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Comparing Diary and Retrospective Reports of Pain and Activity Restriction in Children and Adolescents with Chronic Pain Conditions

Amy S. Lewandowski, M.A[1], **Tonya M. Palermo, Ph.D.**[2], **H. Lester Kirchner, Ph.D.**[3], and **Dennis Drotar, Ph.D.**[4]

[1] Case Western Reserve University

[2] Oregon Health & Science University

[3] Geisinger Center for Health Research

[4] Cincinnati Children's Hospital Medical Center

Abstract

Objective—The current study investigated the daily relationship between pain, activity restriction and depression in children and adolescents with chronic pain, and compared participants' responses on diary and retrospective assessment measures.

Method—Data collection included the administration of diary and retrospective measures of pain, activity restriction, and depression to 93 children with recurrent headache, juvenile chronic arthritis, and sickle cell disease. The study used HLM to examine the relationship between daily pain and activity restriction, and analyses compared participants' responses on diary and retrospective assessment measures.

Results—Using diary measures, daily pain intensity was related to children's levels of activity restriction. Diary completion was predicted by age and diary-type, with younger children and children utilizing electronic diaries demonstrating higher compliance. Pain intensity was significantly higher on retrospective compared to diary measures, demonstrating inflation in retrospective reports of pain. No significant differences between measures of activity restriction emerged.

Discussion—These preliminary results suggest that while retrospective reports of activity restriction may be an acceptable alternative to daily diary assessment for children with chronic pain, retrospective measures of pain intensity may show inflated pain levels. To provide support for the findings, longitudinal research comparing responses to diary versus retrospective measures is recommended.

Keywords

chronic pain; activity restriction; depression; children; adolescents

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Please send correspondence to: Amy Lewandowski, Psychology Department, Mather Memorial Building, #109, Case Western Reserve University, 10900 Euclid Avenue, Cleveland, Ohio 44106-7123, Phone: 330-990-0339, Fax: 216-368-4891, Email: E-mail: amy.lewandowski@case.edu.
Please contact corresponding author for reprints

Introduction

According to recent estimates, 25% of children and adolescents report experiencing pain and about 8% have severe chronic pain[1]. While not all children with chronic pain exhibit significant pain-related disability, research has shown that chronic pain in children and adolescents is associated with activity limitations including school absences, sleep disturbances, and decreased participation in physical and social activities[2,3,4,5].

Accurate measurement is critical for examining the frequency and intensity of pain symptoms and for assessing the domains of functioning that are affected by chronic pain[6]. Due to the subjective nature of pain, self-report pain assessment tools are typically given greater weight in pain assessment. The majority of research on pain and activity limitations in both adult and child chronic pain samples has utilized retrospective self-report measures[7]. Such studies typically measure pain using a single retrospective measure that asks participants to report on their pain over the previous one-week, two-week, or month-long period. Although retrospective measures provide a global account of the frequency or intensity of pain experienced, these measures can be inaccurate[8]. Specific recall errors include inflated reports of pain frequency, intensity, and duration, and activity limitations associated with pain[9,10].

Inaccurate reports of pain and disability have negative implications for research and clinical practice, as they may lead to misleading incidence/prevalence data, inappropriate conclusions regarding the associations between pain and functioning, and improper treatment recommendations[11]. A recent review indicated that when compared to retrospective measures, pain diaries may be a more reliable and valid method of assessing chronic pain because diaries eliminate the problems associated with retrospective recall[9]. Pain diaries have been utilized in studies of children and adults with a broad range of chronic pain conditions, with diary-report periods ranging from one week to two months[10,11].

The disadvantages associated with diary assessment, including back-filling and hoarding of responses, led to the development of innovative electronic diaries that time-stamp entries and prohibit multiple diary entries on the same day[12]. Findings from a randomized trial that compared compliance, accuracy and completeness of electronic versus paper diaries in youth with chronic pain reported that paper diaries were less complete and contained more errors and omissions compared to data gathered electronically[13]. While these data highlight the potential benefits of using electronic diaries in chronic pain assessment and suggest that they may increase the accuracy and validity of pain measurement, other researchers have noted the psychometric and statistical data equivalence of electronic and paper diaries[14].

One advantage of using diary data (paper or electronic) is the ability to examine the temporal relationships between variables. Multilevel daily process analyses (e.g. hierarchical linear modeling) are being used increasingly to analyze pain diary data[15,16,17,18]. These analyses allow for ‘real time’ examination of pain and its associated factors, assess within-person variability, and allow for inferences regarding causality between variables[19]. The majority of chronic pain research using multilevel methods has focused on the daily relationship between pain and psycho-social factors including stress, mood and coping[16,18,20].

Limited multi-level research has examined the association between daily chronic pain and activity restriction in either child or adult populations, although initial evidence suggests the temporal relationship between pain and activity restriction is predicted by pain level. Findings from one study of adults with mixed chronic pain conditions revealed that changes in daily pain were associated in a curvilinear manner with sensory symptoms, affective distress, and activity limitations[21]. In a study of children with arthritis, increased levels of daily pain, fatigue and stiffness predicted restriction in school and social activities[22]. Studies have also shown that pain intensity is not only associated with the degree of activity restriction but the types of activities that children limit. Maikler and colleagues[23] reported that while children with sickle cell disease reduced all activities (social, school, home, play and sports) when pain intensity was high, at low levels of pain, 80% of children continued to participate in less vigorous activities (social, home and school).

The findings from these diary-report studies support previous retrospective research that has demonstrated significant relationships between chronic pain and activity restriction[2,3,4,5]. However, these diary studies, particularly those with children and adolescents, are limited by their inclusion of single pain conditions and the failure to assess activity limitations using a measure with well-established reliability and validity[24]. The next step is to directly compare retrospective and diary reports to determine if the two forms of measurement comparably assess pain and activity restriction. To our knowledge, only one prior study has compared diary and retrospective report of children with persistent pain[10]. The findings from this study revealed inflation in retrospective reports. However, this study was limited to children with headache and did not include an assessment of activity restriction.

The present study had two aims. The first was to expand previous research by using diary assessment to examine the relationship between daily pain and activity restriction in a mixed sample of children with recurrent headache, juvenile chronic arthritis, and sickle cell disease. It was hypothesized that daily diary reports of pain would be associated with daily activity limitations, with higher levels of pain associated with more activity limitations on that day. Moreover, it was predicted that age, gender, and depression would emerge as significant covariates between pain and activity restriction on diary measures. Specifically it was hypothesized that older children, girls, and children with higher levels of depressive symptoms would show stronger associations between pain intensity and activity limitations. Previous research documenting the impact of same day pain on same day activity limitations[22, 23] and the role of age, gender, and depression[25,26,27,28,29] as covariates in retrospective studies provide support for this hypothesis.

The second aim was to compare children's retrospective and diary reports of pain and activity restriction and determine whether measure-type was associated with the level of pain or activity restriction children reported. It was hypothesized that higher levels of pain would be associated with greater disability, and based on studies with other chronic pain samples demonstrating inflations in retrospective measures[8,10] it was predicted that children would report higher levels of pain and greater activity restriction on retrospective measures compared to diary reports.

Finally, exploratory analyses examined if individual factors (age, gender and depression) were associated with completion rates or discrepancies between diary and retrospective reports of pain and activity limitations. Previous research with chronic pain samples has found that age and depressive symptoms were predictive of recall error[10], and that gender and depressive symptoms were related to rates of diary completion[13,30]. It is important to determine if these findings generalize to other pain populations and assessments of activity restriction.

Materials and Methods

Participants

Data were gathered as a part of a larger study examining the impact of chronic pain on the physical and psychological functioning of children and adolescents. The sample consisted of 93 children and adolescents who were diagnosed with recurrent headaches, juvenile chronic arthritis, or sickle cell disease. These pain conditions were selected for inclusion because: 1) they are among the most prevalent chronic pain conditions for children in this age group, 2) they include participants with disease and non-disease related pain, and 3) the groups present with a variety of pain symptoms (e.g., intensity, duration) and different types of activity limitations (e.g., schoolwork, running). Participants were 8–16 years old with a mean age of 12.5 years (SD=2.50), with 69.9% of participants being female. Significant group differences in income and ethnicity emerged; children with sickle cell disease were more likely to be African American and were from lower income backgrounds than youth with recurrent headache or arthritis (see Table 1).

Procedure

Participants were recruited from pediatric specialty clinics at a children's hospital in a large Midwestern city. IRB approval was obtained from the institution prior to data collection. Over a two-year time period, all new and existing patients and their parents that presented to pediatric specialty clinics and met inclusion criteria were approached and invited to participate in the study. Children were eligible for participation if they were between 8 and 16 years old and were diagnosed with recurrent headaches, juvenile chronic arthritis or sickle cell disease. Participants were excluded from the study if they were not between 8–16 years of age and did not speak English. The rate of participation in the study was approximately 94%, and the primary reason for refusal was the time involved in completing questionnaires. After obtaining informed consent, self-report retrospective questionnaires were administered by a trained research assistant during the participant's clinic visit. Following the completion of in-clinic questionnaires, participants were randomized to complete either paper or electronic diaries at home during the week immediately following their clinic appointments. These diary questionnaires, which assessed daily pain and activity limitations, were returned via mail. While the completion of responses to paper versus electronic diaries was not the main focus of the study, 30% of participants were randomized to the electronic diary group so differences in response rates by diary-type could be examined. Families received a $30 gift card as compensation for their participation.

Data from 93 children (64% of the 156 participants recruited) were used in statistical analyses. Children with missing data on retrospective measures and/or diary reports (< 2 days) were excluded. Analyses comparing children with complete versus incomplete data revealed significant differences by income and pain condition. African American children and participants with sickle cell disease were more likely to be excluded due to missing data.

Diary Administration—Children completed a daily diary at the end of each day using either paper or electronic format. The Hewlett Packard Jornada 548 Personal Digital Assistant (PDA) was used for electronic data collection. The PDA was programmed to follow a specific sequence of questions with a built-in response loop. If the child answered 'yes' to question 1 regarding the occurrence of pain that day, the diary would proceed to the questions on different pain features (e.g. intensity, location) followed by assessment of activity limitations. If the child responded 'no' to having pain that day, the diary would skip to the questions on activity limitations. The diary had an audible alarm programmed to remind children to complete the diary (for additional details regarding the PDA, see Palermo, Valenzuela & Stork, 2004). The questions on the paper pain diary were identical to those on the PDA. Like the PDA, children were asked to report their level of pain intensity, mark the locations of their pain, and rate limitations in their daily activities.

Measures

Caregiver Information Form—The participants' caregivers completed a basic demographic form, which provided information on the child's age, race, gender, and family income level.

Depression—Children and adolescents completed the Revised Child Anxiety and Depression Scale (RCADS)[31]. The major depressive disorder (MDD) subscale was used to assess participants' depression levels. T-scores are calculated based on child gender and grade in school. This measure has demonstrated adequate one-week test-retest reliability, and the validity of both subscales has previously been established through relationships with other anxiety and depression measures[31]. The internal consistency of the MDD subscale for the current sample was moderate (α = 0.72).

Pain Intensity—Pain intensity was assessed using the Faces Pain Scale[32]. The scale asks participants to describe the intensity of their pain using one of seven faces with anchors at the two ends representing "no pain" to "worst pain". Both diary and retrospective-report versions of the measures were used for pain assessment. The retrospective version asked participants to report on their average pain intensity over the previous four weeks. The diary-report version asked participants to report on their level of pain intensity daily. The Faces Pain Scale has demonstrated reliability and validity for prospective and retrospective pain assessment in similar samples[33]. The Faces Pain Scale – Revised (FPS-R)[34] was not used in the current study because it was not available when data collection began.

Activity Limitations—The Children's Activity Limitations Interview (CALI)[24] was used to assess pain-related activity limitations. The measure has two formats, a diary and a retrospective-report version, both of which were used in the current study. The retrospective version asks participants to report on 21 activity limitations in a variety of domains over the previous four weeks. Children are then instructed to identify their eight most limited activities and rate the difficulty in completing each activity on a five point scale, ranging from 0 'not difficult' to 4 'extremely difficult'. Children also completed a diary version of the measure over a one-week period following their clinic appointments. On the diary measure, children provided a daily rating of the difficulty of the eight items they identified on the retrospective measure. The CALI has demonstrated reliability and validity in assessing pain related activity limitation in school aged children and adolescents[24]. Internal consistency reliability in the current sample was high (α = 0.87).

Plan for Statistical Analyses

Summary statistics were used to describe the demographic characteristics of the sample. Means and standard deviations were used for continuous data, and categorical items were described using frequency statistics. One-way ANOVA and chi-square analyses were conducted to determine whether there were any significant effects of pain group, age, gender, racial background or income level on pain intensity, depression or activity limitations. Pearson product moment correlations and linear regressions were used to assess the relationship between demographic characteristics and predictor and outcome variables. T-tests were used to compare responses to diary and retrospective reports, and to examine factors associated with diary completion rates.

Multi-level modeling was used to analyze the diary data. Hierarchical Linear Modeling (HLM) is a type of multi-level modeling that allows for estimation of the roles of time and individual factors in predicting the relationship between two variables[19]. HLM assesses whether the level of association between the constructs is accounted for more by individual level characteristics (e.g., level of depression, age, gender) or variability across participants (longitudinal pain trajectories), and enables one to evaluate the temporal relationship between variables (e.g., pain and activity limitations) over time. Data analysis was conducted using both Hierarchical Linear Modeling Version 6.0 (HLM 6) and the Statistical Package for the Social Sciences Version 15.0 (SPSS 15.0). Significance levels were set at $p<.05$.

Results

Descriptive Data: Diary Measures

Data from a total of 591 diary days were used in the analyses, with children reporting pain on 61.6% of diary days. Paper diaries were completed by 65 children and 28 utilized an electronic device. Participants completed an average of 6.38 days of diary report data over the week-long data collection period. Across both types of diaries, significant gender differences on peak pain intensity during the week emerged ($t = -1.99$, $p<.05$), and gender differences in average daily pain intensity approached significance ($t = -1.84$, $p = .07$). Females reported higher pain intensity on diaries than males. Average pain intensity and activity limitation (from both paper and electronic diaries) were calculated by taking the average of all the pain scores and activity limitation across each participant's diary data. Participants reported low to moderate average daily pain intensity (M=2.98, SD=1.81), and total daily activity limitation was moderate (M = 14.95, SD=6.21) (see Table 2).

Children and adolescents using electronic diaries completed an average of 6.89 days, compared to an average of 4.97 days on paper diaries, indicating greater compliance with the electronic format. No significant differences between report of pain intensity or activity restriction emerged when comparing responses on electronic versus paper diaries. Age was significantly associated with diary days completed ($B = -.208$, $p < .05$) with older children completing fewer diary days than younger children. Neither gender nor depressive symptoms were associated with compliance.

Correlations between average diary ratings of pain intensity and retrospectively reported depression ($r = .46$, $p<.001$) emerged, with higher reports of pain being associated with higher levels of depression. In addition, greater diary-reported activity limitation was associated with both greater levels of diary-reported pain intensity ($r = .41$, $p<.001$) and depression ($r = .38$, $p<.001$) (see Table 3). Children with headaches, arthritis, and sickle cell disease did not differ on prospective reports of pain intensity and activity restriction, nor participant age.

When asked to identify the most difficult activities in the last 4 weeks the total sample of participants rated (in order) running, sports, gym, attending after school practice, schoolwork, staying up all day, reading and completing chores. In terms of specific activities, significant differences between children with headache and arthritis emerged. Participants with head pain reported significantly greater activity restriction ($p < .05$) on school attendance, reading, schoolwork, playing with friends, watching television, doing chores, doing activities with friends, eating meals, riding in a bus/car, sleeping, and staying awake all day. In comparison, participants with arthritis reported significantly more restriction in tasks that involved more vigorous activity including sports, running, climbing stairs, walking 1–2 blocks, and riding a bike ($p < .05$).

Descriptive Data: Retrospective Measures

Children and adolescents reported moderate to high levels of pain on retrospective reports (M = 4.57, SD=1.49, range = 1–7). Scores on the retrospective CALI suggested moderate amounts of activity limitation (M=14.84, SD=7.36) (see Table 2). Neither age nor gender was associated with pain intensity or activity restriction. Participants reported normative levels of depression (MDD T-score: M=49.89, SD=11.26, range = 30–73) overall. Groups differed on pain intensity ($F(2,89) = 9.94$, $p<.001$), with children with recurrent head pain reporting the highest levels of pain (see Table 2). No significant differences on activity restriction or depression were found between children with headaches, arthritis, or sickle cell disease.

Aim One: Multilevel Random Effects Models with Diary Data

All diary data points from each participant were assessed as a single trajectory for each participant over the week-long recording period. Using an approach described in previous research[19,35,36], HLM was used to examine the relationship between daily reports of pain and activity restriction. Specifically an autoregressive error structure was used to model the correlation across time (autoregressive error assumes that the correlation between data-points decreases as time between data-points increases). In addition, robust fixed effects estimation was used to protect against model misspecification which can underestimate standard errors[35,36].

Based on recommendations in previous research[35,36], for each predictor (e.g. pain intensity), a person-centered predictor and a between-person predictor were created. This process is necessary because it ensures that the within-person effect is not biased by treating the intercept as a random factor. Specifically creating a person-centered predictor ensures that the predictor (pain intensity) does not contain between-person variance, is not correlated with other between-person factors, and measures only within-person effects. The between-person predictor is an aggregate of the relationship between the predictor (pain intensity) and outcome variable (activity limitations) for all participants across time points[36]. After this process was complete, the main effect of pain intensity on activity restriction was examined. Next, using series of separate multilevel random effects models, age, gender, and depression were entered to test if they had any impact on the relationship between pain and activity restriction.

The outcome variable activity restriction was calculated in two ways: 1) using the average of the activity limitation data reported across each day in the diary collection period; and, 2) using the peak activity restriction reported each day. Peak restriction was determined by using the highest level of restriction reported on one of the eight activities children were asked to monitor. For the total sample, daily peak activity restriction (M = 3.36, SD = 1.23) was significantly higher, t(83) = 11.02, p<.001, than the daily mean level of activity restriction (M = 1.88, SD = .74). However, the correlation between the variables was extremely high (r = .73, p <.001) indicating that separate analyses with the two variables would be redundant. As a result, only average activity restriction was used in subsequent analyses.

Associations between Pain Intensity and Activity Restriction—As hypothesized, HLM models indicated that pain intensity was significantly related to average activity restriction (t = 4.42, p <.001). Higher levels of daily pain were associated with more activity limitation that day (see Table 4). On the 413 days children reported pain, sum scores for daily activity restriction were moderate (M = 16.63, SD = 7.19). On pain-free days, children also reported activity limitations. On 8.8% of the 178 diary days in which children did not endorse having any pain, mild activity restriction was reported (M = 9.86, SD = 3.97), indicating some activity limitation was associated with factors other than pain.

Contrary to hypotheses, when entered into the model, age, gender and depression were not significant covariates indicating that these variables did not impact the daily relationship between pain intensity and activity restriction.

Aim Two: Analyses Comparing Diary and Retrospective Reports

As hypothesized, analyses comparing diary and retrospective measures of pain intensity showed significant differences, t(91) = 9.74, p<.001, between retrospective (M = 4.66, SD = 1.52) and diary reports (M = 3.05, SD = 1.09) indicating that retrospective measures showed the expected higher levels of pain. Contrary to hypotheses, diary-reported activity restriction (M = 14.95, SD = 6.21) was not uniformly different, t(84) = −.14, p=.89, from retrospective activity restriction (M = 14.84, SD = 7.36) (see Table 2). Exploratory analyses indicated that age, gender, and depressive symptoms were not associated with the amount of discrepancy between diary and retrospective measures of pain intensity or activity limitations. Age was associated with diary completion rates, with older children (aged 13–16) completing fewer diary days than younger children (aged 8–12).

Results Summary

Results indicated that daily pain intensity was associated with activity limitations in children and adolescents with chronic pain. Contrary to hypotheses, the relationship between diary-reported pain and activity limitations was not moderated by age, gender, or depression. In support of hypotheses, comparisons of diary and retrospective reports of pain intensity revealed significantly higher levels of pain on retrospective measures. In contrast, no differences between diary and retrospective reports of activity limitations emerged. Exploratory analyses indicated that age was associated with diary completion rates. Contrary to predictions, discrepancies between diary and retrospective measures were not related to age, gender or depression.

Discussion

Findings from the current study revealed that as hypothesized daily pain intensity was related to degree of restriction in daily activities. Importantly, activity restriction was not only related to pain intensity when levels were high, but also when pain was low. This suggests that even at low pain levels, chronic pain conditions impact children's daily functioning in a variety of domains (e.g., sports, school, socialization with friends). This finding was significant for participants in all groups indicating similarity across pain conditions (disease-related and headache pain). Contrary to hypotheses age, gender and depression did not moderate the relationship between pain intensity and activity limitations.

Similar findings regarding the significant relationship between pain and activity limitations have been reported in both child and adult samples. For example, in a sample of children and adolescents with mixed pain conditions pain impacted overall activity level at both high and low levels of pain[21]. However, other studies have indicated that activity limitations are not universal and certain domains of activity restriction are more impacted by pain levels than others. For example, Maikler and colleagues found that children with sickle cell disease decreased participation in all activities (school, play, sports, social) when pain was high but were able to maintain school attendance and social activities when pain levels were low[23].

These findings suggest that more research is needed to elucidate how different levels and types of pain are related to specific activity limitations (e.g., sports, school attendance, spending time with friends). Previous studies have found that relationships between pain intensity and activity limitations depended on the domain of functioning being assessed. While pain was associated with functional disability, it was not associated with either school or social/role functioning[37]. Additional research is also needed to determine whether individual characteristics (e.g., age, gender, coping style) of the child impact activity level in differing domains. For example, is there a stronger relationship between pain and participation in athletic activities for girls versus boys?

Future studies should also continue to examine how perceived competence levels (e.g., social, athletic, academic competence) are associated with pain and activity levels in children with chronic pain conditions. Research on adolescents with irritable bowel syndrome (IBS) demonstrated that perceived academic competence moderated the relationship between IBS symptoms and functional disability. Moreover, gender differences in associations with social and athletic competence emerged; girls who reported low social competence and boys who reported low academic competence showed the strongest relationships between disease symptoms and disability[38]. This research should be expanded to other pain populations to determine if similar associations between pain symptoms, competence, and functioning emerge, and to determine whether age, gender or pain-type impact these relationships.

While children with both disease and non-disease related pain in our study endorsed experiencing restriction in different types of activities, analyses examining associations between specific activities (reports on individual CALI items) and pain intensity were not conducted due to the poor reliability of single items within a measure. The next steps in our research are to factor analyze the CALI to identify whether different domains of activity restriction (e.g. active, routine) emerge, to compare these domains with pain intensity[39], and to replicate this study with a larger and more diverse sample of children with chronic pain conditions.

Findings comparing diary and retrospective reports indicated that as hypothesized children and adolescents reported lower pain intensity on diary compared to retrospective measures. This finding supports previous research[10] indicating that diary reports show less inflation than retrospective measures. Although it cannot be concluded that diary measures are more accurate than retrospective measures, findings suggest that researchers and clinicians should be aware that retrospective responses may be artificially elevated.

In contrast, and contrary to the hypotheses, retrospective activity restriction data were not uniformly inflated compared to diary reports. The failure to find expected inflation in retrospective versus prospective measures of activity restriction suggests that both types of measures function comparably in the assessment of activity restriction. This is a potentially important finding given that the majority of data collected for research studies and clinical purposes are based on retrospective assessment of functional disability or activity restriction.

Possible explanations for the differential findings on diary and retrospective measures of pain and activity restriction involve differences in the saliency of the experiences. For example, high levels of pain may be more salient to children than not participating in a particular activity. As a result, only retrospective reports of pain were inflated. In addition, previous research[37] has shown that the physical and social functioning (e.g. school attendance, parent-child interactions) of children with chronic pain is associated with factors other than pain. Although pain was significantly associated with activity restriction in the current study, children reported activity restriction on 8.8% of days without pain. This finding suggests that other factors in the children’s lives (e.g., mood, stressors, family environment) could have impacted their activity levels and as a result affected their CALI scores. Assessment of social and family factors (e.g., solicitousness, social support) can help to identify specific factors other than pain that related to activity limitations in this population[37].

Exploratory analyses examining individual factors associated with rates of diary completion indicated that age was significantly associated with diary compliance, with older children completing fewer diary days than younger children. This finding may be explained by adolescents’ higher levels of independence and autonomy compared to children. While autonomy was not assessed in the current study, it is likely that parents of adolescents had a less active role in reminding them to complete their diaries or that adolescents had greater independence in deciding whether or not they wanted to complete the diary that day. To address this issue, researchers using diaries with adolescent samples may need to increase adolescent’s motivation to complete diaries by providing additional incentives for the completion of all diary days or making the diary more interesting or rewarding to complete.

Diary-type was also associated with compliance. Participants using the electronic PDA completed an average of 1.92 more days than children using the paper diary. This finding supports a previous literature review and research studies[9,13,40] that reported better compliance with electronic compared to paper diaries. Although exact reasons for better compliance with the PDA are unknown, it is likely that the novelty of the PDA device and daily audible alarm increased compliance. The data from this and other studies highlight the potential benefits of using electronic diaries in chronic pain assessment and suggest that they may increase the accuracy and validity of diary pain measurement.

In contrast to hypotheses, surprisingly neither gender nor depression was associated with diary completion rates. Previous literature has shown that higher levels of depressive symptoms were associated with lower completion rates in children with arthritis[22] and that gender was related to rates of diary completion in both children with sickle cell disease and mixed chronic pain samples[13,41]. It is possible that the relatively small sample size in the current study or the measurement of depression using a retrospective measure may have impacted these relationships.

Similarly, the retrospective assessment of depression may have impacted the findings that indicated depression was not a covariate in the relationship between diary-reported pain and activity limitations. While previous research has shown stability in depression in both clinical and nonclinical samples over a one week time period[31], there could have been daily fluctuation in depressive symptomatology. Other factors (e.g., social stressors, physical health, or changes in peer/family interactions) likely influence the daily level of depressive symptoms that children experience, and future research using daily diary assessments of depressive symptoms are needed to clarify the relationship between depression and daily reports of pain and activity restriction.

While the multi-modal assessment is a strength of this study, several limitations should be considered in interpreting the findings. First, although the diary and retrospective assessments of pain and activity restriction occurred over similar time periods, retrospective measures asked participants to provide ratings of pain and activity restriction over the previous four weeks while diary measures had participants provide ratings for the week following their enrollment in the study. In children with chronic pain conditions, pain intensity can wax and wane over time and it is possible that these fluctuations in pain explain some variability in retrospective as compared to diary measures. However, similar fluctuations in activity restriction would also be expected and these findings showed greater stability.

The current study is limited by a relatively small sample size, which may have impacted the ability to detect significant effects. Also, while power analyses indicated that the sample of 93 participants could detect a medium effect size, the small number of participants with each chronic pain condition precluded separate regression and HLM analyses within each pain condition. Similarly, although the current study used three different pain conditions to examine the relationship between pain and activity restriction, the inclusion of other pain groups (e.g. juvenile fibromyalgia, recurrent abdominal pain) may have led to different results.

Additional research on how individual differences (e.g., temperament, coping style, treatment regimen, pain condition, race) impact the association between pain and activity restriction is needed to increase the generalizability of the results. Moreover, it is important to note that while the racial background and socio-economic characteristics of the participants with sickle cell disease in this sample reflect typical demographic characteristics of this population, the participants with sickle cell disease were from families with lower incomes and comprised a higher percentage of African American participants in the overall sample. Moreover, many of the participants excluded from analyses due to missing data were African American and/or were diagnosed with sickle cell disease. Excluding these children significantly decreased the diversity of the sample and may have impacted the results. Future studies utilizing a more racially diverse sample of children from lower income backgrounds are needed, and researchers need to continue to use methods for retaining participants from minority groups and low socio-economic backgrounds[42].

Future research also needs to continue to examine the benefits of diary versus retrospective data including which modalities of obtaining diary data are the most reliable and require the least response burden. The data from the current study support previous research highlighting the potential benefits of using electronic diaries in chronic pain assessment and suggest that electronic diaries increase the accuracy and validity of prospective pain measurement. Additional research should identify which types of electronic diaries are most reliable and user-friendly for participants to complete.

The results of this study have several important clinical implications. First, the results can help to guide how clinical assessments of pain symptomatology and functioning are conducted. Findings indicated that diary-report may be better for collecting accurate pain intensity data while the current practice of using reliable and valid retrospective measures of activity limitation in clinic settings may be sufficient. Results of this study also emphasized the need to incorporate the assessment of activity limitations into clinical practice. Because persistent pain can significantly impact children's ability to participate in daily activities clinicians need to routinely assess the impact of pain levels on children's functioning and continue to develop new treatments and interventions to ameliorate the functional, social, and psychological impact of chronic pain[43].

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Table 1

Demographic characteristics of the sample

	Values			
Characteristic	**Total Sample**	**HA**	**JCA**	**SCD**
Gender				
Male	28 (30.1%)	21 (38.9%)	4 (13.3%)	3 (33.3%)
Female	65 (69.9%)	33 (61.1%)	26 (86.7%)	6 (66.7%)
Age (years)				
Mean	12.52	12.23	13.01	12.70
SD	2.50	2.40	2.68	2.47
Range	8.09 – 16.77	8.29 – 16.55	8.09 – 16.77	8.71 – 15.60
Child Ethnicity				
Caucasian	69 (74.2%)	43 (79.6%)	26 (86.7%)	0 (0.0%)
African-American	23 (24.7%)	11 (20.4%)	3 (10.0%)	9 (100.0%)
Other	1 (1.1%)	0 (0.0%)	1 (3.3%)	0 (0.0%)
Family Income				
< $19,999	14 (15.0%)	5 (7.4%)	3 (10.0%)	6 (66.7%)
$20,000 – $29,999	7 (7.5%)	6 (11.1%)	1 (3.3%)	0 (0.0%)
$30,000 – $39,999	17 (18.3%)	12 (22.2%)	4 (13.3%)	1 (11.1%)
$40,000 – $59,999	17 (18.2%)	10 (18.6%)	6 (20.0%)	1 (11.1%)
$60,000 – $69,999	7 (7.5%)	4 (7.4%)	3 (10.0%)	0 (0.0%)
> $70,000	28 (30.1%)	16 (29.6%)	11 (36.7%)	1 (11.1%)
Missing data	3 (3.2%)	1 (1.9%)	2 (6.7%)	0 (0.0%)

Table 2

Means and standard deviations of pain intensity, activity limitations and depression

	Mean (SD)			
Variable	**Total Sample**	**HA**	**JCA**	**SCD**
Pain Intensity				
Retrospective	4.66 (1.52)	5.06 (1.25)	3.66 (1.42)	5.56 (1.81)
Diary Report	3.05 (1.09)	4.76 (1.89)	2.80 (0.92)	3.36 (1.64)
CALI sum score				
Retrospective	14.84 (7.36)	16.28 (7.61)	12.47 (6.77)	15.33 (6.56)
Diary Report	14.95 (6.21)	15.03 (6.46)	14.25 (5.88)	16.57 (6.20)
Depression (T-Score)				
Retrospective	49.89 (11.26)	53.42 (11.15)	45.50 (10.30)	50.44 (11.77)
Diary Report	--	--	--	--

Table 3

Intercorrelations among the demographic characteristics, pain intensity, activity limitations and depression

	1	2	3	4	5	6	7	8	9
1. Patient Age	——								
2. Patient Gender	.17	——							
3. Pain Condition	.12	.16	——						
4. Family Income	.12	−.04	−.20	——					
5. Retrospective CALI(Sum score)	.17	−.01	−.15	−.04	——				
6. Diary Report CALI(Sum Score)	.14	.12	.03	−.05	.40**	——			
7. Retrospective Pain Intensity	−.04	−.07	−.14	−.23*	.48**	.40*	——		
8. Diary Report Pain Intensity	.17	.07	−.03	−.30**	.28*	.18	.35**	——	
9. Depression	.01	−.13	−.17	−.29**	.46*	.38*	.36**	.46**	——

Table 4

Summary of multivariate random effects analyses of associations between pain and activity restriction

	Average Activity Restriction		
	B	**t**	**P**
Pain Intensity	0.25	4.41	>.001
Pain Intensity	0.24	4.39	>.001
Age	0.02	1.618	.106
Pain Intensity	0.21	4.33	>.001
Gender	0.06	1.01	.315
Pain Intensity	0.19	2.49	.015
Depression	−0.0001	−0.09	.932