Asthma education program for First Nations children: An exemplar of the Knowledge-to-Action Framework

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BACKGROUND: The prevalence of asthma in Aboriginal children is 6% to 14%. Gaps in knowledge regarding asthma and its management exist in First Nations (FN) communities, and culturally relevant education and resources are required. Studies have recommended that the children's asthma education program, the 'Roaring Adventures of Puff', be modified through partnership with FN communities to be culturally appropriate.

OBJECTIVE: To adapt this knowledge tool and design an effective implementation process for FN knowledge users (children with asthma and care providers), guided by the Canadian Institutes of Health Research knowledge translation framework.

METHODS: The problem was identified, knowledge was identified/reviewed/selected (literature review); knowledge was adapted to the local context (FN working and advisory groups); barriers to knowledge use were assessed (by knowledge users); and interventions were selected, tailored and implemented (modified curricula and the creation of a new activity book and web-based resources, and regional coordinators, asthma educator mentors and community teams were recruited).

RESULTS: Major outcomes were the adapted tools and blueprints for tailoring implementation. Additional outcomes were preliminary observations and outputs from the iterative processes, including information about local context and barriers. Specific additions were roles for community members supported by asthma educators (applying FN teaching models and addressing health care demands); relevant triggers (addressing knowledge gaps); and FN images and stories, themes of circle, sacred teachings, nature and family/elders (culture and addressing low reading levels).

CONCLUSION: The framework model provides a logical, valuable tool for adapting a knowledge tool and implementation process to new knowledge users. Future research should measure uptake, effect on health outcomes of FN asthma sufferers and sustainability.

Key Words: Asthma; Children; Culturally relevant; First Nations; Health education; Knowledge translation

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ccording to the Global Initiative for Asthma (1) and the Canadian Asthma consensus guidelines (2), effective management of asthma requires patient education featuring training in self-management skills (2). Asthma self-management education reduced hospital readmission and morbidity in children (1). Furthermore, such programs contributed to improvements in lung function and feelings of self-control and reductions in school absences, days of restricted activity and emergency department visits (1).

The ‘Roaring Adventures of Puff’ (RAP) program (3,4) developed by the Alberta Asthma Centre (Edmonton, Alberta) is an asthma self-management education curriculum directed at two levels of knowledge users: children with asthma (RAP School) and health care professionals (RAP-IT). RAP is a knowledge tool based on the guidelines (2), which contains the key components for education and promotes the patient-doctor partnership. RAP School is hosted by health care professionals for small groups of children in the school setting. RAP School has been tested in five populations resulting in positive outcomes: improved quality of life for children (5,6) and parents (7); better self-efficacy (6); fewer absences (6); fewer days of interrupted activity (6); fewer urgent health care visits (5-8); and improved parental home productivity (7). RAP-IT, a self-paced online course taking approximately 20 h to complete, has been pilot tested, and health care professionals have positively evaluated its quality, features and applicability to practice (9).

First Nations Asthma is one of the most common chronic conditions of Canadian Aboriginal children, affecting between 6% and 14.6% of this population (10-12). Many factors impose a disproportionate burden of illness on Aboriginal children with asthma and their families (13). These include high smoking rates (13,14) (70% in First Nations [FN] youth [15]); and environmental factors (10,13,14) such
as mold, smoking in homes and road dust contributing to asthma exacerbations (10,16); and geographical, cultural and socioeconomic factors (11) limiting access to care (13). Uncontrolled asthma can also lead to other health concerns such as depression (13,17).

Studies show gaps in asthma knowledge and resources for FN children with asthma living and attending school on reserve, and also for caregivers (18). Pilot studies using RAP School in FN communities suggested that it be modified to better address the needs of FN children with asthma (18,19). The Knowledge-to-Action Framework (Framework) (20) was selected to adapt RAP School to address gaps. This model delineates two concepts: knowledge creation and action (action cycle). Although the model depicts ideal milestones, "in reality, the process is complex and dynamic, and the boundaries between these two concepts are fluid and permeable" (20).

Our objective was to apply the Framework (20) to implement an asthma education program in new knowledge users (eg, FN children with asthma and their caregivers). The current report focuses on the first four phases of the action cycle, namely: identify problem/identify, review, select knowledge; adapt knowledge to local context; assess barriers to knowledge use; and select, tailor and implement interventions.

METHODS

Introduction to collaborative processes and collaborators

Several collaborative processes were designed to inform the adaptation of RAP. These processes (collaborative processes), the collaborating parties (collaborators), their roles and responsibilities, connection to Framework components and outcomes are shown in Table 1. These processes were nonlinear in operation and each contributed to more than one of the action cycle components. For example, workshop participants expanded understanding of the problem's scope and specifics; affirmed the selection of RAP as the knowledge tool; and provided insight to adapt the tool to the local context and to identify barriers and corresponding strategies to implement.

Phase 1: Identify problem/identify, review and select knowledge

The first action cycle phase was substantially completed by partners of the Alberta Asthma Centre (Edmonton, Alberta) before the current project (18,19); they assessed available resources and pilot-tested RAP in FN communities, which led to recommendations that it be adapted to improve its cultural appropriateness (18,19,21).

Phases 2 and 3: Adapt knowledge to local context and assess barriers

To make the tool more likely to be directly relevant to and used by knowledge users, a nationally representative group (advisory group) was convened and a workshop (workshop) tasked with determining what relevance RAP had for FN children and communities, identify strengths and barriers and work through changes to the curricula and delivery model. To facilitate ongoing participation, a collaboration website (collaboration site) was established for all collaborators.

An electronic survey was e-mailed to 60 RAP instructors, health professionals and academics with expertise in asthma education, requesting participation if they had FN health experience. The survey sought recommendations about content and format of RAP School, and RAP-IT, challenges to delivery and strategies to optimize participation and uptake. The Asthma Society of Canada conducted surveys and interviews with 13 FN children with asthma and their caregivers about the activity book used with RAP School (‘Fun Book’).

Phase 4: Tailor and implement the interventions

Input gathered was used to tailor interventions. Provincial coordinators were recruited where there were pre-existing relationships with asthma educators and/or FN communities. Each coordinator invited FN reserve communities to implement RAP, facilitated RAP-IT and acted as an asthma education mentor. Communities were invited to form teams that consisted of health and lay members to obtain approvals, enrol in RAP-IT and host RAP School.

Select activities of RAP School were pilot tested at a 2.5-day camp for 19 FN children with asthma, allergies and eczema. After each activity, children were asked to answer two questions by marking individual ‘bulls-eye’ target surveys, namely: “Did you have fun at this activity?” and “Will this game help your asthma?” After this pilot, the organizer was interviewed about RAP School and its delivery model.

RAP School was implemented in two remote FN community schools by a RAP educator who travelled from an urban centre. RAP-IT was hosted over nine months for a class of 40 individuals comprised of enrolled team members (n=16), coordinators, project partners and others involved in FN health. A telephone survey of enrolled team members solicited information regarding demographics, learning preferences and satisfaction (22).

RESULTS

Outcomes included the adapted RAP knowledge tools, identified barriers and facilitators to implementation, and tailored implementation strategies. Processes used to achieve these outcomes and involved groups along with their roles and responsibilities are described in Table 1.

Phase 1: Identify the problem/identify, review and select knowledge

Collaborators identified gaps in knowledge relating to asthma and asthma management skills. They described the frequency of inhaler use and asthma exacerbations requiring emergency care. They discussed fears of ‘asthma attacks’, feelings of isolation and resulting withdrawal from physical and cultural activities. They identified social and health issues that they believed affected the community’s ability to respond.

Collaborators reviewed the tools and knowledge, and endorsed RAP School as a valuable and appropriate tool to adapt for FN children. They confirmed the school setting where children are a “captive audience”. They emphasized that RAP School contained many important concepts and did not require significant changes to be engaging and have impact on FN children.

Phase 2: Adapt knowledge to local context

Earlier assessments (18,19) suggested that materials should support visual learning, use storytelling and anecdotes from FN families and involve family members. Collaborators expanded these recommendations to make RAP reflect/include FN peoples and address asthma knowledge gaps, learning preferences and barriers to uptake. Collaborators emphasized to avoid generalizing characteristics of any one tribe/nation to all FN communities and to focus on nature, wellness and cultural themes including relevant community triggers (tobacco smoke, mold and overcrowding) and early identification of symptoms, and feelings of isolation and prevention. Themes that emerged from the children’s interviews about the activity book were: reduce the amount of text; keep the drawings and colouring activities; use colour; ensure the activities are fun and exciting; add more pictures; and ensure that information about medications, device technique and airways is easy to understand.

Corresponding modifications were also made to RAP-IT. It was condensed from 12 modules to five, made less text-based by adding avatar narrators, screen casts and video demonstrations, contextualized to FN by adding stories/photos from FN children, their caregivers, community members and health providers and made more interactive by hosting “Sharing Circle” forums, teleconferences and webinars. Hands-on technological support (including teleconferences and screen casts about RAP-IT navigation) and mentorship from asthma educators were provided.

Specific adaptations to RAP School and the Fun Book included incorporating more tactile and outdoor activities; more humour; the imagery of the circle; the seven sacred teachings; and inclusion of elders, family members and the community. Role-playing activities
### TABLE 1
Knowledge-to-Action process: Processes used, groups, and roles and responsibilities

| Process/collaborators | Roles and responsibilities | Outputs |
|-----------------------|----------------------------|---------|
| **Advisory group:** Months 1 to 15 | n=10; elders, an allergist, certified asthma educators, RAP instructors with experience in FN communities, Assembly of FN health policy analyst, FN health advisor, academics with interest in asthma and FN health; Communicated via phone meetings, e-mail and collaboration website | Input into:  | Identified problem/reviewed and selected knowledge: confirmed asthma as a problem, lack of awareness and culturally relevant tools; provided context in FN communities; confirmed value of tool and suitability to FN |
|  |  | • Project design and processes;  | Adapted knowledge tool: provided asthma expertise, gaps in knowledge (eg, medication differentiation and technique), available resources, lessons from previous delivery, gaps in FN content |
|  |  | • Identification of potential partners and implementation sites;  | Assessed barriers: outlined barriers to RAP and health care access at individual/school/health centre/community level |
|  |  | • Adaptation of RAP, RAP-IT  | Tailored intervention: provided advice about criteria and candidates for pilot site communities, ethics and approval processes, recruitment and retention strategies |
|  |  | • Implementation and evaluation methods  | |
| **Workshop** Month 2 | n=12; RAP-IT graduates with FN exposure, FN elders, senior representative from Assembly of FN, asthma coordinators in FN communities; PHSAP and Ontario Lung Association; Academics (with expertise in child health, asthma education, asthma in schools, community development), Winnipeg Children’s Asthma Education Centre, RAP participants from Ontario FN communities, AllerGen researchers | Participate in one-day session involving:  | Identified problem/reviewed and selected knowledge: identified concerns about proper diagnosis, misconceptions about asthma, triggers and medications, high rate of tobacco use, family context (competing stresses, size of family, variety of caregivers, socioeconomic factors), access to care (remoteness, transportation, child care, history of negative health care experiences), low reading levels |
|  |  | • Presentation of previous projects and RAP features;  | Adapted knowledge tool: specific adaptations to activities (triggers; medication technique, themes of nature, family, etc) |
|  |  | • Discussion of problem, local context, barriers, implementation process;  | Assessed barriers: health staff demands and turnover; waryness of ‘research’ |
|  |  | • Input on specific changes to RAP, Fun Book, RAP-IT and delivery model  | Tailored intervention: suggested lay member as facilitator; to adapt RAP-IT for team approach and for lay members; suggested community-based teams implement; advice about whether intervention is “research”, novel evaluation methods, how to obtain approvals, appropriate gifts |
| **Survey** Months 2 to 3 | n=15; RAP School instructors, health professionals (nurses = 80%), and academics with expertise in asthma and FN experience | On-line survey; 42 questions regarding:  | Identified problem/reviewed and selected knowledge: endorsed RAP School as a valuable tool |
|  |  | • Demographics;  | Adapted knowledge tool: recommended to keep it “visual,” hands-on, active, interactive, creative and to employ encouragement/rewards; to make the content more relevant to FN children (eg, including traditional drumming in RAP songs, a medicine wheel, traditional healing, storytelling, community involvement, respect for elders, self-respect, animals and role models) |
|  |  | • Experience;  | Assessed barriers: school ideal setting; limitations to delivery may include: lack of family involvement, “schools already have so many issues to deal with”, kids go home for lunch, getting school approval and kids must give up recess time |
|  |  | • Content and format of RAP School and RAP-IT;  | |
|  |  | • Challenges and barriers to delivery;  | |
|  |  | • Strategies to optimize participation/uptake  | |
| **Collaboration website** Months 3 to 15 | n=79; Advisory group, workshop participants, regional coordinators, community-based teams (including potential teams) and other partners including FN Inuit Health, Alberta Region | Online; voluntary participation;  | Adapted knowledge tool: discussed themes from Workshop, survey and other collaborative activities; input on RAP-IT curriculum, specific RAP School activities; discussion of use of performance arts, pictures/video, Smartboard/computer applications, physical play, music, nature, etc; posted adapted curricula; ongoing feedback on the art, layout and drafts of the new activity book |
|  |  | Facilitated collaboration;  | Tailored intervention: announced webinars, teleconferences and training opportunities, discussion of progress, templates for approval and community engagement; ongoing input on the approach and evaluation |
|  |  | • 11 discussion forums;  | |
|  |  | • Posted project processes, curriculum, templates, new activities, evaluation, training, activity book, toolkits;  | |
|  |  | • Announcements;  | |
|  |  | • Host webinars  | |
| **Interviews of FN children and caregivers (children’s Interviews)** Months 3 to 4 | n=13; FN children with asthma and caregivers | Assessed original activity book of RAP School for:  | Adapted knowledge tool: recommended reducing the amount of text; keeping the drawing and colouring activities; using colour; ensuring that activities are fun and exciting; adding more pictures; ensuring that medications, device and airways information is easy to understand |
|  |  | • Content;  | |
|  |  | • Format;  | |
|  |  | • Suggestions  | |
| **Regional coordinators and certified asthma educators mentors** Months 3 to 15 | n=4; had pre-existing relationships with FN communities | Provided mentorship by:  | Assessed barriers/selected and tailored intervention: provided information about specific facilitators (identifying asthma champions) and barriers (socioeconomic, weather, suicides, nonresponsive school administrators); provided knowledge about asthma and teaching skills tailored to individual needs of community; contributed to webinars when team members expressed need for interactive curriculum; built and sustained relationships with FN communities |
|  |  | • Inviting FN reserve communities to implement RAP;  | |
|  |  | • Liaised with community;  | |
|  |  | • Facilitated RAP-IT;  | |
|  |  | • Supported and consulted on asthma education;  | |
|  |  | • Communicated on the Collaboration website  | |
| **Community-based teams** Months 3 to 15 | n=8; health and lay members | Communities invited to:  | Tailored intervention: Community teams reinforced key messages and sustained asthma education, gathered community input on children’s perspectives and asthma needs, delivered RAP School and supported appropriate access to health care |
|  |  | • Identify team members;  | |
|  |  | • Obtain/guide necessary approvals;  | |
|  |  | • Enrol in RAP-IT;  | |
|  |  | • Host RAP School  | |

*FN First Nations; PHSAP Public Health School; Asthma Project; RAP-IT ‘Roaring Adventures of Puff’ instructor training; RAP School ‘Roaring Adventures of Puff’ children asthma education program (original)*
were developed with input from family members and local nurses to include social and family situations. The wolf was recommended as a culturally relevant mascot based on its symbolism as a teacher and member of a larger community, and for its capacity to howl, which was symbolic of strong lungs. A Dené artist was commissioned to create relevant images in the new activity book, *The Legend of Tahnee the Wolf: My Asthma Journey* (Tahnee Book) (4). Content was added to assist children to identify and address triggers relevant in FN communities. Adaptations emphasized a holistic approach to health, featuring themes of physical activity, prevention and wellness.

**Phase 3: Assess barriers to knowledge use**
Collaborators identified several contextual barriers to knowledge use including individual health (comorbidities), the health system (lack of diagnosis, funding levels, competing staff demands, strain of acute care), access to care (remoteness, child care, negative health care experiences), capacity of family/schools/community to respond (stresses, variety of caregivers, socioeconomic factors), a lack of asthma awareness and low reading levels. They described the tension among asthma prevention, the cultural significance of tobacco and wariness about taking prescription medications. The collaborators focused on immediate barriers to knowledge use relating to reading level, participation, health care issues affecting implementation, approvals and community engagement.

**Phase 4: Select, tailor, implement interventions**
The existing RAP already promoted adaptation to group needs. For example, the number and length of sessions and types of activities of RAP School were chosen after assessment of the individuals, groups and school. However, modifications to new RAP increased the selection and tailoring options. First, collaborators suggested that due to competing demands, staff turnover and technology issues, it would not be feasible in some communities for health professionals to complete RAP-IT and deliver RAP School. As a result, the refined delivery model featured teams comprised of medical and lay members, a hybrid of online and video conferencing training, and mentoring by certified asthma educators (with flexibility to respond to needs in individual communities). Second, suggestions were added to engage communities, strengthen relationships, promote awareness and build capacity through FN community events.

The pilot in the camp setting facilitated further tailoring of the intervention. Modifications were made to the delivery model including flexibility in group size and ages of children, a greater ratio of adults to children, rotation of ‘breakout’ activities for children, and active roles for peer mentors and community members. In the target surveys, children responded favourably to the new and modified activities: 45 of 48 responses rated the ‘fun factor’ as 4/5 or 5/5; 39 of 43 rated the impact as 4/5 or 5/5.

Of 10 community sites invited to implement the intervention, eight agreed to participate. Seventeen team members enrolled in RAP-IT. However, despite ongoing communication and a nine-month window to complete, only one team member completed the course. RAP was implemented in two FN communities by an experienced RAP educator; community members were invited but were not involved in education. Delivery and activities were tailored to accommodate impassable roads, challenging school schedules, community events, children’s preferences and the educator’s observations of which approaches had impact.

Unfortunately, funding and timelines (15 months) for adaptation and implementation were limited and could not be substantially extended. This significantly impacted the implementation phase, which necessarily followed adapting the tool and assessing barriers. Also, a number of the identified barriers delayed community asthma activities such as lack of asthma awareness, competing demands on health services, suicides, reluctance to participate in research and approval protocols. Additional time may have enhanced the ability to foster relationships, respond to local needs and preferences, and build the case for asthma education as a priority, which may have led to implementation in more communities.

**Preliminary observations**
Although evaluation of this project is at the design stage, some preliminary observations are available. As with the knowledge tools and intervention, the evaluation plan has continued to evolve through the development and implementation stages. Because community members expressed fatigue with surveys and interviews, less formal methods have and will be used to collect qualitative data regarding the impact of RAP, along with ongoing barriers/facilitators data. Methods include an art evaluation activity, a survey and qualitative feedback from the RAP educator. Children who completed RAP School have been asked to use a creative medium to answer the following question: “Now that you have completed RAP School, how has (or, how will) it change your life with asthma?” This ongoing activity was designed in collaboration with researchers who used children’s artwork to explore the child’s perspectives about anaphylaxis (23). Current qualitative observations include a letter from a child expressing how much she appreciates the RAP educator’s time and effort, and an observation from a parent that the classes have “really helped her child understand how to better manage her asthma”.

Ten of 11 survey respondents believed that RAP School would help kids with asthma in their community and expressed interest in continued participation, and eight would recommend it to other FN communities. Given the low observed rate of completion of RAP-IT among FN team members, information about barriers to participation (collected after implementation) was particularly important. Among 14 respondents (of this portion of the survey), frequently cited barriers were: difficulties related to the work environment (n=14); lack of work time reserved for the course (n=4); the need to replace other staff in addition to completing one’s own work (n=3); and lack of time because the program was not part of the respondent’s job description (n=3). Other barriers included technical issues (n=7), dislike of course format (n=5), poor timing (n=3), personal demands (n=2) and being too busy (n=10).

**DISCUSSION**
Application of the first four components of the action cycle resulted in three major outputs, namely, the modified curricula (including the Tahnee Book), modified delivery process and a model for collaborative adaptation that could be used in future similar work. Preliminary feedback about RAP School and the Tahnee Book was favourable, but uptake by FN team members has been suboptimal to date. Formal evaluation will be required to determine the success of this approach in bridging identified gaps between asthma guidelines and the needs of FN children for asthma education.

In applying the Framework, we gathered insight that will assist others implementing similar health programs in FN communities and in ensuring an integral role for knowledge users within the implementation process. Collaborators described the complexity of the problem, described its effects and actively participated in adaptation of the knowledge tools and assessment of the barriers. A novel feature of the new RAP is that lay community members assumed the role of instructors and were mentored (via videoconferencing, telephone or e-mail) by certified asthma educators. Similarly, using the school setting reduced barriers related to health service access, attendance and child engagement. Community ‘asthma champions’ learned about asthma and linked families to appropriate health service practitioners and resources. Active involvement from community members in an effort to enhance child participation included elders and community members involved in planning and facilitating educational and cultural activities and acting as peer mentors. A further strength was the flexibility built into the RAP School program (assessment tools and choices of activities, settings, session length, etc.), which streamlined its adaptation to particular user groups. Overall, we believe that our collaborative development approach with active involvement of community members from the design stage increases the likelihood of sustained knowledge use.

It is critical to allocate sufficient time and resources to fully apply the phases of the Framework. Significant time is required to assess
barriers and to tailor interventions. These phases require establishing and maintaining meaningful relationships in the community. Participation was optimal when the project team and/or coordinators had previous relationships with FN communities. The 15-month time-frame was insufficient for proper relationship building, face-to-face meetings, recruitment, adaptation and approval processes, which are part of implementation.

Fostering strong relationships, communication and transparency is essential. A participatory approach contributes to the general purpose of RAP and other health programs – building awareness, capacity and champions – and is consistent with the Tri-Council Policy Statement (24) and Assembly of First Nations’ Guidelines (25). Communities advised that they were impeded by staff shortages, high turnover, competing demands and priorities. Although many confirmed that asthma and lung health were significant issues, and expressed enthusiasm about the project, there were significant fluctuations in participation. Considerable personal contact was required to maintain engagement. We hypothesize that uptake would improve with additional time to explore communities’ priorities, apply appropriate protocol (including community ethics), build on community strengths and existing services and, where possible, address community barriers to engagement.

Presently, two FN communities continue implementation of RAP School. Community ethics approval is pending for the art evaluation activity and child interviews. RAP-IT remains open to team members, as well as newly enrolled FN communities and FN and Inuit Health Branch staff responsible for nursing, chronic disease and education. The Tahehe Book has been disseminated to FN communities, requesting Lung Associations and the Asthma Society of Canada. RAP School continues to be available online (4) and dissemination continues provincially and nationally through meetings with health administrators and FN communities.

CONCLUSION

The Framework model provides a logical and valuable approach for adapting a knowledge tool and implementation process to new knowledge users. Preliminary feedback suggests that RAP is useful and valuable to FN knowledge users. Applying the remaining Framework components will likely lead to uptake and sustainability of the knowledge, impact skills and behaviours and, ultimately, result in positive health outcomes.

AUTHORS’ CONTRIBUTIONS: MD, SM, ADB, DT, OL and NF contributed to the conception and design of the project and to the analysis and interpretation of data. OL co-organized the Advisory Group and Workshop, and designed, implemented and provided data from the Children’s Interviews. NF contributed to the design of the art activity, submission to the community health ethics board and participated as a collaborator. DT was a summer student who supported the design and implementation of the RAP-IT survey and analysis. CS supported community connections, provided advice on implementation and connected the project team with community-based health providers. MD, SM, and ADB drafted the paper. All authors were involved in critically revising the manuscript.

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