

# *Knowledge that people with intellectual disabilities have of their inhaled asthma medications: messages for pharmacists*

**Sharon R. Davis, Seeta Durvasula, Diana Merhi, Paul M. Young, Daniela Traini & Sinthia Z. Bosnic Anticevich**

**International Journal of Clinical Pharmacy**

International Journal of Clinical Pharmacy and Pharmaceutical Care

ISSN 2210-7703

Int J Clin Pharm

DOI 10.1007/s11096-015-0217-x



**Your article is protected by copyright and all rights are held exclusively by Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie. This e-offprint is for personal use only and shall not be self-archived in electronic repositories. If you wish to self-archive your article, please use the accepted manuscript version for posting on your own website. You may further deposit the accepted manuscript version in any repository, provided it is only made publicly available 12 months after official publication or later and provided acknowledgement is given to the original source of publication and a link is inserted to the published article on Springer's website. The link must be accompanied by the following text: "The final publication is available at [link.springer.com](http://link.springer.com)".**

## RESEARCH ARTICLE

# Knowledge that people with intellectual disabilities have of their inhaled asthma medications: messages for pharmacists

Sharon R. Davis<sup>1</sup> · Seeta Durvasula<sup>2</sup> · Diana Merhi<sup>3</sup> · Paul M. Young<sup>1</sup> · Daniela Traini<sup>1</sup> · Sinthia Z. Bosnic Anticevich<sup>1,4</sup>

Received: 12 June 2015 / Accepted: 22 October 2015  
© Koninklijke Nederlandse Maatschappij ter bevordering der Pharmacie 2015

**Abstract** *Background* Fifteen percent of Australians with intellectual disability (ID) are reported to have asthma. People with ID are at risk of poor health knowledge due to deficits in intellectual and adaptive functioning, but their medication knowledge has largely been ignored in research to date. *Objective* To explore the level of understanding of asthma medication use of people with ID who self-administer their inhaled medications, in order to inform future educational support. *Setting* The research was conducted in NSW, Australia, at the participants' homes, the point of health care access, or the offices of relevant support organisations. *Method* In this qualitative study face-to-face interviews were conducted with people with ID using a semi-structured interview guide. The interviews were recorded, transcribed and thematically analysed. Main outcome Identification of barriers to asthma medication self-management by people with ID. *Results* Seventeen people with ID who self-administer their asthma medications were interviewed. Factors influencing their asthma medication knowledge and use included understanding of their illness and the need for medication; aspects of self-management and autonomy versus dependence. This sample of people with ID had a good understanding of the importance of using their inhaled asthma

medications, as well as asthma triggers, and the difference between use of preventer and reliever medications. Both enablers and barriers to asthma medication self-management were identified in the domains of managing attacks, adherence, knowledge of side effects and sources of information on correct use of inhalers. The level of autonomy for medication use varied, with motivation to self-manage asthma influenced by the level of support that was practically available to individual participants. *Conclusion* This research investigated aspects of asthma medication self-management of people with ID. Based on the barriers identified, pharmacists should promote use of spacers and written asthma action plans as well as counsel people with ID about how to recognise and minimise side effects of asthma medications. Specific strategies for pharmacists when educating people with ID and their caregivers include active listening to determine understanding of concepts, exercising care with language, and working with the person's known routines to maximise adherence with preventer medications.

**Keywords** Asthma · Caregivers · Inhaler · Intellectual disability · Interviews · Pharmacists · Qualitative research · Self-management

✉ Sharon R. Davis  
sdav2565@uni.sydney.edu.au

<sup>1</sup> Woolcock Institute of Medical Research and Discipline of Pharmacology, Sydney Medical School, The University of Sydney, PO Box M77, Missenden Rd, Camperdown, NSW 2050, Australia

<sup>2</sup> Centre for Disability Studies, Sydney Medical School, University of Sydney, Camperdown, NSW, Australia

<sup>3</sup> Synergy Medical Practice, Greenwich, NSW, Australia

<sup>4</sup> Sydney Local Health District, Sydney, NSW, Australia

## Impact of findings on pharmacy practice

- Individuals with ID may present to the pharmacy, just like any other individual, independent and ready to administer their own medication. Therefore pharmacists need to be trained in how to optimally communicate with people with ID.
- It is important for pharmacists to be aware when counselling and educating individuals with ID about their asthma inhalers that a different approach is

required. Due to their cognitive impairment, people with ID are likely to need repeated instruction and reinforcement to learn how to use inhalers correctly.

- There is a need to educate people with ID about minimising side effects of asthma medications and perhaps learning how to recognise them.

## Introduction

Asthma is a chronic lung disease defined by the presence of both variable airflow limitation, and respiratory symptoms e.g. wheeze, shortness of breath, cough, and chest tightness [1]. It causes a significant health burden to the community [2], and has an added economic impact in people with severe or profound disability, as they are likely to have other chronic health conditions or co-morbidities [3]. The mainstay of treatment for asthma is medication delivered via the inhalational route, using pressurised metered dose inhalers (pMDIs), dry powder inhalers (DPIs) or nebulisers.

Self-management is a crucial component of ongoing asthma management, and includes self-monitoring of symptoms, adherence to the treatment regimen, the ability to demonstrate the correct use of inhalers, and the identification of triggers [1].

Around 300,000 Australians have intellectual disability (ID) [4]. The definition of ID requires that an individual have an intelligence quotient (IQ) below 70, together with deficits in two or more adaptive behaviours such as self-care and communication [5]. Intellectual disability has been classified as mild, moderate, severe and profound mental retardation [6]. Persons with mild ID (IQ 50–69) may acquire academic skills up to 5th or 6th grade level, and as adults may develop sufficient social and vocational abilities to work and live independently, or in supervised apartments and group homes with a minimum of external support [7]. Persons with ID are at risk of poor health knowledge due to the deficits in intellectual function, as well as the adaptive functioning deficits related to domains such as learning and self-management [5].

One in seven Australians with ID is reported to have asthma [8]. Whilst research to date has not focused on the impact of ID on asthma outcomes, learning difficulties, which are present in people with ID, have been associated with a threefold increase in risk of asthma death in people with severe asthma [9]. Although the reasons behind this increased risk have not been fully identified or explained, learning difficulties and hence psychological factors linked to an individual's ability to self-manage their asthma may be a potential cause.

Recent Australian research has shown that the most commonly prescribed asthma medication for people with ID was short-acting bronchodilators used as required (p.r.n.)

[10]. As for all health consumers, people with ID need to know about their treatment to make decisions for themselves whenever possible [11]. Notwithstanding this, very little research exists on the health knowledge of people with ID [12]. Medication knowledge of people with ID has also largely been ignored in research [13], except in the domain of mental illness where people with ID wanted to know about the indications, possible side effects and contraindications of their psychotropic medications [14]. Furthermore, in respect of asthma specifically, processes inherent in self-management such as self-monitoring of symptoms [15] are underpinned by cognitive and/or behavioural skills [16, 17] and therefore might be expected to present some difficulties for people with cognitive impairment.

With the transfer of care of people with ID from institutions to community living, responsibility for health provision shifted from institutional staff to primary healthcare providers (HCPs) such as general practitioners and pharmacists [18]. Pharmacists encounter patients who have intellectual disability in a variety of practice settings [19, 20]. To deliver appropriate asthma care, pharmacists need to understand the lived experience of patients with ID as it relates to using asthma medications—what they know about those medications, and what particular barriers need to be addressed.

## Aim of the study

The aim of this study was to investigate the level of understanding of inhaled asthma medication use of people with ID, in the context of asthma self-management.

## Ethical approval

The study was approved by the University of Sydney Human Research Ethics Committee.

## Method

### Study design

This was an exploratory study using qualitative methods based on a thematic framework approach [21] and involved conducting one-on-one interviews with people with ID who administer their own medications.

### Setting

The research took place in metropolitan Sydney and Illawarra districts of NSW, Australia. Interviews were

conducted either where the participant accessed health care, or the offices of relevant support organisations, or the participants' homes.

## Recruitment

Government and non-government organisations providing disability support services were invited to identify potential participants. Some organisations cater for community living accommodation in a group home or residential centre, whilst others provide at-home drop-in support for adults with mild to moderate learning disability to live as independently as possible. The nature of support therefore ranged from 24-h assistance with activities of daily living to minimal support with tasks such as money management or cooking. Referring personnel were asked whether a formal assessment of the participant's capacity to consent had been completed and recorded in the client's records (or if substitute consent was required).

A research team member contacted individuals who had agreed to take part, to arrange interviews, explain the study and obtain consent.

Inclusion criteria were as follows:

- adults with ID (clinical judgment/receiving support from relevant organisations), with
- doctor diagnosed asthma, and
- self-administration of asthma medication.

## Interviews

Face-to-face interviews were conducted by the first author, an experienced pharmacist with training in qualitative methodology and inhaler technique. Questions in the semi-structured interview guide were developed to gain information about participants' understanding of asthma medications based on a validated questionnaire for generic medication knowledge of people with ID [13] and a study of asthma medication knowledge in patients with low health literacy [22]. The latter included questions designed to explore patients' understanding of when to use preventer (inhaled corticosteroids) and reliever (beta agonist) medications. Themes that were explored during the interview related to the participants understanding of the effect of adherence to asthma medications on health, the consequences of omitting them, side effects of asthma medications, how they manage flare-ups, and sources of support and advice in managing their asthma. Data relating to participant demographics, and prescribed asthma medications, were also collected. The interviews were audiotaped, and transcribed verbatim. Interview transcripts were assessed iteratively and interviews continued until data saturation was achieved. All data were de-identified.

## Data analysis

Background information was summarised descriptively using SPSS version 22 (SPSS, Chicago). All other data were analysed qualitatively. First open coding was applied to interview responses by the first author, whereby concepts were identified. Subsequently axial coding was conducted, and common concepts related to larger categories. Cross-checking of themes was conducted by the sixth author.

## Results

### Background information

Seventeen participants were recruited and completed the study. All self-managed their asthma medications; most with minimal supervision. Females comprised 65 %, and the median age was 57 years (range 25–68). Seven participants lived independently, three with family, six in supported accommodation such as group homes, and one in a large residential centre. Fourteen participants were prescribed preventer medications (used daily), and three were prescribed reliever medications (used as needed) only. Available information regarding the cause and level of participants' ID, as well as their living situation is listed in Table 1. The majority of participants were noted to have mild ID, however the participants were heterogeneous in their diagnoses.

Participants described a number of factors that influenced their inhaled asthma medication use. These were categorised into three themes: understanding of their illness and need for medication, self-management, and autonomy versus dependence.

#### *Understanding of their illness and need for medication*

Participants' responses provided insights into their understanding of key concepts related to asthma, including the rationale for medications, the difference between reliever and preventer medications, and asthma triggers.

Participants in this study described symptoms associated with their asthma, showing an awareness of their asthma diagnosis, and what their medication did for them:

relax the airway when it's wheezy (P16)

Most participants appeared to comprehend the significance of using their inhaled medications, in that they were able to relate the omission of medication to health consequences:

if I don't take that, I feel a bit funny when I start walking. I get choked up a bit (P10)

If I didn't use it I'd probably be in hospital (P5).



**Table 1** Participant characteristics

ID	Age	Diagnosis/level of ID	Living situation
1	25	Mild ID, attention deficit hyperactivity disorder and bipolar disorder on a background of cerebral palsy	With family
2	57	Mild ID	Supported accommodation
3	60	Cerebral haemorrhage at birth; moderate ID	Large residential centre
4	63	Klinefelter syndrome	Independent
5	33	Aspergers	With girlfriend
6	39	ID, level not specified	With family
7	33	Down syndrome; ID, level not specified	Independent
8	44	ID/mild dyslexia/legally blind	Independent with friend
9	59	Mild ID	Supported accommodation
10	67	Mild ID	Supported accommodation
11	42	Acquired brain injury from traumatic event as an infant	Independent with boyfriend
12	57	Moderate ID	Supported accommodation
13	58	Mild/moderate ID	Supported accommodation
14	35	Mild ID; aspergers; borderline personality disorder	Supported accommodation
15	68	Mild ID	Independent
16	61	Mild ID (recent psychometric test)	Independent
17	42	Hypoxia at birth; ID level not specified	With family

Participants recognised that different medications in inhalers are used for different situations, suggesting an understanding of the difference between reliever and preventer medication:

If I don't take this one, I get sick. This one I have if I'm short of breath (P9)

Participants were often able to identify triggers for their asthma. Some participants explained that the colder weather in winter was when their asthma was problematic,

It's alright in the summer, but in winter, that's it(P10).

Others identified different triggers for their asthma:

If there's a lot of dust, and say if I did a lot of exercise (P1)  
the weather, perfumes, hairspray, wood fires (P17)

### Self management

**Managing attacks** Participants' responses revealed their perceptions of their ability to manage asthma medications used regularly, and also during a flare-up. Several expressed self-confidence in managing their asthma, describing how they pre-emptively aim to prevent attacks:

I carry it around with me in case the wheeze starts

They also appeared to have the insight to keep calm at the onset of an attack:

if it's out of control don't panic (P5)

However, despite knowing what to do, managing an asthma attack was seen as frustrating by some participants, as they did not perceive they got the desired effect quickly enough:

Sometimes it doesn't work instantly. Sometimes you wait... I hate it...it takes a while (P5)

In addition, participants' responses showed varied levels of awareness as to how they would manage if the reliever medication did not work, with only one person referring to something like an asthma action plan:

call the doctor, the ambulance...there's plastic things on the wall (P9)

**Adherence** Participant responses shed light on factors that affected their adherence with asthma medications, both positively—including visual cues and reminders—and negatively, for example side effects, spacers and the stigma of using asthma medications.

Participants mentioned a number of strategies that assisted them with remembering when to use their inhaled medications, which type of medication should be used, and how they should be used. Reminders to use medications that participants reported to be useful included a mobile phone alarm. Visual cues, such as the colour and location of the inhaler were also helpful:

I put this one on the kitchen table; the orange one is beside my bed (P16)

Participants also explained how they match administration of their preventer medications to routine daily events:

I have breakfast, then I get dressed. I have it then (P5)

However, despite the fact that all participants were able to articulate the importance of using their inhalers, some revealed that they may not adhere to their prescribed regimen:

depends what's on my mind at the time...if my minds full of stuff (P1)

Perceived negative connotations from using inhalers in front of others in public or at work, may also have affected participants' adherence. Some participants explained how they felt embarrassed to use their asthma medications:

It's good, but I don't like doing it when I'm around... when I'm with people (P1)

Participants believed in addition that others would not understand why they needed to use them:

Well, I take them to work but they don't understand about the asthma thing at work... they don't understand about your puffers and that (P15)

The complexity involved in correctly using inhalers may also have affected adherence for some users in this study, with several participants reporting that they had experienced physical difficulty with using inhaler devices in the past:

I used to have that (Accuhaler), but it was a bit hard to use (P11)

Although participants were able to describe what a spacer looked like, and that their health provider had recommended using one, their responses indicated that they did not use spacers consistently:

I had something but I lost it (P8)

**Knowledge of side effects** In response to the question "can any bad things happen from using an inhaler" the majority of participants stated simply "no" or "it's perfect", showing little understanding that side effects could result from asthma medication use.

However, some participants were able to articulate (sympathomimetic) side effects of their inhaled bronchodilator medication:

I had a bad reaction...my legs were shaking, my arms were shaking. I went over there again with my mum, and my doctor said use it once and not twice (P7).

Three participants raised the issue of thrush from inhalers containing ICS, without prompting. However, one participant did not appear to correctly understand the concept of

a side effect as she related getting thrush in the mouth to something toxic:

when I go to the pharmacy, they always tell me to rinse your mouth out, cause you can get poison (P15)

Another participant seemed to understand the concept of side effects but described how the doctor dismissed his concerns:

I told the doctors any side effects and they say it's nothing (P16)

**Sources of information regarding asthma management including inhaler use** The means by which participants in this study acquired information about asthma and its treatment varied, with some participants obtaining information personally from a pharmacist, and others relying on caregivers or other personnel to inform them. Additionally, for some participants the way information was conveyed was crucial as written information was a challenge to understand:

it would be hard for me to read because I'm almost blind in one eye and I read things back to front (P8).

Participants reported various sources that they consulted to determine the technique for their inhaler devices, including one male who proactively used technology

I found a clip on YouTube (P5)

The majority reported that they relied on their caregivers, family, respite staff or HCPs to teach them. However, worryingly, some participants explained that they hadn't been shown:

Nope...they only made the expression about *when* you take it (P16)

### *Autonomy versus dependence*

Although all participants in this study self-administered their asthma medications, the level of autonomy for medication acquisition and use was varied. Motivation to self-manage their asthma appeared to be influenced by the level of support that was practically available. Thus some participants who lived independently explained how they take responsibility for medication use, as well as collecting their own prescriptions, and initiating dialogue with the pharmacist.

I ask him what I can do, and he comes out and shows me what to do (P4).

Participants in this study reported a number of people including caregivers who supported them with their asthma management—parents; siblings; HCPs including doctors, specialists and pharmacists; and respite staff. In some cases

participants took a passive role with regard to medication acquisition and administration.

Daniel gets all my asthma stuff (P9)

Participants described the security of having caregiver support when needed,

sometimes I forget; they remind me, they do, the staff (P9)

However they also revealed the frustration they experience when doctors talked to the caregiver rather than directly to them:

“I always have to ask Y, cause the doctors explain it to her” (P15)

## Discussion

The aim of this qualitative study was to explore the understanding of inhaled asthma medication use in the context of asthma self-management of people with ID, to inform future tailored educational support by HCPs including pharmacists. A particular strength of the study was that it elicited health views of people with ID. Although challenges with this kind of research in people with cognitive impairment are acknowledged, [23] this study has shown that useful information can be elicited.

Emerging themes from the research included participants' understanding of their illness and need for medication, facilitators and barriers to asthma medication self-management, and autonomy versus dependence. The study results suggest that these participants were aware of having asthma and the need for medication to treat it. This level of knowledge was pleasing, as people with ID as a group are known to have difficulty relating illness to dysfunction in their body, recognising symptoms as a sign, and reporting and answering questions about them [24]. However it should be noted the participants in this study mostly had mild level of ID; this degree of knowledge may not have been seen in people with more severe levels of ID.

Participants in this study seemed to understand that different medications in inhalers, i.e. relievers and preventers, have different purposes, and were aware of triggers for their asthma. This contrasts with studies of patients with low health literacy [22, 25], where patients with poor reading skills were less likely to know they should take their medications for symptoms and stay away from allergens [25]. This may reflect that people with low health literacy may not be known to HCPs, whereas people with ID are more likely to be known within the healthcare system, and supported with information about medication either directly or through a caregiver. However, whether this knowledge translates to

correct inhaler use is still unclear, as evidenced by one participant in this study reporting that the medication did not work quickly enough during an attack. This raises the question of whether the prescribed medication was indeed used appropriately—that is not quickly enough when symptoms present, too little, not frequently enough, or with incorrect technique.

Several participants in this study reported confidence in their ability to self-manage aspects of their asthma, completing tasks such as acquiring medication from the pharmacy, and self-monitoring their asthma status to decide when to use their reliever medication. Participants also utilised daily routines to assist with remembering to use their preventer medications. With respect to autonomy in their health care, participants' motivation to self-manage their asthma in the current study appeared to be influenced by the level of support that was practically available. The study finding that participants reported a number of people who were influential in their asthma management is consistent with existing literature, which suggests that people with ID often rely on others to assist with managing their health [26]. Social networks for people with ID are made up mostly of family members (43 %); acquaintances such as friends, work colleagues, sports club members (33 %); and professionals including support staff and HCPs (24 %) [27]. In the mainstream community, research by Cheong et al. [28] suggests that through positive interactions, such as provision of quality information, people develop trusting relationships with particular individuals, to whom they later turn for advice.

Several barriers to asthma medication self-management came to light in this study, such as concerns regarding side effects, stigma in using medications, and inconsistent use of spacer devices, reflected in reported intentional and non-intentional non-adherence. These challenges have also been identified in the general community [29–31]. The finding that the majority of participants in this study had minimal understanding of side effects of inhaled asthma medications such as oropharyngeal candidiasis with inhaled corticosteroids. Previous research examining knowledge of side effects of medication in people with ID [11, 13] and that in [32] are similar. One plausible explanation is that the concept of risk identification is complex, abstract, and cognitively demanding. [33].

## Messages for pharmacists

The role of HCPs in asthma management includes provision of information, skills and tools for self-management including training in inhaler technique, information and support to maximise adherence, a Written Asthma Action Plan (WAAP)—a decision support tool for early detection



to prevent or reduce the severity of an attack—and information about avoiding triggers [1]. In the general population, this self-management education and uptake has been shown to improve asthma outcomes [34].

For pharmacists to promote asthma self-management in people with ID and address barriers to asthma self-management such as those identified in this study, they need to be able to engage with people with ID, and adequately communicate with them. To enable this pharmacists' knowledge, skills and training regarding health care provision for people with ID may need to be addressed [19, 35].

When a person with ID presents at the pharmacy counter, it may not be immediately clear that they have an intellectual disability. However people with ID are often accompanied by a family member or a support person, which may make it more obvious. If the person presents independently the pharmacist should, through active listening, determine how much understanding the person has whereby it may become apparent that they have some difficulties with comprehension and expressive language. This approach would be the same as for anyone with a cognitive impairment e.g. dementia, or poor health literacy. The pharmacist would then need to adapt their communication style to the individual's needs.

Strategies for pharmacists when communicating with people with ID about medications generally include using simplified language appropriate to chronological age, focusing on one or two of the most important points; breaking questions or information down into small 'chunks'; using visual aids and leaflets designed for the needs of ID patients [33, 36]; allowing time for the person to process information; and checking that they understand before moving on.

In respect of information provision to maximise adherence with asthma medications specifically, the results of this study suggest that as for all patients people with ID need education about side effects of inhaler use. When providing such education, pharmacists need to consider the impact of ID on the advice that they might give, and exercise care with the type of language used, as people with ID may be more prone to take things literally [37]. This was evidenced in the current study with one participant using the word "poison" to describe her interpretation of the side effect advice given by the pharmacist.

Other influential personnel in the patient's network such as family or employed caregivers, and even respite staff may also need to be provided with information. Here, pharmacists may also need to tailor the information as caregivers have been found to vary in their knowledge of medications, including side effects [38] and their health literacy [20]. However these personnel once educated may be able to more effectively support the person with ID in self-managing their asthma.

This study confirms that daily routines are particularly important for people with ID, so pharmacists should work with the patient to reinforce preventer adherence using regular known routines such as mealtimes. Although the participants in this study did appear to understand the different roles of preventer and reliever medications, pharmacists should confirm that the patient does understand the difference.

When teaching inhaler technique, pharmacists first need to ensure their own knowledge of correct technique is current, as 15–69 % of HCPs across all disciplines cannot demonstrate inhaler mastery [39]. Inhaler technique training may need modification for people with ID [40] to incorporate behavioural strategies such as chaining. With chaining, a task is broken into several steps, which are cumulatively introduced until the task is completed independently to the required performance criteria [41]. Using any inhaler correctly involves an ordered series of steps, thus a person with ID could be instructed to do one more step in the process independently each time inhaler technique is practised. It is acknowledged that people with ID are likely to need repeated instruction and reinforcement in any teaching endeavour [42].

Pharmacists should promote the use of spacers, and educate patients regarding their optimal use, to avoid intentional or non-intentional non-adherence [43]. Spacers are recommended for all patients when using pMDIs for relief of acute asthma, all patients using pMDIs containing inhaled corticosteroids [44], and those patients who are unable to form a good seal around the inhaler mouthpiece [1]. This includes persons with cognitive impairment, which is particularly relevant to the population in the current study.

In practice pharmacists can also support asthma self-management in people with ID by collaborating with the person's GP to ensure a WAAP is in place (in Australia only a GP can write the WAAP). Only one participant in the current study mentioned something like a WAAP, but the uptake of WAAPs is also an ongoing issue in the general Australian community, with only 24 % of people with asthma reporting they had a WAAP in 2011/12 [45]. In Australia no WAAPs tailored for people with ID are currently available for HCPs to use. In the UK there is a tool called an "asthma attack card", which provides decision support about when to use relievers and how much to use [36].

Finally pharmacists can support asthma medication self-management through the provision of medication reviews. Pharmacies that provide medications or medication review services to group homes for people with ID should consider providing inhaler technique training and asthma management education to the support staff, in partnership with disability service providers [20, 46].

## Study limitations

In interpreting the findings of this study, there are several considerations that need to be taken into account. Although no limitation was placed during recruitment, the enrolled participants had to be able to express themselves verbally, and self-administered their asthma medication/s. The potential to generalise to the entire ID population is also limited by the small number of participants, and lack of formal measurement of participants' mental capacity. Additionally, as the participants were recruited through agencies providing support or health care, they may not be representative of all people with ID.

## Conclusion

This is the first study to qualitatively examine knowledge of asthma medication self-management by people with ID who self-administer asthma medications. The research provides information that can assist pharmacists when providing disease-management services and counseling patients with ID. Further research into asthma self-management needs of people with ID who use inhalers might include how people with ID actually use their inhalers, what interventions might be effective and what are the impacts on clinical outcomes.

**Acknowledgments** The authors wish to thank the disability support organisations that assisted with recruitment for this study.

**Funding** No specific funding was received for this project.

**Conflicts of interests** The authors declare no conflicts of interest.

## References

1. National Asthma Council Australia. Australian asthma handbook, version 1.0. National Asthma Council Australia, Melbourne, 2014.
2. Australian Bureau of Statistics (2013c). Australian health survey: health service usage and health related actions, 2011–12. [Internet] 2013 Apr 15. [cited 2015 Mar 20]. Available from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0022011-12?OpenDocument>.
3. Sapra S, Nielsen K, Martin BC. The net cost of asthma to North Carolina Medicaid and the influence of comorbidities that drive asthma costs. *J Asthma*. 2005;42(6):469–77.
4. Wen X. Estimates of prevalence of intellectual disability in Australia. *J Intellect Dev Disabil*. 2004;29:284–9.
5. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-V-TR. Washington: American Psychiatric Association; 2013.
6. Daily DK, Ardinger HH, Holmes GE. Identification and evaluation of mental retardation. *Am Fam Physician*. 2000;61(4):1059–67.
7. Harris JC. Intellectual disability: understanding its development, causes, classification, evaluation, and treatment. New York: Oxford University Press; 2006.
8. Australian Institute of Health and Welfare 2008. Disability in Australia: intellectual disability. AIHW cat. no. AUS 110, AIHW, Canberra.
9. Sturdy PM, Victor CR, Anderson HR, Bland JM, Butland BK, Harrison BDW, et al. Psychological, social and health behaviour risk factors for deaths certified as asthma: a national case-control study. *Thorax*. 2002;57:1034–9.
10. Davis SR, Durvasula S, Merhi D, Young PM, Traini D, Bosnic-Anticevich SZ. Respiratory medication use in an Australian developmental disability clinic population: messages for health care professionals. *Aust J Prim Health*. 2014;20:278–84.
11. Huneke NTM, Gupta R, Halder N, Chaudry N. Difficult decisions: are intellectually disabled patients given enough information to consent to medical treatment? *J Intellect Disabil*. 2012;16(4):265–74.
12. Turk V, Khattran S, Kerry S, Corney R, Painter K. Reporting of health problems and pain by adults with an intellectual disability and by their carers. *J Appl Res Intellect Disabil*. 2012;25:155–65.
13. Arscott K, Stenfert Kroese B, Dagnan D. A study of the knowledge that people with intellectual disabilities have of their prescribed medication. *J Appl Res Intellect Disabil*. 2000;13:90–9.
14. Strydom A, Hall I. Randomized trial of psychotropic medication information leaflets for people with intellectual disability. *J Intellect Disabil Res*. 2001;45(2):146–51.
15. Creer TL. Behavioral and cognitive processes in the self-management of asthma. *J Asthma*. 2008;45:81–94.
16. Smith L, Bosnic-Anticevich S, Mitchell B, Saini B, Krass I, Armour C. Treating asthma with a self-management model of illness behaviour in an Australian community pharmacy setting. *Soc Sci Med*. 2007;64:1501–11.
17. Smith SC, Mitchell C, Bowler S. Patient-centred education: applying learner-centred concepts to asthma education. *J Asthma*. 2007;44:799–804.
18. Ziviani J, Lennox N, Allison H, Lyons M, Del Mar C. Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *J Intellect Dev Disabil*. 2004;29(3):211–25.
19. DiBlasi A, Kendall S, Spark MJ. Perspectives on the role of the community pharmacist in the provision of health care to people with intellectual disabilities: exploration of the barriers and solutions. *Int J Pharm Pract*. 2006;14:263–9.
20. Erikson SR, LeRoy B. Health literacy and medication administration performance by caregivers of adults with developmental disabilities. *J Am Pharm Assoc*. 2015;55(2):52–60.
21. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG, editors. *Analyzing qualitative data*. London: Routledge; 1994. p. 173–194.
22. Paasche-Orlow MK, Riekert KA, Bilderback A, Chanmugam A, Hill P, Rand C, et al. Tailored education may reduce health literacy disparities in asthma self-management. *Am J Respir Crit Care Med*. 2005;172:980–6.
23. Finlay WML, Lyons E. Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychol Assess*. 2001;13:319–35.
24. Dodd K. Feeling poorly: report of a pilot study aimed to increase the ability of people with learning disabilities to understand and communicate about physical illness. *Br J Learn Disabil*. 1999;27:10–5.
25. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. 1998;114:1008–15.
26. Young AF, Naji S, Kroll T. Support for self-management of cardiovascular disease by people with learning disabilities. *Fam Pract*. 2012;29:467–75.
27. van Asselt-Goverts AE, Embregts PJCM, Hendriks AHC. Structural and functional characteristics of the social networks of

- people with mild intellectual disabilities. *Res Dev Disabil.* 2013;34:1280–8.
28. Cheong LH, Armour CL, Bosnic-Anticevich SZ. Patient asthma networks: understanding who is important and why. *Health Expect.* 2014;. doi:[10.1111/hex.12231](https://doi.org/10.1111/hex.12231).
29. Sibbald B. Patient self care in acute asthma. *Thorax.* 1989;44: 97–101.
30. Andrews KL, Jones SC, Mullan J. Stigma: still an important issue for adults with asthma. *J Asthma Allergy Educ.* 2013;4(4):165–71.
31. Guss D, Barash IA, Castillo EM. Characteristics of spacer device use by patients with asthma and COPD. *J Emerg Med.* 2008;35(4):357–61.
32. Australian Medicines Handbook Pty Ltd. Australian Medicines Handbook (online). [Internet]. Adelaide; 2015 [cited 2015 Mar 4]. Available from <http://amhonline.amh.net.au/>.
33. Wong JG, Clare ICH, Holland AJ, Watson PC, Gunn M. The capacity of people with a 'mental disability' to make a health care decision. *Psychol Med.* 2000;30:295–306.
34. Gibson PG, Powell H, Wilson A, Abramson MJ, Haywood P, Bauman A et al. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev* 2009; (3).
35. Davis SR. Medication reviews for people with developmental disability—a call to action (letter). *J Pharm Pract Res.* 2014; 44:159–63.
36. Asthma UK. Easy to read materials. [Internet] 2011 Feb [cited 2015 Mar 16] Available from <http://www.asthma.org.uk/Sites/healthcare-professionals/pages/easy-to-read-materials>.
37. Boardman L, Bernal J, Hollins S. Communicating with people with intellectual disabilities: a guide for general psychiatrists. *Adv Psychiatr Treat.* 2014;20(1):27–36.
38. Rasartnam R, Crouch K, Regan A. Attitude to medication of parents/primary carers of people with intellectual disability. *J Intellect Disabil Res.* 2004;48(8):754–63.
39. Price D, Bosnic-Anticevich S, Briggs A, Chrystyn H, Rand C, Scheuch G, et al. Inhaler competence in asthma: common errors, barriers to use and recommended solutions. *Inhaler Error Steering Committee. Respir Med.* 2013;107(1):37–46.
40. Davis SR, Durvasula S, Merhi D, Young PM, Traini D, Bosnic-Anticevich SZ. The ability of people with intellectual disability to use inhalers—an exploratory mixed methods study. *J Asthma.* 2015;. doi:[10.3109/02770903.2015.1065423](https://doi.org/10.3109/02770903.2015.1065423).
41. McDonnell J, McFarland S. A comparison of forward and concurrent chaining strategies in teaching laundromat skills to students with severe handicaps. *Res Dev Disabil.* 1988;9:177–94.
42. Primeau MS, Frith KH. Teaching patients with an intellectual disability. *Nursing.* 2013;43(6):68–9.
43. Brennan VK, Osman LM, Graham H, Chritchlow A, Everard ML. True device compliance: the need to consider both competence and contrivance. *Resp Med.* 2005;99(1):97–102.
44. Melani S, Zanchetta D, Barbato N, Sestini P, Cinti C, Canessa PA, et al. Inhalation technique and variables associated with misuse of conventional metered-dose inhalers and newer dry powder inhalers in experienced adults. *Ann Allergy Asthma Immunol.* 2004;93(5):439–46.
45. Australian Bureau of Statistics. Australian Health Survey: Health service usage and health related actions, 2011–2012. Table 7. [Internet] 2013 Apr 15. [cited 2015 Mar 20]. Available from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0022011-12?OpenDocument>.
46. Davis SR, Durvasula S, Merhi D, Young PM, Traini D, Bosnic-Anticevich SZ. The role of direct support professionals in asthma management. *J Intellect Dev Disabil.* 2015;40(4):342–53. doi:[10.3109/13668250.2015.1041100](https://doi.org/10.3109/13668250.2015.1041100).