

Epilepsy Self-Management Scale

The Epilepsy Self-Management Scale (ESMS) is a 38 item scale that assesses frequency of use of epilepsy self-management practices. Each item is rated on a 5-point scale ranging from 1, never, to 5, always. Items for the scale were developed from a review of the literature on epilepsy self-management and discussions with people with epilepsy and health care professionals caring for people with epilepsy. The 26 original items were categorized into three areas: a) medication-related, b) safety-related, and c) general lifestyle management. Total scores are found by reverse coding the 12 negatively worded items and summing responses to all 38 individual items. Total possible scores range from 38-190 with higher scores indicating more frequent use of self-management strategies.

The 26-item instrument was evaluated by a panel of experts in epilepsy management familiar with instrument development. Content validity was assessed on the original 26-item version using the procedures described by Waltz, Strickland, and Lenz (1984) yielding a content validity index (CVI) of 93% indicating strong agreement among the reviewers that the items measure self-management practices. Internal consistency reliability reported for a 26-item scale has ranged from .81-.86 (DiIorio et al., 1992; DiIorio et al., 1994). Twelve additional items were written to address lifestyle issues and safety measures and these items. The 38-item scale was factor analyzed yielding 5 factors: Medication, Information, Safety, Seizure, and Lifestyle Management (DiIorio et al., 2004).

References

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Instructions: The following statements describe what people do to manage their epilepsy. Please circle one number for each statement to show how often you do the following. As you answer the questions, please think about your activities in the past year.

	Never	Rarely	Sometimes	Most of the Time	Always
IM 1. I write down how often I have seizures and when they occur.	1	2	3	4	5
LM 2. I do things such as relaxation, guided imagery, and self hypnosis to manage stress. □	1	2	3	4	5
IM 3. I call my doctor when I think I am having side effects from my seizure medication.	1	2	3	4	5
*MM 4. When my seizure medication is running out, I spread out the time between doses.	1	2	3	4	5
IM 5. I keep a record of the types of seizures I have. □	1	2	3	4	5
*SM 6. I stay out late at night.	1	2	3	4	5
IM 7. I keep track of the side effects of my seizure medication.	1	2	3	4	5
*MM 8. When my seizure medication is running out, I take less medication at each time.	1	2	3	4	5
MM 9. I take my seizure medication the way my doctor orders it.	1	2	3	4	5
SeM 10. I stay out of situations that might cause a seizure.	1	2	3	4	5
SeM 11. If I am going away from home, I take my seizure medication with me.	1	2	3	4	5
SeM 12. I call my doctor if I am having more seizures than usual.	1	2	3	4	5
LM 13. I make sure I get enough sleep.	1	2	3	4	5

	Never	Rarely	Sometimes	Most of the Time	Always
LM 14. I do things that I enjoy to help manage stress.	1	2	3	4	5
SeM 15. I have a way to remind myself to take my seizure medication.	1	2	3	4	5
MM 16. I take my seizure medication at the same time each day.	1	2	3	4	5
*SM 17. I would go swimming alone.	1	2	3	4	5
LM. 18. I do things such as relaxation, guided imagery, and self hypnosis to keep myself from having a seizure.	1	2	3	4	5
SeM 19. When the doctor orders blood tests, I have them done. <input type="checkbox"/>	1	2	3	4	5
IM 20. I wear or carry information stating that I have epilepsy.	1	2	3	4	5
*MM 21. I have to put off having my seizure medication refilled because it costs too much money.	1	2	3	4	5
LM. 22. I get enough exercise.	1	2	3	4	5
*SM. 23. I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff. <input type="checkbox"/>	1	2	3	4	5
*MM 24. I miss doctor or clinic appointments.	1	2	3	4	5
*MM 25. If I had side effects from the seizure medications, I would skip a dose without asking my doctor.	1	2	3	4	5
SM 26. I take showers instead of baths.	1	2	3	4	5
MM 27. I plan ahead and have my seizure medication refilled before I run out. <input type="checkbox"/>	1	2	3	4	5

	Never	Rarely	Sometimes	Most of the Time	Always
* MM 28. I miss doses of my seizure medication because I do not remember to take it. <input type="checkbox"/>	1	2	3	4	5
SM 29. I keep the temperature of the water in my home low enough so I do not get burned.	1	2	3	4	5
* MM 30. I skip doses of seizure medication. <input type="checkbox"/>	1	2	3	4	5
SM 31. I check with my doctor before taking other medicines. <input type="checkbox"/>	1	2	3	4	5
SeM 32. I stay away from things that make me have seizures.	1	2	3	4	5
LM. 33. I eat regular meals.	1	2	3	4	5
* SM 34. I climb objects such as high stools, chairs, or ladders.	1	2	3	4	5
IM 35. I talk with other people who have epilepsy.	1	2	3	4	5
* SM 36. I drink a lot of alcoholic beverages such as beer, wine, and whiskey.	1	2	3	4	5
IM 37. I participate in a support group for persons with epilepsy.	1	2	3	4	5
IM 38. I practice what to do during a seizure with my family and friends.	1	2	3	4	5

Subscales:

MM=Medication management

IM=Information management

SM=Safety management

SeM=Seizure management

LM=Lifestyle management

*** Reverse code**