Research report

Exploring parents' knowledge of prodromal high blood glucose symptoms prior to the diagnosis of type 1 diabetes in children

Abstract

Background A high proportion of Queensland children diagnosed with type 1 diabetes presented in diabetic ketoacidosis (DKA) over the last 2 decades. The Statewide Diabetes Clinical Network (SDCN) prepared a campaign to reduce paediatric DKA at diagnosis.

Aims and objectives The overall aim was to prepare the awareness campaign. The specific project objectives were to:

- Explore parents' knowledge of prodromal high blood glucose symptoms requiring medical review.
- Understand where and from whom parents seek child healthcare and advice.

Design Anonymous, self-completed survey.

Setting and participants A link to the survey was posted on the Playgroup Queensland's Facebook page. The target audience were parents of children in Queensland.

Results One hundred and two parents responded. Parents only prioritised two of the four prodromal symptoms of high blood glucose levels when asked to choose which common childhood complaints would prompt them to present to the GP. Most parents accessed their GP for healthcare, although some reported difficulties in getting appointments and cost as barriers. Respondents also accessed community child health and used the personal health records to source information and advice.

Conclusion The results suggest parents may not know the prodromal signs of high blood glucose levels in children. This could lead to delays in seeking a medical assessment and, in turn, the high number of children presenting in DKA at diagnosis. It is anticipated interventions aimed at improving parents' knowledge of prodromal signs will lead to earlier presentations for treatment and ultimately reduce the incidence of DKA at diagnosis.

Keywords Diabetic Ketoacidosis, type 1 diabetes mellitus, child health, hyperglycaemia, signs and symptoms

For referencing Buckley B et al. Exploring parents' knowledge of prodromal high blood glucose symptoms prior to the diagnosis of type 1 diabetes in children. Journal of Children and Young People's Health 2020; 1(1):X-x

DOI https://doi.org/10.33235/jcyph.1.1.x-x

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Introduction

The incidence of type 1 diabetes in Australian children under 14 years of age is 26 per 100,000 children.[1] In Queensland, the rate of children and adolescents under 16 years of age who present in diabetic ketoacidosis (DKA) at diagnosis of type 1 diabetes is increasing over time. A longitudinal study conducted at the Mater and Royal Children's Hospitals in Brisbane between 2001–2011 reported 31.9% (348/1091) of children diagnosed with type 1 diabetes presented to hospital in DKA.[2] Clinical data showed the rate had increased between 2015–2019 to 42.8% (142/355) for children presenting to the newly established Queensland Children's Hospital.[3] A state-wide audit was conducted in 2017 and revealed the average rate was 44.8%.[4] Comparable data was not available from other states in Australia.

The authors suggest the large geographical footprint of Queensland means that families are not able to access tertiary centres as readily. In addition, the hotter climate in Queensland may have an impact. Studies have also shown that rates of DKA at diagnosis are higher in countries closer to the equator, with hotter climates leading to rapid dehydration and metabolic decompensation in young children who have less metabolic reserve.[5] Cooler countries report lower rates of children who present in DKA at diagnosis. New Zealand has maintained a rate of 25% for the last 2 decades[6], while a rate around 14% has been achieved in Scandinavian countries.[7]

DKA is a severe and life-threatening metabolic emergency caused by insulin deficiency. The combination of hyperglycaemia, metabolic acidosis and ketonaemia leads to life-threatening complications including cerebral oedema, cerebral ischaemia and hypoxic brain injury.[8] DKA at diagnosis is associated with poor long-term metabolic regulation and residual beta cell function as assessed by HbA1c for up to 2 years after diagnosis. In addition, long-term suboptimal diabetes control due to DKA at diagnosis is associated with ongoing complications such as eye and kidney disease related to high blood glucose levels.[9–11]

DKA at diagnosis is considered preventable if the prodromal symptoms of high blood glucose (increased tiredness, weight loss, increased thirst and frequent urination) are recognised and acted on by parents and healthcare providers in primary care.[7,12] When children present with the symptoms, a simple and inexpensive finger prick blood glucose test can be performed by primary health clinicians and, if the blood glucose levels are ≥11mmol/L, a referral can be made to the emergency department. Unfortunately, children are seen two to three times in primary care before presenting in DKA at the time of diagnosis.[13] This suggests the need for GPs to have a higher index of suspicion for type 1 diabetes in children and adolescents with common illnesses and exclude hyperglycaemia as an underlying cause.

Given the poor outcomes associated with DKA at diagnosis, much work has been done to raise public awareness of the prodromal symptoms of hyperglycaemia, often referred to as the 4Ts – Tired, Thin, Thirst and going to the Toilet to urinate frequently. A literature reviewed of past campaigns to reduce DKA at diagnosis in children shows mixed outcomes. Localised awareness campaigns in the province of Parma, Italy[14] and Gosford, Australia[15] demonstrated some success by providing intensive collaborations to support primary care clinicians as well as public awareness campaigns. Large scale national public awareness campaigns in Wales and Austria, however, failed to demonstrate any impact.[16,17] Successful campaigns focused on working closely with local primary care clinicians to improve their symptom knowledge and displaying posters in clinic waiting rooms to increase parent symptom recognition. What was not clear through the literature review was what level of knowledge parents had regarding the prodromal symptoms of high blood glucose and need to seek medical care to prevent DKA at diagnosis. A previous investigation to determine the causes of DKA found parents delay seeking help about subtle symptoms. This study concluded that further interventions should ideally explore the relationship between parental knowledge and the duration of symptoms and severity of disease at presentation.[18]

This study is nested within a broader campaign being conducted by the type 1 working group of the Statewide Diabetes Clinical Network (SDCN) funded by Clinical Excellence Queensland. The project is a collaboration between the Townsville Health and Hospital Service (HHS), Mater HHS and Children's Health Queensland HHS. The campaign aims to reduce the rates of DKA at diagnosis of type 1 diabetes through an awareness campaign to be rolled out across the state of Queensland. In order to inform the broader campaign, the project team wanted to explore parents' knowledge of the prodromal signs of high blood glucose levels in children, and find out who they seek health advice from.

Aim

The aim of the project was to gather evidence to inform a broader awareness campaign to reduce rates of paediatric DKA at diagnosis of type 1 diabetes. The objectives of this project included to:

- Explore parents' knowledge of the signs of high blood glucose that require medical review prior to a diagnosis of type 1 diabetes in children.
- Understand where and from whom parents seek child health advice to inform a public awareness campaign to reduce DKA at diagnosis of type 1 diabetes in children.

Study design and methods

The DKA prevention study was approved by the Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (LNR/19/QCHQ/59345).

A co-design approach was used with broad health consumer and clinician consultation to inform a 13-item parent survey. The survey consisted of a combination of multiple choice, rank order and yes/no questions shown in Figure 1.

The Flesch Reading Ease score was used to review question wording to facilitate the involvement of parents with low reading ability. The survey was piloted among a range of staff with young children at the Queensland Children's Hospital (QCH) and Townsville University Hospital (TUH) and refinements were made based on feedback. The survey was embedded in the Microsoft Forms platform to enable completion on a smartphone.

To survey parents of healthy children under the age of 5 in a broad geographical net the project team collaborated with

1. How many children under 16 do you have?	
2. If you need child health information where do you get it?	Pharmacy Child health nurse Family Friends Internet GP Other
3. If you use the internet to find and access child health information please list the names of websites you most commonly use below	
4. Please select the symptoms below that would prompt you to take your child to the GP; please choose up to four answers	Excessively thirsty Lethargy (they have a lack of energy) They begin wetting the bed even though they usually don't do this anymore Going to the toilet to pee more often than usual Nappy rash Groin rash Mouth sores Weight loss High temperature General rash Nausea / vomiting
5. Would you go and see your local Pharmacist about any of the following? (please select all that are relevant to you)	Weighing your baby Infant nutrition information Constipation Blood glucose level check Nappy rash Teething Flu like symptoms
6. Do you have a regular GP that your child sees for child development checks, vaccinations or when they are generally unwell?	Yes ☐ / No ☐
7. Does your GP bulk bill your child's visits?	Yes ☐ / No ☐
8. Does the cost of a GP appointment sometimes stop you from going?	Yes ☐ / No ☐
9. Do you find it difficult to get an appointment with your child's GP when you need one?	Yes ☐ / No ☐
10. Do you use your child's personal health record (red book) for child health information?	Yes ☐ / No ☐
11. Have you ever visited your Community Child Health Centre?	Yes ☐ / No ☐
12. If you answered no to question 11, what are the reasons you have not visited your Community Child Health Centre? (please select all that are relevant to you)	Inconvenient location Inconvenient/unsuitable hours Insufficient services Unwelcome atmosphere No need to attend Not useful Use other services instead Unaware of service
13. What is your postcode?	

Figure 1. Parent survey

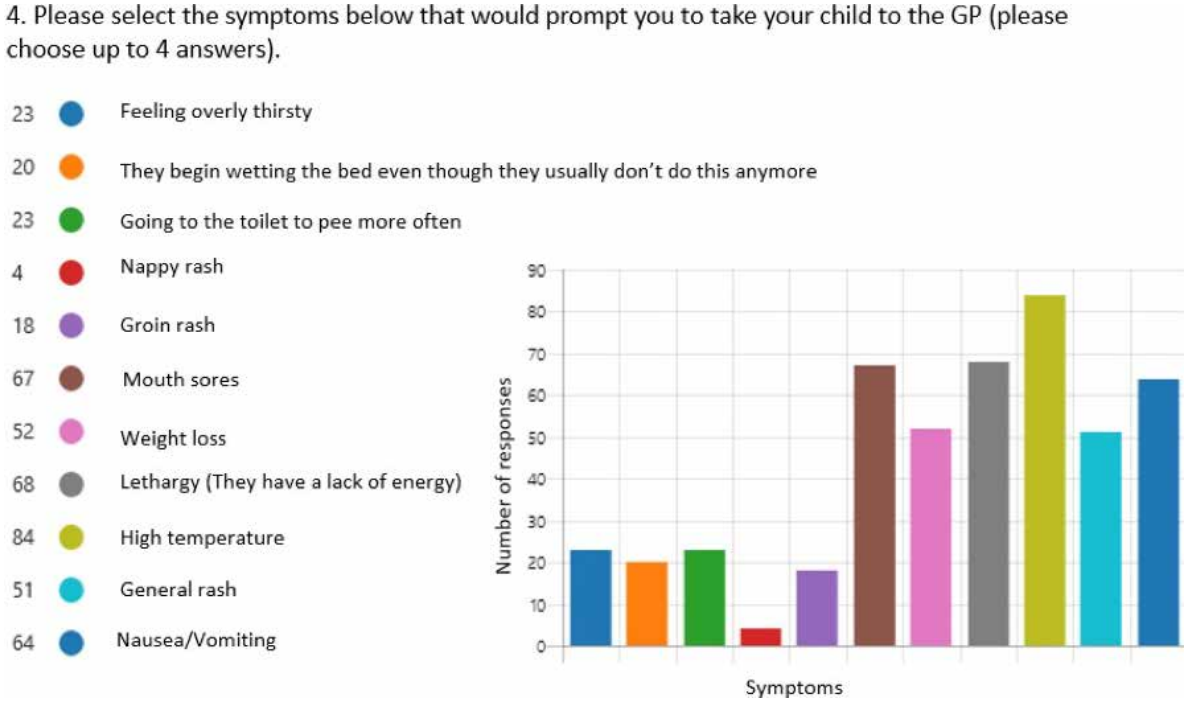

Figure 2. Symptoms that prompted parents to take their child to the GP

Playgroup Queensland who distributed a link to the survey and associated participant information on their Facebook page. A follow-up post was made on the Facebook page 1 week later to encourage participation. Participation in the survey was anonymous, with the responder's postcode being the only demographic information requested to ascertain if responders were from metropolitan or regional areas. There were no exclusion criteria to participate in the study. Parents were blinded to the purpose of the survey. The team aimed to collect at least 100 responses.

The target audience for the survey were parents of healthy children under 5 years of age across Queensland. This age group are less tolerant of insulin insufficiency and includes pre-verbal children who are at high risk of presenting in DKA at diagnosis.[15] Although further studies are needed to explore factors causing delays in diagnosing type 1 diabetes in other age groups, they are beyond the scope of this study. Stakeholders interviewed to inform the broader campaign reported teachers often noticed students with polyuria during class time and adolescents delayed disclosing bed wetting due to embarrassment. No studies on adolescents' knowledge of the signs and symptoms of hyperglycaemia were found in the literature reviewed for this study.

Results

The survey was open between 14 February to 4 March 2020. One hundred and two participants completed the survey. All results are presented as a proportion of the number of people who responded to each question. A total of 42% of the respondents were from metropolitan Brisbane postcodes, 33% from postcodes in Far North Queensland and the remainder from a variety of postcodes from the remainder of the state. Participants had an average of two (range 1–7) children.

Parents' knowledge

Parents were provided with a list of common childhood symptoms (Question 4, Figure 1) and asked to choose the four that would prompt them to take their child to a GP. Participants were blinded to the reason for the survey – the prodromal symptoms were included in the symptoms randomly spread throughout the list. Of the 102 parents who answered this question, the majority were most worried about a child with the following symptoms: high temperature 84 (82%); lethargy 68 (66%); mouth sores 67 (65%); nausea and vomiting 64 (62%) and weight loss 52 (50%). Parents' responses for two of the four prodromal symptoms of high blood glucose had lower scores: feeling overly thirsty 23 (22%); going to the toilet more than usual 23 (22%); and wetting the bed even though they haven't previously done so, 20 (19%). Figure 2 outlines the results.

Where and from whom parents get child health information and healthcare

A total of 83% (85/102) of the respondents reported having a regular GP. Whilst 79% (79/100) of respondents indicated that their GP bulk billed their child's visit, 25% (26/102) indicated that the cost stopped them from attending a GP. Fifty five percent (56/101) of parents found it difficult to get an appointment with their child's regular GP when they needed one.

A total of 57% (59/102) of parents referred to their child's personal health record for child health information and 68% (69/101) of parents reported visiting their Community Child Health Centre. Reasons for not visiting their Community Child Health Centre included: 15 (42%) were unaware of the service; nine (25%) did not need to attend; seven (20%) used other services instead; three (8%) indicated the location was inconvenient; and one (3%) did not find the service helpful.

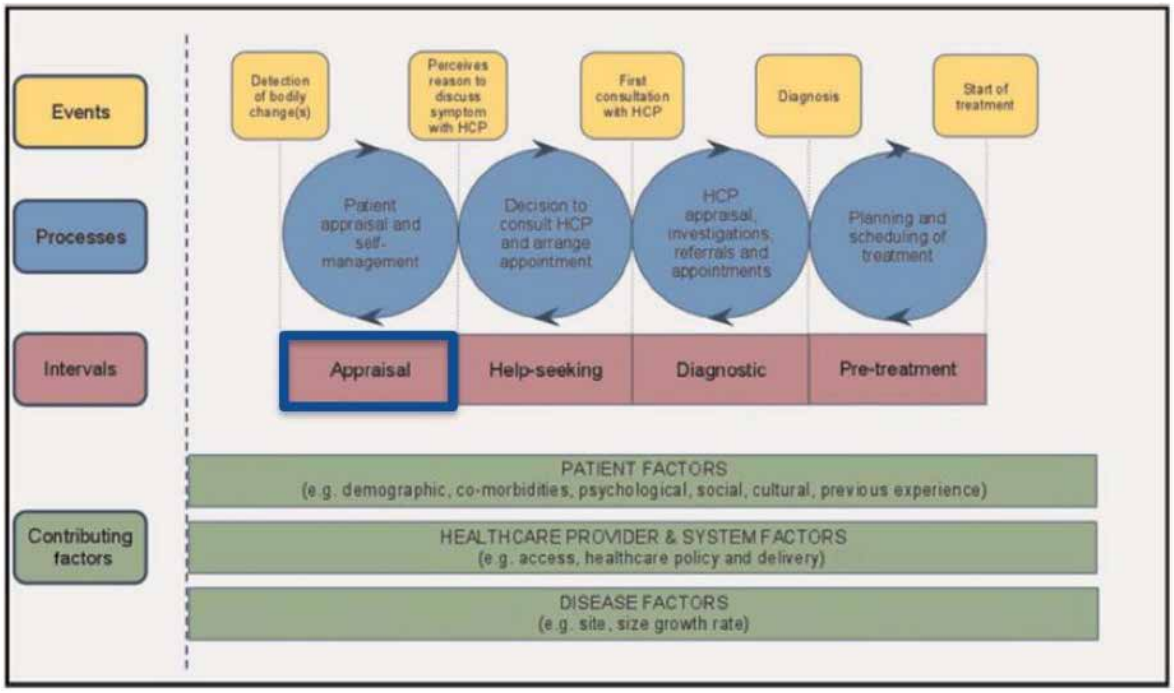

Figure 3. Models of Pathways to Treatment

Discussion

The aim of the project was to gather evidence to inform a broader awareness campaign to reduce rates of paediatric DKA at diagnosis of type 1 diabetes. One of the objectives of this study was to explore parents' knowledge of the prodromal signs of high blood glucose levels in children. The survey provides insight into parents' knowledge of the prodromal symptoms and suggests they may not be aware of the importance of seeing a GP when their child is displaying the symptoms, particularly those of increased thirst and frequency of urination.

Figure 4. Campaign fridge magnet

Researchers report that 93% of children who presented in DKA at diagnosis had polyuria and or polydipsia for a least 1 day with the median of 14 days (range 1–182 days and 1–152 days respectively).[7] Fewer children had enuresis (32%) fatigue (55%) and weight loss (57%).[7,17] This suggests that thirst and going to the toilet to 'pee' more frequently (or starting to wet the bed when this wasn't previously happening) are more common and perhaps the most important of the 4T symptoms that parents need to know about.

Another study reported shorter durations of polyuria and polydipsia in children under the age of 2 years that presented in DKA, despite this group having the highest rates of presenting in DKA.[18] Previous awareness campaigns have not been successful in reducing DKA in this age group.[15,16] Authors suggested that challenges around the child's developmental stage and the fact that they are pre-verbal may contribute to difficulties in detecting polyuria and polydipsia. Detecting polyuria in a child wearing nappies has become more challenging with the advent of highly absorbent disposable nappies. In addition, subtle increases in polyuria may go unnoticed for days if the parents aren't the sole caretaker due to working outside the home.[19]

A further risk factor for DKA at diagnosis is living in a hot climate close to the equator.[19] Queensland parents may ascribe symptoms of thirst, going to the toilet to urinate frequently and tiredness to the hot and humid Queensland climate and may delay seeking help early. Protective factors for DKA at diagnosis include having a first degree relative with diabetes which is associated with a six-fold decreased risk.[5] The results of this survey build on the knowledge gained from a qualitative study exploring causes that lead to DKA at diagnosis.[17] The study used a theoretical model, the Model of Pathways to Treatment (Figure 3) to explore causes for

delays in the different intervals in the pathway to diagnosis and treatment to accurately assess the time intervals.[17]

The study found delays leading to DKA at diagnosis were during the appraisal phase, which was the longest phase. Total duration of symptoms prior to diagnosis ranged from 6–127 days, with over half having symptoms for more than a month. During the appraisal phase, parents took several weeks of a complex cyclical process of iterative decision-making prior to seeking healthcare for their child. Often a physical trigger such as weight loss was the catalyst to seeking healthcare, compared to subtle symptoms of thirst and urinary frequency. Ostensibly their child appeared well, and symptoms were not interfering with daily life, so did not raise parents' concern, whereas symptoms interring with daily life prompted help-seeking consistent with the central role of normality.[17] The results of the survey suggest over half of the parents surveyed would see a GP for signs of lethargy and weight loss, while only 22% were likely to see a GP for thirst and urinary frequency symptoms.

Interestingly, only 19% of participants would seek review if their child started wetting the bed (enuresis) when they had not previously done so. The results of this survey and other studies highlight the importance of educating parents about the symptoms of polyuria/dipsia and enuresis and the need for an urgent medical assessment to prevent DKA.

The survey results were used to inform the identifier message in the public awareness campaign – Diabetes, Know the Signs, Ask. The campaign call to action implores parents to know the 4T signs of hyperglycaemia and ask for a finger prick blood glucose check to prevent DKA at diagnosis of type 1 diabetes in children (Figure 4).

The second objective of the survey was to explore how and from whom parents access child health information. A new finding from this survey is that 57% of parents utilised their child's Personal Health Record (PHR) and 67% visit their child and youth health nurse (C&YHN) for child health information. Subsequently, content has been added to the PHR child health information booklet in the sections: when your child is sick, signs of sickness, and other signs to watch for if your child is unwell.

Content to assist C&YHN in the early identification of prodromal symptoms of high blood glucose has also been added to their practice manual. An online continuous professional development module on the prevention of DKA has been made available for nurses working with children in primary care settings: https://www.ncpdi.com.au/Preventing-DKA-at-Diagnosis

The importance of an accessible family GP who is familiar with the child's medical history is essential for continuity of care and early recognition of symptoms. Multiple primary care contacts prior to diagnosis has been reported as an increased risk factor for presenting in DKA.[5,7,11,18,19] This survey found that 83% of parents had a regular GP for their child; however, 55% (56/101) of parents found it difficult to get an appointment with their child's regular GP when they needed one. Furthermore, 25% of parents reported the cost to see a GP was an issue. This result is similar to several studies reporting low socio-economic status as a risk factor

Figure 5. Campaign poster with identifier message

for DKA at diagnosis.[5] Australia's Medicare system offers bulk billing for children under the age of 16; however, many after-hours GPs do not bulk bill parents who access these services when they cannot get an appointment with their child's regular GP. After-hours GP does not have access to medical records with important growth and development information such as the child's percentile charts, without which weight loss can easily be overlooked, nor recent presentations for non-resolving infections that can be related to ongoing high blood glucose. The survey findings, along with current literature on the causes for DKA at diagnosis, support the need to improve primary healthcare clinician knowledge to consider hyperglycaemia as a cause for underlying common childhood illnesses and for children to have timely access to a regular GP who bulk bills children.

A key solution to reduce DKA at diagnosis instigated by the project has been the development of a Royal Australian College of General Practitioners (RACGP) endorsed consensus guideline for the paediatric management of hyperglycaemia in primary care; this is available at the RACGP website: https://www.racgp.org.au/. It is anticipated this guideline will support GPs' paediatric assessment of the unwell child, particularly where a child may not be known to the GP. The guideline implores the need for a higher index of suspicion of type 1 diabetes in children with common childhood illnesses presenting in primary care. GPs and practice nurses will be offered education about the new guideline. Promisingly, previous GP education efforts have demonstrated improved clinician knowledge can significantly reduce DKA at diagnosis.[20]

The results from the survey also informed the development and refinement of the identifier for the Queensland awareness

campaign to reduce DKA at diagnosis, Diabetes, Know the Signs, Ask (Figure 5). Consumers consulted during the development of the campaign liked the seriousness of the message used in a previous campaign in the United Kingdom plus the 4T signs used in many previous campaigns; these elements have been incorporated in the campaign materials. A distribution campaign has been planned with stakeholders in schools, childcare and primary healthcare. Campaign materials can be accessed via the online CPD at https://www.ncpdi.com.au/Preventing-DKA-at-Diagnosis

The authors acknowledge there are some limitations to this study. The convenience sample were 100 parents who attended playgroup in Queensland. The ethnicity, socio-economic status and other demographic information of the participants were not collected as part of this study. Furthermore, as identifiable data were not collected as part of the study, the authors cannot guarantee that 100 different parents completed the study. For these reasons, the results are not generalisable to all parents in Queensland; however, as an exploratory study it has provided some useful insights as discussed in this paper.

Conclusion

This survey supports the need for targeted interventions aimed at improving parents' knowledge and recognition of the 4T symptoms which leads to a more timely medical review. C&YHNs are strategically placed as first-line clinicians in primary healthcare to improve the child health knowledge of generations of parents by sharing the key messages of the awareness campaign. The additional content in Queensland Health's C&YHN practice manual encourages C&YHNs to be aware of the 4T symptoms for the primary prevention and early identification of high blood glucose in children as this can prevent DKA. C&YHNs play a vital role in preventing DKA by educating parents about the 4T symptoms and empowering parents to advocate for their children when they have symptoms. Fewer children present with DKA when parents consider the diagnosis of diabetes.[16]

Acknowledgements

Funding for the project staff was provided by the Health Improvement Unit of Clinical Excellence Queensland. The project was made possible through a collaboration between Children's Health Queensland Health and Hospital Service (HHS) Mater HHS and Townsville HHS.

Disclaimer

The views expressed in the submitted article are my own and not an official position of the institution nor funder.

Sources of support

Project supported by the type 1 working group of the Statewide Diabetes Clinical Network (SCDN). The project acknowledges the support and contribution Playgroup Queensland provided to conduct the parent survey.

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