HEALTH PROFILES OF FIRST NATIONS CHILDREN LIVING ON-RESERVE IN NORTHERN ONTARIO

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Compliance with Ethical Standards:

This research was conducted with ethical approval, and community approval. All

children and parents provided full and informed consent. Two authors on this paper hold

copyright of the ACHWM which is shared at no cost.

ABSTRACT

BACKGROUND:

The Aboriginal Children's Health and Well-Being Measure (ACHWM$^{©}$) was developed to enable Aboriginal health leaders to gather information on the health of their children. This paper provides health profiles for First Nation children's, living on traditional territory, based on self-report.

METHODS:

The ACHWM was implemented in three First Nations with the informed consent of children and their parents. The ACHWM was completed by children on Android tablets to enhance the feasibility, and sustainability of the assessment. The data were analysed to describe the distribution of health summary and quadrant scores from the pooled sample.

RESULTS:

A total of 196 participants, between 7.6 and 21.7 years of age, completed the ACHWM. Overall, 40% rated their health as excellent or very good. ACHWM summary scores ranged from 39.8 to 98.7 with a mean of 74.1 (95% Confidence Interval [CI] 72.5-75.7). Strengths were reported in the spiritual (mean=78.7; CI 76.7-80.8), physical (mean=77.1; CI 75.1-79.0) and emotional (mean=74.4; CI 72.5-76.3) quadrants. The greatest opportunity for improvement was in the mental (cognition) quadrant (mean=61.6; CI 56.9-63.4). Quadrant scores demonstrated good balance for 44% of participants. The screening process indicated that 16.8% of participating children were in need of further health support and the local mental health workers connected them to services within their home communities.

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INTERPRETATION:

This paper presents initial estimates for child health based on self-report from a large sample of First Nations children, that are important to establish benchmarks for future research and for comparison in other communities and contexts.

KEY WORDS:

Aboriginal, Children, Health, Questionnaire, Benchmarking

WORD COUNT:

2,495

INTRODUCTION

Evidence-based health care is considered a gold standard for clinical practice, policy, and planning [1,2] but is not yet an option for many Aboriginal[i] communities in Canada. Three authors on this paper are First Nations Health Directors, and are responsible for local programming, and require local health data that extends beyond the bio-medical. From their perspectives, the most meaningful data reflect First Nations models of health and are relevant to Aboriginal cultures and contexts. Decision makers who are responsible for Aboriginal children's health are challenged when searching for relevant health statistics, because most available statistics are based on illness [e.g., rates of diabetes[3,4]] rather than wellness. When health data are presented, the results are typically aggregated at the provincial or national levels[5]. As a result, there is a critical absence of health data that is relevant at the local level [6-8]. While national and provincial data are helpful to identify problems, this information is far less helpful in identifying solutions.

There have been several calls for solution-focused action to promote health among Aboriginal children in Canada [9-12]. Since each Aboriginal population is distinct (culturally, politically, and geographically), the assumption that decisions can be made based on provincial or national estimates is inherently flawed. Community-specific data or data aggregated at the local level is essential in tailoring health services to provide cost-effective, high-impact programs and services that are needed to solve critical challenges in Aboriginal child health.

The Aboriginal Children's Health and Well-being Measure or ACHWM[©] was developed to provide First Nation communities and Aboriginal agencies a tool to gather local data

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[i] Note: the term Aboriginal in used in this paper, rather than Indigenous, based on guidance from the participating First Nations advisory committee.
© The copyright for the ACHWM is held by Mary Jo Wabano, Nancy L. Young and Stephen Ritchie. It is shared with Aboriginal communities and agencies free of charge; registration is required.

[13]Throughout the development a key goal was to ensure our implementation model was feasible, sustainable, and would inform local health planning decisions. Our process evolved through a community-university collaboration[13], guided by a Medicine Wheel framework[14]. This measure has been thoroughly tested with First Nations children in Wiikwemkoong, as well as with Métis and Inuit children in urban contexts[15]. The results have demonstrated the validity [16] and reliability [17] of the self-reported ACHWM for children 8 to 18 years of age, when completed using Android tablets.

The aim of this paper is to share the aggregated ACHWM results to generate local evidence and inform health planning at the local level.

METHODS

Setting and design

A population-level cross-sectional survey was conducted between August of 2013 and March of 2015 in the Manitoulin Island region of Northern Ontario. The participating communities were: Wiikwemkoong Unceded Territory (August 2013 to August 2014); M'Chigeeng First Nation (October to November 2014); and Whitefish River First Nation (December 2014 to March 2015) (see Figure 1). Eligible participants, between the ages of 8 and 18 years, were recruited at a variety of locations: schools, the local health centre, and community events.

[Insert Figure 3 approximately here]

The primary outcome measures in this study were a Global Health Rating (GHR) and the ACHWM. Children were asked to complete the ACHWM independently on android tablets with a text-to-speech option that enabled those with low literacy levels to participate.

Data gathered through the surveys were uploaded to a secure server, REDCap (Research Electronic Data Capture)[19], hosted at Laurentian University. The ACHWM has a summary score and four quadrant scores. Each score ranges from 0 to 100, where higher score indicates better health and well-being. At the time of the survey implementation, a 58-item version was the standard, however, to aid interpretation and comparison for future research, the scores were calculated based on the current 62-item version with the additional four items as missing data.

The ACHWM also contains a series of questions within it that have been identified by local mental health workers as important in screening for potential health risks among Aboriginal Children. As part of our implementation process, the research team ensured that a local mental health worker was available at the implementation sites. All children with concerning responses met with a local mental health worker for a brief assessment as part of the implementation process. Referrals to appropriate services were made the same day for all children in need of further support. This step is considered a best practice when implementing a health survey with vulnerable children, respects the children's voices, and ensures their safety.   Informed consent was obtained from all participating children, and their parents when applicable.

Statistical analyses:

The data from all communities was pooled to produce an aggregate picture of child health and to ensure cell sizes were sufficient to protect the confidentiality of participants. The first responses of the survey were used for participants who completed the ACHWM on more than one occasion. Means, standard deviations (SD) and 95% confidence intervals (CI) were computed for the ACHWM Summary Score and the ACHWM quadrant scores: spiritual, emotional, physical, and mental health. Box plots were produced to show the distribution of scores visually.

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The concept of *balance* is particularly important in the Anishinaabek conceptualization of health. According to traditional teachings, balance is reflected when all aspects of health and wellness are equally strong. However, these teachings also recognize that the goal is not to achieve perfect balance at all points in time, but to move towards better balance. To describe the degree of balance in this large sample, we computed a balance score for each individual using the within-person variability method, previously described by Tractenberg and Pietrzak [20]. The balance score used in this paper is the within-person standard deviation of the quadrant scores. We recognize that is it not the traditional way of assessing balance, but are using it as a marker or indicator of balance. On this balance scale, lower numbers indicate optimal balance. Based on discussions within our team, we believe a score of 10 or less represents good balance.

Linear regression analysis was used to explore the effects of age on the summary score, each of the quadrant scores, and the balance score. Finally, we computed the proportion of participants who were identified as being in need of a further emotional health support based on the screening process, as a guide to other communities who are preparing to implement the ACHWM. All analyses were performed using Stata version 14 (Stata Statistics/Data Analysis, Stata Corp LP, College Station, TX).

Ethics approval

This study was approved by the Research Ethics Board (REB) at Laurentian University and the Manitoulin Anishinabek Research Review Committee (MARRC)[18]. To respect community protocols, a Band Council Motion (BCM) was approved in Wiikwemkoong in the spring of 2013 (BCM #418-2013), in Whitefish River in October 2013 (BCM #10-27-13), and in M'Chigeeng in July 2014 (BCM #44.13).

RESULTS

A total of 196 First Nations children participated in the survey: 124 in Wiikwemkoong, 32 in M'Chigeeng and 40 in Whitefish River. They ranged in age from 7.6 to 21.7 years, with a mean of 13.6 (SD=3.69) years. Some participants were over 18 years of age, however they were in school, thus they were included in the analysis. This is in keeping with a First Nations perspective on youth, which extends up to 25 years of age.

Aggregate Results

The GHRs in this sample were: 16% excellent; 24% very good; 44% good; 11% fair; and 5% poor health. The ACHWM summary scores ranged from 39.8 to 98.7 with an average of 74.1 (SD=11.45; CI 72.5 – 75.7), on a scale with a maximum range from 0 (worst) to 100 (best), as is shown in Figure 2. This distribution was slightly skewed (-0.68) but was not kurtotic (3.38). Based on these parameters, parametric statistics were considered to be appropriate.

[Insert Figure 2 approximately here]

The strengths, as reported from the perspective of these children, were in their spiritual, physical and emotional quadrants, with mean scores of 78.7 (SD=14.51; CI 76.7 - 80.8), 77.1 (SD=13.90; CI 75.1 - 79.0) and 74.4 (SD=13.62; CI 72.5 - 76.3) respectively. The greatest opportunity for improvement was in the mental health quadrant, with a mean of 61.6 (SD=12.61; CI 56.9 - 63.4). Note that the mental quadrant reflects the children's assessments of their thinking and problem solving (i.e., intellectual health or cognition), whereas the emotional quadrant reflects what western society considers to be "mental health". The distribution of the summary score and quadrant scores are shown in Figure 3.

[Insert Figure 3 approximately here]

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Sub-Analyses

Scores were explored by age, and older children were found to report slightly lower ACHWM summary scores; decreasing by 0.7 points per year of age (CI 0.26 - 1.13, p=0.002). This slight age effect was apparent across all 4 quadrant scores, with a decrease of: 1.1 point (CI 0.53 - 1.61) per year of age for spiritual; 0.66 (CI 0.13 - 1.18) for physical; 0.54 (CI 0.02 - 1.06) for emotional; and 0.49 points (CI 0.12 - 0.97) for mental health.

When we explored the balance within each participant, using the standard deviation of the 4 quadrant scores, we observed balance scores that ranged from 1 to 24, with a mean of 11.0 (SD=4.69; CI 10.3 - 11.7) and a median of 10.6. Note that a cut point of 10 points or lower was identified *a priori* to indicate good balance, and based on this definition, 44% of our sample had good balance. The distribution of balance scores is shown in Figure 4. There was no apparent variation in balance scores related to age or gender.

[Insert Figure 4 approximately here]

In addition to the main focus of understanding the health of First Nation children, the ACHWM also afforded the opportunity to screen for mental health concerns. The screening process allowed us to identify 33 children (16.8% of participants) who were in need of further assessment, and enabled the mental health workers to connect them to ongoing supports within their home communities.

INTERPRETATION

The results presented in this paper provide a health profile from a relatively large sample of First Nation children living on their traditional territories in rural Northern Ontario. The mean

ACHWM summary score in this sample was 79 and the mean quadrant scores were: spiritual 79; emotional 74; physical 77; and mental 62. Thus these children were strong spiritually and their greatest opportunity was in the mental health quadrant. According to the guidance of the Medicine Wheel, the mental quadrant focuses on thinking, reasoning and problem solving and could also be considered as an intellectual or cognition domain.

It is difficult to put the ACHWM scores into context, since there is limited health data from Aboriginal children reported in the literature. From the global health ratings in this sample, we know that 16% of our study population (and 14% of our sample of youth 12 to 17 years) reported excellent health. This is much lower than the 22.8% of First Nations youth (12 to 17 years) in Ontario who self-reported "excellent" health on the Regional Health Survey (RHS)[4]. Thus, the results reported here are significantly different from the Ontario RHS results; underscoring the importance of local data for planning purposes.

It is also possible to consider the scores reported here in comparison to what we know based on normative data from the PedsQL, which is a generic health-related quality of life measure for children. The interpretation of ACHWM scores were previously established in relation to the PedsQL, because we know that the ACHWM scale is similar to the PedsQL scale (r=0.51 with 0.3 points difference in the PedsQL vs. ACHWM summary scores)[21]. We also know that the mean PedsQL score for an urban school-based population sample was 80.6 (SD=13.3) [22]. Furthermore, Varni's initial validation study of the PedsQL reported a mean Total PedsQL score of 79.6 (SD=15.3) in a sample of 960 children 5 to 18 years of age [23]. This suggests that rural First Nations children, from the Manitoulin region have health scores that approach PedsQL norms. However, there are also many children (16.8% of participants) who have been identified

as needing new mental health services through this study. Thus, additional health and social supports are needed to address these apparent health in-equities.

This paper adds important new information regarding the relationship between self-reported health scores and age in Aboriginal children. Our exploratory analyses suggest that the impact of age is linear and small (reduction of 0.7 points per year of age). Furthermore, our findings suggest the impact extends to all aspects of health and well-being. To our knowledge, one publication has reported on the relationship between heath scores and age among Aboriginal children, and reported that emotional and behavioral problems were more common (23%) in older children (>12 years of age) compared to younger children (18%) [24]. The inclusion of balance scores in this manuscript represents a unique contribution to the literature. We applied an innovative statistical approach to estimate the Anishinaabek construct of balance. This is the first time this construct has been quantified. We were able to statistically analyse the balance scores to identify 44% of the sample with good balance and substantial variability in balance scores between individuals. This analysis may present another way of looking at an individual child's self-reported health. Our results in this section suggest that it is typical for some degree of imbalance across the quadrant scores within each child and that striving for balance is an ongoing exercise.

Limitations

This research has several limitations. First, our sample comprised approximately 25% of the children in each of three communities, and may be considered a sample of convenience. As such, scores may be slightly elevated. Secondly, the data is from three rural First Nations in close proximity to each other, thus has produced a local estimate. Thirdly, our definition of good balance requires further exploration. Finally, the sample did not include Inuit or Métis children.

Despite these limitations, we are confident that these results add substantially to what we know about Aboriginal children's health. We are eager to see results from other populations, and examine how they compare to these profiles.

Conclusion and future direction

The ACHWM is a new, culturally-relevant patient reported outcome measure that should be considered as a potential population health assessment tool for Aboriginal communities. The profiles reported here provide an initial estimate to understand how First Nations children living on their traditional territory in Northern Ontario perceive their health. These initial profiles establish benchmarks, against which these communities may assess changes over time, and may also represent a benchmark to which other communities may compare their profiles. The information presented in this paper may form part of the resources that are needed to support program evaluation within Aboriginal communities, enable communities to learn from one another, and promote the creation of new knowledge that is relevant to Aboriginal communities. In doing so, these communities may identify best practices that may contribute to better child health in the future.

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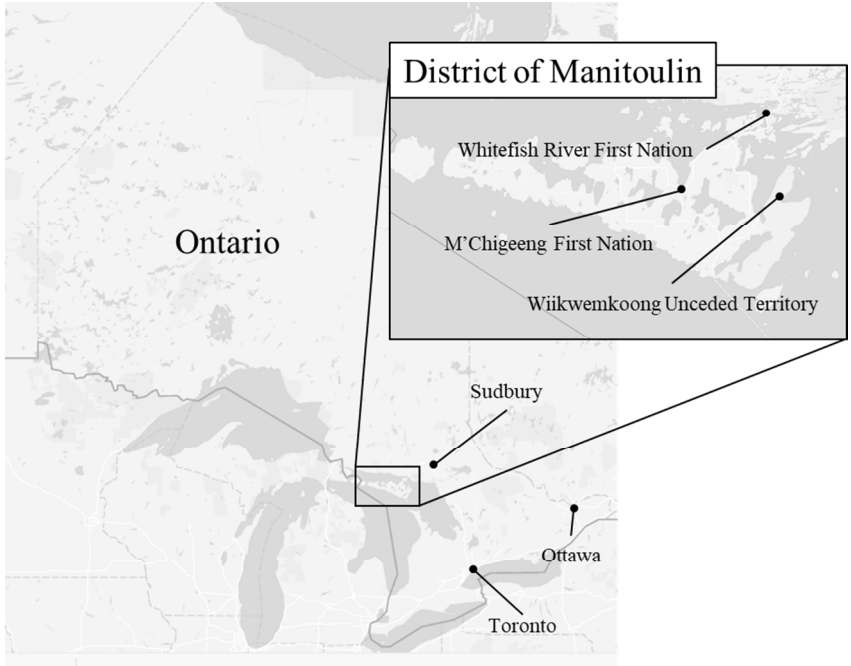
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Figure 1: **Location of participating communities**

District of Manitoulin

Whitefish River First Nation

M'Chigeeng First Nation

Wiikwemkoong Unceded Territory

Ontario

Sudbury

Ottawa

Toronto

Figure 2:   ACHWM Summary Score Distribution
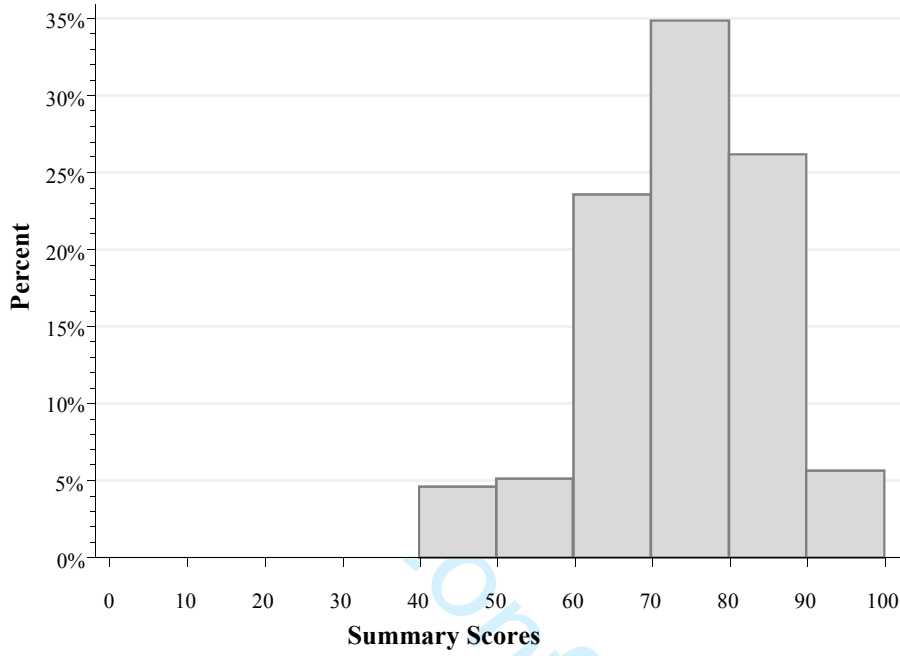
Figure 3: Distribution of ACHWM Summary Score and Quadrant Scores

* Note: Outliers were suppressed to protect the confidentiality of participants.
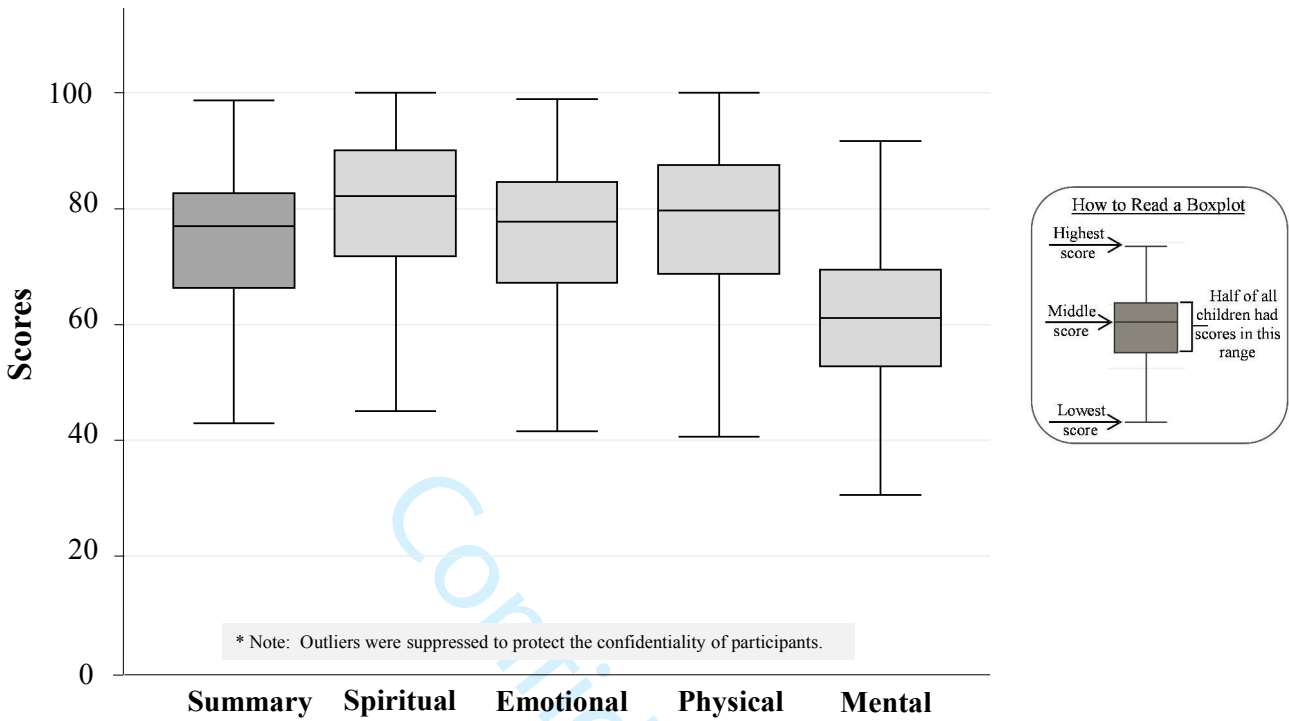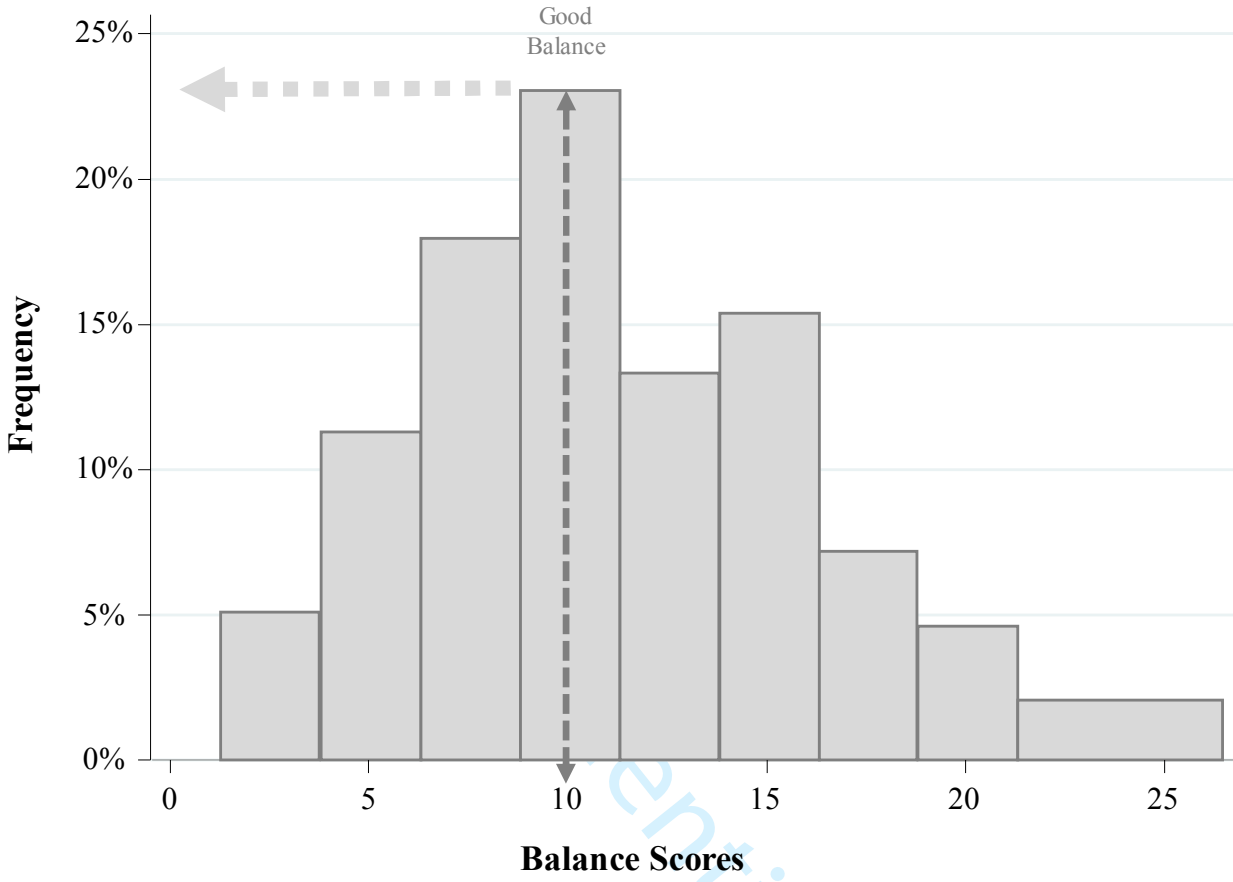
Figure 4: Distribution of Balance Scores (SD of quadrant scores within-person)

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1 √	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2 √	Explain the scientific background and rationale for the investigation being reported
Objectives	3 √	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4 √	Present key elements of study design early in the paper
Setting	5 √	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6 √	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants
Variables	7 √	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8* √	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9 √	Describe any efforts to address potential sources of bias
Study size	10 √	Explain how the study size was arrived at
Quantitative variables	11 √	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12 √	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses
Results		
Participants	13* √	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14* √	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
Outcome data	15*	Report numbers of outcome events or summary measures **NA**
Main results	16 √	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17 √	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses

Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.