

Alignment of Stakeholder Agendas to Facilitate Adoption of School-Supervised Asthma Therapy

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Abstract

Background: School-supervised inhaled corticosteroid (ICS) therapy improves pediatric asthma medication adherence, outcomes, and morbidity. However, school-supervised ICS therapy has not been widely adopted into practice. We developed Asthma Link™ as a sustainable, low-cost model of school-supervised asthma therapy, designed for real-world adoption. Initial outcomes of Asthma Link™ demonstrated a significant improvement in health outcomes.

Objective: In this study, we examined the perspectives of Asthma Link™ participants to identify systems-level barriers and facilitators in order to refine the Asthma Link™ protocol and facilitate real-world uptake of school-supervised asthma therapy.

Methods: Using qualitative research methods, we interviewed 29 participants in Asthma Link™ from 2016-2018. Semi-structured interviews were conducted over the phone. Interviews were transcribed and the transcripts were coded to identify major themes within and across stakeholder groups.

Results: Stakeholders agreed on many facilitators for successful Asthma Link™ execution including the brief and easy to follow procedures and the perceived beneficial health impacts for children involved. Some of the barriers identified were deviations from the protocol and insurance companies denying coverage for two inhalers. However, the participants did propose solutions to address these barriers.

Conclusion: Asthma Link™ is a low-cost, sustainable model of school-supervised asthma therapy that leverages the established infrastructure and collaboration of medical providers, school staff, and families. In this study, we elicited the perspectives from these stakeholder groups and identified agreement in several facilitators, barriers, and proposed solutions that will ultimately inform refinement of the program protocol and support real-world adoption of Asthma Link™ and other similar models.

Introduction

Asthma is one of the most common childhood diseases and a leading cause for pediatric emergency room visits, hospitalizations and school absenteeism.¹ National treatment guidelines recommend preventive inhaled corticosteroid (ICS) therapy for management of persistent asthma, yet ICS therapy is grossly underutilized, with adherence rates at less than 20%.²⁻⁴ Several randomized controlled trials have shown that supervised ICS therapy in a school-based setting improves ICS adherence and asthma outcomes and reduces morbidity.⁵⁻⁸ However, school-based supervised ICS therapy has not been widely adopted into practice.

Evidence-based strategies often are not implemented long-term because they are driven by researchers, are resource-intensive, and do not elicit reflections from local participants or align community stakeholder agendas, which can determine the sustainability of the program long-term.^{9,10} Thus, we developed Asthma Link™ as a low-cost model of supervised asthma therapy in schools, leveraging established infrastructure rather than dedicated research resources and seek to understand the perspectives of participants in the program.¹¹

Asthma Link™ partners three key stakeholder groups committed to pediatric asthma care—pediatric providers, school staff, and families—to provide a real-world approach to school-supervised asthma therapy. As part of their routine practice, medical providers identify and enroll children with poorly controlled asthma and medication non-adherence into Asthma Link™. They send the school nurse an order for daily, supervised ICS administration at school and instruct families to bring the prescribed inhaler to school. The school nurse supervises the child's inhaler administration and provides education to the child, to ensure that he or she understands the importance of adherence and proper inhaler/spacer technique. Families are encouraged to ask questions and engage with the medical provider and school nurse regarding their child's health. Ongoing communication occurs between all three parties throughout the school year via phone and email (Figure 1).

Initial implementation of Asthma Link™ demonstrated a significant decline in emergency room visits, hospital admissions, and rescue medication use among 84 children enrolled in the program.⁷ Given these promising preliminary findings, the next logical step is to refine the program to maximize its scalability and potential impact. End-user feedback is critical to incorporate into intervention refinement, as it can provide information to facilitate promotion and uptake of supervised asthma therapy in real-world settings, where it can have a significant public health impact.^{12,13} Experts in implementation research stress the importance of incorporating local participants' reflections on the intervention into the protocol refinement and into the design of traditional randomized controlled trials which test an intervention.¹⁴

The aim of this qualitative study was to understand the perspectives of medical providers, school staff, and families on systems-level barriers and facilitators in order to refine and adapt Asthma Link™ for scalability into real-world pediatric practice and school communities. This study will also directly inform the design of a prospective randomized controlled clinical trial to test this real-world application of supervised asthma therapy.

Methods

Study Design and Participant Recruitment

We used qualitative research methods to gain a deeper understanding of the perspectives of three stakeholder groups—medical providers, school staff, and families—on systems-level barriers and facilitators and recommendations for improving the current protocol of Asthma Link™.

Participants included a purposeful sample of 29 stakeholders who participated in Asthma Link™ from 2016-2018. This sample selection was based on the feasibility of completing the study in a 1-year time frame and on the number of interviews needed to attain thematic saturation of content.

Children in Asthma Link™ between the ages of 6-18 years old and their parents were recruited for the study through a mailed recruitment flier from University of Massachusetts Memorial Medical Center or in clinic during their visit with the pediatric pulmonologist. For each parent-child dyad, a \$25 Target gift card was provided as incentive for participation. Of the 6 families that were approached, 6 unrelated parents and 4 unrelated children agreed to participate.

Medical providers included general pediatricians, pediatric pulmonologists, nurse practitioners, and community health workers from three pediatric practices in Worcester, MA that were already involved in enrolling patients into Asthma Link™. Providers were recruited through face-to-face contact in clinic. Of the 8 providers contacted, all 8 agreed to participate.

School staff included school nurses, administrators, and teachers in the Worcester, MA Public School district. We chose to contact stakeholders based on schools that had at least 2 children participating in Asthma Link™ to ensure they had sufficient experience with the program. These professionals were contacted via email, using an available staff directory that is utilized as part of regular communication with school staff for the program. Of the 21 school staff who were contacted, 11 agreed to participate. The school nurses represented 8 of the 44 schools in the Worcester Public School system.

Informed Consent

A fact sheet explaining the purpose of the study, confidentiality, and contact information for the program was sent to each participant prior to conducting the interview. At the beginning of the interview, the fact sheet was reviewed and participants were asked for verbal consent and informed that they have the right to refrain from answering any questions posed. Interviews were conducted in a private setting and collection of protected health information about the participants was not required in this study.

Data Collection

Semi-structured stakeholder interviews were conducted over the phone between June 2017 and December 2018 by trained research assistants. The interview guide contained a mix of open- and closed-ended questions. Probes and follow-up questions were used throughout the phone interview as needed. Each interview lasted between 20-40 minutes. This study was approved by the Institutional Review Board at the University of Massachusetts Medical School.

Qualitative Analysis

Interviews were audio recorded, transcribed by a third party, checked for accuracy, and stripped of any identifying information. Transcripts were imported into Dedoose Version 7.6.6 (2017), a qualitative data analysis software. Five initial, randomly selected transcripts were read line-by-line by four team members and using inductive reasoning, preliminary codes were assigned to each unique topic that emerged. Following review of the five transcripts as a group, the analysts refined these codes and specified indications for their use in a universal codebook using an iterative process.^{15,16} The remaining transcripts were coded individually by 3 team members based on the universal codebook. Each team member received greater than 80% on the interrater reliability tests created on Dedoose prior to beginning coding, which supports the high rate of agreement amongst the team members. After individually coding each interview, the team members came together to reach 100% agreement and finalize coding. Previously coded interviews were re-read and checked for accuracy when any changes to the codebook were made.

Upon completion of open coding of each interview, excerpts were exported from Dedoose. The data were organized by code into a matrix. We examined the interview data according to the following constructs: Process, Facilitators, Barriers, Potential Solutions, Target Population, Perceived Impact of Program, and Program Expansion/Dissemination. Within these constructs, researchers looked for alignment in themes across multiple stakeholder groups. Themes that aligned across two or more stakeholder groups or were prevalent within one group are described below.

Results

STUDY POPULATION

Participants included a purposeful sample of 29 stakeholders in the Asthma Link™ program, including 8 school nurses from the Worcester Public Schools, 1 school nurse coordinator, 1 school administrator, 1 teacher, 4 physicians, 3 nurse practitioners, 1 community health worker, 6 parents, and 4 children. Of the 8 pediatric providers, the average years of experience in their respective fields was 8 years. Amongst the school staff, average years of experience was 23 years. Two school staff did not provide information about their length of experience. The parents and parent-child dyads were from low socioeconomic status, reflecting the population that Asthma Link™ primarily serves. One parent declined to provide average annual income. The average age of the children was 13.25 years, with 1 female, 2 Caucasian, and 2 African-American children in the group.

DATA CONSTRUCTS

Process/Protocol

All 3 participant groups correctly described their roles and understood the workflow of Asthma Link™, which matched the stated protocol. This emphasizes the ability of all 3 groups to engage in and follow the intended protocol in real-world practice without guidance from research staff.

Facilitators

Participants identified six themes for facilitators within the Asthma Link™ program that currently ease or support the program's execution (Table 1). These are as follows: (1) Asthma Link™ fits easily into each participant's busy schedule, (2) enrollment and medication administration is quick, (3) there is improved communication between stakeholders about the child's asthma, (4) caring for the child's asthma is a team approach, (5) phone communication is the preferred method of contact for the program, and (6) participants are confident that the medication is administered correctly, routinely, and with proper understanding of the importance of the medication.

Barriers

The participants identified seven barriers that prevent the program from functioning to its highest potential (Table 2). These are as follows: (1) Participants explained that school nurses may think it is the parent's responsibility to administer daily asthma medication, (2) families sometimes fail to bring the medication into school on time, (3) families may be initially offended when they are

introduced to the idea of their child receiving medications at school, (4) insurance will at times not cover two inhalers (one for home and one for school), (5) school staff occasionally have to track down the student in order to meet with the school nurse, (6) it can be difficult for members from one stakeholder group to contact members of the other stakeholder groups, and (7) there is uncertainty about the child's asthma health over the summer when they are not receiving routine medication from the school nurse.

Potential Solutions

Proposed solutions to support the program and target the identified barriers to program success included six themes which were aligned among the stakeholder groups: (1) sending medication directly to the schools through a courier service or community health worker, (2) increasing education about the program for nurses and families to improve understanding of the Asthma Link™ protocol, (3) presenting the program in a non-judgmental way to reduce stigma associated with being in the program, (4) instituting an “asthma champion” or liaison in the medical provider's office to keep up regular communication across the three stakeholder groups (families, pediatric practices, and school nurses), (5) using an electronic system to streamline paperwork but also maintaining a form of direct phone communication, and (6) bringing children and parents in for a visit with the pediatric provider at the end of the school year to discuss adherence strategies for the summer (Table 2).

Target Population

The stakeholders identified three main characteristics of the population that would benefit most from supervised ICS in school (Table 3). These included children with poor ICS adherence at home and/or poorly controlled asthma, children who have unstable home lives and/or may travel between multiple homes, and children with environmental asthma triggers such as tobacco smoke in the home.

Perceived Impact

Upon reflection of the program's impacts and reasons to continue the program, participants produced five themes (Table 4). Asthma Link™ (1) assists/minimizes caregiver duties and burden, (2) creates routine and improves medication adherence, (3) yields improvement in the child's health in terms of decreasing rescue medication use and hospitalizations, (4) improves school attendance and performance, and (5) engages the child in his or her own health by teaching skills needed to practice better self-care.

Program Expansion and Dissemination

Reflecting on expansion of the program, both school nurses and pediatric providers thought that additional students within each school would benefit from the program. School nurses and families thought that school nurses could be well suited to identify children who would benefit from the program. Regarding the construct of dissemination and how to reach non-users of the program in other communities or schools, both school nurses and families thought that the program could be advertised in a more modern technological manner such as through social media to attract the appropriate children and families to the program. Both school nurses and pediatric providers thought it would be appropriate to disseminate knowledge about the program to pediatric providers and school nurses through professional conferences and to families through local health fairs. All three stakeholder groups said they would like to see an information sheet describing the outcomes of the program, which would help with program engagement. School nurses and pediatric providers would like to incorporate Asthma Link™ education and training into their own continuing education credits (Table 5).

Differences Within or Between Stakeholder Groups

Differences within and between stakeholder groups were also identified. School staff expressed that pediatric providers should be responsible for reminding parents to bring in medications to school while pediatric providers thought it was the school staff's responsibility to remind parents about medications. Additionally, some participants believed older children would be more cooperative with the program and therefore would gain more from Asthma Link™ while others believed that the stigma associated with going to the school nurse's office for medication would prevent older children from being active participants in the program. Further, some children felt that they missed parts of their school activities when having to go to the nurse's office for their medications.

Discussion

Although school-supervised asthma therapy has been shown to be successful in the research setting, there has been limited uptake of this evidence-based intervention in practical, real-world settings. Often, the lack of uptake of evidence-based practices is due to misalignment of stakeholder agendas in the real-world setting and failure to elicit feedback on the barriers of successful real-world execution.^{10,17} This lack of adoption of evidence-based strategies into real-world practice is also called “voltage drop” whereby interventions yield decreased benefit and a decline in participation as they move from a research setting into real-world practice.^{18,19} In this study, we examined the perspectives of three stakeholder groups—pediatric providers, families, and school staff—essential to the application and sustainability of our school-supervised asthma therapy program to prevent “voltage drops” of this intervention in the future.

Overall, stakeholders perceived facilitators of the program to be the quick approach that was easy to incorporate into their busy schedules, the team approach with a common goal of asthma care and medication adherence, the improved communication between all three groups, and assurance that the child with poorly controlled asthma would receive their medication every day. Though there could be improvements with the ease of communication, Asthma Link™ did introduce more opportunities for education about asthma for both families and school nurses. The program made school nurses a part of the preventive asthma care team, allowed parents to feel confident that their child was receiving routine care, and gave the children lifelong skills for self-care, which can improve lung function and feelings of self-control, reduce school absenteeism, decrease emergency room visits, and enhance the ability for physical activity.²⁰ This program fit well into the school nurses’ existing schedule, but it did slightly increase the pediatric providers’ workload. However, adding time in the clinic visit to focus on an evidence-based preventive strategy like supervised asthma therapy can reduce the time the patients need to be seen for urgent or acute asthma visits.²¹ Numerous participants suggested creating an “asthma champion” in the physician offices, who would serve as a liaison between the schools, pediatric providers, and families and act as support staff for the clinicians in the pediatric practice, a model that has been shown to increase patient satisfaction, access to care, and perceived quality of care.²²

Barriers identified included families potentially feeling judged or offended when introduced to the program, families not following protocol, and insurance companies not covering two inhalers. However, a number of suggestions were provided to address many of the barriers, including providing more education and engagement with parents to help them understand the purpose of the program, talking to families in a non-judgmental manner about how common it is to have difficulty giving a daily medication (i.e. quoting that 80% of families have difficulty with this to normalize the challenge), having medications sent directly to the schools, writing specific instructions on the ICS prescription to state "dispense 2 inhalers, one for home and one for

school", and communicating with insurance companies about the program so they understand that they will not experience increased costs and are likely to see cost savings with improved asthma outcomes. These proposed solutions are actionable items that will allow us to specifically refine the Asthma Link™ protocol to facilitate real-world execution.

In order to potentially modify parental attitudes when there is initial resistance or reluctance from parents to participate in Asthma Link™, we can incorporate established evidence-based strategies of speaking to parents in the refined program protocol. These include using simple, non-medical jargon, eliminating technology to allow for face to face conversation, building trust and rapport by giving the parent space to voice their concerns and perspectives, being sensitive to emotional needs often through nonverbal cues, and stressing quality of life for both the parent and the child.²³⁻²⁶

All participants were motivated by the positive impacts seen on the child's health. The majority of patients, parents, nurses, and pediatric providers perceived that Asthma Link™ decreased rescue medication use, emergency room visits, and hospital admissions, consistent with the results from our pilot study, and also reported improved attendance, physical activity, and academic performance.⁷ Stakeholders agreed that they would want to continue with the program in the future, as they could clearly see the benefits and the ease with which this could be incorporated into their lives.

The differences within and between stakeholder groups were also acknowledged to assist in program refinement. There were differing opinions between school staff and the pediatric providers on who should be responsible for reminding parents to bring in medications. Furthermore, there was variation within school staff and the pediatric providers about which age group would most benefit from the program. Some of the children expressed that the program hindered with their participation in a few school activities. Clarifying stakeholder roles at the start of the school year, analyzing trends in student cooperation with school nurse visits, and identifying optimal times for medication administration will allow for modification and superior implementation of Asthma Link™ in the future.

Understanding the alignment of stakeholder group agendas and perceptions of the program, supporting the identified facilitators, and creating potential solutions informed by the program participants to address the identified barriers will ultimately allow for more successful real-world implementation of the evidence-based practice of school-supervised asthma therapy.^{13,27} The results from this study will help us develop intervention improvements to facilitate execution of Asthma Link™ in practice and to minimize the voltage drop that is often seen with interventions that move from research settings to real-world practice.

Study Strengths and Limitations

This study elicits the perspectives of the end-users of Asthma Link,TM a real-world approach to school-supervised asthma therapy, and examines the alignment of the perspectives of three stakeholder groups (school staff, families and pediatric providers) regarding the program's implementation. This study answers the professional call for school-based asthma interventions to engage the involved stakeholders and ensure the commitment of involved school personnel, to promote long term success.¹¹ Additionally, the results of this study will be used to refine the Asthma LinkTM program protocol which will be tested in a cluster randomized controlled trial.

A limitation of our study is that it was conducted in one city only, potentially reducing the generalizability of the findings. In the future it will be important to obtain feedback from programs like ours that are implemented in different types of schools and cities with different patient populations. We will incorporate similar qualitative feedback as part of our program implementation in new sites as Asthma LinkTM is tested in larger trials. Our study may have overemphasized the positive impact of the program due to selection bias, as those who participated in the interviews may have been more personally invested in the program and would have been more likely to express positive views of the program.

Conclusion

Given the high prevalence of asthma in children, the poor adherence to daily inhaled corticosteroid therapy amongst this group contributing to asthma morbidity and healthcare utilization, and several studies showing the benefits of supervised ICS therapy in a school-based setting on improving asthma symptoms, a sustainable intervention is needed to address the major public health issue of poor medication adherence in childhood asthma.^{1,2,5-7,28} Asthma Link™ is a low-cost, low-intensity model of supervised asthma therapy in schools that requires the collaboration and communication of medical providers, school staff, and families and has the potential to dramatically improve asthma health outcomes for children. It has been well-accepted into the community and pediatric practices thus far, as it has demonstrated both a positive impact on children and improved communication across pediatric providers, schools and families. With feedback from the major participants in the intervention, we can refine the protocol to include changes in components such as inclusion of an Asthma Champion to improve communication and education/engagement of participants in order to further support the longevity and wider dissemination of this model. Future directions of this work include the development of specific strategies and protocol refinement in order to address the barriers that have been identified and align stakeholder agendas to promote real-world implementation of Asthma Link™. This will lead to our next phase in this research which will be to prospectively test the refined protocol in a cluster randomized controlled trial incorporating new pediatric practices.

Commentary

Not all schools across the United States have school nurses available to administer medications, but these school should still have policies in place for safe administration of medications at school.²⁹ Schools without a dedicated school nurse could utilize a health aid or any staff member in the school who is trained and capable of administering medications to a student. Thus, it is not a requirement for a school to have school nurse to implement the program, but rather that there be a staff member to administer medications. One goal in the future of this research is to connect with school officials to identify and consider strategies for more widespread implementation of this program in schools that do not have dedicated school nursing and to advocate for dedicated school nursing, as studies have shown that school nurses are a cost-beneficial investment of public funding.³⁰

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