

Family Caregivers of People who have Intellectual/Developmental Disabilities and Asthma:
Caregiver Knowledge of Asthma Self-Management Concepts – A Pilot Study

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Running Title: caregiver asthma self-management knowledge

The authors have no conflicts of interest to report related to the conduct of the study or generation of this manuscript. No funding was used to conduct this study. The study received approval by the University of Michigan Human Subjects Committee (IRB).

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/bld.12223](https://doi.org/10.1111/bld.12223)

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Article type : Original Article

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Accessible Summary

- Asthma is a problem for many people
- Some people need help with their medicines for asthma
- People who help with medicines should know how medicines work and how they are used
- This study found that many helpers need more education about asthma medicines

Key words: caregivers; developmental intellectual disability; asthma; self-management, control; medication

Abstract

Background: People who have an intellectual or developmental disability (IDD) and asthma are at greater risk for poor health outcomes. They often require assistance from caregivers when managing their medicines. The objective of this pilot study was to assess the level of understanding of asthma-self management concepts of family caregivers who provide assistance to people who IDD and asthma. Results will inform future needs assessment and intervention studies.

Materials and Methods:

Eighteen caregivers of people who have asthma and IDD completed a mailed survey. The survey included scales to measure asthma self-management concepts, inhaler technique

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knowledge, medication adherence, and control of asthma. The caregivers were instructed to complete most of the scales with reference to the person with IDD.

Results: Most caregivers had acceptable health literacy, but had low scores on the asthma self-management and inhaler technique tests. The most frequently cited barriers to controlling asthma were inadequate caregiver and patient education about the illness as well as knowing and avoiding asthma triggers. The most frequently cited barriers to medication management were knowing inhaler technique, knowledge of medication, and forgetting to use medication. Asthma was controlled in 63.2% of patients, while almost 75% of patients were considered nonadherent to controller therapy.

Conclusions: Most caregivers had inadequate understanding of asthma self-management as well as inhaler technique despite having high health literacy. Improving caregiver and patient knowledge and skills may lead to better asthma control.

Background/Introduction

While asthma appears to be at least as prevalent in people with IDD as compared to the general population, about 8% of the population (Morin, Mélineau-Côté, Ouellette-Kuntz, Tassé, & Kerr, 2012), other studies have documented a higher prevalence of up to 12% (Davis, 2016). People with IDD and asthma are at greater risk for emergency room use, hospitalization and mortality than the general population (Gale, Naqvi, & Russ, 2009; Kerins, Petrovic, Bruder, & Gruman 2008; Reichard, Stolze, & Fox, 2011; Schieve, Gonzalez, Boulet, Visser, Rice, Van Naarden Braun, & Boyle, 2012). People with IDD face challenges related to self-management that often require the assistance of caregivers. In essence, self-management of chronic disease becomes supported self-management, whereby the caregiver is involved to the extent necessary to assist the care-recipient manage their asthma therapy. The person with IDD and the support network of caregivers must work together to control illness. Successful

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management of chronic illness requires an informed and competent team. Factors that should be taken into consideration for self-management to be successful would include considering the patient's level of functioning as well as the environment in which the person lives.

Interventions intended to promote self-management of health should be targeted at both the patient, the support network of caregivers, and the supportive environments in which the patient interacts such as the health system, supports agencies, and extended networks of family and friends. (Marks & Sisirak, 2013) Research has demonstrated that disease-management interventions which include self-management aspects, produce positive impact on health outcomes for people with IDD. For example, a community-based health intervention developed using peers and diabetes educators was successful in increasing physical activity and changing eating behavior, leading to improved clinical outcomes in a group of adults with mild IDD. (Bazzano, Zeldin, Shihady Diab, Garro, Allevato, & Lehrer, 2009) Another study of adults with diabetes and IDD found that most participants were able to participate in self-management activities, although with assistance from caregivers. Support from others was important in this process. (Hale, Trip, Whitehead, & Conder J, 2011). A small study of patients with mild intellectual disability found that the participants had good understanding of the importance of managing their asthma medication regimen. (Davis, 2016)

In patients who have asthma but do not have IDD, asthma is not well controlled. Population-based studies finding that between 55 and 59% of people with asthma are controlled based on assessment of symptoms using standardized instruments (Chapman, Boulet, Rea, & Franssen, 2008; Peters, Jones, Haselkorn, Mink, Valacer, & Weiss, 2007; Schatz, Mosen, Kosinski, Vollmer, Magid, O'Connor, & Zeigeret, 2007). There are no studies of the level of control of asthma for patients with IDD and asthma.

Review of the Literature

Caregivers have an important role in ensuring safe and effective use of medications by people with IDD. Caregivers encompass a wide range of people who provide support for daily functional activities for the person with IDD. Caregivers include family, friends, and employed support personnel hired by the person with IDD or provided by a supports agency. A recent survey of caregivers of adults who have IDD identified their level of involvement in medication

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management for people with IDD, with over 70% of respondents indicating that they obtained medication from pharmacies, reminded the person with IDD to take medication, and physically handed the medication to the person with IDD when it was time to take a dose. (Erickson & LeRoy, 2015) In regards to asthma specifically, an excellent qualitative study provides evidence of the needs that employed caregivers, or direct support professionals (DSPs), have in regards to assisting in the overall asthma management of their clients who have IDD (Davis, Durvasula, Merhi, Young, Traini, & Bosnic-Anticevich, 2015). Davis et al found that DSPs are integral to the support of people with IDD and asthma, and that DSPs feel more training is needed to be able to properly fulfill their role in supporting the health needs of the person with IDD. Specifically, training on appropriate inhaler technique as well as provision of appropriate decision support tools to judge when reliever medications are needed are examples of important findings. The same researchers also provided evidence that people with IDD and asthma often do not perform inhaler technique appropriately (Davis, Durvasula, Merhi, Young, Traini, Bosnic-Anticevich, 2016).

Successful management of asthma requires knowledge of asthma triggers and treatment, correct inhaler technique, understanding an asthma action plan, understanding the use of a peak flow meter, accurate interpretation of breathing symptoms, use of spacer devices, and adherence to therapy. Appropriate management leads to maintained or improved control of asthma, which improves quality of life and reduces morbidity and mortality associated with the illness. Identification of problems associated with medication management may guide interventions to further develop self-management interventions specific to the needs of unique populations such as patients with IDD. Little is known about the overall level of control of asthma in patient with IDD, or of the ability of caregivers who are involved in medication management to adequately manage the medications used to control asthma.

Research Question/Hypotheses

The goal of this pilot study was to assess the understanding of asthma-self management concepts of caregivers who provide medication management assistance to people who have intellectual or developmental disabilities and asthma. Secondary objectives were to measure asthma control and medication adherence of adult patients with IDD and asthma. It is

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anticipated that findings from this study will be used to develop a larger, multicenter study that incorporates assessment and intervention..

Materials/Methods

Subjects and survey method

The subject of this study was the caregiver of an adult (age 18 years or older) patient with IDD and asthma. A large health system located in a Midwestern state (United States) maintains an electronic data-warehouse. Using the query tool DataDirect, investigators are able to search for and identify patients with various demographic and medical characteristics once a study has approval by the human investigations committee. In order to create a sample of caregivers of people with IDD, the investigators followed the logic of first identifying patients with IDD and asthma who were seen by clinicians in the adult general medicine or family medicine clinics within the health system, which would lead to the caregiver who assists in managing medication. To be included in the study, the caregiver must have been age 18 years or older. Caregivers were identified by searching the health system's data warehouse for patients who have asthma, were age 18 years and older, and who had a diagnosis related to IDD. The IDD-related conditions identified for this study were based on ICD9 classifications and included Mental Retardation (317, 318, and 319), Down syndrome, Fetal Alcohol Syndrome, Autism Spectrum Disorder, Other Genetic Abnormalities, Cerebral Palsy, and Developmental Delay. The diagnosis associated with IDD must have been documented at least once in any procedure, visit, or hospitalization/emergent care event from 2012 through 2014. Once the IDD sample was constructed, it was further searched for patients with asthma. The diagnosis of asthma must have been documented at least two times in the electronic health records, from 2013 to the end of 2014. The requirement of being documented at least two times was an attempt to increase the likelihood that the patient had a confirmed diagnosis of asthma. The final list of patients with IDD and asthma underwent a validation check by the investigators reviewing the electronic medical record. The query initially identified 453 patients with IDD diagnosis. When further filtered by asthma diagnosis and chart review to confirm both IDD and asthma diagnosis, 239 subjects were identified for the study sample. Addresses were obtained from the medical record and survey packets sent to the address of the patient, but labeled for

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the caregiver. The cover letter in the survey packet was written to indicate that the study was focused on the caregiver who assists in managing asthma medicine. Three mailings were made, including the initial survey packet, a reminder postcard sent two weeks later, followed by a second survey packet four weeks after the initial mailing to subjects who had not yet responded. A total of 5 patients or caregivers contacted the investigator to opt out of the study and 12 packets were not deliverable and returned. Of the remaining 222 potential subjects, 18 returned survey packets, for a response rate of 8.1%. Therefore, due to the small sample size, this study is considered to be a pilot study, in which we are identifying the most salient and potential caregiver and patient factors that may be associated with asthma self-management concepts as well as control for patients with IDD and asthma, keeping in mind that caregivers are an integral part of successful medication management. The study was approved by the Institutional Review Board.

The study survey consists of a number of questionnaires included to measure specific concepts. The Asthma Self-Management Questionnaire, the health literacy scale, and the inhaler technique questionnaire, are direct measures of the caregiver's understanding and health literacy. The questions about the patient's use of spacer devices, peak flow meters, and having an asthma action plan are asked of the caregiver with the notion that they have direct knowledge of the use or presence of these devices or asthma action plan. The questionnaires assessing asthma medication adherence and asthma control were originally developed to be self-administered by the patient. For this study, the caregiver was instructed to consider the care-recipient when answering each question. As for medication adherence, we feel that the caregiver is knowledgeable to factors related to the medication taking behavior of the care-recipient, as they are often very involved in overseeing medication management. We did not conduct a validation of this technique prior to initiating the study. There is an opportunity for misrepresentation of the findings when someone other than the patient completes the questionnaire. In pre-test, we found that patients with IDD had difficulty completing the instrument. We elected to utilize the caregiver to function as the surrogate responder for the items. Literature, primarily in cancer care, demonstrates that caregiver and patient assessment of symptoms such as pain and fatigue are at least moderately correlated. (Desbiens & Mueller-

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Rizner, 2000; McPherson, Wilson, Lobchuk, & Brajtman, 2008; Poort, Peters, Gielissen, Verhagen, Bleijenberg, van der Graaf, Wearden, & Knoop, 2016). We expected that the caregiver completing the survey would have a close enough relationship with the patient to be able to complete the questions with a fair representation of the answer. This study, being a pilot study, will provide initial evidence as to the feasibility of being able to utilize the caregiver as a survey surrogate. Future research may be conducted to further determine the validity of the process.

Data

Characteristic of the caregiver and the person with IDD

Characteristics of the caregiver included age, gender, race, level of formal education, whether they ever received training in asthma management or medication management, and personal history of medication use. To measure functional independence of the person with IDD, the caregiver was asked how many hours, on average, did the person require support per day. A separate question assessed the level of patient independence in self-managing asthma medication.

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It is assumed that in order for caregivers to provide care, they must have adequate knowledge and understanding of the illnesses and related treatments that the care recipient experiences. We therefore used the Asthma Self-Management Questionnaire to assess caregiver understanding of key components of successful asthma self-management. It consists of sixteen multiple choice questions that assess medication knowledge, trigger avoidance, use of peak flow meters, and asthma disease knowledge. The instrument has good psychometric properties and corresponds to changes in clinical asthma status over time (Mancuso, Sayles, & Allegrante, 2009).

Caregiver inhaler technique questionnaire

A standardized checklist of inhaler technique was used to assess caregiver knowledge of inhaler technique. The checklist was developed and validated as a tool to screen patients for incorrect inhaler technique (Erickson, Horton, & Kirking 1998).

Health literacy of the caregiver

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A three-item brief health literacy screening scale developed by Chew et al. was used to assess health literacy of the caregivers (Chew, Bradley, & Boyko, 2004). The original scale instructs subjects to respond on a 5-point Likert scale to three items: “How often do you have problems learning about your medical condition because of difficulty understanding written information?” (Responses range from all of the time to none of the time); “How confident are you filling out medical forms by yourself?” (Responses range from extremely to not at all); and “How often do you have someone help you read hospital materials?” (Responses range from all of the time to none of the time). The version of the instrument which modified the original third question to, “How often do you have someone help you read instructions, pamphlets, or other written materials from your doctor or pharmacy?” was used for this study. (Morris, MacLean, Chew, & Litenberg, 2006). After reverse-scoring the item addressing confidence with forms, responses to the three items are summed; scores range between 3 and 15, with higher scores indicating higher health literacy.

Patient medication adherence

The Medication Adherence Report Scale for Asthma (MARS-A) was used as a self-report measure of adherence to each of the subject’s controller medications (Cohen, Mann, Wisnivesky, Leventhal, Musumeci-Szabo, & Halm, 2009). The MARS-A is a ten item questionnaire. Medication use is rated on a 5 point Likert scale with higher scores indicating better adherence. The MARS-A has been tested and has strong psychometric properties. The caregiver completed the MARS-A with the focus on the patient medication-taking behavior. A MARS-A score of 4.5 or higher was defined as good adherence.

Patient use of spacer device/Presence of an asthma action plan

A question was asked whether or not the patient uses a spacer device to assist in the drug delivery process for metered dose inhalers. The caregiver was asked whether the patient had an asthma action plan produced by a health care provider.

Asthma control

The Asthma Control Questionnaire (ACQ) was used to measure the level of control of asthma (Juniper, O’Byrne, Guyatt, Ferrie, & King, 1999). The ACQ was developed as a way to

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determine the degree of asthma control using information from the patient about symptoms, medication utilization, and pulmonary function testing. The symptoms-only version of the ACQ was used for the present study, as it does not include pulmonary function test information or the question on medication utilization (Juniper, Svensson, Mork, & Stahl, 2005). It includes five items to assess the patient's limitations due to asthma in performing activities of daily living. Generally, asthma is considered controlled with ACQ scores below 1.5 (Juniper, Bousquet, Abetz, & Bateman, 2006). This value provides a positive predictive value of 0.84 and negative predictive value of 0.63. A more sensitive cut-point described as being more useful for clinical assessment, is 0.75. This value provides a negative predictive value of 0.81 and positive predictive value of 0.72. These two values were used for the current study to differentiate subjects as controlled versus not controlled. The caregiver completed the ACQ with the focus on the patient's symptoms.

Barriers to medication management and asthma control

A qualitative assessment of barriers was conducted using open-ended questions, asking the caregiver to describe barriers associated with using asthma medications safely and effectively, as well as to describe barriers to controlling asthma.

Data Analysis

Description of the sample was conducted using means with standard deviation for continuous variables and frequencies with percentage for categorical variables. Because of the small number of respondents, further comparative analyses between caregiver and patient characteristics and asthma self-management scale scores were not conducted. Qualitative data described by the respondents about barriers to obtaining and used asthma medication were analyzed using a thematic content analysis. This method was performed to identify issues encountered by caregivers around asthma management and medication management were coded. The analysis was performed inductively where the themes emerged from the data. The passages coded were ordered by thematic similarity or relationship into a project codebook and combined to reduce data to conceptualized themes. Finally, through a thorough process of analysis and comparison back to the original transcripts, data were grouped into major themes. The codebooks obtained by each reviewer were discussed at two different times and consensus

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on interpretation of the content was achieved. Final themes were then counted to determine how many times they were mentioned by respondents.

Results

A total of 19 caregivers completed the survey. Characteristics of the respondents are presented in Table 1. All caregivers were family members of the person with IDD, had a mean age of 53 years, were female, and had at least some college training as a measure of formal education. One-third had education in a health-related field. Most respondents were classified as having acceptable health literacy. The person with IDD required supervision, on average, over 18 hours per day. Refer to Table 2 for data on the person with IDD. Almost two-thirds of the people with IDD depended completely on the caregiver to assist them to manage their asthma medication therapy, with approximately another one-third requiring some assistance. Assessment of adherence to asthma medication, assessed by the MARS-A scale and using the predetermined cut-point in the score, found that almost 75% of the patients were classified in the lower adherence. Just over half of the patients had an asthma action plan, and only twelve percent used a peak-flow meter in their overall management of asthma.

The Asthma Control Questionnaire scores ranged from 0 to 4.2 (lower values indicate better control), with a mean of 1.2 (± 1.2). The number of patients considered to have asthma that was controlled was 12 (63.2%) using the score threshold of 1.5. If the more clinically sensitive score of 0.75 was used as the cut-point, a total of 10 (52.6%) patients were considered controlled.

Caregiver scores on the Asthma Self-Management Questionnaire ranged from 12.5 to 81.3, with a mean of 56.6 (± 22). The highest score achievable is 100, indicating the highest level of understanding of asthma management. Examining the correct responses for each question within the ASMQ, the areas of greatest knowledge deficit include interpretation of prescription instructions, correct use of peak flow meters, inhaler technique, how to prevent asthma flare-ups, reasons for asthma flares and what to do when asthma flares occur, and the

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role of exercise with asthma. Refer to Table 3 for individual items of the ASMQ. Caregiver scores on the inhaler technique questionnaire were widely distributed, with a mean score of 6.5 (± 1.6) and a range from 4 to 9, with 10 being the highest possible score indicating the greatest understanding of inhaler technique.

Responses to the open ended questions regarding barriers to asthma control and barriers to asthma medication utilization were summarized into specific themes. Refer to Table 4 for a summary of the responses. Eleven respondents provided their thoughts about *barriers to asthma control*. The most common barrier to controlling asthma was inadequate education of the caregiver and patient about the illness and treatment. The next most common theme mentioned was knowing and avoiding asthma triggers. Concerning medical care of asthma, lack of consistent follow-up and coordination of care for asthma was the third barrier. The final theme was familiarity and ability of the clinician to work with patients with IDD.

Thirteen respondents provided information regarding *barriers to asthma medication management*. The most frequently cited barrier was struggling to know good inhaler technique. That was followed by education of the patient and the caregiver. Forgetfulness was the third most frequently cited barrier, which included forgetting to use the medication at the prescribed time or forgetting to take medication when away from home. The last three barriers were cited once each and included poor communication between caregiver and patient, lack of adequate follow-up by clinicians (too long of a time between visits), and cost of medication.

Discussion

It is generally acknowledged that knowledge of asthma management is necessary to be an effective self-manager (Allen & Jones, 1998; Kotses, Bernstein, Berstein, Reynolds, Korbee, Wigal, Ganson, Stout, & Creer, 1995; Meyer, Sternfels, Fagan, Copeland, & Ford, 2001; vanDerPalen, Klein, & Seydel, 1997). Family caregiver scores on the Asthma Self-Management Questionnaire (ASMQ) in the present study were not that much different from scores reported from the initial development and validation study of the instrument (Mancuso, et al, 2009). The average caregivers' ASMQ score was 56 ± 22 for the present study, while the mean score during the initial development and validation stage was 60 ± 20 , with a 12-month follow-up score of 68 ± 18 . In the qualitative portion of the present study, the most commonly mentioned theme

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that was perceived to be associated with barriers to asthma control and safe medication use by caregivers was knowledge-base for asthma management. This coincides with the relatively poor scores on the asthma self-management questionnaire as well as the inhaler technique questionnaire.

An interesting finding of the current study is that family caregivers had high scores on the health literacy assessment but didn't do well on the Asthma Self-Management Questionnaire or Inhaler Technique Questionnaire. This relationship suggests that family caregivers are capable of understanding and learning asthma self-management information and skills. Although not included in this study, employed direct support staff, another group of caregivers often involved in managing a care-recipient's medications, have been found to have health literacy similar to that of family caregivers (Erickson & LeRoy, 2015). Clinicians and asthma educators, when working with a patient with IDD, should understand that caregivers may provide a significant amount of assistance to patients with IDD. The clinician and educator should determine to what extent the caregiver should be incorporated into asthma self-management training process. The concepts of asthma self-management that seemed to have the greatest deficits identified in this small pilot study include information about asthma flare-ups such as how to prevent flare-ups, reasons for asthma flares, and what to do when asthma flares do occur. An area of concern was understanding the role of exercise with asthma. Another concerning area is that of interpreting prescription instructions as well as use of peak flow meters. Lastly, understanding of inhaler technique was lacking not only in the ASMQ, but also in the separate inhaler technique questionnaire. Appropriate inhaler technique is crucial to adequate delivery of medication to the sites of action within the airways of the lungs and symptom control (Giraud & Roche, 2002). A study to assess the ability of individuals who had IDD and asthma to appropriately use various inhalers found that no person with IDD could correctly use any inhaler device (Davis, et al, 2016). A systematic review of studies of patients who do not have IDD found that 46 to 59% of patients used inhalers incorrectly (Cochrane, Bala, Downs, Mauskopf, & Ben-Joseph, 2000). At the same time, studies have demonstrated that patients, including many who have IDD, are able to learn proper technique

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which leads to improved symptom control (Davis, et al, 2016; Newman, Weisz, Talaei, & Clarke, 1991).

Davis et al conducted a qualitative study of support personnel who provide direct care to people with IDD, documenting their experiences with asthma medication management (Davis, et al, 2015). The primary findings were that support personnel perform many duties, of which medication management is one. Other research confirms that this is true with family caregivers as well. (Erickson, Salgado, & Tan, 2016). Another important finding in the study by Davis et al was that there appeared to be variation in the level of medication training received by employed support personnel. The support personnel perceived that their role in managing their client's medication is important. The study also found that there may be a lack of decision support available to assist caregivers when performing tasks associated with medication management. These perceptions are similar to those reported by family caregivers in the present study. Of the eleven family caregivers answering the open-ended questions related to barriers to controlling asthma, 36% (n=4) cited the need for education of the caregiver and patient, along with being able to identify and understand common triggers and asthma symptoms. As far as barriers to using medication safely, 46% (six of the thirteen family caregivers) were most concerned with knowing and performing inhaler technique correctly, followed again by education of both the patient and caregiver, followed by forgetting to have medication with them when it is time to take it. Less commonly mentioned, but consistent in the themes were issues with communication and coordination of care between patient, clinician, and caregiver. These issues are consistent with findings from another qualitative study of caregivers who assist people with IDD managing their medication (Erickson, et al 2016).

Additional findings from this pilot study were that over a third of the patients with IDD did not have desired control of asthma. This is one of the first studies to provide evidence of the level of asthma control in patients with IDD using a validated measure. A number of potential factors measured in this study that may have contributed to lack of control of asthma included nonadherence with controller medications and a modest level of caregiver understanding of asthma management and inhaler technique. The findings of this pilot study are similar to those of patients without IDD. In the general population, as well as in study

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samples from physician practices, asthma is not well controlled, with population-based studies finding that between 55 and 59% of people with asthma are controlled based on assessment of symptoms using standardized instruments (Chapman, et al 2008; Peters, et al 2007; Schatz, et al, 2007). In a study using telephone-administered surveys of patients with asthma that also included data from the patients' prescribers, it was determined that 59% were uncontrolled, 19% well controlled, and 23% totally controlled. These values are not too dissimilar to those reported in this study. Future research should focus on the patient, treatment, and social variables that may be associated with asthma control.

For asthma to be controlled, patients need to be adherent to controller medication (Jason, Wong McGrath, Covington, Cheng, & Boushey, 2009; Murphy, Proeschal, Brightling, Wardlaw, Pavord, Bradding, & Green, 2012). Studies on medication adherence for people with IDD are not common. The extent of adherence to controller medications by patients in the general population for asthma therapy varies widely based on the method used to assess adherence, treatment type, and age group. Studies have documented adherence rates to controller therapy that range from 20% to 70% in the general population (Baum, & Creer, 1986; DeSmet, Erickson, & Kirking, 2006; Gong, Simmons, Clark, & Tashkin, 1998; Zora, Lutz, & Tinkelman, 1989).

Limitations

The major limitation of this study is the small sample size. This was most likely due to several issues related to the method used to recruit respondents. We did not include an incentive to participate, nor did we reach out to patients other than by mail. In that light, we consider this study to be a pilot study, providing us and other researchers with a glimpse as to what may be important when examining the association between asthma management and asthma control in patients with IDD. It is not possible to generalize the findings of this small study to all caregivers of people with IDD who have asthma, but it does provide a sense of a number of factors that could be more fully explored in future research. Future studies should include not only a larger number of subjects, but also ensure that an adequate number of various types of caregivers are included, which would include family and friends (informal caregivers) and employed support staff, such as direct support professionals staffing group

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homes, supported apartments or townhouses, or direct-hire personnel assisting an individual within their own home. Strategies to enroll paid carers may be to work directly with the staffing and supports agencies which employ these individuals. Other opportunities to increase the sample size and response rates of all types of caregivers would include offering incentives to participate or to meet potential subjects face to face in clinics or other health-related settings.

Another limitation of this study is that it focused on the caregiver rather than on the patient in regard to asthma management and knowledge. Future work should include the patient with IDD. Evidence suggests that patients with IDD do not receive the same level of health education and health promotion opportunities as the general public (Taggart & Cousins, 2014). This may be due to the general misconception that people with IDD lack the cognitive ability to understand their complex disease state and therefore lack the ability to self-manage asthma. However, more than half of people with IDD are capable of understanding and responding consistently to interview questions in research studies as well as comprehend basic medical information (Strydom & Hall, 2001). Identification of problems in medication management among patients with IDD is essential in order to develop interventions that are tailored to address their needs. Future studies could be developed to test the influence of a targeted or tailored asthma self-management program designed for people with IDD. This type of program could be instituted by supports agencies that provide care to people with asthma and IDD. Nationwide, this would potentially impact over two-hundred thousand people with asthma and IDD-related conditions.

Conclusion

The results of this pilot study provide initial insight into the level of knowledge and skill of asthma medication management in caregivers of people with IDD. Family caregivers who responded to this survey were found to contribute substantially to asthma medication management for the person they provide care for. Despite adequate levels of health literacy, the family caregivers had generally poor understanding of overall asthma self-management concepts. These trends reveal gaps in knowledge of asthma management and the potential need for additional education and assessment of skills for the caregivers. Improving caregiver

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and patient knowledge and skills may lead to better asthma control. The present study suggests that conducting well designed, larger studies that include the patient as well as family and paid carers are warranted. ,

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Caregiver asthma self-management knowledge

Table 1. Characteristics of the Caregiver (n=19 respondents*)

Characteristic	Frequency (Percent) or Mean (standard deviation)
Age	53.8 (12.1) Range 28 to 70
Gender - Female	16 (88.9)
Relationship to the patient	
Parent or sibling	19 (100)
Education	
Didn't graduate high school	1 (5.6)
High school graduate or GED	5 (27.8)
Some college or more	12 (66.7)
Education in health care	
Yes	6 (33.3)
Participate in medication administration training	
Yes	5 (27.8)
Health Literacy	
Confidence in filling medical forms by self – Higher Health Literacy	16 (84.2)
Need help reading hospital Materials – Higher Health Literacy	15 (78.9)
Problems learning about medical conditions because of difficulty understanding written information – Higher Health Literacy	16 (84.2)

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Caregiver Asthma Self-Management Questionnaire Score. Higher score = better self-management knowledge	56.6 (22.0) Range 12.5 to 81.3
Caregiver Inhaler Technique Knowledge Score. Higher score (10 maximum) = better technique	6.5 (1.6) Range 4 to 9

** One respondent did not provide answers to questions assessing caregiver age, gender, or education

Table 2. Characteristics of the Patient with Asthma and Intellectual/Developmental Disability (n= 19)

Characteristic	Frequency (Percent)	Mean (standard deviation)
Age		28.3 (11.5) Range 19 to 65
Gender – Female	7 (37)	
Intellectual/developmental disability		
Cerebral palsy	8 (42.1)	
Developmental delay	6 (31.6)	
Autism spectrum disorder	4 (21.1)	
Down syndrome	1 (5.3)	
Number of hours per day the patient requires supervision		18.5 (9.2) Range 2 to 24
Extent to which patient manages asthma medication themselves		
Completely	1 (5.3)	
Needs some assistance	6 (31.6)	
Depends on caregiver	12 (63.2)	
MARS-A Score (asthma medication)		3.65 (1.0)

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adherence scale) Higher score = better adherence		Range 1.5 to 5
Asthma Medication Adherence Scale Score dichotomized ** Higher adherence Lower adherence	5 (27.8) 13 (72.2)	
Does the patient have an asthma action plan? – Yes **	10 (55.6)	
Does the patient use a peak flow meter**	2 (12.5)	
Asthma Control Questionnaire Score. Higher score = lower asthma control		1.2 (1.2) Range 0 to 4.2
Asthma Control Questionnaire Score dichotomized (1.5 cut point) Better asthma control Poorer asthma control	12 (63.2) 7 (36.8)	
Asthma Control Questionnaire Score dichotomized (0.75 cut point) Better asthma control Poorer asthma control	10 (52.6) 9 (47.4)	

** Not all subjects provided answers to these questions.

Table 3. Asthma Self-Management Questionnaire – Individual Item Results (n=19)

Individual ASMQ Questions (..... with correct response)	Number and Percent Correct Response
A main method to prevent asthma flare-ups is to get a flu vaccine	5 (26.3)

Caregiver asthma self-management knowledge

Taking the prescribed two puffs of you inhaler two times a day is not the same as any other regimen	8 (42.1)
If you are not having asthma symptoms you should still avoid triggers	14 (73.7)
Maintenance medicines help prevent future symptoms	15 (78.9)
The correct way to use peak flow meter is to take a deep breath then blow into the mouthpiece as fast as you can	2 (10.5)
Rescue medicines should not be taken more than three or four times a day	16 (84.2)
When using your inhaler, you should inhale slowly	9 (47.4)
After you have used your inhaler, you should hold your breath for several seconds	12 (63.2)
If you are having symptoms and don't know why, the first thing you should do is change your immediate environment	5 (26.3)
Taking more rescue medications than prescribed may mean you need more maintenance medicine	12 (63.2)
The benefit of using a peak flow meter every day is you can detect small changes in lung function even before symptoms start	11 (57.9)
For people with asthma, exercise can help improve breathing capacity	8 (42.1)
Asthma can be cured by there is no known cure for asthma	16 (84.2)
Asthma flare-ups can occur when several minor triggers come together	9 (47.4)

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If you are prescribed a seven-day course of steroid pills you should finish the prescription even if you feel better after several doses	16 (84.2)
Which of the following can help control asthma? Reducing the stress level, drinking plenty of water to stay hydrated, and avoiding foods with sulfites, such as dry fruits and wine	14 (73.7)

Table 4. Themes Present in the Qualitative Assessment

Barriers to Controlling Asthma	Percent of Caregivers (n=11)
Education of patient and/or caregiver	36.4
Asthma triggers and symptoms	27.3
Lack of follow-up/care coordination	18.2
Clinician familiarity/ability to work with patients with IDD	18.2
Barriers to Using Asthma Medication Safely and Effectively	Percent of Caregivers (n=13)
Knowing and performing correct inhaler technique	46.2
Education about medications for caregiver/patient	38.5
Forgetfulness	15.4
Communication between patient and caregiver	7.7
Lack of follow-up/care coordination	7.7
Cost of medication	7.7