A Process for Creating the Aboriginal Children's Health and Well-Being Measure (ACHWM)

Nancy L. Young, PhD,[1] Mary Jo Wabano, BA,[2] Tricia A. Burke, BA,[1] Stephen D. Ritchie, MBA,[3] Debbie Mishibinijima, BA,[2] Rita G. Corbiere[4]

ABSTRACT

OBJECTIVES: The purpose of this study was to identify concepts of health and well-being important to Aboriginal children and youth. These concepts were necessary for the development of a culturally appropriate measure of health.

METHODS: We completed 4 community consultation sessions, 4 advisory committee meetings, and 6 full-day focus groups within the Wikwemikong Unceded Indian Reserve. The focus groups engaged Aboriginal children and youth via relevant cultural teachings, a photography exercise combined with a community bicycling tour, and detailed discussions of health and well-being using photovoice. The process was guided by a conceptual model: the Medicine Wheel. The participants placed their photos on a wall mural and identified their most important concepts. These concepts were synthesized through expert consensus into items and reviewed by the broader community.

RESULTS: The participants ranged in age from 8.2 to 17.7 years (mean age=12.3). Through innovative methods, children and youth identified 206 concepts representing the 4 quadrants of the Medicine Wheel: emotional, spiritual, physical and mental. These concepts were refocused, in collaboration with the community, to create a new 60-item measure of health and well-being that was primarily positive in focus.

CONCLUSION: This study demonstrates the success of implementing a unique process of photovoice in combination with bicycling and informed by an Aboriginal framework. The results confirm the distinct conceptualization of health and well-being in this population and underscore the necessity for a culturally appropriate measure. This study also produced a first draft of the Aboriginal Children's Health and Well-being Measure (ACHWM).

KEY WORDS: Child; health status; Indians, North American; quality of life; photography; questionnaires

La traduction du résumé se trouve à la fin de l'article.

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Children and youth comprise 40% of the Canadian Aboriginal population and experience gross inequities in health compared to their peers.[1-4] Emerging data from health indicators (e.g., morbidity and mortality rates) provide some insights on the patterns of disease among children living off-reserve, based on population-level data.[1,5,6] For example, infant mortality, obesity, diabetes, and depression rates are all much higher than among the general population.[1,5,6] There is little evidence to guide the delivery and assess the impact of local-level health promotion and health care services for Aboriginal children and youth.

Self-report is the gold standard in health and well-being assessment for children over 5 years of age.[7-9] However, we cannot assume that the content of self-report measures, developed for other cultures, is valid for Aboriginal children and youth.[10] The purpose of this research was to identify concepts of health and well-being, from the perspectives of Aboriginal children and youth, to form the basis of a new measure.

Conceptual model

Our research was guided by the Medicine Wheel, a culturally appropriate model of health and well-being[10,11] that was recommended by our community partners. The Wheel's quadrants represent 4 domains of health: spiritual, emotional, physical, and mental. The circular nature is consistent with the concepts of continuity and connectedness[12] that are integral to an Aboriginal worldview. This model was also selected as the cultural framework for the First Nations Regional Longitudinal Health Survey (RHS).[13] While many Aboriginal communities in Canada share the general concepts depicted by the Medicine Wheel, the nomenclature differs.

Review of existing measures of health and well-being

We reviewed existing measures of child and youth health and well-being to determine whether cross-cultural adaptation might be an option. We identified two potentially relevant measures: the Pediatric Quality of Life Inventory (PedsQL) and the Strong Souls. The PedsQL is a generic quality of life (QoL) measure for children[14] that

Author Affiliations

1. School of Rural and Northern Health, Laurentian University, Sudbury, ON
2. Nahndahweh Tchigehgamig Wikwemikong Health Centre, Wikwemikong, ON
3. School of Human Kinetics, Laurentian University, Sudbury, ON
4. Elder, Wikwemikong Unceded Indian Reserve

Correspondence: Nancy L. Young, School of Rural and Northern Health, Laurentian University, 935 Ramsey Lake Road, Sudbury, ON P3E 2C6, Tel: 705-675-1151, ext. 4014, Fax: 705-671-6603, E-mail: nyoung@laurentian.ca

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Please contact Mary Jo Wabano (MJWabano@wikyhealth.ca) or Nancy L. Young (NYoung@laurentian.ca) for more information on the Aboriginal Children's Health and Well-being Measure (ACHWM).

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has been cross-culturally validated in many countries, but not for Aboriginal children and youth. The Strong Souls[15] was developed to measure social and emotional well-being (2 of the 4 domains of health) among Indigenous adolescents (16-20 years) in Australia. When examined in relation to our conceptual model, we found very few items to assess the spiritual component of health and few positive items in the existing measures.

Rationale

Aboriginal children and youth, particularly those living on-reserve, experience serious health inequalities compared to their peers that must be addressed. The evidence necessary to guide health promotion and health services delivery is lacking. The absence of culturally appropriate health and well-being measures is a barrier to improving health outcomes. This paper describes the process of identifying key concepts of health and well-being from the perspectives of Aboriginal children and youth. These concepts form the basis of the Aboriginal Children's Health and Well-being Measure (ACHWM). This is the first step towards gathering new evidence on health at the local level, to aid health services leaders in matching health resources to the needs of the children and youth.

METHODS

We used a mixed methods design carried out via a community–university partnership, based on the principles of community-based participatory research,[16] Indigenous methods,[17-20] measure development,[7,21] photovoice[22,23] and cross-cultural adaptation.[24] The principles of cultural safety[25] informed our approach. The OCAP principles (Ownership, Control, Access and Possession) related to self-determination and self-governance[26,27] were respected. The project was approved by the Laurentian University Research Ethics Board, the Manitoulin Anishinaabek Research Review Committee, the Health Services Committee, and Chief and Council.

This project was guided by two research questions:

1) How do Aboriginal children and youth conceptualize health?
2) What items best enable Aboriginal children and youth to express health quantitatively?

The primary research site was the Wikwemikong Unceded Indian Reserve, home to 3,098 people, of whom 553 (17.8%) were between the ages of 8 and 18 years.[28,29] The residents are from the Ojibway, Odawa and Pottawatomi tribes, and collectively self-identify as Anishinabek. Throughout the study, we consulted with an advisory committee comprised of members from the Health Services Committee, local school representatives, Health Centre staff, a health researcher, and Elders from the Wikwemikong community. We also hosted open community consultation sessions, where the research plans were discussed and results (e.g., initial concepts and draft questionnaire) were reviewed in detail.

Participants

The primary participants in this study were Aboriginal children and youth between the ages of 8 and 18 years, who were capable of self-report.[7,8] This age group is a priority for the Wikwemikong Health Centre staff, who would like to gather information to guide the development and evaluation of health services in the future. Potential participants were recruited through the use of local media, posters and invitations. Upon expressing interest, the children and youth were invited to attend a full-day focus group. Written parental consent and child assent were obtained and all participants were reimbursed for their time.

Figure 1. Bicycling and photography activity

Focus-group process

We organized a series of 6 full-day focus groups in the Wikwemikong community, with approximately 8 participants per group. These groups were stratified by age (8 to 10 years; 11 to 14 years; and 15 to 18 years) and by sex. This was considered important in order to keep the groups relatively homogenous and to encourage the participants to speak freely. The purpose of the focus groups was to explore the concepts of health and well-being. They were carefully planned to ensure that the perspectives of children and youth were at the forefront, using story-telling, photovoice, and many opportunities to engage in activities. These groups were co-facilitated by a member of the Wikwemikong Health Centre and a faculty member from Laurentian University and guided by our conceptual model, which was displayed on the wall.

Each focus group began with a nourishing breakfast. This was followed by a prayer and smudging ceremony led by a local Elder, consistent with local cultural tradition. A general discussion of what health meant to the children and youth followed. Next, the Elder shared the local teachings of the Medicine Wheel with the participants. This model and process were chosen based on outcomes from initial community meetings with the local leaders and key informants. This segment of the focus group was allocated approximately 90 minutes and was held in the Wikwemikong Health Centre's Medicine Lodge.

The participants were then broken up into pairs and asked to choose a research facilitator to join their team. They were instructed to think about where their team wanted to go by bicycle in the community to take photographs of things that reflected health and well-being. The participants were encouraged to plan locations for taking photos relevant to each section of the Medicine Wheel. Bicycling provided a mechanism for participants to take the lead and tour their community. This approach also ensured that participants remained engaged and practised positive health behaviours, and enabled them to develop relationships with the researchers through activity.

Participants were fitted with a bicycle and proper safety equipment. Facilitators carried a backpack containing water, a map, a digital camera, a two-way radio, and a clipboard with pen and paper. Each team bicycled for approximately 90 minutes to take

Figure 2. Wall mural and stickering process

photos that exemplified all 4 quadrants of the Medicine Wheel (see Figure 1). This time period was sufficient to cover a large part of the community and to capture a range of images. The facilitators scribed the exact wording used by the children and youth to explain the significance of the photo, in relation to health and well-being, at the time that each was taken.

When the participants returned, the researchers downloaded the digital images. These were presented as a slideshow while everyone enjoyed a healthy lunch together. Paper and markers were made available for participants to draw pictures or to write word cards for any concepts they wanted to include but could not photograph. Concurrently, the research team organized a second slideshow to guide the afternoon discussion. This second slideshow was limited to the 5 most important photos chosen by each participant, organized in random order. These photos were also printed on cards and distributed to the participants.

After lunch, the participants embarked on a detailed discussion of health and well-being, using the second slideshow. As each photo was projected on the screen, the participant who took the photo was asked to speak about how it related to health or well-being. The notes scribed by the facilitators were used to inform group discussion of the concepts. The participants decided on a label for each photo (concept), and placed the photo concept card in the appropriate quadrant of a large Medicine Wheel. Our photovoice approach was based primarily on methods described by Castleden et al.[22] who built on previous descriptions.[23,30] This method was selected to stimulate the generation of concepts while keeping the participants active and engaged. It was effective in "sharing power, fostering trust, developing a sense of ownership",[22] consistent with our collaborative community-based approach. These sessions were audiotaped, so that the participants' words would inform the development of items.

This concept generation process was augmented by the inclusion of items from the PedsQL, Strong Souls, advisory committee meetings and community consultation sessions. This process was intended to ensure that important concepts were not missed, and to determine the relevance of items from the PedsQL and Strong Souls in the context of Aboriginal child and youth health. These items were interspersed with the photos as part of the second slideshow. Participants were asked whether the additional items were relevant to them, and if so, to place them on the Medicine Wheel alongside their photo concept cards.

Table 1. Source of 206 Concepts

Source	Frequency	
	n	(%)
Photo	102	(50%)
Written card	9	(4%)
Advisory committee meetings	8	(4%)
Community consultation sessions	2	(1%)
PedsQL	25	(12%)
Strong Souls	60	(29%)
Total	206	(100%)

The focus-group process created a wall mural (see Figure 2) that documented the relevant health and well-being concepts and their locations within the Medicine Wheel framework from the collective perspectives of the participants. Participants reviewed the mural and were asked whether anything important was missing. If so, they recorded the concept on a blank card and added it to the mural. They then used 10 stickers each to denote the concepts that they believed were the most important, based on personal preferences. This entire process was repeated with each of the 6 groups.

Analysis

The information from each focus group was recorded and included: the concept; the source of the concept (e.g., photo, word card, PedsQL, Strong Souls, advisory committee, or community consultation session); the domain (physical, mental, emotional or spiritual quadrant); and the numbers of stickers. This information was analyzed by the research team. Results were presented to two expert panels comprised of Aboriginal health experts and academics. The first panel used the pooled information from the focus groups to combine related concepts and organize them into domains based on the consensus of the 6 focus groups. A second expert panel reviewed the work of the first panel, looked for differences related to age and sex, and then developed the concepts into items. They were also asked to determine response options. The result of this process was a provisional draft of the Aboriginal Children's Health and Well-being Measure (ACHWM). The detailed results, including the provisional draft of the ACHWM, were then shared at a final advisory committee meeting, followed by a community consultation session. Further modifications to the ACHWM were agreed upon during these consultations.

The culmination of the process was a review meeting with the children and youth who participated in the initial 6 focus groups. They reviewed the draft ACHWM and placed the 60 items on a Medicine Wheel, to indicate the domain of each item now that the concepts had been developed into questions. This process aided in the refinement of the first draft of the ACHWM and produced a collage of their photos for display in the community.

RESULTS

This study was characterized by a strong community–university partnership. We met with the study advisory committee on 4 occasions between July 2011 and July 2012. We held 4 community consultation sessions during the same time period. We completed 6 focus groups between August 2011 and October 2011. A total of 38 children and youth participated (mean age=12.27, standard deviation=2.91; range: 8.16 to 17.72 years); of these, 22 were girls (58%). The final review meeting (July 3, 2012) included 15 of the children and youth (of whom 6 were girls) who had previously participated in the 6 focus groups.

Table 2. Initial Distribution of Concepts by Domain From the 6 Focus Groups Combined

Domain	Number of Concepts	Number of Stars	Example Concept for Domain (Participants' Words)
Emotional	60	120	Long-time friend
Mental	27	46	Music
Physical	37	51	Fun & exercise
Spiritual	40	85	Animal life - get reborn, circle of life
2 Domains	10	18	Beautiful - makes you want to smile - fun
3 Domains	7	10	Felt pretty lonely much of the time
Overall (4 Domains)	25	48	Different paths in life you can take
Total	206	378	

Table 3. Final Distribution of the ACHWM Concepts and Items by Domain

Domain	Number of Stars n (%)	Number of Concepts n (%)	Number of ACHWM Items n (%)	Example ACHWM Item
Spiritual	124 (33%)	63 (31%)	16 (27%)	I feel a connection to Mother Earth…
Emotional	152 (40%)	80 (39%)	22 (36%)	I enjoy celebrations in my community…
Physical	53 (14%)	38 (18%)	13 (22%)	I eat healthy foods…
Mental	49 (13%)	25 (12%)	9 (15%)	I have time on my own to relax with an activity I like…
Total	378 (100%)	206 (100%)	60 (100%)	

Perspectives of children and youth

During the bicycling activities, the groups of children/youth covered a variety of different routes, with most groups covering more than half of the main village, including many off-road segments. They captured a total of 399 photos, and selected 190 of these as the most important. Each of these 190 photos was discussed during one of the focus-group sessions, along with ideas generated from the advisory committee meetings and community consultation sessions, and items from the PedsQL and Strong Souls.

From these discussions, the 38 participants identified 206 concepts as important, as determined by the number of stickers participants had placed on each concept card. The 206 concepts came primarily from the children and youth (54%), with the remaining coming from other questionnaires (41%) and the community (4%). Additional detail on the sources of the concepts is shown in Table 1.

Although the Medicine Wheel contained 4 quadrants, the children and youth strongly believed that some of the concepts belonged to more than one domain. The distribution by domain of the 206 concepts is presented in Table 2. A total of 17 concepts were placed in 2 or 3 domains, and 88% of these came from either the PedsQL or the Strong Souls. In contrast, the 25 concepts placed in the "overall" domain (which was created by the participants to reflect all 4 domains) came from a variety of sources: 44% from the Strong Souls, 40% from the children and youth, and 16% from the advisory committee.

The words used by participants were captured both via audiorecording and in writing on the concept cards and proved essential to maintaining the focus on the perspectives of children and youth during the development of items. Some examples are presented in Table 2.

Perspectives of experts

Expert panel meetings were held on November 4, 2011 and February 8, 2012. The first expert panel reviewed the 206 concepts from the 6 different focus groups and distilled these down to 46 groups of concepts. The second expert panel tackled the challenge of developing the concepts into items. They did not identify any items that were specific to gender, but identified one item (related to suicide) that was age-specific. This item was later modified by the advisory committee, who requested we ask this question of all children and youth. The PedsQL and Strong Souls were used as models for the style of questions and responses.

The end-product was a provisional draft of the ACHWM for Aboriginal children and youth between the ages of 8 and 18 years. It contained 60 multiple-choice items that utilized 3 different types of response sets: frequency; degree of importance; and yes/no. In addition, 5 open-ended questions were included to gather more information. The distribution of domains included in the ACHWM is shown in Table 3, along with information on the relative importance of each domain (number of stars and number of concepts), the number of ACHWM items created for the domain, and example items.

The sources of the 60 items were reviewed to assess the relevance of the original PedsQL and Strong Souls items: 1 item came from the PedsQL and 2 from the Strong Souls. Thirteen items were identified that originated in part from the PedsQL and Strong Souls items, and were combined and modified based on the discussions with the children, youth, community members, advisory committee, and the expert panels. An additional 40 items were original concepts generated by the children and youth. Finally, 4 items came from the advisory committee.

The formatted questionnaire was reviewed by the advisory committee and shared at a community consultation session on May 8, 2012. The community members requested some wording changes and that we mix the positive and negative items to ensure balance throughout the questionnaire. A final community consultation session was held on July 3, 2012 at which time community members endorsed the ACHWM. They were eager to complete the testing of the measure so that it could be implemented into local practice to evaluate the effectiveness of programming and guide the delivery of health services. Although additional validation testing is an essential prerequisite to implementation, the community–university collaboration was considered a success by all.

DISCUSSION

This study sought to identify the concepts of health and well-being, from the perspectives of Aboriginal children and youth, through a series of full-day focus groups. We succeeded in recruiting and retaining a sample of 38 participants, representing the full age range (8 to 18 years) and including both boys and girls.

We developed and tested a novel and rigorous process for concept identification that has proven successful with Aboriginal children and youth living on-reserve. By carefully planning the focus-group activities, with the support of the Elders, we were able to take the abstract concept of health and make it accessible for the children and youth. Bicycling and photography were used to facilitate the translation of health into concepts that were real via a process that was engaging and fun. Various activities were interspersed throughout the day and were essential in maintaining the engagement of children and youth over a 6.5-hour period. The bicycling activity was a favourite with the participants, many of whom asked us to "do it again".

The natural progression and experiential nature of the focus-group activities ensured that we were able to maintain focus on health and well-being, in the context of the participants' First Nations community, and resulted in the discovery of 206 concepts. The role of children and youth was considered the priority throughout this study. Careful attention was paid to their ideas and the words they used to describe their photos. We also ensured that the participants had an opportunity to identify their most important concepts. This information guided the evolution of the concepts into 60 items that reflected the perspectives of children and youth. We were also attentive to the value of the conceptual model (the Medicine Wheel), which was extremely helpful in focusing the participants and making the domain organization task manageable.

This child-centric study was extremely informative and effective. We discovered that relatively few of the PedsQL questions (1 item) and Strong Souls questions (2 items) were endorsed in this study without modification. An additional 7 PedsQL questions and 12 Strong Souls questions were included, but required modification to make them meaningful in this context. Therefore, the validity of existing measures, in the context of Canadian Aboriginal children and youth, is questionable. This underscores the importance of testing existing measures before they are applied to other cultures, and when necessary, developing culturally appropriate measures.

The main outcomes of this research include: 1) the identification of a conceptual model of health articulated by the community and verified by children and youth; 2) the recognition that very few items from existing measures were relevant in this context; 3) the development of a method of concept identification that has proven successful; and 4) the creation of a draft version of a culturally relevant measure co-owned by the Wikwemikong community.

CONCLUSIONS

This study demonstrates the success of implementing photovoice, via an innovative combination of bicycling and an Aboriginal conceptual framework. The full-day focus-group process was well received by the children, youth, health centre staff, advisory committee, and the community. Aboriginal children and youth will engage in research if the methodology is appropriate. Hence, the process has relevance to other communities.

The results show that the conceptualization of health and well-being is unique in this population, underscore the necessity of a culturally appropriate measure, and culminate in the creation of the ACHWM. It will be important to assess the relevance of the ACHWM in other First Nations communities across Canada, along with its construct validity and reliability. When complete, the ACHWM will facilitate the assessment of health patterns within a community, and eventually across communities vis-à-vis comparisons. Data on health and well-being patterns is needed to guide community health promotion and health care policies and evaluate service delivery, so that Aboriginal communities may develop a new path to health and well-being for their children and youth.

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RÉSUMÉ

OBJECTIF : Cerner les concepts de la santé et du bien-être qui importent aux enfants et aux jeunes autochtones. Ces concepts ont été nécessaires à l'élaboration d'un indicateur de santé culturellement approprié.

MÉTHODE : Nous avons mené 4 séances de consultation communautaire, tenu 4 réunions du comité consultatif et organisé 6 groupes de discussion d'une journée dans la réserve indienne non cédée de Wikwemikong. Les groupes de discussion ont proposé aux enfants et aux jeunes autochtones des enseignements culturels pertinents, un exercice de photographie combiné à une excursion à vélo dans la communauté et une discussion approfondie sur la santé et le bien-être par la méthode Photovoice. Le processus s'est guidé sur le modèle théorique de la « roue médicinale ». Les participants ont placé leurs photos sur une murale et cerné les concepts les plus importants pour eux. Ces concepts ont été résumés par des spécialistes, en consensus, et examinés par la communauté élargie.

RÉSULTATS : Les participants avaient de 8,2 à 17,7 ans (âge moyen=12,3 ans). En employant des méthodes novatrices, les enfants et les jeunes ont cerné 206 concepts représentant les 4 secteurs de la roue médicinale : émotionnel, spirituel, physique et mental. Ces concepts ont été peaufinés, en collaboration avec la communauté, pour créer un nouvel indicateur de la santé et du bien-être en 60 éléments. La perspective adoptée était principalement positive.

CONCLUSION : L'étude montre qu'il est possible de mettre en œuvre un processus original, combinant la méthode Photovoice au vélo et éclairé par une grille autochtone. Les résultats confirment la conception distincte de la santé et du bien-être dans cette population et soulignent le besoin d'un indicateur culturellement approprié. L'étude a aussi produit une première version d'un « indicateur de la santé et du bien-être des enfants autochtones » (ACHWM).

MOTS CLÉS : enfant; état sanitaire; Indiens d'Amérique Nord; qualité de vie; photographie; questionnaires