***Appendix 1: Responses to Urdu 5D itch scale and median and IQR (n=262)***

|  |  |  |  |
| --- | --- | --- | --- |
| **Domain** | **Statement** | **Responses** | **N (%)**  |
| **Duration**      | During the last 2 weeks, how many hours a day have you been itching?      | Median [IQR] | 1.0 [1.0-2.0] |
| Less than 6hours/day | 169 (64.5) |
| 6-12 hours/day | 58 (22.1) |
| 12-18 hours/day | 27 (10.3) |
| 18-23 hours/day | 3 (1.1) |
| All day | 5 (1.9) |
| **Degree**      | Please rate the intensity of your itching over the past 2 weeks      | Median [IQR] | 2.0[2.0-3.0] |
| Not present | 31 (11.8) |
| Mild | 140 (53.4) |
| Moderate | 70 (26.7) |
| Severe | 15 (5.7) |
| Unbearable | 6 (2.3) |
| **Direction**      | Over the past 2 weeks has your itching gotten better or worse compared to the previous month?      | Median [IQR] | 2.0[1.0-3.0] |
| Completely resolved | 106 (40.5) |
| Much better but still present | 75 (28.6) |
| Little bit better but still present | 70 (26.7) |
| Unchanged | 9 (3.4) |
| Getting worse | 2 (0.8) |
| **Disability: Sleep**      | Rate the impact of your itching on the following activities over the last 2 weeks      | Median [IQR] | 3.0[2.0-3.0] |
| Never affects sleep | 49 (18.7) |
| Occasionally delays falling asleep | 81 (30.9) |
| Frequently delays falling asleep | 76 (29) |
| Delays falling asleep and occasionally wakes me up at night | 33 (12.6) |
| Delays falling asleep and frequently wakes me up at night | 23 (8.8) |
| **Disability: Leisure/Social**      | Rate the impact of your itching on the following activities over the last 2 weeks      | Median [IQR] | 1.0[1.0-3.0] |
| Never affect activity | 141 (53.8) |
| Rarely affects activity | 46 (17.6) |
| Occasionally affects activity | 49 (18.7) |
| Frequently affects activity | 24 (9.2) |
| Always affects activity | 2 (0.8) |
| **Disability: Housework/ Errands**      | Rate the impact of your itching on the following activities over the last 2 weeks      | Median [IQR] | 1.0[1.0-2.0] |
| Never affect activity | 147 (56.1) |
| Rarely affects activity | 52 (19.8) |
| Occasionally affects activity | 45 (17.2) |
| Frequently affects activity | 12 (4.6) |
| Always affects activity | 6 (2.3) |
| **Disability: Work/School**      | Rate the impact of your itching on the following activities over the last 2 weeks      | Median [IQR] | 1.0[1.0-2.0] |
| Never affect activity | 175 (66.8) |
| Rarely affects activity | 38 (14.5) |
| Occasionally affects activity | 35 (13.4) |
| Frequently affects activity | 12(4.6)  |
| Always affects activity | 2 (0.8) |
| **Distribution bin score**      | Mark whether itching has been present in the following parts of your body over the last 2 weeks. If a body part is not listed, choose the one that is closest anatomically.  | Median [IQR] | 2.0[1.0-2.0] |
| Score bin 1 | 130 (49.6) |
| Score bin 2 | 104 (39.7) |
| Score bin 3 | 21 (8) |
| Score bin 4 | 2 (0.8) |
| Score bin 5 | 5 (1.9) |
| **Total score of 5D itch scale**     | Ranged from 5-25 | Median [IQR] | 10.0[8.0-12.0]  |
| 5-10 (Mild pruritus) | 136 (52.0) |
| 11-19 (Moderate pruritus) | 125 (47.7) |
| 20-25 (severe pruritus)  |  1 (0.3) |

***Score bin:*** A scoring bin was used for the body parts affected by pruritus, where 0-2 body parts were scored as 1; 3-5 body parts were scored as 2, 6–10 body parts were scored as 3, 11–13 body parts were scored as 4, and 14–16 body parts were scored as 5.

***Appendix 2: Responses to Urdu functional assessment of non-life-threatening condition (FANLTC) (n=262) [score range from 0-5]***

|  |  |
| --- | --- |
| **Statement** | **N (%)** |
| **Physical wellbeing**  |  |
| Lack of energy |  |
| *Not at all* | 26 (9.9) |
| *A little bit* | 40 (15.3) |
| *Some what* | 90 (34.4) |
| *Quite a bit* | 58 (22.1) |
| *Very much* | 48 (18.3) |
| Have nausea |  |
| *Not at all* | 15 (5.7) |
| *A little bit* | 58 (22.1) |
| *Some what* | 90 (34.4) |
| *Quite a bit* | 58 (22.1) |
| *Very much* | 41 (15.6) |
| Having trouble meeting the needs of my family |  |
| *Not at all* | 20 (7.6) |
| *A little bit* | 35 (13.4) |
| *Some what* | 74 (28.2) |
| *Quite a bit* | 87 (33.2) |
| *Very much* | 46 (17.6) |
| Have pain |  |
| *Not at all* | 17 (6.5) |
| *A little bit* | 50 (19.1) |
| *Some what* | 89 (34) |
| *Quite a bit* | 75 (28.6) |
| *Very much* | 31 (11.8) |
| Bothered by side effects of treatment |  |
| *Not at all* | 15 (5.7) |
| *A little bit* | 44 (16.8) |
| *Some what* | 75 (28.6) |
| *Quite a bit* | 84 (32.1) |
| *Very much* | 44 (16.8) |
| Feel ill |  |
| *Not at all* | 7 (2.7) |
| *A little bit* | 33 (12.6) |
| *Some what* | 59 (22.5) |
| *Quite a bit* | 76 (29) |
| *Very much* | 87 (33.2) |
| Forced to spend time in bed |  |
| *Not at all* | 16 (6.1) |
| *A little bit* | 32 (12.2) |
| *Some what* | 71 (27.1) |
| *Quite a bit* | 70 (26.7) |
| *Very much***Social/Family wellbeing** | 73 (27.9) |
| Feel close to my friend |  |
| *Not at all* | 45 (17.2) |
| *A little bit* | 53 (20.2) |
| *Some what* | 82 (31.3) |
| *Quite a bit* | 54 (20.6) |
| *Very much* | 28 (10.7) |
| Get emotional support from my family |  |
| *Not at all* | 8 (3.1) |
| *A little bit* | 11 (4.2) |
| *Some what* | 59 (22.5) |
| *Quite a bit* | 68 (26) |
| *Very much* | 116 (44.3) |
| Get support from my friends |  |
| *Not at all* | 41 (15.6) |
| *A little bit* | 39 (14.9) |
| *Some what* | 55 (21) |
| *Quite a bit* | 58 (22.1) |
| *Very much* | 69 (26.3) |
| My family has accepted my illness |  |
| *Not at all* | 8 (3.1) |
| *A little bit* | 10 (3.8) |
| *Some what* | 45 (17.2) |
| *Quite a bit* | 88 (33.6) |
| *Very much* | 111 (42.4) |
| Satisfied with family communication about my illness |  |
| *Not at all* | 6 (2.3) |
| *A little bit* | 16 (6.1) |
| *Some what* | 81 (30.9) |
| *Quite a bit* | 82 (31.3) |
| *Very much* | 77 (29.4) |
| Feel close to my partner |  |
| *Not at all* | 45 (17.2) |
| *A little bit* | 43 (16.4) |
| *Some what* | 83 (31.7) |
| *Quite a bit* | 71 (27.1) |
| *Very much* | 20 (7.6) |
| Satisfied with my sex life |  |
| *Not at all* | 97 (37) |
| *A little bit* | 69 (26) |
| *Some what* | 75 (28.6) |
| *Quite a bit* | 21 (8) |
| **Emotional wellbeing**  |  |
| Feel sad |  |
| *Not at all* | 31 (11.8) |
| *A little bit* | 45 (17.2) |
| *Some what* | 82 (31.3) |
| *Quite a bit* | 59 (22.5) |
| *Very much* | 45 (17.2) |
| Satisfied with how I am coping with my illness |  |
| *Not at all* | 14 (5.3) |
| *A little bit* | 39 (14.9) |
| *Some what* | 109 (41.6) |
| *Quite a bit* | 60 (22.9) |
| *Very much* | 40 (15.3) |
| Losing hope in the fight against my illness |  |
| *Not at all* | 40 (15.3) |
| *A little bit* | 49 (18.7) |
| *Some what* | 80 (30.5) |
| *Quite a bit* | 73 (27.9) |
| *Very much* | 20 (7.6) |
| Feel nervous |  |
| *Not at all* | 28 (10.7) |
| *A little bit* | 48 (18.3) |
| *Some what* | 86 (32.8) |
| *Quite a bit* | 71 (27.1) |
| *Very much* | 29 (11.1) |
| Worry that my condition will get worse |  |
| *Not at all* | 23 (8.8) |
| *A little bit* | 49 (18.7) |
| *Some what* | 76 (29) |
| *Quite a bit* | 69 (26.3) |
| **Functional wellbeing**  |  |
| Able to work |  |
| *Not at all* | 66 (25.2) |
| *A little bit* | 81 (30.9) |
| *Some what* | 69 (26.3) |
| *Quite a bit* | 39 (14.9) |
| *Very much* | 7 (2.7) |
| My work (include work at home) is fulfilling |  |
| *Not at all* | 60 (22.9) |
| *A little bit* | 63 (24) |
| *Some what* | 87 (33.2) |
| *Quite a bit* | 45 (17.2) |
| *Very much* | 7 (2.7) |
| Able to enjoy life |  |
| *Not at all* | 51 (19.5) |
| *A little bit* | 52 (19.8) |
| *Some what* | 98 (37.4) |
| *Quite a bit* | 54 (20.6) |
| *Very much* | 7 (2.7) |
| Have accepted my illness |  |
| *Not at all* | 3 (1.1) |
| *A little bit* | 23 (8.8) |
| *Some what* | 82 (31.3) |
| *Quite a bit* | 67 (25.6) |
| *Very much* | 87 (33.2) |
| Sleeping well |  |
| *Not at all* | 22(8.4) |
| *A little bit* | 55 (21) |
| *Some what* | 93 (35.5) |
| *Quite a bit* | 76 (29) |
| *Very much* | 16 (6.1) |
| Enjoying the things, I usually do for fun |  |
| *Not at all* | 44 (16.8) |
| *A little bit* | 47 (17.9) |
| *Some what* | 75 (28.6) |
| *Quite a bit* | 79 (30.2) |
| *Very much* | 17 (6.5) |
| Am content with the quality of my life right now |  |
| *Not at all* | 33 (12.6) |
| *A little bit* | 44 (16.8) |
| *Some what* | 112 (42.7) |
| *Quite a bit* | 64 (24.4) |
| *Very much* | 9 (3.4) |