

## Family Members' Perspectives on Patient Participation in Spinal Cord Injury Rehabilitation

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### Abstract

**Purpose:** To examine the importance and experiences of patient participation in spinal cord injury (SCI) rehabilitation from the perspective of family members, and compared with patients' views.

**Method:** Family members (N=83) and discharged patients with SCI (N=141) completed the Patient Participation in Rehabilitation Questionnaire (PPRQ), assessing the importance and experiences of the domains Respect and integrity; Planning and decision-making; Information and knowledge; Motivation and encouragement; and Involvement of family. Importance ratings were compared between all family members and patients, and experience ratings were compared between patient-family dyads (N=74).

**Results:** Both family members and patients rated all participation domains as very or extremely important (m  $\geq 4.0$  of max 5). Family members rated all domains as slightly more important than did patients; however, patients rated Planning and decision-making more important than the family members ( $\Delta=0.20$ ;  $p<0.01$ ). No significant differences were found between patients and family members regarding experience ratings and agreement was substantial (ICC=0.63-0.80).

**Conclusions:** Current guidelines recommend involvement of family members in SCI care and rehabilitation. This study shows that family members, and patients alike, also considered their involvement as very important and that they were often given opportunities to be involved. Moreover, patients and family members shared perceptions of conditions necessary for facilitating and promoting participation. Although considerable congruence was found between family members' and patients' assessments, agreement was not perfect. As incongruence between patients and family members regarding the quality and delivery of care may disturb the rehabilitation process and its outcomes, it is important that differences in perspectives be identified and successfully resolved. The PPRQ may be useful in assessing patients' and family members' views of patient participation and in detecting disparities between them.

**Keywords:** Family involvement; Patient participation in Rehabilitation Questionnaire (PPRQ); Person-centered care; Spinal cord injury; Agreement

### Introduction

Patient participation in care and rehabilitation is widely advocated [1-3] and has been shown to enhance functional outcomes [4-6]; treatment adherence [7]; and patient satisfaction [8]. Similarly, active involvement of families in the patients' care and rehabilitation planning and decision-making is recommended [3,9-13] and may contribute to improved outcomes [12,14,15]. Family involvement<sup>1</sup> is also considered an essential element of service delivery and quality care and rehabilitation [16,17].

Persons with spinal cord injury (SCI) generally value family involvement in planning and decision making in their rehabilitation [18]. Family members play an important role in the SCI care and

rehabilitation by providing patients with emotional support to cope with their condition [19]; giving consolation and serving as links to life outside the hospital [20]; and acting as discussion partners [21]. In fact, families are often considered integral members of SCI rehabilitation teams [20], who in partnership with the patient and the staff negotiate the patient's rehabilitation [14].

Despite potential benefits of involving family members, staff members are sometimes reticent to engage families in planning and decision-making due in part to lack of time and concerns about their own abilities to deal with the family, but also due to concerns about the family members' personal motives and qualifications in making decisions [15,22]. A common concern is that family involvement may threaten patient autonomy in decision making, where it is feared that the patient may forgo his or her own wishes, needs and preferences for care and rehabilitation and acquiesce to those of the family [22]. In fact, previous studies have shown that families are often unable to identify patient preferences for decision-making [23,24].

<sup>1</sup> I.e. involvement from partners, parents, children, friends and other significant others to the patient.

As patient-family disagreement in decisions about treatment may jeopardize successful care [25], it is important that differences be recognized and reconciled [22]. To date, no studies have examined patient participation from the perspective of family members or in relation to patients' perspectives in SCI rehabilitation. Thus, this study aims to examine the importance and experiences of patient participation in SCI rehabilitation from the perspective of family members, and compared with patients' views.

## Materials and Methods

### Participants and data collection

The target population comprised patients with SCI and their family members. The patient population comprised all patients aged 18 to 80 years who were treated at the SCI unit at Sahlgrenska University Hospital in Gothenburg, Sweden between 1999 and 2010 (n=276). All data were collected in 2011, i.e. 1-11 years after injury (mean=six years). The patient data collection is reported in detail elsewhere [26]. Family members were recruited via the patients. At recruitment the patients were asked if they had a family member that had been involved during their rehabilitation, and if they wanted to invite him or her to participate in this study. A total of 46 patients (17%) actively declined, either because they did not have a family member that had been involved during the rehabilitation or did not wish to involve a family member. Patients (n=222) were mailed two questionnaire packages including the PPRQ, an information letter and postage-paid return envelope, one for themselves and one for their family member (excepting the 46 patients who declined). Reminder letters were sent after two months, again to the patients' address. Participation was voluntary and participants were allowed to respond anonymously by removing the ID number.

In total, 86 (59%<sup>2</sup>) family members and 145 (53%) patients returned questionnaires. Three questionnaires from family members and four from patients were incomplete and considered unevaluable. Questionnaires that were not returned anonymously were paired into 74 patient-family dyads. Table 1 shows the socio-demographic and clinical characteristics of the family members and patients for the total sample and for the dyads, respectively. There were no significant differences between the dyad group and their counterparts in the total sample regarding any demographic variable or PPRQ domain scores. Nineteen of the 46 patients who actively declined to involve a family member responded to the questionnaire and these patients had significantly lower experience ratings on Motivation and encouragement compared to those patients with a family member (p<0.01). Family members were significantly older than patients (p<0.00), presumably due to the fact that 27.7% were parents to the patient. The patients were predominantly males and most family members were women, whereof 34 were wives or female cohabitants and another 20 were mothers.

	Family members				Patients			
	Total sample		Dyads		Total sample		Dyads	
	N	Valid %	N	Valid %	N	Valid %	N	Valid %

<b>Total N</b>	83		74		141		74	
<b>Gender</b>								
Men	16	19.3	13	17.6	101	71.6	53	71.6
Women	67	80.7	61	82.4	40	28.4	21	28.4
<b>Age at injury ^</b>								
Mean (SD)	51.69 (12.78)		51.27 (12.77)		42.78 (16.40)		44.16 (16.72)	
<b>Relation</b>								
Husband/wife/ cohabitant	44	53.0	40	54.1				
Parent	23	27.7	18	24.3				
Sibling	5	6.0	5	6.8				
Child	8	9.6	8	10.8				
Other relative	2	2.4	2	2.7				
Friend	1	1.2	1	1.4				
<b>Cause of injury</b>								
Traumatic					117	83.0	64	86.5
Non-traumatic					24	17.0	10	13.5
<b>Mobility</b>								
Wheelchair user					75	53.2	41	55.4
Walk with walking aid					21	14.9	10	13.5
Walk without walking aid					37	26.2	18	24.3
Totally recovered					8	5.7	5	6.8
<b>Education</b>								
High school or less					105	74.5	54	73.0
University					36	25.5	20	27.0
^ Age missing for 9 family members and 1 patient in the total sample and for 1 family member and 1 patient in the dyads.								

**Table 1:** Socio-demographic and clinical characteristics for family members and patients in the total sample and in the dyads, respectively.

### Measurement

The PPRQ is a 23-item, self-report questionnaire assessing central aspects of patient participation [26]. PPRQ consists of five subscales: Respect and integrity (6 items); Planning and decision-making (4 items); Information and knowledge (4 items); Motivation and

<sup>2</sup> As family members could only be recruited through the patients, the response rate for families was calculated with the number of responding patients (n=145) as the denominator.

encouragement (5 items); and Involvement of family (4 items). The questionnaire has been psychometrically evaluated in SCI patients and shown to adequately assess central aspects of patients' experiences of participation in SCI rehabilitation [26].

The family members and the patients were instructed to rate items with respect to how important they were for care and rehabilitation (importance ratings; Likert scale from 'extremely important'=5 to 'not at all important'=1) as well as how often they occurred (experience ratings; Likert scale from 'always'=5 to 'never'=1). Mean values were calculated for each PPRQ domain. Questionnaires were considered incomplete if >50% of the items were missing. Missing items were replaced using the half-scale method [27], i.e. when at least half of the items in a scale are endorsed; missing values are replaced with the mean of the remaining items in its scale.

### Statistical analysis

Descriptive statistics were used to characterize respondent socio-demographic and clinical characteristics as well as importance and experience ratings. Differences between the total sample and dyads were evaluated by means of Chi-square and t-test. The Mann-Whitney U test and Kruskal-Wallis test were used to examine if ratings differed by various demographic variables. Spearman correlations were computed between domain scores and time elapsed since injury.

Differences in importance ratings between family members and patients were evaluated by the Mann-Whitney U test. Experience ratings were analyzed for dependent patient-family dyads using Wilcoxon's test. A Bonferroni correction was used to adjust for multiple tests, hence  $p < 0.05$  was divided by the number of tests performed (here: 5 PPRQ domains, giving a significance level of 0.01). Furthermore, effect sizes (Cohen's  $d$ ) were calculated as mean differences divided by the pooled standard deviation of patients and family members and were interpreted as  $d \geq 0.2$  and  $< 0.5$ , small effect;  $d \geq 0.5$  and  $< 0.8$ , moderate effect; and  $d \geq 0.8$ , large effect [28].

Agreement between patient-family dyads was evaluated with intra-class correlations (ICC). Magnitudes of correlations were interpreted as:  $< 0.20$  slight;  $0.21-0.40$  fair;  $0.41-0.60$  moderate;  $0.61-0.80$  substantial; and  $0.81-1.00$  almost perfect [29]. Furthermore, the dyads were considered to agree if they differed  $< 1.0$  in their sub-scale scores.

The internal consistency reliability of the PPRQ domains was evaluated in the family member sample by means of Cronbach's  $\alpha$ . Coefficients  $> 0.70$  are considered acceptable for group comparisons [27].

All analyses were performed using SPSS version 22 (Statistical Package for the Social Science, Chicago, IL, USA).

## Results

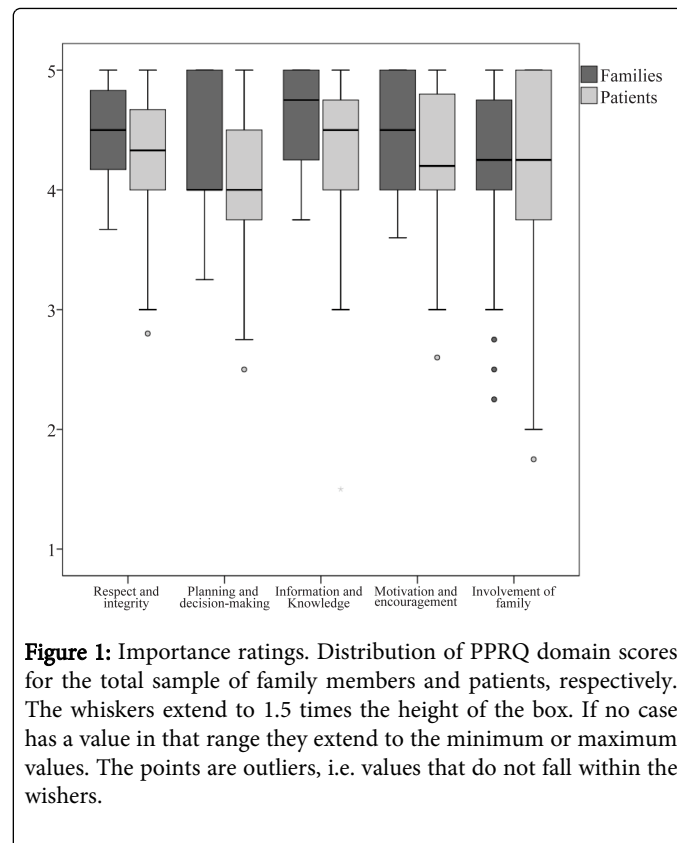
### Internal consistency reliability

Cronbach's  $\alpha$  coefficients were acceptable in all domains regarding importance and experience ratings for both family members and patients (importance: 0.72-0.88 for family members versus 0.78-0.88 for patients; experience: 0.89-0.95 versus 0.89-0.91).

### Family members' importance ratings

Mean importance ratings were above 4.0 (very important) on all domains (Table 2 and Figure 1). Nearly all family members (98%)

rated Information and knowledge as very important or higher and 92% rated Respect and integrity and Motivation and encouragement, 85% rated Planning and decision-making and 80% rated Involvement of family as very important or higher.



**Figure 1:** Importance ratings. Distribution of PPRQ domain scores for the total sample of family members and patients, respectively. The whiskers extend to 1.5 times the height of the box. If no case has a value in that range they extend to the minimum or maximum values. The points are outliers, i.e. values that do not fall within the whiskers.

Women rated all domains, except Motivation and encouragement, as significantly more important ( $p < 0.01$ ) than did men, and effect sizes were large for Planning and decision-making ( $ES = 1.19$ ,  $CI$  0.60-1.75;  $\Delta = 0.55$ ;  $p < 0.000$ ) and moderate for Respect and integrity ( $ES = 0.71$ ,  $CI$  0.15-1.26;  $\Delta = 0.28$   $p = 0.009$ ) and Involvement of family ( $ES = 0.65$ ,  $CI$  0.09-1.19;  $\Delta = 0.40$ ;  $p = 0.007$ ). No significant differences were found in relation to any other socio-demographic or clinical variables. Correlation coefficients between the domain scores and time elapsed since injury ranged from 0.007 to 0.029 ( $p > 0.05$ ).

### Comparisons of importance ratings between family members and patients

Patients had significantly lower importance ratings than family members regarding Planning and decision-making ( $\Delta = 0.20$ ;  $p = 0.01$ ); however, the effect size was small ( $ES = 0.37$ ,  $CI$  0.10-0.64) (Table 2). Fewer patients had domain scores corresponding to 'very important' or 'extremely important' compared to the family members. The largest difference was shown for Planning and decision-making, where 66% of the patients versus 85% of the family members had domain scores corresponding to 'very important' or 'extremely important' (Figure 1).

	Valid cases (family members / patients)	Family members' mean (SD)	Patients' mean (SD)	p-value	Effect size (95% CI)
Respect and integrity	83/141	4.46 (0.40)	4.34 (0.49)	0.141	0.26 (-0.01-0.53)
Planning and decision-making	83/140	4.31 (0.50)	4.11 (0.56)	0.010	0.37 (0.10-0.64)
Information and knowledge	83/139	4.59 (0.39)	4.42 (0.51)	0.016	0.36 (0.09-0.65)
Motivation and encouragement	82/139	4.48 (0.46)	4.30 (0.51)	0.013	0.37 (0.09-0.64)
Involvement of family	83/139	4.22 (0.64)	4.17 (0.78)	0.991	0.07 (-0.20-0.34)

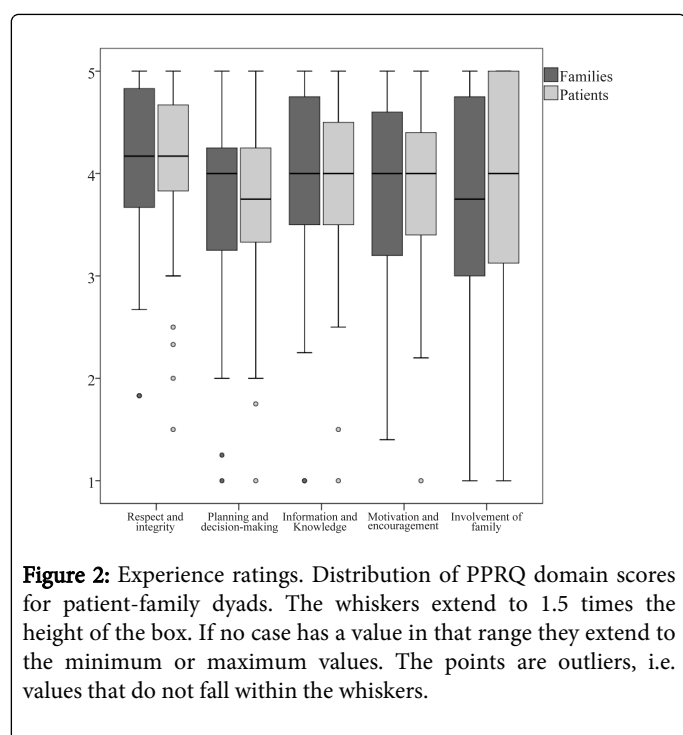
Possible response range 1-5  
Mann-Whitney U-test was used to compare families' and patients' means, bolded p-values are significantly different, p<0.01.  
Effect sizes should be interpreted as follows: ≥0.2 and <0.5, small; d ≥0.5 and <0.8=, moderate; and d ≥0.8, large effect.

**Table 2:** Importance ratings. Comparisons of PPRQ domain scores between family members and patients.

As was the case with family members, comparisons of socio-demographic and clinical variables yielded significant differences only with regard to gender, where women patients assigned significantly higher importance (p<0.05) to all domains than did men. Moderate effect sizes were noted for two domains, Respect and integrity (ES=0.56, CI 0.19-0.93; Δ=0.27; p=0.001) and Involvement of family (ES = 0.50, CI 0.11-86; Δ=0.37; p=0.017), whereas effect sizes for the other domains were small.

### Family members' experience ratings

Mean experience ratings were high on all domains (m>3.60) (Table 3). Two-thirds of the family members had domain scores corresponding to 'often' or 'always' on Respect and integrity, approximately three-fifths on Information and knowledge and Motivation and encouragement and about half on Planning and decision-making and Involvement of family (Figure 2).



**Figure 2:** Experience ratings. Distribution of PPRQ domain scores for patient-family dyads. The whiskers extend to 1.5 times the height of the box. If no case has a value in that range they extend to the minimum or maximum values. The points are outliers, i.e. values that do not fall within the whiskers.

There were no significant differences in experience ratings in relation to any socio-demographic or clinical variables. Correlation coefficients between the domain scores and time elapsed since injury ranged from -0.072 to 0.053 (p>0.05).

### Comparisons of experiences in patient-family dyads

No significant differences were found between family member and patient ratings on any domain and all effect sizes were small (Table 3, Figure 2). In addition, intra-class correlations were all substantial (ICC=0.630-0.800) (Table 3). No significant differences were found between dyads who disagreed (Δ>1 point on 5-point scale) versus dyads who agreed on any socio-demographic or clinical variables.

As was the case for family members, no significant differences in patients' experience ratings were found in relation to any socio-demographic or clinical variables.

### Discussion

This study showed that family members of patients with SCI assign high importance to different aspects of patient participation, as do patients. Family members and patients also showed good agreement regarding their experiences of patient participation. Hence, family members' perspectives on the importance and experiences of central aspects of patient participation in SCI rehabilitation correspond well with those of patients.

Although agreement between patients and family members on the importance of patient participation was high, some minor differences were in evidence. Specifically, family members assigned slightly greater importance to all domains of participation and a statistically significant difference, albeit with a small effect size, was found for the domain Planning and decision-making. It may be speculated that families have a more idealized, 'outside' view of patient participation and want only the most optimal standards of care and rehabilitation for their loved ones [30]. The patients, on the other hand, may have a somewhat more modulated, 'inside' view of the relative importance of participation, based on their first-hand experiences of having undergone rehabilitation. As has been shown previously, patients' preferences and capacities for participation may vary during the course of rehabilitation [20,31] and it may be that the patients' lower importance ratings reflect that optimal care and rehabilitation is one in which participation is not necessarily always expected or desired, but

rather tailored to each patient's unique and varying preferences and capacities [32]. It should be stressed, however, that patient-family member disagreement was negligible and thus our results fail to

corroborate other studies reporting lesser agreement in other patient groups [23,24].

	Valid cases	Family members' mean (SD)	Patients' mean (SD)	p-value	Effect size (95 % CI)	ICC
Respect and integrity	72	4.11 (0.74)	4.10 (0.75)	0.311	0.01 (-0.31-0.34)	0.700
Planning and decision-making	72	3.86 (0.81)	3.74 (0.79)	0.238	0.14 (-0.19-0.46)	0.679
Information and knowledge	72	3.93 (0.90)	3.97 (0.78)	0.712	-0.05 (-0.37-0.28)	0.797
Motivation and encouragement	71	3.90 (0.87)	3.85 (0.81)	0.507	0.06 (-0.27-0.39)	0.755
Involvement of family	72	3.60 (1.15)	3.82 (1.13)	0.132	-0.19 (-0.52-0.14)	0.630

Possible response range 1-5.  
 Wilcoxon's was used to compare means within the dyads.  
 Effect sizes should be interpreted as follows:  $\geq 0.2$  and  $< 0.5$ , small;  $d \geq 0.5$  and  $< 0.8$ , moderate; and  $d \geq 0.8$ , large effect.  
 ICC should be interpreted as follows:  $< 0.20$  = slight;  $0.21-0.40$  = fair;  $0.41-0.60$  = moderate;  $0.61-0.80$  = substantial;  $0.81-1.00$  = almost perfect.

**Table 3:** Experience ratings. Comparisons of PPRQ domain scores for patient-family dyads

Excepting gender, socio-demographic and clinical variables were not associated with family members' or patients' importance ratings on any domain. Our finding that women patients considered patient participation to be more important than did men is in line with some previous studies assessing other importance aspects in relation to care and rehabilitation [32-34], whereas other studies have not found a gender difference [35,36]. Thus, larger studies are needed to examine the role that gender plays in patient participation in SCI rehabilitation, as well as in care and rehabilitation in general. The fact that the other socio-demographic and clinical variables studied were not associated with importance ratings confirms previous findings that patients' needs, capabilities and preferences for participation are highly individual, independent of e.g. education level, age, mobility level or cause of injury [18,37,38].

In rehabilitation in general and in SCI rehabilitation in particular, family members are encouraged to be active members of the rehabilitation team [3,20]. The family can help connect the "pre-injury world" with the "post-injury identity" as they see the inner person as "the same person as before" [39] and thus they play a crucial role in helping the patients cope with his or her injury and in providing them with emotional support [19,40]. As discussion partners in planning and decision making [21], family members may serve as sounding boards for the patient and contribute with information that the patient may have forgotten or missed. They may also serve as advocates for the patient in meetings with the staff. Our results suggest that family members also generally consider their involvement to be very important, and nearly equally important as patient involvement. However, the individual patient's preferences for involving the family in SCI rehabilitation must be respected regarding which family members are to be involved and the extent of their involvement [18].

The importance ratings principally reflect preferences or ideals for care and rehabilitation, whereas experience ratings reflect perceptions of the degree to which opportunities and conditions for participation were actually provided. As was the case with importance ratings, experience ratings of participation were high, indicating that the family members felt that opportunities and conditions for participation were provided often or always. Importantly, patients showed substantial agreement with their family members in this

regard, which is in line with another study among cancer patients showing good agreement on aspects such as receiving information about treatments, progress and self-care; being given opportunities to participate in decisions; and being treated with engagement and understanding by the staff [41].

Cronbach's  $\alpha$  coefficients were all above 0.70 for all PPRQ domains in the family member sample and nearly as high as in patients [26], indicating good internal consistency for group level comparisons [29] and suggesting that the PPRQ may be used with some confidence in assessing the importance and experiences of patient participation among family members of patients with SCI. Nonetheless, other psychometric properties of the family member version of the PPRQ need to be evaluated. Moreover, as was the case in the patient version [26], ceiling effects were present for the importance ratings and therefore more work needs to be done to evaluate the utility of the PPRQ importance ratings both for use in research and clinical settings.

There are some methodological considerations that should be kept in mind when interpreting the results of this study. It is important to point out that patient and family assessments were conducted on average six years after injury. The retrospective nature of the assessments naturally has implications for both the results and the applicability of the PPRQ for use during initial, rehabilitation intense inpatient care. There is a risk that the respondents have changed their internal standards, values and/or meanings, i.e. response shift [42], and thus that their assessments may not truly reflect their perceptions of patient participation during rehabilitation. There is also a risk for recall bias since retrospective assessments have the disadvantage that people are likely to remember situations that are particularly salient and minimize other aspects [43,44]. However, this study did not show any significant correlations between domain scores and time elapsed since injury. The response rate for family members was relatively low and it is not possible to determine if this owed to the fact that family members themselves chose not to respond or that they could not respond because the patient did not give them the questionnaire. Either way, the family member sample may not be fully representative of the target population and potential selection bias due the sampling procedure may have inflated our estimates of patient-family agreement. Furthermore, we cannot exclude the possibility that

patients and their family members completed the questionnaires together, which would also naturally inflate our estimates of patient-family agreement.

## Conclusion

Current guidelines recommend involvement of family members in SCI care and rehabilitation. This study shows that family members, and patients alike, also considered their involvement as very important and that they were often given opportunities to be involved. Moreover, patients and family members shared perceptions of conditions necessary for facilitating and promoting participation. Although considerable congruence was found between family members' and patients' assessments, agreement was not perfect. As incongruence between patients and family members regarding the quality and delivery of care may disturb the rehabilitation process and its outcomes, it is important that differences in perspectives be identified and successfully resolved. The PPRQ may be useful in assessing patients' and their family members' views of patient participation and in detecting disparities between them.

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