

Title: Chicago Public School Nurses Examine Barriers to School Asthma Care Coordination

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ABSTRACT:**Objective/Design:**

Well documented asthma disparities in Chicago pose a continual challenge for the Chicago Public Schools (CPS). Coordinated Health Care for Complex Kids (CHECK) is a health care demonstration project funded by a Centers for Medicare and Medicaid Services Health Care Innovation Award. A collaborative partnership was formed between CHECK and CPS. With CHECK support, CPS administered a survey to 160 nurses to understand the asthma problems nurses perceived and interest in intervention.

Results:

Seventy-five percent (n=120) completed the survey. While asthma was the top diagnosis managed by 95%, 72% reported gaps in asthma understanding. Appropriate communication between school nurses and providers occurred 33% of the time; 18% believed they received sufficient support to follow-up on deficient paperwork. The barriers mentioned were lack of medications (73%), time (67%), and communication with providers (61%). When asked their opinions on potential interventions, 78% of nurses supported web-based applications, 66% community health workers, and 66% stock albuterol in schools.

Conclusions:

The greatest barriers for CPS nurses with asthma management are time and communication. Potential interventions such as web-based communication applications and community health workers in schools were well received.

Keywords:

Asthma

Centers for Medicare and Medicaid Services

Community Health Worker

Community-based participatory research

Health Disparities

Nurse

Pediatric Asthma

Schools

School-based asthma

Survey

Vulnerable population

BACKGROUND:

Chicago Public Schools (CPS) is the third largest school district in the country serving 371,382 children in 646 schools¹. Children in CPS are reported as 37.7% African American, 46.5% Hispanic and 9.9% White¹. Asthma disparities regarding both prevalence and morbidity in different racial/ethnic groups in Chicago have been well described:²⁻³ African American children in Illinois, with the greatest concentration in Cook County where Chicago is located, are five times more likely to present to an emergency room and four times more likely to be hospitalized due to asthma than their non-Hispanic white counterparts⁴. This should translate into high rates of asthma in CPS. However, a 2014 study reported only 4.5% of CPS students possessed documentation of a physician diagnosis of asthma⁵, suggesting existing documentation significantly underestimates the asthma burden in CPS^{2, 5-6}.

Asthma is a main reason for school absenteeism, with 13.8 million school days missed in 2013⁷⁻⁸. CPS does not currently differentiate causes of school absenteeism, but overall CPS absenteeism ranged from 6.9-7.2% from 2014-2017⁹. CPS rates have been lower than administrative goals and are a major source of focus in CPS¹⁰. Missing school adversely affects school outcomes¹¹ and children, regardless of diagnosis, living in low-income areas are more affected by school absenteeism¹². Barriers to school-based asthma management include availability of nursing and other trained health care personnel in schools^{7, 13}, communication^{7, 14-15}, and lack of medications^{7, 16}.

Coordinated Health Care for Complex Kids (CHECK) is a large health care demonstration project awarded by a Health Care Innovation award funded by the Centers for Medicare and Medicaid Services (CMS) that services Cook County. CHECK enrolls children and young adults from birth to age 25 who are enrolled in Medicaid fee-for-service or one of the

partnered managed care plans and have an established chronic disease diagnosis. Asthma represents 72% of the patients enrolled in CHECK. The full CHECK model is described in detail elsewhere¹⁷⁻²⁰.

One of the main goals of CHECK is to reduce school absenteeism for children with chronic disease through interventions involving the school and community health workers (CHWs). CHECK took a collaborative approach to this goal, working closely with leadership in CPS to ensure relevance and feasibility of the work conducted. As the CHECK program was beginning, CPS leadership worked with the CHECK data team to set up the attendance data transfer and identify mutually beneficial uses of those data. CHECK and CPS leadership also engaged in detailed discussions about how best to support asthma management both within the clinical and school settings. CPS leadership suggested starting with a survey of all the CPS nurses to better understand the needs and interests within schools. This survey would help to determine the best options for standardizing asthma management in CPS. A standardized asthma management must be mindful of local school and community cultures regarding asthma, the unique clinical and social needs of children, and budget issues including a significant nursing shortage. This manuscript describes the CPS nurse survey and results, conducted as a first step toward understanding options for standardizing asthma management in CPS.

METHODS:

Design:

Survey Development:

Three CPS nurse leaders and three CHECK physician leaders (two general pediatricians and one allergist/immunologist) worked collaboratively to create a survey that addressed the main concerns regarding asthma care in the school. One school nurse leader drafted most of the questions with physician and nurse input. Survey questions were created based on the lived experience of nursing administrator with decades of experience in school nursing. Areas of focus included questions meant to solicit opinions on nurses' view of current asthma communication and management strategies, identification of barriers and gaps in asthma management, and possible intervention strategies to facilitate asthma care delivery. Input from a work-group that included several more CPS nurses was incorporated into the final survey. Multiple versions were drafted with input from both CPS and CHECK. A final version was agreed upon and then translated into a Google® survey. Because of time and resource limitations, validity and reliability testing were not performed.

The final anonymous survey included a total of 16 questions to be administered to school R.Ns. Respondents were asked two open-ended questions: one asked about barriers to communication with providers and the other provided a space for general comments. The rest of the questions were related to perceptions of asthma as a top diagnosis dealt with in schools, appropriate communication between nurses and parents as well as providers, ability to obtain paperwork and forms from families and providers, support to follow-up on deficient paperwork, barriers to asthma management in schools, and ease of translation of asthma plans into 504 plans. These questions aimed to solicit school nurse insights into possible intervention strategies to

overcome perceived barriers including direct communication between nurses and providers, standardized asthma plans, community health workers, web-based applications, and directly observed therapy. These particular interventions were specifically chosen because of their strong evidence base²¹⁻²² and interest from CPS and community leadership. Survey questions on perceptions were rated using an odd number-item Likert-type scale. Frequency items were rated on a 5-point scale (1=never to 5=always). Strength of agreement questions were rated on a 5-point scale (1=strongly disagree to 5=strongly agree).

Sample:

Survey Administration:

The survey was administered to school registered nurses within district-run schools only (515 schools) and did not include nurses from charter schools where health services are administered differently (131). At the time of this survey, there were 160 registered nurses for district-run schools. The nurses surveyed included registered nurses who are certified school nurses and nurses practicing in the role of the Health Service Nurse (limited scope of practice)²³⁻²⁴ within the school environment. The survey did not include licensed practical nurse (LPN) nursing staff assigned to specific students with particular health care needs.

The survey was administered electronically using Google® survey. CPS nursing leadership distributed the survey via email on December 12, 2016, to the 160 nurses. The survey was closed on January 9, 2017. Two email reminders were sent to enhance the response rate. There was no incentive provided for completion of the survey.

Human Subjects:

The University of Illinois at Chicago Institutional Review Board and the Chicago Public Schools Research Review Board determined the study was exempt from human subject requirements.

Analytic Strategy:

For analysis of this mixed methods study, frequency items from the survey were collapsed into “never/rarely/sometimes” and “often/always”. (A sensitivity analysis demonstrated there was no significant difference when “sometimes” was categorized with “rare” or “often”). Strength of agreement were collapsed into “strongly disagree/disagree/neutral” and “agree/strongly agree”. Statistical significance was ascertained using Fisher’s Exact Test or Mantel-Haenszel Chi-Square where appropriate. Analyses were conducted using SAS 9.4.

The researchers used conventional content analysis for the open-ended response questions²⁵ This method of qualitative analysis was appropriate due to the lack of existing research on the nature of the relationships between school nurses and physicians. The open-ended design of the questions allowed the school nurses to introduce topics and themes that had not been conceived of by the team during survey development. Two team members independently read all open-ended responses, allowing themselves to immerse themselves in the data. Using the language of the responses, the researchers together operationalized codes based on the themes that emerged from the data. These team members reread all responses and assigned codes to the responses. Inter-rater reliability²⁶ was 87%. Analyses were conducted using ATLAS.ti 8 and Microsoft Excel 2010.

RESULTS:

Demographics (Table 1):

A total of 120/160 nurses participated (75% response rate); their demographics are shown in Table 1. Complete survey data was available for 117 of the 120 responses (97.5%). CPS nurses were women and represented both certified school nurses (76%) and health service nurses (23%). Responses were not associated with type of nurse certification (p-values ranged from 0.12 to 0.92 across all response categories). All CPS School nurse regions (North, Central and South) were represented and responses did not vary by region (p-values ranged from 0.14 to 0.98 across all response categories). The average length of service for nurses was 12.7 years.

Basic Asthma/Policy Questions (Figure 1):

Asthma was identified by 114 (95%) of school nurses as one of the main diagnoses encountered and managed in CPS. Despite asthma being a common diagnosis, 86 (72%) felt a gap exists in the general school staff's understanding of asthma and how to manage it. Because school nurses are not in every school every day, they rely on other school staff to help intervene if asthma were to emergently worsen. Appropriate communication between school nurses and health care providers outside the school was also an issue. Only 39 (33%) of nurses were able to communicate effectively with providers, with only 44 (37%) of nurses receiving complete paperwork from providers often or always. Additionally, there were concerns with receiving health-related paperwork from families with 25 (21%) of families often/always turning in necessary paperwork. Seventy-nine (66%) nurses strongly agreed/agreed to the statement "I believe shared data between healthcare providers and school nurses directly without relying on the parent would be helpful in planning and the treatment of my students with asthma." The

minority of nurses (22 or 18% of nurses) reported they receive the support needed to follow-up on deficient paperwork.

Barriers to Asthma Care: (Figure 2)

The most common barriers that the nurses brought up in open-ended questions were lack of medications (86 or 73% of nurses), time (81 or 67% of nurses), form/policy issues (65 or 61% of nurses) and provider communication (52 or 35% of nurses). Themes reported by fewer than 10% of CPS nurses included technology, lack of diagnosis, 504 plans (in place for students with disabilities to receive accommodations or modifications to attend school using general curriculum)²⁷ issues, triggers, lack of primary care physician follow-up, language barriers, asthma van, and inhaler technique. Lack of medications was pervasive in nearly all comments.

Parental dilemmas with childcare and ability for time off to care for sick children is highlighted by school nurse remarks. *“There is no or insufficient space in the school setting to properly care for students with asthma or students experiencing exacerbations. We bear the burden of employers that do not provide paid time off for their employees. Of course, a parent is going to send their child to school if they have no one to care for their child and they will lose a day of pay or maybe even their jobs.”* Time is also related to school nurse ratios which were mentioned multiple times; one nurse stated *“I believe a nurse needs to be in a school more than once a week.”*

A need for standardizing forms and collaboration with providers and school were commonly cited: *“Health care offices understanding the role of the school nurse, and what supports can be provided in the school”*. Difficulty getting the right forms in place was a huge issue: *“...physicians receive CPS forms...yet they send old forms, incomplete without signatures*

and dates”. The nurses pointed out that schools are providing care and need to be a place for asthma education and coordinated efforts of care: *“...schools are one of the last places you have an opportunity to affect medical health knowledge and change. We have a ‘captive’ audience.”*

Communication can take place in many ways, but most frequently a paper form with specific patient information regarding an illness and prescribed treatment such as an asthma action plan is common for the school nurse-healthcare provider interaction. Sometimes communication streams breakdown. One nurse highlighted this issue citing communication failures. *“Communication starts at the nursing level. If the nurses could help us communicate with physicians it would be a great help. I find the ball is dropped sometimes at the nursing level and then the doctor doesn't have a clue; and we have to start from the beginning. Forms are rarely comprehensive; information is always missing.”* This nurse was recognizing the important role school nurses play in communication and the need for school nurses to communicate with outside providers in order to ensure accurate information. Communication breakdowns can occur at every level. Ways to help support nurses, providers, and families effectively communicate with each other is crucial to improving asthma management in schools.

Lack of medications, specifically albuterol, available to nursing and other school staff was highlighted in this emotional example: *“Filling out this survey brought back a painful memory of the day I almost lost a child about two years ago. He had no inhaler. He collapsed in my arms. My eyes are full right now. I can't go on with my story. He did survive.”* Although self-carry laws permit albuterol to be with children, nurses often note a lack of albuterol available. Similarly, *“I would like to see students more adequately managed by their health care providers - many students who seem like they would benefit from daily preventative regimens are*

not on them - and many families seem to have received little to no education on asthma, proper management etc.”

Proposed Solutions (Figure 3):

One possible solution was offered by a school nurse that addresses the concept of a standardized approach to asthma management: *“...having one agreed upon action plan that we all use that is user friendly and very clear could be helpful as well. Some nurses use different forms and if a student transfers, the new school staff may not be familiar with the other action plan and may have difficulty following it.”* Our goal is to find a way to standardize asthma management plan in CPS hopes to embody what this nurse describes.

Support of proposed solutions (strongly agree/agree) was 93 (78%) of nurses for a web-based application, 79 (66%) for community health workers, (79) 66% for stock albuterol policy for schools and 73 (61%) for directly observed therapy. Some nurses were neutral on these interventions (20%, 24%, 21% and 25%, respectively). Very few people opposed the initiatives with only 8.3% (10/120) against or neutral to the three interventions. Forty-three percent (52 nurses) agreed to all three of the top initiatives surveyed including the web-based application, CHWs and stock albuterol in schools. Tools to improve communication would influence the work flow of nursing: *“Having a web based system to gather information like we do immunizations and having the ability to access it easily. Having the ability to email directly to doctors (we rarely get emails from MDs and that would save on the lag time between calls and phone tag).”*

Although stock albuterol was overall well supported, some concerns from the minority of responders are important to take into consideration. One nurse highlighted her worry by stating

"Keeping prescribed rescue inhalers in school does not address needed asthma management at home, and could lead to parents thinking the school has them, so the child does not need his/her own. Are we going to stock insulin pens and Diastat® too?" Also, providing daily medications or rescue medications would be a difficult addition to an already overextended school nurse in the current environment: *"The providing of direct services for asthma management is very difficult in my 'daily duties' due to my time availability and the inability to detect when the medication will be needed (except during an exacerbation period)."* Providing medications will require the district to address nursing shortages and possibly result in the training of non-clinical personnel to administer medications routinely. These considerations need to be addressed when interventions are planned to make sure what is proposed is actually feasible and affordable in the CPS or any school-based environment.

Associations (Table 2):

Additional analyses of communication concerns were completed when it became obvious that communication was one of the key barriers nurses identified. We wanted to see if appropriate communication was associated with issues with forms, etc. Interestingly, despite 39 (33%) nurses reporting that they often have appropriate communication with the primary care doctor, they also stated that the primary care doctor rarely supplies proper information (n=62 or 52%) regarding form completion and documentation. This highlights the complexity of communication between providers, and how there could be issues on multiple levels.

DISCUSSION:

This survey provides a glimpse into everyday challenges of nurses regarding asthma management in the third largest school system in the United States. Although not the first school-based nurse survey¹³, our survey effectively solicits opinions that can help shape interventions that are feasible in our large urban school system. System-level interventions that include schools are critically needed in places like Chicago where asthma health disparities have persisted for decades in low-income²⁸ and predominantly minority children^{1, 5, 28} with significant asthma morbidity²⁹. The language in the examples that nurses provided demonstrate that they are very aware of the hardships faced by children and eager for solutions. Despite their desires to help, CPS, like many inner-city school districts are plagued by budgetary concerns, staffing issues, competing priorities, antiquated communication systems among other factors that limit their ability to supervise children with chronic diseases, such as asthma. School nurses play a vital role in keeping our children healthy and safe in school; interventions and advocacy that help improve nurse per school ratios and support the school nurse role is a crucial public health concern.

Nurses reported difficulty completing their tasks due to time, communication and form/policy barriers. These results were evident in both the quantitative and qualitative portions of the survey. This is similar to what others have reported and demonstrates the need to improve the links between families, schools and healthcare systems²⁹. More efficient ways to complete paperwork and communicate with families and providers would allow nurses to have more time for their other tasks and to work directly with students. Until recently, almost all communication in CPS was via paper systems, fax and telephone. Recent improvements in technology formats offer an opportunity to initiate more technology-driven platforms to help mitigate

communication barriers. Calling busy medical practices on the phone is not feasible in this current healthcare climate; alternate methods such as interactive electronic health records (EHRs) or community health workers who can bridge the communication gap may offer potential solutions. Advocacy for improved school nurse ratios regionally and throughout the country is also desperately needed to ensure enough nurses are available for the children they serve. The goal should be to use technology and other resources to reduce the administrative burdens on nurses, thereby allowing nurses to actually provide health guidance and clinical care.

Nurses in our survey did not frequently highlight inhaler technique as a barrier. To CHECK leadership, this was surprising as inhaler technique in children is frequently reported as a barrier to effective asthma management³⁰⁻³². However, CPS has been fortunate to receive regular inhaler technique training for staff and posters are placed in schools that demonstrate proper technique. One future consideration would be to monitor inhaler technique data to ensure nurses are able to consistently demonstrate proper inhaler technique, and that skills do not degrade over time. An additional barrier that was less frequently mentioned was the “asthma van”. The asthma van available at CPS is serviced by Mobile Care Chicago. Mobile Care Chicago provides asthma services to 40 schools and public daycare centers annually in Chicago. Future interventions to help bridge the medical and school sectors may include a mobile clinics such as asthma vans that links larger medical systems and school districts to direct care. This would ensure proper paperwork and allow for data sharing to take care of particularly difficult asthma or other chronic disease cases.

Our survey asked nurses about possible interventions to address the main barriers mentioned and all intervention ideas were well received. The choice of solutions discussed in the survey were those that the CHECK and CPS leadership had openly discussed as agreeable

potential interventions. One of the goals of both CHECK and CPS leadership is to reduce school absenteeism in our children with young disease as well as formulate a feasible and sustainable comprehensive asthma management program that would actually work in the CPS system. This survey helped guide us where to start further formative work to develop this program further. The majority of nurses endorsed the use of community health workers (CHWs) in the schools to help improve the communication barriers. The roles of the CHWs need to be properly discussed before interventions take place. CHWs provide education, navigation, and advocate for families³³⁻³⁴; they do not provide clinical care and are not intended to replace school nurses. A pilot of CHWs in the school to help determine where the need is and their specific roles would be a good first step in determining the potential for integration of CHWs into the CPS system district-wide.

Technology interventions, such as a digital application for parent/provider communication or to convey asthma plans, were supported. Given the lack of current web-based applications or universal EHR, this makes direct communication between the medical, school and family domains difficult. Most times the communication is done telephonically or via fax with potential for communication breakdowns. Directly observed therapy was well received, although it did receive the most negative comments in open-ended responses. Similar interventions have been successful in other school districts³⁵. Further nurse discussions are recommended about the role and effectiveness of directly observed therapy prior to considering this approach in CPS given the significant concerns raised in our survey.

Lastly, stock albuterol for asthma exacerbations in schools is a policy proposal being discussed on the regional, state and federal level.³⁷ Stock albuterol in schools was shown to reduce emergency room trips for asthma after implementation of a stock albuterol policy in

Arizona³⁶. CPS nurses overall favored policy efforts to stock schools with the necessary medications to treat asthma exacerbations. At the time this survey was implemented, initial discussions on stock albuterol policy had begun but no formal legislation had been introduced³⁸; subsequently, stock albuterol was passed in the state of Illinois August 2018. Issues with implementation will have to be addressed in the near future, given that there is a significant nurse shortage and it is unclear how best to supply and administer stock albuterol to children with asthma throughout the state. Additionally, self-carry laws without the requirement of a doctor's permission were already in place in the state of Illinois. Policymakers and advocacy groups can use the findings from our survey to support the creation of stock albuterol legislation nationally and locally.

Limitations:

Limitations of our study include possible selection bias. Although we had a high survey response rate (75%) and responses were anonymous, our results may not be representative overall of the CPS nurses and may not be generalizable to other school districts. We also could not ascertain if the nurses represented an elementary, middle or high school. As this was a community-created instrument, the survey did not undergo any psychometric testing to confirm validity and reliability of survey questions. This may have led some of the questions to be open to the school nurses' interpretation and may not accurately represent what a more rigorously tested survey may have accounted for. Also, surveys such as this do not allow for an in-depth exploration of responses. For example, a moderate proportion of nurses responded neutrally to several questions which we were unsure how to interpret. We coded neutral responses with negative responses to ensure endorsements of ideas were not overestimated, but we do not know why respondents did not have opinions on these items.

Conclusions:

Our survey of the nursing workforce in CPS highlights areas of need as well as support for interventions to address standardizing school-based asthma management for children and youth in Chicago. Health providers and administrators need to work collaboratively with school nursing and its leadership to identify necessary and acceptable approaches to asthma care management in the schools. These may include the introduction of interactive web-based platforms for HIPPA and FERPA compliant chronic disease communication, the use of CHWs within the school and/or mobile clinic space to help bridge the medical, school, and community sectors, as well as consideration of policy and further implementation of stock albuterol to improve emergency medication availability in asthma. Tools, such as the School-based Asthma Management Program or SAMPRO³⁹ created by the American Academy of Allergy, Asthma and Immunology, exist to help guide school districts to standardize asthma management programs and reduce nurse administrative work³⁹⁻⁴⁰. Further, policymakers need to address school nurse staffing shortages and help legislatively to support the vital role of school nursing in Chicago, in Illinois, and across the country. This will require innovative partnerships across a range of public and private sectors. Asthma interventions, preferable those that function on multiple levels, and additional policies are needed to keep our children with asthma safe and healthy.

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Table 1. School Nurse Demographics (n=120)

<i>Total (%)</i>	
<i>School Nurse Classification</i>	n=120
<i>PEL-Certified School Nurse</i>	91 (76%)
<i>Health Service Nurse</i>	28 (23%)
<i>Other, unlisted</i>	1 (0.8%)
<i>Age (n=120)</i>	
<i>21-30 years</i>	10
<i>31-40</i>	25
<i>41-50</i>	46
<i>51-60</i>	30
<i>61 and over</i>	9
<i>Chicago Public School Region (n=113)</i>	
<i>North</i>	46 (41%)
<i>Central</i>	38 (34%)
<i>South</i>	29 (26%)
<i>Gender</i>	
<i>Female</i>	120 (100%)
<i>Male</i>	0 (0%)

Table 2. Associations between Nurse Report of Communication and Other Survey Responses (N=117)

	Appropriate communication between health care providers and school nurses occurs:		
	Often (n=39)	Sometimes (n=62)	Rarely (n=16)
“How often” survey questions*			
I find that providers rarely supply appropriate information ¹ (n=81)	33	85	94
I find that parents rarely supply sufficient information ¹ (n=92)	22	55	15
“Agreement” survey questions**			
I agree there are gaps in the school's staff understanding of asthma ¹ (n=86)	22	53	11
I agree that nurses should be able to provide daily meds to high-risk students (n=71)	28	32	11

* Survey questions regarding frequency

** Survey questions regarding level of agreement

¹ Significant at p<0.05