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ORIGINAL RESEARCH ARTICLE

Translation and evaluation of the Infant Characteristics Questionnaire in a sample of Swedish patients with craniosynostosis

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ABSTRACT

Background: Research on the psychological development of infants with craniosynostosis would benefit from further properly validated tailored measures. **Aim**: Our study aimed to translate and evaluate the Infant Characteristics Questionnaire (ICQ; Bates et al., 1979) for use with parents of infants with craniosynostosis in Sweden. **Methods:** Participants included parents of 83 infants (67.5% boys) with isolated craniosynostosis (sagittal: n = 51, metopic: n = 32), and an average age of 184.7 days (SD = 67.1). Parents completed the ICQ and interviews were conducted with 22 of the families. The interviews were analyzed using conventional qualitative content analysis. **Results:** Reliability in terms of internal consistencies were sufficient for the overall scale (α = .85), the Fussy/Difficult (α = .80) and Unadaptable (α = .76) subscales, close to acceptable for the Unpredictable subscale (α = .66), and low for the Sociable subscale (α = .45). Parents found the ICQ relevant for capturing important aspects of their infants' temperament, and the instructions and questions easy to understand. However, many parents noted that the question regarding their child's first reaction to solid food was not applicable and some suggested adding more questions about sleeping difficulties. **Conclusion:** Overall, the ICQ seems to be acceptable to parents of children with craniosynostosis in Sweden – a prerequisite for continued use and development. Future studies should investigate additional psychometric properties, including factorial validity, to further establish its usefulness in Swedish populations, both with and without craniosynostosis.

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Introduction

Craniosynostosis (CS) is a condition characterized by prematurely fused suture(s) in the cranium, which results in an atypical head shape [1]. Isolated CS is the most common type of CS and occurs when one suture (e.g. metopic, coronal or sagittal) in the skull is fused. CS can also be multiple, as well as associated with numerous syndromes [2]. Approximately 100 new cases of CS are diagnosed annually in Sweden [3], and the worldwide birth prevalence of isolated CS is usually estimated to approximately 5 per 10,000 live births [2]. When left untreated, CS can cause serious complications such as disruptions in brain development, blindness, and even death [1]. Therefore, to minimize the risk of increased intracranial pressure and to restore a normal head shape, CS is usually treated with surgery within the child's first year of life [4].

Psychological development in infants with CS

Although treatment outcomes mainly have been measured by medical variables (e.g. intracranial volume, blood loss, and recovery time), there are also studies exploring developmental aspects in children operated for craniosynostosis (CS), such as cognitive functions and health-related quality of life [5–12]. Most studies on psychological outcomes following CS surgery have focused on older children and/or adolescents [13], and little is known about the psychological outcomes and impact in infancy. In addition, previous research on psychological development in infants with CS is generally limited by a variety of methodologies and a lack of longitudinal studies, and studies assessing cognitive status in infants with CS vary in their conclusions [13]. For instance, previous results generally indicate improvements in different cognitive and motoric functions among infants with single-suture CS following surgery [e.g. 5, 14], but there are also contradictive findings [12].

The study by Bellew et al. [5] showed that surgery seems to be specifically beneficial when it comes to gross motoric functioning in infants with CS, where the infants with CS gained their delay in this area post-surgery. Importantly, in this study [5] it was also noticed that parents often commented on how motoric abilities noticeably improved postoperatively, indicating not only a statistical difference in functioning but also one of clinical relevance. Parental observations of accelerated developmental progress in children with CS post-surgery have also been documented in prior qualitative research [15, 16]. For example, Alperovich et al. [15] found that parents generally perceived their children's development as age-appropriate and largely unchanged after surgical intervention. Notably, however, approximately one-third of the parents reported improvements in their child's attentional abilities following surgery [15]. From a clinical perspective, healthcare professionals' [17] experiences also suggest that, at postoperative visits, parents of children with CS sometimes report that their child is happier, sleeps better, and is easier to understand and handle – changes that all can be related to temperament. However, these clinical reports still await scientific examination.

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Temperament and the Infant Characteristics Questionnaire

Temperament is a common term to describe an infant's way of being and usually includes individual differences in behaviors pertaining to domains such as affect, activity, attention, and sensory sensitivity [18]. During early childhood, an individual's reactions to their environment are predominantly understood as influenced by temperament [19]. The specific combination of temperament traits in infants influences how they are perceived, with some temperamental profiles leading to their characterization as more compliant and others as more challenging to manage. For example, infants with a combination of low activity level, and high levels of regularity and adaptability are often described as 'easy', while infants with strong and intense reactions and low levels of regularity and adaptability often are described as having high needs or being 'difficult' [20]. Although temperament is considered congenital and relatively constant, it also interacts with both medical conditions and environmental factors such as parental responsiveness and care [21, 22]. For instance, the review by Valeri et al. [22] of neonatal pain and developmental outcomes indicated that, for infants born preterm, neonatal pain-related stress is associated with alterations in negative affectivity temperament.

The Infant Characteristics Questionnaire [ICQ; 23] is a measure assessing parental perception of infant temperament, focusing on difficult temperament. The measure exists in slightly different versions depending on the age of the child (6, 13, and 24 months). The most commonly used and most evaluated version is the 6-months version, which consists of four subscales measuring to which degree the parent perceives their child to be demanding (i.e. fussy/difficult), adaptable, social, and predictable [23]. The ICQ has previously been translated and evaluated in different countries, including the Netherlands [24], Canada [in French; 25], Portugal [26], and Finland [27]. Moreover, although the ICQ was developed in general populations, it has previously also been used specifically in clinical groups of children with Down's syndrome [28], epilepsy [29], and children born prematurely [30]. Regarding previous use of the ICQ in Sweden, the Fussy/Difficult subscale has been included in a couple of publications using population samples of Swedish mothers with children from 6 months up to 3 years of age [31, 32]. However, the whole ICQ has not previously undergone a formal translation to, and psychometric evaluation in, Swedish, nor has it been previously evaluated among infants with CS.

Aim

Studies of psychological development in infants with CS are lacking, and most focus solely on neurocognitive development [13]. Hence, as a first step to expand the knowledge of psychosocial aspects of CS in infancy, the aim of our study was to translate and perform a first step evaluation of the ICQ (23; 6-months version) for use with parents of infants with CS in Sweden. The evaluation process included assessments of the measure's face validity and reliability.

Methods

Participants and procedure

Parents of infants with CS (N = 83) participated, and mothers and fathers filled out the questionnaire together. All children were around 6 months old (M_{age} = 184.7 days; SD = 67.1), and 67.5% were boys. All children included had an isolated CS, either sagittal (n = 51), or metopic (n = 32). Parents of infants with other forms of craniosynostoses, craniofacial syndromes and developmental disability, as well as non-Swedish speaking parents, were excluded from the study.

Participants were recruited in conjunction with planned visits to the Department of Plastic Surgery at Sahlgrenska University Hospital, Gothenburg, Sweden. Parents of infants with CS were informed about the study and asked to fill out a Swedish version of the ICQ. Data were collected between August 2015 and June 2020. After filling out the questionnaire, parents of the first 25 children were invited to participate in interviews, and parents of 23 children accepted. One family was later excluded from the study when it was found that the child had a developmental disability, resulting in 22 interviews.

Measure: The Infant Characteristics Questionnaire

The Infant Characteristics Questionnaire [ICQ; 23] is a measure of parents' perceptions of their infants' temperament with a focus on difficultness. There are separate forms for infants aged about 6, 13, and 24 months, respectively, containing 24, 32, and 32 items. The 6-months version also includes four additional items (A-D), described as experimental and not included in subscale calculations. In our study, we administrated the 6-months version using all 28 items (24 original and four experimental). The questionnaire was obtained and used with permission from the author.

Parents rank each item on a 7-point scale, indicating the level of perceived difficulty in dealing with the described behavior, with higher points indicating more difficulties. Example items include 'How easy or difficult is it for you to calm or soothe your baby when he/she is upset?' and 'What kind of mood is your baby generally in?'. The ICQ includes the following four subscales: Fussy/Difficult, Unadaptable, Dull, and Unpredictable [23]. However, in accordance with previous studies [28], we decided to name the second factor Sociable instead of Dull (with higher scores for less sociable). The ICQ is scored using the Norms for ICQ composite scores [33].

Psychometric properties

Previous psychometric reports of the ICQ have generally indicated sufficient to good reliability (internal consistency and test-retest) for the measure as a whole as well as for the subscale Fussy/Difficult, but more inconsistent results for the subscales Unadaptable, Sociable, and Unpredictable [e.g. 23, 24, 28]. For instance, Slonims and McConachie [28], reported an internal consistency of α = 0.78 for the Fussy/Difficult subscale, and α = 0.61 to 0.65 for the rest of the subscales, in a sample of parents of infants with Down's syndrome. This can be compared with original reports from Bates et al. [23] with alpha-values ranging from α = 0.39 (Sociable) to 0.79 (Fussy/Difficult). Consistent with previous reports, acceptable to good internal consistencies for the Fussy/Difficult subscale (ranging from α = 0.77 to α = 0.83), have also been reported in Swedish studies using general population samples [31, 32]. Alpha values in our sample are reported in Table 1. Regarding validity the evidence base is a bit scarcer, but the ICQ has generally shown good convergent validity with other measures of parent report child behavior [23, 25].

Translation process

The translation of the ICQ from English to Swedish followed recommendations from the World Health Organization [34]. Two independent professional translators with Swedish as native language, translated the ICQ from English to Swedish resulting in two Swedish versions of the questionnaire. After comparing the two Swedish versions and discussing choice of words, the final version was sent to back translation. The back translation from Swedish to English was performed by a professional translator with English as a native

language. Then, a comparison was made with the back translated version and the original version of the questionnaire in the research team. We found some differences between the two English versions that we discussed, and subsequently the Swedish version was adjusted to the most preferable expressions. A significant adaptation in the translation process involved changing 'mother' to 'parent', as this was considered more culturally relevant in a contemporary Swedish context.

Interviews

In order to assess the face validity of the ICQ among parents of children with CS, a subsample of the participants was interviewed about their thoughts on the questionnaire. The interviews took place in conjunction with the parents filling out the Swedish translation of the measure. All interviews followed the same semi-structured guide and included questions concerning the instructions and response alternatives (e.g. if they were clear enough and how they could be improved), the questions (e.g. if any question was difficult to understand), and their thoughts about the questionnaire in general (e.g. questions about the perceived relevance). All interviews were performed by the last author and each interview lasted between 5 and 15 min.

Analysis

The interviews were analyzed using conventional qualitative content analysis [35]. We chose this method since conventional qualitative content analysis is particularly useful in areas where previous research is limited. The process begins with thoroughly reading all the data multiple times to gain an overall understanding. Next, the data are examined word by word to identify and derive codes. During this stage, the researcher notes initial impressions, thoughts, and preliminary analyses. These codes are then organized into categories based on their relationships, allowing for the formation of meaningful clusters that group the data in a structured way [35]. The analysis was performed jointly by the first and last author.

Ethics

Prior to data collection, the study was reviewed by the Regional Ethical Review Board in Gothenburg (reference number: 856-13). The study was conducted according to principles in the Declaration of Helsinki.

Results

Missing values and reliability

Rates of missing data on the ICQ items were generally low (≤ 2%) and, as indicated by a Little's MCAR test, data were missing completely at random: $\chi^2(459) = 415.5$, $p = 0.928$. Notably, item 8 (i.e. the infant's response to their first solid food) had a very high rate (30.1%) of missing responses. Also, two items concerning parents' perceptions of their child's ability to play (item 18 and 26) had a slightly higher than average rate of missing responses (3.6 and 4.8%, respectively).

As displayed in Table 1, the internal consistency (reported in terms of Cronbach's alpha) was good for the scale as a whole (both the original 24-items version and the 28-items version), as well as for the subscales Fussy/Difficult and Unadaptable. The subscale Unpredictable had an alpha value close to acceptable, while the internal consistency of the subscale Sociable was low.

Table 1. Means, standard deviations and Cronbach's alpha values for the ICQ and its subscales.

ICQ Scales	Range	M	SD	α	Norms[a] M (SD)
ICQ: 24 items[b]	24–168	68.61	14.80	0.85	-
ICQ: 28 items	28–196	81.76	16.83	0.87	-
Fussy/Difficult	6–42	18.85	5.23	0.80	17.77 (5.88)
Unadaptable	4–28	8.65	3.47	0.76	8.90 (4.00)
Sociable	3–21	7.99	2.60	0.45	5.88 (1.85)
Unpredictable	3–21	8.06	2.79	0.66	7.32 (2.69)

ICQ, Infant Characteristics Questionnaire.

[a]Norm data provided by Bates et al. (1979) using a US sample, $N = 345–365$.

[b]'ICQ: 24 items' refers to the original version of the questionnaire and 'ICQ: 28 items' to the version including four experimental items.

Face validity: results from the interviews

Parents' responses to the interview questions resulted in the following three categories: (1) Clear structure and instructions, (2) Clarification of questions, and (3) Relevance of the questionnaire.

Clear structure and instructions

Parents generally reported no difficulties in understanding the instructions. However, several parents expressed a preference for the inclusion of 'not applicable' as one of the response options. This issue was in particular pointed out in relation to item 8 (reaction to solid food), which many perceived to be inapplicable and therefore left unanswered.

Overall, the parents were satisfied with the structure of the questionnaire as well as the response alternatives. However, it was also mentioned that it might have been easier with fewer response options and one parent suggested that all alternatives (and not just the endpoints and the middle) should have text associated with the number. However, importantly, the numbers were overall considered to be in concordance to the qualitative answers and the participants were able to find an answer that suited them.

Clarification of questions

A majority of the parents stated that they did not experience any difficulties in understanding the questions. Some parents gave examples of items that would benefit from clarifications. In relation to item 5, two parents mentioned that they found it difficult to interpret the word 'fussy' (translated to 'kinkig' in the Swedish version). Parents also requested better examples in question 20 regarding the child's reaction to changes. For instance, it was highlighted that 'going to church' is irrelevant to most, and that 'going on trips' is too indefinite.

A few parents stated that question 24 (rating the overall degree of difficulty) was unclear, but when they were asked to describe it in their own words, it was evident to us that they had interpreted the question correctly.

Relevance of the questionnaire

All parents but one reported that they found the questionnaire to be relevant in relation to their infant with CS. The parent that did not find it relevant found the items to be too general or difficult to interpret and suggested that there would be more open-ended questions for parents to describe their perceptions of the child more freely. Discussing specific items, questions relating to their child's ability to play (item 18 and B), and reactions to restrictions such as sitting in a highchair (item C) were by some parents considered to be more

relevant for older children. Also, as mentioned previously, some parents questioned the relevance of item 8, relating to first reactions of solid food. When asked whether the questionnaire omitted any relevant questions regarding their child, most parents responded negatively. However, six parents notably suggested that the questionnaire should include additional questions about sleep, such as those addressing regularity and the child's sensitivity to being awakened.

Discussion

This study describes the translation and preliminary evaluation of the ICQ (23; 6-months version), for use with parents of infants with CS in Sweden. In addition to the translation from English to Swedish, we performed face validation using interviews to explore parents' perceptions of the questionnaire. The ICQ was also distributed to the parents of 83 infants with CS in order to explore the reliability of the measure in this patient group.

Concerning the reliability of the ICQ, our results were in line with previous studies [23, 24, 28]. In our sample, internal consistencies were sufficient for the measure as a whole (α = 0.85), as well as for the subscales Fussy/Difficult (α = 0.80), and Unadaptable (α = 0.76). The internal consistency for the subscale Unpredictable (α = 0.66) was close to acceptable, but the internal consistency for the subscale Sociable (α = 0.45) was notably low. The strong performance of the Fussy/Difficult subscale and the weak performance of the Sociable subscale align closely with findings from previous research [23, 28, 31]. The persistent poor performance of the Sociable subscale in terms of reliability warrants the questioning of its usefulness as a measure of sociable temperament in infants. An important next step in the development of a Swedish version of the ICQ would be to collect enough data to thoroughly explore the factor structure of the measure – preferably both among infants with and without CS. Such an exploration would likely shed more light on the relation between the original subscales and the relevance of the subscale Sociable in Swedish samples. Relatedly, Carneiro et al. [26], found a factor structure different from the proposal by Bates et al. [23], for the Portuguese version of ICQ in a community sample of children between the age of 11 and 20 months. For instance, the Portuguese version of the ICQ included a joint factor for the subscales Sociable and Unadaptable (i.e., Negative adaptation to change/not sociable), and explained that this interconnection may be due to the relationship that exists between the way the child relates in interactions with others and how the adaptation to novelty, particularly to new people, occur [26]. If the concepts of unadaptable and (un)sociable in the context of ICQ constitute two sides of the same coin is something that calls for further exploration using the Swedish version.

The ICQ was developed in a sociocultural context different from that of contemporary Sweden. In addition, we sought out this measure with the aim of using it among parents of children with CS – a group in which it has not previously been employed. Therefore, a key part of this study was dedicated to face validity in terms of the parents' perceptions of the measure. Overall, parents considered the measure effective in capturing key aspects of their infants' temperament. They also found the instructions and questions to be generally clear and easy to interpret. However, several noteworthy observations were made. Many parents commented that the question regarding their child's reaction to solid food (item 8) was not applicable to their situation. This was also clearly indicated by a high rate of missing responses (30.1%) to this particular question. The perception of the question as not applicable could be due to the fact that the children had not yet been introduced to solid food or that the term ('fast föda' in Swedish) was misinterpreted. To avoid the latter, it is recommended that this item in future use of the scale contains a short description of the term or is clarified using examples. Parents also found that the example 'going to church' is largely irrelevant to the majority of individuals in Sweden. To enhance the questionnaire's adaptability to the Swedish context and to ensure inclusivity for people of various religious backgrounds, we recommend that this example be either removed or rephrased (e.g. 'going to the supermarket') in future use. Almost a third of the parents interviewed also mentioned that they would have found it beneficial to include more questions about sleeping behavior and difficulties. Future studies exploring psychological development in infants with CS should therefore consider adding a measure related to sleeping difficulties as these aspects were particularly highlighted as being of importance in our group.

The ICQ 6-months version includes 24 items and four additional experimental items [33]. In our interviews, two of these additional items were specifically highlighted, as some parents noticed that they seemed more relevant for older children (i.e. item B relating to the child's ability to play, and item C relating to reactions to restrictions such as in a highchair). Taking these results into account, along with the fact that the experimental items are not included in the subscale calculations, and previous evaluations [33] suggesting that items A and B likely belong to the Fussy/Difficultness factor (while items C and D do not significantly enhance the measure), we recommend adopting the 24-item Swedish version, excluding the four additional items, for future use.

Limitations

This study should be viewed in the light of its limitations. Firstly, although the aim of the study was to translate the ICQ and perform a first step-evaluation including an exploration of internal consistency and face validity, it would have been valuable to also include other aspects of reliability and validity. In order to gain a better understanding of the ICQ's psychometric properties and usefulness in both Swedish and CS populations, future studies are encouraged to utilize larger samples and explore its factorial, as well as construct (e.g. convergent and incremental), validity. However, the rigorous translation process and exploration of face validity should be considered as important strengths of our study.

Another limitation concerns the lack of information about the parents in this study. For instance, we lack both demographic information concerning parents' age and educational level. This limitation is in line with much previous research on children with CS and it has been highlighted that better control of parental background variables is needed to enhance the quality of CS research [13]. Moreover, since previous studies have indicated that parental and relationship factors such as maternal depression [36], and attachment quality [30], might influence ICQ ratings, these and other parental factors might also be worth considering in future studies. In relation to this, most previous studies using the ICQ have involved only mothers, whereas a strength of this study is that both mothers and fathers participated. However, since the parents completed the questionnaires as couples, we are unable to determine whether the responses equally reflect the views of both mothers and fathers. Additionally, this design limited our ability to explore potential gender differences in the ratings and reliability analyses. Notably, during the interviews, the interviewer (last author) observed that both mothers and fathers generally were equally engaged in discussing the questionnaire and its specific items. This observation could be seen as an indication that most mothers and fathers also actively participated in completing the questionnaire.

Conclusion

The Swedish version of ICQ [23] did, in accordance with previous psychometric reports and with the pronounced exception of the Sociable subscale, display acceptable to good reliability. Importantly, the ICQ seems to be acceptable to parents of children with CS in Sweden – a prerequisite for continued use and development. In order to further increase the understanding of the measure's usefulness in Swedish populations with and without CS, future studies should explore additional psychometric properties, including the factorial validity.

Disclosure statement

The authors report there are no competing interests to declare.

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