

Enhancing PROMIS Score Interpretation Through a Story-Based Scoring Guide: Development and Methodological Insights

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1 INTRODUCTION

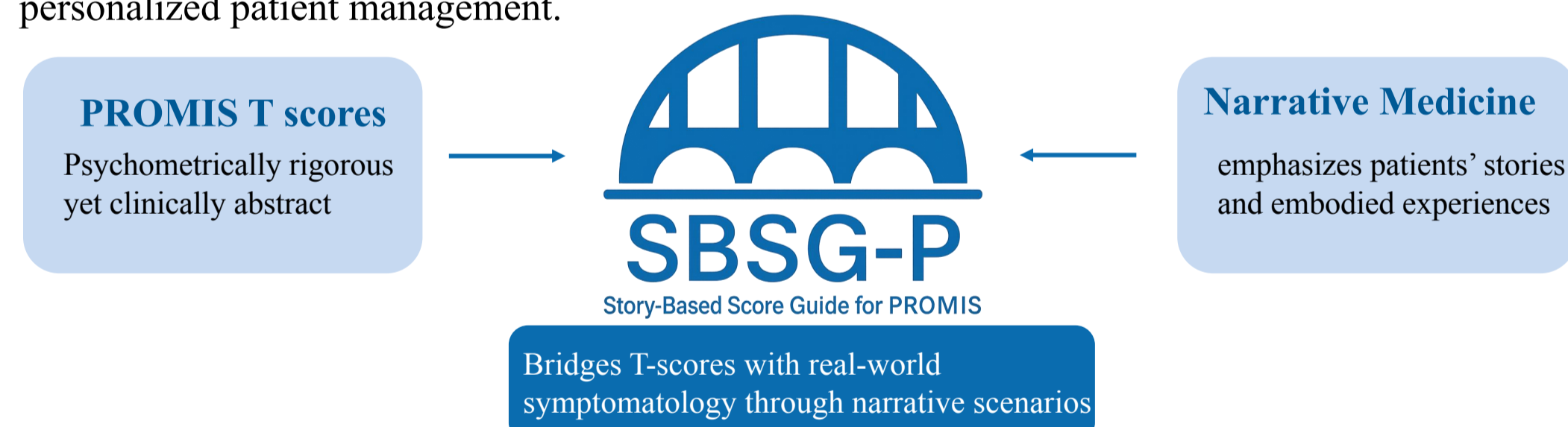
With the rise of precision medicine and patient-centered care, patient self-reports have become a critical foundation for clinical decision-making and healthcare resource allocation. The Patient-Reported Outcomes Measurement Information System (PROMIS) provides standardized and psychometrically robust assessments across multiple health domains. However, PROMIS T-scores often remain insufficiently intuitive and disconnected from real-world clinical contexts, making it difficult to link scores with patients' lived experiences.

Narrative medicine underscores the significance of patient narratives, capturing experiential and contextual nuances beyond numerical data. By integrating narrative approaches with psychometric assessments, an opportunity emerges to enhance the interpretability of PROMIS scores.

To address this gap, this study propose the **Story-Based Score Guide for PROMIS (SBSG-P)**, a novel methodological framework that maps T-scores onto structured narrative scenarios. SBSG-P aims to bridge numerical scoring with real-world symptomatology, thereby enhancing clinical interpretability, supporting communication, and enabling more personalized, context-sensitive decision-making.

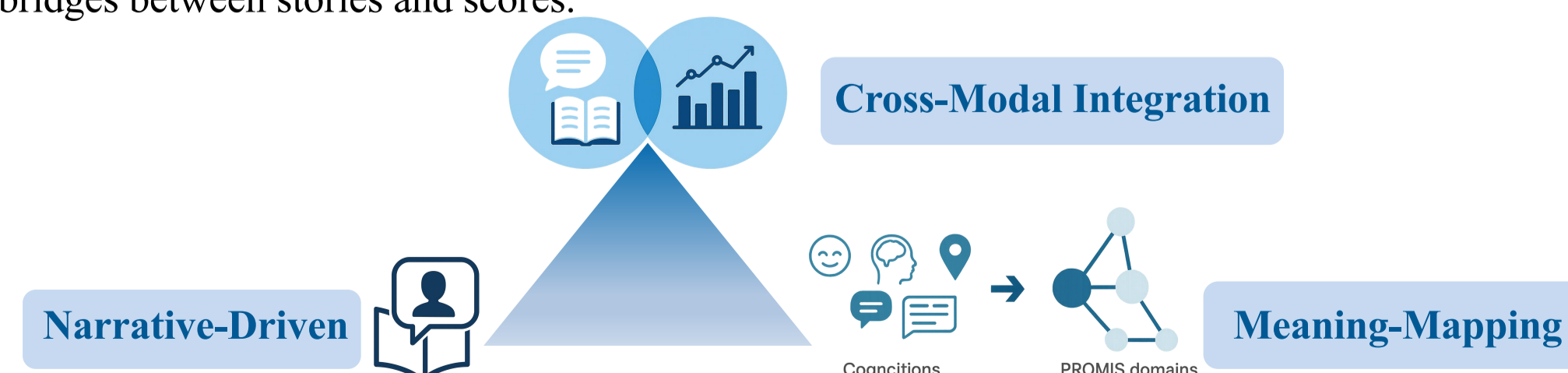
2 AIM

- ◆ Present the theoretical foundation, key concepts, and developmental process of the Story-Based PROMIS Score Guide (SBSG-P).
- ◆ Provide healthcare professionals with an innovative interpretive tool that makes PROMIS scores more contextually relevant and clinically precise.
- ◆ Support clinical practice by informing treatment decisions, intervention strategies, and personalized patient management.



3 Key Concepts

- ◆ **Narrative-Driven**
 - Patient stories (symptoms, life histories, metaphors) are the core input, ensuring PROMIS scoring reflects lived experiences.
- ◆ **Cross-Modal Integration**
 - Merges qualitative narratives with quantitative PROMIS scores to generate context-rich yet comparable indicators.
- ◆ **Meaning-Mapping**
 - Links emotions, cognitions, and contexts in narratives with PROMIS domains, building semantic bridges between stories and scores.



4 Development Progress

◆ Stage 1. Drafting Story-Element Scripts

- **Research Planning**
 - Define study objectives and specify the focal clinical problems.
 - Select an appropriate PROMIS instrument with established reliability and validity in the relevant population.
 - Establish T-score thresholds for severity classification.
- **Data Collection**
 - Quantitative Pre-Assessment: Conduct a cross-sectional PROMIS survey; generate standardized T-scores ($M = 50, SD = 10$).
 - Qualitative Interviews: Using maximum variation sampling ($\approx 10-20$ participants per severity stratum, until data saturation), purposive stratification (high, moderate, low severity) guided semi-structured interviews to elicit patient narratives on symptoms, coping strategies, and metaphorical expressions.
- **Data Analysis**
 - Summative Content Analysis: Combine frequency counts with contextual interpretation.
 - Critical Discourse Analysis: Identify low-frequency but conceptually salient terms.
 - Preliminary Script Development: Construct scenario-based narrative scripts mapping symptom severity to authentic patient language.

◆ Stage 2. Validation of Story-Element Scripts

- **Focus Group Discussions**
 - Focus group discussions (FGDs) were conducted with multidisciplinary clinical professionals to review the preliminary story-based PROMIS score guide. Experts examined draft narrative scripts with reference to both patient-derived accounts and their own professional judgment, thereby providing an initial assessment of interpretability, clinical feasibility, and content validity.
- **Delphi Surveys**
 - An iterative consensus process (2-3 rounds) refined the guide. Experts independently rated scoring dimensions and behavioral anchors, with anonymized feedback redistributed until consensus was achieved.
 - Validity Indicators:

Indicator	Definition	Interpretation
Response Rate	Percentage of experts completing each round	Higher values indicate strong engagement
Authority Coefficient (Cr)	Average of experts' familiarity (Cs) and judgment basis (Ca)	$Cr \geq 0.70 \rightarrow$ high authority
Coefficient of Variation (CV)	Standardized measure of dispersion across ratings	Lower CV \rightarrow greater consistency
Kendall's W	Coefficient of concordance among experts (0-1)	Higher W \rightarrow stronger consensus

◆ Stage 3. Clinical Validation

- **Data Collection**
 - Eligible patients were recruited and asked to complete two tasks at the same time point:
 - 1. Select the narrative category within the SBSG-P that best reflected their current health state.
 - 2. Complete the PROMIS short form, with raw scores converted to standardized T-scores.

Method	Purpose	Key Indicators	Interpretation Criteria
Linear Weighted Kappa	Classification consistency between SBSG-P categories and PROMIS severity levels	Weighted Kappa (95% CI), Z-tests, Monte Carlo power estimation	$Kappa \geq 0.6 =$ clinically acceptable; $0.4-0.6 =$ borderline
Pearson Correlation	Linear association between narrative levels (ordinal 1-4) and PROMIS T-scores	Correlation coefficient (r)	$r \geq 0.70 =$ strong concordance
Bland-Altman Analysis	Individual-level agreement between SBSG-P theoretical T-scores and observed PROMIS T-scores	Mean difference (bias), 95% limits of agreement (LoA)	Small bias & $>95\%$ within LoA = good agreement

5 CONCLUSIONS

◆ **Methodological Innovation:** The Story-Based PROMIS Scoring Guide (SBSG-P) constitutes an innovative integration of narrative medicine and psychometric assessment, offering an interpretation framework that is simultaneously patient-centered, contextually adaptive, and measurement-sensitive.

◆ **Clinical Relevance:** By establishing semantic linkages between PROMIS T-scores and patients' lived experiences, the framework enhances the interpretability of patient-reported outcomes, facilitates shared decision-making, and provides potential utility for chronic disease monitoring and personalized care.

◆ **Future Perspectives:** With the rapid advancement of artificial intelligence technologies, particularly large language models, the SBSG-P framework holds promise for scalable development and broader application. Future research should prioritize multi-center validation to consolidate its clinical applicability and advance the paradigm of patient-reported outcomes from mere data collection toward the integration of measurement and meaning.

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