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A Clinical Scale for Measuring Functional Caregiving of Children Assisted with Medical Technologies

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Abstract – A clinical scale with linear properties was constructed from a 76 item self-report questionnaire about mothers' confidence to provide complex medical care for children in their homes. Sample consisted of 53 mothers with children assisted by medical technology. Self-confidence ratings were scored with a five category rating scale. Mothers provided self ratings on a broad range of caregiving tasks across home, neighborhood, and community. Ratings were transformed to linear scale values with a Rasch model for rating scales. Overall parameterization was successful with minimal threats to dimensionality based on item and person fit analysis, as well as Principal Components Analysis of measurement model residuals. An iterative procedure reduced 76 items to 15 items with minimal loss of measurement properties.

Keywords: Functional Caregiving, Children Assisted with Medical Technology, Rasch measurement

1. INTRODUCTION

Advanced medical technologies are increasing children's survival from catastrophic illnesses, severe injuries, and congenital health conditions but at extraordinary long term financial cost. Children benefiting from medical technologies frequently require lifelong caregiving. Mothers now typically care for Children Assisted with Medical Technology (CAMT) in their homes after participating in a hospital parent training program. Hospital training, however, assumes mothers have confidence to care for CAMT, and an objective method is needed to assess mothers' confidence to operate complex medical equipment in their homes, as well as provide emergency care.

Functional Caregiving (FC) is a theory about mothers' confidence to provide care for children with disabilities [1]. In this research, FC provides conceptual foundations for measuring mothers' caregiving confidence about CAMT tasks and responsibilities. In previous CAMT research, an FC dimension was operationally defined with 76 questionnaire items that addressed three technologies, namely, trachesotomy, tracheostomy and ventilator, and BiPAP/CPAP [2]. Results from an FC implementation at Children's Hospital, Chicago established adequate measurement reliability (.88) and precision (RMSE=.56) for a preliminary Trachesotomy Scale. Dimensionality was investigated with Rasch model fit statistics and Principal Components Analysis (PCA) of model residuals. Rasch model co-calibration of trachesotomy and tracheostomy/ventilator items was also successful. Differential Item Functioning, however, found certain items with limitations for specific populations.

FC scale properties after raw score transformation to linear values with a Rasch model include simultaneous conjoint additivity, as well as item and person parameter separation during estimation that is independent of specific population samples. Objectivity, separability, and linearity are properties important for measuring caregiving change of individual mothers. Altogether, these characteristics of rigorous measurement now assert objective FC latent trait properties.

1.1 Purpose

The purpose of this research was to develop a shorter, more efficient FC scale to measure mothers' confidence to care for CAMT in their homes. Current form with 76 items is impractical both for clinical staff and mothers of CAMT. Successful FC tracheostomy parameterization in prior studies now raises need for a much shorter, more efficient clinical form but with comparable validity and precision.

2. METHOD

2.1 Sample

The sample consisted of 53 mothers of CAMT in their homes. All children were assisted with one of three technologies, namely, trachesotomy, tracheostomy and ventilator, or BiPAP.

2.2 Data

Mothers were presented 76 caregiving items associated with CAMT in homes, and a rating scale to indicate their confidence. The rating scale consisted of five categories (1,2,3,4, and 5).

2.3 Analysis and Procedure

Responses to 76 trachesotomy caregiving items were first parameterized with a one parameter logistic Rasch model for rating scales [3], which was implemented with WINSTEPS software [4]. After PCA identified FC-related item structures in residuals, following procedure was implemented:

- Items forming alternative construct patterns in model residuals with factor loadings greater than .2 were removed from FC measurement. Remaining items established an FC core.
- Hardest and easiest items from deleted subset were iteratively reintroduced to the FC Core to increase dimension range and variance of sample ratings.
- Items were then re-calibrated (FC core + highest + lowest) to estimate a Minimum FC scale.

Finally, test reliability of the Minimum FC scale was optimized by iteratively re-introducing borderline items (factor loadings >.2) that PCA showed consistent with the FC dimension constrained by desired form length.

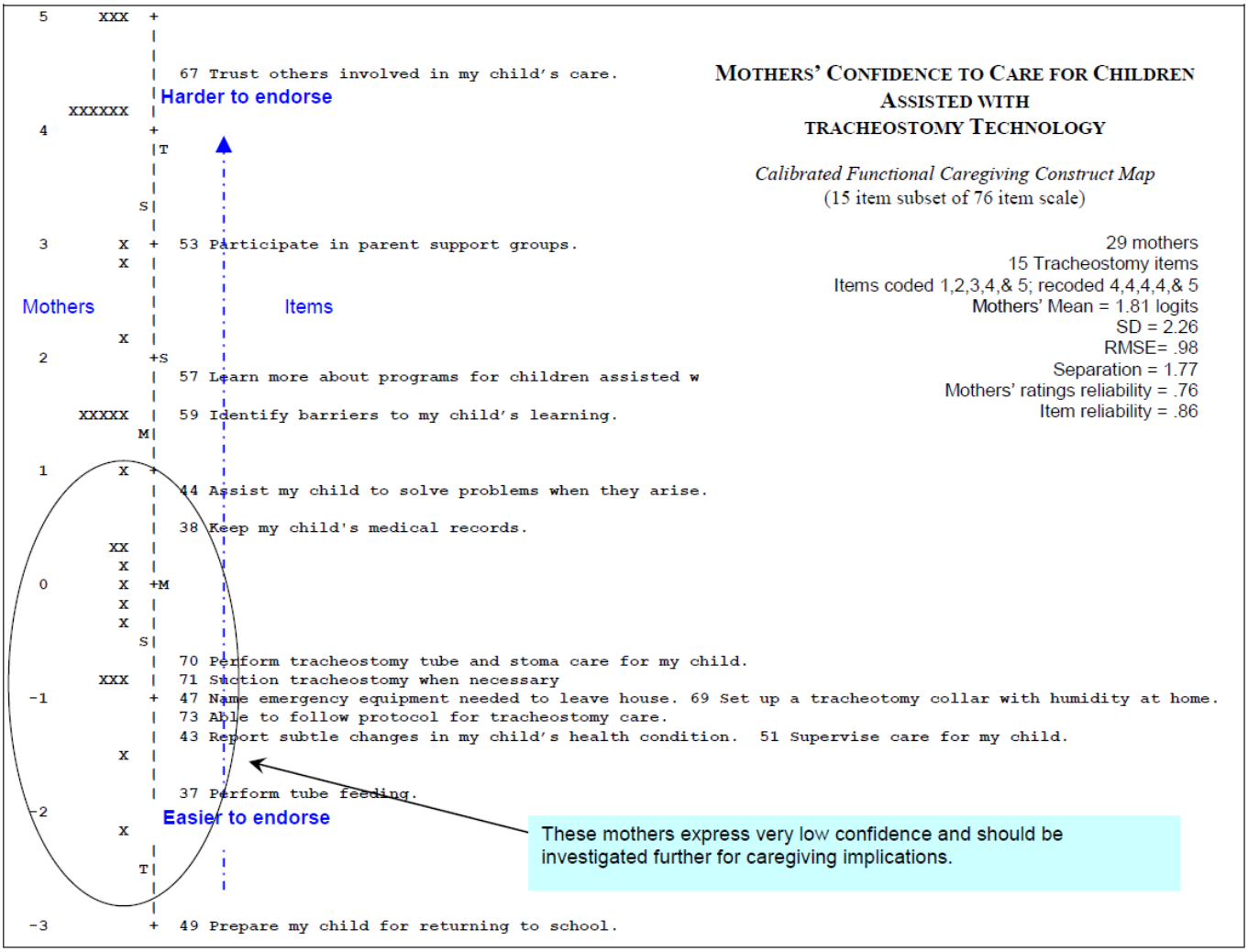

Figure 1. FC variable map based on shortened form.

3. RESULTS

Mean of mothers' confidence measures based on 15 items was 1.81 logits, SD = 2.26, where zero was defined by overall item mean. Measure precision based on Root Mean Square Error was .98 logits, while Separation was 1.77 and Reliability, .76. Figure 1 presents a linear map of 15 items and 27 mothers on a common FC caregiving construct, which is defined by "easy" to endorse caregiving items near bottom, while item difficulty increases as frequency of endorsement declines. Item 37 "Tube feeding" and Item 49 "Prepare my child for returning to school" were easiest for mothers to endorse. Item 53 "Participate in parent support groups" and Item 67 "Trust others involved in my child's care" were hardest items to endorse. Results show many mothers are located very high on the confidence dimension but several mothers are very low. Figure 2 presents a bi-calibration plot of mothers' confidence measured with 76 items versus the shortened 15 item scale, which show remarkably high convergence. Rank order correlation between measures is .995.

4. CONCLUSION

A shortened form of 15 items shows mothers' confidence measures are statistically invariant with a 76 item form. Mothers' confidence to care for CAMT can now be measured with a clinical scale that only requires two or three minutes to collect data. Results show a group of mothers with very low CAMT caregiving confidence should be examined further in validity studies to establish caregiving implications of the shortened scale. Future research should also establish caregiving benchmarks to advise intervention, as well as investigate statistical invariance between the shortened form and item bank person parameters. Future studies should now examine relationship between mother's confidence and linear measure of mothers' competence to verify validity and effectivenss.

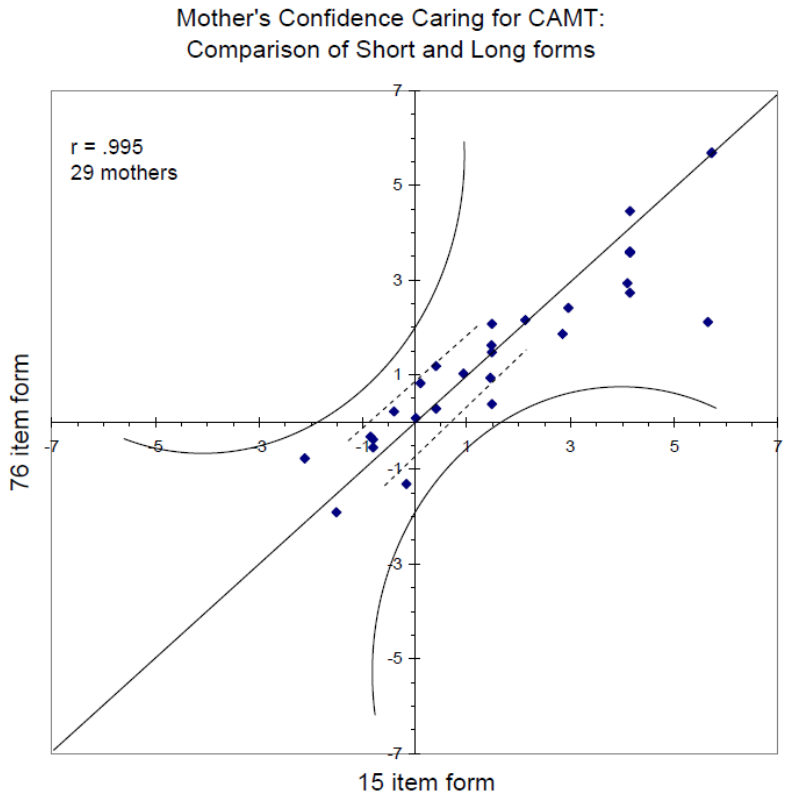

Figure 2. Measurement comparison of mothers' confidence based on 76 items versus 15 items.

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