

Dysphagia and Feeding Difficulties Post-Pediatric Ingestion Injury: Perspectives of the Primary
Caregiver

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Abstract

Purpose: To explore the experiences of children with dysphagia and/or feeding difficulties post-chemical or button battery ingestion injury from the perspective of the primary caregiver.

Method: Five primary caregivers of children with a history of dysphagia and/or feeding difficulties post-ingestion injury (4 chemical, 1 button battery) completed the Children's Picky Eating Questionnaire (CPEQ), and participated in a semi-structured interview. Interviews explored experiences of caring for a child with dysphagia and/or feeding difficulties, impressions of services and supports, and additional impacts to the child and family. Content analysis was used to identify key themes.

Result: Primary caregiver report and CPEQ results confirmed all children had some degree of persisting dysphagia and/or feeding difficulties at time of interview (mean 4.13 years' post-injury). Interviews identified five key themes: 1) The initial trauma of the injury, 2) The experience of associated and ongoing medical issues, 3) Managing altered oral intake, 4) Experiences of services and support, and 5) Impacts on the child, primary caregiver, and wider family unit. All caregivers reported significant challenges and concerns, and potential areas of service improvement were highlighted.

Conclusion: The current data highlights specific issues experienced by primary caregivers, and poses areas for improving primary caregiver and family supports. Family-centered models of care are needed to support the whole family unit in caring for a child with dysphagia and/or feeding difficulties post-ingestion injury.

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1. Introduction

Dysphagia (impaired swallowing function) is highlighted in numerous single case reports and retrospective cohort studies as a frequent consequence of pediatric chemical or button battery ingestion [1–4]. The injury mechanism of acidic and alkaline chemicals versus button battery ingestion differs. Acids (pH <2) cause coagulation necrosis and have limited

penetration, as opposed to alkalis (pH >12) which cause liquefaction necrosis, penetrating deeply into tissues. Alkali ingestion is typically associated with more serious injury and greater complications as substances are innocuous and a larger amount is typically swallowed. Recent research has challenged this distinction, with both strong acids and alkalis shown to cause diffuse and rapid tissue penetration [5,6], and with tissue damage worsening over a period of weeks following the initial injury [7]. On the other hand, button batteries result in focal electrochemical damage, as well as necrosis, within the area of impaction [3,8]. The esophagus is the most common area of button battery impaction due to anatomical narrowing [9]. While injuries sustained are heterogeneous, depending on the type, concentration and amount of ingested substance as well as duration of contact with tissues, the injury location has direct ramifications for dysphagia and development of acute or chronic feeding difficulties [3,10,11].

At hospital admission for chemical or button battery ingestion, up to 35% of children present with acute onset dysphagia [1,12]. Up to 20% of affected children develop esophageal strictures as early as three weeks' post-injury, which cause obstruction in up to 80% of cases [8, 3] and often require repeated dilatations and surgical management [4]. In addition, feeding difficulties (such as food refusal, disruptive mealtime behaviors, and restricted dietary quantity and variety) may also develop, with or without the presence of dysphagia [13]. The primary focus of the literature to date has been on the optimal medical and surgical management of ingestion injuries, with little investigation of the experience or care needs for children and their families with dysphagia and/or feeding difficulties post-injury.

Whilst the literature to date has largely focused on the medical and surgical management of ingestion injury, there is emerging evidence that patients and their families present with significant ongoing multidisciplinary support needs [14]. Gavage feeding is frequently required post-ingestion injury (i.e., nasogastric tube, gastrostomy), with up to 20% of children being discharged from their initial acute admission nil per os (NPO) and enterally fed [14]. While having a vital role in maintenance of nutrition, gavage feeding can result in undesirable sequelae including oral hypersensitivity, oral motor delays, fear of PO intake secondary to periods of time spent NPO, primary caregiver stress, and tube dependency [15,16].

Despite the relative frequency of altered PO intake post injury, research studies have found only one-third of children with impaired PO intake (i.e., dysphagia and/ or gavage

feeding) post-injury are referred for feeding therapy during acute admission, or in the four months following discharge [17]. A significant proportion of children with dysphagia and/ or feeding difficulties are consequently discharged home from hospital without the involvement of a wider multidisciplinary team.

The management of dysphagia and feeding difficulties in the absence of appropriate supports and services may result in reduced quality of life and wellbeing for the primary caregiver [15]. Parents of children with dysphagia and/ or feeding difficulties secondary to medical compromise have been found to report stress and anxiety surrounding mealtimes and nutrition management, as well as a global reduction in confidence towards caring for their child [18]. In addition, gavage feeding, while being an essential acute intervention for children with dysphagia or feeding difficulties, often results in caregiver stress, guilt, and an inability to experience feeding as a positive bonding experience [19–21]. Given the social nature of feeding, the wider family unit is also impacted, as participation in communal mealtime activities can be reduced [19].

Primary caregiver experiences of living with a child requiring extensive medical care post-injury have been explored within other medical populations, including acquired brain injury [2,22,23] and burn injury [24,25]. The challenges of caring for a child with dysphagia and alternative feeding requirements has also been explored [26,27]. Ingestion injury often results in the need for complex, protracted medical care, as well as compromised PO intake, however the needs of caregivers and families have not been adequately explored. Examination of the cumulative effects of dysphagia and feeding difficulties post-traumatic injury may have implications for rehabilitation and management. Therefore, this study aims to explore the perspectives of primary caregivers caring for a child with dysphagia and/ or feeding difficulties because of chemical ingestion injury. This information will help to inform therapy service needs and other multidisciplinary supports required to ensure comprehensive evidence-based care.

2. Methods

A mixed-methods design was used to obtain information surrounding primary caregivers' experience of caring for a child with dysphagia and/or feeding difficulties following chemical ingestion injury.

2.1 Participants

A non-probabilistic, purposive sampling approach was used. The primary caregivers of children who (a) had received treatment for a chemical or button battery ingestion injury (b) had documented dysphagia or feeding issues consequently, and (c) had been admitted to a quaternary children's hospital in Brisbane, Australia, between January 2008 and December 2013, were eligible for inclusion. Chemical ingestion injury was defined as any burn to the oral cavity, oropharynx, larynx and/or upper gastrointestinal tract (esophagus and stomach) caused by ingestion of caustic materials (acid or alkali). Button battery ingestions were those that presented with evidence of batteries impacted within the esophagus as confirmed by endoscopy and/ or radiography. A retrospective search of medical records using International Classification of Functioning (ICD-10) diagnostic codes, that denote burns or corrosion to larynx and trachea and esophagus (specifically T27.0-T27.3, T28.0-T28.4, T95.8, and K22.2), led to identification of a cohort of 51 children [17]. Length of stay for these children was significantly associated with injury severity, and the primary caregivers of the 21 children with the longest hospital admissions (7–66 days) were identified for participation as it was expected that these children would have experienced acute and long-term issues related to their injury. One participant had indicated they did not wish to be contacted for research purposes, and was excluded. Invitations to 20 primary caregivers were sent via mail, with a second invitation sent if no correspondence was received within two weeks of initial invitation. There was no response to 15 invitations, with six returned due to incorrect current addresses. Five primary caregivers (25%) consented to participate and were recruited to the study. All five primary caregivers were female and identified themselves as the primary caregiver both at time of injury and at time of subsequent interview. All children were typically developing at the time of the injury based on caregiver report. Demographic information regarding the children at time of hospital discharge is given in Table 1. Details of dysphagia, PO intake, feeding difficulties, and subsequent surgical/ medical intervention since discharge and at the time of interview are included in Table 2. Instrumental assessment data relating to swallow function was not available for all participants in this study. However, a prospective case study analysis of two children post-ingestion injury which includes this information has been published elsewhere [28].

Insert Tables 1 and 2 about here

2.2 Procedure

Participant recruitment began in September 2014, and telephone interviews were conducted from December 2014 to February 2015 after signed informed consent. Ethical approval was obtained from relevant university and hospital human research ethics committees.

The telephone interview was administered in two parts. First, the primary caregiver completed the modified Children's Picky Eating Questionnaire (CPEQ [29]) to explore current mealtime behaviors as reported by primary caregiver. To aid response clarity, stimulate further discussion during the semi-structured interview, and to ensure data was complete, the CPEQ was conducted verbally. The CPEQ contains nine questions related to perceptions of "picky eating". Each question is ranked on a 7-point Likert scale. Four questions are negatively scored, so that a higher score indicates more problematic feeding behaviors (e.g., 1 = not at all, and 7 = to a great extent). Five questions are positively scored (e.g., where 1 = extremely poor, and 7 = extremely good).

For the remainder of the telephone session, the primary caregiver took part in a semi-structured, individualized interview. A topic guide was utilized to ensure all key topic areas were addressed in each interview. At the commencement of the interview, primary caregivers confirmed information collected from the chart review, including details of injury, presence and nature of dysphagia, medical/ surgical intervention, and feeding status at discharge. Caregivers were then asked to discuss PO intake post-injury and at hospital discharge; 3) current PO intake; 4) medical intervention post-discharge (i.e., esophageal replacement, esophageal dilatations); 5) services accessed (i.e., SLP, occupational therapy, social work), and 6) additional services that may have been beneficial. During interviews, open-ended questions were adapted, omitted or elaborated upon depending on the individual participant and their responses to maintain a conversational style and avoid limiting participant freedom of response. All interviews were conducted in the presence of two SLPs; one an experienced pediatric-feeding specialist to ensure the complexities of this population were fully explored, the other the study lead. Given the heterogeneous nature of participants' experiences, the final content covered in the individual interviews frequently extended beyond set questions, led by the issues raised by the primary caregivers. Participants were encouraged to speak openly, and comment on past and present issues with PO intake, the impact of dysphagia and/ or feeding difficulties on family and mealtimes, as well as service and support needs. Interview duration ranged from 30 to 90 minutes.

2.3 Data Analysis

2.3.1 CPEQ data.

Normative data for CPEQ results are limited, and therefore, available normative data [30] that most closely aligned to the children's ages at time of interview were used to interpret results (i.e., the children aged 3.75 and 3.91 years were compared to normative data for 3.5 year old children). Each child's score was expressed as the number of standard deviations above or below the normative mean value for children with typical feeding behaviors in respective age groups. Scores more than one standard deviation above or below normative data were considered to indicate eating/ mealtime behaviors deviated significantly from typical mealtime behaviors.

2.3.2 Semi-structured interview.

Each interview was audio-recorded, transcribed verbatim, and de-identified for analysis. Qualitative content analysis techniques [31] were used to analyze the patterns of responses. An inductive approach was used to allow the data to shape abstracted themes. The analysis procedure followed the following steps: 1) The interviews were played back, transcribed and then checked at least twice for accuracy; 2) Each item in the transcript was categorized, and grouped to form themes; 3) Three authors checked the themes against the original transcripts to ensure agreement; 4) The themes were then grouped in mutually exclusive categories to reflect the messages portrayed in the original transcripts, and; 5) The authors then reviewed the original transcripts to ensure all relevant themes had been extracted and that the final categories reflected the sentiments expressed in the interviews. All participants were provided with a summary of their interview for review; no revisions or additions were requested.

3. Results

3.1 Frequency of issues with mealtime behaviors and feeding

3.1.2 Primary Caregiver Report

At time of interview (mean 4 (range 1-9) years post-injury), all children were consuming some or all their nutritional needs orally (Table 2). Four of the five children were

consuming a modified texture diet (i.e., modified diets +/- thickened fluids), of which three (Child 1, 2 and 3) required some gavage feeding. Only one child (Child 5) was consuming a full age-appropriate PO diet, and this child had returned to standard diet two months' post injury (23 months prior to interview). All primary caregivers reported issues with PO intake, including odynophagia, dysphagia, and PO intake restricted to certain textures (e.g., soft foods). All caregivers also reported the use of compensatory strategies at mealtimes, such as the use fluid flushes, small bolus size, and slow rate of PO intake.

3.2.2 CPEQ Data

Four out of five caregivers considered their child to have feeding difficulties (Table 3; Question 1). Scores ranged from +2.4 to 3.73 SDs, with higher scores suggestive of increased presence of undesirable feeding behaviors. Similarly, 3/5 reported overall feeding behavior that fell >1 SD below normative data for non-picky eaters (Question 3; range = -1.33-7 SD). Three primary caregivers reported they frequently had to provide a reward for consumption of family foods (Question 6; range = +1.8-2.47 SD), and that they had to prepare special foods because their child did not like the food eaten by the rest of the family (Question 7; range = +1.1-7.71 SD). Three reported frequently using persuasion to ensure consumption of family foods (Question 5; +1.06-2.5 SD).

Four of five primary caregivers reported their child was eating a wide variety of foods (Question 2; +1.4-1.6 SD; higher scores indicating desirable feeding behaviors). Three of five reported their child consumed more food than norms for non-picky eaters (Question 4; +1.27-1.46), with one child reported to be consuming less food than norms for picky eaters (-3.58 SD). Three caregivers reported their child often tried new and unfamiliar foods at home (Question 8; +1-4.89 SD). One child was reported as being less willing to try new and unfamiliar foods than normative data (-2.08 SD).

Insert Table 3 about here

3.2 Analysis of interview data

Five overarching themes emerged from the semi-structured interviews. These pertained to the nature of issues experienced by the primary caregiver following their child's discharge, their service and support needs, and the impact of the dysphagia and feeding difficulties on the child and family mealtime experience.

3.2.1 Theme 1: The initial trauma of the injury

Primary caregivers spoke often about the significant trauma associated with the initial injury event and the experience of having a child in hospital. Two caregivers highlighted that witnessing the ingestion injury, and the need for emergency medical intervention, was a “traumatic time” [P5] while three discussed the impacts of the lengthy and repeated hospitalizations: “He was in hospital on and off for quite a while” [P4]. It was noted by most that there was considerable disruption to the family unit during this time, with the primary caregivers reporting impacts to the family unit “[the] family comes to the hospital” [P3]. Although the primary caregivers spoke positively about their interactions with hospital staff, “they are like our family...” [P2], they also reported being “disheartened” [P3] by the environmental factors of the admission, such as uncomfortable or limited sleeping options while their child was an inpatient: “At times, you have to sleep in a chair, or make the best of the floor” [P3].

3.2.2 Theme 2. The experience of associated and ongoing medical issues

Four primary caregivers spoke at length about the additional medical issues their child experienced following the ingestion injury. In particular, frequent illness was noted, with two primary caregivers referencing ongoing vulnerability: “It [illness] reminds us that it’s not always peaches and cream...he still has that fragility about him” [P3], and, “He got hammered by everything. Everything that could go wrong went wrong at the same time.” [P4]. Primary caregivers also spoke about the complications of surgical intervention. Four detailed that overcoming the injury, and the presence of secondary issues (e.g., “they didn’t realize it had also burnt a hole in his windpipe” [P4]), meant that recovery was difficult and protracted. The need for long-term, repeated medical and surgical intervention to maintain patency of the esophagus was also discussed. One caregiver expressed specific concern regarding the ongoing nature of these procedures, and the heightened risk of esophageal perforation: “We know the more he has, the greater the risks become” [P3]. However, all acknowledged that there were also benefits of ongoing treatment, including improved PO intake. Four caregivers commented on the psychological impact of the often unpredictable and compounding nature of these associated medical issues: “Lots...of different things have arisen that we never thought of...it’s kind of like an avalanche” [P2].

3.2.3 Theme 3. Managing altered PO intake

As a group, the caregivers discussed a wide range of mealtime changes regarding managing dysphagia and feeding difficulties. All reported altering meal preparation because of dysphagia and feeding difficulties, including cutting food into small pieces, avoidance of certain foods, small portions, and adding extra sauces to meals. Four reported they had to modify foods: *“Whatever food I was giving her was literally as fine as custard” [P1]*. One primary caregiver noted that their child was now anxious about mealtimes: *“She asks [repeatedly] what’s for dinner...often she wants to see it while it’s being cooked” [P1]*. They also reported concerns regarding aspiration following the injury: *“She can aspirate...we can’t make her eat because it’s not safe to do so” [P2]*, and for some the consequences of aspiration added to the ongoing medical issues: *“She got pneumonia which they say was related to aspiration” [P1]*.

Four of the primary caregivers spoke about the need for long-term non-PO feeding: *“He will never, ever be able to eat normally, and he will never not have a mic-key [gastrostomy]” [P3]*. Three spoke specifically about the challenges of achieving adequate nutrition, including ensuring meals are never missed, seeking dietetic input, providing high calorie meals, and using mobile calorie counting applications to monitor intake. One reported: *“One of the biggest struggles that I face [now] is trying to get enough calories into her” [P2]*. To manage her child’s feeding difficulties, one primary caregiver reported: *“We don’t fight him, we just let him eat whatever he wants” [P4]*.

3.2.4 Theme 4. Experiences of services and support

Across the group of primary caregivers, contact with a range of allied health professionals, including feeding therapy, dietetics, or physiotherapy was described. Unfortunately, the caregivers reported several issues related to obtaining the specialized allied health input that could cater for complex issues: *“Getting treatment for him was extremely difficult” [P3]*. Most of the primary caregivers reported that they found it difficult to coordinate care and obtain support when needed: *“They [allied health professionals] don’t [help] unless we ask for it...they don’t follow you up at all. They just assume parents will do the right thing” [P1]*, though one caregiver expressed satisfaction with the services received: *“The hospital was amazing...without her [SLP] we wouldn’t be here today” [P4]*.

Primary caregivers cited difficulties accessing appropriate services, traveling to attend appointments, and organizing their own follow-up care. One noted: *“We spend a lot of time*

travelling hundreds of kilometers away [to hospital appointments]” [P2]. Two primary caregivers thought it would have been beneficial to have a central coordinator for their child’s care: *“When it starts getting hard, it would’ve been really good to have one person”* [P1]. In the absence of coordinated care, most described the arduous process of engaging with various medical and allied health teams independently *“[this was] exhausting”* [P3]. The primary caregivers reported they needed to be a strong advocate for services for their child: *“Because of the person I am, I had made sure we had exhausted every opportunity for treatment...but I think there’s a lot of families who are unable to do that”* [P1].

A predominant issue discussed by primary caregivers was the perceived lack of education and sufficient support provided for managing non-PO feeding post-hospital discharge: *“It was a ten-minute run down before we went home, which left me shaky, because that’s all really scary and new to me”* [P5]. Four primary caregivers reported that obtaining the required support was difficult. Many described having to acquire information and education regarding the injury on their own: *“There’s so many questions you could ask...honestly, it’s trial and error. Work it out for yourself”* [P1], and, *“you start waking up and realizing the road you have ahead, and there’s just no support”* [P5].

Three primary caregivers mentioned the importance of family support and counselling following the trauma of ingestion. One reported: *“Without [family support], I would’ve been a nervous wreck and unable to cope”* [P2]. Overall, caregivers reported feeling overwhelmed. They view support services as vital: *“For anybody going through what I’ve been through, and what we’ve been through as a family...I nearly fell completely apart. You need to push counselling on people”* [P1].

3.2.5 Theme 5. Impact on the child, primary caregiver, and wider family unit

The experience of having a child with a traumatic injury, coupled with the primary caregivers’ other responsibilities, resulted in significant impact on the primary caregivers interviewed. All caregivers spoke about the effect that having a child with ingestion injury has had on their daily life, as well as continuing to manage other responsibilities: *“I’m a single mum so I was doing it on my own. There was work, there was hospital, there were so many people to remember, and I had to remember to do things for her. It was colossal”* [P5]. One stated that: *“We live off no sleep a lot of the time”* [P1]. Two caregivers discussed financial difficulties secondary to reduced work capacity. These challenges, in conjunction with the

grief of caring for an unwell child secondary to traumatic injury, had significant negative impact on the primary caregiver: *“Some really terrible things happened, and those things have made us really sad and despondent at times. It’s just been incredibly difficult”* [P3].

These impacts were not confined to the primary caregivers, and all commented on the impact on the child. As noted by one: *“It [the recovery] nearly killed us, but it nearly killed her”* [P1]. Similarly, one caregiver spoke about the impact the injury has had on enjoyment of mealtimes and PO intake: *“He couldn’t eat...that was his favorite thing to do”* [P4]. All caregivers noted that the long periods of hospitalization, as well as the invasive procedures, had impacted the child: *“I’d like to access a psychologist to get her out of thinking that all hospital trips are going to be painful...we’ll drive up the street, past the hospital, and she’ll immediately put her head away”* [P2]. One primary caregiver commented that: *“He’s a kid who’s been in hospital a lot, and that comes with its own set of issues”* [P3]. However, many commented positively about their child’s resilience, *“I think that [her mental attitude] had a lot to do with her recovery...she uses her scars, they are like her badge of honor”* [P5].

In addition to the primary caregiver and the child, the wider family unit was also impacted. One primary caregiver reported that her relationships with her other children had been affected by time spent away from the family home for hospital admissions and appointments: *“They [siblings of the injured child] think their mother doesn’t love them, because I’m not there for them”* [P2]. Primary caregivers also reported that family mealtimes were now disrupted due to dysphagia and feeding difficulties: *“It can be quite disruptive, because I have to sit with him until he’s finished...”* [P3], with another noting that: *“For 12 months, we never really ate together as a family”* [P1]. To minimize the impacts experienced by the family, one noted that since the injury she has had to learn to advocate not only for the injured child, but also, *“for myself, and for my husband, and my other children”* [P4].

4. Discussion

Dysphagia and SLP involvement following pediatric chemical and button battery ingestion injury is currently under-explored within the literature. While traumatic stress is expected in caregivers of acutely unwell children irrespective of diagnosis and prognosis, chemical and button battery ingestion injury has additional multifactorial impacts (i.e., sudden onset, protracted difficulty with PO intake, the potential need for long-term invasive medical intervention) that may further compromise caregiver well-being. This study provides insight

into the experiences of caring for a child with dysphagia and feeding difficulties following chemical ingestion injury, with a view to providing clinicians with heightened insight into management of this population. Although the group of primary caregivers interviewed had children of differing ages and with heterogeneous injuries, all reported considerable lifestyle changes and similar associated stresses and concerns. Many also identified areas for future service improvements. The current data highlights specific issues experienced by primary caregivers, and poses areas for improving primary caregiver and family supports.

The psychological impact of the extensive and invasive medical care required post-injury emerged as a strong theme, which aligns with existing pediatric burns literature [24,25,32]. Caregivers discussed the trauma of witnessing their child undergo medical procedures, as well as the challenges associated with the prolonged need for medical intervention. Specific impacts on daily living included sleep disturbance, reduced work capacity, and financial difficulties. Depending on severity, chemical ingestion injuries may require protracted, and oftentimes invasive (e.g., routine gastroscopy), medical intervention. Additionally, consideration of nutritional and psychosocial needs is equally as important, and may mitigate the impacts of such complex procedures. Therefore, primary carer education regarding anticipated stressors, as well as access to psychological support is an important management consideration for this population [24]. It is suggested that further research with this population should incorporate psychosocial measures of functioning as a means of measuring impact on the child, primary caregiver and wider family unit.

At an average of 4.13 years post injury (range = 23 months to 9.5 years), only one child had returned to full, regular diet. However, the caregivers of all children described some degree of ongoing feeding difficulties, such as the need for compensatory strategies and mealtime modifications to assist intake. It is important to recognize that the presence of ongoing mealtime and PO intake issues in this clinical population may be contributed to by physical/anatomical changes post injury. Modified texture meals and strategies such as small portions and pacing of PO intake can help to mitigate issues arising from the ingestion injury and subsequent esophageal surgery. However, it is also possible that some additional behavioral issues related to feeding may be present. Because of the ingestion injury and any subsequent invasive surgical and medical procedures required, children might have altered anatomy that results in discomfort whilst eating. It is known that repeated, aversive experiences associated with PO intake or contact around the face or mouth could result in a

decreased desire to eat, and present as difficult mealtime behavior to parents [21,33] even after resolution of the original medical condition. In addition, the presence of dysphagia (that may present as unpleasant coughing or choking during PO intake) may result in the child's reduced ability and willingness to eat [34]. Responses on the CPEQ are suggestive of behavioural difficulties as per the original intent of the questionnaire, but may also be reflective of underlying medical issues that necessitate meal modification (e.g., the child cannot eat the same food as the family as they can only manage soft food). Assessment of feeding issues in this population therefore requires consideration of sensory/ learned behaviors, anatomical limitations, (which may change over time with surgical/ medical intervention), maintenance of nutrition, safety (i.e., risk of aspiration) and social impacts [35–37]. Potential assessment and treatment considerations within this population are further outlined in Figure 1.

\Insert Figure 1 here\

Given that children develop oral motor skills for eating and drinking sequentially during the early years of life, interruptions to skills development, and aversive experiences, may have impacted on feeding development and willingness to return to pre-morbid PO intake in the children in the study who were younger than two years of age [38–40]. The oldest child in the study was over 14 years of age at time of injury, and reported to be tolerating a normal (i.e., non-modified) diet when the primary caregiver was interviewed two years' post-injury. Additionally, there were no reported difficult mealtime behaviors on the CPEQ for this older child. It is postulated that, at the time of injury, this child already had well-established feeding skills and an intrinsic enjoyment of eating. A lack of developmental obstacles for this individual may have contributed to their return to a full PO diet. Thus, age at the time of injury is likely to be an important factor to consider in developing rehabilitation programs for this population of children.

Periods of non-PO feeding are common among children with chemical ingestion injury [3] and all primary caregivers had managed, or were still managing non-PO feeding at the time of interview. The stresses and concerns related to providing non-PO feeding, particularly early post injury were a common theme in the interviews. Primary caregivers expressed concerns regarding the limited available supports for managing non-PO feeding, and that they received inadequate education prior to hospital discharge. This finding is not unique to this group, and parents of children receiving enteral feeding are likely to experience

stress [27]. The concerns raised by the primary caregivers in this study highlight the importance of ensuring there are appropriate services available to support caregivers who must provide non-PO feeding. Facilitating better access to specialist training and support in the initial stages post injury may help to alleviate these early fears/concerns.

Across the group of primary caregivers, a wide range of allied health support services were accessed at various stages post injury, including dietetics, SLP, physiotherapy, and psychology. While some were pleased with their experiences, a majority felt they did not receive adequate support, and that there was an absence of ongoing and coordinated care. This may reflect the common issue that initiation of care by allied health professionals relies on referral from the medical and surgical teams who typically manage children post-ingestion injury in the acute phase [17], and that allied health input may not be considered a priority at the time of acute injury. Additionally, there are often no allied health professionals allocated specifically to care of children with ingestion burn injuries [41]. Factors impeding comprehensive multidisciplinary involvement in pediatric acute care have been identified in other populations, including a lack of care guidelines [42] and conflicting views regarding the patient's readiness to participate in therapy [43]. Caregiver and family needs following traumatic injury change over time, and while professionals do well in supporting patients in the rehabilitation setting, many underestimate future care needs [44]. Although recall bias needs to be considered regarding experiences of services and support, the current interviews suggest the need for further improvements to the coordination of services, as well as recognition for the need for long-term maintenance and reviews.

Primary caregivers also commented on their own ability to cope as well as impacts to the family unit arising from the initial injury and recovery period. Consistent with the current interviews, prior research has found parents report several physical, social, and psychological impacts following traumatic injury to a child [45]. Studies examining parental stress following thermal burn injury report parents experience significant guilt from one to ten years' post-injury to their child, depending on injury severity [46]. Undesirable impacts of child injury can also extend to the wider family unit. Siblings have been found to feel isolated, unimportant and resentful [47], experience disruption to the family routine [48] and have reduced behavioral and academic performance [49]. There is a paucity of programs that provide education to assist caregivers with supporting the wider family unit post-childhood injury. Considering the current and existing experiences, models of family-centered,

coordinated care should be incorporated to ensure not only the patient, but the whole family unit is appropriately supported in the weeks, months and years following ingestion injury. An approach that considers the individual needs of a family, based on their priorities and preferences around mealtimes and feeding (including meal preparation and non-PO feeding) is important to maintain quality of life for the child and family. Considering too the broad psychosocial impacts that the current caregivers described, involvement of social work and/or appropriate mental health professionals to address the individual needs of the family members, and not exclusively the health comprised individual, need to be considered.

This study is the first to provide an in-depth investigation of the experience of primary caregivers of children with dysphagia and/or feeding difficulties following severe ingestion injury. Although the number of participants was small, this is reflective of the low incidence of severe ingestion injury with long term feeding consequences in the pediatric population [3,50]. Despite this, and the heterogeneous nature of each primary caregiver's experience, high consensus was often noted regarding issues raised. It is acknowledged that patients in this study were managed through the same quaternary hospital, and some issues raised, such as access to services, may not reflect the exact experience of children admitted to other centers. However, limited involvement of speech pathology in the care of children with ingestion injuries has been reported as a common occurrence across acute-care facilities servicing this population [51]. Furthermore, there are many features of this research that can be applied to other populations in exploring the impact of complex medical conditions or traumatic injury on families. Future prospective research of both the child and the family unit following severe ingestion injury is needed so that the specific needs, nature and timing of required services for supporting altered PO intake issues can be more fully identified.

5. Conclusion

Pediatric chemical and button battery ingestion injury is a complex medical issue that may result in the need for long-term medical care, and compromised PO intake. There is currently limited information to guide practitioners in mitigating stressors experienced by primary caregivers, and the wider family unit. This investigation highlighted that primary caregivers of children following ingestion injury experience wide ranging impacts and challenges in caring for a child with complex medical issues and altered PO intake needs that can extend to the wider family unit. Numerous issues were raised regarding the adequacy of support services, highlighting areas for improvement, particularly in education and

coordination of long-term multidisciplinary follow-up and goals for rehabilitation, such as increasing PO intake, optimal diet/fluid modification, feeding intervention, and primary caregiver education. Such models of home-based, coordinated multidisciplinary care have been employed in other pediatric populations [52–54] and should be considered for this population. Medical teams can also ensure that ongoing surgical intervention is coordinated with psychological and feeding interventions. Improvements should be made to ensure that all family members have access to adequate support following a child's traumatic injury, particularly in the long-term. Adoption of family-centered models of care may be one method by which to achieve such improvements.

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Declaration of Interest

Conflicts of interest: None.

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Table 1.

Injury Details and Characteristics of Admission (n = 5)

Variable	n (%)		
Injury etiology			
Alkali substance	4		(80)
Button battery (20 mm 3v lithium)	1		(20)
Injury severity [#]			
Grade I	1		(20)
Grade II	3		(60)
Grade III	1		(20)
PICU admission	4		(80)
Altered oral intake during admission	5		(100)
Gavage feeding during admission	5		(100)
Feeding therapy during admission	3		(60)
	M	SD	Range
Age at injury (years)	4	5.7	1-14.16
Length of PICU admission (days)	8	3.3	4-12
Duration of acute admission (days)	29	22	12-66

Note. [#]Injury severity determined using Zargers (1991) Endoscopy Grading of Injury Severity; PICU = pediatric intensive care unit

Table 2 Child and Injury Characteristics at Time of Interview (n = 5)

Parameters	Cases				
	1	2	3	4	5
Age at injury (years)	1.8	1.6	1	1.8	14.2
At interview (years)	3.7	3.9	5.6	11.3	16.3
Months post-injury	23	27	55	118	25
Ingested material	Caustic soda	Caustic soda	Button battery	Caustic soda	Caustic soda
Enteral feeding					
Commenced	7 months	1 month	2 months	1 month	9 days
Ceased	Ongoing at time of study	Ongoing at time of study	Ongoing at time of study	24 months	1.5 months
Current mode of nutrition	PO + non-PO	PO + non-PO	PO + non-PO	PO only	PO only
Non-PO feeds	Bolus feeds 2x daily + continuous overnight feeds	As required	As required	-	-
PO intake					
Commenced	12 months	3 months	5 months	4 months	2 months
Current diet	Soft/ pureed	Soft	Soft/ pureed	Soft	Regular
Currents fluids	Mildly thick	Thin	Mildly thick	Thin	Thin
Intervention					
Esophageal dilatations	As required	Every 3-4 weeks	Every 6-8 weeks	Every 6-8 weeks	Annually
Surgical	-	Staged esophageal replacement	-	Fistula repair + staged esophageal replacement	Esophageal replacement
Issues with PO intake	Restricted	Insufficient	Dysphagia	Dysphagia	Odynophagia
Mealtime modifications and strategies	Fluid flushes Flavor modification	Fortification to increase calorie intake	Supervision Pacing	Small portions Fluid flushes Supervision Pacing	Small portions Pacing
Current SLP involvement	No	No	Yes	No	No

Note. SLP = speech-language pathology, PO = per os

Table 3.

Comparison of Primary Caregiver Ratings on the CPEQ with Normative Data for Children with Typical Feeding Behaviours

	Questions	Norm [*] M ± SD	Case 1 45 mths Score (↑↓SD)	Case 2 47 mths Score (↑↓SD)	Norm [∞] M ± SD	Case 3 67 mths Score (↑↓SD)	Norm* M ± SD	Case 4 136 mths Score (↑↑SD)	Case 5 195 mths Score (↑↓SD)
Negatively scored	1. To what extent would you consider your child to have a feeding problem? [§]	1.9 ± 1.1	6 (↑3.73)	6 (↑3.73)	1.9 ± 1.1	6 (↑3.73)	1.6 ± 1.0	4 (↑2.4)	1 (↓0.6)
	5. How often do you attempt to persuade your child to eat a food? ^ψ	3.4 ± 1.5	7 (↑2.4)	5 (↑1.06)	3.8 ± 1.8	4 (↑0.11)	3.4 ± 1.4	5 (↑1.14)	1 (↓1.71)
	6. How often do you provide a food reward for eating a food you think your child should eat? ^ψ	2.3 ± 1.5	6(↑2.46)	5 (↑1.8)	2.5 ± 1.8	1 (↓0.83)	2.0 ± 1.3	5 (↑2.31)	1 (↓0.77)
	7. How often do you prepare a special food for your child because he/she does not like what the rest of the family is eating? ^ψ	1.9 ± 1.0	6(↑4.1)	3 (↑1.1)	1.5 ± 0.8	1 (↓0.63)	1.6 ± 0.7	7 (↑7.71)	1(↓0.86)
Positively scored	2. Overall, to what extent does your child like a wide variety of foods from those that you think he/she should eat? [§]	5.6 ± 1.0	7 (↑1.4)	5 (↓0.6)	5.4 ± 1.1	7 (↑1.45)	5.4 ± 1.0	7 (↑1.6)	7 (↑1.6)
	3. Rank your child's eating behavior as a whole (extremely poor to extremely good eater) ■	5.6 ± 1.1	5.5 (↓0.1)	3.5 (↓1.91)	5.8 ± 0.6	5 (↓1.33)	5.9 ± 0.7	1 (↓7)	7 (↑1.57)
	4. In general, at the end of the meal how often has your child eaten the amount you think he/she should eat? ^ψ	5.1 ± 1.3	7 (↑1.46)	5 (↓0.07)	5.3 ± 1.2	1 (↓3.58)	5.6 ± 1.1	7 (↑1.27)	7 (↑1.27)
	8. How often does your child try new and unfamiliar foods at	2.5 ± 0.9	2 (↓0.55)	2 (↓0.55)	2.7 ± 0.9	7 (↑4.78)	2.6 ± 0.9	3.5(↑1)	7 (↑4.89)

home?^Ψ

9. How willing is your child to try new and unfamiliar food when offered? δ	4.7 \pm 1.3	4 (\downarrow 0.54)	2 (\downarrow 2.08)	4.5 \pm 1.6	5 (\uparrow 0.31)	4.8 \pm 1.4	3.5(\downarrow 0.93)	7 (\uparrow 1.57)
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♦ = Carruth and Skinner (2000) norms for 42-month old children

∞ = Carruth and Skinner (2000) norms for 67-month old children

* = Carruth and Skinner (2000) norms for 84 month old children

§ Question 1 and 2 were rated with 7 = to a great extent and 1 = not at all

■ Question 3 was rated with 7 = extremely good and 1 = extremely poor

Ψ Question 4 to 8 were rated with 7 = always and 1 = never

δ Question 9 was rated with 7 = extremely willing and 1 = never

negatively scored = higher score indicates greater frequency of undesirable feeding behaviors

positively scored = higher score higher frequency of desirable feeding behaviors

$\uparrow\downarrow$ = number of SDs above or below the normative group mean reported by Carruth & Skinner (2000)

Values >1 SD above or below the norm group mean are in bold typeface

ACCEPTED MANUSCRIPT

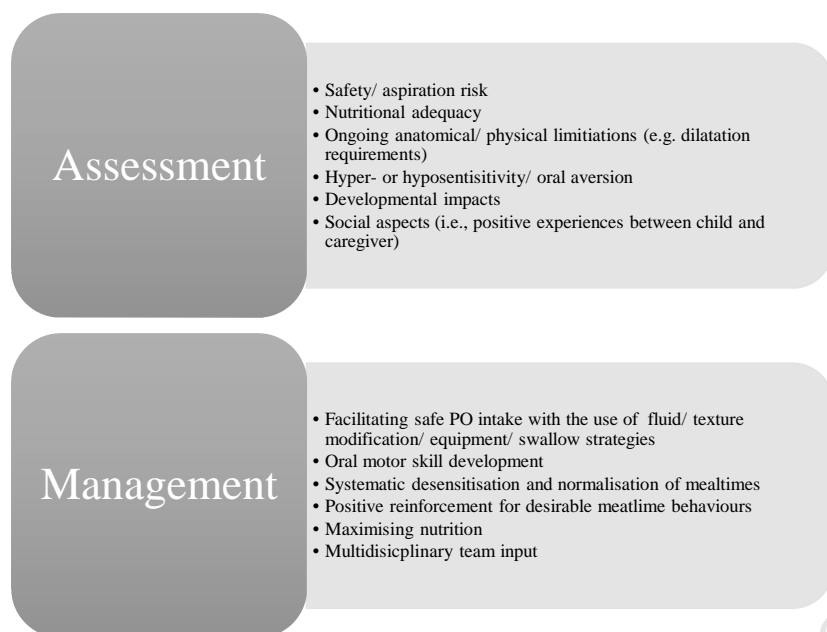


Figure 1. Potential assessment and management considerations of professionals providing feeding therapy to children post-chemical ingestion injury