, processing information and then having to recall and then working out an answer or a response... he's actually stopped using Messenger now to communicate with his friends... he has been kicked out of [the group message]... it's hard on him' (Father, 9 year old boy, head, spinal and limb injuries)

Managing the emotional impact of injury

Parents' emotional wellbeing was closely linked with their child's overall wellbeing and recovery. When the child's physical or emotional recovery was slow or problematic, parents often experienced stress, anxiety and changes in mood, which limited their emotional wellbeing. Two years following injury, the majority of parents (18/22) had mostly or fully recovered their emotional wellbeing. These parents witnessed improvements in their child's physical state and emotions and felt positive about the future for themselves and their child. The family unit had moved on from the injury and life had generally returned to how it was pre-injury. These parents felt very lucky their child had survived and recovered so well.

However, some of these parents also admitted that some things had changed because of the injury. For example, some parents' perspectives on life and priorities in life had shifted. Aspirations for their child had changed dramatically after injury. Before injury, parents had wanted their child to excel in different endeavours (e.g. sport, school) but after injury, they wished only for a regular child with a happy childhood. They were concerned other children might not treat their child the same as others because of changes in the child's functioning and/or appearance, and worried about lost friendships and school yard bullying:

'[It's] changed my point of view about what is important in life. Before [I wanted my daughter to be in the] best school and [be] the best student ...but nowadays I talk to her and say, you try your best, [the] most important thing is just be a happy girl' (Mother, 8 year old girl, head injury)

Some parents were more protective of their child because the child was still recovering (physically and/or emotionally) from injury. Others were protective even though the child had recovered, because they now believed '*life is so fragile*' (Father, 12 year old boy, head injury). A focus on protection led some parents to restrict the types of activities they allowed their child to participate in, such as contact sports:

'It just sort of brought us to the realisation that you know, you could lose your child at any time [so you have] to be careful' (Mother, 1 year old boy, head injury)

A few parents identified they would sometimes inadvertently treat their injured child differently to their other children. For example, they would praise ordinary things their injured child did, such as completing homework, which they would not do for their

other children. This change in parents' behaviour often made siblings resentful of their injured sibling's 'special' treatment. Conversely, a couple of parents reported that the injury had brought their children closer together. For example, siblings banded together to support their injured brother or sister and make sure they were never left out of activities because of their injury:

'He's got lots of brothers and sisters and they help him out and do everything for him, if he needs to go somewhere or do something they make sure that he's included' (Mother, 12 year old boy, spinal cord injury)

Two parents who were directly involved in the incident that resulted in their child's injury, for example driving a car involved in a collision, continued to experience feelings of guilt and regret two years following the event. These parents acknowledged that although family, friends and health professionals told them the incident was not their fault, it was hard not to blame themselves:

'They told me that the car [collision] is just an accident, it's not your fault, but sometimes that guilty feeling still comes back' (Mother, 8 year old girl, head injury)

One father described how his wife, who was involved in the injury-causing incident, continued to have PTSD two years after their child's injury:

'The greatest impact has been on my wife [because] she was involved in the accident herself... she still suffers PTSD quite severely and that manifests in being overwhelmed with situations, being very claustrophobic and just not able to handle a lot of pressure' (Father, 4 year old girl, head injury)

Four parents (father of 9 year old boy with head, spinal and limb injuries; mother of 7 year old girl with multiple intra-abdominal injuries; father of 10 year old girl with spinal column and limb fractures; mother of 12 year old boy with spinal cord injury), continued to experience negative emotions as a result of their child's injury. These parents struggled to regain their wellbeing because their child's physical and emotional recovery was slow. They often wondered whether their child would ever make a full recovery and felt helpless knowing there was nothing they could do to help their child:

'[There's] this worry in the back of my head all the time... is this going to affect her for the rest of her life?... She still sometimes wakes up at night scared and the other night she [had] another nightmare about cars and monsters and us in cars' (Mother, 7 year old girl with multiple intra-abdominal injuries)

It was especially difficult for parents who believed the injury or associated complications had robbed their child of a bright future. Parents felt sadness for what could have been, and were frustrated about life limitations for their child and the family. Injury had substantially changed their life circumstances and the future outlook for their child. These parents were distressed and anxious and lacked optimism or hope for the future:

'[She was] a high functioning athlete and then suddenly that's all gone... all ball sports are gone because [she] can't catch and throw and raise [her] arms over [her] head...and there's no potential for recovery... it's pretty demoralising' (Father, 10 year old girl, spinal column and limb fractures)

Most parents who were struggling with their emotional wellbeing sought professional support from their family doctor/general practitioner, mental health social workers, psychologists or psychiatrists to help them manage. Two parents continued to receive professional care for their mental wellbeing two years following their

child's injury, and another parent was taking antidepressant medication to manage their mood.

Being resilient and finding ways to adapt

Parents described their perspectives on resilience in the face of child injury, and identified various strategies they used to support themselves, their child, and family. Most parents viewed that being resilient was important to helping them and their child manage the impact of injury and also influenced the child's recovery. Although resilience was defined in different ways by parents, it was generally considered to be about: being strong in the face of adversity, '*keep on going, regardless of what happens*' (Father, 9 year old boy, head, spinal and limb injuries); having a positive mindset; being able to cope with hurdles in life, '*coping with what's before you and getting through it the best you can*' (Mother, 12 year old boy, spinal cord injury); being flexible and adaptive; and having the determination to make things work.

Some parents believed they were resilient people but admitted that 'staying strong' was not always easy. One father (12 year old girl, multiple intra-abdominal injuries) admitted that '*something as simple as having enough sleep*' was important to being resilient. Other parents felt they had become more resilient as a result of their child's injury due to changing how they viewed stressful events or situations:

'[It's] probably made us a bit more resilient... little things that used to be a big deal [are] not a big deal anymore.... you get upset or angry about certain things and then you sort of stop and think about it and go, hey, that's really not a big problem [I'll just] move on [and] not make a big deal out of it' (Father, 1 year old boy, facial injuries)

Parents also admired and praised their child's ability to adapt positively in the face of challenging experiences like long-term pain and functional impairments. They were inspired by their child's positive adaptation which in turn positively influenced their own responses to their child's injury:

'He's absolutely amazingly happy. Nobody can believe how happy. He's got a wheelchair but he's got a very good attitude to life and he doesn't let it get him down' (Mother, 12 year old boy, spinal injury)

Parents drew on a range of strategies and resources (Table 3) to help them adjust following their child's injury, including keeping a positive outlook, being flexible, adaptable and grateful. Most parents acknowledged that what kept them going was gratitude for the fact their child was still alive. No matter how hard things became after the injury, parents felt they were still more fortunate than families who had lost a child. This was especially the case for those who had a child with poor physical outcomes:

'Every now and then when I see his scar I'm mixed with joy for the fact that he's fine... [it's a] little bit like, geez we were lucky' (Father, 12 year old boy, head injury)

Parents also highlighted the importance of accepting support when it was offered to them and seeking out support for themselves when they needed it. For example, accepting support from others was especially important when ongoing medical care for their child was needed. They, for instance, accepted flexible work arrangements offered by their employer or help with childcare and household tasks from family and friends:

'[If] someone offers to cook you a meal, take it; [if] someone offers you to go have a lie down for a few hours while they watch your child, take it' (Mother, 12 year old girl, multiple abdominal organ injury)

Table 3
Strategies and resources used by parents to support their resilience.

| | |
|-----------------------------------|--|
| Parent | <ul style="list-style-type: none"> - Having a positive attitude (about life in general) - Being grateful (that their child had survived their injuries) - Being flexible and adaptable |
| Family & friends | <ul style="list-style-type: none"> - Positive cognitive appraisal and meaning-making of adverse events including injury - Having strong relationships - husband/wife, family, friends and support networks |
| Healthcare & community | <ul style="list-style-type: none"> - Being able to talk openly with family and friends about the experience of their child's injury - Seeking psychological support from health professionals - Seeking help with everyday activities e.g. through hiring a cleaner or nanny to reduce the burden on the parent - Seeking financial support to help pay for medical expenses e.g. financial support from the Transport Accident Commission - Using flexible working arrangements offered by employer allowing the parent to remain in the workplace but have time off when they needed to care for their child - Using services offered by medical case managers to coordinate medical treatments and support the parent in understanding the medical process and medical information provided |

Parents also had to identify and seek out the support they needed for themselves, for example psychological support provided by health professionals, or, for those parents residing in the state of Victoria, financial support provided by the Transport Accident Commission (TAC):

'the TAC have been absolutely brilliant financially... any bills that came through, TAC just said, send them to us, we'll sort it out... it was reassuring to get a ten thousand dollar helicopter bill and ring up and say, this is our TAC number and then [the bill] was gone' (Father, 1 year old boy, head injury)

'[He's got a] teacher's aide at school, so he's got someone with him at school... his physio and his OT and counsellor [are all] paid through the TAC' (Father, 9 year old boy, head, spinal and limb injuries)

Many parents also reported that getting back to a 'normal' life and returning to routine as soon as possible, was important to their ability to adapt following child injury. These parents made a conscious effort to do the things they used to do before their child's injury, such as spending time with family and friends, organising and going on family holidays, exercising, and making time for themselves to pursue their interests, education or career.

Discussion

This is the first study to report on parent psychosocial wellbeing and resilience two years following child injury and the findings provide new knowledge in the field. A key finding was that parents' experiences and needs were closely related to their child's physical and emotional recovery, and the support services available to them. Parents reported that the impact of their child's emotional recovery and mental health following the injury were linked to their physical recovery. For most children, if a positive physical recovery resulted, their emotional recovery was also positive. Where a child's physical recovery was limited or slow in progress, greater attention was needed to support emotional recovery for both the child and parent. These findings are supported by a previous study where 12-month health related quality of life remained below baseline for psychosocial health in children who were admitted to NSW paediatric trauma hospitals [25].

Parents reported they were offered psychological and emotional support by family and friends but not by health professionals. Parents who required emotional support for themselves at any stage of the two years post their child's injury, had to independently seek it. These findings confirm those of an Australia wide survey of health professionals who reported physical needs are better met than psychosocial needs and that there are no routine follow-up support services post-discharge for injured children or their families [26]. Given the evidence that some parents and children continue to experience psychological distress two years following child injury, it is recommended that health professionals provide parents with anticipatory guidance and information on how to access psychological support for them and their child, at the child's discharge from hospital.

In respect to their psychosocial wellbeing, parents in this two year follow-up study reflected each of the three psychosocial recovery trajectory patterns identified in a study at one year following child injury: *resilient*; *recovering* and *distressed* [16]. Parents who were resilient and doing well in the current study reported finding multiple positive ways to adapt, and identified key psychosocial resources including support from family and friends, psychological support, and financial support for their child's treatment. Financial support was an important resource that alleviated family burden and distress in relation to child injury. Parents in Victoria were grateful they had access to the Transport Accident

Commission (TAC), especially those who were aware that had they resided in another state in Australia, they would not have access to the same level of financial support. TAC is a statutory insurer of third-party personal liability operating in only one state (Victoria) in Australia. The purpose of the TAC and similar schemes across Australia is to fund treatment and support services for people injured in vehicle crashes, although the level of support varies. To alleviate parent and family financial distress and burden following child injury financial and treatment support services should be consistent across Australian states and territories.

Many parents reported that getting back to a 'normal' life and returning to routine as soon as possible was important for their own and the family's wellbeing. These parents made a conscious effort to do the things they used to do before their child's injury. A number of parents also reported changing their perspectives on stressful situations, and how they viewed their child's injury. Positive meaning-making and cognitive appraisal of stressful events are key resilience factors [27] and can be supported by health professionals to help improve parent adaptation following child injury. Most parents were also grateful for the healthcare received and their child's survival. Gratitude has been found to promote positive outcomes following trauma. Vieselmeyer et al. [28] concluded that resilience operates to prevent adverse outcomes while gratitude may promote positive outcomes following trauma.

Parents reported changes in expectations for their injured child, and different parenting approaches to their injured and non-injured children. In the aftermath of major disruption in a family, like child injury, a key parental role is to maintain or restore family routines and rules that promote a sense of stability and wellbeing amid adversity [29]. Adjustments to parenting can broadly impact on family function and dynamics, and while some adaptations may promote family cohesion and flexibility post injury [29], others may contribute to stress, for example discord between siblings. Given the impact of parenting on family resilience and wellbeing, there is a clear need for parenting support post child injury, to prevent potential adverse outcomes for family dynamics and child development, particularly when an injured child experiences ongoing functional and behavioural impairment. These findings should be considered by clinicians when supporting parents following injury. Given the life changing nature of critical injury, clinicians should consider a multifaceted approach to buffer the effects of emotional trauma by cultivating resilience and enhancing gratitude as a means to decrease post-traumatic stress [28].

These results reflect the numerous individual, family and societal impacts of injury and provide further evidence that improved psychosocial care and outpatient follow-up is required to minimise the long-term emotional impact of injury for injured children, and related psychosocial wellbeing of parents.

Each family unit and family member has different traits and coping mechanisms, and family appraisal and any interventions should be tailored as such. A coordinated model of care that provides psychosocial care both during hospitalisation and post-discharge would reduce the psychological care gap for injured children and their families, particularly in key care transitions such as from hospital to community [30]. The 'Family Forward' intervention reported reductions in trauma and grief responses at six weeks post a child's injury [31]; however it appears that a long-term social work family case management approach is required to ensure continuity of care, integration of support and early targeted intervention to prevent long-term adverse outcomes.

Limitations

This study is limited to one group of English-speaking parents from the Australian context. Other parents may have had different

perspectives. Future research could include a wider group of parents from a range of cultural backgrounds and contexts.

Conclusions

A long-term dedicated trauma family support role is required to ensure continuity of care, integration of support and early targeted intervention to prevent long-term adverse outcomes for critically injured children and their families. Early and ongoing psychosocial intervention would help strengthen parental adaptation and address families' psychosocial support needs following child injury.

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Declaration of Competing Interest

All authors state that they have no competing interests to declare.

Supplementary materials

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CRedit authorship contribution statement

Kim Foster: Conceptualization, Investigation, Writing - original draft. **Connie Van:** Investigation, Writing - original draft. **Andrea McCloughen:** Investigation, Writing - review & editing. **Rebecca Mitchell:** Writing - review & editing. **Alexandra Young:** Data curation. **Kate Curtis:** Writing - original draft.

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