A screening mechanism to recognize and support at-risk Aboriginal children

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ABSTRACT

OBJECTIVES: The Aboriginal Children's Health and Well-Being Measure© (ACHWM) was developed to assess health from the perspectives of Aboriginal children. The purpose of this paper is to document the screening process, embedded within the ACHWM, and assess its effectiveness.

METHODS: The ACHWM was implemented in 2014/2015 with children 8 to 18 years of age living on the Wiikwemkoong Unceded Territory. Survey responses were screened to identify potential risk, using an automated algorithm run on computer tablets. Local mental health workers conducted brief mental health assessments to identify and support children at-risk. Data were analyzed to estimate effectiveness of this screening process.

RESULTS: A total of 293 children completed the ACHWM. The screening tool identified 35% with potential risk. Mental health workers confirmed 18% of all participants as being at-risk, and all were referred for support. The sensitivity of the tool was 75% while specificity was 79%. Improvements to the screening algorithm resulted in a specificity of 97% and negative predictive value of 95%, with no loss of sensitivity.

CONCLUSION: Responsible population health surveys require a process to recognize and respond to answers indicative of health risks. This paper provides an example of a screening and triage process that enabled our survey team to screen responses in real time, respond to potential risk immediately, and connect participants to local support services. This process proved essential to conducting an ethical survey. The high specificity and negative predictive value make it an effective triage tool that is particularly valuable in Aboriginal communities and with higher-risk populations.

KEY WORDS: Mental health; early medical intervention; child; adolescent; Indigenous population; surveys and questionnaires

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There is a movement towards gathering population-based data in First Nations communities, to support health services planning and evaluation for their members, and to support requests for program funding. While these initiatives are intended to have favourable impacts at the local level, it is important to ensure that the well-being of individual participants is protected during the data-gathering process. This requirement is in accordance with Canadian research guidelines on the ethical conduct of research involving humans, which state that special provisions must be made when conducting research with vulnerable populations.[1]

Aboriginal* children are vulnerable for three reasons: they are a cultural minority, are of young age, and have a high prevalence of mental health concerns. For example, the Regional Health Survey (RHS) indicates that 20% of Ontario First Nations youth (12–17 years of age) reported "experiences of depression or sadness", and 7% reported a previous suicide attempt.[2] Public health data estimate the suicide rate for First Nations youth at 28 per 100,000 in 2000, compared to 6 per 100,000 for Canadian youth in 2007.[3] Several reports document rates of mental illness and suicide that are five times the national average.[4–8]

Given the high prevalence of poor mental health among Aboriginal youth in Canada, it is critical that population surveys include a process to ensure the safety of participants whose responses indicate potential risk to themselves or others. We were unable to identify any published best practices to operationalize this requirement. We learned that some projects provide a phone number of a crisis support line, while others do not have a formal protocol. These strategies were not acceptable to this research team or to the mental health team who were our advisors. Therefore, it was essential to develop a new process to respond quickly to children whose survey responses suggest potential risk of harm.

We sought to ensure that our process would be feasible to carry out quickly in a resource-limited environment and be grounded in evidence. The standards for screening measures recommend evidence of sensitivity and specificity.[9] Sensitivity has been

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defined as the ability to identify individuals with the condition of interest (probability of a positive test; in this case, children at risk of mental illness) among patients with disease, from within a larger population.[10,11] It is a measure of case identification. Specificity is defined as the ability to exclude all individuals who are truly not at risk (probability of a negative test) from within a larger population.[10,11] Ultimately evidence of impact on children's health is important, and is the focus of ongoing research.

The child health measure that was used in this study was the Aboriginal Children's Health and Well-Being Measure (ACHWM) or Aaniish Naa Gegii (meaning *How are you?* in Ojibway). The ACHWM was created for and with Aboriginal children and youth,† between the ages of 8 and 18 years, to assess health from their perspectives.[12] The initial development work was conducted in collaboration with First Nations children in Wiikwemkoong Unceded Territory. The measure has four quadrant scores, representing the four directions of the medicine wheel. The validity and reliability of the ACHWM have previously been established,[13–15] as has its relevance to other Aboriginal communities in Ontario.[16–18]

The objective of this paper is to describe the ACHWM screening process and evaluate its effectiveness.

METHODS

As part of the development of the ACHWM, the team at the Nadmadwin Mental Health Clinic (NMHC) in Wiikwemkoong were asked to advise the research team on the process that should be followed if children identified during their survey the potential to harm themselves or others. The NMHC team identified responses to 21 key questions within the ACHWM that were indicative of potential risk, based on their expertise. Responses were coded with yellow flags for moderately concerning responses (e.g., selecting "always" in response to "I am in a bad mood") and red flags for highly concerning responses (e.g., selecting "always" in response to "I get so worried I feel it in my body"), based on their recommendations. Children whose answers contained at least two yellow or one red flag (or more) were considered to be potentially at risk. These screening criteria were programmed into the ACHWM tablet-based application used by children to complete the survey.

A total of 293 participants between the ages of 8 and 18 years were recruited from Wiikwemkoong as part of annual community surveys conducted in 2014 and 2015. They were recruited at local schools, the health centre, youth centre, and community events, or as part of an evaluation of the Outdoor Adventure Leadership Experience (OALE) program in 2015. Informed consent from children and their parents was required for participation. As part of the consent process, participants were informed that this was a general health survey and that they may be asked to speak with a mental health worker to talk about their survey experience.

The survey was implemented in small groups by a team comprised of researchers and local mental health workers. The screening process had two main components: a) the automated algorithm was run on the tablets to identify potential risk based on their flags; and b) all children who were potentially at-risk met with a local mental health worker for a brief assessment, to determine whether they were truly at-risk. A random sample of children who were not identified as potentially at-risk were also referred for a brief assessment to ensure the process did not lead to stigmatization. There was one variation in this process: all children who completed the survey as part of the OALE program were assessed by a mental health worker. A total of 132 mental health assessments were completed.

Those who were confirmed by the mental health worker as being at-risk received initial support and were booked for a follow-up appointment for further assessment and treatment. If a child was in crisis, the brief assessment was extended to ensure the participant's safety.

Analysis

The analysis included participants from three main groups: children who completed the community survey in 2014, children who completed the community survey in 2015, and children who completed the screening process as part of the OALE program in 2015. The demographics of each group were summarized. We also computed the mean (and standard deviation) for the ACHWM summary scores and Emotional Quadrant Scores (EQS – aggregate score from the 24 emotional questions within the 62 ACHWM questions) for each group.

We estimated the frequency of potential risk based on the flag system and the prevalence of true risk based on the mental health team's expert brief assessment results for the pooled sample. Sensitivity and specificity of the screening tool were assessed in the OALE sample, in which 100% of participants in this sample were assessed by a mental health worker. The mental health workers' clinical assessments served as the current standard for defining risk. The positive predictive value (PPV) and negative predictive value (NPV) were then calculated using Bayes' theorem.

We then examined the data to determine whether the screening algorithm could be improved. First, we examined each of the flagged questions to determine how often it was important in identifying a child at-risk. Next we examined the distribution of the EQS using the data from the 2014 and 2015 community surveys. We sought to determine if there was a cut-off point in the EQS that discriminated best between the at-risk and not-at-risk groups. All analyses were performed using Stata version 14 (Stata Statistics/Data Analysis, StataCorp LP, College Station, TX).

This process was approved by the Laurentian University Research Ethics Board, the Manitoulin Anishinabek Research Review Committee (MARRC) and the Wiikwemkoong Chief and Council.

RESULTS

This study included 124 children who participated as part of the 2014 community survey, 132 from the 2015 community survey, and 37 from the OALE program evaluation. Some children completed the ACHWM more than once. Because the average time between assessments exceeded one year, and the mental health of youth is dynamic,[19] we included the repeat assessments in this paper. One case was excluded because the participant completed the survey twice within three months.

2014 community survey sample

The 2014 sample of 124 participants had a mean age of 14.5 (SD 3.9) (range 7.6 to 21.7) years and more than half were girls (56%).

† The terms "child" and "children" are used in this paper to refer to both children and youth.

Most participated at school (61%), with an additional 24% participating at community events, 10% at the health centre and 5% at the youth centre.

In this sample, 35% gave responses on the ACHWM that were indicative of potential risk. Clinicians confirmed that 50% were truly at-risk and these children were connected to the local services; 23% were first-time referrals. We estimated the prevalence of the outcome (children at-risk) to be 18% (95% CI: 12%–25%) for this community in 2014.

The ACHWM summary score mean for these 124 children was 72.5 (SD 11.6). The mean EQS was 72.5 (SD 14.2). The mean EQS for the subgroup who were not at-risk was 76.3 (SD 11.4) compared to 54.8 (SD 12.6) in the subgroup confirmed to be at-risk.

2015 community survey sample

This sample of 132 participants in 2015 had a mean age of 13.2 (SD 3.4) (range 8.2–21.8) years and more than half (52%) were boys. Most (83%) participated at school, 13% participated at the youth centre and 4% participated at community events.

In this sample, 38% had concerning answers on the ACHWM, indicating potential risk. All children in this potential-risk group were assessed by a mental health worker, and 48% were confirmed to be at-risk. In this at-risk group, 50% were first-time referrals. We estimated the prevalence of the outcome (children at-risk) to be 18% (95% CI: 12%–25%) for this community in 2015.

The ACHWM summary score mean for these 132 children was 75.1 (SD 11.7). The mean EQS was 74.9 (SD 13.3). The mean EQS for the subgroup who were not at-risk was 78.7 (SD 11.1), compared to 58.1 (SD 8.7) in the subgroup confirmed to be at-risk.

We combined the data from the 2014 and 2015 community surveys to yield a pooled sample of 256 children from which to estimate the child at-risk prevalence. A total of 46 children were identified by the mental health workers as being at-risk. This yielded a combined child at-risk prevalence of 18% (95% CI: 14%–23%) for this community.

OALE program evaluation sample

Members of the mental health team assessed 100% of the OALE sample on the same day as the participants' surveys were completed. This sample of 37 youth had a mean age of 14.2 (SD 1.64) (range 9.6–18.1) years, and 62% were boys, with the largest group (65%) being 13 or 14 years of age.

In the OALE sample, 27% had concerning answers on the ACHWM, indicating potential risk. All 37 children were assessed by a mental health worker, 30% were confirmed to be at-risk, and 3% of these were first-time referrals to the local mental health clinic.

The ACHWM summary score mean in the OALE sample was 74.0 (SD 9.2). The mean EQS for these 37 children was 74.6 (SD 11.7). The mean EQS for the subgroup who were not at-risk was 76.9 (SD 9.6), compared to 56.0 (SD 11.6) in the subgroup confirmed to be at-risk.

Estimates of sensitivity and specificity of the screening tool were computed using the OALE program evaluation sample, because 100% completed an individual risk assessment with a mental health worker. The results are shown in Table 1.

When the frequency of responses on each of the 21 flag questions were analyzed, 3 questions did not contribute to the screening assessment: #19 (*I do things to keep myself safe*), #28 (*I stay home from school*) and #42 (*There are things in my life that make me happy*). The local mental health workers are the resident experts in this field and agreed that the flags on these questions be removed, leaving 18 questions to contribute to the screening process in the future.

Table 1. Estimates of sensitivity and specificity based on initial algorithm

	Estimate	95% CI	
Sensitivity	75.0%	19.4%	99.4%
Specificity	78.8%	61.1%	91.0%
Positive predictive value	43.5%	15.9%	74.6%
Negative predictive value	93.5%	76.4%	99.4%

Table 2. Cut points based on emotional quadrant scores in isolation

2014 community survey		2015 community survey	
EQS cut-off point	**Correct classification rate**	**EQS cut-off point**	**Correct classification rate**
<70	57.8%	<70	73.5%
<69	60.0%	<69	75.5%
<68	62.2%	<68	77.6%
<67	66.7%	<67	79.6%
<66	**66.7%**	**<66**	**79.6%**
<65	64.4%	<65	77.6%
<64	62.2%	<64	75.5%
<63	60.0%	<63	73.5%
<62	62.2%	<62	73.5%
<61	64.4%	<61	73.5%
<60	64.4%	<60	69.4%

Bold indicates the optimal cut-off point in the above data sets.

The analysis of the EQSs for all participants in the 2014 and 2015 community surveys showed that an EQS below 66 was optimal for determining the at-risk group. These results are presented in Table 2. It is important to note that 2% of all participants in the community surveys (or 11% of the children who were confirmed to be at-risk) had risks that would not have been detected by the new screening process. However, almost all of these children were already receiving support. Furthermore, the addition of this second criterion would increase the specificity of the screening tool from 79% (based on the flag criterion alone) to 97%, thus achieving significant efficiency by reducing the number of brief assessments by more than half. Based on these results, we recommend using both criteria to identify potential risk: 2 or more flags, and an EQS below 66.

Updated estimates of effectiveness of screening

The revised algorithm (2 or more flags plus an EQS < 66) was then applied to the OALE sample and updated estimates of sensitivity, specificity, PPV and NPV were generated. The number of children identified as at potential risk decreased from 30% to 11%. The sensitivity and specificity of the revised algorithm were 75% and 97% respectively, and the PPV and NPV were 85% and 95% using Bayes' theorem. Thus, the revised algorithm improved the precision of the screening tool without increasing the rate of misclassification. These results are shown in Table 3.

Table 3. Estimates of sensitivity and specificity based on the revised algorithm

	Estimate	95% CI	
Sensitivity	75.0%	19.4%	99.4%
Specificity	97.0%	84.2%	99.9%
Positive predictive value	84.5%	36.4%	99.7%
Negative predictive value	94.7%	80.2%	99.5%

DISCUSSION

This paper has demonstrated a feasible system to screen survey responses and act on them immediately. The process was designed by local mental health experts in one First Nation, facilitated by a tablet-based approach, and enabled the mental health team who met with all children who required support on the same day as the survey. This is a key innovation, supporting ethical research practice, and is essential when working with a high-risk population.[1]

The initial screening tool was successful in identifying children in need of mental health support. However, through statistical analysis of the algorithm results compared to mental health worker assessments, we were able to optimize the process by adding an EQS < 66 as a second criterion, in addition to the previous 2-flag criterion. The revised algorithm was more efficient, focusing brief assessments on children with greatest needs. The performance improvements are evident in the revised sensitivity and specificity values. This efficiency is particularly important in the context of First Nations reserves, because it optimizes the use of limited resources. However, there is the risk of missing some children who need support. Thus the decision to use the original or revised screening process must be made by each community, based on their priorities and availability of resources.

It is also important to recognize that approximately one third of the children who were identified by the mental health workers as being at-risk were new to local mental health services. This suggests that the screening tool provides a new means of identifying children in need of support who are currently not being identified by standard practice. This culturally-appropriate screening tool offers enhancements to existing triage processes and support for children with poor mental health, and thus is an important innovation for Aboriginal communities.

The early identification of mental health needs in this group of previously unidentified children has the potential to lead to better health outcomes. This is a key advantage of the ACHWM in population-based research. However, there were also a very small group of children in need of support who were not identified through routine practice or via the ACHWM. The ability to identify and support these children is a key challenge under discussion with the local mental health team.

Limitations

This study has several limitations worthy of consideration. First, the samples were not generated by random selection, and may reflect a participation bias. The most vulnerable sector of the population, including those with mental health challenges, may not have consented to participate. Thus the actual prevalence may be higher in this community than the 18% estimated in this study. Our estimate was similar to the estimate of 25% of youth who reported depressed mood in the 2008/2010 Regional Health Survey.[2] However, the RHS estimates share many of the same limitations as our study. Furthermore, the sensitivity and specificity estimates provided in this study are based on an individual interview with a local mental health worker – a subjective process that has not been formally validated, but is a well-established best practice across First Nations health centres. Finally, the order of administration of the assessments should also be considered. The interviews occurred after completion of the ACHWM, which may have prepared the participants to disclose issues related to their mental health. Despite these limitations, we believe that our results provide important new evidence that is robust.

CONCLUSIONS

This paper provides an example of how surveys with Aboriginal children may be done effectively and efficiently, while ensuring the safety of all participants by working in collaboration with local mental health workers. This new screening process is unique in that it is immediate, ensures that children's safety is prioritized, and operationalizes social accountability on the part of the research team.

This paper also provides estimates of the sensitivity (75%) and specificity (97%) for the revised ACHWM screening process. These estimates should inform other communities who wish to consider the ACHWM screening approach. Furthermore, the experience in Wiikwemkoong provides a benchmark that enables new communities to estimate the magnitude of support required from local mental health teams to ensure adequate resources are on site during survey implementation.

The model presented here is recommended as part of best-practice standards for responsible survey research and community-based program evaluation.

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RÉSUMÉ

OBJECTIFS : On a élaboré l'outil de sondage Aboriginal Children's Health and Well-Being Measure (ACHWM) pour évaluer la santé selon la perspective des enfants autochtones. Le but de notre article est de décrire le processus de dépistage intégré dans l'ACHWM et d'en évaluer l'efficacité.

MÉTHODE : L'ACHWM a été administré en 2014-2015 à des enfants et des jeunes de 8 à 18 ans vivant sur le territoire non cédé des Wiikwemkoong. À l'aide d'un algorithme automatisé exécuté sur des tablettes électroniques, les réponses au sondage ont été criblées pour repérer les personnes potentiellement à risque. Des intervenants locaux en santé mentale ont mené de brefs examens de santé mentale pour repérer et soutenir les enfants et les jeunes à risque. Les données ont été analysées pour estimer l'efficacité de ce processus de dépistage.

RÉSULTATS : En tout, 293 enfants et jeunes ont répondu au questionnaire ACHWM. L'outil de dépistage en a identifié 35 % comme présentant un risque potentiel. Les intervenants en santé mentale ont confirmé que 18 % des participants étaient à risque et les ont aiguillés vers des services de soutien. La sensibilité de l'outil était de 75 %, et sa spécificité, de 79 %. Des améliorations à l'algorithme de dépistage ont donné lieu à une spécificité de 97 % et à une valeur prédictive négative de 95 % sans perte de sensibilité.

CONCLUSION : Pour être responsables, les enquêtes sur la santé de la population ont besoin d'un processus d'intervention pour les réponses qui soulèvent des inquiétudes. Notre article présente l'exemple d'un processus de dépistage et de triage qui a permis à notre équipe de sondage de cribler les réponses en temps réel, d'intervenir immédiatement en cas de risque potentiel et de mettre les participants en rapport avec des services de soutien locaux. Ce processus s'est avéré essentiel à la conduite d'un sondage éthique. La haute spécificité et la valeur prédictive négative du sondage en font un outil de triage efficace particulièrement précieux dans les communautés autochtones et auprès des populations à haut risque.

MOTS CLÉS : santé mentale; intervention médicale précoce; enfant; adolescent; population d'origine amérindienne; enquêtes de santé