

Burn Model System©

Pediatric Itch Interference

Proxy or Self Report

User Guide

Version 1.0 – English and Spanish

Updated: March 27, 2019

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The contents of this user guide were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DPGE0004). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this user guide do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

BURN MODEL SYSTEMS (BMS) PEDIATRIC ITCH INTERFERENCE

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Copyright Statement and Users' Agreement

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Permission to use the Burn Model System Pediatric Itch Interference measure must be requested prior to use or publication from burndata@uw.edu. Permission will always be given for non-commercial use. The BMS Pediatric Itch Interference measure may not be sold or incorporated into a product to be sold without written permission, by anyone including clinicians and researchers. The instrument may not, under any circumstances, be changed in any way without explicit permission from the authors as even minor changes may alter performance. Any other use, including translation, requires advance written permission from the authors or the University of Washington.

Please cite the Burn Model System Pediatric Itch Interference user guide and short forms as follows:

Burn Model System Pediatric Itch Interference measure. Version 1 User Guide. 2019.

<<http://burndata.washington.edu/statistical-and-analytical-expertise>>. Accessed on [insert date].

Terms of Use

The Burn Model System Pediatric Itch Interference Scales are **free of charge** for non-commercial use. Examples of non-commercial use include administration of surveys in clinical practices for purposes of monitoring patients or administration for research purposes. Presentation or publication of results using the instruments should include a statement that indicates which instrument (including version number) was used and a reference to the BMS National Data and Statistical Center website (<http://burndata.washington.edu/>).

Permission to use the instruments does not grant permission to modify the wording or layout of items, to distribute to others in any form, or to translate items into any other language. Permission to modify, distribute, or translate must be requested in writing from the study principal investigator, Dagmar Amtmann, PhD, at dagmara@uw.edu or burndata@uw.edu.

Questions about the Pediatric Itch Interference Instruments

If you have questions about the instruments or their use in clinical care or research, please contact the Burn Model Systems National Data and Statistical Center (BMS NDSC) at the University of Washington.

Mailing Address

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Overview of the Pediatric Itch Interference Scales

The Burn Model System Pediatric Itch Interference Scales are Item Response Theory (IRT) based instruments intended for measuring itch interference in school age children with a burn injury. The Burn Model System Pediatric Itch Interference Scales are publicly available, psychometrically sound short forms for measuring itch

interference that can be administered on paper or computer. The Itch Interference Scales were developed in Spanish and English, and have not yet been translated into other languages.

Itch Interference: Construct and Definition

The Burn Model System Pediatric Itch Interference Scales measure the interference of itch on daily activities and emotions experienced by school age children under 18 years old with a burn injury. One of the scales was developed to be self-report, while the other was developed to be answered by a parent or caregiver of the child (proxy report). The questions on both the self-report and proxy report scales were developed with participation of researchers and clinicians with expertise in burn care for adult and pediatric burn patients. The scale was developed to be very brief and ask about those activities or emotions that are potentially most highly impacted by itching. Important aspects considered when choosing items for the scales included itch interference with: (1) sleep, (2) emotional health, (3) activities of daily living, and (4) overall quality of life.

Development Sample

The Burn Model System Pediatric Itch Interference Scales were initially administered to a sample of pediatric burn patients (ages 7-18 years) and/or their parent/caregiver enrolled in the Burn Model System National Longitudinal Database. The proxy scale was administered to 260 parents or caregivers of children with a severe burn injury. In addition, 247 children with burn injury completed the self-report version of the scale. Of these, 243 were pairs in which both the parent and the proxy completed the itch scale. The children were all participants from the Burn Model System National Longitudinal Database study. The proxy and self-report items were calibrated separately to an item response theory model using responses from the proxy and child report separately. The majority of the respondents completed the scales in Spanish (76%) and the average age of the child at the time of completion of the itch measures was 13 years. Additional characteristics of the children with burn injury can be found in the table below.

More information about the Burn Model System, including inclusion criteria and enrollment procedures can be found at <https://msktc.org/burn/model-system-centers> and <http://burndata.washington.edu/>.

Because the itch scales were calibrated in this sample, a score of 50 with a standard deviation of 10 on the scales is representative of the average level of itch interference in this sample. The sample was a convenience sample and does not represent the entire population of pediatric burn patients.

Characteristics of Pediatric Burn Sample Used for Calibrating the Itch Interference Scores to an IRT model (N=264)

	<u>Mean (SD) or %</u>
Self-report Itch Interference	50.0 (SD: 8.8)
Proxy Report Itch Interference	49.9 (SD:8.7)
Age of Child at Administration	13.1 (SD:2.9)
% Total Body Surface Area Burned (TBSA)	44.5 (SD:18.2)
Years After Burn Injury	5.0 (SD:4.6)
Child Age Group	
7-9 years	20%
10-13 years	36%
14-18 years	44%
Language of Administration	
English	22%
Spanish	78%
Gender of Child	
Male	68%
Female	32%
Ethnicity (N=261)	
Hispanic	80%
Non-Hispanic	20%
Race	
White	18%
Black	3%
Mexican	17%
Unknown	61%

Instructions for Using the BMS Itch Interference Scales

Choosing an Instrument and Mode of Administration:

Both the proxy and self-report scales consist of only 5 items. Because items were calibrated to an item response theory model it is possible to administer a subset of the 5 items, while still scoring individuals on the same metric using item response theory software. However, this would have significant impact on the reliability of the scores, and is not recommended given the already brief nature of the scales. Also, please note that one item on both scales relates to schoolwork. Because of this the scales are recommended for use in children 7 years and older.

Below you will find investigator versions with individual item scoring indicated. It is best practice **not to administer the version that shows scoring to the participants**. Instead, patient versions of the scales should be used with no scoring information and are available through the website at

<http://burndata.washington.edu/statistical-and-analytical-expertise>.

The 5-item proxy and self-report measures can be administered electronically (by computer or tablet) or on paper. The measures require less than five minutes to administer. The correlation between proxy and self-report scores is 0.69. You do not need to use both the proxy and the self-report scales at the same time, either one can be used independently as they are scored separately.

Scoring

The proxy and self-report scales are each scored by summing the responses to the 5 individual items and transforming the summary score to an IRT-based T-score using the conversion tables provided. **The summary score should not be used for any purposes**. All reliability and validation information relates to the IRT based T-scores. Raw scores/codes for each item range from 1 to 5 as indicated in the investigator/clinician versions below. Only complete responses with no missing data can be scored using the provided conversion scoring table. However, information on scoring with missing data is also provided under “Scoring with Missing Data” below. Detailed instructions for scoring are outlined here:

5-Item Self-Report Form: These instructions are only valid if there are complete responses with no missing data on all 5 items. Step 1: The 5 items are summed using the values provided for each response available in the clinician/researcher version of the form. This will give a summary score that ranges from 5 to 25. This is **not** a score that can be used for clinical or analytical purposes. Step 2: Using the Summary Score to T-score Conversion Table for the **Self-Report Form**, use the summary score to look up the IRT-based T-score in the column labeled “T-score” in the conversion table (page 8 below). For example, a person with a summary score of 10 would have a T-score of 56.0. This T-score is your final score you will use for all analyses.

5-Item Proxy-Report Form: These instructions are only valid if there are complete responses with no missing data on all 5 items. Step 1: The 5 items are summed using the values provided for each response

available in the clinician/researcher version of the form. This will give a summary score that ranges from 5 to 25. This is **not** a score that can be used for clinical or analytical purposes. Step 2: Using the Summary Score to T-score Conversion Table for the **Proxy-Report Form**, use the summary score to look up the IRT-based T-score in the column labeled “T-score” in the conversion table (page 9 below). For example, a person with a summary score of 17 would have a T-score of 62.8. This T-score is your final score you will use for all analyses.

Scoring with Missing Data: If any responses are missing you **cannot** score the measures without item response theory software. The summary score to T-score tables **are not valid** for these cases.

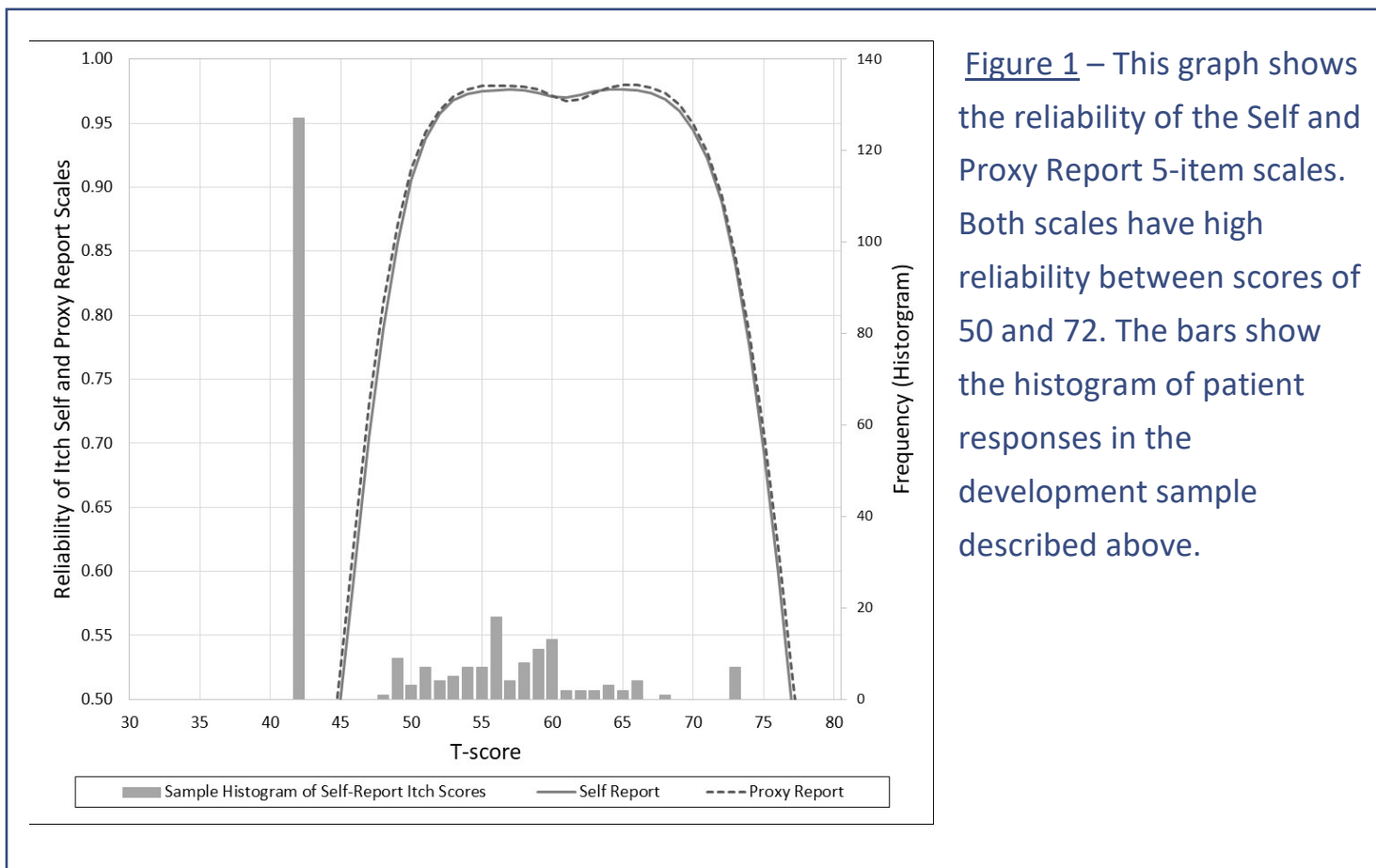


Figure 1 – This graph shows the reliability of the Self and Proxy Report 5-item scales. Both scales have high reliability between scores of 50 and 72. The bars show the histogram of patient responses in the development sample described above.

Interpreting Itch Interference Scores

The Self and Proxy Report Pediatric Itch Interference T-scores are standardized scores with a mean of 50 and a standard deviation (SD) of 10. T-scores of 50 represent the mean score of the pediatric burn sample described on page 4 above that was used to calibrate the items to an IRT model. A higher T-score represents a higher

level of itch interference. Based on a normal distribution of itch interference T-scores, 50% of children with a severe burn injury have a T-score of 50 or higher (see Figure 1 below). A respondent that receives a T-score of 60 has reported a level of itch interference approximately 1 standard deviation above the mean of other children with a burn injury and their itch interference level is higher than 84% of individuals in the calibration sample above.

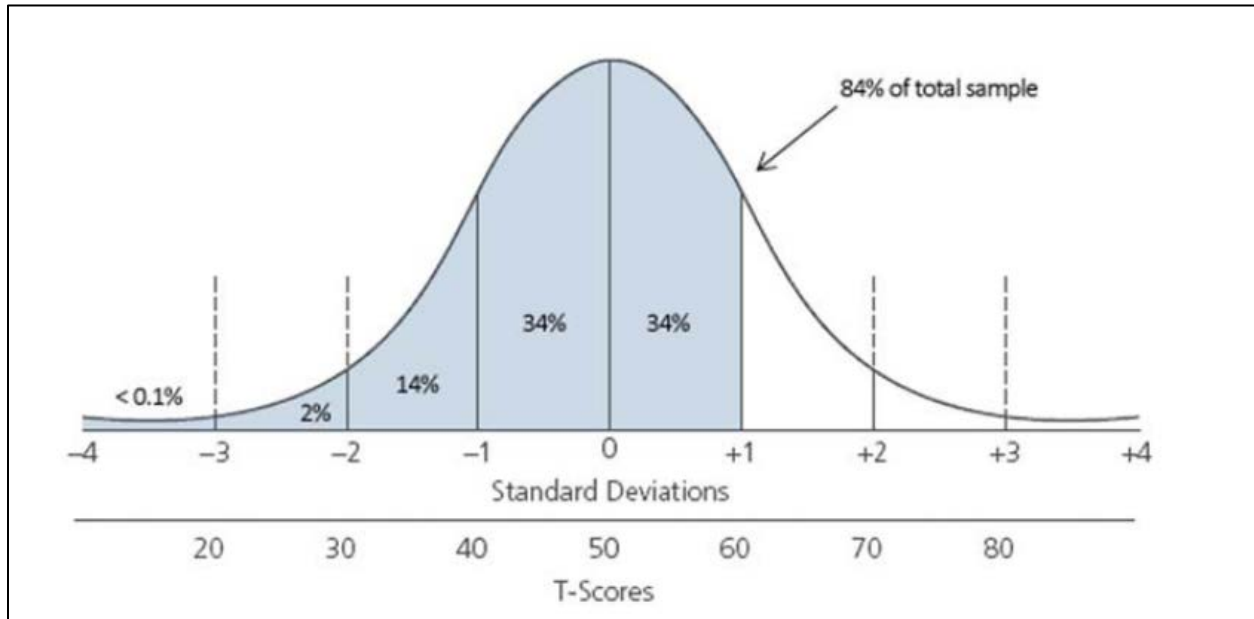


Figure 2 – A BMS Itch Interference T-score of 60 indicates that approximately 84 percent of persons in the calibration sample reported lower itch interference, as reflected by the shaded area.

Summary Score to T-score Conversion Tables

5 Item Short Form V.1.0 – Self-Report Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
5	42.5	6.5
6	50.4	3.1
7	51.8	3.1
8	53.7	2.3
9	54.8	2.3
10	56.0	1.9
11	56.9	1.8
12	57.9	1.8
13	58.8	1.9
14	59.7	1.9
15	60.6	1.9
16	61.5	1.9
17	62.3	1.9
18	63.3	1.8
19	64.2	1.8
20	65.1	1.8
21	66.1	1.9
22	67.1	2.0
23	68.5	2.3
24	69.7	2.4
25	73.6	4.0

5 Item Short Form V.1.0 – Proxy Report Summary Score to T-score Conversion

Summary Score	T-score	SD of T-score
5	42.4	6.4
6	50.3	2.9
7	51.7	2.9
8	53.6	2.1
9	54.7	1.9
10	55.8	1.7
11	56.8	1.7
12	57.7	1.7
13	58.7	1.8
14	59.7	1.8
15	60.8	1.8
16	61.8	1.8
17	62.8	1.8
18	63.8	1.7
19	64.7	1.6
20	65.6	1.6
21	66.5	1.7
22	67.5	1.8
23	68.8	2.2
24	70.0	2.4
25	73.7	4.0

BMS Pediatric Itch Interference Investigator or Clinician Forms

Versions 1.0 – English and Spanish

BMS Pediatric Itch Interference Self-Report Short Form V. 1.0 – English Language
 (Investigator/Clinician Version)

Pediatric Itch Interference

Instructions: Please respond to each item by marking one box per row.

In the past 7 days ...		Never	Almost Never	Sometimes	Often	Almost Always
1. I had trouble sleeping when I was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. I felt angry when I was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. It was hard for me to pay attention when I was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. It was hard for me to have fun when I was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (I don't do schoolwork)	Never	Almost Never	Sometimes	Often	Almost Always
5. I had trouble doing schoolwork when I was itching	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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Pediatric Itch Interference - Proxy Report

Instructions: Please respond to each item by marking one box per row.

In the past 7 days ...		Never	Almost Never	Some-times	Often	Almost Always	
1. My child had trouble sleeping when he/she was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
2. My child felt angry when he/she was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
3. It was hard for my child to pay attention when he/she was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
4. It was hard for my child to have fun when he/she was itching		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
	N/A (He/She doesn't do schoolwork)	Never	Almost Never	Some-times	Often	Almost Always	
5. My child had trouble doing schoolwork when he/she was itching		<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Efectos de la picazón

Instrucciones: Porfavor responda a cada pregunta o enunciado marcando una casilla por línea.

En los últimos 7 días ...		Nunca	Casi Nunca	A veces	A menudo	Casi Siempre
1. Tuve problemas para dormir cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Me sentí enojada cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Fue difícil para mi prestar atención cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Fue difícil para mi divertirme cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (Yo no hago trabajo escolar)	Nunca	Casi Nunca	A veces	A menudo	Casi Siempre
5. Tuve problemas haciendo tareas escolares cuando tenia comezón	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Efectos de la picazón - Informe Proxy

Instrucciones: Porfavor responda a cada pregunta o enunciado marcando una casilla por línea.

En los últimos 7 días ...		Nunca	Casi Nunca	A veces	A menudo	Casi Siempre
1. Mi niño(a) tiene problemas al dormir cuando tiene comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Mi niño(a) se siente enojado(a) cuando tiene comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Era difícil para que mi niño(a) pusiera atención cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Era difícil para que mi niño(a) se divirtiera cuando tenia comezón		<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
	N/A (Mi hijo(a) no hace trabajo escolar)	Nunca	Casi Nunca	A veces	A menudo	Casi Siempre
5. Mi niño(a) tiene problemas haciendo tareas escolares cuando tiene comezón.	<input type="checkbox"/>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5