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Cross Cultural Adaptation and Validation of a Self-Reporting Tool to Assess Health-Related Quality of Life for Egyptians with Extremity Bone Sarcomas in Childhood or Adolescence

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Cross-cultural adaptation and validation of a self-reporting tool to assess health-related quality of life for Egyptians with extremity bone sarcomas in childhood or adolescence

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Declaration of Authorship

I, Nesma Farid, declare that this thesis titled, "**Cross-cultural adaptation and validation of a self-reporting tool to assess health-related quality of life for Egyptians with extremity bone sarcomas in childhood or adolescence**" and the work presented in it are my own. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University.
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- Where I have consulted the published work of others, this is always clearly attributed.
- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
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Signed:
Nesma Medhat Mohamed Farid

Date:
30-10-2022

Abstract

Validated self-reporting tools are required to evaluate the functional outcome and health-related quality of life (HRQOL) for Egyptians who had extremity bone sarcomas in their childhood or adolescence. Thus, we pursued cross-cultural adaptation and validation of the pediatric Toronto Extremity Salvage Score (pTESS) and Toronto Extremity Salvage Score (TESS) to assess the physical function of children and adult survivors following surgeries of extremity bone sarcomas. Modified versions of pTESS and TESS, which contain additional mental domains, were developed to allow the evaluation of HRQOL using a specific instrument for childhood bone cancer. The internal consistency of the original pTESS and TESS as well as their modified versions was assessed with Cronbach's alpha. The intraclass coefficients (ICC) were calculated for test-retest reliability, and the correlations between scores of the generic Pediatric Quality of Life Inventory (PEDSQL 4.0) and each of the pTESS and TESS scores were used to confirm convergent validity. Exploratory Factor Analysis (EFA) was only feasible for pTESS-leg; therefore, the construct validity of the remaining versions was assessed by calculating the average inter-item correlation coefficients. The pTESS/TESS scores were also compared based on various patients' characteristics. In a total sample of 233 included participants, 134 responded to pTESS leg, 53 to TESS-leg, 36 to pTESS-arm, and only 10 to TESS-arm. All versions of pTESS and TESS showed excellent internal consistency (Cronbach's alpha > 0.9), good test-retest reliability (ICC >0.8), moderate to strong correlations with PEDSQL, and acceptable average inter-item correlation coefficients (≥0.3). Based on the scree plot, 3 factors were extracted for pTESS-leg in which all mental items were loaded on a separate factor with acceptable factor loadings (>0.4). Using the original versions of pTESS/TESS-leg only, adults showed significantly higher scores than younger participants. In the large group representing limb salvage surgery in lower extremities, those who were still receiving chemotherapy, had done primary surgery within only one year, or had tumors located in the tibia showed significantly inferior pTESS/TESS scores. In conclusion, the culturally adapted pTESS and TESS are shown to be valid and reliable self-reporting tools for assessing the functional outcome in Egyptians affected with extremity bone sarcomas. The added mental domains enabled the assessment of the overall health status of this particular population. Future studies should evaluate the ability of pTESS and TESS to track progress over time and include more participants, especially those with upper extremity tumors.

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Last but not least, I would like to dedicate this thesis to my father, the late Medhat Farid, who could not have been a greater role model for his daughter.

Contents

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List of Abbreviations

AUC	**American University in Egypt**
CAT	**Computerized-adaptive testing**
CCHE	**Children cancer hospital Egypt**
COVID-19	**Coronavirus disease 2019**
EFA	**Exploratory factor analysis**
HRQOL	**Health related quality of life**
ICC	**Intraclass coefficient**
IIC	**Inter-item correlation coefficient**
IQR	**Interquartile range**
MSTS	**Musculoskeletal Tumor Society**
N/A	**Not applicable**
PEDSQL	**Pediatric Quality of Life Inventory**
PNET	**Primitive neuroectodermal tumor**
PODCI	**Pediatrics Outcomes Data Collection Instrument**
PROMIS	**Patient-Reported Outcome Measurement Information System**
PROs	**Patient-reported outcomes**
pTESS	**Pediatric Toronto Extremity Salvage Score**
pTESS-arm	**Pediatric Toronto Extremity Salvage Score of upper extremity**
pTESS-leg	**Pediatric Toronto Extremity Salvage Score of lower extremity**
SD	**Standard deviation**
SF-36	**36-Item Short Form Survey**
TESS	**Toronto Extremity Salvage Score**
TESS-arm	**Toronto Extremity Salvage Score of the upper extremity**
TESS-leg	**Toronto Extremity Salvage Score of the lower extremity**
VAS	**Visual Analogue Scale**

Chapter 1

Introduction

1.1. Background and significance

Osteosarcoma and Ewing sarcoma/ Primitive neuroectodermal tumor (PNET) are the first and second most common types of malignant bone tumors that account for 6 percent of all childhood cancers (Degnan et al., 2022; Heare et al., 2009; SEER program, 2011). Over two-thirds of bone sarcomas are primarily located in extremities, mostly affecting the lower limbs (57%), and less frequently occurring in the upper limbs (13%) (Heare et al., 2009; SEER program, 2011). Surgery that involves a wide resection of malignant bone tumors is considered the mainstay of treatment, whereas chemotherapy is vital for improving 5-year event-free survival rates that can range from 60 to over 70% in localized bone cancer (Smeland et al., 2019; Womer et al., 2012). In Ewing sarcoma, local control modalities would involve postoperative radiation therapy when surgical margins are shown to be positive for viable tumor cells (Gaspar et al., 2015). Radiotherapy alone is also an acceptable alternative to surgery, especially for unresectable lesions of Ewing sarcoma/PNET (Gaspar et al., 2015). Similar clinical outcomes were shown with radiotherapy in Ewing sarcoma, compared to surgery, in terms of event-free survival, overall survival, and distant failure rates; however, higher rates of local recurrence were noted (DuBois et al., 2015; Dunst et al., 1996). Moreover, functional impairment is not only an expected outcome of post-surgical complications as radiotherapy may also lead to limb length discrepancies and joint contractures (Gutowski et al., 2016). In general, children with extremity bone sarcomas would undergo limb salvage surgery, such as allograft bone replacement or reconstruction with endo-prosthesis; advanced cases are more prone to amputation, particularly with Osteosarcoma diagnosis in which radiotherapy is not an equivalent option for local control. (Gaspar et al., 2015; Hoffman et al., 2013). Although surgery is crucial for cure, it contributes to a relatively higher rate of impaired physical function among survivors of childhood cancer (Hoffman et al., 2013; Stokke et al., 2015).

Few studies have measured patient-reported outcomes (PROs) for children with bone sarcomas. They either used generic health-related quality of life (HRQOL) measures, such as Pediatric Quality of Life Inventory (PEDSQL) 4.0 generic core instruments and Pediatrics Outcomes Data Collection Instrument (PODCI), or disease-specific tools for evaluating functional outcomes after surgery such as Toronto Extremity Salvage Score (TESS) and Patient-Reported Outcomes Measurement Information System (PROMIS) (Bekkering et al., 2012; Frances et al., 2007; Hinds et al., 2009; Stokke et al., 2015; Sun et al., 2012; Wilke et al., 2019).

Despite the fact that previous results were quite conflicting, due to the heterogeneity of the recruited groups and chosen tools, survivors of childhood bone sarcoma had generally shown inferior HRQOL outcomes, compared to the population norms (Barrera et al., 2012; Bekkering et al., 2012; Sun et al., 2012). Regarding the used generic tools, both of PEDSQL and PODCI have been validated in pediatric orthopedic settings, but PEDSQL is a quite shorter form that was shown to be more reasonable for usage in the child population (Mahan et al., 2014). However, these tools are still considered broad measures that could be missing important items for assessing the extent of physical disability (Davis et al., 1996). In contrast, a disease-specific tool would optimally evaluate the functional outcomes after local control in patients with bone sarcomas. The Musculoskeletal Tumor Society (MSTS) scoring system has been widely used as a disease-specific instrument for assessing the functional and emotional outcomes in orthopedic oncology, but apart from one domain, all other items should be filled by the surgeon, not the patient (Leopold, 2019). Since the interpretation of physicians could significantly differ from the patients' perception of their own functional outcomes, the MSTS had been commonly substituted by the patient-reported TESS to avoid assessment bias (Davis et al., 1996; Ghert, 2017; Leopold, 2019).

Although TESS has been extensively used for assessing physical function after surgery, it was originally developed for an age group ranging from 12 to 60 years, and it includes items that seem irrelevant for children and adolescents (Davis et al., 1996; Piscione et al., 2019). Accordingly, the pediatric Toronto Extremity Salvage Score (pTESS) was developed and validated to be used for North American patients aged from 8 to 17.9 years (Piscione et al., 2019). Not only different languages but varying cultures necessitate the validation of self-reporting tools when intended for use in diverse settings (Beaton et al., 2000; Guillemin et al., 1993; Leopold, 2019). Thus, the pTESS needs to be evaluated and validated across various pediatric populations, similar to the cross-cultural adaptation and validation of TESS that have been done in several countries (Bolia et al., 2021; Kim et al., 2015; Ogura et al., 2015; Rossi et al., 2020; Sæbye et al., 2014; Saraiva et al., 2008; Trost et al., 2021; Willeumier et al., 2017; Xu et al., 2016). To consider a HRQOL instrument valid and reliable, psychometric properties, such as construct validity, convergent validity, internal consistency and test-retest reliability, should be assessed and reported (DeVon et al., 2007; Guillemin et al., 1993; Leopold, 2019).

In respect to the physical domain of health status, pTESS and TESS would be superior to generic quality of life (QOL) measures for assessing patients with extremity bone sarcomas (Kim et al., 2015; Rossi et al., 2020). On the contrary, pTESS and TESS lack a mental domain which is essential in evaluating the overall HRQOL of these patients (Ghert, 2017; Ogura et al., 2015). Previously reported TESS scores were proved to be highly correlated with the physical and social domains of the 36-Item Short Form Survey (SF-36), but not linked to its mental component score (Ghert, 2017; Ogura et al., 2015; Trost et al., 2021). The reliance on a complementary

HRQOL measure in addition to the pTESS/TESS would provide a thorough assessment of the overall health condition. For instance, Stish et al. (2015) had used TESS and PEDSQL together to reflect on the functional outcome and HRQOL, respectively. Nevertheless, it is expected that respondents would consider such a combined survey too long and tedious to complete. The PROMIS is a single computerized-adaptive testing (CAT) tool with several domains, including physical function and depression form, and it seems a proper choice that has been previously used following orthopedic surgeries (Ploetze et al., 2019; Wilke et al., 2019). Using CAT for obtaining PROs is generally preferable due to the customized selection of items, based on the participants' choices in the preceding items, which guarantee convenient and efficient assessment for respondents and researchers (Brodke, 2016; Ghert, 2017). However, it might be unreasonable to offer a CAT tool in Egypt where computer illiteracy is expected to be prevalent among a portion of its poorer residents; less than a quarter of Egyptian households in rural areas own a computer (Demographic and Health survey program, 2015). Adding a mental domain to the disease-specific pTESS or TESS could be a better alternative that would fit various cultures, especially in developing countries.

To our knowledge, PEDSQL is the only validated HRQOL measure that can be readily used for the Egyptian child population (El-Beh et al., 2018). In addition to confirming the reliability and validity of the Egyptian PEDSQL version, El-Beh et al. (2018) have found than children with chronic conditions and critical illness, including acute lymphocytic leukemia, had lower scores compared to healthy Egyptian children. Such outcomes were comparable to global findings which also showed similar PEDSQL mean scores across different healthy populations (El-Beh et al., 2018; Reinfjell et al., 2006; Varni et al., 1999). In a single center in Egypt (Children Cancer Hospital Egypt [CCHE] -57357), different types of surgeries are feasible for patients with extremity bone sarcomas, such as vascularized autograft, adult prosthesis, minimally invasive expandable prosthesis and rotationplasty; due to the high cost and unavailability, non-invasive expandable prosthesis and allograft bone replacement are not used (El Ghoneimy, Shehab, Farid, 2022; El Ghoneimy, Zamzam, et al., 2021). The MSTS scoring system is the only method that is routinely used to assess the functional outcomes in this population (El Ghoneimy, Shehab, Farid, 2022). Even though most of the recruited patients in a previous CCHE study had shown excellent MSTS scores, the comparison of these scores across different surgical modalities has not been reported before. Moreover, self-reporting tools for assessing PROs had not been tried yet (El Ghoneimy, Shehab, Farid, 2022). The recently validated Egyptian version of PEDSQL represents a great opportunity for evaluating the validity of other disease-specific and patient-derived tools. Accordingly, the cultural adaptation and validation of pTESS as well as conducting a modified version that includes an additional mental domain would provide a single self-reporting instrument for assessing the functional outcome and HRQOL in Egyptian children with extremity bone cancer. This would be more informative than using the original version of pTESS and more convenient than relying on the broad PEDSQL survey. Likewise,

the validation of TESS is required, so it can be used for adult survivors of childhood bone cancer. These validated Egyptian versions of pTESS and TESS could provide PROs with acceptable soundness that would aid the orthopedic surgeons in decision making and emphasize the importance of considering the impact of different local control modalities on the HRQOL.

1.2. Hypothesis and specific aims

In Egypt, there is a lack of validated tools to measure the extent of physical disability and QOL following surgeries of extremity bone sarcomas. Our hypothesis was that pTESS (for pediatrics) and TESS (for adult survivors) are reliable and valid self-reporting tools for assessing the functional outcome of Egyptians who underwent surgery for extremity bone sarcomas in their childhood or adolescence. The primary aim of this study was to perform cross-cultural adaptation and validation of pTESS and TESS, while the secondary aims included modifying pTESS and TESS to involve additional mental domains, comparing the modified version scores of participants to their original version scores, and evaluating these modified forms as potential HRQOL measures specialized for patients with extremity bone sarcomas. Other secondary aims were measuring the HRQOL among respondents who participated at different time points from the date of primary surgery and assessing differences in scores based on various characteristics of the respondents, such as age, gender, histological diagnosis, or tumor location.

Chapter 2

Methods

2.1 Study design and setting

This is a cross-sectional study in which data were collected using the modified pTESS and TESS, which contain mental domains, in addition to the PEDSQL 4.0 generic core instrument. Since the Arabic PEDSQL had been already validated in Egypt (El-beh et al., 2018), the scores of its child form and adult form were used to validate the culturally adapted pTESS and TESS, respectively. Avoiding assistance at the time of the survey, by any of the study members or parents, was guaranteed to eliminate the risk of bias and ensure that all measures would be self-reported.

2.2 Target population and survey methods

Patients were considered eligible for recruitment in the study if they had been diagnosed with Osteosarcoma or Ewing sarcoma/PNET of upper or lower extremities in their childhood or adolescence, undergone primary surgery (+/- revision surgery) at least three months before the time of participation, visited the orthopedic clinic between January 2022 and June 2022, and aged 8 years or over. Those who had progressive disease/relapse after surgery, or were unable to fill out the questionnaires on their own were excluded from the study. A revision surgery done in less than 3 months was a reason for exclusion only if the patient did not revisit the clinic later in the study period. We also excluded participants who asked for significant guidance that was beyond clarifying a few words within the survey, and those who had more than 25% of their pTESS/TESS responses as missing values or "not applicable" or missed over 50% of the PEDSQL items (Figure.1). The demographics and clinical data of all patients were originally available in their electronic medical records and routinely collected via REDCap software, a disease efaspecific registry. Hence, all the characteristics of interest in this study were simply exported for analysis (Table.1).

Eligible patients were targeted to fill out the survey at their periodic follow-up visit to the orthopedic clinic at CCHE. After one week, we asked the respondents to answer the survey again by sending a link to its electronic form via WhatsApp. These retests were required for assessing the test-retest reliability. Responses to retest were done within one to six weeks after the initial tests. Those who responded after 2 weeks were asked if they believe their conditions had considerably changed in the test-retest interval.

2.3 Instruments

As per the previously published guidelines, we performed a cross-cultural adaptation of all the studied forms, apart from the previously validated PEDSQL (Beaton et al., 2000; Guillemin et al., 1993). The initial two translations of pTESS and TESS were independently done by an informed translator (orthopedic surgeon) and an uninformed translator (with a medical background). This was followed by two independent back translations that were done by a naive professional translator and another bilingual individual with a medical background. The translators and authors of the study reviewed all the translated versions and agreed on further minor modifications before confirming the final forms of pTESS and TESS.

The TESS is a self-reporting questionnaire with two versions, for the upper extremities (29 questions) and lower extremities (30 questions). After reviewing the instructions with participants, it takes around 10 minutes to complete this survey. Each question assesses the difficulty of performing a certain task related to dressing, work, or other usual physical and social activities. Because we expected that our young adult population had not completed their education yet, we modified the questions, originally asking about work performance, to ask about either studies or work, whichever applies to the participant. The answers are basically ordered in a 5-point scale that were supposed to start with "Impossible to do". However, we changed the order and wording of responses to be similar to pTESS where options start with "not hard at all" and end with "too hard I can't do this". All items also included a 'not applicable' option (N/A) that should be discarded when calculating the final standardized score which ranges from 0 to 100; higher scores indicate better outcomes (Davis et al., 1996).

The pTESS is a recent format that has been developed for assessing the functional outcome of the pediatric population. The total number of questions is 27 for the upper extremity version and 30 for the lower extremity version. The final scores of respondents were calculated exactly as TESS, while the last 2 overall questions in TESS (questions A and B) were replaced by two general Visual Analogue Scales (VAS) scored on a line from 1 to 10 (Piscione et al., 2019).

Both of the modified versions of pTESS and TESS included the same additional mental domain which involved 6 questions that were adopted from the pediatric anger, fatigue, cognitive, and depression domains of the Neuro-QOL system as well as the mental component of SF-36; the widely used tool for assessing HRQOL (Lai et al., 2012; Ware & John, 2000). Although the core of this mental domain was kept unchanged, we simplified the wording to suit our pediatric population. The possible responses to each of the additional mental items represent a 6-point ordinal scale. To follow the same standardized scoring used

for the original pTESS and TESS, we rescaled these items to a 5-point range without changing the number of possible responses (Kalmijn, 2014). The rescaled values were only used upon calculating the total standardized score, while the original scale was used in descriptive analyses to avoid confusion during data interpretation.

The PEDSQL 4.0 generic core survey was used to measure the HRQOL of all participants. It takes about 4 minutes to complete this questionnaire which consists of 23 items that cover 4 domains; physical, emotional, social, and school/work functioning. The adult forms of PEDSQL were used for those who were 18 years or above at the time of the survey. Any missing responses in PEDSQL were considered invalid and excluded from the final scores which range from 0 to 100 with higher scores indicating superior HRQOL. (El-beh et al., 2018; Varni et al., 1999).

2.4 Validation and statistical analysis

The scores of all the answered questions (other than N/A responses) were added for computing the total standardized scores of the modified pTESS and TESS. Responses to the additional mental items were excluded while calculating the final scores of the original pTESS and TESS versions. Since we found that some final scores were not normally distributed, we intended to report median scores and interquartile range (IQR) for all pTESS and TESS groups. We tested the difference between scores of original pTESS/TESS and modified pTESS/TESS using paired t-test. The internal consistency of all pTESS and TESS was assessed by Cronbach's alpha in which pairwise deletion of N/A and missing responses was done, instead of list-wise deletion, to prevent dropping several valid cases from the analysis. We also checked the occurrence of floor or ceiling effects by identifying whether more than 15% of participants obtained the highest or lowest possible score, respectively (McHorney & Tarlov, 1995). The test-retest reliability was determined by evaluating the ICC values based on the criteria suggested by Koo & Li (2016). For construct validity, an exploratory factor analysis (EFA) was intended to explore the latent structure of the modified pTESS and TESS, and examine the grouping of items after adding the mental domain. The varimax rotation method was chosen and the rotated factor loadings were considered acceptable if exceeding 0.4. The extracted number of factors was based on Kaiser's criteria and observing the "elbow" point in a scree plot (Braeken & Van Assen, 2017; Cattell, 1966). However, we were able to conduct EFA for pTESS-leg only, as other versions involved insufficient numbers of participants. Thus, we have only checked if the average inter-item correlation coefficient for the remaining groups fell between 0.3 and 0.7 (DeVon et al., 2007; Ferketich, 1991). For convergent validity, the scores of pTESS and TESS (the original and modified versions) were compared to the scores of PEDSQL by reporting Pearson or Spearman's rank correlation coefficient, depending on the nature of the outcome data.

Moreover, differences in total scores based on patient characteristics were examined using the Mann-Whitney U test. For variables involving more than 2 groups, Kruskal-Wallis H test was used instead. The number of participants who did amputation or rotationplasty was very small (n=6); therefore, they were excluded when comparing differences in scores, based on other factors, to avoid affecting the results of the limb salvage surgery group, which represents the largest group of patients. Those who had temporary spacers in their lower extremities were also excluded from any analyses other than the survey validation since future improvement is expected after reconstruction. Alternatively, spacers in the upper extremities were intended to be permanent which made their corresponding cases eligible for inclusion even during the assessment of secondary aims. All the statistical tests were carried out using SPSS software (version 20) and R statistical environment (version 3.4.4).

2.5 Ethical considerations

This study was approved by the institutional review board of CCHE and the American University in Cairo (AUC) (See Appendix 2). Written consent forms were obtained from participants and/or their legally authorized representatives, depending on the respondents' age. A safe climate was provided for participants while completing the survey.

Figure 1: Flow diagram of the survey respondents

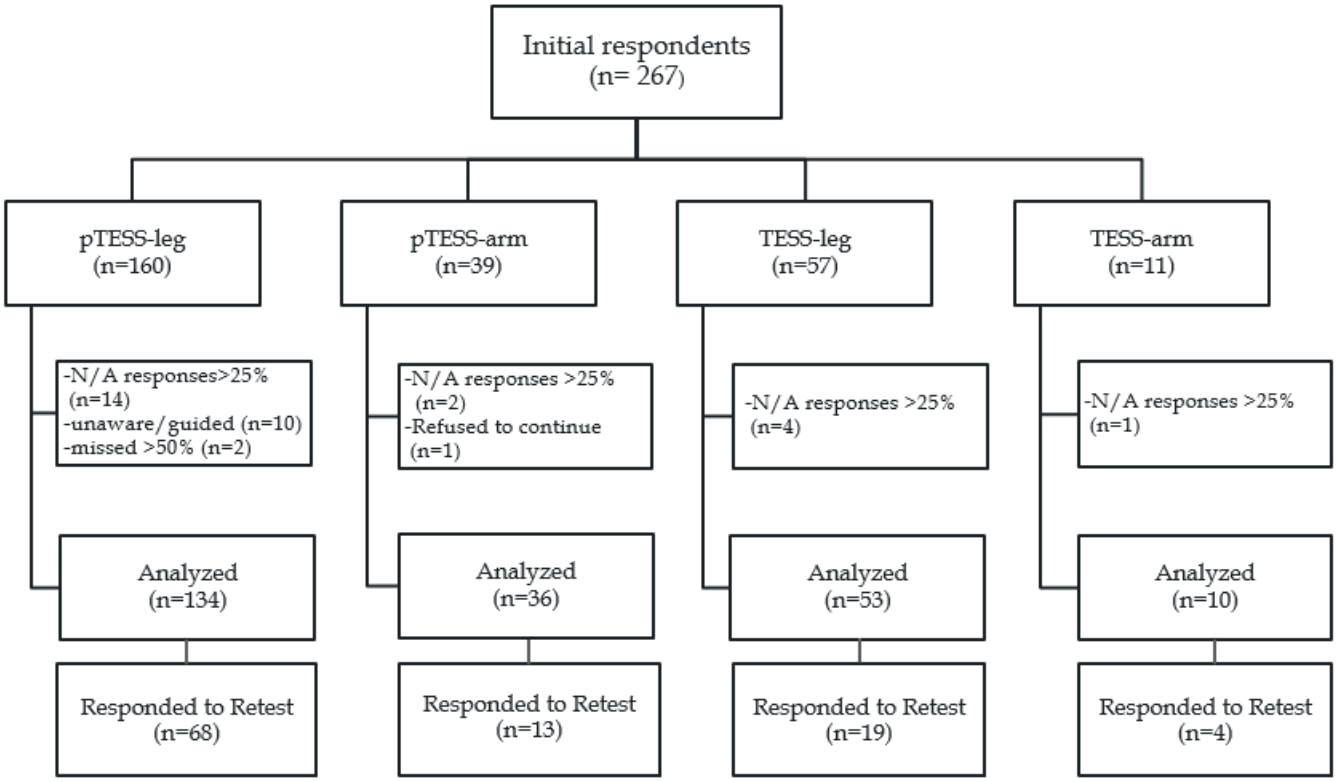

Table 1: Characteristics of respondents

Characteristic	Lower extremity		Upper extremity		Overall (%)
	Pediatric (%)	Adult survivors (%)	Pediatric (%)	Adult survivors (%)	
Eligible	134	53	36	10	233
Age, years	14.3 (8-17.9)	20.6 (18-32)	13.3 (8-17.9)	20.8 (18-24)	15.6 (8-32)
Gender					
Male	70 (52)	27 (51)	14 (39))	5 (50)	116 (50)
Female	64 (48)	26 (49)	22 (61)	5 (50)	117 (50)
Diagnosis					
Osteosarcoma	91 (68)	41 (77)	9 (25)	4 (40)	145 (62)
Ewing sarcoma	43 (32)	12 (33)	27 (75)	6 (60)	88 (38)
Component					
Osseous	132 (99)	53 (100)	33 (92)	8 (80)	226 (97)
Extra-osseous	2 (1)	0	3 (8)	2 (20)	7 (3)
Tumor location					
Tibia	24 (18)	18 (34)	0	0	42 (18)
Femur	94 (70)	31 (58)	0	0	125 (54)
Fibula	13 (10)	4 (8)	0	0	17 (7)
Talus/Calcaneous	3 (2)	0	0	0	3 (1.5)
Humerus	0	0	19 (53)	8 (80)	27 (11.5)
Radius/ulna	0	0	3 (8)	0	3 (1.5)
Scapula	0	0	9 (25)	2 (20)	11 (5)
Shoulder/Clavicle	0	0	3 (8)	0	3 (1.5)
Metacarpal	0	0	2 (6)	0	2 (1)
Months from surgery	27.8 (3-156)	73.7 (3-169)	31 (3-135)	71.1 (25-112)	38 (3-169)
Type of LC					
Surgery	130 (97)	50 (94)	27 (75)	7 (70)	214 (92)
Surgery + RTH	4 (3)	3 (6)	0	1 (10)	8 (3)
ECI	0	0	9 (25)	2 (20)	11 (5)
Type of surgery					
Amputation	3 (2)	1 (2)	1 (3)	0	5 (2)
Rotationplasty	2 (1.5)	0	0	0	2 (1)
Limb salvage	129 (96.5)	52 (98)	26 (72)	8 (80)	215 (92)
Prosthesis	76 (59)	35 (67)	7 (27)	3 (37)	121 (56)
VFG	29 (22)	14 (27)	5 (19)	5 (63)	53 (25)
Non-VFG	0	0	2 (7)	0	2 (1)
Spacer/fixation	9 (7)	0	9 (35)	0	18 (8)
Fibulectomy/resection	15 (12)	3 (6)	3 (12)	0	21 (10)
Chemotherapy status					
On treatment/end < 1 month	23 (17)	1 (2)	5 (14)	0	29 (12)
Finished treatment	111 (83)	52 (98)	31 (86)	10 (100)	204 (88)

Chapter 3

Results

3.1 Respondents' characteristics

In a total sample of 267 participants, only 233 were included in the analysis of which 187 answered the pTESS/TESS for the lower extremity, while 46 completed the upper extremity forms. In both groups of upper and lower extremities, the median age of adults was over 20 years. Pediatrics of the upper extremity had a slightly lower median age, 13.3 years compared to 14.3 years in the lower extremity group. As expected, osteosarcoma diagnosis was more common in the lower extremities, while Ewing sarcoma cases were more frequent in the upper extremity group. The humerus and femur bones were the most common sites in the upper and lower limbs, respectively. The median durations from surgery in adults of lower and upper extremities were considerably higher than pediatrics by over 40 months. Most of the patients (88%) had finished chemotherapy at the time of the survey (Table 1).

3.2 Total scores and item responses in upper and lower extremities

For the 187 participants who answered the lower extremity forms, either pTESS or TESS, and the other 46 who responded to the upper extremity survey, the median (IQR) scores of the modified versions were 69.2 (20.5) and 73.1 (20.2), respectively. While the median scores of the original versions were 72.5 (21.9) for the lower extremity and 76.0 (23.4) for the upper extremity. The original versions represented significantly higher scores compared to the modified pTESS/TESS versions (p-value <0.001).

Out of the 187 respondents with lower extremity sarcomas, 134 patients completed the pTESS and 53 answered the TESS (Table 1). The average score among the original items of pTESS was 3.7. As shown in Table 2, the lowest median score per item was equal to 1, and it was found with "running" (question 28) in which it was rated "too hard I can't do this" by 68 pediatric respondents. The average score across the additional mental questions was 4. Although the median score of the item related to anxiety (question 31) was 4, its most repeated rating was "most of the time" (score=2). Regarding the TESS extremity form, the average item score was 3.95 for the original items and 3.2 for the mental items. The lowest median score per item was 3, but mode scores as low as 1 were noted in "kneeling" (question 13) and "getting up from kneeling" (question 23). Across the mental questions, "Do you easily get in a bad mood" (question 35) had the lowest median score, which was equal to 3, denoting "a good bit of the time" rating. While "feeling nervous or afraid of what will happen" (question 31) showed the

lowest mode score, which was equal to 1.

As for the upper extremity group, 36 were included in the analysis of the pTESS-arm. The average score among the original items and the mental items was 3.7 and 3.4, respectively. The lowest median scores were 2 and 2.5, which were obtained with only two questions; "carrying heavy things" (question 15) and "lifting a box to a high shelf' (question 19). Only 10 respondents were analyzed in the TESS upper extremity group, and they had an average item score of 4.2 in each of the original and the mental domain. The lowest median score per item was 2.5, and it was only found with "lifting a box to a high shelf" (question 20) (Table.2).

3.3 Validation

The Cronbach's alpha exceeded 0.9 in all the tested versions (Table.3). In TESS-leg, omitting question 6 (gardening), 17 (driving), and 25 (participating in sexual activities) increased the Cronbach's alpha from 0.78 to 0.92. These questions were chosen by more than half of the respondents as "N/A". The remaining versions did not show an improvement in internal consistency upon removing any items. All versions also revealed good test-retest reliability in which ICC values were more than 0.8 (Table.3). Moderate to strong correlation coefficients, that range from 0.55 to 0.86, resulted upon testing PEDSQL scores against the scores of pTESS and TESS. As shown in Table 3, the inclusion of mental scores enhanced the correlation between PEDSQL scores and lower extremity scores, of both pediatric and adult forms. Total scores have not shown floor or ceiling effect in any of the tested versions.

In addition, the average inter-item correlation coefficients for the original pTESS and TESS as well as their mental domains were all within the desirable range since they were all above 0.3 and below 0.7 (Table.3). Upon performing EFA for pTESS-leg, 3 factors were extracted based on the clear elbow shown in the scree plot (Figure.2). All the mental items had loaded on a separate factor with factor loadings that range from 0.43 to 0.77. Questions number 16, 21, and 23 to 30 loaded on factor 2; these questions are generally related to social interaction or relatively harder physical activities. Although walking upstairs (question 14) or up/down a hill (question 19) showed moderate factor loadings, between 0.4 and 0.6, they cross-loaded on factors 1 and 2. The only items that demonstrated weak factor loadings, below 0.4, were bending down on knees (question 12), and standing straight (question 20).

3.4 Children and adolescents versus adults

The median scores of the modified pTESS and TESS of lower extremities were 68.2 and 71.9, while their equivalent original version scores were 69.3 and 77.0. The difference between pediatric and adult groups was statistically significant in the original version scores only (p-value =0.038). In the upper extremities, the modified pTESS and TESS median scores were 72.7

and 80.3, while the corresponding original version scores were 76.0 and 81.0. No statistically significant differences were revealed upon comparing the scores of pTESS and TESS in the upper extremities.

3.5 Scores based on respondents' characteristics

The modified and original versions scores of the lower extremity that were obtained prior to reaching one year from surgery were 63.1 and 63.0, respectively; these scores were significantly lower than those obtained beyond the one year from surgery (70.8, 74.1; p-value = 0.001, <0.001) (Table.4). No significant improvement was shown at 2 to 8 years after surgery. Conversely, the duration spent since primary surgery did not affect any of the upper extremity scores (Table.4). Other factors that showed a statistical difference in the lower extremity group were the chemotherapy status and tumor site (p-value = 0.047, 0.002). Those who had finished chemotherapy, or had their tumors located in the fibula and femur, but not tibia, showed favorable outcomes in terms of both modified and original pTESS/TESS scores. The median modified score after ending chemotherapy was 70.2 compared to only 64.9 in those who were still receiving treatment, and the median equivalent original score was 73.2 compared to 63.6. While the median modified and original scores in the fibula group were 73.5 and 76 differing from the corresponding scores in the femur group, which were 70.9 and 73.2, and tibia group that were 61.5 and 65.4 (Table.4).

3.6 PEDSQL measures

The mean ±SD (median) of PEDSQL scores for pediatric lower extremity and upper extremity were 57.3±18.1 (58.3) and 59.8± 22.5 (59.2), respectively. While the mean adult lower and upper scores of PEDSQL were 66.1±23.1 (67.9) and 77.5±13.9 (80.1). Although TESS-leg (the original version) relatively showed the weakest correlation with PEDSQL in which the correlation coefficient was only equal to 0.55 (Table.3), a considerably enhanced correlation resulted upon evaluating TESS-leg to the PEDSQL's physical domain only (r=0.687, p-value <0.001).

Table 2: Median and mode scores of pTESS and TESS

	pTESS leg		TESS leg		pTESS arm		TESS arm	
	Median	Mode	Median	Mode	Median	Mode	Median	Mode
Question 1	5	5	5	5	5	5	5	5
Question 2	5	5	4	5	5	5	5	5
Question 3	5	5	5	5	5	5	5	5
Question 4	5	5	5	5	5	5	5	5
Question 5	5	5	4	5	5	5	4	3
Question 6	3	1	N/A[a]	N/A[a]	4.5	5	5	5
Question 7	5	5	5	5	5	5	5	5
Question 8	3	3	5	5	5	5	5	5
Question 9	5	5	3	3	5	5	5	5
Question 10	5	5	5	5	5	5	3.5	3
Question 11	5	5	5	5	4	3	5	5
Question 12	3	5	5	5	4	5	4.5	3
Question 13	5	5	3	1	4	5	5	5
Question 14	4	3	4	5	5	5	4	4
Question 15	4	5	4	4	2.5	2	5	5
Question 16	3	1	4	5	4	5	3	3
Question 17	5	5	N/A[a]	N/A[a]	3.5	5	5	5
Question 18	4	5	5	5	4	5	4.5	5
Question 19	4	3	4	4	2	1	3.5	3
Question 20	5	5	5	5	4	5	2.5	5
Question 21	3	1	3	3	5	5	5	5
Question 22	5	5	5	5	5	5	5	5
Question 23	5	N/A	3	1	5	5	5	5
Question 24	5	5	4	5	5	5	5	5
Question 25	4	5	N/A[a]	N/A[a]	5	5	4.5	5
Question 26	5	5	4	3	5	5	4.5	5
Question 27	4	1	4	5	4.5	N/A	5	5
Question 28	1	1	5	5	3	2	5	5
Question 29	3	1	5	5	4	6	4.5	5
Question 30	2	1	5	N/A	4	6	3.5	4
Question 31	4	2	4	1	4	1	5	5
Question 32	5	6	4	4	3.5	6	4.5	6
Question 33	5	6	4	5	3	1	4.5	5
Question 34	5	6	5	6			5	5
Question 35	4	6	3	3			5	5
Question 36	4	6	4	4				
Total score	68.2		71.9		72.7		80.3	
Original score[b]	69.3		77.0		76.0		81.0	

[a]Excluded from the total score (as internal consistency improved upon this item removal)

[b]Standardized score of original versions

Table 3: Validation of pTESS and TESS

	Lower extremity					Upper extremity				
	α [a]	IIC[b]	ICC[d]	r-PEDSQL[e]	p-value	α [a]	IIC[b]	ICC[d]	r-PEDSQL[e]	p-value
PTESS	0.94	0.33		0.65	<0.001	0.93	0.35		0.638[f]	<0.001
Modified pTESS	0.94	0.4[c]	0.824	0.75	<0.001	0.93	0.51 [c]	0.834	0.64[f]	<0.001
TESS	0.92	0.3		0.551	<0.001	0.94	0.37		0.836	0.003
Modified TESS	0.93	0.54 [c]	0.822	0.751	<0.001	0.94	0.49 [c]	0.828	0.858	0.001

[a]Cronbach's alpha- raw alpha was calculated for pTESS and TESS
- standardized alpha was calculated for Modified version of pTESS/TESS
[b]The Average Inter-Item Correlation coefficient
[c] The IIC of mental domains only
[d] Intraclass cofficient
[e]Correlation with PEDSQL (pearson correlation coefficient except [f])
[f] Spearman correlation coefficient

Figure 2: Scree plot for pTESS-leg

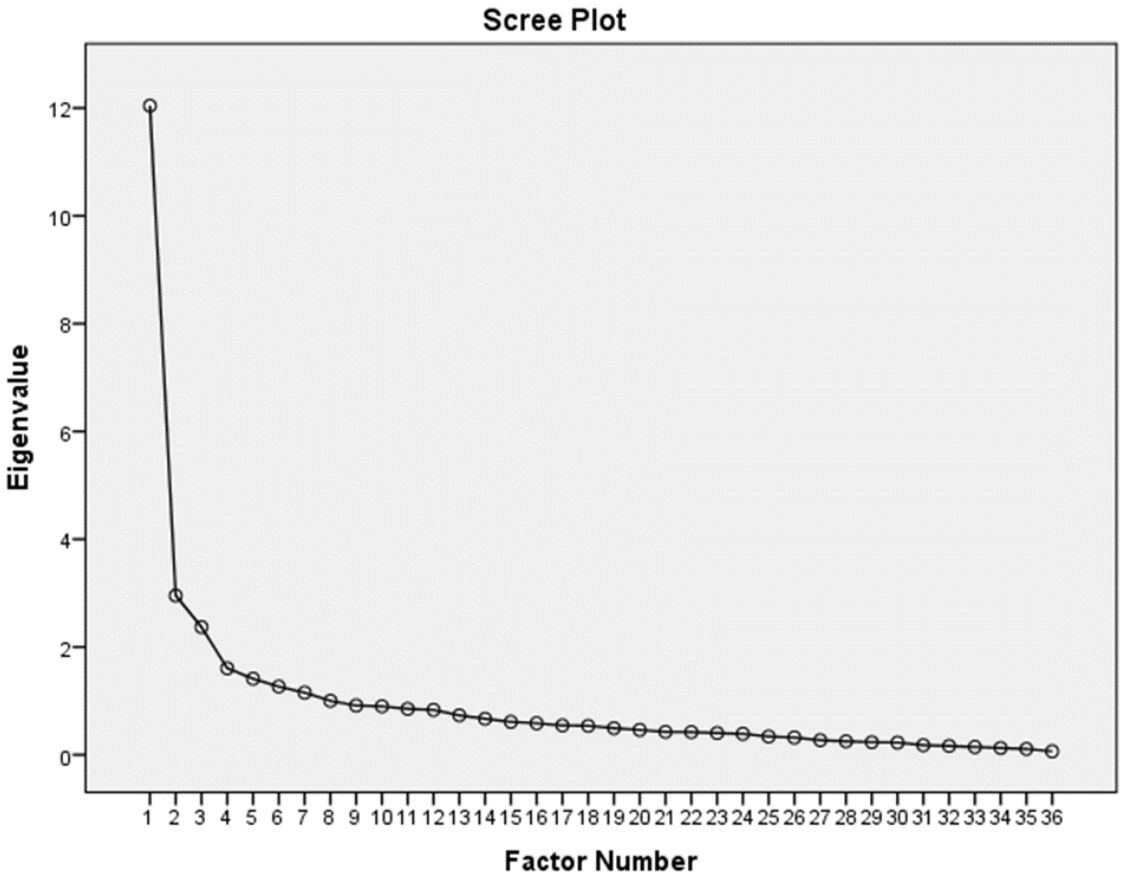

Table 4: Total scores in the limb salvage group

	n	LE- Modified[a]		LE- Original[b]		n	UE- Modified[a]		UE- original[b]	
		Median (IQR)	*P*-value	Median (IQR)	*P*-value		Median (IQR)	*P*-value	Median (IQR)	*P*-value
Overall[c]	172	69.2 (20.5)		73.0 (21.7)		45	73.1 (20.0)		76.1 (22.3)	
Age group			0.124		0.04*			0.239		0.492
Pediatric	120	68.5 (20.6)		70.7 (23.9)		10	80.3 (31.7)		81.0 (30.9)	
Adult	52	72.6 (19.0)		77.0 (19.4)		35	73.0 (17.3)		76.1 (19.1)	
Gender			0.809		0.38			0.175		0.383
Male	86	69.3 (22.3)		71.8 (24.5)		19	75.0 (23.8)		81.5 (23.1)	
Female	86	69.1 (16.3)		73.1 (24.5)		26	72.7 (22.8)		75.9 (29.3)	
Diagnosis			0.077		0.204			0.99		1
Osteosarcoma	120	67.3 (21.2)		71.2 (24.3)		32	73.8 (19.7)		76.5 (20.4)	
Ewing sarcoma	52	72.9 (15.9)		74.6 (19.3)		13	72.3 (25.8)		76.1 (28.2)	
Tumor location[d]			0.002*		0.007*			0.427		0.293
Tibia	41	61.5 (21.7)		65.4 (26.1)						
Femur	112	70.9 (18.1)		73.2 (20.6)						
Fibula	17	73.5 (14.7)		76.0 (13.9)						
Humerus						27	70.2 (16.2)		72.6 (26.6)	
Scapula						11	74.5 (19.1)		77.1 (22.7)	
≥1 year from surgery			0.001*		<0.001*			0.561		0.819
No	32	63.1 (27.9)		63.0 (28.4)		10	75.0 (17.3)		72.8 (18.4)	
Yes	140	70.8 (19.4)		74.1 (19.9)		35	73.0 (22.0)		76.9 (29.2)	
Limb salvage[d]			0.308		0.17			0.506		0.369
Prosthesis	111	69.1 (19.4)		72.9 (19.8)		10	72.2 (12.4)		74.4 (19.3)	
VFG	43	68.1 (24.9)		72.2 (26.4)		10	69.0 (35.7)		74.0 (36.5)	
Fibulectomy	16	73.2 (12.5)		75.5 (12.6)		*				
ECI						11	74.5 (19.1)		77.1 (22.7)	
Chemotherapy			0.047*		0.023*			0.93		0.428
On therapy[e]	20	64.9 (24.7)		63.6 (26.8)			68.4 (18.0)		69.2 (19.7)	
Ended therapy	152	70.2 (21.5)		73.2 (22.6)			73.8 (20.9)		77.0 (23.0)	

[a]Modified versions of pTESS/TESS
[b]Original versions of pTESS/TESS
[c]Temporary spacers of lower extremity were excluded
[d]Talus and calcaneous (n=2) were excluded from this comparison
[e]Those who ended treatment in less than one month were included in "on therapy" group

Chapter 4

Discussion

In Egypt, there is a lack of validated tools for measuring the functional outcome and HRQOL following surgeries of childhood bone sarcomas. We performed cross-cultural adaptation and validation of the recently developed pTESS to be used for Egyptian pediatric patients with extremity bone tumors. The same process was carried out for TESS to be used for adult survivors of childhood bone cancer. The study also modified the original versions, to include a mental domain, and examined the validity of the modified versions to measure the HRQOL of this specific population. All versions showed no floor or ceiling effects, excellent internal consistency, and high test-retest reliability. The moderate to strong correlations with PEDSQL scores also confirmed the convergent validity.

4.1 Modified pTESS/TESS and HRQOL

The significantly higher scores of the original pTESS/TESS versions, compared to the total scores of their modified versions, suggest considerable psychological distress that is worth assessment when evaluating the HRQOL for patients undergoing surgeries of bone sarcomas. Such a need for overall health status assessment was also recognized by Ogura et al. (2015) and Xu et al. (2016). Moreover, Stish et al. (2015) have previously reported an association between the functional outcome and QOL, including the emotional aspect, in survivors of Ewing sarcoma. This finding is consistent with our results that proved a correlation between the original pTESS/TESS, representing the functional outcome, and PEDSQL scores, the generic QOL measures. This correlation also ensures the convergent validity of the original pTESS and TESS. Moreover, the further stronger correlations that were shown between the modified versions of pTESS/TESS and PEDSQL indicate that the added mental domain enhanced the ability of pTESS/TESS to evaluate the HRQOL, not only the functional outcome. It is worth mentioning that this improvement was obvious with scores of the lower extremity but not evident in the upper limbs. Disabilities in lower limbs can be more visible due to limping, while clothing usually hinders the visibility of upper limb deformities, which would barely affect the general appearance of patients with sarcomas in the upper limbs. Although the low social acceptance, related to the cosmetic appearance, can affect mental health, further investigations are needed to find out why including the mental domain showed a greater change in our lower extremity scores (Fauske et al., 2016).

4.2 pTESS

With regard to pTESS, the median scores of the arm and leg original versions in this study were somewhat lower than the mean scores reported by Piscione et al. (2019); 76 vs. 81 and 69 vs. 77, respectively. However, the consistency and reliability were comparable in both studies. These measures were also retained within the acceptable range upon further assessment of our modified versions. For construct validity, we additionally conducted EFA of the modified pTESS-leg in which "standing straight" seemed to be the most irrelevant item since it represented the lowest factor loadings and was highly cross-loaded across 2 of the 3 demonstrated factors. A closer view of this item shows that around 65% of respondents found it 'not hard at all' to stand straight, even though some of these respondents might only be able to stand straight using a shoe lift to correct limb length discrepancy. Having a convenient solution for this complication could explain the irrelevance of this item to other activities that are less likely to be simply enhanced by a minor intervention/nonsurgical treatment. "Bending down on knees" is another item with low factor loadings, and it might require clarifying the degree of kneeling and revisiting the translated Arabic words in future assessments. Conversely, the six mental items were correlated and perfectly loaded within the same factor, which can verify the validity of this extra domain. As for the pTESS-arm, the power of the performed analyses was probably affected by the small sample size. Higher number of respondents in this group is needed to confirm the current results and permit conducting EFA for the modified version of pTESS-arm. However, the resulting Cronbach's alpha, ICC, and average inter-item correlation coefficients of pTESS-arm are still promising since their values were quite acceptable despite the few responses, especially within the retest group. Such measures were also analogous to previous pTESS validity measures (Piscione et al., 2019).

4.3 TESS

The original TESS-leg revealed a median score that was slightly higher than those reported in Italy and Greece (Bolia et al., 2021; Rossi et al., 2020), and comparable to Vienna (Trost et al., 2021), while being inferior to several other scores (Kim et al., 2015; Ogura et al., 2015; Sæbye et al., 2014; Saraiva et al., 2008; Willeumier et al., 2017; Xu et al., 2016). However, the heterogeneity in study designs, diagnoses, tumor sites, and treatment modalities makes it harder to compare these findings. It is also important to note that previous studies have validated TESS with different respondents; some were below 18 years old, while others were either adult at the time of primary surgery or have become adults after years from the end of therapy. On the contrary, our TESS-leg group was confined to adult survivors of childhood bone cancer since the study was conducted in a pediatrics center. Stish et al. (2015) found that adults with pediatric Ewing sarcoma had higher scores than those who were adults at the time of diagnosis. For better assessment, this would be further evaluated, in the future, with the inclusion of Osteosarcoma

diagnosis and a higher number of participants. Moreover, Stish et al. (2015) have not mentioned the mean age of respondents below 18 years old; this would have provided a more valuable interpretation as surgeries done in preadolescence are expected to be more challenging than those done in adolescence and adulthood (Kaneuchi et al., 2022). Thus, accounting for age at the time of primary surgery would be valid in future studies. This could have explained our inferior scores reported by survivors of preadolescent surgeries who have probably faced multiple revision surgeries before filling out the survey. Hence, investigating the impact of the number of revision surgeries on HRQOL would be useful in future studies. Moving to TESS-arm, fewer studies are available for this group which is expected due to the small number of adult patients who had bone sarcomas in the upper limbs. Our TESS-arm median score was again similar to that of Vienna (Trost et al., 2021), but lower than other scores (Kim et al., 2015; Rossi et al., 2020; Willeumier et al., 2017; Xu et al., 2016). Those who responded to TESS-arm represented the smallest group in our study, including ten participants only. Even though this number was far below the recommended sample size for proper validation, the resulting measures were quite favorable which would encourage the assessment of the current TESS-arm version in further studies. Concerning the validity of TESS-leg, its recruited number was greater than the arm group, but it was still insufficient for performing EFA. Nevertheless, the average inter-item correlation coefficient was acceptable, and the internal consistency was considerably improved upon removing questions 6,17, and 25. The irrelevance of these questions might be explained by the cultural differences between Egypt and Canada, where TESS was first developed and validated. Gardening (question 6) seems to be an uncommon activity in Egypt, and even though the word "gardening" was translated to an Arabic word that could also mean farming, several participants answered that they don't do any of these agricultural activities. Moreover, most of the respondents were young adults who are less likely to engage in sexual activities (question 25) or learn to drive at their current age (question 17). Therefore, removing these 3 questions from the TESS-leg version would be more convenient in future assessments.

4.4 Pediatric and adult participants

Although the scores of adults were expected to be significantly higher than those of pediatrics, this was only apparent in the lower extremity group when comparing the original versions scores but not the modified versions scores. Since the gap between pediatrics and adults was reduced upon including the mental domain scores, long-term psychological effects that could last beyond the improvement of physical function might be considered. Another possibility is that adults are generally more aware and well-informed of their health condition which could affect their mental health to a greater extent (Mouratidi et al., 2016). The absence of any differences in the upper extremity group is possibly due to the insufficiency of this small sample size to detect a significant difference or the chance that fewer severe complications would result from upper limbs surgeries and affect mental health (Kaneuchi et al., 2022).

4.5 Responses and different characteristics

In addition, those who exceeded one year post-surgery in the lower extremity group had better outcomes, while no significant difference was found at later time points from surgery. This result was consistent with previous findings that showed significant enhancement after one year from surgery, but minor improvements in the functional outcome and HRQOL at 2 to 7 years later (Bekkering et al., 2012; Sun et al., 2012; van Egmond-van Dam et al., 2017). As expected, being on chemotherapy was linked to worse outcomes in the lower extremities; this was the case in previous measures for both pediatric and adult groups (Hinds et al., 2009; Piscione et al., 2019). However, the fact that those who were still receiving chemotherapy had been at earlier time points from surgery could be a significant confounder. Thus, a higher number of diverse respondents is required to enable multivariate analysis in future studies. Furthermore, the impact of chemotherapy status in the upper extremity group could have been shown if more participants were included in the analysis, which also entails an extensive assessment in the future. The tumor site was also a significant factor in the lower extremity group in which the tibia bone was associated with inferior scores, compared to femur and fibula. This finding can be attributed to the higher incidence of various complications in tibial resections (Grimer et al., 2016; Pala et al., 2015). With respect to the histological diagnosis, higher scores were noted in Ewing sarcoma of lower extremity, but with a p-value that is still not significant (0.07). There is a lack of studies evaluating the HRQOL in pediatric Ewing sarcoma versus Osteosarcoma; however, the previously reported scores for Ewing sarcoma were generally better than those of Osteosarcoma (Piscione et al., 2019; Stish et al., 2015). It was not obvious in our study if the reason behind better outcomes among Ewing sarcoma cases is due to the presence of soft tissue lesions as the number of the available extra-osseous cases was insufficient to compare their outcome to those of osseous lesions. In general, a greater proportion of patients diagnosed with Ewing sarcoma have their primary tumor located in the diaphysis of long bones which may permit a joint-sparing resection, while in Osteosarcoma, the majority of primary lesions are located in the metaphysis which would necessitate a joint-sacrificing resection (Wirth et al., 2021). Patients with preserved natural joints may score, functionally and psychologically, better than those with artificial joints (Abe et al., 2012). It is also important to note that the larger gap in scores, in this study, was found within the modified version which might explain differences in HRQOL that are not solely related to physical function. Overall, a greater sample size and a prospective analysis would provide better interpretation for the impact of different characteristics on QOL in childhood bone cancer.

Not only the small sample size within the limb salvage group, but the few participants with amputation surgeries also prevented us from comparing the outcomes of limb salvage to those of amputation or rotationplasty. Piscione et al. (2019) have not found differences in pTESS

scores between both groups. Nevertheless, other previous studies have shown conflicting results regarding limb salvage surgeries versus amputation. For instance, Malek et al. (2012) reported enhanced gait with limb salvage but similar perceived quality of life regardless of surgery type, Mason et al. (2013) found that limb-sparing was associated with better QOL, while Barrera et al. (2012) and Saraiva et al. (2008) oppositely found that limb salvage surgeries in lower extremities have shown inferior HRQOL. This contradiction emphasizes the importance of comparing different types of surgeries within our studied population to be able to conclude its preferences based on the specific types of prosthetic implants and artificial limbs available for Egyptian patients.

Since we have not included a control group in this study, which was the first to validate pTESS and TESS in Egypt, we could not compare the presented scores to healthy Egyptian subjects. Our reported PEDSQL scores have shown to be fairly lower than those of healthy children in Egypt, but similar to the mean scores of Egyptian children with chronic conditions (El-Beh et al., 2018). This deviance from the healthy population proves the need for the evolving advanced surgical techniques and individualized tools that are being introduced in orthopedic oncology (Benady et al., 2022; Holzapfel et al., 2016).

4.6 Limitations

Besides the small sample size of the upper extremity groups, there were other limitations in this study. Owing to its cross-sectional nature, the ability of pTESS and TESS to detect changes in functional outcomes over time still needs to be investigated. Selection bias could have occurred by excluding patients who had recent revision surgery since those who were less frequently subjected to revision surgeries might have had a better chance of participation. Moreover, a relatively higher proportion of excluded respondents were of younger age which suggests that the self-reporting tool can be challenging in some instances, and it might not be fully representative of the younger population. Not to mention that the long-term effects of chemotherapy, such as cardiotoxicity, and the Coronavirus Disease 2019 (COVID-19) could have interfered with our findings. For example, patients with cardiotoxicity may have lower scores in moderate to vigorous activities due to their cardiac condition, not their physical impairment. While the COVID-19 pandemic was expected to be a possible reason for answering “I don’t do this” in school-related items, particularly with immunocompromised patients who were still receiving chemotherapy and avoiding school attendance. Finally, the socio-economic status was not evaluated in this study even though it could have affected the outcome measures.

Chapter X

Conclusion and Future Work

Our culturally adapted versions of pTESS and TESS are considered valid and reliable self-reporting tools for Egyptians with extremity childhood bone sarcomas. The modified versions that include a mental domain provide an added benefit for assessing the overall health status of this unique population. The presented outcomes can bring hope during the treatment phase and help patients and their families to expect enhanced outcomes after finishing chemotherapy and beyond one year from the primary surgery. It is recommended to further study whether obtaining PROs on a routine basis, during the orthopedic follow-up visits, would enable healthcare providers to monitor progress over time, verify the current findings, especially in the upper extremity groups, and stratify HRQOL measures by local control modality to aid in clinical decision-making. Our study also calls for encouraging innovative surgical technologies on a national level to prevent long-term surgical complications and enhance the QOL of patients with extremity bone sarcomas.

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Appendix 1

The Egyptian version of pTESS/TESS

استبيان ما بعد جراحات انقاذ الأطراف
استبيان تورونتو المعدل للأطفال
استبيان للساق
Pediatric Toronto Extremity Salvage Score (pTESS-Leg)

في الاسئلة اللي جاية هنسالك علي بعض الاشياء بتعملها في الحياة و عايزين نعرف اذا كان سهل عليك انك تعملها الاسبوع اللي فات. ممكن تكون في حاجات مقدرتش تعملها لكن مفيش مشكلة. عايزينك تختار الاجابة اللي تحس انها صح بالنسبة لك.

لو سمحت لا تطلب من والديك مساعدتك في الإجابات. لو محتاج مساعدة في قراءة كلمة ، ممكن تطلب منهم قراءتها لك ، ولكن لازم تجاوب بنفسك.

مثال:

ركوب العجلة :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

لو في حاجة كنت متعود تعملها لكن بسبب رجلك مش قادر تعملها دلوقتي اختار الاجابة رقم "5 "صعب جدا. لا أستطيع أن أفعل هذا" لو مش متعود تعمل النشاط ده ، اختار الإجابة "6".

الإصدار: ديسمبر 2021

عايزين نعرف اذا كان من السهل عليك القيام بالأنشطة التالية الأسبوع الي فات:

1) لبس البنطالون :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

2) لبس الحذاء:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

3) لبس الشراب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

4) الاستحمام من غير مساعدة احد:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

5) تنظيف غرفتك:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

6) القفز او النط علي رجل واحدة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

7) المساعدة في التسوق

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

الإصدار: ديسمبر 2021

8) تحريك الحاجات الثقيلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

9) الدخول والخروج من حوض الاستحمام (البانيو):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

10) القيام من السرير:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

11) القيام من علي الكرسي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

12) تنثني ركبتيك:

1 مش صعب ابدا	**2**صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

13) تقدر تشيل حاجة من الأرض:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

14) طلوع السلم:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

الإصدار: ديسمبر 2021

15) نزول السلم :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

16) ركوب الدراجة او العجلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

17) المشي في منزلك او بيتك :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

18) المشي بالخارج او بره البيت:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

19) طلوع أو نزول مرتفعات مثل شوارع مش مستوية او تلال:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

20) الوقوف بشكل مستقيم (مفرود):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

21) إذا سندت علي ركبك، تقدر تقوم تقف؟:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

الإصدار: ديسمبر 2021

22) الدخول والخروج من السيارة هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

23) المشاركة في الأنشطة المدرسية هي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

24) الذهاب إلى المدرسة كل يوم ، لآخر اليوم هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

25) لعب ألعابك المفضلة هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

26) اللعب مع الأصدقاء والعائلة هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

27) ممارسة الرياضة اللي متعود عليها :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

28) الجري:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

الإصدار: ديسمبر 2021

29) تقدر تكمل لعب او تمارس الانشطة زي اصحابك (المواكبة مع الأصدقاء):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

30) المشي لمدة طويلة (أكثر من ساعة) هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

أسئلة عن المشاعر

31) عندك إحساس بالقلق او الخوف من اللي ممكن يحصل؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

32) عندك احساس بالحزن و إن مافيش حاجة ممكن تفرحك ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

33) عندك إحساس بالتعب و انك مش عايز تلعب او تشارك في اي حاجة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

34) عندك مشكلة تركز في المدرسة او فى وقت المذاكرة والواجب؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

35) هل تشعر بسهولة ان مزاجك سئ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

الإصدار: ديسمبر 2021

36) هل تشعر انك عايز تزعق او تكسر حاجة عندما تكون مضطر للانتظار أو مايحصلش اللى انت عايزه؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

عمل كل الأشياء التي أريد أن أفعلها هي:

(الرجاء وضع علامة على السطر التالى)

كيف تشعر اتجاه ما يمكنك فعله ؟:

(الرجاء وضع علامة على السطر التالى)

هل نسينا نسألك عن شيء تاني صعب تعمله؟

اطبعها او اكتبها على هذه الخطوط:

_____

_____

_____

ايه اكتر حاجة ضايقتك بالنسبة للعملية؟

_____

_____

_____

أرجوك اتاكد انك جاوبت كل الأسالة

شكرا علي وقتك و اجابتك للاسئلة

الإصدار: ديسمبر 2021

PAEDIATRIC TESS (pTESS-Arm)
ARM QUESTIONNAIRE

استبيان ما بعد جراحات انقاذ الأطراف

استبيان تورونتو المعدل للأطفال

استبيان للذراع

في الاسئلة اللي جاية هنسالك علي بعض الاشياء بتعملها في الحياة و عايزين نعرف اذا كان سهل عليك انك تعملها الاسبوع اللي فات. ممكن تكون في حاجات مقدرتش تعملها لكن مفيش مشكلة. عايزينك تختار الاجابة اللي تحس انها صح بالنسبة لك.

لو سمحت لا تطلب من والديك مساعدتك في الإجابات. لو محتاج مساعدة في قراءة كلمة ، ممكن تطلب منهم قراءتها لك ، ولكن لازم تجاوب بنفسك.

مثال:

استخدام القلم

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

لو في حاجة كنت متعود تعملها لكن بسبب ذراعك مش قادر تعملها دلوقتي اختار الاجابة رقم "5 "صعب جدا. لا أستطيع أن أفعل هذا"

لو مش متعود تعمل النشاط ده ، اختار الإجابة رقم "6".

1) لبس البنطلون:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

2) ربط رباط الحذاء:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

3) لبس الشراب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

4) الاستحمام من غير مساعدة احد:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

5) لبس الجاكت :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

6) قفل زراير القميص:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

7) الطباعة او الكتابة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

8) تلوين صورة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

.

9) غسل اسنانك:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

10) استخدام فرشاة الشعر :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

11) تنظيف غرفتك:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

12) تقطيع او تقشير الفاكهة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

13) تقطيع الطعام(مثل الدجاج) اثناء الاكل :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

14) الشرب من كوب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

15) حمل اشياء ثقيلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

16) المساعدة في التسوق:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

17) مد اليدين لاعطاء او الحصول علي اموال:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

18) حمل حقيبة علي الظهر:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

19) رفع صندوق و وضعة علي رف عالي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

20) وضع مفتاح في القفل و لفه:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

21) شد او دفع الباب لفتحة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

22) التقاط الاشياء الصغيرة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

23) **عمل الواجب المدرسي:**

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

24) الذهاب للمدرسة كل يوم:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

25) اللعب بالعابك المفضلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

26) اللعب مع الاصدقاء والعائلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

.

27) ممارسة الرياضة المفضلة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

أسئلة عن المشاعر

28) عندك إحساس بالقلق او الخوف من اللي ممكن يحصل؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

29) عندك احساس بالحزن و إن مافيش حاجة ممكن تفرحك ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

30) عندك إحساس بالتعب و انك مش عايز تلعب او تشارك في اي حاجة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

31) عندك مشكلة تركز في المدرسة او فى وقت المذاكرة والواجب؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

32) هل تشعر بسهولة ان مزاجك سئ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

33) هل تشعر انك عايز تزعق او تكسر حاجة عندما تكون مضطر للانتظار أو مايحصلش اللى انت عايزه؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

عمل كل الأشياء التي أريد أن أفعلها هي:

(الرجاء وضع علامة على السطر التالى)

كيف تشعر اتجاه ما يمكنك فعله ؟:

(الرجاء وضع علامة على السطر التالى)

هل نسينا نسألك عن شيء تاني صعب تعمله؟
اطبعها او اكتبها على هذه الخطوط:

_____

_____

_____

ايه اكتر حاجة ضايقتك بالنسبة للعملية؟

_____

_____

_____

أرجوك اتاكد انك جاوبت كل الأسالة
شكرا علي وقتك و اجابتك للاسئلة

استبيان ما بعد جراحات انقاذ الأطراف
استبيان تورونتو
استبيان للساق
Toronto Extremity Salvage Score
(TESS-Leg)

في الاسئلة اللي جاية هنسالك علي بعض الاشياء بتعملها في الحياة و عايزين نعرف اذا كان سهل عليك انك تعملها الاسبوع اللي فات. ممكن تكون في حاجات مقدرتش تعملها لكن مفيش مشكلة. عايزينك تختار الاجابة اللي تحس انها صح بالنسبة لك.

لو سمحت لا تطلب من والديك مساعدتك في الإجابات. لو محتاج مساعدة في قراءة كلمة ، ممكن تطلب منهم قراءتها لك ، ولكن لازم تجاوب بنفسك.

مثال:

ركوب العجلة :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

لو في حاجة كنت متعود تعملها لكن بسبب رجلك مش قادر تعملها دلوقتي اختار الاجابة رقم "5 "صعب جدا. لا أستطيع أن أفعل هذا" لو مش متعود تعمل النشاط ده ، اختار الإجابة "6".

الإصدار: ديسمبر 2021

عايزين نعرف اذا كان من السهل عليك القيام بالأنشطة التالية الأسبوع الي فات:

1) لبس البنطالون :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

2) لبس الحذاء:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

3) لبس الشراب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

4) الاستحمام من غير مساعدة احد:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

5) القيام بالأعمال المنزلية الخفيفة مثل التلميع و الترتيب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

6) القيام بأى نشاط زراعى:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

7) تحضير وتقديم وجبات الطعام

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

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8) الذهاب للتسوق:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

9) القيام بالأعمال المنزلية الشاقة مثل تحريك أثاث/ أشياء ثقيلة أو الكنس:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

10) الدخول والخروج من حوض الاستحمام (البانيو):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

11) القيام من السرير:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

12) القيام من علي الكرسي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

13) تنثني ركبتيك أو تركع:

1 مش صعب ابدا	**2**صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

14) تقدر تشيل حاجة من الأرض:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

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15) طلوع السلم:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

16) نزول السلم:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

.

17) قيادة السيارة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

18) المشي في منزلك او بيتك :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

19) المشي بالخارج او بره البيت:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

20) الجلوس:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

21) طلوع أو نزول مرتفعات مثل شوارع مش مستوية او تلال:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

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22) الوقوف بشكل مستقيم (مفرود):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

23) إذا سندت علي ركبك، تقدر تقوم تقف؟:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

24) الدخول والخروج من السيارة هو:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

25) علاقة زوجية/ حميمة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

26) إتمام واجباتي المعتادة في الدراسة أو فى العمل (يشمل العمل وظيفة خارج المنزل أو ربة منزل):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

27) أعمل نفس عدد ساعات زملائى بالعمل (يشمل العمل وظيفة خارج المنزل أو ربة منزل) **أو أكمل اليوم الدراسى لأخره:**

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

28) المشاركة في الأنشطة الترفيهية المعتادة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

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29) التواصل الاجتماعى مع الأصدقاء والعائلة (حضور تجمعات و احتفالات):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

30) ممارسة الرياضة اللي متعود عليها:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

أسئلة عن المشاعر

31) عندك إحساس بالقلق او الخوف من اللي ممكن يحصل؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

32) عندك احساس بالحزن و إن مافيش حاجة ممكن تفرحك ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

33) عندك إحساس بالتعب و انك مش عايز تشارك في اي حاجة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

34) عندك مشكلة تركز في الشغل أو الدراسة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

35) هل تشعر بسهولة ان مزاجك سئ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

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36) هل تشعر انك عايز تزعق او تكسر حاجة عندما تكون مضطر للانتظار أو مايحصلش اللى انت عايزه؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

بشكل عام، عمل كل الأشياء التي أريد أن أفعلها هي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعلها

بشكل عام، كيف تشعر اتجاه ما يمكنك فعله (مستوى قدرتك) ؟:

1 قادر تماما	**2** عدم قدرة بسيطة	**3** عدم قدرة متوسطة	**4** عدم قدرة شديدة	**5** غير قادر تماما

هل نسينا نسألك عن شيء تاني صعب تعمله؟
اطبعها او اكتبها على هذه الخطوط:

ايه اكتر حاجة ضايقتك أو صعوبات واجهتك بسبب العملية؟

أرجوك اتاكد انك جاوبت كل الأسالة
شكرا علي وقتك و اجابتك للاسئلة

الإصدار: ديسمبر 2021

TESS (TESS-Arm)
ARM QUESTIONNAIRE

استبيان ما بعد جراحات انقاذ الأطراف
استبيان تورونتو للذراع

في الاسئلة اللي جاية هنسالك علي بعض الاشياء بتعملها في الحياة و عايزين نعرف اذا كان سهل عليك انك تعملها الاسبوع اللي فات. ممكن تكون في حاجات مقدرتش تعملها لكن مفيش مشكلة. عايزينك تختار الاجابة اللي تحس انها صح بالنسبة لك.

لو سمحت لا تطلب من أحد مساعدتك في الإجابات. لو محتاج مساعدة في قراءة كلمة او فهم سؤال، ممكن تسأل ، ولكن لازم تجاوب بنفسك.

مثال:

تقشير الخضار أو الفاكهة

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

لو في حاجة بسبب ذراعك مش قادر تعملها دلوقتي اختار الاجابة رقم "5 "صعب جدا. لا أستطيع أن أفعل هذا"
لو مش متعود تعمل النشاط ده أو مش مهتم تجربه، اختار الإجابة رقم "6".

1) لبس البنطلون:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

2) ربط رباط الحذاء:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

3) لبس الشراب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

4) الاستحمام من غير مساعدة احد:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

5) لبس تيشرت/بلوفر/جاكت:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

6) قفل زراير القميص:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

7) ربط ربطة عنق (كرافتة) أو فيونكة على رقبة البلوزة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

8) وضع المكياج أو الحلاقة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

.

9) غسل اسنانك:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

10) استخدام فرشاة الشعر :

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

11) القيام بالأعمال المنزلية الخفيفة مثل الترتيب أوالتلميع:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

12) القيام بأى نشاط زراعى:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

13) تحضير وتقديم وجبات الطعام:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

14) تقطيع الطعام (مثل الدجاج) اثناء الاكل:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

15) الشرب من كوب:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

16) القيام بالأعمال المنزلية الشاقة مثل تحريك أثاث/ أشياء ثقيلة أو الكنس:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

17) الذهاب للتسوق:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

18) مد اليدين لاعطاء او الحصول علي اموال:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

19) حمل كيس تسوق أو شنطة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

20) رفع صندوق و وضعة علي رف عالي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

21) وضع مفتاح في القفل و لفه:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

22) شد او دفع الباب لفتحة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

23) الكتابة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

24) التقاط الاشياء الصغيرة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

25) إتمام واجباتي المعتادة في الدراسة أو العمل (يشمل العمل وظيفة خارج المنزل أو ربة منزل):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

26) أعمل نفس عدد ساعات زملائى بالعمل (يشمل العمل وظيفة خارج المنزل أو ربة منزل) أو أكمل اليوم الدراسى لأخره:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

27) المشاركة في الأنشطة الترفيهية المعتادة:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

28) التواصل الاجتماعى مع الأصدقاء والعائلة (حضور تجمعات و احتفالات):

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

29) ممارسة الرياضة اللي متعود عليها:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعل هذا ابدا	**6** لا أفعل هذا

أسئلة عن المشاعر

30) عندك إحساس بالقلق او الخوف من اللي ممكن يحصل؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

31) عندك احساس بالحزن و إن مافيش حاجة ممكن تفرحك ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

32) عندك إحساس بالتعب و انك مش عايز تلعب او تشارك في اي حاجة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

33) عندك مشكلة تركز في الشغل أو الدراسة؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

34) هل تشعر بسهولة ان مزاجك سئ؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

35) هل تشعر انك عايز تزعق او تكسر حاجة عندما تكون مضطر للانتظار أو مايحصلش اللى انت عايزه؟

1 فى كل الأوقات	**2** فى معظم الأوقات	**3** فى كثير من الأوقات	**4** فى بعض الأوقات	**5** فى قليل من الأوقات	**6** لا أشعر فى أى من الأوقات

بشكل عام، عمل كل الأشياء التي أريد أن أفعلها هي:

1 مش صعب ابدا	**2** صعوبة بسيطة	**3** صعوبة متوسطة	**4** صعب جدا	**5** صعب جدا و لا استطيع فعلها

بشكل عام، كيف تشعر اتجاه ما يمكنك فعله (مستوى قدرتك) ؟:

1 قادر تماما	**2** عدم قدرة بسيطة	**3** عدم قدرة متوسطة	**4** عدم قدرة شديدة	**5** غير قادر تماما

هل نسينا نسألك عن شيء تاني صعب تعمله؟
اطبعها او اكتبها على هذه الخطوط:

_____

_____

_____

ايه اكتر حاجة ضايقتك أو صعوبات واجهتك بسبب العملية؟

_____

_____

_____

أرجوك اتاكد انك جاوبت كل الأسالة

شكرا علي وقتك و اجابتك للاسئلة

Appendix 2

Institutional Review Boards approvals

THE AMERICAN UNIVERSITY IN CAIRO
INSTITUTIONAL REVIEW BOARD

Case# 2021-2022-082

To: **Nesma Farid**
CC **Sungsoo Chun**
Sherihan Hassan

From: **Heba Kotb Chair of the IRB**
Date: 29th December, 2021

Re: IRB approval

This is to inform you that I reviewed your revised research proposal entitled

> "Cross-cultural adaptation and validation of a self-reported tool to assess quality of life for Egyptian children with extremity bone sarcomas"

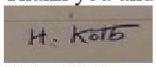
It required consultation with the IRB under the "expedited" category. As you are aware, there were minor revisions to the original proposal, but your new version addresses these concerns successfully. Your proposal used appropriate procedures to minimize risks to human subjects and that adequate provision was made for confidentiality and data anonymity of participants in any published record. I believe you will also make adequate provision for obtaining informed consent of the participants.

This approval letter was issued under the assumption that you have not started data collection for your research project. Any data collected before receiving this letter could not be used since this is a violation of the IRB policy.

Please note that IRB approval does not automatically ensure approval by CAPMAS, an Egyptian government agency responsible for approving some types of off-campus research. CAPMAS issues are handled at AUC by the office of the University Counsellor. The IRB is not in a position to offer any opinion on CAPMAS issues, and takes no responsibility for obtaining CAPMAS approval.

This approval is valid for only one year. In case you have not finished data collection within a year, you need to apply for an extension.

Thank you and good luck.



Heba Kotb
IRB chair, The American University in Cairo
2078 HUSS Building
T: 02-26151857
Email: hebakotb@aucegypt.edu

Institutional Review Board
The American University in Cairo
AUC Avenue, P.O. Box 74
New Cairo 11835, Egypt.
tel 20.2.2615.1000
fax 20.2.27957565
Email: irb@aucegupt.edu

مؤسسة مستشفى سرطان الأطفال-مصر
Children's Cancer Hospital Foundation - Egypt
57357

Organization Accredited by Joint Commission International

December 16th 2021

Dr. Nesma Farid
Clinical Research Associate
Research Department
Children's Cancer Hospital Egypt 57357

Dear Dr. Nesma Farid
This is to certify that the Institutional Review Board (IRB) at the Children's Cancer Hospital 57357 Egypt (CCHE 57357) has reviewed and approved the study entitled: "Cross-cultural adaptation and validation of a self-reported tool to assess quality of life for Egyptian children with extremity bone sarcomas."

Approval is granted for one year starting from December 16th 2021

The research may not continue after the approval period without the additional IRB review and approval for continuation.

Sincerely Yours,

Prof. Dr. Mohamed Zakaria Gad.
IRB Chairman - Children's Cancer Hospital Egypt (CCHE-57357)
Professor of Biochemistry & Head of Clinical Biochemistry Unit
Vice-Dean of Faculty of Postgraduate Studies & Research
The German University in Cairo.

Date of CCHE-IRB Approval: 16-December-2021

CCHE - IRB
Approval 16/12/2021
Serial no 64/2021
Exp. no 15/12/2022
Sig.

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