Turkish adaptation and validation of the EMpowerment of PArents in THe
Intensive Care (EMPATHIC-30) questionnaire to measure parent
satisfaction in Neonatal Intensive Care Units

Öznur Tiryaki¹, Hamide Zengin²*, Nursan Çınar³, Mutlu Umaroğlu⁴, Jos M. Latour⁵

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¹Institute of Health Sciences, Sakarya University, Turkey
²Faculty of Health Sciences, Department of Pediatric Nursing, Bilecik Şeyh Edebali University, Turkey
³Faculty of Health Sciences, Department of Pediatric Nursing, Sakarya University, Turkey
⁴Faculty of Medicine Basic Medical Sciences, Biostatistics, Sakarya University, Turkey
⁵Faculty of Health: Medicine, Dentistry and Human Sciences, School of Nursing and Midwifery, University of Plymouth, United Kingdom

Conflict of interest statement
The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest

Author contribution statement
OT contributed to the design of the study, contributed to data collection, data analysis and interpretation, drafted the first manuscript. HZ contributed to data collection, data analysis and interpretation, provided revisions to early drafts. NÇ contributed to data collection, data analysis and interpretation, provided revisions to early drafts. MU contributed to data collection, data analysis and interpretation, provided revisions to early drafts. JML contributed to the design of the study, drafted the first manuscript. All authors contributed, read and approved the final manuscript.
ABSTRACT

Aim: The aim of this study was to translate and validate the shortened version of the ‘EMpowerment of PArents in THe Intensive Care’ (EMPATHIC-30) questionnaire into Turkish to measure parent satisfaction in the Neonatal Intensive Care Units (NICU).

Method: The study used a cross-sectional design. The data of the study were collected from parents with infants staying in the NICU of a training and research hospital in Sakarya, Turkey, between July 2018-2019 after obtaining ethical approval. Totally, 238 parents (234 mothers, 4 fathers) agreed to participate in the study and completed the questionnaire. Of these, 35 mothers were recruited two weeks later for the test-retest reliability analysis. The questionnaire was translated using back and forward translation. Reliability and validity test were performed to measure the psychometric properties of the Turkish EMPATHIC-30.

Results: The mean age of the parents was 28.27 (SD 5.93), and 48.3% of them were primary school graduates. The infants: 55.9% were male, the mean gestational age was 36.89 (SD 3.25) weeks, and mean length of hospital stay was 9.36 (SD 10.17) days. The mean scores of each item with a six-point scale of the EMPATHIC-30 questionnaire ranged between 4.01 and 4.87. The Cronbach’s alpha of the total questionnaire was 0.95. Cronbach’s alpha of the five domains (Information, Care and Treatment, Organization, Parent Participation and Professional Attitude) ranged between 0.80 and 0.92. Pearson correlation coefficient between the domains and total questionnaire was r=0.988. The Intraclass Correlation Coefficient was 0.998 in the test-retest evaluation. Confirmatory factor analysis was performed for construct validity and was moderate; Comparative Fit Index=0.792, Tucker–Lewis Index=0.770, Standardized Root Mean Square Residual= 0.0811, and Root Mean Square Error of Approximation=0.107.

Conclusion: The Turkish version of EMPHATIC-30 has adequate psychometric properties. The EMPATHIC-30-Turkish questionnaire is an easy and appropriate instrument which can be used to measure satisfaction of Turkish parents with infants staying in the NICU.

Keywords: EMPATHIC-30; Parents; Infants; Satisfaction; Neonatal Intensive Care Unit; Reliability; Validity.

Contribution to the field

Family-centered care practices not only increase parental satisfaction but also improve the quality of care. A search of the literature revealed that there are no questionnaires available to measure parent satisfaction among Turkey parents in the NICU. The EMPATHIC-30 questionnaire is widely used in many countries to measure family satisfaction. Our findings are in line with previous investigations of the adaptation of EMPATHIC-30 in other languages. It seems that the EMPATHIC-30 instrument can be applied to measure parental satisfaction and can be adapted in different cultural and linguistic backgrounds.
INTRODUCTION
The hospitalization of an infant in a neonatal intensive care unit (NICU) is a stressful situation for both parents and the infant (1). This may affect the family’s daily routines and may lead to changes in their roles and responsibilities in the family environment (2). Besides these changes in the family environment, not knowing the NICU environment, encountering medical devices, and changing duties in the care of their infant can cause anxiety and fear among parents and family members (3).

Family-Centered Care (FCC) interventions have been developed and implemented to minimize stress and anxiety experienced by parents and accelerate the healing process of infants (4, 5). An important element in maintaining the FCC approach is effective communication. Furthermore, developing mutual trust, reducing conflict, minimizing stress levels of parents and improving parental satisfaction are components of FCC (6,7,8). It is known that parents whose have experienced an admission of their infant in the NICU need information on many issues during admission, at discharge and when at home after hospital discharge. These information needs can be clustered in five themes: communication, parental role clarity, emotional support, information resources and financial resources (9). Studies exploring problems of parents with premature infants in the NICU identified that parents experienced difficulties in bonding with their infant, breastfeeding, being worried when separated from their infant and difficulties with information and communication with healthcare professionals (10, 11).

Implementing the principles of FCC can reduce hospital length of stay, improve the bonding between parents and infants, and increase parent satisfaction (8, 12). Parental satisfaction is used as an indicator to measure quality of care and the use of satisfaction surveys is an effective method for evaluating health services (13). Currently, there are no validated parent satisfaction instruments available for parents in Turkish NICUs. Although the 65-item EMPATHIC-N has been developed and tested specifically for parents in the NICU, there is no short version of this questionnaire (14). To reduce the burden of parents we preferred a shorter version and therefore opted for the short version of the EMPATHIC questionnaire, the EMPATHIC-30 (14,15). Therefore, the aim of this study was to translate, culturally adapt, and validate the EMPATHIC-30 questionnaire to measure parent satisfaction in Turkish NICUs.

MATERIALS AND METHODS
Design
The study used a cross-sectional descriptive design. Ethical approval was obtained from the hospital research ethics committee (02/04 /2018-72) and written consent was obtained from the parents who participated in the study. Data collection was performed between July 2018 and July 2019.

Setting
The study setting was at the NICU of the Sakarya Training and Research Hospital in the west of Turkey. The tertiary NICU serves the province of Sakarya. The NICU has a capacity of 29 beds: one level III unit with 18 beds, one level II unit with nine beds, and one level I unit with six beds. The level III unit admits infants with a birth weight <1500 grams, the level II unit admits infants with a birth weight between 1500-2500 grams and the level I unit has infants >2500 grams. Parents can visit the NICU once a day between 15.00-16.00. Before the infant’s discharge, mothers are invited to stay 24 hours during the final two to three days of admission while being accommodated in the parent guesthouse of the hospital. During these days, parents receive specific training and involvement of care before going home with the infant.
Participants
Annual admission rate of the NICU is around 900 infants. Parents were selected with simple random sampling selection according to the inclusion criteria. Inclusion criteria were: mothers or fathers whose infants stayed in the NICU for at least two days and speak and understand Turkish. During the study period, 260 parents were invited. Of these, 22 parents declined the invitation. The final study sample consisted of 238 parents (234 mothers, 4 fathers) who agreed to participate in the study, provided written consent and completed the questionnaire. Of these study participants, 35 mothers agreed to be contacted for the test-retest of the Turkish EMPATHIC-30 questionnaire.

EMPATHIC-30 questionnaire
The EMPATHIC-30 questionnaire consists of three parts (16). The first part includes demographic questions such as parent’s age, education level, income level, number of children in the family, and working status. Furthermore, mother's type of birth, number of pregnancies, birth / postpartum problem status and characteristics of the infants such as infant’s gender, gestational week, days of NICU stay, and feeding type have been added. The second part of the EMPATHIC-30 questionnaire included the 30 items divided in five domains. The short version of the EMPATHIC-30 questionnaire was developed from the EMPATHIC initial version (15). This version was developed in eight Pediatric Intensive Care Units (PICU) in the Netherlands (15). Further statistical redundancy testing with 3354 parents resulted in the short version of the EMPATHIC-30 questionnaire (16). The EMPATHIC-30 consists of five domains: Information (5 items), Care & Treatment (8 items), Organization (5 items), Parent Participation (6 items) and Professional Attitude (6 items). The answer option scale is a 6-point Likert type (1=certainly no; 6=certainly yes) and each item has an additional "Not Applicable" option. The reliability estimates (Cronbach’s α) of the domains were adequate and ranged from 0.73 to 0.93. Approval to use the EMPATHIC-30 was granted by the developer (J.M. Latour) and was part of the research team.

Translation and Cultural Adaptation
The translation and cultural adaptation process followed the Principles of Good Practice for the Translation and Cultural Adaptation of Patient-Reported Outcomes Measures described by the task force of the International Society for Pharmacoeconomics and Outcomes Research (17). This 10-step process included:
Step 1: Preparation: Permission was granted by the developer to use EMPATHIC-30 questionnaire. The EMPATHIC-30 was revised before translation; PICU or ICU was reworded to NICU.
Step 2: Forward translation: The translation was performed in Turkish language by two translators independently. With approval of the developer, the EMPATHIC-30-UK was used for the translation.
Step 3: Reconciliation: The translated version was reviewed on meaning and spelling of the items by PICU and research experts.
Step 4: Back translation: The Turkish EMPATHIC-30 was translated back to English by one translator.
Step 5: Back translation review: The translation was found to be sufficiently translated to the original questionnaire.
Step 6-Harmonization: The questionnaire was reviewed by the research team and the developer and was found to be suitable for the Turkish population.
Step 7: Cognitive debriefing: The Turkish EMPATHIC-30 was reviewed by nine experts in Child Health and Diseases Nursing Department, Department of Child Health and Diseases,
Department of Child Psychiatry, and Internal Medicine Nursing Department. The experts were asked to assess the suitability and clarity of each item. They were asked to rate each statement between 1 and 4 points (1 point: not appropriate, 2 points: slightly appropriate, 3 points: appropriate, 4 points: completely appropriate), and write their opinions and suggestions for each item.

Step 8: Review of cognitive debriefing results and finalization: In line with the opinions of the experts, the items were reviewed, and necessary changes were made. As a result of the evaluation of experts, all items were corrected in terms of language and expression with the suggestions and contributions of experts.

Step 9-Proofreading: The Turkish EMPATHIC-30 questions were reviewed. After applying the final version of the scale to 10 parents, it was decided that there were no unclear expressions.

Step 10-Final Report: This paper presents the final report and further validity testing.

Data Collection
The data of the study were collected from parents when their infants were discharged from the NICU. Parents visiting the newborn outpatient clinic two weeks after discharge received the questionnaire and the consent form. Data collection was in line with the original EMPATHIC studies where data was collected two to three weeks after discharge (14-16). The questionnaires, in paper version, were completed during the outpatient clinic visit and completion time was between 10-15 minutes.

We planned to use a minimum of 10% of the total sample for the test-retest (18). In order to assess the test-retest reliability of the questionnaire two weeks later, parents (n=35) who previously agreed to be contacted were asked by phone to meet at the outpatient clinic at their preferred day and time to complete the second questionnaire.

Data Analysis
Number and percentage (n, %) were used to define categorical variables in order to identify the characteristics of the data of 238 participants; mean and standard deviation was used to define numerical variables. Test-retest reliability analysis was performed using the correlation coefficient (r) and intraclass correlation coefficient (ICC). Confirmatory factor analysis (CFA) is tailored to unraveling the empirical structure of the interrelationship of the 30 statements. The final model was based on both theoretical and statistical plausibility. The measures applied in this study were v2 test of model fit, and the ratio of v2 df \3 represents a good model fit. Other tests used for the model fit were: comparative fit index (preferably CFI C 0.95), Tucker–Lewis index (preferably TLI C 0.95), root mean square error of approximation (preferably RMSEA \0.08), and the weighted root mean square residual (preferably WRMR\0.90) (19). Data were evaluated with the statistical software program IBM SPSS Statistics 22 and type 1 error (α) was set at 0.05.

RESULTS
Of the 238 parents who returned the questionnaire, 98.3% were mothers with a mean age 28.27 (SD 5.93). Furthermore, 48.3% were primary school graduates, 21% were employed, and 44.5% had moderate income. According to pregnancy histories, 38.1% mother had their first baby, 78.1% had pregnancy planned, 95.8% had spontaneous pregnancy, 42.9% had normal birth, 42.9% had at least one child. 55.9% of the infants were male with a mean gestational age of 36.89 (SD 3.25) weeks and the mean birth weight was 2863.82 (SD 238.03) grams. Hospital length of stay was 9.36 (SD 10.17) days. During the hospital stay, 56.7% of the infants received only breast milk, 42.4% received both breast milk and formula (Table 1).
The Cronbach’s alpha of the domains of the EMPATHIC-30 questionnaire ranged from 0.804 to 0.922 (Table 2). The mean scores and standard deviations are presented in Table 2. The mean score, standard deviation, and total Cronbach's alpha coefficient of each item are presented in Table 3. The lowest mean score was the item ‘We received understandable information about the effects of the medication’ (mean 4.01, SD 1.40). The highest rated item was “The team respected the privacy of our child’s and of us” (mean 4.81, SD 0.89).

The Pearson correlation coefficient (r) with the total score of each domain ranged from 0.806 to 0.900 (Table 4). One month after the test, 35 parents completed the retest questionnaire and the Pearson correlation coefficient between the two evaluations was r=0.988; Intraclass correlation coefficient was ICC=0.998. Confirmatory factor analysis for the construct validity confirmed a moderate model fit with the preferred values of Comparative Fit Index and the Tucker-Lewis Index slightly below the preferred ≥0.95. The Root Mean Square Error of Approximation (preferably <0.08) was 0.107 while the Standardized Root Mean Square Residual RMSEA was adequate performed with 0.081, preferably <0.90 (Table 5).

DISCUSSION

Family-centered care practices not only increase parental satisfaction but also improve the quality of care (20). A search of the literature revealed that there are no questionnaires available to measure parent satisfaction among Turkey parents in the NICU. The EMPATHIC-30 questionnaire is widely used in many countries to measure family satisfaction (21 -23). Our findings are in line with previous investigations of the adaptation of EMPATHIC-30 in other languages. It seems that the EMPATHIC-30 instrument can be applied to measure parental satisfaction and can be adapted in different cultural and linguistic backgrounds.

As a result of the analysis, the Cronbach’s alpha values in our study of the five domains (between 0.804-0.922) showed that the reliability levels of the questionnaire are high. In the original study of the shortened EMPATHIC-30 study, the Cronbach’s alpha values ranged between 0.73 and 0.81 (16). Other studies translating and validating the EMAPTHIC-30 in Italy, Spain and Brazil reported similar internal consistency figure compared to the original study (16, 22-24). Surprisingly, a study in South Africa reported much lower Cronbach’s alpha on domain levels; between 0.25-0.59 (21). The authors addressed these differences because of a limitation of their small study sample of 100 parents influencing the scores (21).

The means of all items in the EMPATHIC-30 in our study were all below 5. This is in contrast with all other similar studies (16, 21-25). The study in South Africa is the only study reporting that all items had a mean score above 5 (21). This might indicate that parent satisfaction is culturally dependent. However, another explanation could be the family-centered care practices that may vary across countries. In our study and setting it can be argued that family-centered care is not yet fully implemented and therefore parents might have rated the satisfaction items lower as reported in other countries. Further studies are needed to explore the relationship between different family-centered care practices and parent satisfaction outcomes (26,27).

In our NICU, parents whose infants are hospitalizing generally take the role of visitors while their babies are cared for and treated by nurses and doctors. However, when parents are accepted as members of the healthcare team and value their own knowledge and skills, they feel more adequate and safer in caring for their infants (28,29). In this case, it becomes easier to deal with changes in the family role. Although our study is important in terms of revealing that the satisfaction of parents in this regard is not at the desired level, we think that this
questionnaire, which has been adapted in Turkish will increase the interest in the subject and contribute to improving family-centered care practices in Turkish NICUs.

The highest rated domain of the Turkish EMPATHIC-30 questionnaire was the domain of 'Professional Attitude'. This was comparable with the EMPATHIC-30 AUS study in Australia, while other similar studies from Italy, Brazil and Greek-Cyprus demonstrated the highest mean values in the domain "Care and Treatment" (12,23,24,25). Variables such as functioning of the international health system, the NICU conditions and the demographic characteristics of parents and their expectations might affect their perceptions of health. The high level of trust in nurses and doctors in our study increased the value of 'Professional Attitude'. However, and overall, our findings indicate that a revisit of our family-centered care practices is needed. Consequently, we have extended the visiting policies, provided visuals and information about family-centered care for parents on boards in the NICU and waiting rooms, further brochures for parents about family-centered care practices such as their involvement in care are in progress and in-service family-centered care training for NICU staff will commence in the near future.

Our study warrants some limitations. First, the number of fathers participating in the study was low. This might be because in our culture, fathers are often working during the daytime and have limited time to visit the NICU while also caring for siblings and other socio-economic issues. Another limitation is the translation process. Although agreed by the developer, we did not use the original Dutch version but instead the translated English version which has been used in the UK. We acknowledge that our study included only parents from a NICU in one hospital. Further multi-center testing would be needed and could enhance the acceptability of the validated Turkish version of the EMPATHIC-30 instrument. Finally, most parents who participated in the study were those whose infants were admitted to the level I and II units. Further research is needed to assess parent satisfaction across all levels of care in a Neonatal department.

CONCLUSION

Based on the results of our study, the Turkish version of EMPATHIC-30 is a reliable and valid instrument that can be used to measure satisfaction of the parents in NICU settings. The EMPATHIC-30 Turkish can be considered as a benchmark tool to learn from parental reported outcomes of other NICUs. Finally, the instrument can be used among parents from Turkish origin in other countries.
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### Table 1. Descriptive Characteristics of Parents and Infants

| Characteristics                                      | N=238 | %   |
|------------------------------------------------------|-------|-----|
| **Participant**                                      |       |     |
| Mother                                               | 234   | 98.3|
| Father                                               | 4     | 1.7 |
| **Education**                                        |       |     |
| Primary education                                    | 115   | 48.3|
| High school                                          | 79    | 33.2|
| License                                              | 49    | 16.8|
| Postgraduate                                         | 4     | 1.7 |
| **Working Condition**                                |       |     |
| Yes                                                  | 50    | 21  |
| No                                                   | 188   | 79  |
| **Income Status** (family's own statement)           |       |     |
| Good                                                 | 55    | 23  |
| Middle                                               | 106   | 44.5|
| Bad                                                  | 77    | 32.5|
| **Gender of Infant**                                 |       |     |
| Girl                                                 | 105   | 44.1|
| Male                                                 | 133   | 55.9|
| **Number of Children**                               |       |     |
| 1                                                    | 102   | 42.8|
| 2                                                    | 73    | 30.7|
| ≥3                                                   | 63    | 26.5|
| **Person Taken Information Related to Infant**       |       |     |
| Doctor                                               | 205   | 86.1|
| Nurse                                                | 24    | 10.1|
| Doctor and Nurse                                     | 5     | 2.1 |
| Medical secretary                                    | 4     | 1.7 |
| **Total Pregnancy Number of Mother**                 |       |     |
| 1                                                    | 92    | 38.7|
| 2                                                    | 64    | 26.9|
| 3                                                    | 51    | 21.4|
| 4                                                    | 13    | 5.4 |
| ≥5                                                   | 18    | 7.6 |
| **Birth Type**                                       |       |     |
| Normal                                               | 102   | 42.9|
| Cesarean                                             | 136   | 57.1|
| **Planned Pregnancy**                                |       |     |
| Yes                                                  | 174   | 73.1|
| No                                                   | 64    | 26.9|
| **Infant Feeding Type**                              |       |     |
| Breast Milk Only                                     | 135   | 56.8|
| Breast Milk and Formula                              | 101   | 42.4|
| Only Formula                                         | 2     | 0.8 |
| **Age Parents (mean, SD)**                           | 28.27 (5.93) | min-max: 15-48 |
| **Infant Gestational Age in weeks (mean, SD)**       | 36.89 (3.25) | min-max: 26-41 |
| **Infant’s birth weight (mean, SD)**                 | 2863.82 (238.03) | min-max: 630-5800 |
| **Length of stay NICU in days (mean, SD)**           | 9.36 (1.17) | min-max: 2-78 |

SD=Standard Deviation
Table 2. Mean (SD) and Cronbach’s α of the domains of the Turkish EMPATHIC-30

| Domains                | Mean | Standard Deviation | Min | Max | Cronbach Alpha |
|------------------------|------|--------------------|-----|-----|----------------|
| 1. Information         | 21.87| 4.54               | 8   | 30  | 0.831          |
| 2. Care & Treatment    | 35.98| 6.36               | 20  | 48  | 0.848          |
| 3. Organization        | 22.54| 4.22               | 9   | 30  | 0.804          |
| 4. Parent Participation| 27.69| 4.71               | 15  | 36  | 0.869          |
| 5. Professional Attitude| 27.85| 5.10               | 9   | 36  | 0.922          |
Table 3. Descriptive analysis EMPATHIC-30 items

| EMPATHIC-30 items                                                                 | Mean | Standard Deviation | Cronbach's Alpha if Item Deleted |
|----------------------------------------------------------------------------------|------|--------------------|---------------------------------|
| 1. We had daily talks about our child’s care and treatment with the doctors      | 4.59 | 1.04               | 0.953                           |
| 2. We had daily talks about our child’s care and treatment with the nurses       | 4.44 | 1.14               | 0.953                           |
| 3. The doctor clearly informed us about the consequences of our child’s treatment | 4.56 | 1.08               | 0.952                           |
| 4. We received clear information about the examinations and tests                 | 4.27 | 1.19               | 0.952                           |
| 5. We received understandable information about the effects of the medication    | 4.01 | 1.40               | 0.954                           |
| 6. The doctors and nurses worked closely together                                 | 4.74 | 0.91               | 0.952                           |
| 7. We were well prepared for our child’s discharge by the doctors                 | 4.22 | 1.48               | 0.955                           |
| 8. We were well prepared for our child’s discharge by the nurses                  | 4.31 | 1.40               | 0.955                           |
| 9. The team was alert to the prevention and treatment of pain in our child       | 4.75 | 0.80               | 0.952                           |
| 10. Our child’s comfort was taken into account by the doctors                     | 4.80 | 0.83               | 0.952                           |
| 11. Our child’s comfort was taken into account by the nurses                      | 4.76 | 0.87               | 0.953                           |
| 12. Every day we knew who was responsible for our child, regarding the doctors   | 4.12 | 1.32               | 0.952                           |
| 13. Every day we knew who was responsible for our child, regarding the nurses    | 4.27 | 1.28               | 0.952                           |
| 14. The team worked efficiently                                                  | 4.64 | 1.01               | 0.952                           |
| 15. The IC-unit could easily be reached by telephone                              | 4.31 | 1.28               | 0.955                           |
| 16. There was enough space around our child’s bed                                 | 4.45 | 1.21               | 0.953                           |
| 17. The IC-unit was clean                                                         | 4.69 | 0.95               | 0.952                           |
| 18. Noise in the IC-unit was muffled as good as possible                          | 4.45 | 1.15               | 0.952                           |
| 19. During our stay the staff regularly asked for our experiences                | 4.41 | 1.13               | 0.952                           |
| 20. We were actively involved in decision-making on care and treatment of our child | 4.47 | 1.09               | 0.951                           |
| 21. We were encouraged to stay close to our child                                | 4.72 | 0.93               | 0.952                           |
| 22. We had confidence in the doctors                                             | 4.87 | 0.77               | 0.952                           |
| 23. We had confidence in the nurses                                              | 4.87 | 0.79               | 0.952                           |
| 24. Even during intensive procedures we could always stay close to our child     | 4.36 | 1.25               | 0.953                           |
| 25. We received sympathy from the doctors                                        | 4.48 | 1.14               | 0.952                           |
| 26. We received sympathy from the nurses                                         | 4.49 | 1.12               | 0.952                           |
| 27. The team worked hygienically                                                 | 4.72 | 0.92               | 0.952                           |
| 28. The team respected the privacy of our child’s and of us                       | 4.81 | 0.89               | 0.952                           |
| 29. The team showed respect for our child and for us                              | 4.80 | 0.85               | 0.952                           |
| 30. At admission we felt welcome                                                 | 4.55 | 1.05               | 0.952                           |
**Table 4.** Correlations of Domains and total EMPATHIC-30

| Domains              | Total  |
|----------------------|--------|
| 1. Information       | 0.806  |
| 2. Care & Treatment  | 0.900  |
| 3. Organization      | 0.847  |
| 4. Parent Participation | 0.874 |
Table 5. Compliance Index Values of Measurement Model

| EMPATHIC-30 items | Compliance Index Values |
|-------------------|-------------------------|
| CFI               | 0.792                   |
| TLI               | 0.770                   |
| RMSEA             | 0.107                   |
| SRMR              | 0.081                   |

CFI = Comparative Fit Index; TLI = Tucker–Lewis Index; SRMR = Standardized Root Mean Square Residual; RMSEA = Root Mean Square Error of Approximation.