MTSOSD

MODIFIED TRANSPLANT SYMPTOM OCCURRENCE AND SYMPTOM DISTRESS SCALE

Instructions

Taking medication after transplantation is associated with certain side effects, which may or may not be distressing to you.

In this questionnaire, each question is divided into two columns, as shown in the example below.

Example:

1. I have had itching	My itching was
O *Never* O *0ccasionally* ☒ *Regularly* O *Almost always* O *Always*	*not distressing at all* — *terribly distressing* *0 1 (2) 3 4*

The ***left*** column asks about the ***occurrence*** of the **side effects**. Please indicate how frequently or how severely you have experienced a given symptom **during the past 4 weeks** by checking off the appropriate answer.

In the ***right*** column you will find questions asking you whether these symptoms are **distressing** to you. Please circle the number that corresponds with how distressing this symptom is to you.
If a symptom **does not occur**, answer **"never"** or **"not"** in the left column and go directly to the **next question**.

At the end of the questionnaire, you can add additional side effects that you may have experienced during the **past 4 weeks**. Please check if you have completed all items and all pages. Please also be sure that you have completed both the right and left column of the questionnaire.

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Developed to assess occurrence and distress experienced by the side effects of Cyclosporine, Tacrolimus, Micophenolate Mofetil, Azathioprine, Prednisolone, Sirolimus, LEA29Y.
Partly based on the Transplant Symptom Frequency and Symptom Distress Scale: Lough ME, Lindsey AM, Shinn JA, Stotts NA. Life satisfaction following heart transplantation. J Heart Transplantation 1985; 4: 446-449 & Lough ME, Lindsey AM, Shinn JA, Stotts NA. Impact of symptom frequency and symptom distress on self-reported quality of life in heart transplant recipients. Heart Lung 1987; 16: 193-200.

During the past 4 weeks (including today):

1. I have had <u>itching</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>itching</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
2. I have had <u>chest pain</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>chest pain</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
3. I have had <u>wind</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>wind</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
4. I have had <u>increased thirst</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>increased thirst</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
5. I have felt <u>restless</u> or <u>nervous</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>restlessness</u> or <u>nervousness</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
6. I have had <u>hearing loss</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>hearing loss</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

During the past 4 weeks (including today):

7. I have had an <u>abnormal skin color</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>abnormal skin color</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
8. I have had <u>increased sweating</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>increased sweating</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
9. My <u>face and neck</u> have been <u>red</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	The <u>redness</u> in my face and neck was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
10. I have had <u>brittle fingernails</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>brittle fingernails</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
11. My <u>breasts</u> have been <u>larger</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>breast enlargement</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
12. I have had <u>sores on my lips and/or in my mouth</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>sores</u> on lips and/or in mouth were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

During the past 4 weeks (including today):

13. I have had an altered voice

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My altered voice was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

14. I have had oily skin

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My oily skin was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

15. I have felt dizzy

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My dizziness was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

16. My hands have trembled

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My trembling hands were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

17. I have had an increased urge to urinate

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My increased urge to urinate was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

18. I have had a feeling of warmth in my hands and feet

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

The feeling of warmth in my hands and feet was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

During the past 4 weeks (including today):

19. I have had bruises more easily

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My bruises were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

20. I have had sores or warts around my genitals

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My sores or warts around genitals were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

21. I have had spots on my face and/or my back

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My spots on my face and/or back were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

22. I have had an excessive appetite

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My excessive appetite was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

23. I have felt depressed

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My feelings of depression were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

24. My gums have swollen

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My swollen gums were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

During the past 4 weeks (including today):

25. I have had swollen glands in my neck, armpit or groin

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My swollen glands were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

26. I have had thinning of hair or hair loss

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My hair thinning or hair loss was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

27 A. I have had menstrual problems ***(for females only)***

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My menstrual problems were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

27 B. I have had erectile problems ***(for males only)***

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My erectile problems were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

28. I have had a puffy face (moon face)

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My puffy face was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

29. I have had swollen ankles or feet

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My swollen ankles or feet were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

During the past 4 weeks (including today):

30. I have had <u>diarrhea</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>diarrhea</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
31. I have had <u>tingling or numbness</u> in my hands or feet O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>tingling or numbness</u> in my hands or feet was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
32. I have had <u>back pain</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>back pain</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
33. I have had a <u>brittle skin</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>brittle skin</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
34. I have felt <u>anxious</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My feelings of <u>anxiety</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
35. I have been experiencing <u>mood swings</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>mood swings</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

During the past 4 weeks (including today):

36. I have had <u>headaches</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>headaches</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
37. My <u>facial features have changed</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>changed facial features</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
38. I have had <u>fat deposits</u> on my neck and back (“buffalo hump”) O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>fat deposits</u> on neck and back were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
39. I have had difficulty <u>concentrating</u> and/or <u>memory problems</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>concentration difficulties and/or memory problems</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
40. I have had <u>warts on hands and feet</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>warts on hands and feet</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
41. I have had <u>increased hair growth</u> on face and body O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>increased hair growth</u> on face and body were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

During the past 4 weeks (including today):

42. I have had <u>sleep difficulties</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>sleep difficulties</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
43. I have had <u>muscle weakness</u> O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>muscle weakness</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
44. My <u>sense of taste</u> has changed O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	The <u>change in my sense of taste</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
45. I have had a <u>poor appetite</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>poor appetite</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
46. I have felt <u>tired</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>tiredness</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
47. I have had <u>lack of energy</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>lack of energy</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

During the past 4 weeks (including today):

48. I have had stomach complaints, I have felt nauseous and/or I had to vomit

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My stomach complaints, nausea or vomiting were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

49. I have had pain in my joints

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My joint pain was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

50. I have had a rash on my skin

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My skin rash was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

51. I have had muscle cramps

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My muscle cramps were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

52. I have had nightmares

- O *Never*
- O *0ccasionally*
- O *Regularly*
- O *Almost always*
- O *Always*

My nightmares were

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

53. I have been short of breath

- O *Not*
- O *A little*
- O *Moderately*
- O *Greatly*
- O *Very greatly*

My shortness of breath was

not distressing at all — *terribly distressing*

0_____1_____2_____3_____4

During the past 4 weeks (including today):

54. I have had a <u>dry skin</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>dry skin</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
55. I have had <u>palpitations</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>palpitations</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
56. I have had <u>constipation</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>constipation</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
57. I have had <u>difficulty seeing</u> well O *Not* O *A little* O *Moderately* O *Greatly* O *Very greatly*	My <u>seeing difficulties</u> were *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
58. I have had a <u>reduced interest in sex</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>reduced interest in sex</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*
59. My eyes have been <u>sensitive to light</u> O *Never* O *0ccasionally* O *Regularly* O *Almost always* O *Always*	My <u>sensitivity to light</u> was *not distressing at all* — *terribly distressing* *0_____1_____2_____3_____4*

Please check if you have completed all items and all pages.

Please also be sure that you have completed both the right and left column of the questionnaire.

THANK YOU VERY MUCH FOR YOUR COOPERATION