



'At a loss of what to do': A qualitative analysis of parents' online discussion forums on their administration of asthma inhaler to their young children

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Title page**Title**

'At a loss of what to do': A qualitative analysis of parents' online discussion forums on their administration of asthma inhaler to their young children

Running head

Qualitative analysis of parent online discussion

Structured abstract:

Objective: Difficulties in using inhaler devices is well known amongst the adult population, however, little is known about how parents administer inhaler devices to young children and the accompanying difficulties. The purpose of this paper is to explore the underlying concepts and practical issues that parents encountered in administering asthma inhaler to young children.

Methods: This is a qualitative study using applied thematic analysis on parent written discourses on asynchronous online discussion forums and blogs in the topic of administration and use of asthma inhaler devices to their young children.

Results: The essence "at a loss of what to do" summarizes the experiences of parents administering inhaler devices to their young children. Findings describe the problem, the situation, the emotions, the confusion and the assurance that parents faced in the administration of the inhaler. Parents struggled with child's resistance and its accompanying conflict, with both parents and children experienced distress over the administration. Results highlight the coping strategies when parents chose to use force or not to use force in the administration, their endeavour to determine the details and administration procedure, as well as the assurance they gave themselves and one another after administration.

Conclusion: The results affirmed parents' lack of training and understanding of administering inhaler devices to young children and highlighted the needs for healthcare professionals to enhance their partnership and clinical care for parents of young children with respiratory issues.

Keywords:

Young children. Inhaler administration. Qualitative research. Asthma. Adherence. Internet forum.

1
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3 Persistent misuse of inhaler devices including metered dose inhalers and other inhalers is frequent
4 among the adult population (1, 2). However little is known on how parents undertake the inhaler
5 administration procedure for their young children with asthma. The prevalence of correct inhaler technique
6 among adults was only 31% in the area of coordination of steps and inspiration techniques as revealed by a
7 recent systematic review (3). Poor asthma control was found to be significantly associated with poor inhaler
8 techniques and poor self-reported adherence (4). Subsequently, it yields poor clinical outcomes and
9 undesirable financial problems such as emergency visits, which could be detrimental especially for young
10 children. Conversely, good inhaler technique will likely influence adherence and improve asthma control. It is
11 essential for parents to acquire proper inhaler techniques in order to ensure successful treatment of childhood
12 asthma for their young children, in advance of them being able to independently administer medications for
13 themselves.
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16
17 To investigate parents' experience on administering inhaler devices to their young children, it was
18 decided to collect parent narratives on queries or experiences of administering inhalers to young children. One
19 advantage of collecting online narratives is accessibility of people whose voices were previously unheard or are
20 geographically removed from the researcher (5, 6). Online data sources could come from various avenues,
21 however, online discussion forums and personal blogs seem to be prevalent and generally accepted platforms
22 for parents to share common concerns. Patients or their caregivers in both online discussion forums and blogs
23 share powerful stories from first-person perspective, interact with their peers, and elicit support, information
24 and advice from them (7, 8). Asynchronous online discussion forums of relevant topics can provide a source of
25 data which is flexible, spontaneous and rich for a qualitative study. Blogs provide a source of naturalistic data
26 in textual form which are publicly available and low-cost. Researchers can collect substantial amount of data
27 without undergoing interviews and transcriptions (6).
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30
31 The aim of the current study is to explore parent experience in administering different inhalers with
32 accessories such as spacers or aero-chambers, or nebulizers on their young children through collecting and
33 analysing parents' discussions on the online forums and blogs of such topic.
34
35

36 **Methods**

37
38 The study design was a qualitative analytic study on the asynchronous online discussion forums and
39 blogs eliciting parents' responses to administration of asthma inhalers to their young children.
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42 **Ethical considerations**

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3 Due to ethical reasons we only used online forum discussions that could be entered without having to
4 sign in and web blogs which were open to the public. Due to the public and anonymous nature of online forum
5 discussions, no personal or demographic data about the sample was available. No informed consent was
6 therefore sought from individuals who were involved in forum discussions and web blogs. Additional measures
7 were used to further ensure anonymity and confidentiality according to the ethical guidelines in the British
8 Psychological Society for internet-mediated research (9). Addresses of the websites of online discussion
9 forums and web blogs from which the data were collected would not be disclosed. Quotes presented in the
10 results section were first put back to search engines to see if they were traceable to original postings. In the
11 case when quotes were traceable and identified in websites, additional paraphrasing of the quotes was done
12 to the quotes in order maintain anonymity and confidentiality.

21 **Data collection**

22 We first identified websites where parents discussed the care of children with asthma by conducting
23 searches in web search engines (i.e. Google, Yahoo and Bing) using search strings such as 'mothers parents
24 taking care of children with asthma forums blogs', 'mothers parents mom dad mommy daddy children child
25 son daughter asthma forums blogs', 'children's asthma problem experience with medicaments medication
26 blog forum'. This resulted in the identification of 28 websites and each was screened to determine its
27 relevance and appropriateness in relation to the research topic. Identified websites were single discussion
28 forum threads, single blog posts and larger and active parenting websites. Advanced titles searches were done
29 within these parenting websites to identify more discussion forum threads. For instance, instead of using the
30 term *toddler*, keywords like *baby*, *son*, *daughter*, *dd* (*dear daughter*) and *ds* (*dear son*), and *child* was used for
31 each search string as some of these are common internet abbreviations used in these websites. Advanced
32 searches resulted in 65 online forum discussion threads across 27 websites and one blog post which were
33 downloaded and extracted in April 2015 (See *Data Extraction Summary* at Appendix 1). Some online discussion
34 threads and the web blog did not indicate the post-date. For those threads with post-date, there was a big
35 range of date of posting for some individual messages in threads and posts which were noted between
36 February 2005 and December 2014. A total of 467 unique sender names were identified and were mostly
37 pseudonym. The posts revealed that the messages were posted mostly by mothers of young children (i.e.,
38 infants, toddlers, and pre-schoolers).

56 **Data analysis**

1
2
3 We used applied thematic analysis for qualitative data analysis as it is known for using a
4 predetermined set of transparent procedures to generate themes from textual data (11). Downloaded
5 transcripts from online discussion forums and blog were read repeatedly to ensure familiarity with the data.
6
7 The data was imported into NVivo to manage data reduction. First level coding was conducted to identify key
8 structural topics. Forty-eight topics were identified. These topics were then reviewed individually to determine
9 their relevance to the research aims. The quotes in these topics were qualitatively compared for further coding
10 to generate themes and subthemes. Finally, preliminary themes and subthemes were presented to research
11 team members for comparison with the original data. Consensus of themes was achieved among the team
12 members.
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20 Results

21 This section presents the essence, the themes and the subthemes from the analysis of parents'
22 experiences extracted from the online discussion forums and the blog. The data represented a total of 467
23 unique sender names in 65 discussion threads and a blog from 27 websites.
24
25
26

27 The outcomes of the analysis are presented in Table 1. It delineates the problem, situation, emotions,
28 decision and confusion that parents had to face in the administration of the inhaler. In addition, while parents
29 made decisions if they should use force in their administration, they also considered the kind of the coping
30 strategies they used to facilitate the administration. Regardless of the coping strategies, parents also gave
31 reassurance to themselves and one another after the administration procedure that their child would get used
32 to the administration.
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39 **Overarching theme: "At a loss of what to do"**

40 The essence "At a loss of what to do" summarizes the experiences of parents administrating asthma
41 inhaler to their young children. Parents on online forums expressed that they were not sure what to do when
42 their child received a diagnosis, a prescription or an inhaler, even after various attempts of using different
43 methods or directions provided by others for administration.
44
45
46
47

48 "My toddler has just been diagnosed with asthma, but *I'm at a loss as of what to do?*" (F14, 3, UK)

49 "Feeling like a total failure that I can't manage this! You know when you have such a small window to treat
50 before hospital visit needed, and I can't get on top of it at home" (F13, 2, ES)
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1
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3 “So I am now wondering if anyone has any tips? We tried following the directions and giving 1 puff and getting
4 her to breathe in on the other side of the chamber but she said she didn't taste or feel anything? We did the
5 second one but it didn't seem to do anything either.” (F17, 1, LG)
6
7

8 Specifically, the parents' loss of what to do was from five sources: 1) the problem arising from child's
9 resistance to the administration of asthma inhaler, 2) the situation characterising the conflict between parent
10 and child in administration, 3) the emotions of distress expressed by both parent and child before and during
11 the administration, 4) the decision of whether parents should use force in administration and their reasons
12 and 5) the confusion of determining the substantive details and steps of administering different asthma
13 inhalers. Parents specified coping strategies that arose from using force or not using force as they
14 endeavoured to manage the administration procedure better. Despite of all these, parents expressed
15 optimism and gave assurance to themselves and others that their child would get used to the situation.
16
17

24 **The Problem: Child's Resistance to Administration of Asthma Inhaler**

25 The problem that frequently drove parents to the online platform for help was child's resistance to
26 the administration of asthma inhaler. Children actively resisted and refused to use the inhaler or its
27 accessories, e.g. plastic mask/spacer.
28
29

30
31 “My son was diagnosed with asthma and now needs an inhaler. He is VERY resistant to using it. I tried a lot of
32 logical approaches and got nowhere. I am not sure what my DH (dear husband) said but DS (dear son) did try
33 and is now crying and upset. DS said the inhaler hurt his tongue and totally refuses to try again.” (F9, 2, LE)
34
35

36
37 “DS (18 months) has been given an inhaler for what they suspect is asthma, and we've been told to give it to
38 him every day. He absolutely refused the mask, and we've now got one of those large plastic cones to try, but
39 every time we try to give him he goes wild, and gets really upset.” (F7, 1, SC)
40
41

43 **The Situation: Conflict between Parent and Child in Administration**

44 The situation that parents faced was the constant conflict or fight between them and their child in the
45 administration of the inhaler, arising from child's resistance and parental responsibility for administering the
46 inhaler medication.
47
48

49
50 “At first with DS it was a constant fight to get it into him ...” (F7, 17, SZ)
51

52
53 “Well title says it all really.... He had to have it 4 times and it got increasingly difficult as we went along. I am
54 expecting battles tomorrow.” (F7, 20, CB)
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1
2
3 “He hated the enormous contraption he was first given and it would take DH and I both pinning him down to
4 administer it, all 3 of us would end up stressed and in floods of tears.” (F7, 16, CM)

6 7 **The Emotions: Distress over the Administration**

8 Both children and parents were distressed about having to receive or administer the medication
9 through the inhaler. Children ‘hated’ it and were ‘upset’ about the process. Crying and screaming were
10 common behavioural manifestations of their distress.
11

12
13
14 “We ended up traumatising him with all the inhaler wrestling matches - he also had nightmares about it and
15 used to cry whenever it was time to take the inhaler.” (F1, 5, PJ)

16
17
18 “When DS had to use an inhaler he hated it... But it was not an option for him not to ... He screamed like he
19 was being killed ... I felt it was Ok for him to cry for a minute.” (F9, 1, RM)

20
21
22 “The trouble is that he will not use his inhaler. The last twice we have tried he has become so worked up he
23 vomited.” (F7, 28, HMB)

24
25
26 Parents were worried about their child’s emotional distress. They felt horrible, heartbroken and
27 distressed seeing their child’s discomfort before and during the administration.

28
29
30 “It’s horrid. It’s even more horrid when you’re out in public and people look at you like you are harming them.”
31 (F6, 5, LT)

32
33
34 “Yes, we used to go through the ‘trauma’ of giving the inhaler which in our house is known as the gas mask. DS
35 had his worst tantrum ever in front of the asthma nurse - *I cringe now thinking about it.*” (F7, 30, H)

36
37
38 “She too cried a lot when she saw us getting the inhalers ready and used to thrash around as we held it to her
39 face. It was a case of giving her a bear hug and trapping her hands and legs. *Was heart-breaking.*” (F8, 2, ET)

40 41 **The Decision: To Use Force or Not to Use Force**

42
43 Parents recognised that the advantages and disadvantages, as well as the respective coping strategies
44 of using force or otherwise in the administration of the inhaler. Sometimes parents could not decide which
45 was better for the child at that moment.
46

47
48
49 “Right now it takes my husband and I both and she screams the whole time. Part of me says that’s probably
50 not a bad thing because then the medicine is getting into her lungs, but another part of me is feeling awful for
51 having to do this!” (F18, 1, AY)

52 53 54 **Reasons for Using Force**

1
2
3 **'It's for their good'**. Parents believed that taking the medication is for the child's own good. Using
4 force, though it is hurting to parents, is far better than facing a much worse situation such as having to go to
5 the hospital or having an asthmatic attack. Parents knew that children needed the medicine so it is necessary
6 to use force to accomplish the task.
7
8

9
10 "Just grab him and force him to take it. it's for his own good" (F14, 37, C)

11
12 "I was just hopeful that there was a nice way to do it as I find it so difficult to be the bad guy! But, as you all
13 say, *it's for his own good.*" (F10, 3, LH)

14
15 "I had a good knack (in the early days) of holding my son and using one arm to hold down his arms while
16 slightly leaning on him so he couldn't kick his legs. It sounds barbaric but I wasn't harming him and *he got the*
17 *medication he needed.*" (F10, 2, AI)

18
19 **'It's ok to scream or cry'**. Parents had the general impression that it does not matter if their child
20 cries or screams during the administration of the inhaler. The reason being that crying or screaming facilitates
21 the child to take in more air or breathes which would expedite the absorption of the medicine.
22

23
24 "The hospital always tells me it's good if she's crying because she's breathing in lots of air, therefore getting
25 the inhaler!" (F7, 7, GM)

26
27 "I think you just have to sort of pin them down and get on with it, if they cry it's good in a way cos they are
28 inhaling at least." (F1, 2, J)

29
30 "It seems very cruel to continue when they are crying, but on the positive side, their airways are fully extended
31 and receive the medication much better" (F10, 5, TB)

32
33 "Hopefully she can make the transition to a fun game - otherwise, as much as it's not fun - you are right and
34 screaming certainly does ensure she gets the medicine!" (F18, 1, DT)

35 36 37 38 39 40 41 42 43 **Reasons for Not Using Force**

44
45 **Concern for hurting or traumatising the child.** Parents were concerned that they would hurt or
46 traumatise the child psychologically if they used force during administration.
47

48
49 "Does anyone have tips for nebulizing a 1 year old? It was easy in the doctor's office because she was so sick
50 she didn't fight the mask. Now that she is feeling better it's like wrestling a rabid 18lb raccoon. ... I've been
51 basically putting her in a modified headlock, which doesn't work that well. *I'm also afraid I'll hurt her if I*
52 *restrain her too firmly.*" (F26, 1, AY)
53
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55
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1
2
3 “At the hospital the asthma nurse said “you've got to pin him down and force it on him” but that seems so
4 horrible, the time we tried he seemed *totally traumatised*.” (F7, 1, SC)

6 7 **Coping Strategies When Using Force**

8
9 **One person pinning or holding down.** Parents most frequently described a variety of methods of
10 pinning or holding the child down while they administered the inhaler medication alone by force. The parent
11 below illustrated one of the ways how she coped with the administration by herself.

12
13
14 “Even when he doesn't want to take his medicine it is now easy for me on my own. I sit him on my lap, hold
15 him tight to me facing away and hold the face mask to his face.” (B1, 1, AY)

16
17
18 In particular, they engaged in specific methods in getting the administration done by themselves.

19
20 **Burrito method.** This method involves wrapping the child with a blanket or towel so that their arms
21 are out of the way to block the administration of inhaler medication.

22
23
24 “We usually recommend wrapping them in a blanket or bath towel to keep hands out of the way. ... The little
25 ones also learn very quickly that once they are wrapped it is going to happen and it gets easier and quicker”.
26 (F7, 5, MJ)

27
28
29 **Legs-over-child's arms method.** This method involves restraining the child by sitting on the floor and
30 placing the child's head between the legs or locking the child's arms underneath the legs. Then the parent
31 would have a pair of free hands to administer the inhaler medication.

32
33
34
35 “My pediatrician gave us an excellent technique for giving it to an infant. Lie the baby down on the
36 bed and sit with your legs down either side, their head at the top of your legs and place their arms under your
37 legs. This holds them in place and you don't have to use any force and you can hold their heads steady
38 between your legs when you put the mask over their face”. (F16, 1, RH)

39
40
41
42
43 **Two persons pinning or holding down.** Parents described of managing the moving child by having one
44 person holding the children and the other person administering the inhaler medication.

45
46
47 “We have to give her the Ventolin through the spacer by holding her down with one of us holding each side of
48 her head while the other one does the spraying” (F5, 1, GO)

49 50 **Coping Strategies When Not Using Force**

51
52
53 **Minimize awareness.** Parents used distraction such as tickling and funny noises, songs and music,
54 television, story reading or games to downplay the stress of the administration process. Some chose to
55 administer the inhaler or nebulizer treatment on the child while they were sleeping. While some children
56
57

1
2
3 responded positively on receiving medication while sleeping, others might wake up, fight and resist the
4
5 treatment.

6
7 “Try tickling him or making him laugh somehow, as that will distract him and also helps him inhale the
8
9 medicine” (F10, 3, RP)

10
11 “We decided to sing to my daughter, Twinkle Twinkle was the song of choice. She ended up joining in the
12
13 actions and the whole thing was a lot less of a nightmare. Distraction was the key, I think. Good luck!” (F7, 4,
14
15 BB)

16
17 “Sleeping did work the first night once (when he was really poorly) but he was sleeping so lightly that it was
18
19 the only successful time!” (F1, 1, XR)

20
21 **Empower the child.** Parents shared that when their child was put to be ‘in charge’ of the
22
23 administration procedure, letting them play or participate in the process through pretend play with toys and
24
25 people, it could actually help them get used to it. Another way of empowering the child was to explain to the
26
27 child of how the procedure could make them feel better.

28
29 “Apparently if you let them play with it, and give ‘puffs’ to their teddies etc they get more used to it.” (F7, 9,
30
31 LN)

32
33 “we found that by mommy and daddy (and even the cat) pretending to have a go and getting her to show off
34
35 to people and ... she seems to have finally adjusted but it has taken a while, she also has a second chamber and
36
37 an empty inhaler that she plays with giving her dolls and teddies their medicine!” (F20, 1, AM)

38
39 “We tried lots of different things too but the things that helped the most were letting him put it on our faces,
40
41 letting him try to depress the inhaler into the air so that he could see what was going on” (F8, 1, W)

42
43 “I would sit him down and tell him that they are to make him feel better and he should take them.” (F7, 6, BV)

44
45 **Make the process fun.** Parents made the administration fun by decorating the inhaler to their child’s
46
47 preference or using songs and games to engage the child.

48
49 “Things we've done to make it more 'fun' is to let them decorate their spacers with stickers, let their teddy
50
51 bears have a puff, use the countdown method before the spacer rocket blasts off (if they count out loud at
52
53 least they're breathing it in).” (F10, 1, HB)

54
55 **Make it natural.** Parents observed that if they made the administration as part of the child’s routine,
56
57 for instance, making it the same time and same place, it helped with child’s acceptance of the administration
58
59 procedure.
60

1
2
3 “To start with he used to go into massive meltdowns whenever he had to have his inhalers. Making it part of
4 his routine really helped us. Make sure that DS uses it at the same time(s) each day so that it becomes as much
5 of a habit as brushing his teeth.” (F7, 9, CT)
6
7

8 **Put in incentives.** Parents gave reward and praise when the child complied with the administration
9 procedure. Tangible reward such as favourite food or items, preferred activities and intangible rewards like
10 excessive praise were used to coax for compliance.
11
12

13
14 “I used to give DS a sticker to put on the spacer everytime he used it ...Chocolate reward everytime he uses it?
15 Till he gets used to it. ...Lots of praise.” (F7, 11, AD)
16

17
18 “She prefers to hold it herself, and we have always lavished so much praise on her for doing it that now she
19 says 'good girl' when she sees the puffer coming.” (F7, 11, HJ)
20
21

22 **The Confusion: Determine the substantive details of administration**

23
24 Parents were confused and unsure about the types of drug delivery device they should use, e.g.
25 whether their child should use a nebulizer over a metered dose inhaler (MDI) with or without a spacer/ valved-
26 holding chamber. They questioned the effectiveness of particular drug delivery devices, given their own or
27 child's struggles in using the device. They also had questions on how to cope with a substantial amount of
28 details when executing particular steps of the administration procedures, more so with issues of using MDI
29 with a spacer/ chamber. For instance, how to administer puffs from a MDI, how to breathe using a spacer and
30 how long it takes the child to inhale the correct amount of medication.
31
32

33
34 “Yes definitely because with the nebulizer they breathe all the medicine in naturally vs the inhaler where we
35 are forcing them to take a deep breath my daughter is 2 and still doesn't really understand much of what I say
36 so I would definitely use the nebulizer over the inhaler.” (F19, 1, ED)
37
38

39
40 “So we used the mask for the first time last night. I think this is the first time he got his full dose! But he fought
41 it and my DH wanted me to go back to the nebulizer. I told him as would see how this goes first.” (F4, 1, BH)
42
43

44
45 “My DS is 11 months old and fights it as well, but at least the spacer is much quicker than the nebulizer (which
46 he fights, too)! Our pulm [*pulmonologist*] told us 6 breaths and he should have all of the medication. Our
47 spacer has a little flap that moves in and out every time he takes a breath. We also have a mask that doesn't
48 have that, so with that one I would try to count his breaths based on the mask fogging up. Hope that helps,
49 and give the spacer a chance, it is so much quicker!” (F4, 1, BN)
50
51

52
53 “That is exactly what DS has. So if I can't get him to count to 5 has he not got enough?” (F7, 8, MB)
54
55
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The Assurance: 'Child will get used to it'

By their experiences parents felt that the children would get used to the administration, through trial and error of different methods, regardless of whether they are using force or not. The assurance of parents was about their firm belief that things would get easier as they 'kept at it', especially when the child felt the benefit of the medication. Parents persevered doing what they felt were right and made the strategies as part of their routine. Parents used these beliefs of assurance to encourage other parents online.

"Your doctor is right - as frustrating as it is, you DO have to just get on with it really, trial and error until you find something that works. Just persevere and I promise you she WILL get used to it!" (F10, 2, AI)

"The doctor placed her on a nebulizer with albuterol. She hated it at first, cried and struggled, ... After the first few sessions of struggling, she calmed down and even would even fall asleep if it was close to nap time while on the nebulizer treatments. ... I think the struggle is worth it, and talking with a lot of parents, all the kids seem to have the same reaction, but grow accustomed to inhaler treatments, especially once they feel the results." (F18, 1, SW)

"The greatest news is that most toddlers generally get used to the neb machine within 2-4 days because it becomes routine to them." (F20, 1, US)

Discussion

The purpose of this qualitative study was to investigate on the phenomenon of parents' experience in administering inhalers to young children for their asthma and to better understand the challenges associated with the long term adherence to medicines in children with asthma. the impact on their families and the coping strategies adopted. The results highlighted that parents were at a loss of what to do when they were prescribed with an asthma drug delivery device. Families faced the difficulties of child's resistance and subsequently parent-child conflict arising from the administration of asthma inhaler needed to find existing resources within the families or new resources in the community to cope with the crisis and move towards adaptation. The dialogues on the online forums expressed enthusiastic suggestions and recommendations by other parents in the online community. However, these dialogues did not describe much on parents' reliance on healthcare professionals as a resource to cope with 'the crisis'. It may imply that the reduced quantity and quality of time spent between carers of paediatric patients and healthcare professionals. One may raise questions on the level of healthcare provider-caregiver alliance which contributed to the poor knowledge and understanding of asthma management among these parents. The results also expose some misguided

1
2
3 perceptions that were held by parents and healthcare professionals in their management of child's resistance
4 during the administration, i.e., crying was acceptable or even welcome during the inhaling of medicine. Finally,
5
6 clinicians need to expand their views of treatment beyond the first step of prescription, adopt a patient and
7
8 family centred care (PFCC) approach and continuity of care.
9

10
11 Even though the findings were presented in a linear fashion, we were acutely aware that parents
12
13 were not using a single method, nor did they dichotomise in the management of inhaler use such as either
14
15 using force or not using force. Instead, parents used a combination of methods, with trial-and-error to see
16
17 which one worked for their child at a particular moment in time. We also appreciated the complexity of
18
19 possible conditions and personalities that a young child might have in term of respiratory problems – that
20
21 there is no one-size-fits-all solution for inhaler use. That led us to think that parents' experience of 'what
22
23 works' for them might not be necessarily useful for others due to the complexity of the situations which is
24
25 highly individualised. There might be some advantages of receiving generalised useful strategies that are
26
27 applicable for all, however, in order to maximise the benefits for patients and families, it is still essential to
28
29 receive proper consultation and advice from physicians and clinicians for an individualized tailored
30
31 management plan for respiratory problems including the usage procedure of a particular inhaler.

32
33 Another interesting highlight from the findings was the reason for using force in administration. The
34
35 majority of our findings supported a prevalent view of many parents and clinicians that it is acceptable for the
36
37 child to cry or scream during the inspiration of medicine from inhaler or nebulizer. The rationale was that the
38
39 child would take in more air or breathe and thus facilitate in inhaling the medicine. As such, parents and
40
41 clinicians found an acceptable ground in using force for child's compliance or cooperation of inhaler use, even
42
43 when it might mean that such actions would trigger more crying and screaming. Interestingly, this popular
44
45 view that was held by parents and healthcare professionals end up being a misguided concept. In our findings,
46
47 there existed a small proportion of negative cases from which parents disagreed the rationale of using force
48
49 and triggering more crying for child's effective inhalation. For instance, a parent said 'Don't pin him down - a
50
51 crying screaming child shallow breathes and the medication won't be as effective.' (F7, 1, SM). According to
52
53 the Inhaler Error Steering Committee (12) and ERS/ISAM Task Force Consensus Statement (13), it is not
54
55 recommended to administer the inhaler to a struggling child as it is difficult to achieve a good seal of facemask.
56
57 Crying and screaming cause most of the inhaled drug deposits stay in upper airway due to shallow and rapid
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3 breathing, but not in the lungs. Therefore, it is more optimal for children not to cry or scream in order to
4 receive the right dosage of medicine. Instead, children need to be instructed to take calm deep breaths during
5 the inhalation of medications. Current findings of parents' lack of knowledge and skills in operating the inhaler
6 with spacer or chamber for children supported the literature (14). These findings revealed that parents' fear
7 and belief did make a substantial impact of their administration behaviours in inhaler use. In addition, the
8 findings also affirmed previous studies where they found that less than desirable portion of healthcare
9 professionals (15-69%) were able to demonstrate correct inhaler use and knowledge (12).

16 The confusion presented in the parent discourse reflected parents' sense of perplexity in executing
17 various steps of inhaler administration. Parents' confusion also implied inadequate training and explanations
18 that were given to parents and thus they had to look for external source for assurance of getting the right
19 inhaler device and method. That cast an uncertain light on the existing healthcare provider- patient/parent
20 partnership in the area of asthma management. The alliance between clinicians, child patients and parents is
21 eminent. Only when parents gain confidence and trust from healthcare professionals then can they start
22 gaining working knowledge and reduce some of their confusion. A patient- and family-centred care (PFCC)
23 approach has the potential to advance the quality of asthma care and management (15). Within the
24 framework of care, clinicians play a crucial role in respecting caregivers' values in care decisions and their roles
25 in improving care practices (16). Clinicians can explore and help parents reflect upon what they had been
26 prescribed and influence parents' belief about the inhaler use as this serves important part of asthma
27 management. More research studies are needed to understand the nature of PFCC in the context of asthma
28 management as well as to investigate on the effectiveness of PFCC interventions in asthma management.
29 Special focus of investigating on children from underrepresented groups in the societies as different cultural
30 groups have different health belief systems from which how illnesses should be treated and hence affect
31 prognosis (17).

46 The confusion which parents expressed also implied a lack of continuity of care from their healthcare
47 providers. As discussed earlier, asthma treatment plans are required to be adjusted and individually tailored,
48 not just one-off but over a period of time reflecting the stepped-care approach to pharmacological
49 management. Initial trial plans that are not followed up might remain unadjusted accurately and not suitable
50 to the child and the family. The correct choice of inhaler device and the prescription of an appropriate holding
51 spacer according to the size and age of the child can maximise the success of the treatment. Lack of continuity

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3 of care also caused the rise of paediatric emergency department visits and related healthcare costs (18).
4 Continued monitoring of asthma self-management by trained medical professionals is pivotal in a holistic
5 treatment approach for the child with asthma or respiratory problems (19). Adequate training, beyond written
6 instructions, including verbal instructions, demonstration, and practice are necessary; a one-on-one training is
7 highly recommended and was demonstrated to have substantial increase in correct inhaler usage (20, 21). It
8 was even suggested that after training the child and the caregivers on the use of inhaler device, asking them to
9 demonstrate the procedure for affirmation of learning and further optimising of the administration (19). The
10 use of digital technology such as app based or internet based tools which include tracking of adherence, or
11 provide a combination of lectures, real-time one-on-one online training and coaching can be a vital solution to
12 disseminate training and consolidate skills for both clinicians and caregivers (22).
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22 **Strengths and limitations**

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24 This study uses a novel approach to data collection, where the participants are unaware of the
25 researcher, this is sometimes referred to as non-reactive research (23). Active approaches include interviews
26 or surveys where participants are aware of the researcher and there is a risk that they respond in a socially
27 desirable fashion, adapting accounts conscious of being under scrutiny. The cloak of anonymity can lead to
28 frankness in participants of an online forum discussion which can rarely be found in face-to-face interviews.
29 Not only has the data greater validity, its collection is less labour-intensive and it is already transcribed.
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36 There is a potential theoretical weaknesses of digital data like online forums or blog posts as you
37 cannot be sure whether members are really who they claim to be. It has been suggested that "In cyberspace,
38 participants can create and assume identities limited only by their imaginations" (p.972) (24). Also there is no
39 opportunity of triangulation with the members of an asynchronous online forum discussion. Since not all
40 people have access to the internet, the data may not be representative of people of all socio-demographic and
41 income groups, but for qualitative analysis where breadth of response rather than generalizability of the
42 findings is important so this limitation is less important.
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49 **Conclusion**

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51 Treating respiratory problems in young children is more than just prescribing medication. It always
52 starts from there but there are additional steps that clinicians need to do to guarantee optimal treatment
53 effectiveness. The treatment process involves building an alliance with caregivers with young children with a
54 Patient and Family Centred Care (PFCC) approach, educating child and family, and monitoring and adapting the
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individualised tailored treatment plan and training them using their unique inhaler device. Correct medication and dosage is just as important as the rest of these measures for the improvement of the long-term outcomes of children with respiratory problems.

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Table 1 Themes of Parents' Experiences in Administrating Asthma Inhaler Devices

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| 1 | |
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| 5 | The Problem: Child's resistance to administration of asthma drug delivery devices |
| 6 | The Situation: Conflict between Parent and Child in Administration |
| 7 | The Emotions: Distress over the Administration |
| 8 | Parent's distress |
| 9 | Child's distress |
| 10 | The Decision: To Use Force or Not to Use Force |
| 11 | Reasons for Using Force |
| 12 | 'It's for their good' |
| 13 | 'It's ok to scream or cry' |
| 14 | Reasons for Not Using Force |
| 15 | Concern for hurting or traumatising the child |
| 16 | Coping Strategies When Using Force |
| 17 | One person pinning or holding down - Burrito method; Legs-over-child's arms method |
| 18 | Two persons pinning or holding down |
| 19 | Coping Strategies When Not Using Force |
| 20 | Minimize awareness |
| 21 | Empower the child |
| 22 | Make the process fun |
| 23 | Make it natural |
| 24 | Put in incentives |
| 25 | The Confusion: Determine the substantive details of administration |
| 26 | The Assurance: 'Child will get used to it' |
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Appendix 1

Data Extraction Summary of Online Forums and Blogs

| Online discussion forums (F) or Blogs (B) | Number of forum or blog threads | No. of unique names identified | Range of dates of posts |
|---|---------------------------------|--------------------------------|---|
| F1 | 5 | 6 | 6 th – 7 th Aug 2011 |
| | | 6 | 10 th Jan- 2 nd Mar 2013 |
| | | 9 | 21 st Nov 2008 - 24 th Apr 2010 |
| | | 10 | 9 th Feb -25 th Sept 2014 |
| | | 4 | 26 th Oct -12 th Nov 2012 |
| F2 | 2 | 5 | 1 st Apr (year not indicated) |
| | | 6 | 17 th -19 th Apr (year not indicated) |
| F3 | 2 | 6 | July 2010 |
| | | 4 | Apr 2010 |
| F4 | 2 | 9 | 10 th – 18 th Sept 2012 |
| | | 5 | 25 th – 26 th Oct 2011 |
| F5 | 1 | 13 | 22 nd Feb – 9 th Mar 2009 |
| F6 | 2 | 4 | Eight years ago (threads don't specify dates) |
| | | 4 | 7 years 7 months ago |
| F7 | 12 | 5 | 5 th Jul 2010 |
| | | 5 | 17 th Oct 2008 -13 th Nov 2012 |
| | | 10 | 1 st – 3 rd Jun 2012 |
| | | 4 | 17 th Jan 2011 |
| | | 6 | 29 th Jan 2012 |
| | | 4 | 21 st Feb 2008 |
| | | 7 | 29 th Dec 2012 - 19 th Jan 2013 |
| | | 10 | 19 th Feb 2009 |
| | | 9 | 1 st Feb 2005 |
| | | 9 | 4 th - 5 th Apr 2010 |
| | | 17 | 2 nd - 5 th Nov 2007 |
| | | 4 | 2 nd – 5 th Dec 2014 |
| F8 | 2 | 4 | 7 th – 9 th June 2010 |
| | | 6 | 7 th – 9 th Apr 2010 |
| F9 | 2 | 3 | No dates indicated |
| | | 7 | No dates indicated |
| F10 | 6 | 9 | No dates indicated |
| | | 7 | No dates indicated |
| | | 6 | No dates indicated |
| | | 8 | No dates indicated |
| | | 4 | No dates indicated |
| | | 6 | No dates indicated |
| F11 | 3 | 3 | 14 th – 15 th Oct 2013 |
| | | 5 | 14 th Oct -13 th Dec 2014 |
| | | 4 | 10 th Dec 2013 |
| F12 | 2 | 7 | No dates indicated |
| | | 4 | No dates indicated |
| F13 | 2 | 8 | No dates indicated |
| | | 5 | No dates indicated |
| F14 | 6 | 3 | 5 years ago (threads don't specify dates) |
| | | 2 | 5 years ago (threads don't specify dates) |

| | | | |
|-------|----|-----|--|
| | | 5 | 5 years ago (threads don't specify dates) |
| | | 3 | 7 years ago (threads don't specify dates) |
| | | 9 | 6 years ago (threads don't specify dates) |
| | | 6 | 8 years ago (threads don't specify dates) |
| F15 | 2 | 6 | No dates indicated |
| | | 10 | No dates indicated |
| F16 | 1 | 11 | No dates indicated |
| F17 | 1 | 7 | 7 th – 15 th Sept 2009 |
| F18 | 2 | 34 | 22 nd Oct 2008 |
| | | 16 | 9 th – 10 th Oct 2010 |
| F19 | 1 | 4 | 6 years ago (threads don't specify dates) |
| F20 | 1 | 18 | 12 th Mar 2008 |
| F21 | 1 | 7 | 8 th - 11 th Feb 2005 |
| F22 | 1 | 4 | No dates indicated |
| B1 | 1 | 1 | No dates indicated |
| F23 | 1 | 2 | No dates indicated |
| F24 | 1 | 4 | No dates indicated |
| F25 | 2 | 7 | No dates indicated |
| | | 4 | No dates indicated |
| F26 | 2 | 12 | No dates indicated |
| | | 15 | No dates indicated |
| Total | 66 | 467 | |