Understanding caregiver perspectives on challenges and solutions to pediatric asthma care for children with a previous hospital admission: a multi-site qualitative study

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ABSTRACT
Objective: Pediatric hospital admissions for asthma provide an opportunity to trigger a review of the current management with an aim of preventing readmissions. However, caregiver voices on how best to improve care are missing.

Methods: As part of a larger, mixed methods cohort study, we identified caregivers of children aged 3–18 years who had an index hospital admission to a tertiary pediatric, mixed adult and pediatric, or regional hospital in Victoria, Australia, between 1st September 2017 and 31st August 2018 with a discharge diagnosis of “Asthma” or “Wheeze” based on International Classification of Disease-10 coding. We conducted qualitative semi-structured interviews with a purposive sample of 39 caregivers. We used content analysis to identify themes from the data.

Results: Caregivers identified both challenges associated with asthma care for children with a previous hospital admission as well as solutions to improve care and potentially reduce readmissions. Key challenges included: unclear pathways for follow up care, inconsistent advice, lack of personalized management, delays in getting a diagnosis, delays in the prescription of a preventer medication, and difficulty accessing primary care during exacerbations. Follow up with an “asthma specialist”, early access to a trial of preventer medication, personalized Written Asthma Action Plans and increased access to and quality of community-based asthma support services were identified as key solutions.

Conclusions: Caregivers have identified several potential solutions that could be implemented to improve care and possibly reduce pediatric asthma hospital readmissions. The challenge now is to co-design, embed and evaluate these in healthcare systems.

Introduction
Asthma is the most common chronic disease in children, affecting approximately 12–14% of children globally and 10% of Australian children (1,2). Pediatric asthma is a major contributor to healthcare utilization, accounting for over 17,000 hospitalizations for Australian children aged 5–14 years in 2017–18 (3). It is not known what percentage of these are for asthma readmissions, however, data from a large (n = 53,156) database of Australian children identified a 16–23% 12-month readmission rate for children aged 2–12 years (varying by age and sex) in 2009, up from 14–18% in 1997 (4). Additionally, preliminary data from the Childhood Asthma REadmissions (CARE) study, a cohort study of children from the state of Victoria, Australia, identified a 34% 12-month readmission rate (5). This represents a rise from 10 years ago and is higher than China (5%) and America (22%) (4,6,7).

Unplanned pediatric asthma readmissions come at significant financial cost to healthcare services and have adverse physical, psychological and financial effects on the patient and their family. In 2015, health system expenses associated with asthma for Australian children cost and estimated AUD$352.9 million, with funding for Emergency Department (ED) and hospital admissions making up 27% (8). Understanding factors for readmission can inform interventions to reduce readmission rates and consequently health system
A recent systematic review identified factors associated with readmissions, including child age, previous hospitalizations and underlying chronic medical conditions (9). However, these factors are not readily modifiable.

Except for some older children who have full or shared responsibility for asthma management (10), caregivers largely provide the day-to-day care for children with asthma, including making decisions about health services utilization. Therefore, their perspectives are integral to designing effective patient-centered interventions to reduce hospital readmissions. Existing qualitative data from Australian caregivers is limited to exploring experiences of caring for children with asthma more generally, recruited from general practitioner (GP) clinics (11). A United Kingdom (UK) qualitative study of 30 families explored perceptions of asthma management with British South Asian and White British families, to identify barriers and understand high hospitalization rates specifically in British South Asian children aged 4−12 years (12). Children were not required to have a previous asthma hospital admission for caregivers to take part (12). The study identified many barriers were similar for British South Asian and White British families with both groups reporting limited understanding of asthma causes and triggers, confusion about medications, delays in diagnosis, fragmented care, and inconsistent advice from healthcare providers (12). An international systematic review synthesizing qualitative evidence of the lived experiences of caregivers in the management of their children with asthma found key challenges (struggle to attain a definitive diagnosis and treatment plan) and enablers (education, supportive relationships, regular follow up and easy access to appointments) (13).

However, to the best of our knowledge, no study has examined caregiver views on how best improve care and reduce asthma hospital readmissions in children who have been previously admitted across a range of hospital types. A previous review showed care provided in tertiary pediatric hospitals differs from mixed pediatric-adult or regional hospitals and therefore representation from families attending a range of hospital types is important (14). Further, no study has identified views of caregivers of older (i.e. > 12 years) children or caregiver views on potential solutions to improve care and reduce readmissions. Therefore, this study aims to identify caregiver-reported challenges and modifiable solutions relating to childhood asthma care among children with at least one hospitalization, for the purpose of informing future strategies to reduce readmissions.

**Methods**

**Setting**

This qualitative study was nested within the CARE study (Australia New Zealand Clinical Trials Registration (ANZCTR) ID 12619001658101). Eligible participants were the primary caregivers of children aged 3−18 years who had an index admission to The Royal Children’s Hospital (RCH, tertiary pediatric hospital), The Northern Hospital (TNH, mixed adult-pediatric hospital), or University Hospital Geelong (UHG, mixed adult-pediatric hospital) between 1st September 2017 and 31st August 2018 with a discharge diagnosis of “Asthma” or “Wheeze” based on International Classification of Disease-10 coding. Participants in the CARE cohort represent children whose caregivers consented to take part in the study. The children were followed using linked hospital administrative data for a minimum of one year.

**Recruitment**

For the broader study, primary caregivers of eligible children were mailed a research invitation letter with a two-week period to opt-out of further contact regarding the study. If no opt-out reply was received, caregivers were contacted by a member of the research team to confirm eligibility and provide verbal consent. From a cohort of 767 (children whose caregivers consented to take part in the study), a purposive sample of 96 caregivers who had consented to be contacted for an interview were invited via phone to complete a semi-structured phone interview and 39 caregivers consented and completed the interview. The purposive sample was selected to include caregivers of children across a range of ages, from all three hospitals, from a range of socioeconomic status (SES) groups, and those with and without asthma readmission. Caregivers who did not take part did not differ significantly from participating caregivers with respect to child age and sex. Sampling continued until data saturation was reached. SES was measured according to postal code of residence using the index of relative socioeconomic advantage and disadvantage (15).

**Procedures**

RJ and PP interviewed consenting caregivers by telephone following the interview guide (see supplementary materials). Participants were asked about their child’s asthma; what they do when their child is unwell with asthma; any difficulties in managing their
child's asthma; ways to improve asthma management and prevent hospital readmissions; and to discuss their child's hospital discharge. Interviews were approximately 30-min and were completed between September and December 2019. Interviews were recorded, externally transcribed, de-identified, checked for accuracy and coded using NVivo 12.0 (16). Reporting is in accordance with the CONsolidated criteria for REporting Qualitative research (COREQ) (17). The study was approved by The Royal Children's Hospital Human Research Ethics Committee (HREC 38295).

Analysis

RJ, PP and BT conducted the qualitative data analyses. RJ and PP are research assistants with a Master of Public Health and Master of Public Health Nutrition. PP is the parent of a child with asthma and BT is a clinician with experience treating children with asthma. BT, PP and RJ are all female and were not previously known to participants.

To identify themes from transcribed interview data a content analysis approach was used (18). Each transcript was coded by two authors. RJ and PP initially read and inductively coded the interviews they conducted, developing an initial coding framework. BT inductively coded all interviews blinded from the coding of RJ and PP. BT then compiled codes from all coders and developed a final coding framework. Coding and emergent themes were discussed within the research team to ensure consensus. The final version of the coding framework was applied to all transcripts. Child age, readmission status and index hospital were analyzed as key subgroups. A reflective journal and field notes were retained to log decisions and reflections.

Results

Characteristics of the 39 participants and their children are outlined in Table 1.

Major themes emerging from the interview data are presented below with representative quotes (see Supplementary Table 1 for corresponding child age and index hospital type). All quotes are pseudonymized and where necessary, truncated.

Unclear follow up care

Challenges

Many caregivers - of both children with and without readmissions - described pathways to accessing asthma follow up care as confusing and unclear:

They [hospital] are focused on the current issue. They're not getting a plan ... I'm not getting, 'okay. You can just come back and see an outpatient clinic'. (P1170)

Reasons for this included hospital discharge processes being "rushed" (PO459) and both verbal discharge and the Written Asthma Action Plan (WAAP) not including information about accessing follow up care:

I can't even remember what it said but it [WAAP] was basically two sentences... there was no review... it didn't say information about when you should get it checked again. (P0288)

Solutions

Caregivers wanted their child to be 'followed up' after a hospital admission for ongoing asthma education, to review progress and address questions:

it would be great if a child who has asthma does have a specialist that they meet with once every six months ...because you do kind of feel like you're going a little bit blind, as a parent. (P0222)

Most caregivers thought that an 'asthma expert' should provide follow up care rather than a general practitioner (GP) (sometimes called 'family doctors'), feeling that GPs are not specialized enough:

I would love to be able to see a specialist... just someone that we can see that sees asthma in kids all the time rather than a GP. (P0391)

Respiratory nurses and asthma educators were considered 'asthma experts':

What I would absolutely love... is a nurse or some practitioner that was dedicated to asthma management within the community. (P1028)

Some caregivers reported using a Community Asthma Program (CAP), a program with no out-of-pocket cost providing asthma education and support for children with asthma or Salbutamol responsive wheeze from an asthma nurse educator (19). Reported benefits included time spent with the family, education, personalized and continuity of care:

she did some whole, big long, hour long session with her and ...she explained to CHILD how big your breathing tubes are when you're okay and how little they go to when you've got asthma. (P0288)

Other caregivers who had not accessed a CAP suggested CAP-style care to improve their child's asthma management:

a consultation with a respiratory nurse to talk about their child's presentation, I think that would be helpful. (P0061)
Inconsistent advice about asthma management

Challenges

Inconsistent advice about asthma management was reported by caregivers between: different GPs; GPs and hospital clinicians; different clinicians and nurses within the same hospital admission; and between verbal advice and the WAAP. Receiving inconsistent advice was only reported by caregivers (n = 17) of children who were readmitted within the observation period. Main areas of inconsistencies were eligibility for preventer therapy, what signs should trigger Salbutamol (also referred to as ‘Ventolin’ by caregivers) treatment, medication technique, and when to attend hospital:

So she could have a hospital admission and during the three days that she's there, three different nurses will tell her to change her technique... That's just so confusing for her. (P0061)

I go to a family clinic that has three GPs...They kind of all have slightly different ideas about preventers – we sort of suffered with this. (P0391)

So, the treatment that we've had in hospital has contradicted the asthma plan. (P0883)

Inconsistent advice was implicated in lack of access to preventer therapy and reduced confidence in managing acute exacerbations:

...then they tell the different information to me... So that's why sometimes it's a bit confusing for me. Like...what do I need to do for the next episode? (P1533)

Solutions

Caregivers would like consistent advice on key aspects of their child's asthma management, such as "consensus" (P0061) on medication techniques. Some caregivers also noted the importance of explaining changes in asthma management, especially medication changes:

It gets confusing. And even when we got the new round of puffers, even the residents at the hospital wouldn't explain it to me and I was really frustrated. (P0315)

Delayed or unclear diagnosis

Challenges

Caregivers of children with and without readmission reported a delay in getting an asthma diagnosis, leading to many caregivers feeling confused, overwhelmed, or frustrated:

The only thing I feel like that's hard around asthma is the diagnosis of it. … because he hasn't necessarily been diagnosed with asthma, even now that he's five and is on a preventer. They still sort of say that he gets a viral wheeze. (P0649)

There was also difficulty conceptualizing terminology such as ‘viral wheeze’ and a perception that this is not taken seriously:

The fact that it was diagnosed as viral asthma. Is that really a thing? Is it? If someone's having trouble breathing, should it be called viral asthma? Or should it be called some kind of other asthma... Because it was played down so much that we didn't recognize and realize how serious this could be. (P1483)

Solutions

Caregivers identified that a diagnosis of asthma was associated with feelings of relief, validation, and empowerment and was perceived as an enabler of access to education and a management plan. Many caregivers wished their child was diagnosed earlier:

If I could change anything at all about our experience in managing it, it would be getting the diagnosis initially and being allowed to manage it. (P0968)

A minority of caregivers were able to understand ‘viral wheeze’. These caregivers were given an
explanation (including about the uncertainty of a future asthma diagnosis), an action plan and prescription of a preventer:

It was picked up fairly early ... there was a thought process of 'look let's defer to asthma, let's treat this as asthma. It may not be, it may be very self-limiting. It could be just a post-viral presentation but let's treat it as that and see how we go.' As it was, he was on the money. It was very, very, very straightforward for me. (P1028)

Timely access to community health services

Challenges

During asthma exacerbations, caregivers reported feeling fearful, lacking confidence and having difficulty accessing primary care and decision-making supports. Caregivers of children with and without readmission reported wanting to avoid going to an ED if possible, because of concerns about "taking up resources" (P0022).

Caregivers of children who were readmitted expressed a desire for improved access to and quality of primary care services for acute asthma management including the use of high dose inhaled bronchodilators during an exacerbation (also called 'hour of power'):

...Those 24-hour clinics, having people there who can manage asthma effectively... would...potentially reduce the hospital presentations, because really that night she didn't need to go to hospital. She could have been managed with an 'hour of power' in a clinic. (P0061)

Barriers to primary care management of acute exacerbations included difficulty accessing an urgent appointment, perceived lack of GP expertise in asthma, perception that the GP will just refer them to the ED, and that many exacerbations occur at night:

It's very hard to even have a regular GP these days. You can't even get in when you're actually sick, you've got to book weeks in advance. (P0968)

We ended up not bothering going to the GP... It just takes extra time and then costs a lot of money and you end up in the same place anyway. (P0650)

We're in the middle of the night dealing with a child that can't breathe and you can't really call anyone but the ambulance and the hospital... (P0315)

Some caregivers reported utilizing the federal government helpline 'Nurse-on-call' out of hours. For some, this helped make the decision to go to ED. Others found such services had too low a threshold for recommending going to an ED:

If we ring the nurse on call, they always tell us to take her to hospital. (P0061)

Solutions

Many caregivers mentioned wanting access to a nurse-led, asthma-specific hotline:

if there was like a person to call and speak to...I suppose we've already got nurse on call...but something specific to asthma would be good. (P0649)

A minority of caregivers recalled instances where they were able to get a walk-in appointment at extended hours super clinic that prevented an ED presentation:

We've got a super clinic just one- or two-minutes' walk from our house ... and they've got a nurse up there ... having that clinic out there has actually reduced the number of times he's gone to hospital... (P1649)

Medication access

Challenges

Few caregivers reported adherence difficulties or negative views toward common asthma medications. Caregivers acknowledged medication cost but did not report this as a barrier, often prioritizing the medications despite the cost:

It is what it is. They can't breathe otherwise. (P0075)

Some caregivers reported difficulty in accessing preventers for their child due to clinician reluctance to prescribe preventers for children with viral induced wheeze:

We sort of suffered a lot at the beginning without preventer. No one, even the hospital was saying we don't put kids on preventers with viral induced asthma\...I don't think they kind of understood the stress that that caused... (P0391)

Solutions

Many caregivers reported their child going on a preventer medication as a turning point, helping reduce exacerbations. There was a desire for increased education about preventers, the prescription of a preventer trial earlier, and ongoing surveillance and advice regarding their use:

...It [preventer] was life changing like instantly. It was amazing. She was just a different child within a month. (P1060)

Maybe having a regular checking or clinic where you could just go in ... and they review what they're
on and how often they're taking it and taking the opportunity to review. (P1632)

**Lack of personalized written asthma action plans (WAAP)**

**Challenges**

All caregivers reported their child having a WAAP. Caregivers generally reported that on balance the WAAP is useful but was "generic" (P0650, P0152). This was seen as both a strength and a limitation. Caregivers of children who were readmitted within the observation period and those whose children have (caregiver-reported) severe asthma noted that standard WAAPs are too simplistic and do not reflect effective management during an exacerbation. However, caregivers felt a simple plan and low threshold for seeking medical attention is appropriate when the child is in the care of someone other than the primary caregiver/s:

I think it is a bit generic for a family ... living a severe asthma lifestyle, but then I understand that there needs to be a level of standardization whereby people aren't taking risks with kids' lives. (P0152)

Caregivers of children without readmission, or with infrequent symptoms more commonly reported the standard WAAP is applicable to their child and acts as a reassurance or "refresher" (P1060, P1079):

I only need to refer to it when she's got a virus that's affecting her asthma...So, I'm pretty happy with it. It's just my little reassurance. (P0222)

**Solutions**

Many caregivers felt that their child's WAAP would be more effective if it was personalized – including specific asthma triggers (and what *doesn't* trigger their child's asthma i.e. exercise) and details about how their child may individually present with asthma:

You want to see the triggers there. (P1549)

if there was some flexibility of that template that the (Victorian state) Department of Education requires, that would be great ... For example, it only allows for you to enter one set of reliever instructions. So, you can't actually put on the plan that she has Symbicort [budesonide and formoterol] and Ventolin in the event of an exacerbation. (P0061)

Three children had personalized WAAPs because of a collaborative effort with their GP or asthma educator. Two of these children were readmitted but their caregivers reported the personalized plan increased caregiver confidence and prevented hospital presentations:

I feel like we really do have a good action plan now that's working for her...I think that's where my confidence comes from now, our preventative plan...So we haven't had a hospital admission this year... her symptoms and presentation really haven't been that different...the only difference is our preventative plan has gotten better. (P0459)

**Discussion**

Caregivers from a range of socioeconomic groups reported key modifiable challenges associated with asthma readmission that related to both hospital (unclear follow up, inconsistent advice and diagnosis, delay in diagnosis and preventer access, and lack of personalization of WAAP) and community management (lack of timely access and quality support).

Many challenges identified in our study are consistent with previous research, namely unclear follow up, inconsistent advice, delays in or struggles to attain diagnosis and access to community care (12,13). Only caregivers of children who were readmitted reported receiving inconsistent or confusing advice in our study. Our study design cannot confirm a causal relationship between inconsistent advice and readmission but nonetheless, inconsistent advice causes unnecessary confusion for families and strategies to minimize this should be explored. Additionally, the inconsistent advice reported by caregivers regarding WAAP and inpatient care may reflect a misunderstanding of the WAAP purpose and indicates a need for further education.

Lack of access to treatment plans and medication confusion were challenges to optimal asthma care identified in previous research but not by caregivers in our study (12,13) Social desirability bias may play a role in caregiver responses, with previous literature identifying that although caregivers often report they know their child's asthma medication, a large portion are unable to name the medication (20). Although all caregivers in our study had a WAAP, they wanted these plans to be more personalized, with triggers and the option for multiple medications included. Additionally, caregivers in our study did not report medication confusion (unless from inconsistent advice) but rather challenges with attaining preventer medications.

Caregivers identified practical solutions to these key challenges that may reduce readmissions for pediatric asthma. These included the need for care
providers in both the acute and long-term follow-up settings to be an ‘asthma expert’, with caregivers perceiving respiratory nurses and asthma educators as asthma ‘experts’. This emphasizes the importance of hospital and community services better connecting families with existing community service already providing this type of support, such as Community Asthma Programs (CAPs) (18). Future strategies aimed at improving access to specialist follow up asthma care will need to work closely with GPs, who are often the gatekeepers to accessing specialist care in Australia.

Caregivers also want a clear explanation of the diagnostic process and plans of managing future symptoms, regardless of whether the child had been diagnosed with asthma or “viral wheeze”. This highlights the need for clear communication between clinicians and families regarding diagnosis in young children, with perhaps a willingness to label recurrent wheeze as asthma so families can understand and manage their child's diagnosis.

Caregivers in our study reported wanting earlier access to preventer medication, often noting this as a turning point that reduced their child's hospital readmissions. This finding is contrary to a previous Australian study which found caregivers view preventer medications unfavorably (11).

Caregiver perception of challenges and solutions to readmission were relatively consistent across index hospital type and child age, with the exception of delayed access to preventer therapy, which was primarily reported by caregivers of younger children (<6 years).

This study presents the views of caregivers in their own words. It is understandable why some caregivers may find the lack of diagnosis and preventative medications frustrating for preschool children as there is a lack of strong evidence for effective treatments in this group and inherent diagnostic uncertainty. Caregivers may not always understand the practicability of implementing their suggested solutions, however, to ensure future health services are appropriately patient- and family-centered, it is essential to consider this perspective. The perspectives of children were not explored, which may differ to those of their parents. Caregivers were English speaking, so our findings may not generalize to culturally and linguistically diverse families. Caregivers completed interviews 1–2 years after index hospital admission which may impact recall regarding their child's care during this period. Additionally, participants were predominantly mothers however, mothers are often the main caregivers for a child's health.

Caregiver perspectives are often missing when designing healthcare pathways but are essential to designing feasible and acceptable solutions. Our study presents the views of caregivers from a range of socioeconomic groups, whose child has had at least one asthma hospital admission to different hospital types.

**Conclusion**

Caregivers want clearer communication about asthma diagnosis, especially in young children. In line with best practice recommendations, caregivers want wheeze or asthma admissions to prompt collaborative interventions to prevent further readmissions, which may include trial of preventer therapy and a personalized WAAP. There is a need for increased access and quality of community care at the time of asthma exacerbations. Clearer pathways to follow up are also needed, including better access to asthma nurse educators and CAPs. Future research evaluating multi-faceted interventions are needed to understand the feasibility of implementing these solutions and their effectiveness on asthma control and health services use.

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**Declaration of interest**

The authors report no conflict of interest.

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