

# Testing the Imperforate Anus Psychosocial Questionnaire (IAPSQ) on a Sample of Egyptian Children

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**Citation:** Farrag S, Abu kassim NL, Shehata S (2019) Testing the Imperforate Anus Psychosocial Questionnaire (IAPSQ) on a Sample of Egyptian Children. Arch Pediatr 4: 170. DOI: 10.29011/2575-825X.100170

**Received Date:** October 28, 2019; **Accepted Date:** November 08, 2019; **Published Date:** November 13, 2019

## Abstract

Imperforate anus is a malformation of the anus, children with such type of congenital malformation usually undergo reconstructive surgery and be looked after by pediatric surgery nurses due to the problems with constipation and fecal incontinence after the colostomy is closed. Lack of control over bowels may affect a child's psychosocial adjustment.

**The Aims of This Study are:** (a) To evaluate the psychometric properties of the Arabic version of the Imperforate Anus Psychosocial Questionnaire (IAPSQ) on a sample of Egyptian children. (b) To assess the effect of (IA deformity, hypospadias, and rectal prolapse) on the psychosocial functioning of Egyptian children. (c) To compare the psychosocial functioning of children with congenital anomalies of the anus with those suffering from chronic diseases.

**Methodology:** Subjects and Methods Study sample consisted of 35 children (with congenital anomalies of the anus) from Mansoura University Children's Hospital (n=30), and Alexandria University Hospital (n=5), in Egypt.

**Data Collection:** The data set of the current study was obtained within 3 months (from January to March 2017).

**Data Processing, Statistical Analysis and Results:** Rasch analysis was used to evaluate the psychometric properties of the IAPSQ, as well as to generate the item difficulty and person ability measures. Analysis of the psychological dimension (23 items) gave a low person reliability (.37). With regard to the social dimension (12 items), the Rasch analysis showed a person reliability of .54. Comparisons between the Swedish Sample and the Egyptian Sample

**Psychological Domain:** The Egyptian sample scored this item higher, indicating greater perceived concern by their mothers. It is more of a concerned for the Swedish sample compared to the Egyptian sample. Fathers are perceived by the Egyptian sample to be less loving and thinking more about their conditions compared to their mothers.

**Social Domain:** Children distribution for this domain is also well spread out similar to the Swedish sample. Comparison between the two groups indicated that children with imperforate anus malformation has a higher quality of life (mean = 2.26 logits) compared to those children with chronic disease (mean = 1.78 logits). Reliability of measures is also higher for the study group (.76) compared to the comparison group (.41). The results of the DIF analysis showed that no significant DIF across the study and control groups.

**Keywords:** Cross Cultural Research; Imperforate Anus Psychosocial Questionnaire (IAPSQ); Multidisciplinary Practice; Parents involvement; Pediatric Surgery Nursing; Psychosocial Functioning / Quality of Life

## Introduction

Imperforate anus is a malformation of the anus; 1:4000 children are affected [1]. The extent to which the bowel is malformed varies. Children with intermediate or high imperforate anus generally receive a temporary colostomy. A reconstruction of the anal canal and the anus is performed when the child is about three months old. The newly created anus is narrow and must be manually dilated for two to three months in order for it to become adequately sized [2]. When the colostomy later is closed, it is common that problems with constipation and fecal incontinence develop among these children with imperforate anus [3,4]. The surgical management of low imperforate anus is generally made in a one-stage procedure in the neonatal period without creating a colostomy. As functional bowel problems are common children with imperforate anus often need regular enemas to prevent or reduce constipation and fecal incontinence. Lack of control over bowels may affect a child's psychosocial adjustment [5]. Associations have been found between soiling and psychiatric and psychosocial dysfunction [6]. Fecal incontinence and flatus are often inconvenient and produce an unpleasant smell [7], which is hard to hide and can be experienced as shameful.

Imperforate anus is an unusual malformation which requires advanced care. The caring of these patients has several aspects including the surgical reconstruction of the anus and the follow-up treatment, the family aspects, the child's psychosocial and physical function, and the aspects of the child's experiences of the medical treatment due to the malformation. This malformation and the multifaceted consequences lack research from the perspective of caring science. To attain most positive treatment results, there needs to be evidence based care and requirement of special competence, for nurses involved in the medical care and the follow-up treatment of children with chronic condition.

Pediatric nurses provide information to develop these practices. Specialist nurses involved in the care of children with imperforate anus (or other types of anomalies of the same nature) have a central task in assisting the child with functional bowel problems as well as giving support concerning psychosocial difficulties the child and their parents may encounter. Further, specialist nurses involved in care of children with imperforate anus have an obligation to encourage the parents and to strengthen them in the coping process and care of the child [8].

The overall aim of this clinical research project was to explore how imperforate anus may affect the psychosocial functions of children, their everyday life and their parents' life too; in order to optimize care for the children and as well for their families. This project also compares the results against the Swedish population. As the measurement of psychosocial functioning was based on an Arabic version of the Imperforate Anus Psychosocial Questionnaire

(IAPSQ), the psychometric properties of the questionnaire is also assessed to ensure the reliability and validity of the measurements derived from the questionnaire.

## Objectives of The Study

- To evaluate the psychometric properties of the Arabic version of the Imperforate Anus Psychosocial Questionnaire (IAPSQ) on a sample of Egyptian children.
- To assess the effect of (IA deformity, hypospadias, and rectal prolapse) on the psychosocial functioning of Egyptian children.
- To compare the psychosocial functioning of children with congenital anomalies of the anus with those suffering from chronic diseases.

## Methodology

### Subjects / Sample Characteristics

The sample of the present study consisted of 35 children (children who had congenital anomalies of the anus) from Mansoura University Children's Hospital (n=30), and Alexandria University Hospital (n=5), in Egypt. The study participants were not less than six years old, to ensure that they were able to read the questionnaire and write their own answers. A comparison group of patients (n=30) with other chronic health problems and / or those who had a one-day surgery were recruited to answer the questionnaire. This group was obtained from Mansoura University Children's Hospital via hospital records and through the help of hospital staff in the registration office.

### Setting

The study sample was obtained via the hospital records of the pediatric surgery patients who had their surgical treatment at Mansoura University Children's Hospital and Alexandria University Hospital, Egypt. Since the children and their family's compliance in visiting the surgery clinic for follow up purpose; was low, the study sample was small and therefore the researcher had to wait for a long time to collect this number of subjects. The study didn't explore the reasons behind the low rate of surgery clinic follow up by those children, however it could be related to the fragmented care or due to the absence of families /children having the same problem to support patients of IA or other congenital anomalies. {McCormick ME1, Ward E2, Roberson DW3, Shah RK4, Stachler RJ5, Brenner MJ6 (2015) Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams. *Otolaryngol Head Neck Surg.* Dec;153(6):914-20. doi: 10.1177/0194599815599525.}. It

could also be related to lack of educational Pamphlets that should be available and appropriate for this kind of patients. If these pamphlets were having consistent language, quantity and quality of content, and especially in relation to the capacity of helping in the homecare decision making process} This would have increased the follow up rate in these clinics.

### **Data Collection**

The data set of the current study was obtained within 3 months, (from Mansoura University Children's Hospital) while the 2<sup>nd</sup> data set was obtained from Alexandria university hospital from January to March 2017. Data processing, statistical analysis and interpretation of the analysis, compilation of data for scientific publications persisted approximately for one year.

### **Research Instrument**

**The Imperforate Anus Psychosocial Questionnaire (IAPSQ):** is a questionnaire covering the psychological (emotional, emotional/cognition, self-determination) and social dimensions including items about school, sport activities, peer relationships, self-esteem and emotional health. This questionnaire, which was developed by Nisell et al (2006), was used on children with a more severe type of the anorectal malformation, high and intermediate imperforate anus, at the Astrid Lindgren Children's Hospital, in Stockholm, Sweden [9,10].

The Swedish colleagues provided the research team with the English version of the instrument. One of the researchers who is natively bilingual undertook the process of translation from English to Arabic, and back translation of the instrument from the Arabic translated version back to the English. The Arabic version was further evaluated by experts who are familiar with congenital anomalies.

### **Ethical Consideration**

These types of malformation are found on a sensitive part of the body and the consequences are often associated with impurity and shame. Questions about this subject are sensitive and may arouse difficult feelings among the children and their parents. Therefore, the researchers (nurses and medical doctors) had to obtain a written and/or oral consent from the parents of those children. The study proposal was submitted to the IRB approval for each setting included in the study. Approval was given as the committee responded that research does not contain any invasive procedure for the children and safety is guaranteed.

### **Consent**

In accordance with Fraser guidelines (Gillick v West Norfolk and Wisbech AHA [1986] AC 112) it is recognized that the child or young person should be involved in their own care

and contribute to decisions according to their understanding and competence. patients were provided with appropriate information on the procedure to be undertaken and its associated risks. Such information was provided in writing to support patients and their families in making informed decisions. It was also necessary for those involved in the care of children to understand that consent not always required to share information about a child. Obtaining families' consent for their children to participate in research within the Arab region was not an easy task, specifically in Egypt, as people hesitate to provide a written consent for participation in any type of research. However, they can easily provide an oral consent and this is simply explained as a culturally sensitive issue.

### **Data Analysis**

In data analysis, the same approach in classifying items of the instrument into two broad categories were followed: (I) Psychological, and (II) Social. The psychological domain consisted of 23 items with the following sub-categories [quite the same as carried out in the original study]: emotional (12 items); emotional/cognition (7 items); self-determination (4 items). The Social domain comprised 12 items.

To evaluate the psychometric properties of the instrument, several tests of reliability and validity were carried out using Rasch analysis. Rasch analysis is an item response theory model. It was used to evaluate the psychometric properties of the IAPSQ, as well as to generate the item difficulty and person ability measures. Validity of the items were assessed through item fit statistics and the Rasch dimensionality analysis, which involves principal components analysis of residuals. Distribution of item difficulty was also evaluated to determine how well the measured construct is defined in terms of the increasing difficulty of the items. Ordering of the items were compared against those found in the Swedish sample. Comparison of the two populations was deemed appropriate as both were analyzed using the same statistical method.

## **Results**

### **Overall and Sub-Construct Analysis**

In the overall analysis, all 34 items showed a person reliability of .51 with 2 items with negative point measure correlations and 5 items with point measure correlations less than 0.1 (Table 1). Subsequent analysis, after deletion of these items resulted in a person reliability of .70. Analysis of the psychological dimension (23 items) gave a low person reliability (.37). One item had negative point measure correlation (Item 12: 'I feel sad'), and two items had point measure correlation below .10 (Table 1). Item 12 was then reversed coded, and this resulted in a person reliability coefficient of .57. Deletion of Item 12 (I feel sad) and Item 13 (I

feel angry) gave a slight change in the person reliability (.58). Since the improvement in reliability is almost negligible, Item 13 (I feel angry) was kept and not removed from analysis. The amount of variance explained by the measures (person and item) was 60.9% of the total variance.

Domains / Dimensions	Cronbach's Alpha Coefficient	Comments
Psychological (23 items)	.37 (initial analysis)	After deletion of items 12 ("I feel sad")
	.57 (after deletion)	
Social (12 items)	.54 (initial analysis)	After deletion of item 24 ("How do you like school?") and item 25 ("How is your relationship with your teacher")
	.71 (after deletion)	

**Table 1:** Summary of reliability coefficients for initial and final analysis after deletion of misfitting items.

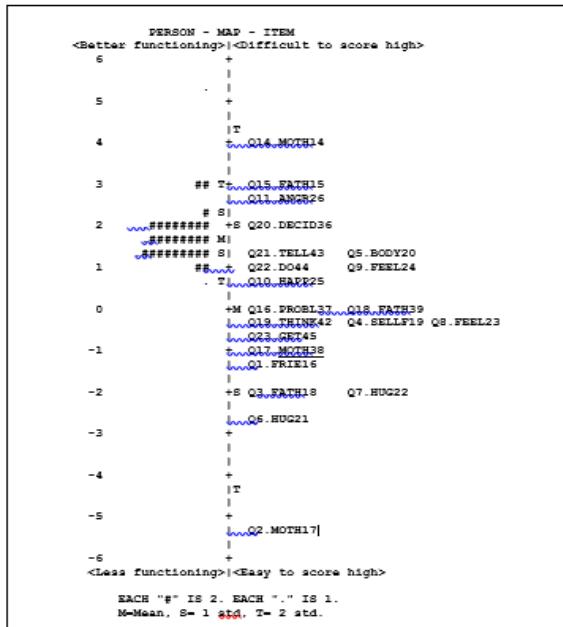
With regard to the social dimension (12 items), the Rasch analysis showed a person reliability of .54. One item (Item 24 – "I like school") had a low point measure correlation (.01) and fit statistics outside the recommended range (Infit MNSQ, 1.57; Outfit MNSQ 1.75). After removing the item, the person reliability improved to .63. However, another item (Item 25, Relationship with teacher) showed some misfit (Infit MNSQ, 1.70; Outfit MNSQ 1.88). Removing both items increased the person reliability to .71. All other items showed acceptable fit statistics and the variance explained by the measures (both persons and items) was 67.7% of the total variance (Table 2).

Item	Measure	Model S.E.	Infit MNSQ	Infit ZSTD	Outfit MNSQ	Outfit ZSTD	Pt-Measure Correlation
<b>Overall Analysis</b>							
Q12. I feel sad	1.94	0.20	1.52	2.6	1.50	2.5	-.45
Q18. Father think about condition.	-0.26	0.18	1.06	0.4	1.06	0.4	-.02
Q13. I feel angry.	3.81	0.21	1.18	1.0	1.16	0.9	.01
Q15. Father feels when he thinks about your condition	2.69	0.20	1.11	0.1	1.09	0.6	.01
Q24. Do you like school?	-1.40	0.19	1.33	2.0	1.36	2.1	0.3
Q2. Does your mother love you?	-5.29	0.71	0.99	0.2	1.01	0.3	.03
Q14. Mother feels she thinks about your condition	3.55	0.21	1.21	1.20	1.20	1.1	.08
<b>Psychological Domain</b>							
Item	Measure	Model S.E.	Infit MNSQ	Infit ZSTD	Outfit MNSQ	Outfit ZSTD	Pt-Measure Correlation
I feel sad	1.87	0.20	1.52	2.6	1.51	2.6	-.38
I feel angry	3.69	0.20	1.15	0.9	1.13	0.8	.01
Does your mother love you?	-5.61	0.71	0.99	0.21	0.96	0.2	.05
<b>Social Domain</b>							
Item	Measure	Model S.E.	Infit MNSQ	Infit ZSTD	Outfit MNSQ	Outfit ZSTD	Pt-Measure Correlation
Item 24: I like school	-1.31	0.20	1.57	3.2	1.75	3.9	.01
Item 25: Relationship with teacher	-0.32	0.19	1.43	2.5	1.49	2.7	.23

**Table 2:** Item fit statistics for Overall and Individual Analysis of the Psychological and Social Domains.

## Person and Item Distribution

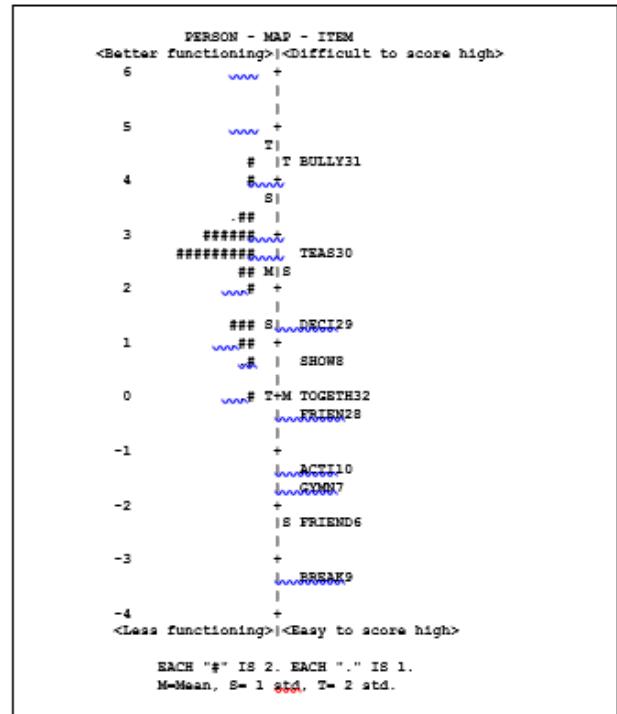
Persons distribution for both the psychological (0.59 logit to 5.30 logits) (Figure 1) and social domains (-0.03 logit to +6.05 logits) (Figure 2) are less spread out compared to the distribution of items (Psychological dimension, -5.48 logits to +3.88 logits; Social Dimension, -3.35 logits to +4.44 logits). Item reliability for the Psychological domain was .98 with a separation of 8.03. For the Social domain, item reliability was .99, with separation index of 9.30.



**Figure 1:** Psychological Dimension (21 Items with Item 12 [I feel sad] and Item 13 [I feel angry] removed).

## Comparisons between the Swedish Sample and the Egyptian Sample Psychological Domain

The most apparent difference between the two samples are the distribution of items along the logit scale. Items are more spread out for the Egyptian sample spanning more than 9 logits compared to the Swedish sample (about 4 logits). The ordering of the items relative to other items on the scale are rather similar. The most important difference relates to the item “Does your mother think about your condition?” (MOTH38). The Egyptian sample scored this item higher, indicating greater perceived concern by their mothers. Another is the item, “How much do you like your body” (BODY20); it is more of a concerned for the Swedish sample compared to the Egyptian sample. Fathers are perceived by the Egyptian sample to be less loving and thinking more about their conditions compared to their mothers.



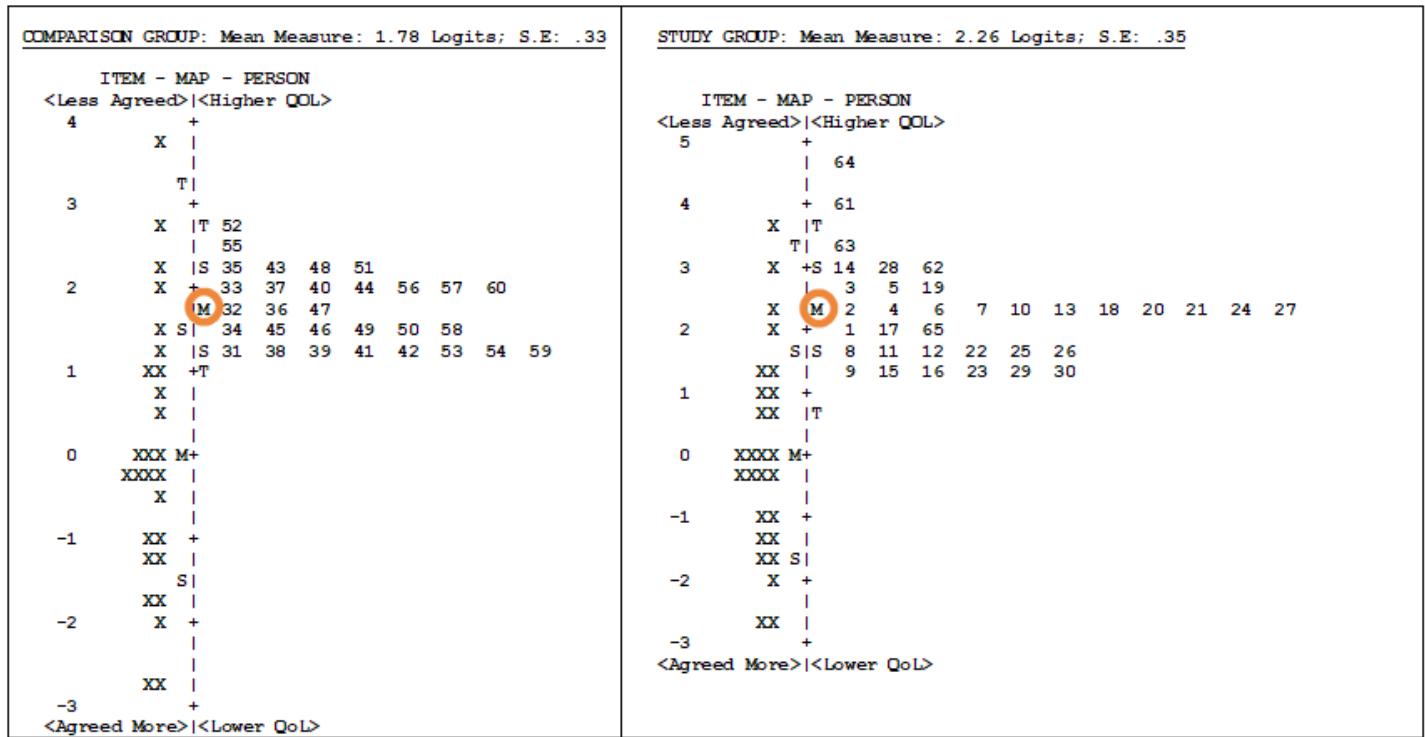
**Figure 2:** Social Dimension (10 items with Item 24 [I like school] and Item 25 [Relations with teacher] removed).

## Social Domain

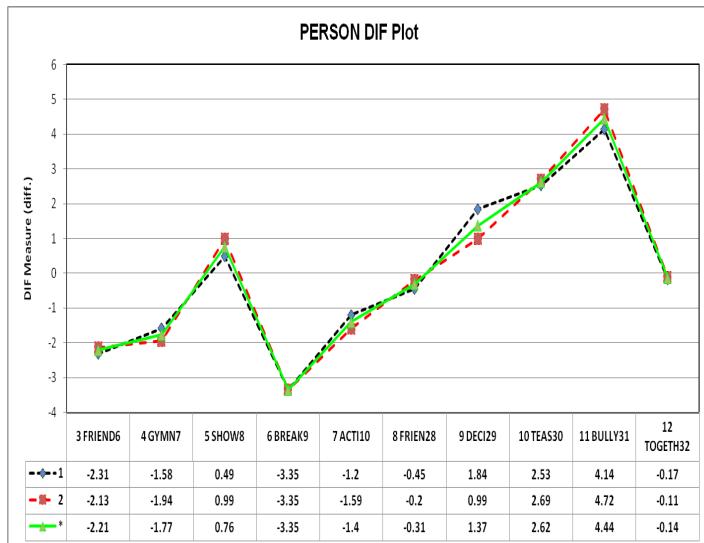
Similar to the psychological domain, the item distribution is larger for the Egyptian sample (approximately 8 logits) compared to the Swedish sample (approximately 2 logits). The item that showed clear difference in difficulty level is the item, “Have you been bullied at school? (BULLY31). This item is more easily agreed to by the Swedish sample compared to the Egyptian sample. Activities, gym, breaks, and friends are similarly perceived by both the Swedish and Egyptian sample. Children distribution for this domain is also well spread out similar to the Swedish sample.

## Comparison of Study Group (Imperforate Anus) With The Comparison Group (Other Chronic Disease)

Comparison between the two groups indicated that children with imperforate anus malformation has a higher quality of life (mean = 2.26 logits) compared to those children with chronic disease (mean = 1.78 logits). Reliability of measures is also higher for the study group (.76) compared to the comparison group (.41) [11-16] (Figure 3).

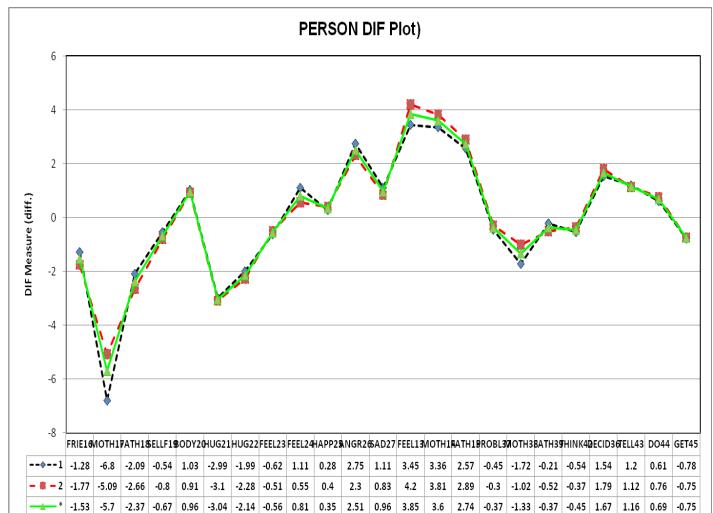


**Figure 3:** Distribution of items and persons in study and comparison groups.



**Figure 3 (a): DIF analyses of the psychological items. No significant DIF ( $p < .05$ )**

Note: 1= Study Group, 2= Control Group. 3=Baseline (Combined)



**Figure 3 (b) ... DIF analyses of the social items. No significant DIF ( $p < .05$ )**

Note: 1= Study Group, 2= Control Group. 3=Baseline (Combined)

It is shown above that all groups combined in a single analysis as per the Stockholm study. The results of the DIF analysis demonstrated that, no significant DIF across the study and control groups.

## Discussion

In comparison to the Swedish sample, the person reliability for our Egyptian sample is generally lower due to the lack of variability as a result of exclusion of healthy subjects. Our Egyptian sample of children were also less distributed on the Logit Scale for the same reason as they consisted of post-operative subjects and children with chronic health conditions (comparison group). A healthy group of children were not recruited as the researchers were primarily interested in comparing these two groups of children and how the Arabic version of the instrument measures the psychological functions of Egyptian children compared to the original Swedish children who had similar health conditions. It is worth mentioning that the social domain of the instrument gave better measurement (Cronbach's Alpha = .71) which means that our patients' responses to the items in this domain is more consistent as compared with the psychological domain [17-23].

**Psychological Domain:** Comparison of item ranking: compare with the Swedish sample

**Social Domain:** Comparison of item ranking: compare with the Swedish sample

### Response profile of the Egyptian sample:

- Respondents responses that don't fit the general structure.
- Children's responses to fathers' involvement and attitude towards the children's condition).

Interpretation of patients' responses regarding family's (mother's involvement)

In children's wellbeing in the light of cultural differences

## Author's Contribution

Study conception and design: Dr. S. Farrag

Data acquisition: Dr. S. Farrag and Prof. S. Shehata

Analysis and data interpretation: Prof. Noorlide Abu Kassim and Dr. S. Farrag

Drafting of the manuscript: Dr. S. Farrag

Critical revision: Prof. Noorlide Abu Kassim and Dr. S. Farrag

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