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ORIGINAL ARTICLE

The role of direct support professionals in asthma management

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Abstract

Background Respiratory disease is common in people with intellectual disability (ID). The inhaled route is preferred for medication administration in treating respiratory diseases, including asthma. People with ID often need assistance with taking medicines due to cognitive, physical, and sensory impairments; in supported accommodation this assistance is provided by direct support professionals (DSPs).

Method A qualitative study design was used to explore DSPs' experiences with asthma medication management. Data were collected via in-depth, semistructured, face-to-face or telephone interviews.

Results Key findings included the complex balance of duties undertaken by DSPs, and a lack of consistency in asthma management processes across sites.

Conclusions This exploratory research suggests that DSPs are involved in asthma management and required to use clinical judgement, but are not provided with education and tools to manage asthma in, and foster correct inhaler use by, their clients. This highlights the need for tailored guidelines that integrate with the principles of the National Disability Insurance Scheme.

Keywords: *direct support professionals, caregivers, medications, intellectual disability, inhalers, nebulisers, asthma*

Introduction

Approximately 15% of Australians with intellectual disability (ID) are reported to have asthma. Asthma is a chronic inflammatory disorder of the airways that is associated with increased airway hyper-responsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness, and coughing (Global Initiative for Asthma, 2014). In treating respiratory diseases, inhalation is the favoured route of administration, using metered dose inhalers, dry powder inhalers, or nebulisers. The only published study of the use of respiratory medications in adults with ID (in people attending an Australian outpatient health assessment clinic) showed that both inhalers and nebulised medications are being prescribed (Davis et al., 2014).

Guidelines for asthma management (National Asthma Council Australia, 2014) promote the

concept of “self-management.” This requires a patient with asthma to be able to understand the use of asthma medications (e.g., the use of p.r.n. [as needed], or “reliever,” medication vs. regular, or “preventer,” medication) and to use the correct inhaler technique. Inhaler technique is not intuitive and needs to be individually taught (Bauman, 1997). The guidelines additionally state that all patients and/or carers should have a written self-management plan to help make appropriate treatment adjustments in response to changing symptoms, and to know when to use primary care or emergency medical services.

In the twentieth century, many people with ID lived in institutions where nurses or medical officers delivered all care, including the administration of medications. This meant that trained healthcare

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providers were involved in all aspects of disease management for people with ID. Following the devolution of institutions, a sizeable proportion of people with ID live in supported accommodation. Types of supported accommodation include group homes (suburban houses accommodating up to six people) and large residential centres (facilities that provide accommodation for usually more than 20 people). In these residences, people with ID are predominantly cared for by paid caregivers called direct support professionals (DSPs).

The responsibilities of DSPs are broad, and include the provision of day-to-day personal care, monitoring of client health, administration and management of finances, household management, planning leisure activities, skill development, and community inclusion (Bigby, Frederico, & Cooper, 2004; Hewitt & Larson, 2007). It is recognised that DSPs support the health needs of their clients (Gray-Stanley & Muramatsu, 2011), and Australian research shows that a number of factors impact on the DSPs' ability to address their clients' health care. Factors such as staff turnover, the need to engage in shift work, the reliance on casual staff, limited training in developmental disability, and low socioeconomic status all affect the ability of DSPs to support client health needs (Centre for Developmental Disability Health Victoria, 2014; Iacono, Humphreys, Davis, & Chandler, 2004).

In managing clients' healthcare needs, DSPs work from a health plan that is developed for individual clients, generally by a registered nurse (RN). This plan provides the relevant information and steps to be undertaken by a DSP in providing support to an individual client. It may also incorporate various healthcare plans providing detailed information on the management of specific health issues, such as epilepsy or asthma. The intention of the healthcare plan is that when undertaking the procedure, the DSP worker is required to exercise judgement only within their generic competency and responsibility (Government of South Australia, Department for Communities and Social Inclusion, 2011; Health Professions Regulatory Advisory Council, 2006; Health Welfare Advisory Committee, 2006; Manthorpe & Martineau, 2008; Productivity Commission, 2011).

In practice, DSPs are required to assist in disease self-management by people with ID, despite the fact that these DSPs have varied knowledge, experience, and understanding of the need for medication (Donley, Chan, & Webber, 2012; Rasaratnam, Crouch, & Regan, 2004) and self-management (Cardol, Rijken, & van Schroyen Lantman-de

Valk, 2012). How they cope under these circumstances, and in particular with the management of asthma, is not known.

Therefore the aim of the study was to explore DSPs' experiences and perceptions of asthma management for people with ID in supported accommodation, including what support DSPs may need in assisting their clients.

The study was conducted between September 2012 and March 2013.

Methods

Study design

Due to the exploratory nature of our topic, a descriptive qualitative study design, combining empirical and grounded theory approaches, was adopted.

Setting

The setting for this study was residential sites providing around-the-clock access to support for people with ID in New South Wales (NSW), Australia. For these people, a needs assessment determined that supported accommodation was the best option to meet their support needs, manage identified risks, and maximise their independence. In this study, clients ranged in age from 11 to 79 years, and varied in their level of functional and intellectual abilities. Specific types of supported accommodation in this study included large residential centres (two), a respite home for children (one), group homes (seven), and group homes for complex medical needs (two). At the group homes providing complex medical care, full-time RNs are employed in addition to DSPs. Both government and nongovernment (NGO) service organisations administer these supported accommodation sites. In 2012, over 2,500 people were employed as DSPs in NSW (Department of Ageing, Disability and Home Care, 2012).

Recruitment

To recruit government employees, the Metropolitan North region of the NSW Department of Ageing, Disability and Home Care (ADHC) was contacted by one of the research team and asked to distribute information about the study to employees working in group homes ($n = 115$) housing people with ID. An email was sent from ADHC to the team leader at all group homes in that region outlining the project and asking whether asthma medications were being used at their site. Responses were received

from 61 homes (53%), of which 24 (39%) indicated that they had a client receiving asthma medication. At this stage the researchers followed up individual homes to invite staff to be interviewed.

NGOs ($n = 17$) providing services to people with ID were identified through previous research links and literature searching. Four of these were discovered to provide advocacy only; for the other 13 organisations, a research team member initially made contact by telephone and/or email to ascertain interest in the project. If willing to be involved, the organisation contacted accommodation managers at individual sites to determine if there were any clients for whom asthma medications were prescribed. At this point, the managers were contacted to explain the project further and invited to nominate individual DSPs to take part. Interested DSPs were asked to contact the researchers to arrange a convenient interview time. Participant information statements were subsequently provided, and DSPs signed a written consent form. All participating organisations gave written permission for their employees to be involved in the study.

Specific inclusion criteria were that DSPs had administered or assisted with administering asthma medications to a person with ID within the last 5 years. Any person who did not speak English was excluded, as no funding was available for the use of interpreters.

Interview process

The DSPs were asked questions relating to medication administration, and challenges and facilitators in administering asthma medications, and previous asthma training received. A semistructured interview guide was specifically designed by the researchers to facilitate this, as no validated instrument exists. The guide was informed by a combination of expert opinion and empirical research within the fields of asthma and health behaviour (Basheti, Reddel, Armour, & Bosnic-Anticevich, 2007; Bauman, 1997; Bosnic-Anticevich, Sinha, So, & Reddel, 2010). Interviews were conducted by the first author, research student and registered pharmacist, who had attended workshops in qualitative design.

Data collection

Data were collected via in-depth, semistructured, face-to-face or telephone interviews with DSPs in NSW. The face-to-face interviews were conducted at the place of employment of the DSP concerned.

Data analysis

All interviews were audio-recorded, deidentified, and transcribed verbatim. Analysis was performed using strategies from grounded theory (Corbin & Strauss, 2008). First, open coding was undertaken, where concepts were identified from responses to the interview questions, by the first author, and similar ideas grouped together; for example, “perception of client ability to use inhalers” or “source of information”. In the next phase (axial coding), concepts were related to more expansive categories; for example, “working environment” and “medication training” under “organisational structure and governance.”

Two researchers assessed the interviews iteratively, allowing themes from early interviews to be explored in later ones. Independent crosschecking of the data was undertaken by the sixth author. Consensus of researchers was reached prior to finalisation of categories. Interviews were checked with participants if ambiguities needed clarification. NVivo Version 9 software was used to facilitate coding. Recruitment continued until saturation of ideas and concepts was reached.

Ethics

The study was approved by The University of Sydney’s Human Research Ethics Committee. A student research agreement was also completed with ADHC. A separate ethics application was requested and completed for one of the NGOs.

Results

The interviews took between 30 and 45 minutes each. Twenty-two DSPs were interviewed: seven in face-to-face interviews and 15 by telephone. Of the 24 government-run group homes where respiratory medications were said to be administered, five (21%) returned the researcher’s calls, resulting in seven DSPs consenting to participate. Of these, two participants worked in a group home where children attended for respite. Five NGOs were eligible and willing to participate, yielding 15 interviewees. Clients prescribed respiratory medications at 14 individual residential sites were represented.

Demographics

Thirteen females and nine males were interviewed. There was a broad cross-section of ages and number of years of working in the disability sector. Concerning training in disability, the majority of participants indicated they had completed TAFE

Table 1. Demographic data for direct support professionals

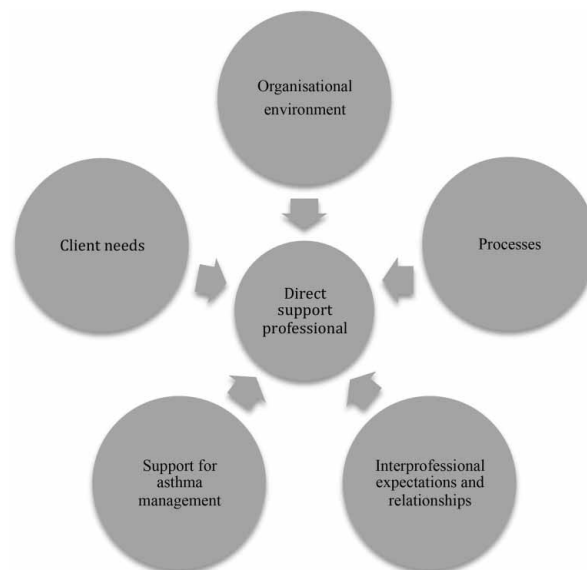
Characteristic	
Gender	Male (41%)
Age (<i>M</i>)	43
Years worked in disability sector (<i>Mdn</i>)	6 years
Disability training courses completed	Certificate III (5) Certificate IV (9) Frontline management (3)
Previous health training	3 (14%)

(Technical and Further Education) courses. Several participants had undertaken courses at a tertiary level, including an Associate Diploma in Child Studies, Diploma in Youth Studies, and a Bachelor of Arts (Psychology). Three participants had previous nursing training: one was an enrolled nurse in aged care, one worked in intensive care overseas, and the third was an assistant in nursing in aged care (not allowed to give medications). More detailed demographic information about participants is presented in Table 1.

Direct support professionals and asthma management

Participants identified a number of different duties that they undertook, ranging from assisting the client with activities of daily living, such as personal grooming, meals, and shopping, to medication administration and visits to see the doctor. Workplace roles varied from direct client support to supervisory, but all participants indicated that they give medications as required. Allocation of duties within the residential settings in our study depended on the client mix. In two group homes, designated as complex medical care, full-time RNs were also on site. However, they did not necessarily cover an entire 24-hour period. In the other group homes, DSPs had day-to-day responsibility for clients' health, including medication administration.

Overall, DSPs saw their role as supporting their clients to live as independently as possible, but at the same time, supervising their clients' health care, including medication use. This impacted on how asthma was managed, as DSPs had to decide the degree to which their clients were able to self-manage their asthma, and when they needed to step in and assist. Organisational structure and processes, interprofessional relationships, peer support, client characteristics, and the knowledge, skills, and training of the DSPs all influenced how this played out in practice.

**Figure 1. Balancing act for DSPs.**

Participants identified a number of factors that fundamentally affected the way in which they conducted their duties, including healthcare management. These were categorised and grouped into five key themes, which are summarised in Figure 1 and Table 2.

Organisational structure and governance. Participants raised a range of matters that could broadly be categorised under the theme of organisational structure, including working environment and training.

Working environment. Participants felt that the rostering of staff on a particular shift greatly influenced

Table 2. Factors perceived by DSPs to affect their role in asthma management

Factors	
1	Organisational structure and governance Working environment Medication training
2	Interprofessional expectations and relationships
3	Processes Documentation of medication orders Healthcare plans Sharing of information with other stakeholders
4	Client Perception of disease severity Perception of ability of client to self-manage Client behaviour
5	Support for asthma management Knowledge of asthma management Knowledge and skills to administer inhaled medications Skills to support asthma client self-management

the duties they carried out. In practice this means that an individual DSP may not be aware of disease management for every client, as one participant explained:

The day-to-day stuff we all take care of, but the medical appointments, all documentation around that particular client is done by the key worker. (P24)

Medication training. The level of medication training received by participants was identified as variable. Some DSPs felt they were well prepared with regard to medication administration, as they had worked through an education package and been assessed for competency:

What we actually have to do is to complete a package ... then do a written test, which gets taken away and marked. (P14)

Others, however, did not perceive medication training provided by the organisation to be adequate. They felt this impacted on their knowledge of medication administration, with one participant identifying that most information is from peers. Consequently, the people that they worked with were identified as important in assisting them in carrying out their duties:

I think training is really important ... everything here is by word of mouth. (P23)

Interprofessional expectations and relationships. Direct support professionals believed that they had an important role to play in the health care of their clients; furthermore, they felt that the client's doctor expected this. Participants felt that this was driven by the fact that clients' health was a priority; supporting a client required them to also assist in terms of daily health needs:

Even though you're busy, and need to do other things, you've got to put priority and think he needs the spray first and do everything else later. (P9)

Taking medications was viewed as a vital part of clients' daily health needs:

Observe them and make sure they take it; it's their health you're dealing with. It's pretty much the most important thing we do in our job I think. (P21)

Once a GP recommends a certain medical therapy, we're obliged to follow GP recommendations, and then it's up to us to administer that and get the client on board. (P20)

Direct support professionals identified that communication had an impact on how supported they felt in assisting clients with health needs, including asthma. Participants' experience of interactions with GPs varied. Some DSPs experienced a collaborative approach with GPs and/or nurses, which meant that they felt invested in the process:

We're lucky we have an excellent GP here where we have our own healthcare plan that we do together. (P20)

Others found that the interaction with GPs was at arm's length, or was undertaken with the RN on site, which disempowered the DSP:

We're not instructed straight from the GP ... that all has to flow through the nurse; it's never just the support worker, being told what's to be done because we can't carry that kind of responsibility. (P12)

Processes. Regarding duties that DSPs performed for clients' health care, DSPs felt that due to their repetitive nature, the duties followed established processes, which reoccurred daily regardless of the challenges or barriers that DSPs encountered. These processes particularly related to medication administration via medication charts, client health plans, and communication with staff and other stakeholders.

Documentation of medication orders. Participants reported that medication administration was managed by way of individual client medication administration forms, which were completed by a medical practitioner, and the form signed by a DSP when a medication was given or supervised. Several DSPs raised the inadequacy of these forms when assisting with clients' use of asthma medications. A lack of detail resulted in frustration for a number of participants, as they did not have sufficient instructions to administer the medication (e.g., whether to use a spacer and/or facemask). One manager expressed that not having instructions in writing meant that it was difficult to get the desired course of action across to all staff:

Some of the GPs will say spacer, but might just prescribe salbutamol, and we have to figure out how to deliver it. (P4)

If I suggest to GP would you mind ... there is a column, maybe just write few directions what to do. That will be a major struggle. They do tell you roughly, but you need it in writing, because I can't

be here all the time and pass it on to everybody. It would be easier if it's written down. (P22)

Healthcare plans. With respect to client health care, as well as medication administration support, participants expressed that they often had to consider the changing health status of the client; this was particularly the case for asthma status. Most DSPs indicated that the process by which they would know how to deal with any deterioration in asthma status was to consult the asthma healthcare plan in the client's file (note that in Australia, asthma plans must be written by a medical practitioner, thus prior organisation and assessment will have occurred). The generally held sentiment by DSPs was that they did not need to know about asthma medications, as the plan would cover any contingencies:

We don't make decisions about medications; we just follow plans. (P10)

We make the judgement call basically by following the residents' individual protocol – it will say, for example, if he starts to breathe heavily for more than 5 minutes that it's time to p.r.n. (P23)

Although, in the main, asthma plans were provided for individual clients, some DSPs expressed that the plans were not fit for purpose – that what was required was something more clear and concise:

We haven't had a clear asthma management plan for this client; I guess just having clear instructions for the direct care staff and casuals who might be coming into the house ... needs to be very simple ... we just need to know what to look out for, what to take and when to call an ambulance. (P10)

If they read through that asthma management plan, they would still struggle to follow the actions. (P5)

Not all participants were aware if a plan existed, however, and some indicated actioning it was not their responsibility:

I need to check this, as I'm not doing this kind of job; my client support officer, she get in touch with client's GP or specialist. (P8)

Sharing of information with other stakeholders. In managing clients' medications, DSPs revealed that they liaised with a variety of stakeholders, such as day activity staff, healthcare providers, including GPs and pharmacists, and clients' families. Participants indicated that there were processes by which information is communicated regarding medication instructions:

If it's a regular medication and we're expecting to see some changes in the client, or monitoring for any reason, that would be communicated to all the staff through our communication processes. (P10)

Participants appeared to understand the importance of sharing information regarding medication administration, such that the client is not exposed to risk of harm:

When she goes on activities ... usually when they will be administering anything they will tell you on the day that they are doing it. Kind of rules so we don't overdose her, just in case. (P22)

However, participants also revealed that explanations about medications are usually not conducted one on one with each DSP, but via writing in a communications book, or by word of mouth. Thus individual DSPs may have little understanding of the rationale for any monitoring required:

The GP will go through it with whatever staff member takes them and then we educate the rest of the staff. (P21)

Look, if there's anything that needs to be known, the pharmacist will tell me. I pass it on to the rest of the team. (P23)

Client. Participants mentioned that another key factor that impacted on their ability to support the client in asthma management was the client themselves with regard to assumed severity of the client's disease, the level of ID, and behaviours exhibited.

Perception of disease severity. DSPs' perception of the severity of their client's disease appeared to influence whether they felt they needed to assist in the management of the asthma. Several DSPs expressed that the client's asthma wasn't severe, which appeared to equate in their mind to "not much management" required:

I don't think she's a really bad asthmatic as such ... if she takes the preventative, she's pretty much right. (P17)

Perception of ability of client to self-manage. DSPs' perception of the level of a client's ID also affected the level of assistance they believed they needed to provide to individual clients to manage their asthma. Some participants described how the level of ID affects their client's ability to self-manage. In addition, there appeared to be an assumption by some DSPs that if the level of ID is mild, the

person will (automatically) know how to use an inhaler:

If we had somebody with severe intellectual disability, they would need to some extent manage it themselves, but they may not have the comprehension to make decisions or the awareness on what to look out for. (P10)

I'm comfortable that they know how to use it ... she is quite independent and quite aware of her asthma and she only has very mild intellectual disability. (P10)

Client behaviour. Participants identified a number of clients' behavioural idiosyncrasies that influenced asthma medication administration. In particular, they cited irrational or uncooperative behaviours; for example, a client choosing to toss away their medication, or wishing to continue with a medication regimen that was once part of their daily routine but no longer therapeutically desirable:

The most challenging thing is when the person won't cooperate and you know he needs to have it cause he's breathing really heavy ... you've got to put everything aside even though you're busy. (P9)

She was meant to be using it every day; she's pretty independent. She was always throwing it away. (P6)

He says I want it three times a day ... I want it morning, I want it lunch, before I go to bed ... even the doctor said, "I'm happy if you want to put it down to one," but no ... so it just goes on. (P8)

Participants also expressed that they had to keep a close watch, as a client's cognitive status may change depending on comorbidities:

This client has epilepsy as well. So if there's any seizure activity he can get confused and forget things. We're definitely more vigilant in checking things when he's had a seizure. (P21)

The DSPs were able to reflect on and describe strategies that they had personally developed to address these challenges, which took into account the client's level of understanding. Strategies included aligning timing of medication administration to other routines, use of accessory devices, such as spacers and facemasks, and exercising patience. Participants felt that it was important for clients to have some level of control regarding their asthma medication:

If you start to rush them or are impatient, then you've lost the battle with any type of medication. And

explaining to them ... tell them in their terms, on their level, what it's for ... then they've got some control with what's going on with their medication and they understand it to a certain degree. (P11)

Support for asthma management. Participants mentioned a range of factors associated with their role in assisting clients with asthma management. These related to DSPs' understanding of the disease and its management, their knowledge and skills around the use of inhaled medications, and how they could support the clients in asthma self-management.

Knowledge of asthma management. Participants indicated that the spectrum of their involvement in asthma management ranged from giving regular preventer medications, to coping in an acute situation. They also expressed that if the client cannot judge when reliever medication is necessary then the DSP has to take on that responsibility:

It's more challenging when it's hands on and you've got someone there having an asthma attack, you've got to have your wits about you and you've got to have good staff around you too that cooperate. (P9)

That's a hole we have at the moment and we have had for some time just leaving it up to the client, with no specific support for that p.r.n. So it's been more up to staff judgement with no specific guidelines for all the staff. (P10)

With regard to DSP perceptions of how much they needed to know about asthma, responses varied. A few participants expressed a desire to know more about asthma; others felt comfortable as they had access to an RN; and others didn't perceive a need for this information:

Definitely the awareness of the illness – what asthma is, how severe it can be, that it is life threatening. So people are aware of that and why we give medications, and how to monitor somebody and encourage them to administer medications. (P10)

I would call the on call nurse, I would say, these are the signs so and so are experiencing and they're the ones who do the final call. We always have support and backup ... takes the responsibility off you. (P14)

In the 5 years no one has had an asthma attack. I've never felt I didn't know what to do. Maybe I'm lucky. (P18)

Eight DSPs indicated that they had some personal experience of asthma (they or a family member had

received treatment for asthma at one time) and therefore had some baseline knowledge:

I think my personal experience, being an asthmatic has helped, definitely, and I think if I hadn't had that, I maybe would have asked the doctor to run me through it. (P21)

Some managers expressed that it is always better to err on the side of caution, and allow the doctor to assume responsibility and treat the clinical situation:

Because we are not the doctors, I am trying always to tell my staff, if you are here, is no harm, even if they're perfectly fine, to take them to the GP. (P22)

Finally, regarding DSP perceptions of the priority of healthcare delivery, there appeared to be a belief that contingency procedures are critical for some medical conditions such as epilepsy but not asthma:

We have specific procedures for *those* medications on the client's file. (P7)

Knowledge and skills to administer inhaled medications. Participants expressed that they may not be doing the best job of managing their clients' asthma, as they had not received any training in the use of inhalers or nebulisers. They did not perceive that they were alone in this:

There's no proper training as such to give the inhaler to the client. Somehow that's why I haven't directly helped the client. (P5)

I do know quite a few people who've been in the industry a long time and no one's done anything that I'm aware of. (P23)

The lack of training in nebuliser use was of particular concern for several participants:

You have to administer the nebuliser when the client has a really bad attack and basically I wouldn't have a clue what to do. (P5)

Participants mentioned a variety of sources for obtaining information for how to use inhalers or nebulisers, ranging from GP demonstrations to pre-planned information sessions provided by the service organisation. Some participants expressed disappointment that they had had to find out this information themselves:

The doctor went through it yesterday but without an actual demonstration; they just explained steps. (P10)

I've done a bit of reading – we've got some asthma first aid pictures, and from there I've gained a bit of information. (P4)

Some participants indicated that their organisation had arranged to demonstrate the types of inhalers and how they should be used:

We've had someone come in and teach us how to use inhalers and what a preventative was, and what a reliever was ... I remember she put all the inhalers on the table and showed everybody what a spacer was. (P14)

With regard to their preferences for any future training in inhalational devices, the majority of participants felt that a "hands-on" demonstration would be the way to go:

Visually to show the steps and how things should happen ... what not to do is also very important I think; and a demonstration – getting people to do it themselves. (P11)

Skills to support asthma client self-management. DSPs expressed that when supporting clients in the administration of regular asthma medications, they both supervised self-medication (e.g., with reassurance and verbal prompting, but the client retains responsibility) and administered medication (e.g., preparing the inhaler and giving the required dose to the client as per instructions). Participant responses showed that they wanted to be "person centred" in their support, but this was problematic, as vigilance is required even when clients are deemed to be capable of self-managing their medications:

I think it's a comfort, reassuring her to do it with us also ... I don't think she would have the Ventolin. (P17)

He turns the little dial, but sometimes he doesn't turn it, so you've got to watch him very closely and like put his hand on it and tell him how to do it cause we like them to do their own medications. (P9)

Discussion

In this exploratory qualitative study, we aimed to gain a deeper understanding of DSPs' perceptions regarding asthma management for people with ID in supported accommodation. The main findings were that provision of health care in supported accommodation is complex, with DSPs constantly balancing competing priorities. The research additionally

suggests that there may be a mismatch between what support organisations consider best practice and processes for disease management in situ. With regard to asthma management specifically, this was not consistent across sites.

The approach chosen for this research was a combination of empirical and grounded theory. Prior research has shown that although healthcare providers such as GPs and pharmacists physically show patients how to use inhalers, only 15–69% of healthcare providers, across all disciplines, can demonstrate correct inhaler technique (Price et al., 2013). Likewise, 28–68% of patients with asthma do not use metered-dose inhalers or dry powder inhalers well enough to benefit from the prescribed medication (Fink & Rubin, 2005). Since DSPs are neither healthcare providers nor patients, we used an exploratory approach to understand the factors that affect how they handle asthma medications. Despite achieving saturation of themes in the interviews, it is not yet possible to say that the research has generated a new theory regarding DSPs and management of people with ID and asthma in supported accommodation. However, it has helped to contextualise the role of DSPs and to identify their support needs with respect to asthma management.

In this study a number of factors affecting the way DSPs manage asthma came to light, with DSPs constantly being required to balance multiple complex and sometimes competing factors across the range of duties. First, DSPs expressed that they need to balance creating a “homey” atmosphere with the provision of health care, which has been noted as an important programmatic decision for the operation of a community residence (Jacobson, Silver, & Schwartz, 1984). Second, DSPs in this study revealed that they balance duty of care in managing a client’s health with providing person-centred care, as their clients varied in their ability to function independently.

Participants in this study perceived that their role in their clients’ health care included putting instructions from healthcare providers into action, which concurs with previous Australian research showing that GPs often rely on support workers due to their clients’ communication difficulties (Iacono et al., 2004, p. 277).

However, the participants appeared to receive little support in this, possibly due to the lack of a standard mechanism for information sharing. They felt that their ability to communicate their clients’ health needs to healthcare providers was affected by the organisational environment of the residence; for example, the co-location of an RN. In particular, this influenced interactions with GPs and

pharmacists regarding medications. In the two group homes where a nurse was on site, participants reported concerns about relaying information incorrectly due to a lack of medical training, with the impact being that some DSPs felt disempowered. At locations where no nurse was on site, the DSPs appeared to take on more responsibility for decision-making, including medication administration.

The overarching approach by support organisations in the delivery of health care to clients with ID appears to be one of risk management. This research uncovered that for asthma management, processes regarding how DSPs administer medications and share information with other stakeholders were generally in place; however, they were not consistent across sites. Reasons for this may include the knowledge and expertise of the managers within the different support organisations. Thus, some residences had risk management processes established for a client’s day activities, including communication of medications used and supply of emergency inhalers; for other sites, these were lacking. This study also revealed perceived process deficiencies affecting administration of regular (daily) asthma medication, as well as the actioning of asthma healthcare plans by DSPs when asthma status worsens. In respect of regular asthma medication, incomplete documentation of patient requirements by doctors often resulted in the DSPs having to solve how to deliver prescribed inhaled therapy to their clients (e.g., whether to use a face mask). This is of concern, as DSPs do not appear to have been trained to do so.

With respect to processes surrounding the actioning of asthma healthcare plans, some participants considered that the plans in situ were not written simply and clearly enough for DSPs to action, which is in line with recent research on the suitability of plans generally (Yin et al., 2013 p. e116). Most important, with regard to the competency of the person actioning the plan, deficiencies in the process were highlighted in that the majority of DSPs in this study had not received training in delivery of asthma medication; that is, the correct use of inhalers or nebulisers. In Australia, to assist clients with medications, DSPs must have completed TAFE courses in medication administration; these courses are quite general, with little focus on the inhalational route. In addition, there does not appear to be any requirement for DSPs to demonstrate competency in technique with these devices. By contrast, in residential aged-care facilities, it is recommended that nurses and other “suitable” personnel be trained in the use of inhalers (Australian

Pharmaceutical Advisory Council, 1998). This highlights the need for training in the use of inhalers and nebulisers that is specifically tailored for the needs of DSPs.

From this research it is evident that the skill set requirement for DSPs is broad ranging. With regard to asthma management specifically, the DSPs in this study reported both empowering clients to develop skills to manage their inhaled medications wherever possible, and administering inhaled medications as needed. Although different skills and competencies are required for supervising clients to self-medicate with inhalers (person-centred care with client taking responsibility) and administering medication (Bradford, 2012), each requires training in the correct use of inhalational devices. With reference to social cognitive theory constructs in health behaviour, behavioural capability mandates that if a person is to perform a particular behaviour, they must know what the behaviour is and how to perform it (Baranowski, Perry, & Parcel, 2002).

One particularly challenging and under-recognised duty in residences without an RN on site, was the need for DSPs to identify deteriorating respiratory function in their clients, and decide when to give, or encourage, the use of p.r.n asthma medication. Clinical assessment was not perceived by participants in this study to be part of their role. However, notwithstanding the availability of asthma healthcare plans, there is still a need for DSPs to take on the self-monitoring (response to symptoms) aspect of asthma self-management if clients themselves are unable. This is particularly relevant in the management of asthma in people with ID, where the difficulty of using objective measures such as spirometry and peak flow meters has previously been identified (Davis et al., 2014). However, it requires a level of training and judgement, and it is arguable whether DSPs can do this without training and experience.

An inherent factor complicating the administration of asthma medication in people with ID is challenges presented by the clients themselves; negative client behaviours identified by DSPs in this study included lack of cooperation, and fighting the facemask used with both inhalers and nebulisers. Insights from paediatrics could potentially inform optimal inhalation therapy in adults with ID; research in children using facemasks has shown that patient cooperation, including fighting the mask and crying, remains the main limiting factor in aerosol therapy, and aerosol deposition on the face occurs (Erzinger, Schuepp, Brooks-Wildhaber, Devadason, & Wildhaber, 2007).

With respect to overall asthma management, individual DSPs in this study made assumptions that

demonstrated a lack of awareness. These included rating the client's ability to know how to use an inhaler based on their level of ID, not the presenting clinical situation, and not believing that procedures are necessary for worsening asthma compared with, say, epilepsy. In general, asthma did not feature prominently in the priority of support that DSPs provide. This suggests that some DSPs may not realise the life-threatening potential of asthma. Targeting these assumptions through education may improve asthma management of these clients.

Despite the range of challenges identified, there is evidence from other chronic diseases that DSPs can support people with ID to manage their conditions if given appropriate education and training (Cardol et al., 2012, p. 383; Donley et al., 2012, p. 286). Direct support professionals have been noted to be good educators (Landesman, 1988) and it would therefore seem practical to empower DSPs to work with their clients to improve medication use in asthma. To facilitate this, resources tailored to an appropriate literacy level are needed for these caregivers to assist people with ID in asthma self-management. In this study, DSPs identified a lack of educational resources to empower people with ID to self-manage their asthma; a similar situation has been noted for educational material about diabetes for people with ID (Cardol et al., 2012, p. 387). In the United Kingdom, "easy English" versions of patient education leaflets on asthma and inhalers are available (Asthma UK, 2014, para. 1), and may provide a good starting point for this kind of activity.

Current Australia guidelines for best practice asthma care (National Asthma Council Australia, 2014) were developed for use by healthcare providers and essentially focus on promoting patient self-management of asthma via education. Although the guidelines include special considerations for adolescents, pregnant women, older adults, Aboriginal and Torres Strait Islander peoples, and people from culturally and linguistically diverse backgrounds, they do not specifically cater for people other than "older adults" with cognitive deficits or multiple comorbidities. As such, the guidelines are not very practical for DSPs, who are responsible for clients' asthma management on a day-to-day basis.

Limitations of this study

We acknowledge several limitations in interpreting our findings. These include that the interview questions sought perceptions, and there was no direct observation of the interaction of DSPs in assisting their clients. Extensive background information for clients being supported was not sought as part of

the study protocol. The small sample size means that the results might not be representative of all DSPs in supported accommodation in NSW. It is possible that participants with asthma, or with members of their family with asthma, may have been more interested in participating. The low government response rate may in part be due to the seasonal timing of interviews, but may also reflect the already heavy workload of DSPs, the number of concurrent research projects being conducted with people with ID, and lack of perceived importance of asthma management by service organisations. Confirmatory quantitative analysis for other jurisdictions, perhaps including an observational study, may clarify if the findings in this study translate more widely.

Conclusions and implications for practice

Our research shows that DSPs are currently involved in the management of asthma in people with ID in supported accommodation. Complex processes that are not sufficiently flexible with regard to the asthma management of individual clients drive the extent of involvement. We believe that DSPs need more support for this role, by way of training in the correct use of inhalational devices, to achieve mastery. Direct support professionals also need appropriate decision support tools to judge when reliever medications are needed, in order to execute an asthma healthcare plan effectively. Additionally, as RNs are integral to the development of healthcare plans, it is important that they are trained and understand the need for the correct technique for use of asthma inhalers.

There are a number of practical challenges to the implementation of such training with the advent of the National Disability Insurance Scheme (NDIS; National Disability Insurance Scheme Launch Transition Agency, 2013). First, under the NDIS, funding packages for people with disability to use for their support needs will be provided, but it is currently unclear how indirect costs of service delivery, including DSP training and professional development, will be funded. A potential solution is for NDIS packages to include provisions for suitably qualified professionals to provide training for DSPs in supporting people with asthma.

The nexus between individual supports and guideline implementation, including the role of both healthcare providers and DSPs, has yet to be articulated. For education and training to succeed, health provider peak bodies will need to develop practice guidelines for supporting people with ID and asthma.

Disability organisations will need to develop protocols and procedures, in consultation with

pharmacists or asthma educators, about how DSPs administer or support people to self-administer inhaler medications. These should include specific guidance about recognising asthma severity and detailed instructions with pictures about inhaler use. This would then need to be linked to training.

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