



Patients' Perspective of Tetrabenazine in the Treatment of Huntington Disease and Other Hyperkinetic Movement Disorders

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OBJECTIVES

To review the utilization, efficacy and tolerance of tetrabenazine (Xenazine), a monoamine depleting drug, three years after approval of the drug in 2008 by the Food and Drug Administration for the treatment of chorea associated with Huntington disease.

BACKGROUND

We previously reported the results of our survey assessing patients' access to tetrabenazine one year after FDA approval (Mov Disord 2010 (Suppl 2):S275). We now report long-term results and compare them to the initial survey.

METHODS

A follow-up questionnaire was constructed to assess patients' experiences, costs, and attitudes related to perceived efficacy and tolerability of tetrabenazine prescribed for the treatment of a variety of hyperkinetic movement disorders >2 years following FDA approval. The questionnaires were administered to all patients currently taking tetrabenazine for HD and other indications and are followed at the Baylor College of Medicine Parkinson's Disease Center and Movement Disorders Clinic (PDCMDC). The results were compared to those obtained from a survey within the first year of approval.

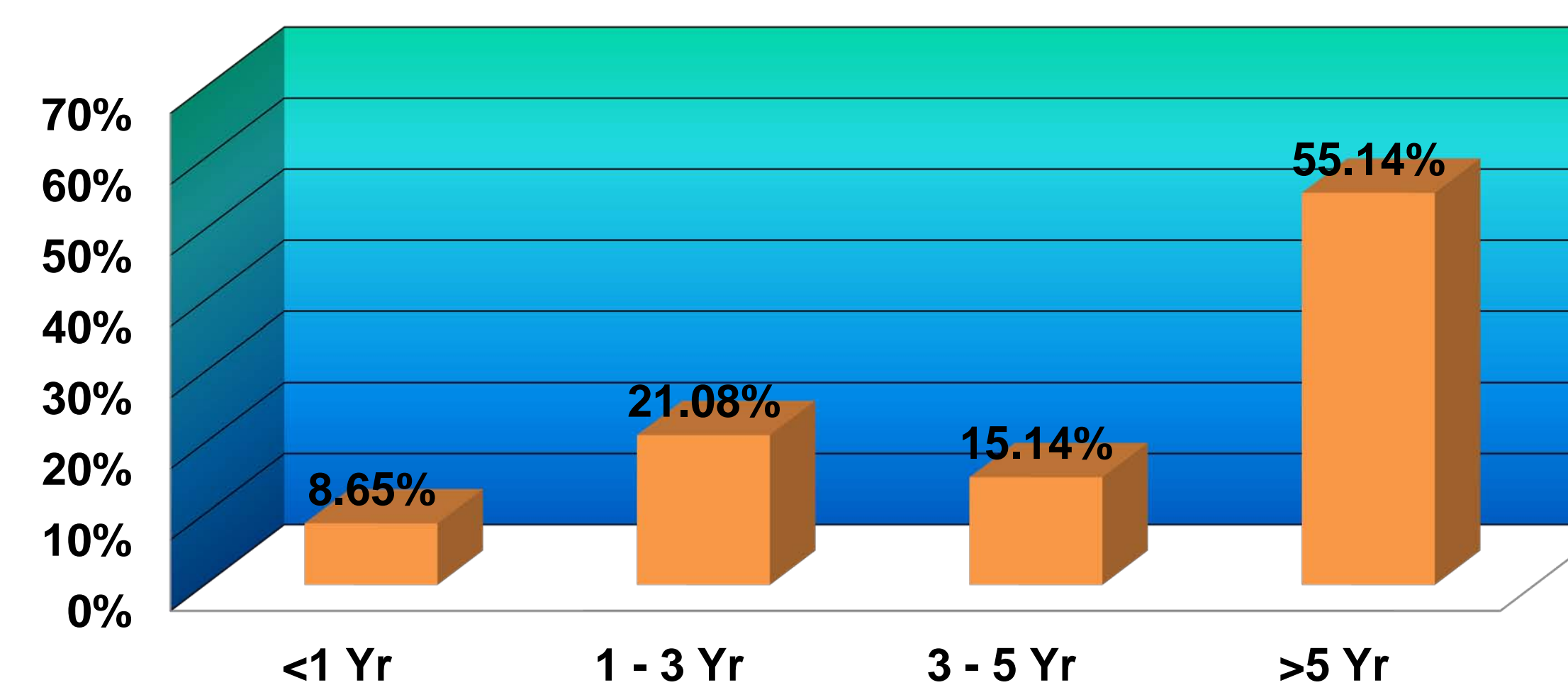
RESULTS

The questionnaire was distributed to 310 patients and 185 (59.7%) completed the survey. * The respondents included 67 (36.2%) patients with Tourette's syndrome, 53 (28.7%) with tardive dyskinesia, and 33 (17.8%) with HD. Tetrabenazine use for more than 5 years was reported by 48 (25.9%) of respondents. Prior to taking tetrabenazine, 172 (93.0%) patients indicated their movement disorder made them moderately to severely ill. Approximately 85.9% of patients taking tetrabenazine were taking 0-100 mg daily with 12.9% taking 101-200 mg daily. 150 side effects from tetrabenazine were reported by 123 (66.5%) patients, with drowsiness (35.9%) being reported the most. With the current Specialty Pharmacy Program, 108 (60.0%) patients were initially approved for coverage of tetrabenazine by their insurance carrier; 75% of the claims were successfully appealed. In the 2 years since its launch into the US market, insurance companies have been more reluctant to cover the cost of this medication. 27.2% of all patients have been denied by their insurance company at least one time. Costs have also been affected 2 years later with 41.9% of respondents indicating a change in their out of pocket expenses. 12.6% of those respondents indicated that they are now paying 2 or 3 times more than they were at the time of the initial survey. Of the responders, 139 (76.4%) patients stated that they were satisfied or very satisfied with their response to tetrabenazine and 111 (78.7%) with the Specialty Pharmacy Program. 83.6% of patients indicated they were satisfied or very satisfied with the overall process to obtain tetrabenazine.

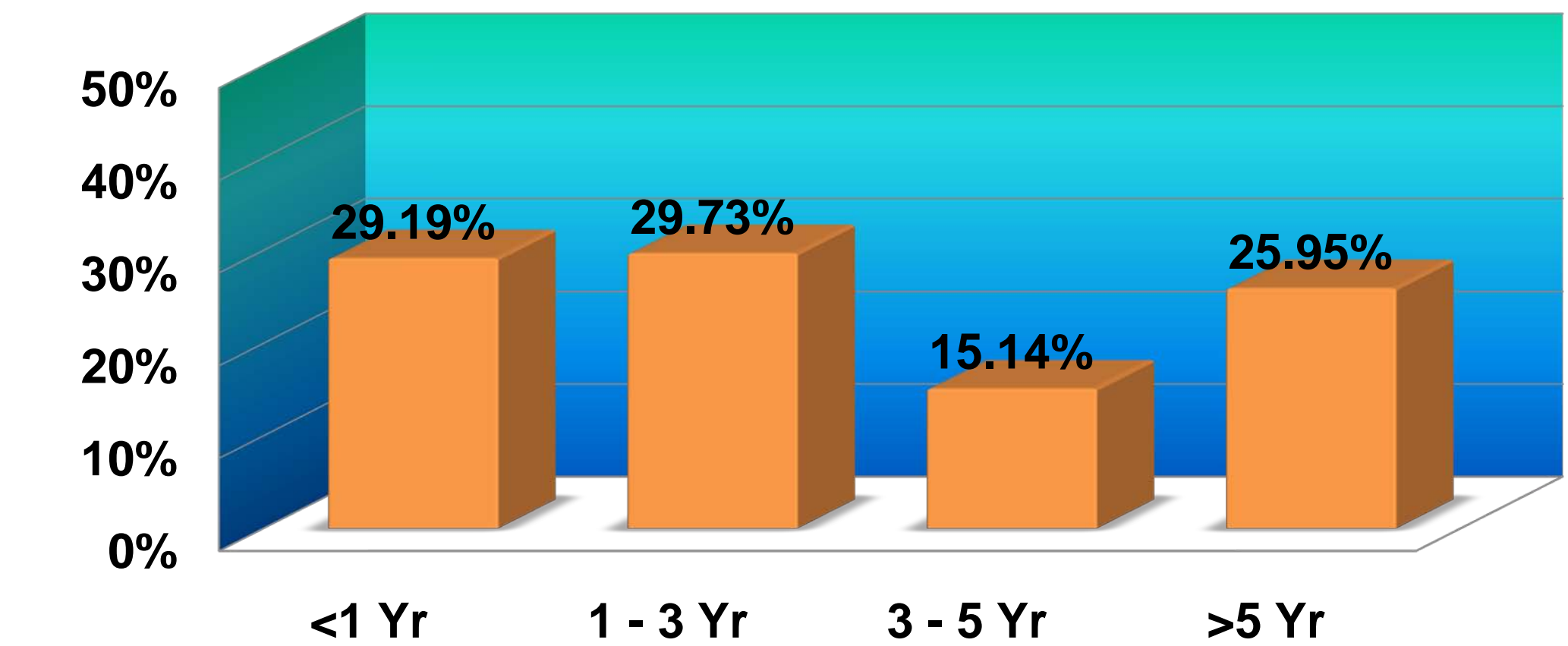
CONCLUSIONS

Our survey indicates a high level of satisfaction among patients prescribed tetrabenazine for their hyperkinetic movement disorder with cost-effective access to the drug via a specialty pharmacy system. The benefits have been maintained for >2 years since the FDA approval.

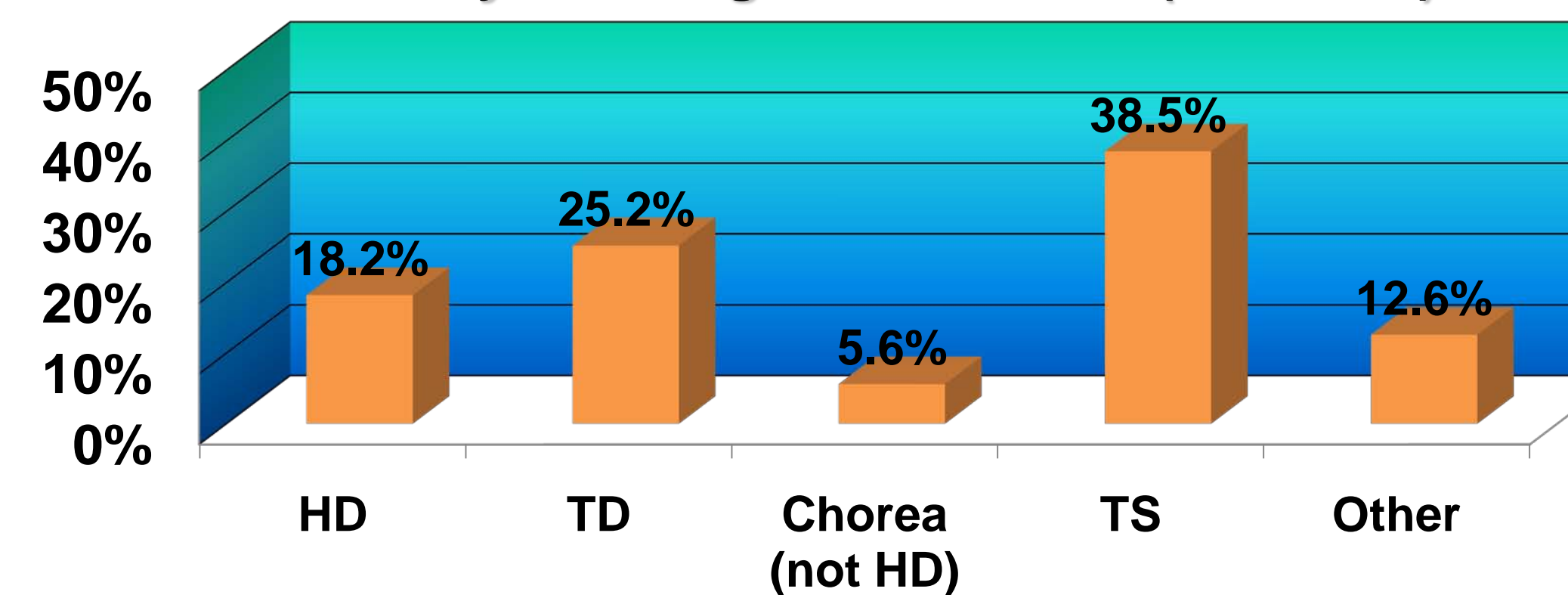
How long have you had symptoms for which you are being treated with tetrabenazine (Xenazine)?



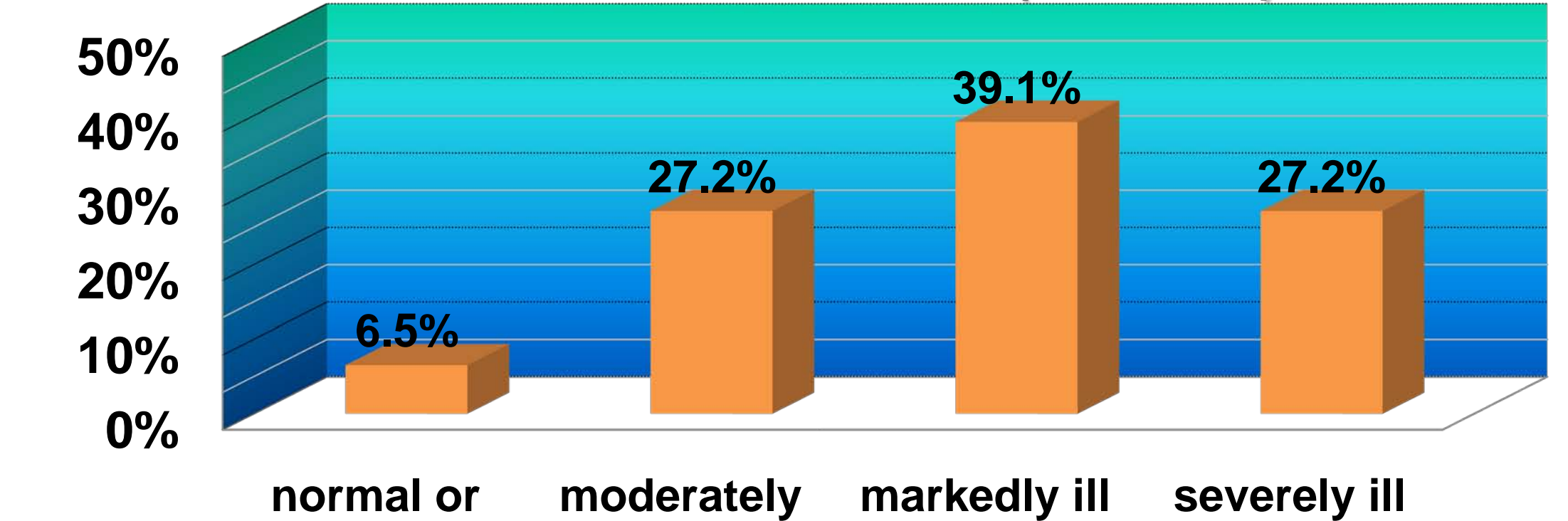
How long have you been taking tetrabenazine (Xenazine)?



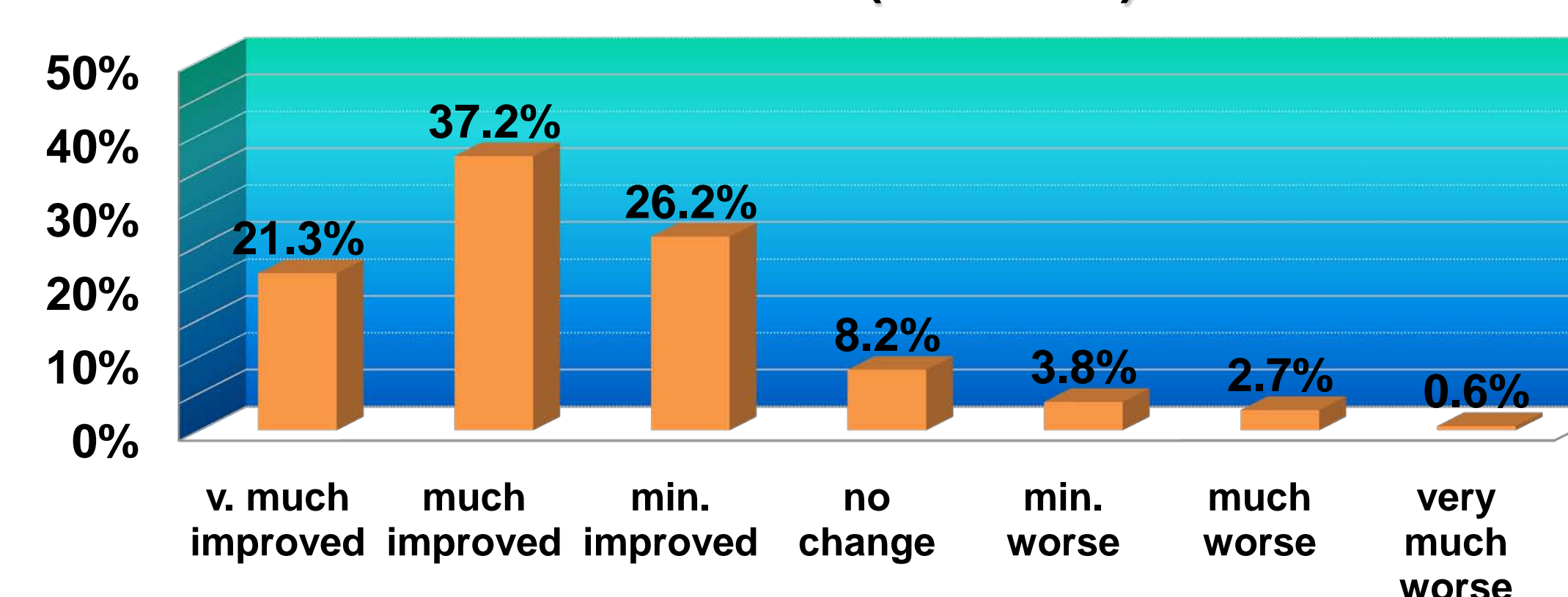
What are you taking tetrabenazine (Xenazine) for?



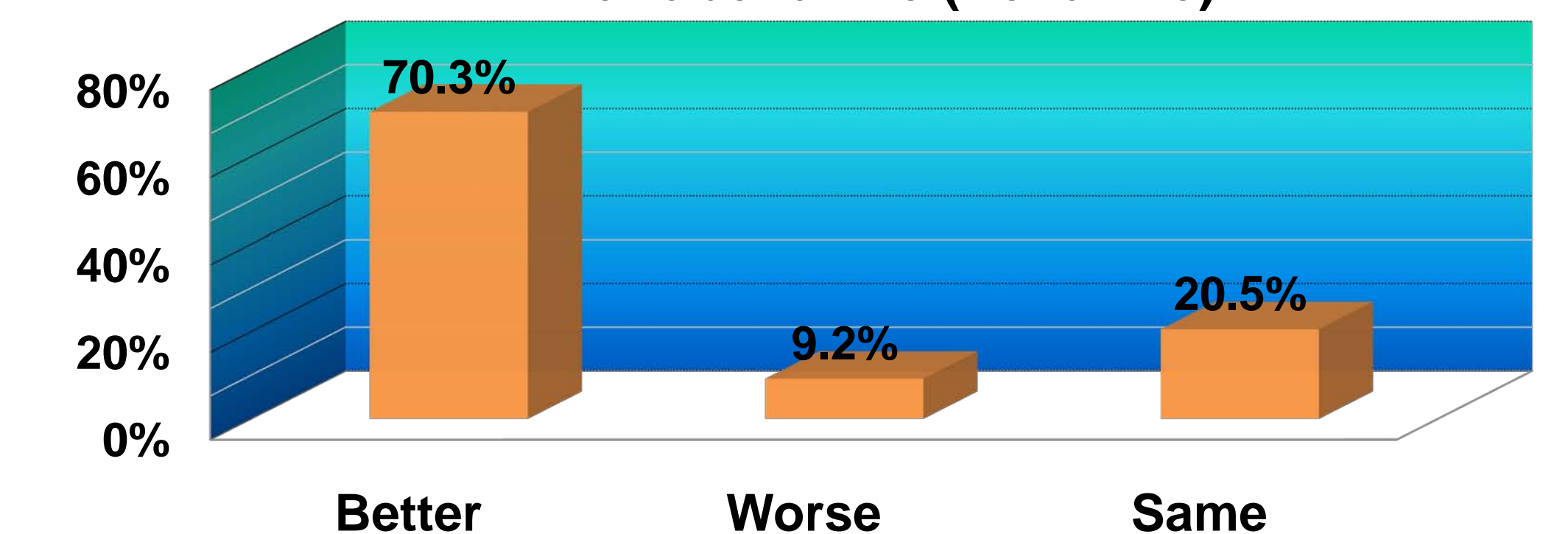
How would you rate your overall illness PRIOR using tetrabenazine (Xenazine)?



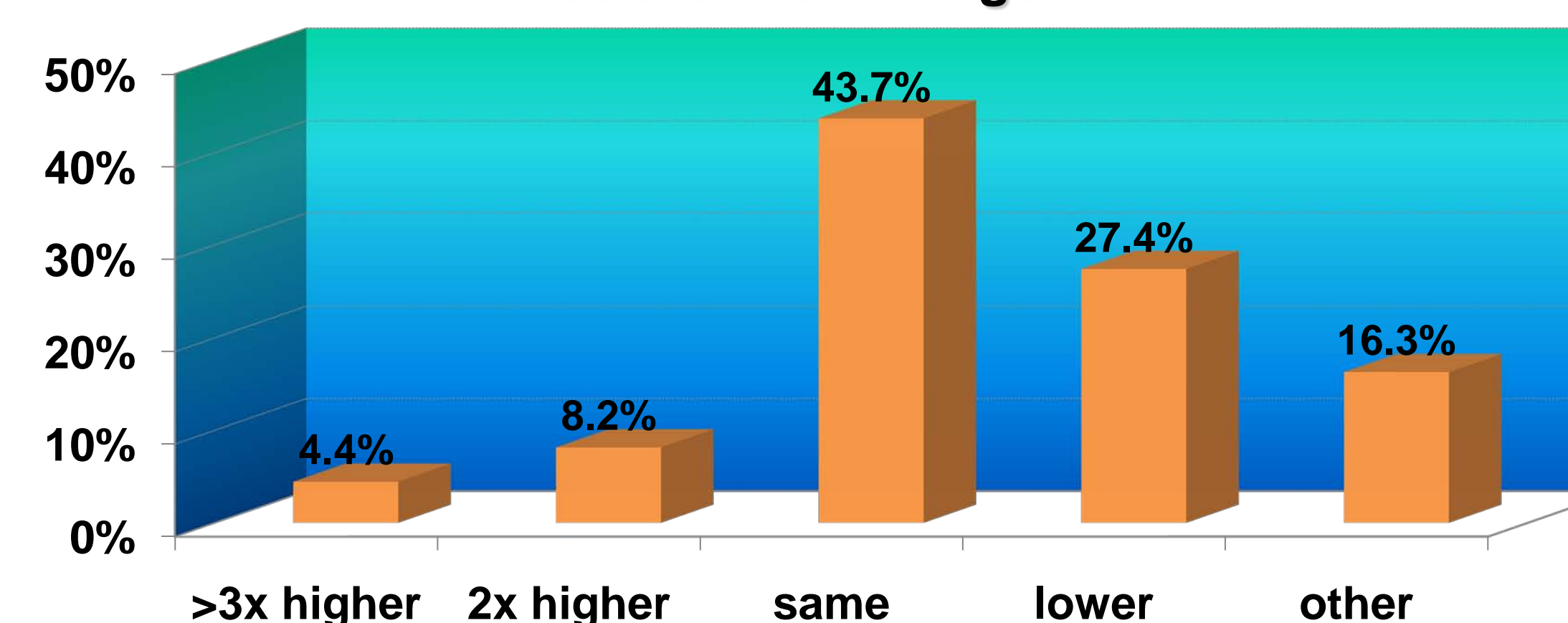
How would you rate your symptoms WHILE using tetrabenazine (Xenazine)?



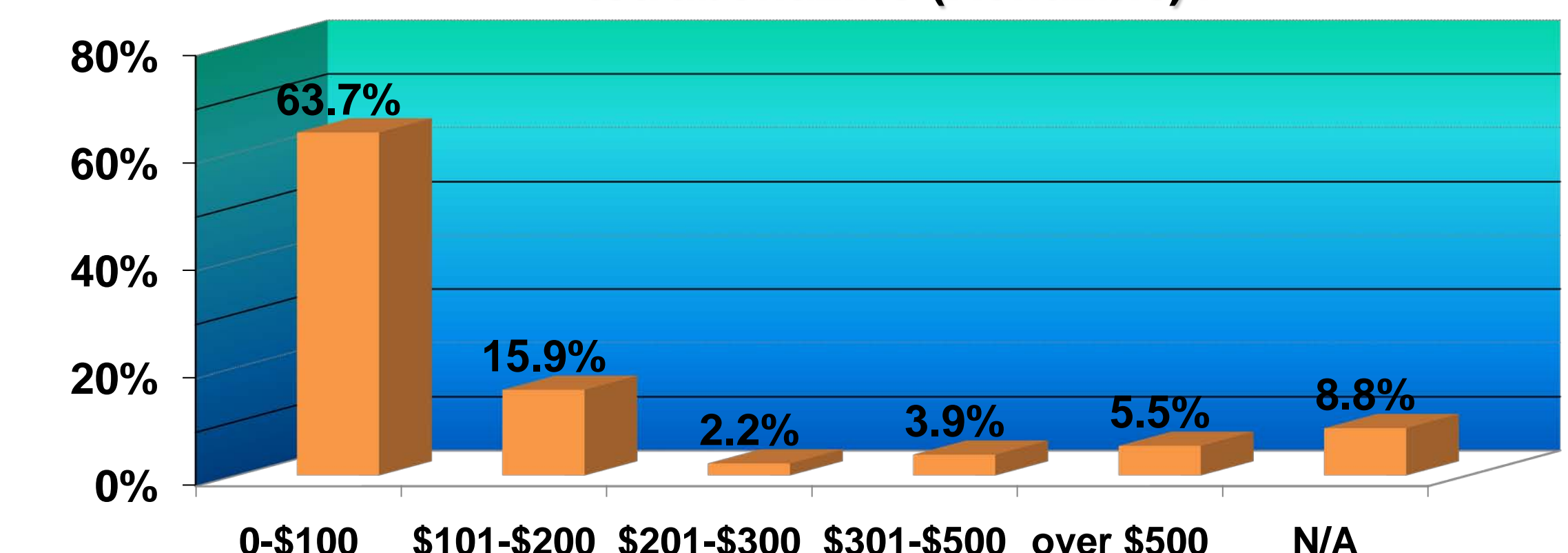
How would you rate your condition since initiation of tetrabenazine (Xenazine)?



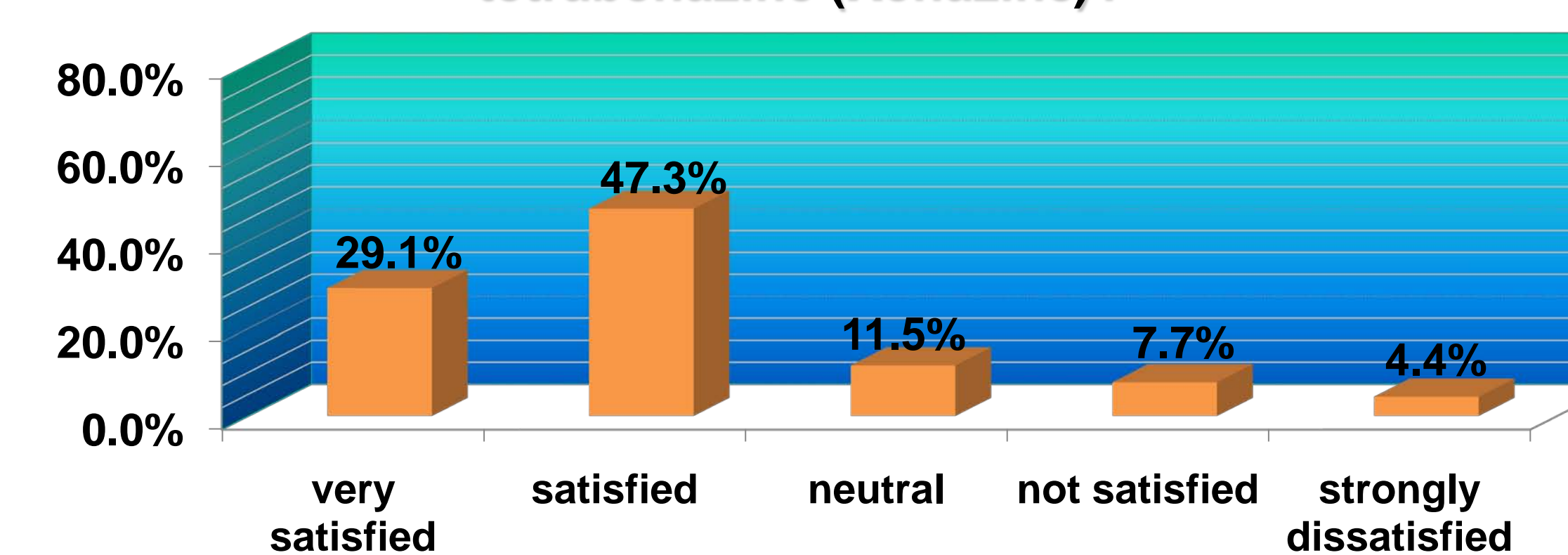
Since you began using tetrabenazine (Xenazine) how has the cost changed?



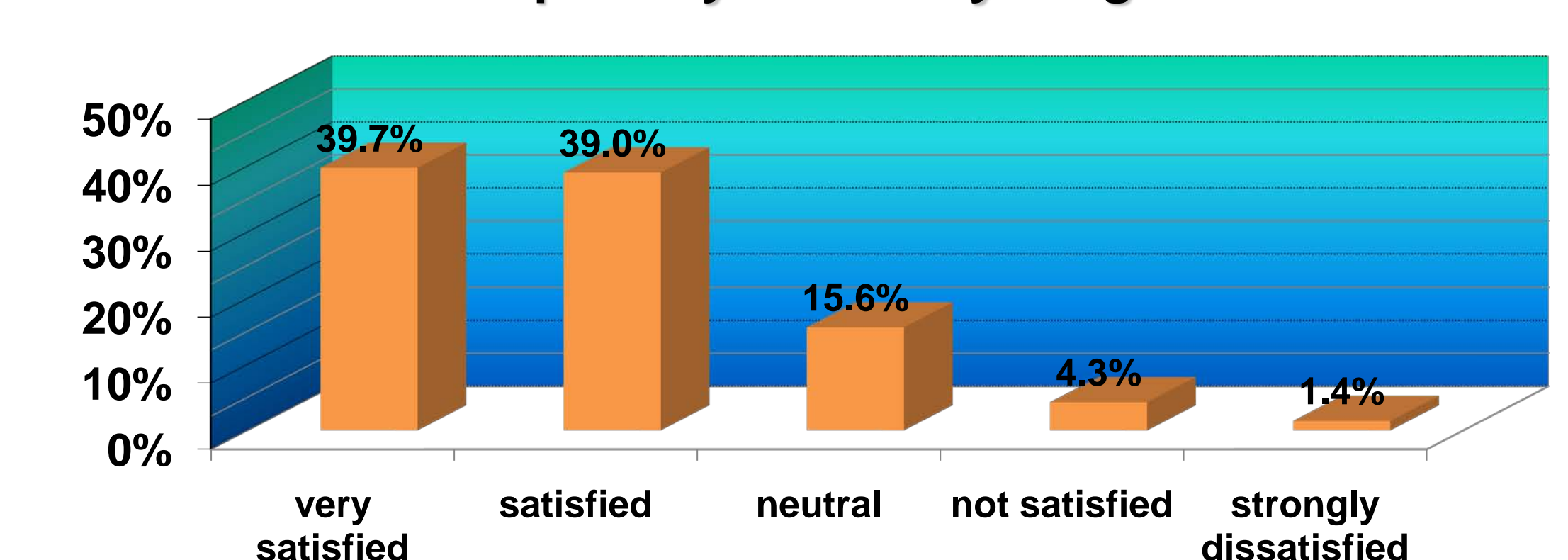
How much is your current out-of-pocket expense for tetrabenazine (Xenazine)?



How would you rate your overall satisfaction with tetrabenazine (Xenazine)?



How would you rate your overall satisfaction with the Specialty Pharmacy Program?



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