


ORIGINAL ARTICLE

Group-urotherapy for children with complex elimination disorder: An Australian study

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Abstract

Elimination disorders are common in children and are associated with increased levels of psychological distress for both the child and their family. Despite successful treatments for elimination disorders, 30% of children do not respond to standard treatments to achieve continence. In these cases, a Urinary and Faecal Incontinence Training Program for Children and Adolescents (UFITPCA) has been established as an adjunct to existing therapy. The aim of the study is to explore the experiences of children who participated in the program. A qualitative design was employed with female children, aged 7–8 years, ($n = 4$) who participated in the UFITPCA program participated in a 60-min focus group interview. The parents of the children ($n = 4$) were also interviewed. Data was collected at the end of the 9-week program and analysed to identify themes that encompassed the experiences of the UFITPCA program and associated outcomes amongst both the children and their parents. Three central themes were emerged from the data, which included: Make it Stop, I'm not Alone, and Look at what I can do now. These findings were encapsulated by the desperation and frustration of children and parents prior to commencing the program; the widespread positive implications for the children's wellbeing from having engaged in a program with others just like them, and their sense of satisfaction of putting their newfound knowledge into practice. Both children and parents recognized a change in their child's overall sense of wellbeing and parents identified that their children felt more in control of symptoms and how they responded when symptoms arose. The children experienced an increase in their acceptance and self-efficacy of their symptoms.

KEYWORDS

childhood, group program, incontinence, patient experience, therapy resistant, urotherapy

What we currently know

While the majority of children with elimination disorders achieve continence through standard evidence-based treatment, some experience a prolonged treatment resistant trajectory and these children are classified as having a complex elimination disorder (CED). A sophisticated group-

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urotherapy program has been developed by a team of European experts that has shown success in reducing symptom frequency amongst children experiencing CED. Despite this, there is a dearth of literature exploring the experiences of children engaged in a treatment program for CED.

What does this article add

The current study presents a close exploration of the experiences of children aged 7–8 years who engage in a modified group urotherapy program delivered in regional Australia for the first time. In addition, the voices of the parents are included given the widespread impact CED has been shown to have on families. Improving our understanding of these experiences will help health professionals to better comprehend how best to motivate children and parents to engage in these further treatment opportunities.

1 | INTRODUCTION

Disorders of elimination are common, effecting up to one in five children worldwide and are reported to be a psychologically distressing series of conditions for both the child and families.¹ Disorders of elimination, include both day and night urinary incontinence, as well as faecal incontinence. Each of these is defined through the International Childrens' Contience Society (ICCS). Nocturnal enuresis being described as intermittent incontinence of urine occurring during sleep and day time wetting is classified as the leakage of urine in discrete amounts amongst children aged 5 years and older, at a frequently as at least once a month for three consecutive months.²

Irrespective of the sub-type, incontinence has been shown to have a negative impact upon children's quality of life^{1,3} as well as that of their parents^{4,5} and wider family.⁶ School age children live with a constant sense of fear about being exposed in front of their peers,^{7,8} which has the potential for serious implications for the child's psychosocial well-being and comorbid psychopathology as they progress into adolescence and adulthood.^{3,4,6,9,10} For parents, the degree of the perceived impact tended to correspond with the incontinence sub-type that their child experienced,⁶ with functional constipation and faecal incontinence in children being identified as leading to family conflict,¹¹ with increased parental depression, and lower quality of life.¹²

Thankfully, with evidence-based interventions, the majority of children who experience incontinence are able to be successfully treated and achieve continence.¹ Even in situations where children do not achieve continence, studies routinely identify a correlation in reduced symptom frequency with improvements in measures of psychological wellbeing, and self-esteem amongst children.^{1,13–16} There are a series of standardized treatments that are recommended for each sub-classification of incontinence; including incontinence alarms, and pharmacological therapy, as well as urotherapy.^{2,17,18}

There are however, children who do not respond to these standardized treatments and are said to have a complex elimination disorder (CED).¹⁹ Approximately 30% of children are therapy-resistant and experience a prolonged trajectory of periodic symptoms, consistent with remission and exacerbation that relate to either the bladder or the bowel or both.^{19,20} Children and adolescents with CED and their families have been reported as feeling neglected by the healthcare system because of

their ongoing resistance to standard treatment options.¹⁹ At times these same frustrations have been reported by treating clinicians and have led towards unnecessary and ineffective treatments or a pause in therapy all together. These experiences have been identified as leading to feelings of abandonment and even a sense of incompetence in their healthcare treatment.^{13,19,21} Moreover, the chronic nature of the incontinence amongst children with CED coupled with a lack of available therapeutic pathways, has been shown to lead to psychological strain, low levels of self-esteem and feelings of helplessness amongst children and families.^{22,23}

To address these complex elimination issues amongst children, a manualised bladder and bowel training program was developed.¹⁹ The program integrates (not only the elements of standard urotherapy), a number of psychotherapeutic elements including, psychoeducation and cognitive behavioural interventions (e.g., perceiving and dealing with emotional states, stress management, relaxation techniques). The group approach supports children to share experiences with other children, fostering an increase in self-esteem through recognizing that they are not alone in their experience, while at the same time increasing treatment compliance, and development of social skills. The UFITPCA program consists of nine sessions, with seven sessions focused on bladder training and two sessions that focus on faecal incontinence and constipation.¹⁹ To support the consistent operationalisation of the UFITPCA program, the developers,¹⁹ have published a user guide, inclusive of visual presentations and supporting documentation, for specialist clinicians to use in their practice with children and families that meet the criteria for CED.

Despite the value of urotherapy programs to children with CED, to the best of our knowledge the experiences of parents and children with CED engaging in the specialized urotherapy treatment of the UFITPCA program has not been previously explored. The aim of this current study, therefore, is to present one element of a larger study²⁴ that focuses on a close exploration the experiences of children aged 7–8 years who engaged in the modified UFITPCA program as an approach to managing their CED symptoms and improving their sense of wellbeing. In addition, the experiences of the parents of these children are also examined in light of the widespread negative impact of CED has on a family. It is anticipated that improving our understanding of this experience will help educators, health professionals and families to better comprehend how to motivate children and parents to engage in these further pathways.

2 | METHODS

2.1 | Study design

This qualitative study was intended to gain an in-depth understanding of the everyday meanings that the children experiencing CED and their parents constructed of their experiences with and of the urotherapy program, using a hermeneutic phenomenological approach informed by the philosophy of Hans-Georg Gadamer.²⁵ The hermeneutic phenomenological approach enabled the essence of the experience to be explored through the words of those people immersed within the phenomena itself.

2.2 | Research setting

Data were collected at the conclusion of the 9-week UFITPCA program. The study setting was a single-site specialist continence service in regional Australia. The focus group interviews with the children and the one-on-one interviews with parents were undertaken in this setting.

2.3 | Participants

It was expected that a group of 12 children and their parent(s) would be recruited to three separate programs across a 12–18-month period of data collection. Due to unprecedented requirements during the COVID-19 pandemic only four children (all female) and their parent(s) could be recruited to the initial program conducted prior to the restrictions prevented the program's continuance. All children had to meet the inclusion criteria for the program: (1) the child has a history of bladder and bowel disorder diagnosed and managed by the specialist continence service; (2) the child did not achieve continence following standard treatment and is therefore considered to have CED; (3) the child is otherwise developmentally healthy, (4) is able to comprehend and converse in English; and (5) aged 6–10 years. Parent participants were required to be the parent/guardian of a child engaged with the UFITPCA program.

Approved by the institutional Human Research Ethics Committee (HREC/55643/BHSSJOG-2019-185 482 v3) was received prior to commencement of the study. The study was conducted in adherence with the ethical principles for medical research on human beings as set out in the Declaration of Helsinki. All participants, including the children provided written informed consent/assent prior to commencing the collection of any data.

2.4 | Data collection

Specialist continence clinicians, representing the disciplines of physiotherapy and nursing, who have undergone specific post-graduate education in paediatric continence therapy, worked with the detailed UFITPCA program manual¹⁹ and remained as faithful as possible to the outlined program. However, following a close

reading they undertook to contextualize the program for an audience of Australian children. For example, language changes from American vernacular to Australian, including, 'pee' changed to 'wee', spelling changed to Australian spelling, e.g., 'Esophagus' to 'Eosophagus'. Some activities were adjusted to suit the Australian audience also, including using local food and drink choices for activities relating to diet and fluids.²⁴

At the final session of the 9-week program children and parents were invited to participate in an interview with the research team. Parents participated in a one-one interview with a member of the research team to understand their experience of the UFITPCA. Children, all of whom were female, from the UFITPCA program on the other-hand were invited to participate in a focus-group interview seeking to understand their experience of being a part of the UFITPCA program. The children were interviewed together at the end of the program and being comfortable and feeling supported by their new peer group, they each spoke openly about their experiences.

Each interview was conducted by a member of the research team, who had not been involved in the delivery of the UFITPCA program or the selection of the children who attended the program. The one-on-one interviews with parents lasted between 45 and 75 min and began with an open question 'Can you tell me what it has been like for you to have your child engage in the UFITPCA program?'. Similarly, focus group interviews were conducted with the children for approximately 60 minutes. The children were asked 'Can you please tell me about what it has been like for you to be a part of this program?' and then 'How has the program helped you?'. The children were encouraged by the researcher to take turns to share their responses and were able to contribute to the answers of other children.

2.5 | Data analysis

Qualitative interviews were analysed using an approach outlined by Colaizzi,²⁶ which followed the procedural steps (verbatim transcription, extraction of significant statements, identify similarities in formulated meanings, group the similar meanings, create an exhaustive statement).²⁴ Close contact with the experiences was maintained through engagement with the audio recordings and transcribed interviews, supporting the identification of significant statements that pertained to the phenomena of interest. The meanings formulated were then clustered together to form themes that encompassed the experiences of the UFITPCA program for both the children and their parents.

3 | FINDINGS

The experience of children with CED engaging in a modified UFITPCA and their parents were embodied by way of three central themes that arose from the data analysis and capture the essence of their collective experience: *Make it Stop, I'm not Alone*, and *Look at what I can do*

now. Each of these is unpacked in detail below. In terms of the quotations provided below, each child is associated with the respective parent: Child 1 is the daughter of Parent 1 and so on.

3.1 | Make it stop

Children and their parents outlined a journey described as a roller-coaster as they navigated the health services seeking a resolution to their symptoms. When invited to be part of the program the children described that they had been experiencing an increase in the severity of their symptoms. The child and the parents described a feeling of desperation underscored by a strong sense of wanting someone or something to 'make it stop'.

Well I've been wetting my pants at school so that's - so - and I've had a few poo accidents at school so that's how I came here. (Child 1).

When I was asked about coming here, I was like this, oh make it stop. (Child 2).

The exasperation of parents was palpable along their child's contenance journey and they were eager to find something to make it stop for their child and family.

I think when it came up, as I say it was really, it was almost like we'd been clutching at straws because nothing was working. So, it came up, and it was a chance, well we cannot - you know we do not know, we have got to try everything.... it really was a case of, I'll try anything now because we just were not seeing an improvement with anything else. (Parent 1).

I felt like we'd kind of given up almost. We were like, this is just what it is now. We were like, we'll give it a shot, see how it goes. But we were not very optimistic to be totally honest (Parent 2).

Despite exhausting the available treatment options, both the children and parents came to the UFITPCA having experienced an overwhelming increase in their child's CED symptoms. While both parent and child wanted to make it stop, parents carried a burden of not knowing where to turn next in their roller-coaster journey to find a solution for their child.

3.2 | I'm not alone

Children emphasized their initial reluctance to form part of the UFITPCA program feeling embarrassed about their symptoms and the seemingly uncontrollable nature of them. Despite the reluctance once the children commenced the program there was an overwhelming sense of relief and empowerment at the realization that they were not alone in their struggles and that there were other children just like them. The following is indicative of the views of the children more broadly:

Well, actually, at first, I did not want to go because I thought people would make fun of me and people would tell - I thought that I was the only one, yeah, but then when I came here, I realized that I'm not. (Child 3).

This element of the investigation sought to encourage open dialogues between the participants and as such an all-female group was established with positive results.

It was good because I like making new friends and I like to talk about it because they are all girls and I now know girls who have the same problems. (Child 4).

The parent participants echo the overwhelming benefits of their children coming together. Having often been on a 'roller-coaster' ride of attempting to help their children, the parents were very supportive of the group nature of program as a vehicle for helping their children.

Usually, we sit here with one person talking in a room about what we can do to solve it, and that's probably not really the way to go. So instead, they are in there doing a few fun tasks, and there's four girls in the group. They're able to discuss it quite openly, and because they are all having the same issue, there's no judgement in there. (Parent 1).

The change in (daughter) from when I dropped her off to when I picked her up, was quite dramatic. Because I think she'd finally found a group of people that are like her. They're going through the same issues. She just realized she wasn't alone in this and it does not just happen to her. It happens to a lot of people. (Parent 2).

Children experienced a strong sense of empowerment from being part of a group of children experiencing similar symptoms. Recognizing that they were not alone in their struggle, the program provided a judgement free and supportive space, perhaps for the first time.

3.3 | Look at what I can do now...

Having completed the UFITPCA program children shared their experience of putting their newfound knowledge into practice. Children described with pride their feeling of being in control over the frequency of symptoms and their recognition and response to neurological stimuli, as if it had been discovered for the very first time.

If I find that I have a wee, I feel pleased because I know that there's one there, and I will not have an accident if I go straight away. (Child 1).

The overall outcomes of the UFITPCA program for the children were positive for each individual child. The following is indicative of the broader group.

I have not had a wee accident in a long, long time. (Child 4).

I feel a bit more calm because I've been - I have not been having as much accidents since I came to PUG (Paediatric Urotherapy Group). (Child 1).

The experiences of the parents also lends itself to the overall positive outcomes of the program for their child and the parent's capacity to support their child. Parents described the influence that the program had on their child's symptom frequency.

I'd say it's a lot less frequent (symptoms), definitely. It's not stopped, we know that much. But I think it's almost now as if she realizes, perhaps, she's feeling something. (Parent 1).

I do not think the actual symptoms have changed, but I think how she responds and reacts to it has. (Parent 2).

The parents also described the 'intangible' outcome of the program such as an influence on their child's confidence and instilling a sense of empowerment amongst the family.

She's confident, and I think part of this probably helps because, well, she certainly wasn't this confident if we go back six months. (Parent 1).

So, she's saying to us, oh, I think I need to go to the toilet now or else I might have an accident...so, because of that we can offer more support and we feel a bit more empowered as well. (Parent 2).

Insights into both the tangible and intangible outcomes of the UFITPCA program were articulated by both parents and children. While parents did not report a notable reduction in the frequency of their child's symptoms, the way in which their child is now able to both respond to their biological signals as well as engage confidently in more open conversations with their parents about their CED are certainly considered strengths of the program.

4 | DISCUSSION

This study sought to explore the experiences of parents and children aged 7–8 years undergoing urotherapy for the management of CED. A central finding from this study centred around the widespread positive implications for the child's wellbeing from having engaged in a group urotherapy program. Both children and parents indicated that the group nature of the program had influenced the child's sense of isolation in their condition experience as well as their confidence to discuss their CED more openly with others. For many within the group, this was the first time that they had engaged with other children with the same kinds of elimination issues and therefore had the possibility of sharing their experiences without apprehension. These findings coincide with those from Saarikoski et al.,⁸ who explored the experiences of children engaged in a Voiding School experience and highlighted the importance of peer group and social acceptance. Equit et al.,¹⁹ argues that the strength of peer support is one of the central justifications for the group approach and is supported consistently in existing qualitative studies that explore approaches to different sub-categories of incontinence.^{1,27} These benefits of peer-peer interaction, as a vehicle of helping children come to accept their condition, is also highlighted in studies that explore the experiences of children with other health related considerations, such as hearing loss,²⁸ diabetes²⁹ and multiple-sclerosis.³⁰ While the influence of the all-female child cohort on their ability to communicate openly about their elimination issues amongst those participants in the current study is difficult to quantify, previous research^{31,32} is suggestive of this approach as having some value. We suggest that future studies that seek to compare the therapeutic outcomes for mixed and single-sex cohorts of children will offer a valuable contribution to the literature and for practice.

The findings identify the capacity of the UFITPCA program to influence a change in the perception of both symptom frequency and severity amongst children and parents. While at times children and parents appeared to have different perceptions about changes in symptom frequency, it is noteworthy that the self-belief embodied by the children might reasonably influence the child's overall emotional positivity. We postulate that the children with CED are likely to experience a degree of self-stigmatization where they internalize the stereotypes and prejudices of the general population and is characterized by low self-esteem and negative feelings.³³ Previous research amongst those experiencing alterations in mental health seems to

support the effectiveness of programs that bring together contact with others experiencing similar conditions on improving self-esteem amongst adolescent and adult populations.^{33–35} While there are limited studies that examine child populations, we suggest that the influence of the group approach to therapy may have had a profound effect on the self-stigma of children within the program and improving their sense of personal competence and worth. Arguably, this finding is consistent with improved levels of self-efficacy,³⁶ and increased self-awareness,¹⁹ which were identified previously as outcomes of standard urotherapy programs. In the context of this study, there is an opportunity for studies that examine changes in self-stigma and its influence on self-esteem within the CED population of children.

Children and parents described their tumultuous journey through the healthcare system prior to being invited to the UFITPCA program. This is reflected elsewhere by Buckley et al.,³⁷ who suggest that incontinence in children is a neglected clinical area and by Equit et al.,¹⁹ highlighting that children and families have been reported as feeling 'neglected' by the healthcare system because of their treatment resistance, which in turn, leads to a sense of frustration and incompetence in their team of healthcare professionals. The prolonged nature of elimination issues for these children and their families is particularly problematic. Caldwell et al.,¹⁵ found that children with nocturnal enuresis were at great risk of behavioural and psychological disorders, particularly in the presence of treatment failure³⁸ warranting early intervention. Worryingly, a study by Gontard et al.³⁹ found that up to 40%–50% of children experiencing faecal incontinence and daytime wetting meet the criteria for a diagnosable psychiatric disorder. Moreover, links between prolonged symptoms and health related quality of life leading to serious psychosocial consequences into adult life have also been identified.⁴⁰ Thank even in situations where children do not achieve continence, studies routinely identify a correlation in reduced symptom frequency with improvements in measures of psychological distress, self-esteem, and even behavioural symptoms amongst children^{1,13–16} In combination, these factors highlight a need for early intervention from a multidisciplinary team.

This study suggests that incontinence in children represents a neglected area of understanding that is complicated by a complex immixture of psychological and physiological factors. Parents, health, and education practitioners are well placed to provide tangible mechanisms for support through targeted social contact and maintaining open dialogue. While the smaller number of participants is a limitation, the deep level of engagement with children and families offered useful insights into these otherwise overlooked experiences. A larger qualitative exploration will work to capture the nuanced perspectives of these stakeholder groups to inform practice. In addition, future studies might do well to compare the therapeutic outcomes for mixed and single-sex children.

5 | CONCLUSION

This study aimed to understand the experiences of a group of female children aged 7–8 years, who engaged in the UFITPCA program and their parents. Recognizing the implications of a small sample size, the

findings from this study suggest that the UFITPCA program exerts an especially profound impact on children in the context of encountering other children with whom they have a shared experience. While the children did not achieve continence, they have experienced an increase in their acceptance and self-efficacy of their symptom management. Children and families recruited to the study have likened their experience to one of a 'roller-coaster' ride through the healthcare system as they search for possible solutions. The UFITPCA program offers children with CED and their families a valuable, intervention that provides a promising foundation for future research.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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