

Patient-Reported Reasons for Antiseizure Medication Non-Adherence in a Tertiary-Care Epilepsy Cohort: A Descriptive Analysis Using the WHO Multidimensional Adherence Framework

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Abstract

Medication non-adherence contributes to poor seizure control, yet patients' own reasons for missing antiseizure medication (ASM) doses are rarely documented in Indian epilepsy cohorts. We describe patient-reported reasons for missed ASM doses in a tertiary-care epilepsy cohort in Western Rajasthan, India, classified using the WHO five-dimension adherence framework. Of 274 adults in a parent cross-sectional cohort, 49 (17.9%) had a reason for a missed dose recorded; 4 with a non-specific response were excluded, leaving 45 classifiable reasons. Socioeconomic factors, principally travel and work-related demands, accounted for 22 of 45 reasons (48.9%), followed by patient-related factors, mainly forgetfulness (10, 22.2%). Health-system-related, condition-related, and therapy-related factors each accounted for 4-5 reasons (8.9-11.1%). Logistical and socioeconomic barriers outweighed forgetfulness or medication-related concerns in this cohort, suggesting adherence-support strategies emphasising refill logistics and flexible follow-up may be more relevant than reminder-based interventions alone.

Keywords: Adherence, Antiseizure Medications, Epilepsy, Non-Compliance, Rural Practice.

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Introduction

Adherence to antiseizure medications (ASMs) is a major determinant of seizure control, yet non-adherence remains common and its causes are frequently multifactorial.¹ The World Health Organization (WHO) proposed a five-dimension framework classifying barriers to adherence as patient-related, condition-related, therapy-related, health-system-related, and socioeconomic — explicitly moving away from a purely patient-blaming view of non-adherence. [1] India's persistent epilepsy treatment gap has been extensively documented, [2] and prior Indian work has examined healthcare workers' perceptions of barriers to epilepsy care access and adherence. [3] However, patients' own, self-reported reasons for missing individual ASM doses — as opposed to healthcare-worker perceptions, or adherence measured only as a categorical outcome — remain sparsely reported from Indian tertiary-care settings. We describe such reasons in a cohort of adults with epilepsy attending a tertiary-care neurology service in Western Rajasthan, classified using the WHO

framework, as a preliminary step toward identifying which type of adherence-support intervention may be most relevant to this population.

Materials and Methods

This is a descriptive sub-analysis of a parent cross-sectional observational cohort of 274 consecutive adults (≥ 18 years) with epilepsy attending the Department of Neurology, Sardar Patel Medical College and PBM & Associated Group of Hospitals, Bikaner, over a 12-month period (institutional ethics committee approval; written informed consent obtained from all participants). The parent cohort's treatment patterns, seizure outcomes, and quality-of-life findings have been reported separately; [4] this analysis addresses a distinct question — patients' self-reported reasons for missing ASM doses — that has not been examined in that or any other report from this dataset. At their study visit, patients who reported having missed at least one ASM dose were asked,

as part of the structured questionnaire, to state the reason in their own words; this was recorded as free text and was not restricted to patients with an overall 'poor' compliance rating — of the 49 patients with a reason recorded, 39 (79.6%) had an otherwise 'good' overall compliance rating, indicating that most reasons reflect isolated missed doses rather than sustained non-adherence.

Recorded reasons were reviewed, near-duplicate free-text entries were normalised (e.g., 'Work'/'work'), and each was independently classified into one of the five WHO adherence domains by the first author.

Four patients whose recorded reason was non-specific ('NM'/not mentioned, with no further detail recoverable from the structured questionnaire) were excluded from the domain classification, leaving 45 classifiable reasons. Given the small subgroup size and the fragmentary nature of individual reason categories (13 of 17 remaining distinct reasons had fewer than five occurrences), only descriptive statistics (frequencies and percentages) are reported; no inferential comparisons across reasons or against clinical outcomes were performed, and none are reported here.

Results

Of 274 patients in the parent cohort, 49 (17.9%) had a reason for a missed ASM dose recorded; 4 with a non-specific response were excluded, leaving 45 classifiable reasons. This subgroup had a mean age of 30.2 ± 10.6 years and mean epilepsy duration of 9.0 ± 9.0 years; 24 (53.3%) were male, 24 (53.3%) resided in rural areas, and 40 (88.9%) were receiving polytherapy — broadly comparable to the parent cohort's overall composition (62.0% male, 44.9% rural). [4]

Socioeconomic factors — principally travel to the treatment centre and work-related demands — accounted for the largest share of reported reasons (22/45, 48.9%), followed by patient-related factors, chiefly forgetfulness (10/45, 22.2%). \

Health-system-related factors (running out of medication supply), condition-related factors (self-discontinuation after perceiving adequate seizure control), and therapy-related factors (fear of harm, dissatisfaction with treatment, or switching to alternative systems of medicine) each accounted for a smaller proportion (4–5/45, 8.9–11.1% each) [Table 1, Figure 1].

Table 1: Patient-reported reasons for missed antiseizure medication doses, by WHO adherence domain (n = 45)

WHO adherence domain	Representative reasons	n	%
Socioeconomic	Travel, work/household demands, family events	22	48.9
Patient-related	Forgetfulness, mood	10	22.2
Health-system-related	Medication supply exhausted	5	11.1
Condition-related	Self-discontinued after perceived seizure control	4	8.9
Therapy-related	Fear of harm, dissatisfaction, switched systems, drug change	4	8.9

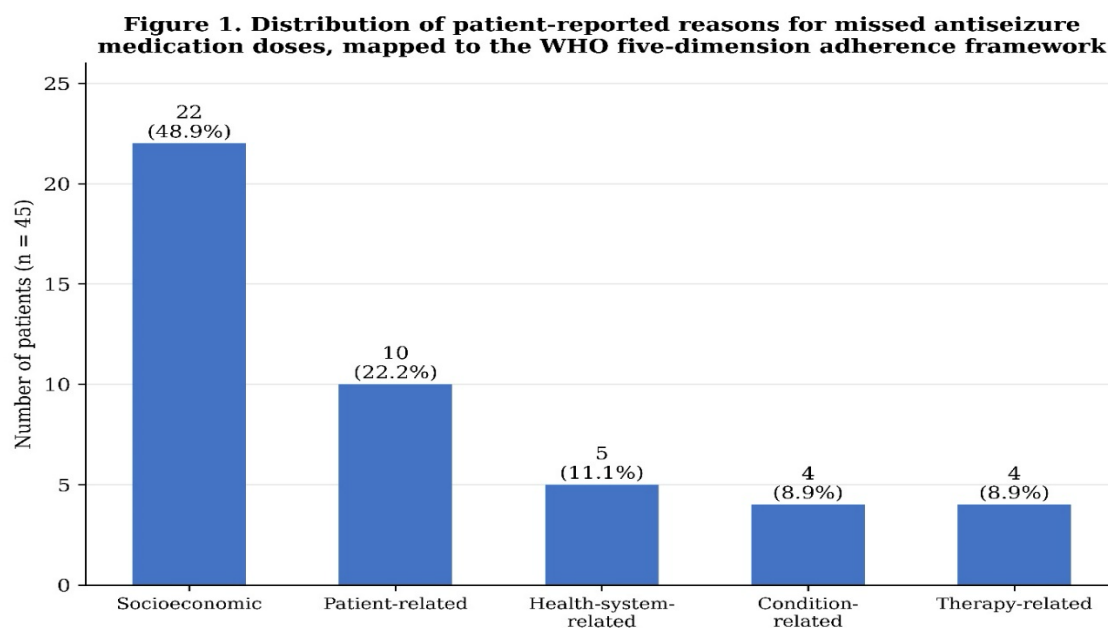


Figure 1: Bar chart showing the distribution of patient-reported reasons for missed antiseizure medication doses across the five WHO adherence domains (n = 45).

Discussion

In this cohort, socioeconomic and logistical barriers — not forgetfulness or medication-related concerns — were the leading patient-reported reasons for missed ASM doses. This distinction matters clinically: forgetfulness-driven non-adherence is typically addressed through reminder-based interventions (alarms, blister packs), whereas the socioeconomic barriers dominant here (travel, work) are better addressed through structural changes — longer prescription-refill intervals, telemedicine follow-up, or drug dispensation closer to patients' residence. This finding complements, rather than duplicates, prior Indian work: Tomlins and Pearson reported healthcare workers' perceptions of barriers to epilepsy care in India, which similarly identified logistical and systemic factors, but from the provider's perspective rather than patients' own reasons for specific missed doses. [3] Two prior JNRP studies have examined reasons for ASM nonadherence directly from patients: Chinnaiyan et al., in a rural Karnataka cohort, used a comparable patient-related/condition-related/therapy-related/socioeconomic/health-care classification and likewise found forgetfulness among the leading reasons; [5] Govil et al., in a below-poverty-line cohort, similarly identified forgetfulness (39.3%) and unavailability of medication at the hospital pharmacy (13.1%) as leading reasons, in a setting where only 72.7% received ASMs entirely free, with the remainder needing to purchase medication when hospital stock ran out. [6]

ASMs at our centre are dispensed free of cost under a government scheme; the health-system-related reason identified here (medication supply exhausted) therefore most plausibly reflects intermittent stock-outs at the treatment centre or delayed patient return for a scheduled refill — sometimes because the patient reached the centre late — rather than a direct cost barrier, distinguishing our setting from the combined free-and-purchased model reported by Govil et al. [6]. This analysis has important limitations. The subgroup is small (n=45 classifiable reasons) and represents patients with any recorded missed dose rather than a systematically ascertained sample of all non-adherent patients; most had an otherwise 'good' overall compliance rating, so these findings describe reasons for occasional missed doses rather than sustained non-adherence. Reasons were captured as unprompted free text rather than through a validated, structured adherence-barrier instrument, and reflect a single retrospective self-report rather than prospective, repeated assessment. Four responses (8.2% of those with a reason recorded) were too non-specific to classify and

were excluded, which may have introduced selection effects within this already-small subgroup. Given the small size of most individual reason categories, formal statistical comparison across domains or against clinical outcomes was not attempted, and these findings should be regarded as descriptive and hypothesis-generating rather than confirmatory.

Conclusion

In this tertiary-care Indian epilepsy cohort, logistical and socioeconomic barriers were the most frequently reported reasons for missed ASM doses, ahead of forgetfulness or medication-related concerns. Adherence-support interventions in similar rural and semi-urban settings may benefit from prioritising logistical solutions — such as extended refill intervals and telemedicine-based follow-up — over reminder-based strategies alone. Larger, prospective studies using validated adherence-barrier instruments are needed to confirm these preliminary findings.

Acknowledgment

Ethical Approval: This study was approved by the Institutional Ethics Committee. Written informed consent was obtained from all participants, in accordance with the Declaration of Helsinki.

Data availability: Data are available from the corresponding author on reasonable request.

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