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Research article

The Montana Postural Care Project: A pilot study implementing posture care management in a rural, low-resource region

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A B S T R A C T

Background: Mobility impairment limits control of posture and body alignment. This leads to altered body shapes, co-occurring problems with pain and sleep, cardiopulmonary concerns, digestive health issues, and emergent health outcomes, which further complicate functions of daily living. 24-hour posture care management was developed to remedy these challenges by restoring body symmetry.
Objective: To determine the feasibility of introducing posture care management to a rural-based, medically complex patient population, evaluate response of body symmetry, and examine its impact on pain and sleep quality.
Methods: This pilot study employed a longitudinal, quasi-experimental study design from March 2016 to September 2018. The posture care management intervention introduced positioning support for use when lying down, a personalized training workshop for caregiver teams, and in-home initial and follow-up assessments to provide materials and collaboratively develop a personalized care plan. Participants were followed pre-post for 6–9 months.
Results: A total of 73 participants enrolled in the study; 55 (75 %) completed. The majority were male (55 %) with a median age of 11. Most caregivers were immediate family members, and most participants had 1+ diagnosis characterized as a neurodevelopmental disorder. A majority of participants improved body symmetry (56–76 %), and 53 % with comparable information saw improvement in body symmetry with no worsening of pain or sleep quality.
Conclusion: This study established the feasibility of administering posture care management in North America. These findings provide preliminary evidence of improvements in body symmetry and address concerns that posture care management can interfere with pain and sleep. Future research should consider levels of caregiver engagement and explore remote-monitored options of a posture care management intervention.

1. Introduction

Mobility impairment is defined as motor deficits limiting gross and fine motor ability, resulting from nervous or musculoskeletal system dysfunction. These factors challenge an individual's ability to assume, maintain, or change physical positions independently. Mobility impairments are frequently seen in persons with neurodevelopmental disorders (NDs), conditions with atypical nervous system development affecting brain function with associated motor, seizure-related, sensory, intellectual, or behavioral impairments [1,2]. Many conditions that impair mobility are classified as NDs, including cerebral palsy (CP), spina bifida, Rett syndrome (RTT), and

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chromosomal abnormality-related conditions. NDs typically develop during infancy or early childhood; while traumatic brain injury (TBI) and muscular dystrophy (MD) may appear at later stages of childhood or adult life. However, all share common problems related to physical movement and coordination [3–7].

Persons with mobility impairment often have limited control of posture and alignment in upright orientations (i.e., sitting and standing) and present with unstable postures in the horizontal orientation (lying down). These individuals may require significant external positioning support promoting midline orientation and symmetry, in order to avoid assuming asymmetrical body postures for extended periods of time. Neuromuscular scoliosis (NMS) is a non-congenital spinal deformity often seen in persons with a mobility impairment who are unable to achieve and maintain appropriate alignment of the spine and trunk against gravity [8]. Windswept lower body posture, soft tissue contractures, kyphosis, and hip dislocations are frequently associated with persons with mobility impairments, particularly those with NMS [9–11]. Emergent health service delivery is also affected, as persons with atypical chest shapes pose an increased risk when administered standard life support or cardiopulmonary resuscitation [12]. Moreover, persons with a wide range of NDs, in general, also experience co-occurring problems associated with pain and sleep [13–15]. This further complicates one's ability to sit, stand, or lie down comfortably, participate in activities of daily living, and cardiopulmonary and digestive functioning [16,17].

A growing theory in epidemiological research claims that a combination of habitual, asymmetric postures, and extended downward gravitational forces may be associated with body shape distortions like plagiocephaly, windswept hips, and scoliosis [18–20]. Persons with mobility impairment and a limited movement repertoire may find themselves in a habitual, 'preferred' posture with increased exposure to these harmful effects. In response to the mounting evidence, a therapeutic positioning intervention called variously "24-h posture management", or "postural care", was developed to improve outcomes for persons at risk of developing secondary complications [21]. This brief report combines both schools of thought and refers to the intervention as posture care management (PCM), for inclusivity.

PCM involves maximizing an individual's alignment by supporting whole body posture throughout the entire 24-h day. In essence, PCM supports an individual's body toward their most symmetrical alignment during all activities and orientations that impact posture and function in human beings: lying, sitting, and standing. The link between postural control in lying and attaining functional sitting is well-documented; children with CP at Levels IV-V on the Gross Motor Function Classification System (GMFCS) are recommended to begin posture management programs in lying as soon as possible, in sitting at 6-months, and in standing at 12-months [22,23]. This contrasts with standard efforts in North America that under-prioritize providing positioning supports in the lying orientation, with the exception of preterm babies [24–26].

Early evidence suggests PCM can successfully restore body symmetry and improve range of motion [27–30]. However, concerns have been expressed regarding increased risk of pain and sleep impairment with use of PCM [31]. The objectives of this study were threefold: 1) determine the feasibility of introducing PCM to a rural-based, medically complex patient population, 2) evaluate the response of PCM on measures of body symmetry, and 3) examine the impact of PCM on pain and sleep quality.

2. Methods

2.1. Study design and Setting

This pilot study employed a longitudinal, quasi-experimental study design. It was carried out through the Montana Posture Care Project (MPCP) developed by Posture 24/7, a nonprofit organization devoted to education and outreach regarding the therapeutic practice of posture care management in North America. The MPCP introduced PCM to families with individuals who have mobility impairment throughout Montana. Montana is in the northwest part of the US with an overall area of 380,832 square kilometers. Montana's population is approximately one million and is the third least densely populated state in the county. Over 80 % of Montana counties are 'frontier,' classified as having fewer than three people per square kilometer, a threshold met by only nine countries and territories worldwide [32].

2.2. Study participants

The MPCP project was implemented from March 2016 to September 2018. Participants were recruited by convenience sampling methods through outreach with disability services provided across Montana. Caregivers and/or family members of persons with mobility impairment learned about the MPCP project through their local service agencies and contacted the principal investigator for participation, at which point they were given an application to complete and return. These applications collected prospective participants' diagnoses and clinical conditions, assistive and medical technology, and demographic- and caregiver-specific information. Inclusion criteria for the study required participants to have a medically diagnosed disability-related mobility impairment and be either at risk of or with a current altered body shape. As a pilot study, the study investigators were inclusive in specifications of what constituted altered body shapes. Written informed consent was obtained from all participants or proxies, with assent from minors where feasible.

2.3. PCM intervention

The PCM intervention consisted of physical and educational components: 1) introduction of a positioning support for participants to use when lying down, 2) a personalized training workshop, 3) an initial in-home assessment, 4) a follow-up assessment, 5) and

ongoing support. The training workshops were provided at regional locations across Montana to minimize travel distance for caregiver teams, as shown in Fig. 1. These workshops were administered over 1–2 days and delivered to all individuals involved in the care of study participants, which included family members, therapists, nurses, personal care assistants, and direct service professionals. Training topics focused on the biomechanics of preserving and improving body symmetry, assessing pain and sleep quality, thermoregulation, behavioral change, and techniques for implementing the PCM intervention for study participants. Training materials were provided in the form of lectures, group discussion, demonstrations, and simulations.

After completing the training workshop, the study investigators went to participants' physical homes to conduct an initial in-home assessment whereafter posture support materials were provided, current daytime positioning and mobility equipment for sitting and standing were reviewed and modified as appropriate, and a personalized PCM plan was developed in collaboration with the caregiver teams. Posture support materials consisted of a double layer non-slip mesh, a pressure-relieving airflow mattress pad, lateral hip and trunk supports, and a knee and hip alignment positioner. The study investigators then trialed different posture supports for participants in the lying orientation to identify a therapeutic position that was both safe and comfortable for the participant, as shown in Fig. 2. In several cases, additional customization was required and everyday household items, such as rolled-up towels, cushions, or stuffed toys were utilized. Caregiver teams were instructed to facilitate this therapeutic position whenever the study participant was in a lying down orientation throughout the study period, after which the study investigators returned to the participants' physical homes to conduct a follow-up assessment. Throughout the study period, participants' caregiver teams were given virtual access to MPCP personnel with regular check-ins via telephone and a private support group on Facebook.

■ Measurements and Outcomes

Data were collected longitudinally at two time points to enable a pre-post comparison of the PCM intervention. The first time point was at the initial in-home assessment, and the second was approximately 6–9 months later at the follow-up assessment. At both time points, study investigators collected measurements of body symmetry, pain, and sleep. Demographic and clinical characteristics were also collected at the initial in-home assessment. Body symmetry measurements were captured using three testing procedures from the Goldsmith Indices of Body Symmetry (GIoBS): 1) the "right/left chest ratio" denoting the distance from the xyphoid process to the lateral border on each side of the chest, 2) the "depth/width ratio" denoting the distance of chest width and chest depth at its deepest point level with the xyphoid process, and 3) the "abduction ratio" denoting the distance of the right and left hip external rotation and

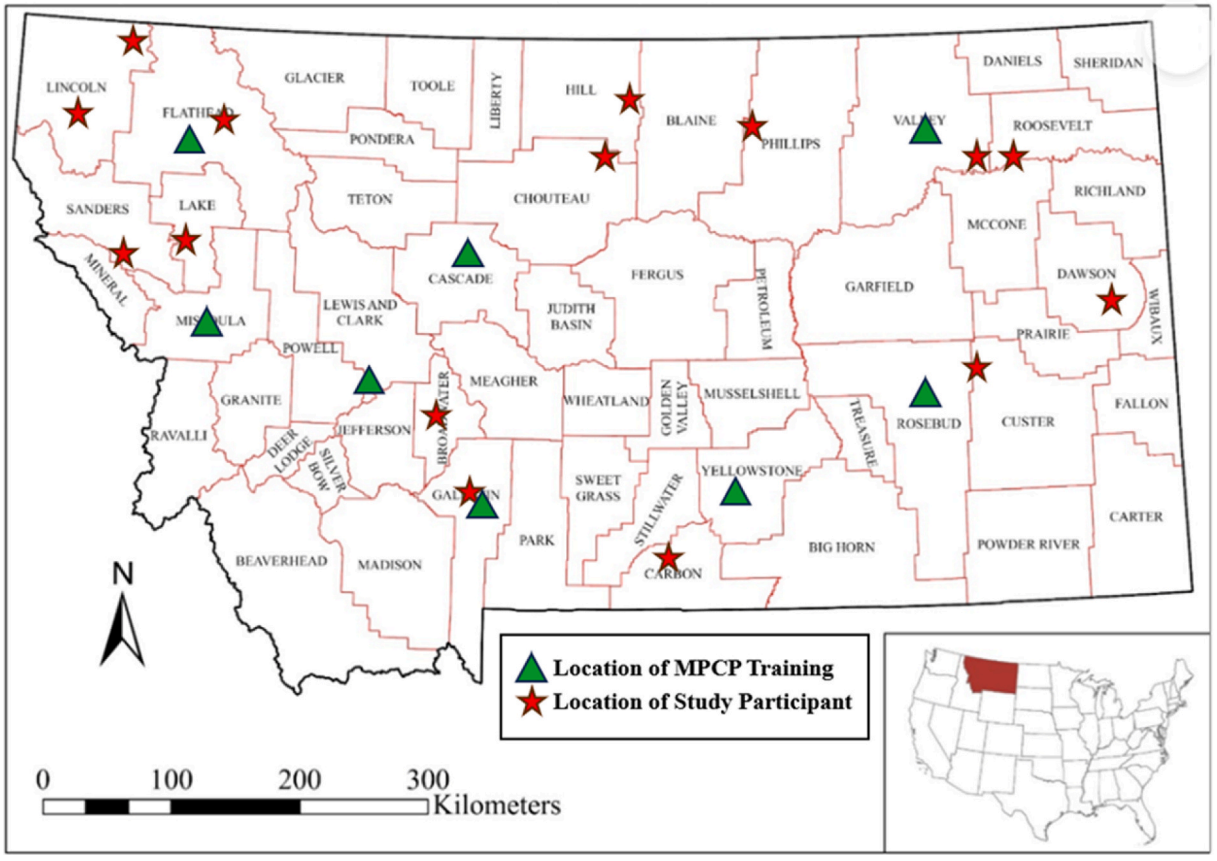

Fig. 1. Map of Montana: Locations of the posture care training and study participants.

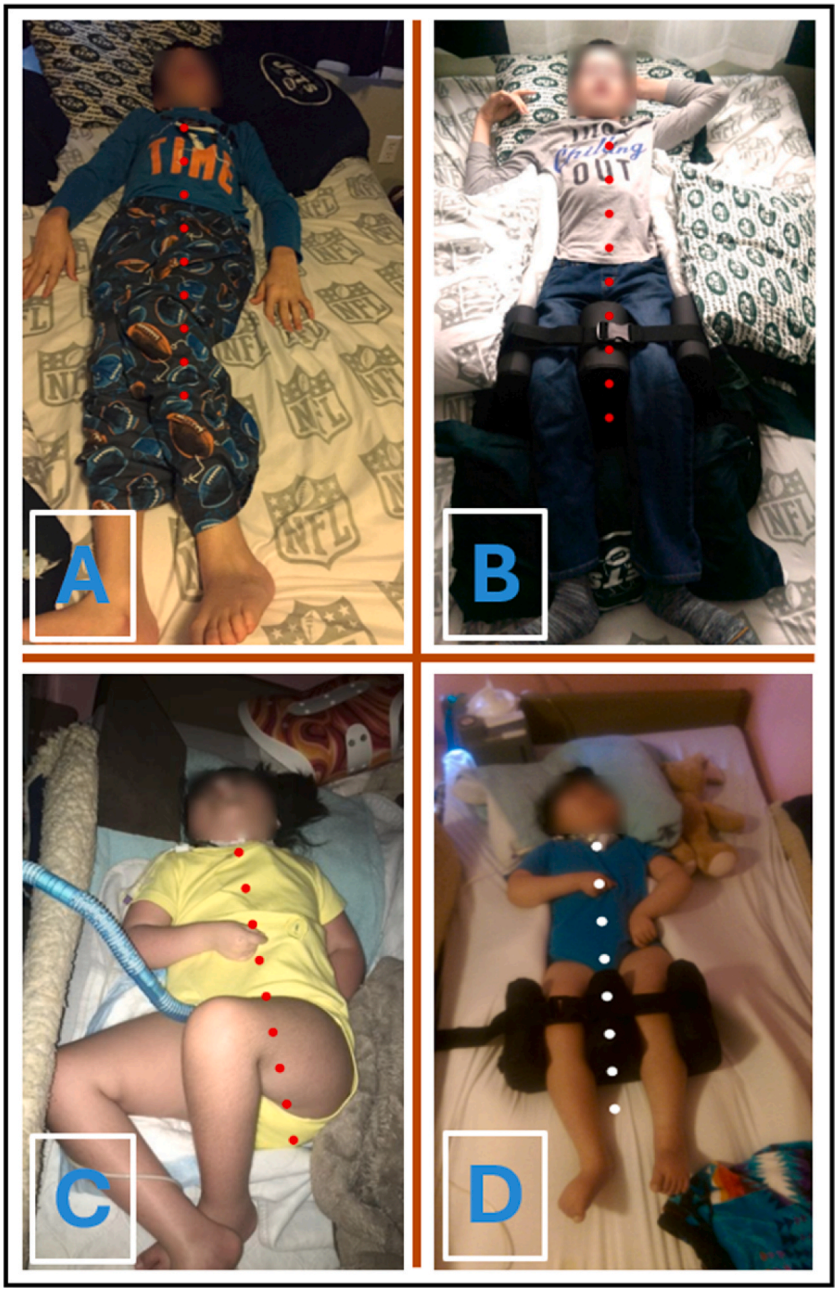

Fig. 2. Examples of Supine-Lying Positions Before and After Posture Care Management Intervention
Note: A and B represent the same participant; A shows supine-lying position before study implementation, and B shows supine-lying position at follow-up. C and D represent the same participant; C shows supine-lying position before study implementation, and D shows supine-lying position at follow-up.

abduction. The ideal values for a right/left chest ratio, depth/width ratio, and abduction ratio are 1.0, a range between 0.65 and 0.85, and 1.0, respectively. Pain was captured using the Paediatric Pain Profile (PPP), and sleep was captured using the Pittsburgh Sleep Quality Index (PSQI) or the Children's Sleep Habits Questionnaire (CSHQ), depending on the age of the participant. Body symmetry measurements were captured manually by study investigators and pain and sleep were collected via self-report or caregiver team's proxy assistance with study participants. Each of these clinical and psychometric tools have strong validity and reliability properties [33–36]. Descriptive statistics were used to compare categorical changes of an outcome either having improved, stayed the same, or declined from pre-to post. Due to limited sample size, no control group, and no overall consideration of statistical power, as common with pilot studies, no statistical tests were deployed.

3. Results

3.1. Study participants

A total of 73 participants were enrolled in the MPCP pilot study. Several were lost to follow-up prior to their follow-up assessment, mostly for reasons unrelated to the study (n = 13). During follow-up assessments, several additional participants had not implemented their PCM plan as originally designed (n = 5). Fifty-five participants completed the study, indicating an overall completion rate of 75 %. Fig. 3 shows a flow diagram containing details of program completion.

Table 1 provides a full description of participants' demographic and clinical characteristics. The majority of participants were male (55 %), and most caregivers of participants were immediate family members (81 %). The median age was 11, and the interquartile range (middle 50 % of participants) were between the ages of 5 and 19. Ultimately, the study reflected a highly diverse age range (1–67). Over forty unique diagnoses were represented among participants as several had co-occurring disorders. The most frequent included CP (68 %), chromosomal abnormality (16 %), epilepsy (14 %), developmental delay (10 %), MD (7 %), and spina bifida (7 %). Most participants had at least one diagnosis characterized as an ND (95 %).

3.2. Changes in body symmetry

With variations in participants' behavior, not all body symmetry measurements could be collected for all participants. Several of the youngest children could not tolerate the process given previous healthcare related trauma, or were too small for use of the GIoBS lower body symmetry measuring device. However, all measurements were captured for most participants who completed the study (right/left chest ratio: n = 49, 89 %; depth/width ratio: n = 49, 89 %; abduction ratio: n = 43, 78 %).

Fig. 4 shows the results of body symmetry measurements for Right/Left Chest Ratio (A), Depth/Width Ratio (B) and Abduction Ratio (C) among study participants who completed the study. Participants' average distance away from the ideal ratio decreased from pre-to post for all body symmetry measurements (right/left ratio: 0.18 to 0.13 units; depth/width ratio: 0.11 to 0.08 units [using 0.75]; abduction ratio: 8.30 to 6.52 units). The majority improved their right/left chest (73 %) and abduction (56 %) ratios. Approximately 33 % also improved their depth/width ratio, however close to half of participants (43 %) were already within the ideal range and required no measurable improvement (as indicated in the darker shade of green for participants who "Stayed in ideal range"). Collectively, 76 % of participants yielded a positive outcome for their change in depth/width ratio.

3.3. Individual Results and changes in pain and sleep

We examined individual changes in each health outcome by participants who completed the study. This included the three measurements of body symmetry (right/left chest ratio, depth/width ratio, and abduction ratio), two measurements of pain (on a 'good day when the participant is at their best' and on a 'bad day when the participant has their most troublesome pain'), and one measurement of sleep quality as shown in Fig. 5. Aggregate examination of results showed all 55 participants saw improvement in at least one health outcome. Considering all measures across all participants, 64 % of those captured had improved. Among those with comparable responses from baseline to follow-up, 55 % reported an improvement in 'good day' pain levels, 51 % reported an

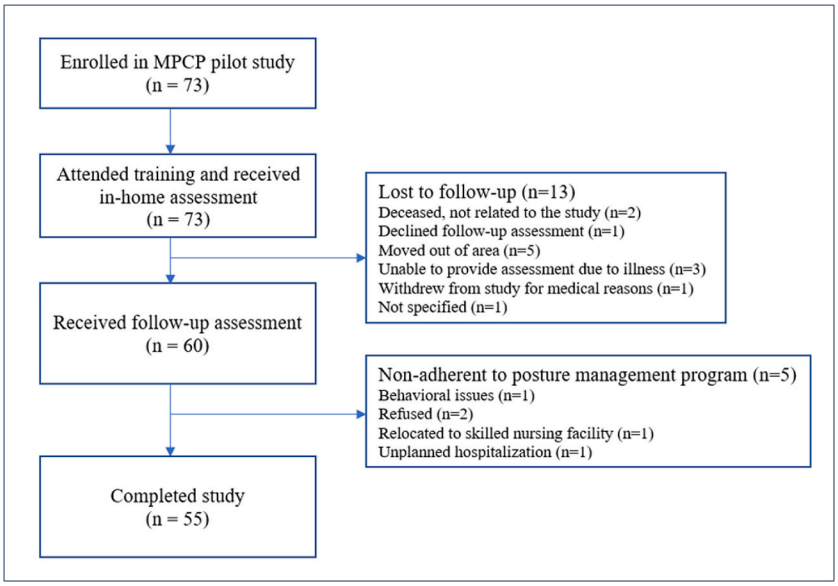

Fig. 3. Flow diagram of study participation.

Table 1
Demographic and clinical characteristics of study participants.

Variable	All Participants (n = 73)
Median age (Q1, Q3, year	11 (5, 19)
Age group, no. (%)	
≤10 years of age	33 (45)
11–20 years of age	21 (29)
21–30 years of age	6 (8)
31–40 years of age	6 (8)
41–50 years of age	2 (3)
51–60 years of age	1 (1)
≥61 years of age	4 (5)
Female, no. (%)	33 (45)
Caregiver(s), no. (%)	
Direct Support Professional	19 (26)
Family	59 (81)
Nurses	11 (15)
Diagnosis, no. (%)	
Autism	3 (4)
Amputation	2 (3)
Cerebral Palsy	50 (68)
Chromosomal Abnormality	12 (16)
Developmental Delay	7 (10)
Epilepsy	10 (14)
Muscular Dystrophy	5 (7)
Spina Bifida	5 (7)
Traumatic Brain Injury	4 (5)
Other Neuromotor Impairments	2 (3)

Note: Median indicates the 50 % percentile, Q1 indicates the first quartile or the 25th percentile, Q3 indicates the third quartile or the 75th percentile; Q1 to Q3 denotes the Interquartile range, no. = number. Participants may have had more than one caregiver. Cerebral Palsy included Complex Brain Malformation (n = 1), Encephalopathy (n = 2), Hemorrhagic Hydrocephalus (n = 1), Schizencephaly (n = 1), hypotonia (n = 2) and polygyria (n = 1); Chromosomal Abnormalities included 48 XXX chromosomal disorder (n = 1), Rett Syndrome (n = 1), Schauff-Yang Syndrome (n = 1), Sturge Weber Syndrome (n = 1), Tetrasomy 18p (n = 1), West Syndrome (n = 1), Angelman Syndrome (n = 1) and Wiederman-Steiner Syndrome (n = 1); Epilepsy included Seizures (n = 5) and Lennox-Gastaut Syndrome (n = 3); Muscular Dystrophy included Duchenne Muscular Dystrophy (n = 2) and Spinal Muscular Atrophy Type I (n = 1); Traumatic Brain Injury included Head Injury (n = 1); Other Neuromotor Impairments included Arnold Chiari Malformation (n = 1) and Ehlers-Danlos (n = 1); Diagnoses not included: Kidney issues (n = 1), Cancer, not specified (n = 1), and Deaf (n = 1).

improvement in 'bad day' pain levels, and 69 % reported improvement in overall sleep quality. When combining responses of body symmetry, pain, and sleep, 53 % of participants with comparable information saw an improvement in at least one measure of body symmetry and no worsening of either their pain or sleep.

4. Discussion

This pilot study successfully determined the feasibility of introducing PCM to a rural-based, medically complex patient population in North America. Furthermore, we observed improvements in body symmetry measurements among the majority of study participants. Finally, we observed the majority who experienced an improvement in their body symmetry also did not worsen their pain or sleep quality. All study participants were exposed to training and implementation of PCM for the first time in this study. These findings address concerns that therapeutic positioning can negatively interfere with pain and sleep [31].

Much of this study's success and high retention can be attributed to the degree of resources allocated by study investigators, which is not always feasible. Throughout the three and a half years of the study period, MPCP personnel traveled an estimated total distance of 21,514 km across the state of Montana. This was done to minimize burden for study participants and caregiver teams, many of whom must travel long distances to obtain specialty disability care which further exacerbates the already pressing health challenges associated with access to care in rural regions. For many participants, this intervention posed a viable noninvasive, cost-effective alternative to surgery that would require extensive out-of-state travel, with out-of-pocket expenses and loss of work time.

Additionally, meeting participants and caregiver teams in their natural home environment promoted collaboration through local team building and comradery. These efforts increased caregivers' skills in their responsibilities as well as their overall engagement in the study, both of which may have influenced participants' retention and overarching success with PCM [37]. This was observed qualitatively in the current study and should be examined with more scientific rigor in future research.

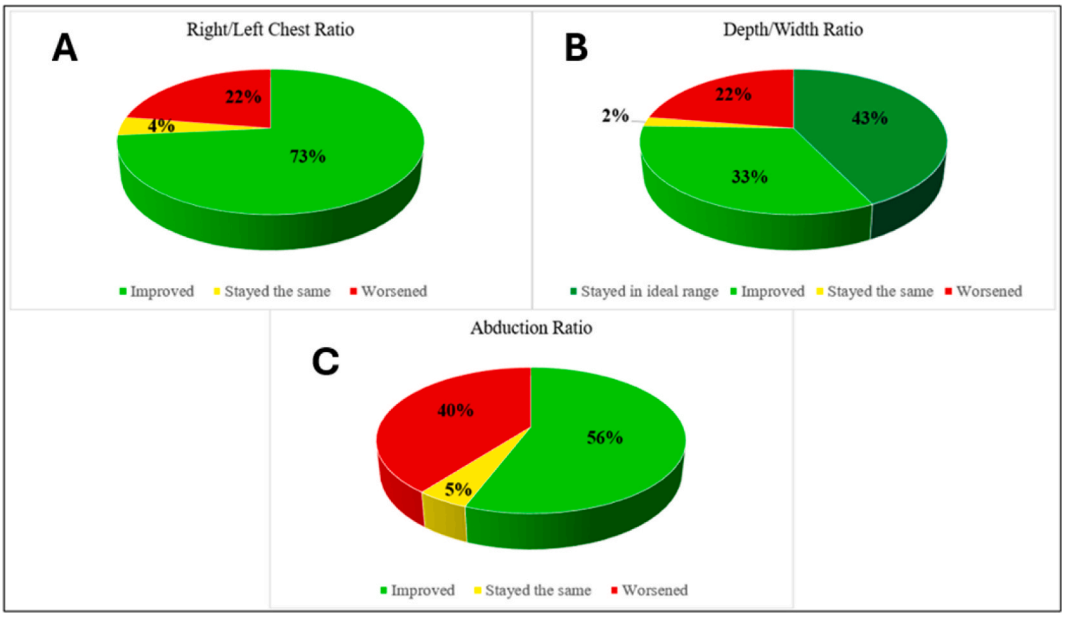

Fig. 4. Body Symmetry Results Among Participants who Completed the Study.

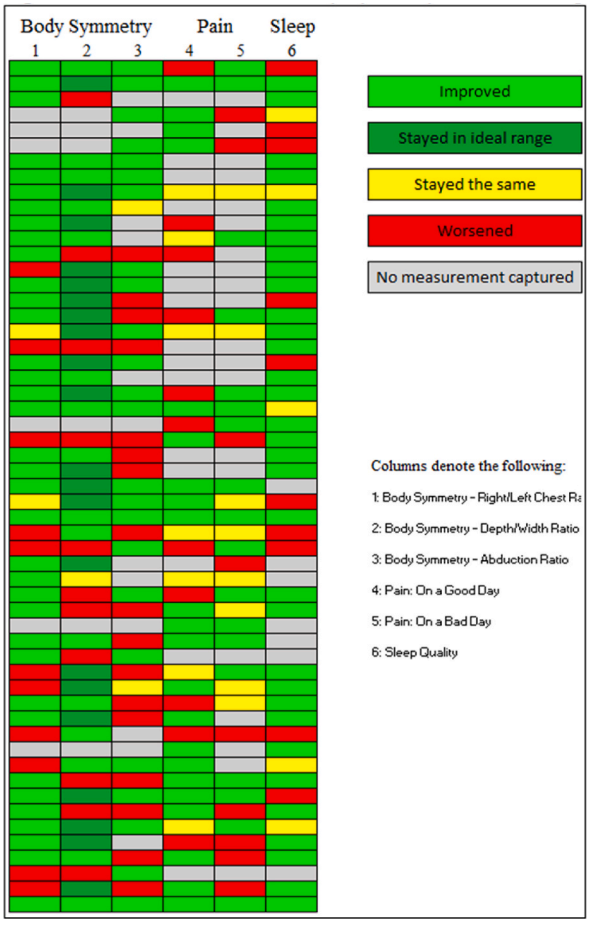

Fig. 5. Individual results for body symmetry, pain, and sleep.

It is also appropriate to note the role that telemedicine could play in the implications of this area of research. Technological advances and capabilities enabled the deployment of telemedicine into standard practice for many generalized and specialized forms of healthcare since the inception of the 2019 novel coronavirus (SARS-CoV-2, COVID-19) pandemic [38–40]. Telemedicine may also provide respite for rural areas that have shortages of specialized healthcare services, including PCM, that may offer a remote-monitored option. For the current study, this may exist in the form of training workshops delivered remotely, a train-the-trainers program to instruct local practitioners in methods of assessment and implementation, and virtual oversight by PCM experts. A lesson learned from this study is to consider other options for body symmetry assessment that do not require the use of specific instrumentation, training, and cost that is associated with the use of the GIoBS.

We believe it is important to address the study's limitations. Although we observed a majority of participants improve their health outcomes, complete data across all health outcomes were not ascertained across all participants who completed the study; 24 % did not capture all body symmetry measurements, 36 % did not report complete information on pain, and 13 % did not report information on sleep. Particularly, the lower body symmetry measurements from the GIoBS were difficult to administer to the smallest participants as the measurement device was too large. This provides further consideration to explore other measurement tools and options for body symmetry and/or adjust population parameters to age-specific groups for future studies. Moreover, this pilot study did not have a control group or control for any specific diagnoses or clinical conditions, both of which will be required to measure efficacy in the future. However, a patient population this complex lends credence to the challenge of sufficiently controlling for such characteristics. There are inherent limitations to any self-report data collection. The current study collected pain and sleep quality from proxies of study participants (a member of the caregiver team), and this information was paired with physical measurements captured by study investigators, which should be viewed as both a strength and limitation. There is also the consideration of dosage as participants' level of use of the PCM intervention was partially dependent on caregivers' practices. In some cases, individuals not on the caregiver team who did not receive PCM training, administered care for participants. This calls to question the consistency with which the PCM intervention was administered and can account for attenuated signals in health outcomes.

5. Conclusion

This study established the feasibility of administering posture care management in North America. These findings provide preliminary evidence of improvements in body symmetry and address concerns that posture care management can interfere with both pain and sleep. Future research should consider levels of caregiver engagement and explore remote training and monitored options of posture care management intervention.

Ethics statement

This study was reviewed and approved by the University of Montana Institutional Review Board and Fort Peck Tribal Institutional Review Board with approval number 199-16. All participants (or their proxies/legal guardians) provided informed consent to participate in the study and publish data. Minors provided assent when developmentally able to do so.

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Data Availability statement

Data will be made available on request.

CRediT authorship contribution statement

Tamara Kittelson: Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Arwen Kittelson-Aldred:** Writing – review & editing, Investigation, Conceptualization. **Jean M. Justad:** Writing – review & editing, Resources, Funding acquisition, Conceptualization. **Lee Ann Hoffman:** Writing – review & editing, Resources, Conceptualization. **Nicholas C. Coombs:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Tamara Kittelson via Posture 24-7 reports article publishing charges were provided by Montana Council on Developmental Disabilities. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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