

Patient insights research exploring disease awareness, patient life experience, and current management of visceral leishmaniasis in Bihar, India

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CONCLUSIONS

- Albeit in a relatively small sample size, this study reveals the barriers to disease awareness and access to care for patients with VL in the Bihar area.
- It shows that, while patients with VL seek care for symptoms early on, diagnosis follows, on average, 14 days following symptom onset.
- The current standard-of-care therapy is often not available in the healthcare center of diagnosis, which can further the delay in treatment administration.
- Oral therapy as an alternative to current parenteral treatment is preferred both by patients and caregivers of pediatric patients.

BACKGROUND

- Visceral leishmaniasis (VL) is mostly prevalent in rural areas and affects, almost exclusively, low-income populations with limited healthcare access.¹
- There are little data on patients' perspectives, their diagnosis and treatment experiences, and how these experiences influence their expectations about treatment options.
- In India, the current standard-of-care therapy consists of 10 mg/kg single-dose liposomal amphotericin B by intravenous infusion. While highly efficacious, infusions are challenging in resource-limited settings and require close monitoring. Hence, liposomal amphotericin B treatment is currently limited to tertiary centers (restricted to public hospitals).²

Research objectives

- To gain insights regarding patients' experiences of the disease, diagnosis, and treatment.
- To better understand current barriers to disease awareness and diagnosis and treatment access.
- To explore acceptability of an oral treatment formulation among adult patients and caregivers of pediatric patients.

METHODS

A qualitative research study was conducted, using moderator-facilitated discussion, with a predefined set of screening criteria and following a protocol-defined discussion guide.

Research location

- Ten districts across Bihar, India, that account for the majority of VL cases.

Participants

- Eighteen adult patients and 12 caregivers of children who reported being diagnosed and treated for VL within the last 12 months were included.

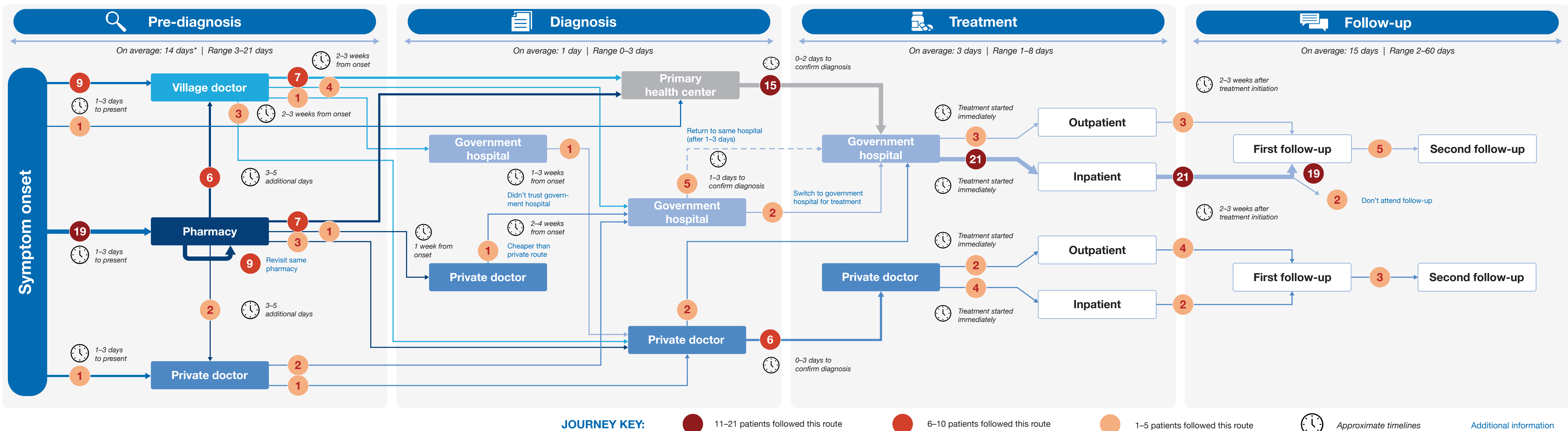
Participant identification and interviews

- District hospitals were visited to identify villages/townships of hotspots of patients with VL in past 24 months (per study eligibility criteria).

- Recruiters met with local pharmacists, community healthcare professionals (HCPs), and local leaders/village council members to confirm relevance of target areas.
- Recruitment was conducted door-to-door, where consent was gained for screening.
- Patients were recruited via a screening questionnaire to determine eligibility and willingness to take part in the interview.
- Self-reported VL of participants/caregivers: 12/30 patients/caregivers had a VL card; 13/30 had lost/no longer possessed a VL card; 5/30 were unable to confirm diagnosis.
- Sixty-minute, face-to-face, in-depth interviews were conducted in Hindi by a local partner agency.

RESULTS

Figure 1. Summary of life experiences of 18 adults and 12 caregivers of children with VL



*Excluding one anomaly of 90 days. Mean, median, and range breakdowns (with and without outlier) below.
- Mean 16.4 days (with outlier); 13.8 days (without outlier).
- Median 12 days (with outlier); 7.5 days (without outlier).
- Range 3–90 days (with outlier); 3–21 days (without outlier).
VL, visceral leishmaniasis.

Figure 2. Breakdown of patients' experiences of VL

	Onset of symptoms	First touchpoint(s) – primary care	Present to diagnosing clinic	Receive diagnosis and treatment	Treatment initiation	Symptoms resolved	Follow-up
Timeline	Day 0	First touchpoint within 3 days* of experiencing symptoms (range 1–25 days)	~2–3 weeks after first experiencing symptoms (range 2–100 days)	+1 day on average (range 0–3 days)	0–2 days on average	Patients started feeling better ~1 week after treatment was initiated (range 1 day–2 months)	All patients offered follow-up, at variable periods (range 2 days–2 months)
Additional detail	Symptoms include fever, body pain, fatigue, loss of appetite	Patients seek advice from local medical shop/ pharmacist and given oral treatment – i.e., paracetamol Half then visit another primary care setting (i.e., primary health centers or village doctor) after a couple of days of no improvement Some patients (n=9) revisit the same pharmacy multiple times	n=26 specify receiving a blood test for diagnosis and n=7 also describe a clinical assessment and/ or urine sample Happens across a range of clinics (n=15 primary health centers, n=7 government hospitals, n=8 private) In government setting, patients often prescribed treatment for symptoms (non-specific to VL) while waiting for results	Small delay of several days to confirm diagnosis while diagnostic tests are run, in both private and government hospital settings	65% switch to a different practice setting for treatment (n=19) and therefore experience a delay of 1–2 days in starting treatment. Otherwise, treatment initiated immediately	~1 week after treatment is completed, patients start to resume normal activities/work	Majority of patients (n=18) attend one follow-up. Eight patients report attending a second follow-up Consultation consists of a blood test and potential treatment for strength

*Median 3 days; mean 3.8 days.
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Disclosures

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