Development of a Transition Process Scale for High-risk Infant’s Caregiver

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Abstract

Background: Transition into parenthood is a major developmental life event and is very significant because development in infancy is affected by the transition process of mothers parenting an infant. This study aimed to develop the assessment tool for transition process of high risk infant’s caregiver in Korea.

Methods: The participants were 246 mothers of premature infant born with gestational age (< 37 weeks) or low birth weight (< 2500 gm), of less than 24 months of age. Preliminary items were derived from transition process scale for parent of children with autism. Factor analysis was performed to test construct validity of the scale, the correlation between transition processes and parenting efficacy was used for testing predictive validity.

Results: The final scale was composed of 23 items divided into 5 factors: wandering (7 items), devotion (5 items), acceptance (4 items), denial (4 items), frustration (3 items). The total variance for validity described by the 5 factors was 60.8% and the reliability of the scale was total Cronbach’s α 0.90 and wandering 0.85, devotion 0.78, acceptance 0.72, denial 0.72, and frustration 0.71. Correlation between transition process and parenting efficacy was statistically significant; wandering (r= -0.61, P <.001), devotion (r= -0.60, P< .001), acceptance (r= 0.30, P <.001), denial (r= -0.31, P <.001) and frustration (r= -0.27, P <.001).

Conclusion: This final assessment scale will be used to investigate high-risk infant caregiver’s transition process and provide basic data for program development to provide differentiated support and care at each process.

Keywords: Caregiver, High risk, Infant, Scale, Transition

Introduction

Low-birth-weight (LBW) or preterm infants with a gestational age under 37 weeks are more likely to have diseases or developmental disorders, or die due to physical immaturity as they age (1). In particular, they may experience the greatest stress during the initial transition process before and after discharge from the hospital (1) and this issue is not restricted to infancy, but can persist throughout the growth phases. Therefore, many researchers have tried to develop and apply diverse post-discharge intervention programs for LBW infants (2-8).

Most of these intervention programs focus on the health status and nervous and cognitive development of infants 1 week to 12 months after discharge or on the improvement of the mother-child interaction.

Infanthood is the period when initial experiences in life begin to accumulate (9) and it is more important than any other developmental stage because a caregiver’s insensitive nursing or lack of attachment for the first two years can have long-term effects even in childhood.

Transition is defined as a process requiring a sense of responsibility to reorganize a goal and behavior,
and acquire a new self-concept (10). In particular, the transition into parenthood is “a major developmental life event” (11) and is very significant because it provides an opportunity to change family members’ values and living priorities as well as to make new interpretations of and adjustments to one’s own life. The transition into motherhood, adjustment process, and transition into parenthood are very complicated and difficult with many physical and psychological obstacles (12). Parents may feel helpless about childrearing and tired from the full-time work involved in caring for their baby at home one month after discharge from the hospital; they may only become confident in caring for the baby three months after discharge (13). In particular, mothers of high-risk infants, such as preterm ones, may become very worried about their child and have difficulties with parenting due to their vulnerability and the likelihood of disability (14). As such, development in infancy is affected by the transition process of the mothers who are parenting the infant and the process can be prompted by the infant’s developmental changes (15).

Research on the transition process in life for autistic children’s parents (16) has found that they can accept constantly changing stress and conflict instead of being limited to a specific period. Some parents might have reached the acceptance stage while others could stay in other stages, including wandering or devotion, and return to the previous stage depending on their own situation. In other words, the transition process can be repetitive and can vary significantly according to individuals and their situations.

As a concept similar to the transition process, Thornton and Nardi (17) divided the maternal role acquisition process into four stages: 1) pregnancy, 2) feeling confident and satisfied as a mother through delivery and parenting, 3) getting attached to child, and 4) establishing identity. Sixty-four percent may acquire maternal identity around the fourth month and about 4% fail to acquire the role even in the first year. Comparative research on maternal behavior between preterm infants’ mothers and those of normal children (18) shows that parenting confidence increases between the fourth and twelfth months, and maternal confidence decreases significantly between the eighth and twelfth months.

However, research on maternal role acquisition or identity is mostly restricted to twelve months or so after birth and fails to reveal the likelihood of stagnation or repetition according to situation, unlike the transition process. It is therefore necessary for nurses to understand correctly the transition into motherhood, or their necessary adjustment, in order to assist high-risk infants’ parents who are having trouble with role acquisition to adjust and provide them with more comprehensive and integrative care during the transition process (12).

Most studies on mothers of high-risk infants, such as preterm or low-birth-weight children, have tried to measure parenting stress, parenting efficacy, mother-child attachment, and child temperament (19-22). Moreover, limited research has been conducted for high-risk infants aged 24 months or younger who are in the critical developmental period; in this research, multiple causes have been found, with no attention paid to the transition process in life, which could involve a combination of these variables. Until now, there has been no scale to assess their transition process. Thus, this study aimed to develop a validated, reliable scale to assess the parenting transition process for high-risk infants’ caregivers.

Materials and Methods

Study Design
This study presents the results of methodological research that derives evaluation items and tests the validity and reliability of the transition process scale for high-risk infant’s caregiver (TPS-HIC) in Korea.

Setting and Samples
Purposive sampling was used to recruit caregivers who visited the outpatient center for newborns at the pediatrics department or caregivers with children aged 24 months or younger high-risk infants registered at the development clinic of Seoul University Hospital that serves the state-wide majority
of premature infants from both rural and urban settings and two public health centers located in Seoul, Korea. High-risk infants were defined as preterm infants (<37 weeks’ gestational age) or low birth weight infants (<2,500 gm); congenitally deformed infants, infants with cerebral-palsy hearing or vision disorders, and infants with severe cerebral hemorrhage at birth were excluded. The mothers of the infants who met the criteria were introduced by the pediatrician to the author and handed the questionnaire. It has been suggested that to assess adequately factorial validity in psychometric testing of an instrument, there should be a ratio of 10 respondents for each item (23). The instrument at this point contained 29 items, except for demographic information. Therefore, we assumed that 290 participants would be appropriate. However, this population was a small group and excepting some questionnaires that failed to meet our selection criteria or contained insincere answers, we finally used 246 copies for analysis in this study. Data collection was performed between February and September 2013.

Procedure
Testing of the assessment scale was comprised of two steps: 1) a reliability and validity test, and 2) a predictive validity test of the scale.

Measurements
Transition process scale
The transition process scale in this study was the one developed by Lee, Hong, and Ju (16) for autistic children’s parents and permission was obtained to use it by the authors. The original tool was composed of a total of 29 items in five factors: denial, wandering, devotion, acceptance, and frustration and was a four-point Likert scale with 4 ‘totally yes’ and 1 ‘totally no’; Lee et al. (16) estimated the reliability coefficient of the scale to be 0.82 for the denial, 0.86 for the wandering, 0.72 for the frustration, 0.86 for the devotion, and 0.88 for the acceptance. The first factor of denial refers to neglect and failure to accept; the second factor of wandering is characterized by loss of meanings in living, instability, and distance from others; the third factor of devotion involves being focused on child in life, dependence on treatment, and getting exhausted; the fourth factor of frustration is characterized by lower expectation, refusal to make a comparison, and open-mindedness; and the fifth factor of acceptance involves acceptance, feeling grateful, and interdependence (16).

Criterion-related validity
Concurrent validity or predictive validity can be examined to test criterion-related validity; in this study, on the basis of the results that the transition process is significantly correlated with parenting efficacy for low birth weight infants’ parents and that the more satisfied with parenting, the more confident in parenting (24), the Parenting Efficacy Scale (Korean version), modified by Ahn and Park (25), was used. It took into account the applicability of perceived parenting competence as developed by Floyd, Giliom and Costigan (26) to Korean culture and the age of the participants’ children. It comprised 15 items in total 12 from the Parenting Confidence Scale and 3 from the Under Control Scale to measure predictive validity. The scores range from 15 to 60; the higher score, the greater efficacy in the parenting role. Cronbach’s α was 0.73 in Ahn and Park (25) and 0.79 in this study.

Data analysis
The data were analyzed using SPSS version 18.0 for Window. Cronbach’s α and item to total correlation coefficient were used to determine internal consistency for reliability of the scale and Pearson’s correlation was used to estimate correlation coefficient for test-retest reliability of each item. Factor analysis was performed to test construct validity of the scale and principal component analysis, including varimax rotation, was used, with the number of factors based on the initial eigen value of ≥1.0. Pearson’s correlation coefficient with parenting efficacy measurements was estimated to test predictive validity.

Results
General characteristics
The characteristics of the participants in this study are summarized in Table 1. Of 246 participants,
209 high-risk infants (85%) were discharged from neonatal intensive care units after getting treatment. The mean gestational age of infants was 31.5 weeks, with 35.8% being <30 weeks, and 106 (43.0%) weighed 1,500 to 2,499 gm at birth. The present age was 9.5 months (±7.55), mostly ranging from 7 to 12 months. As for health problems, 161 (65.4%) had a nursing problem related to growth, 94 (38.2%) cardiopulmonary problems, 74 (30.1%) sleeping disorder, and 58 (23.6%) sensory problems, such as sight or hearing. The mean age of caregivers was 33.8 years (±3.99), ranging from 21 to 45 years. 190 persons (80.3%) were college graduates or at higher educational levels and 36.8% had monthly household income (SES) of 4 thousand dollars or more.

Table 1: General characteristics (n=246)

| Variables                          | Categories            | n   | %    | Mean  | SD  |
|------------------------------------|-----------------------|-----|------|-------|-----|
| Infant                             | Hospital place at birth |      |      |       |     |
|                                     | Nursery               | 37  | 15.0 |       |     |
|                                     | Neonatal intensive care unit | 209 | 85.0 |       |     |
| Gender                             | Male                  | 124 | 50.4 |       |     |
|                                     | Female                | 122 | 49.6 |       |     |
| Gestational age (wk)               | ≤30                   | 88  | 35.8 | 31.5  | 25.97 |
|                                     | ≥37                   | 14  | 5.7  |       |     |
| Birth weight (gm)                  | <1000g                | 54  | 22.0 |       |     |
|                                     | 1000-1499             | 73  | 29.7 | 1520  | 0.58 |
|                                     | 1500-2499             | 106 | 43.0 | (range 370-3080) | |
|                                     | ≥2500                 | 13  | 5.3  |       |     |
| Current age (months)               | 0-1                   | 51  | 21.2 | 9.5   | 7.55 |
|                                     | 2-6                   | 49  | 20.3 |       | (range 0-24) |
|                                     | 7-12                  | 65  | 27.0 |       |     |
|                                     | 13-18                 | 43  | 17.8 |       |     |
|                                     | ≥19                   | 33  | 13.7 |       |     |
| Feeding problem                    | yes                   | 161 | 65.4 |       |     |
|                                     | no                    | 85  | 34.6 |       |     |
| Activity & speech problem          | yes                   | 90  | 36.6 |       |     |
|                                     | no                    | 156 | 63.4 |       |     |
| Respiration & heart problem        | yes                   | 94  | 38.2 |       |     |
|                                     | no                    | 152 | 61.8 |       |     |
| Sleeping problem                   | yes                   | 74  | 30.1 |       |     |
|                                     | no                    | 172 | 69.9 |       |     |
| Sensory problem (visual & auditory)| yes                   | 58  | 23.6 |       |     |
|                                     | no                    | 188 | 76.4 |       |     |
| Caregiver                          | Educational level (yr) |      |      |       |     |
|                                     | ≤9                    | 4   | 1.6  |       |     |
|                                     | 10-12                 | 52  | 21.1 |       |     |
|                                     | ≥12                   | 190 | 80.3 |       |     |
| Socioeconomic status (dollars/month)| <1500                | 5   | 2.0  |       |     |
|                                     | 1500-1999             | 27  | 11.0 |       |     |
|                                     | 2000-2999             | 78  | 31.8 |       |     |
|                                     | 3000-3999             | 45  | 18.4 |       |     |
|                                     | ≥4000                 | 90  | 36.8 |       |     |
| Age (yr)                           |                       | 33.8| 3.99 | (range 21-45) | |

*no responses are excluded.
Reliability test
Internal consistency
Cronbach’s α and item to total correlation coefficient were used to determine internal consistency in this study. This study had Cronbach’s α = 0.90 and item-total correlation of r = 0.40 to 0.71, with correlation scoring >0.40 for all items (Table 2). In case an item was deleted, Cronbach’s α rather decreased or varied insignificantly for each factor; therefore, the item was not deleted.

As for reliability of the scale, Cronbach’s α was 0.90 for all the items, 0.85 for Factor 1, 0.78 for Factor 2, 0.72 for Factor 3, 0.72 for Factor 4, and 0.71 for Factor 5. As for the mean of the five factors, the wandering got 1.95 (±0.64), the devotion 2.18 (±0.66), the acceptance 3.52 (±0.52), the denial 1.50 (±0.55), and the frustration 1.24 (±0.43) (scale 1~4) (Table 3).

Stability
To secure stability of the TPS-HIC scale, the same questionnaire was used to make a retest in 20 subjects at a four-week interval. Correlation coefficient was estimated to be r = 0.16 to 0.90 for each item and the total correlation coefficient, which was the mean of correlation coefficient for each item, was estimated to be r = 0.69 (Table 3).

Table 2: Factor analysis of final measurement for transition process for high-risk infant’s caregiver

| Original item no. | Factor component |
|-------------------|------------------|
|                   | 1                | 2    | 3       | 4       | 5       |
| 1                 | 0.71             | 0.21 | -0.23   | 0.06    | -0.04   |
| 15                | 0.69             | 0.21 | 0.01    | 0.08    | 0.32    |
| 14                | 0.63             | 0.17 | 0.05    | 0.27    | 0.23    |
| 13                | 0.61             | 0.30 | -0.31   | 0.30    | -0.01   |
| 28                | 0.56             | 0.38 | -0.16   | 0.03    | 0.19    |
| 12                | 0.53             | 0.09 | 0.12    | 0.36    | 0.13    |
| 26                | 0.50             | 0.33 | -0.21   | 0.21    | 0.27    |
| 16                | 0.23             | 0.81 | 0.02    | 0.14    | -0.02   |
| 25                | 0.20             | 0.67 | -0.24   | 0.01    | 0.04    |
| 29                | 0.38             | 0.63 | -0.11   | -0.04   | 0.08    |
| 19                | 0.09             | 0.59 | 0.28    | 0.18    | 0.22    |
| 6                 | 0.36             | 0.48 | -0.16   | 0.37    | 0.13    |
| 11                | 0.09             | 0.01 | 0.73    | -0.16   | -0.18   |
| 21                | -0.10            | -0.33| 0.67    | -0.26   | -0.16   |
| 24                | -0.33            | -0.10| 0.66    | 0.17    | -0.00   |
| 9                 | -0.12            | 0.08 | 0.65    | 0.03    | -0.33   |
| 10                | -0.04            | 0.13 | -0.21   | 0.77    | 0.23    |
| 5                 | 0.20             | 0.06 | 0.02    | 0.74    | -0.06   |
| 7                 | 0.33             | 0.19 | 0.10    | 0.54    | 0.25    |
| 17                | 0.39             | 0.06 | -0.11   | 0.44    | 0.42    |
| 8                 | 0.15             | 0.05 | -0.17   | 0.03    | 0.83    |
| 20                | 0.08             | 0.36 | -0.37   | 0.14    | 0.63    |
| 13                | 0.33             | 0.07 | -0.21   | 0.28    | 0.62    |
| eigen values      | 7.82             | 2.22 | 1.74    | 1.16    | 1.06    |
| % of variance     | 16.2             | 13.1 | 11.0    | 10.7    | 9.9     |
| Cumulative variance (%) | 34.0   | 43.7 | 51.2    | 56.3    | 60.8    |

Kaiser-Meyer-Olkin (KMO) = 0.88, Bartlett’s test of sphericity: χ²=2407.91, P < .001

Validity Test
Content validity test
To test the content validity of the transitional period scale, we employed an item-level content validity index (I-CVI), which computed the proportion of 3 or 4 point answers by the 10 experts who have experience working over 2 years as a nurse and nurse manager in neonatal intensive care unit. Three questions with an I-CVI score less than 0.80 were deleted; ‘My life itself is meaningless’, ‘I feel shame in taking my child with me’, ‘I think my child is a special gift from God’.

Construct validity test
Factor analysis was used to determine if theoretical construction of the scale is similar to the sub-
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concepts of the original scale and if it had construct validity (27). The Kaiser-Meyer-Olkin (KMO) value was estimated to be close to 1 (0.88), confirming goodness-of-fit of the entire data to the factor analysis model; Bartlett's test of sphericity, which reflects goodness-of-fit of the factor analysis model, varied significantly, implying that variables were not independent from one another but correlated and that they were suitable for principal component analysis ($P < .001$, Chi-Square: 2407.91) (Table 2).

**Factor extraction**
To minimize the number of variables with high loading on a single factor, varimax rotation was used in factor analysis. Five factors had an initial eigen value of $\geq 1.0$ and only those items with factor loading of $\geq 0.3$ were selected since they could best signify the factor (28). Those items with communality of $<0.4$ for the rate of explanation by the extracted factor and three items with different meanings were excluded; finally, 23 items were selected.

Factor 1 accounts for 16.2% of the total variance, Factor 2 13.1%, Factor 3 11.0%, Factor 4 10.7%, and Factor 5 9.9%. Therefore, the total cumulative explanation rate was 60.8% (Table 2).

**Table 3:** Reliability and average of final measurement for transition process for high-risk infant’s caregiver

| Original item no. | Factor name & items | Mean | SD  | Item to total correlation | Cronbach’s α if item deleted | Test-retest (n=20) | Cronbach’s α |
|-------------------|---------------------|------|-----|---------------------------|-------------------------------|-------------------|-------------|
| **Factor 1. Wandering** |                      |      |     |                           |                               |                   |             |
| 1                 | I feel everything is confusing | 2.09 | 0.85 | 0.58                       | 0.83                          | 0.67              | 0.85        |
| 15                | I often cry because of my child | 1.62 | 0.78 | 0.65                       | 0.82                          | 0.54              |             |
| 14                | I feel unhappy when comparing my child with others | 2.06 | 1.02 | 0.60                       | 0.83                          | 0.74              |             |
| 3                 | I feel fear and hopelessness | 2.13 | 0.87 | 0.69                       | 0.82                          | 0.90              |             |
| 28                | I'm tired of living because of my child | 1.73 | 0.78 | 0.58                       | 0.83                          | 0.54              |             |
| 12                | It is heartbreaking to think about my child | 2.26 | 0.99 | 0.53                       | 0.84                          | 0.62              |             |
| 26                | I am at a loss about the future | 1.77 | 0.88 | 0.66                       | 0.82                          | 0.77              |             |
| subtotal           |                     | 1.95 | 0.64 |                            |                               |                   |             |
| **Factor 2. Devotion** |                      |      |     |                           |                               |                   |             |
| 16                | I don’t have my own life. | 2.29 | 0.97 | 0.71                       | 0.68                          | 0.71              | 0.78        |
| 25                | I spend time doing what I want to do | 2.32 | 0.99 | 0.49                       | 0.76                          | 0.76              |             |
| 29                | I have a lot of burden and stress | 2.51 | 0.90 | 0.64                       | 0.71                          | 0.78              |             |
| 19                | I don’t care for anybody but my child | 2.06 | 0.86 | 0.40                       | 0.79                          | 0.60              |             |
| 6                 | I feel sorry for myself | 1.73 | 0.83 | 0.55                       | 0.74                          | 0.92              |             |
| subtotal           |                     | 2.18 | 0.66 |                            |                               |                   |             |
| **Factor 3. Acceptance** |                      |      |     |                           |                               |                   |             |
| 11                | I feel joy in my child | 3.76 | 0.60 | 0.53                       | 0.65                          | 0.84              | 0.72        |
| 21                | I'm satisfied with my life | 3.17 | 0.75 | 0.56                       | 0.62                          | 0.82              |             |
| 24                | My child made me thankful for small things. | 3.62 | 0.63 | 0.47                       | 0.68                          | 0.84              |             |
| 9                 | I've gained rather than lost from my child | 3.52 | 0.83 | 0.50                       | 0.67                          | 0.72              |             |
| subtotal           |                     | 3.52 | 0.52 |                            |                               |                   |             |
| **Factor 4. Denial** |                      |      |     |                           |                               |                   |             |
| 10                | I don’t like to meet people | 1.46 | 0.77 | 0.51                       | 0.65                          | 0.40              | 0.72        |
| 5                 | I want to hide my child's prematurity | 1.51 | 0.74 | 0.50                       | 0.66                          | 0.67              |             |
| 7                 | I shrink up like a sinner because of my child | 1.70 | 0.84 | 0.53                       | 0.65                          | 0.75              |             |
| 17                | I am afraid of people staring | 1.34 | 0.62 | 0.50                       | 0.67                          | 0.16              |             |
| subtotal           |                     | 1.50 | 0.55 |                            |                               |                   |             |
| **Factor 5. Frustration** |                      |      |     |                           |                               |                   |             |
| 8                 | I would like to give up my child | 1.09 | 0.38 | 0.61                       | 0.60                          | 0.93              | 0.71        |
| 20                | I am exhausted with no hope | 1.28 | 0.55 | 0.54                       | 0.60                          | 0.89              |             |
| 13                | I don’t accept my child’s problem | 1.35 | 0.66 | 0.52                       | 0.68                          | 0.35              |             |
| subtotal           |                     | 1.24 | 0.43 |                            |                               |                   |             |

Correlations $r = 0.69$

Total Cronbach’s $\alpha = 0.90$

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Naming of factor

Factors were named according to the extent of including items of the original scale and naming of factors in each stage of the transition process was identical to the original one.

Factor 1 was named the ‘wandering,’ contained 7 items in total, and had factor loading of r = 0.50 to 0.71. Three items ‘I feel fear and hopelessness’, ‘It is heartbreaking to think about my child’, and ‘I'm tired of living because of my child’ were included in the wandering, as in the original scale. Four items ‘I feel everything is confusing’, ‘I often cry because of my child’, ‘I feel unhappy when comparing my child with others’, and ‘I am at a loss about the future’ were included in the devotion or denial in the original scale but were included in Factor 1 in this study.

Factor 2 was named the ‘devotion,’ contained 5 items in total, and had factor loading of r = 0.48 to 0.81. Two items ‘I don’t have my own life’ and ‘I don’t care for anybody but my child’ also belonged to the devotion stage in the original scale and the items belonging to the wandering stage in the original scale ‘I have a lot of burden and stress’ and ‘I feel sorry for myself’ and ‘I spend time doing what I want to do’ were included in Factor 2 in this study.

Factor 3 was named the ‘acceptance,’ contained 4 items in total, and had factor loading of r = 0.65 to 0.73. All the items but the deleted ones from the original scale were included in the acceptance as they were. ‘I feel joy in my child’, ‘I’m satisfied with my life’, ‘My child made me thankful for small things’, and ‘I’ve gained rather than lost from my child’ were composed as items and named the acceptance just as in the original scale.

Factor 4 was named the ‘denial,’ contained 4 items in total, and had factor loading of r = 0.44 to 0.77. Three items ‘I want to hide my child’s prematurity’, ‘I shrink up like a sinner because of my child’, and ‘I am afraid of people staring’ were included in the denial stage in this study as in the original scale. However, ‘I don’t like to meet people’ belonged to the wandering stage in the original scale but was included in Factor in this study. Items in Factor 4 are characterized by refusal to accept the fact about child, wish to hide it and parents’ own shrinkage and were named the denial stage. While the original scale had the item ‘I want to hide my child’s disability,’ ‘disabled child’ was revised into ‘premature child’ based on validity test by experts.

Factor 5 was named the ‘frustration,’ contained 3 items in total, and had factor loading of r = 0.62 to 0.83. Two items ‘I would like to give up my child’ and ‘I am exhausted with no hope’ were included in the frustration stage in this study as in the original scale and the item ‘I can’t accept my child’s problem’ was added in this study. The item ‘I don’t accept the disability of my child’ in the original scale was revised into ‘I don’t accept my child’ problem’ in this study.

To determine the transition process of high-risk infants’ caregivers, 29 items in the transition process scale for another area were finally reduced to 23 items: Seven for the wandering, 5 for the devotion, 4 for the acceptance, 4 for the denial, and 3 for the frustration.

Criterion-related validity (predictive validity) test

As for correlation with the parenting efficacy scale, the five factors were all statistically significant: r = -0.61 (P < .001) for the wandering, r = -0.60 (P < .001) for the devotion, r = 0.30 (P < .001) for the acceptance, r = -0.31 (P < .001) for the denial and r = -0.27 (P < .001) for the frustration. Predictive validity was confirmed for the scale in this study: negative correlation was found with wandering, devotion, denial, and frustration, which have a negative meaning, and positive correlation was found with the acceptance, which has a positive meaning (Table 4).

Discussion

This study aimed to develop a scale to assess the transition process in life, related to the parenting by high-risk infants’ principal caregivers. Most infants in this study were preterm infants aged under 37 weeks, who were discharged from neonatal intensive care units, or those with a birth weight <2,500 gm who had problems with nursing, cardiopulmonary functions, activity/language, sleeping, and senses (sight/hearing).
They were classified into high-risk factors in this study; mothers who tend to be their principal caregivers are known to experience much psychological stress and anxiety since their child is in a neonatal intensive care unit immediately after birth; they even experience depression due to the health and developmental problems their children face, unlike normal children, while their child ages (14).

Parents of children with disabilities, such as autism, may go through several stages of psychological change after their child’s diagnosis including denial, wandering, devotion, and acceptance called the transition process in life (29). However, no scale to measure the transition process during the first 24 months of infancy, which is critical in development, has been developed for high-risk infants’ caregivers.

Determining the transition process is significant to ascertain how shocked and wandering the caregiver is or if he/she has already accepted the reality of the situation in order to provide nursing, education, and assistance suitable for each stage (16). This study developed a scale to assess the transition process in life mainly among high-risk infants’ caregivers.

The scale in this study had 23 items in five factors wandering, devotion, acceptance, denial, and frustration in accordance with Lee and colleagues (16), who divided the transition process in life into five factors for autistic children’s mothers.

The first factor of ‘wandering’, which has the greatest explanation power, is set as the second stage by Lee and colleagues (16); it implies confusion about everything, frequently weeping because of the child, and feeling heartbroken and hardened from comparisons with other children. The item “It is heartbreaking to think about my child” scored an average of 2.26 and “I feel fear and hopelessness” also scored high (2.13). This factor is characterized by still feeling confused and depressed about the child’s conditions. ‘Wandering’ involves high levels of emotional stress, including feelings of unfairness, anxiety, sadness, shock, disappointment, and a sense of guilt (30); if the score is high in this factor, it is necessary to offer correct information about the current condition and potential of the child, and to have more interventions with the family.

In the second factor of ‘devotion’, mothers have much burden and stress, feel as if they do not have their own life, feel sorry for themselves, and do not care for anybody but their child. They feel sorry for themselves because their child becomes the center of their life, and they undertake therapy or education. In other words, this is the most emotionally unstable stage because they spend much time in search of rehabilitation, special diets, and medication, and stick to their child, having no time to care for themselves (30). Many of the preterm infants especially infants with very low birth weight in this study have bronchial, cardiac, or sight problems or difficulties with the development of gross motor skills needed for sitting down, standing up, and walking. Thus, they need treatment constantly in the rehabilitation or ophthalmology departments as well as in pediatrics. Twins’ mothers mostly have little time for makeup or grooming because they take both children to the hospital or clinic by themselves.

In the third factor of ‘acceptance’, caregivers feel gratitude and joy due to their child, and become

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**Table 4: Correlations between transition process and parenting efficacy**

|               | Wandering | Devotion | Acceptance | Denial | Frustration |
|---------------|-----------|----------|------------|--------|-------------|
| Wandering     | 1         |          |            |        |             |
| Devotion      | 0.67***   | 1        |            |        |             |
| Acceptance    | -0.37***  | -0.30*** | 1          |        |             |
| Denial        | 0.60***   | 0.45***  | -0.26***   | 1      |             |
| Frustration   | 0.53***   | 0.41***  | -0.53***   | 0.50***| 1           |
| Parenting efficacy | -0.61*** | -0.60*** | 0.30***    | -0.31***| -0.27*** |

*** P < .001
satisfied with their living. “I’ve gained rather than lost from my child” implies positive acceptance and suggests the stage in which they have come to accept their child’s problems, are able to provide care based on interactions at the child’s level, and are becoming strong (31-32). This was positively correlated with parenting efficacy; psychological indexes, such as a sense of well-being or happiness, are correlated with maternal confidence (11). Therefore, it is necessary to provide greater assistance to improve parenting confidence and to help them reach the acceptance stage.

The fourth factor of ‘denial’ was set as the first stage by Lee and colleagues (16) and includes four items: “I don’t like to meet people,” “I want to hide my child’s prematurity,” “I shrink up like a sinner because of my child,” and “I am afraid of people staring.” This implies serious conflict situations that involve an attempt to reduce or neglect problems (32). Autistic children’s parents not only perceive their child as different from other children because of their ignorance of autism, but also refuse to accept the reality of the situation and are highly irritated by incorrect diagnosis, advice, and blame (33).

The fifth factor of ‘frustration’ includes three items: “I don’t accept my child’s problem,” “I would like to give up my child,” and “I am exhausted with no hope.” Parents may experience this factor because no notable change is found in their child despite their efforts, and they feel emotionally, physically, and financially burdened (16). While it is difficult to compare directly the study participants who scored lowest for frustration with the parents of autistic children or those with serious chronic disorders, they seem very likely to experience frustration since high-risk infants have developmental disorders whilst growing and developing. Therefore, a strategy is necessary to provide accurate knowledge about high-risk infants’ developmental process, possibility of problem occurrence, and prevention and treatment, and to help them mentally adjust or prepare.

In the analysis of its reliability, the overall Cronbach’s α value was 0.90, and the values for individual factors ranged from .71 to .85. These figures are higher than the 0.80 (range=0.72-0.88) of Lee et al. (16). A Cronbach’s α value over 0.70 is considered reliable in exploratory research in general by Nunnally (23), which verifies the reliability of this research.

The birth of a high-risk infant can make a family feel sad along with the agony and worry, and produce a sense of crisis, anxiety, and loss. High-risk infants’ mothers are more likely to have internally a sense of inferiority compared to the mothers of normal infants, and lack confidence in their own knowledge and skills necessary to care their baby, thus affecting their role as mother (21). Parenting efficacy encompasses both level of perceived knowledge of appropriate child-rearing behaviors and degree of confidence in one’s ability to perform parenting tasks. Regarding confidence in parenting, “caring for their infants is crucial for the healthy adaptation to parenthood and the development of positive parent-infant relationships” (34); mothers with higher parenting confidence are more likely to undertake flexible and consistent parenting behavior, while low confidence can cause helplessness about parenting and arouse negative parenting behavior (35). It was reported that parenting efficacy mediates between attachment for an infant’s mother and the infant’s development (36), that parents participating in an intervention program to promote transition for parents of low-birth-weight infants obtained higher parenting confidence, and that parenting confidence is correlated with parents’ satisfaction with parenting and greater satisfaction that can potentially lead to higher parenting confidence (24). Therefore, the higher the parenting efficacy, the more positive the parenting attitude. The predictive validity of the scale could potentially be tested by determining the correlation between each factor of the transition process and parenting efficacy. A negative correlation was found with wandering, devotion, denial, and frustration, which are negative factors in the transition process, and a positive correlation was found with acceptance, which is a positive factor. The scale in this study was proven valid in predicting parenting efficacy. This was achieved by demonstrating that depression and anxiety during pregnancy, and ambivalence and conflicts as a mother may lead to lower confi-
ence in the parental role and those psychological indexes, such as a sense of happiness or well-being, are correlated with maternal confidence (37).

Some limitations must be considered when analyzing the present data. First, the data were drawn from one general hospital, located in Seoul. Therefore, the study results cannot be conclusively applied to all Korean high-risk infants’ caregivers. Nevertheless, the sample hospital is one of the largest hospitals in Korea, performing over 200 premature infant admissions per year. Consequently, this sample is considered representative of high-risk infant caregivers in Korea. Second, this study did not identify the sequential stages of the transition process; thus, it is expected that further research will determine how the transition process is formed and changed in terms of infant age; stress-causing situations, such as health problems; and the levels of parenting confidence, and will help develop a theory of the transition process.

Conclusion

Previously, there was no scale to measure the transition process in life for caregivers during the important two-year growth and development period after high-risk infants are discharged from neonatal intensive care units. In this context, a scale with high validity and reliability, which can determine the stage to which high-risk infants’ caregivers belong in the transition process, has been developed and can be applied to specialized education and intervention programs for each stage. Therefore, the study results can be applied to community practice.

Ethical consideration

Approval was obtained from the Institutional Review Board of Seoul National University Hospital before conducting this study. To induce the subjects to make spontaneous participation and protect them, the researcher and a research assistant personally read to them the explanation about the purpose of this study, anonymity of the collected data, confidentiality of the data, no other use than academic one of the data, and possibility of withdrawing the study and asked them to put their signature before completing the questionnaire. After giving the written consent, they were asked to make a self-report of the questionnaire. Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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