ORIGINAL ARTICLE

# PATIENT REPORTED BARRIERS TO DIAGNOSTIC AND TREATMENT DELAYS IN NASOPHARYNGEAL CARCINOMA (NPC) IN MULTIETHNIC MALAYSIA

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## ABSTRACT

*In Malaysia, nasopharyngeal carcinoma (NPC) is frequently diagnosed at advanced stages, but the underlying patient experiences driving diagnostic and treatment delays remain poorly understood. This qualitative descriptive-interpretive study explored the pathway to treatment among 21 NPC survivors recruited at a tertiary cancer center in Northern Malaysia. Semi-structured interview data were analyzed using thematic analysis guided deductively by the Model of Pathways to Treatment (MPT), while allowing inductive insights to emerge. Four major themes spanned the MPT intervals: symptom misinterpretation; work and geographic barriers to help-seeking; provider-level clinical misjudgment and system-level referral fragmentation; and financial toxicity. In the appraisal interval, limited NPC awareness, non-specific symptoms, and culturally familiar explanations reduced the perceived urgency of seeking care. Work obligations, limited labor protections, and distance from specialist services constrained help-seeking; diagnostic progress was further slowed by provider misjudgment and fragmented referrals. After diagnosis, financial toxicity among informal and low-income workers impeded timely treatment initiation. The findings extend the MPT by showing that delay can be recursive, nonlinear, and structurally embedded in multiethnic and low- and middle-income country settings. For Malaysian public health practice, the findings support culturally tailored NPC symptom education, targeted primary-care training and escalation protocols, coordinated referral navigation, and employment and financial support matched to the barriers identified.*

***Keywords:*** *Cancer, social determinants of health, health system access, low- and middle-income countries (LMICs), health risks, health equity.*

## INTRODUCTION

Nasopharyngeal carcinoma (NPC) is a distinct epithelial malignancy with marked geographic and ethnic variation in incidence and mortality. More than two-thirds of global NPC cases occur in East and Southeast Asia [1,2]. Within Southeast Asia, Malaysia reports one of the region's highest incidence rates, with national cancer registry data placing NPC among the country's most common cancers [3]. Although NPC has historically been most prevalent among Chinese and certain indigenous groups, Malays also experience the disease, while Indian Malaysians consistently show lower incidence [3].

In Malaysia, NPC remains a significant public health concern, particularly among men [4]. Despite advances in diagnostic imaging and the availability of targeted therapies, most cases continue to be diagnosed at advanced stages. More than 60% of Malaysian patients are diagnosed at Stage III or IV, when the five-year survival rate falls to approximately 44%, compared with more than 90% among patients diagnosed at Stage I [5-8]. This persistent pattern indicates continuing gaps in early symptom recognition, diagnostic assessment, and timely treatment initiation.

Delayed cancer diagnosis is particularly pronounced in many low- and middle-income countries (LMICs), where limited healthcare access, financial constraints, health-system fragmentation, and sociocultural norms can impede progression towards diagnosis and treatment [9,10]. In Southeast Asia, these challenges are further shaped by ethnic diversity, culturally mediated symptom interpretation, and hybrid public–private healthcare systems that influence how patients navigate care [11,12]. Malaysia therefore provides an important context for examining how sociocultural and structural conditions interact across cancer care pathways.

National registries and institutional studies have documented delayed presentation among Malaysian patients with NPC [5,7,8,13]. Previous quantitative studies have reported diagnostic delays lasting several months and have associated these delays with reliance on traditional medicine, healthcare-system inefficiencies, and limited primary-care familiarity with NPC [13-15]. However, relatively little is known about how patients experience and navigate these barriers within Malaysia's multiethnic sociocultural and healthcare contexts [13,16]. Quantitative evidence can identify the duration and correlates of delay but offers limited insight into how barriers emerge, interact, and accumulate across individual care pathways.

To examine these processes, the present study adopts the Model of Pathways to Treatment (MPT) [17]. The MPT is an evidence-based framework that

organizes the pathway from symptom onset to treatment initiation into four intervals: appraisal, help-seeking, diagnostic, and pre-treatment. Although the model has been applied internationally in oncology research [18-20], its use remains limited in Southeast Asian LMIC settings, where cultural interpretations, socioeconomic constraints, provider responses, and healthcare arrangements may shape progression across these intervals [17,21,22].

Specifically, this study aims to identify the patient-, disease-, healthcare provider-, and system-level barriers contributing to diagnostic and treatment delays among NPC patients in Northern Malaysia across the four MPT intervals, while examining the model's applicability within a multiethnic LMIC setting.

## METHODS

This study employed a qualitative descriptive-interpretive design [23] to explore how NPC patients in Malaysia experience and navigate the pathway from symptom onset to treatment initiation.

The study was conducted at the Advanced Medical and Dental Institute (AMDI), in Bertam, Penang. AMDI is a tertiary-level academic hospital that serves a multiethnic population from rural, semi-urban, and urban regions in Northern Malaysia.

Purposive sampling was employed to recruit a demographically diverse cohort of patients with NPC. Eligible participants were Malaysian citizens aged 18 years or older who had completed curative NPC treatment and attended routine follow-up consultations at AMDI, USM; clinical eligibility was assessed with an oncology specialist. Information power was assessed iteratively rather than by a predetermined numerical target, considering the focused study aim, the specificity and diversity of the sample, the richness of the 30–60-minute interviews, the use of the MPT as an established analytical framework, and the material's capacity to support comparison within and across all four intervals [24]. The 21 interviews included contrasting narratives across ethnicity, age, gender, occupation, socioeconomic position, locality, and disease stage, alongside recurring barriers within each interval; together, these features were judged to provide adequate conceptual coverage for the study aim.

Data were collected through semi-structured, in-depth interviews conducted between May 2024 and February 2025. The interview guide was developed *a priori* based on the four intervals of the MPT: appraisal, help-seeking, diagnostic, and pre-treatment [17,25]. The guide was informed by prior oncology studies applying the MPT [11,18]. It included open-ended questions exploring symptom interpretation, care-seeking decisions, interactions with healthcare providers (HCP), and treatment initiation, with probes on traditional medicine use, prior knowledge of NPC, and structural facilitators or barriers.

The interview guide was pilot-tested with two NPC survivors, and minor refinements were made prior to data collection. All interviews were conducted by the first author, a Malaysian Chinese male with prior qualitative research experience in cancer and health communication, ensuring consistency across interviews. No financial or material compensation was provided to participants, as participation was voluntary.

Interviews were conducted in participants' preferred language (Bahasa Malaysia, Mandarin, or English) in a private hospital space, lasted 30–60 minutes, were audio-recorded with consent, and were transcribed verbatim. No interpreter was used. The first author is multilingual: Mandarin is his first language, while Bahasa Malaysia and English were acquired through formal education and are used in academic, professional, and everyday communication. Analysis was conducted on the verbatim transcripts in their original languages, with translation deferred until reporting. The first author translated selected Bahasa Malaysia and Mandarin quotations into English and checked each rendering against the source-language transcript; where literal translation risked reducing culturally specific meaning, the original term was retained with an explanatory gloss.

### Data analysis

Data were analyzed using thematic analysis as outlined by Braun and Clarke [26]. An initial codebook was developed combining deductive codes based on the four intervals of the MPT and inductive codes emerging from participants' narratives. Transcripts were manually coded by the first author and reviewed iteratively by the two authors. Code discrepancies were resolved through discussion and consensus to enhance analytical reliability. NVivo 14 software was used to support data organization and retrieval. Emerging themes were grouped under the model's four intervals, enabling a structured yet context-sensitive analysis of delay mechanisms.

The first author's position as a Chinese Malaysian male trained in anthropology and sociology created both cultural proximity to and distance from participants' accounts. This shaped interpretation by prompting clarification of culturally specific illness idioms, attention to gendered and occupational assumptions, and comparison of emerging interpretations against full transcripts and contrasting narratives rather than treating shared nationality or language as automatic understanding. A reflexive journal and analytic memos documented how these assumptions and interpretive decisions developed; peer debriefing with the second

author was used to question alternative readings and refine themes.

## RESULTS

This study explored patients' experiences along the NPC pathway to treatment using the MPT. Table 1 summarizes participants' demographic and clinical profiles. The sample comprised 21 NPC survivors, predominantly Malay (n = 18), with three Chinese participants and no Indian participants. This distribution reflects the study site's catchment and recruitment context and should not be interpreted as representative of national NPC epidemiology [3]. Participants' residential locations were classified as urban, semi-urban, or rural based on Malaysia's health service distribution. Cancer stage was reported according to the AJCC (8th edition) using clinical records at diagnosis.

**Table 1:** Participant Demographics

| Participant | Age | Gender | Ethnicity | Occupation | Region | Cancer Stage |
|---|---|---|---|---|---|---|
| P1 | 60 | Male | Malay | Retired technician | Rural | IV |
| P2 | 44 | Male | Malay | Construction contractor | Semi-urban | I |
| P3 | 36 | Male | Malay | Construction Inspector | Urban | II |
| P4 | 36 | Male | Malay | Government officer | Rural | III |
| P5 | 42 | Male | Malay | Police officer | Rural | IV |
| P6 | 47 | Male | Malay | Administrator | Rural | IV |
| P7 | 20 | Female | Malay | Student | Urban | IV |
| P8 | 44 | Female | Chinese | Market grocer | Semi-urban | III |
| P9 | 50 | Female | Malay | Tailor | Semi-urban | III |
| P10 | 33 | Female | Chinese | Pharmacist | Urban | III |
| P11 | 37 | Male | Malay | Administrator | Rural | I |
| P12 | 34 | Female | Malay | Former Engineer (Unemployed) | Semi-urban | III |
| P13 | 55 | Male | Malay | Manual labor | Semi-urban | III |
| P14 | 58 | Female | Malay | Housewife | Semi-urban | III |
| P15 | 18 | Male | Malay | Student | Semi-urban | III |
| P16 | 35 | Male | Malay | Tyre shop owner | Semi-urban | IV |
| P17 | 42 | Male | Malay | Janitor | Rural | I |
| P18 | 45 | Male | Chinese | Former Welder, now hawker | Semi-urban | III |
| P19 | 63 | Male | Malay | Retired Army | Semi-urban | III |
| P20 | 57 | Male | Malay | Construction worker | Rural | IV |
| P21 | 51 | Female | Malay | Food vendor | Rural | III |

Across the four MPT intervals, participants described intersecting patient-, cultural-, provider-, and system-level barriers that cumulatively delayed diagnosis and treatment. Delays rarely stemmed from a single event but accumulated as patients navigated ambiguous symptoms, competing obligations, and fragmented care systems. Themes are presented below following the sequential care pathway; Table 2 summarizes key barriers across intervals.

**Table 2:** Identified Barriers and Contributing Factors Impacting NPC Patients' Pathway to Diagnosis and Treatment

| MPT Interval | Theme (Barrier) | Contributing Factors |
|---|---|---|
| **Appraisal** | Symptom Misinterpretation | Patient: Health literacy, prior health beliefs, symptom normalization;<br>Disease: Subtle and non-specific symptom presentation |
| | Low Awareness | Patient: Limited cancer literacy;<br>System: Limited NPC-focused public education and community health communication |
| | Cultural and Traditional Health Beliefs | Patient: Cultural health models, traditional interpretations, reliance on self-treatment |
| **Help-Seeking** | Work Obligations | Patient: Employment demands, financial priorities, role responsibility (e.g., breadwinner, sole operator);<br>System: Limited employment protections, particularly for low-wage and informal workers (e.g., lack of paid medical leave) |
| | Geographic Barriers to Specialist Access | System: Unequal healthcare facility distribution |
| **Diagnostic** | Clinical Misjudgment | Provider: Limited NPC familiarity, over-reliance on common diagnoses, incomplete examination, and premature reassurance; |
| | Disjointed Referrals | System: Fragmented referral chains, limited inter-facility communication, repeated investigations, and delays in specialist appointments |
| **Pre-Treatment** | Financial toxicity and Treatment Access | Patient: Income instability, informal employment;<br>System: Limited financial support, out-of-pocket costs |

**Appraisal**

*Symptom Misinterpretation and Low Awareness*

Within the appraisal interval, many participants described initially misinterpreting their early symptoms as benign, delaying timely recognition of disease severity. This reflected the interaction between limited NPC awareness and the disease's non-specific presentation.

Many participants normalized symptoms as minor or self-limiting. P10, a pharmacist, delayed seeking care for six months, explaining: "At first, I thought it was sinusitis, so I bought medicine (OTC) to take on my own." Others similarly reported having never heard of NPC prior to diagnosis. P21 from rural Kedah stated, "No, no. I didn't know. Only after getting it, then I knew what the cancer is like." These accounts illustrate how limited public awareness and symptom ambiguity delayed escalation of care.

*Cultural and Traditional Health Beliefs*

Culturally embedded health beliefs further shaped symptom appraisal. Participants commonly attributed symptoms to temporary bodily imbalances or occupational strain, delaying formal help-seeking.

P18, a Chinese participant, interpreted persistent blood-tinged phlegm as 热气 (excessive internal heat): "I just thought my body was heaty," and relied on cooling herbal remedies. Similarly, P20, a Malay construction worker, attributed headaches and nasal bleeding to heat exposure at work: "I thought it was because of *kerja panas* (working in hot environments) … just a regular headache."

Such interpretations normalized symptoms and reduced perceived urgency for medical evaluation.

**Help-Seeking**

*Work Obligations*

During the help-seeking interval, work commitments frequently delayed medical consultation. Patient-level responsibilities intersected with system-level constraints such as limited access to paid medical leave.

P10 delayed care due to being the sole pharmacist at her workplace: "Very busy, no time to see a doctor." P18, a factory welder and sole breadwinner, continued working despite worsening symptoms: "If I stop working, how can I feed them?" P21, a food vendor, described having to suspend her business entirely during treatment.

These accounts illustrate how income insecurity and limited labor protections constrained timely care-seeking, particularly for self-employed and low-wage workers.

*Geographic Barriers to Specialist Access*

Geographic inequities further impeded help-seeking, especially for rural participants. Limited local access to ENT and oncology services necessitated long-distance travel, compounding delays.

P4 from rural Sik reported, "There's no specialist care… they referred me to Sungai Petani." P16 noted, "There's no chemo or radiotherapy in Perlis… I have to come to Penang." Such journeys involved repeated referrals and substantial travel costs.

Centralization of specialist services thus delayed access while imposing additional financial and logistical burdens.

**Diagnostic**

*Clinical Misjudgment*

At the provider level, delayed diagnosis followed limited familiarity with NPC, over-reliance on common diagnoses, incomplete examination, and premature reassurance despite persistent or worsening symptoms.

P5 experienced a nine-month delay despite expressing concern about cancer: "The doctor said it couldn't be cancer… he didn't even examine it." His diagnosis was ultimately made at Stage IV. Similarly, P19 received repeated treatments for over a year before diagnosis: "No improvement… it took twelve tests before they detected my cancer." These accounts indicate provider-level failures in symptom recognition, examination, and diagnostic escalation.

*Disjointed Referrals*

At the system level, referral and diagnostic processes remained fragmented after NPC was suspected. P13 waited 5–6 months for a specialist referral, while P14 described transfers across private and public facilities with repeated testing. These delays reflected long waits for specialist appointments, repeated investigations, and weak coordination across facilities rather than an individual clinician's diagnostic judgment.

**Pre-treatment**

*Financial Toxicity and Treatment Access*

Financial toxicity significantly shaped access to timely treatment following diagnosis. Participants with unstable incomes or informal employment faced substantial out-of-pocket costs and treatment disruptions.

P17, a janitor earning approximately RM2000 monthly, described paying for treatment incrementally: "I paid the fee bit by bit." While community support provided limited relief, it was insufficient to offset cumulative costs. P18 delayed seeking care until financial assistance from a family member became available. In contrast, P10 reported that financial stability enabled smoother care navigation: "My salary is quite okay, so the whole process went smoothly."

These contrasts highlight how financial security—or its absence—directly shaped treatment continuity and delay.

**DISCUSSION**

The findings of this study extend existing evidence on cancer diagnostic delays in multiethnic LMIC settings, particularly in Southeast Asia. Like prior qualitative research on Malaysian breast cancer [16,27], this study identified symptom misinterpretation shaped by limited health literacy and culturally embedded beliefs as a key contributor to delayed illness recognition. Consistent with the literature, participants in this study similarly normalized early symptoms through familiar cultural and occupational frames, delaying escalation of care.

Economic and geographic barriers to help-seeking identified here also align with prior Malaysian studies. Rajaram et al. [16] highlighted how role obligations, poverty, and lack of workplace protections delayed help-seeking among low-income Malaysian women with breast cancer. In this study, such constraints were particularly salient among men in informal employment or rural settings, where income insecurity and long travel distances constrained timely access to care. These patterns reflect broader LMIC conditions, where fragmented health systems and weak labor protections limit healthcare access.

On the health system side, diagnostic delays linked to misjudgment and weak referral pathways echo earlier findings that Malaysian primary care providers may lack familiarity with NPC's subtle presentation [13]. This study contributes patient-level evidence demonstrating how limited NPC recognition and fragmented

referral processes extend diagnostic timelines even when care is actively sought.

While the MPT provided a useful organizing framework, the findings also highlight important conceptual limitations when applied in LMIC contexts. First, the model's emphasis on individual cognition can understate how structural constraints—such as job insecurity, geographic inequity, and financial toxicity—shape access across all intervals. In this study, delayed decisions were rarely due to low motivation but reflected constrained choices rooted in economic precarity and limited healthcare access. Financial toxicity, defined as the material and psychological burden associated with cancer-related costs [28,29], emerged as a cross-cutting mechanism. Participants' accounts illustrate how treatment costs, income loss, and daily living expenses continued to shape care trajectories even after diagnosis.

Second, the MPT assumes a linear progression through appraisal, help-seeking, diagnostic, and pre-treatment intervals. Our findings instead reveal iterative movement across stages, particularly when misdiagnoses or premature reassurance prompted symptom reappraisal and delayed re-presentation. These dynamics suggest that pathway models require greater sensitivity to non-linearity and structural constraint in resource-limited settings.

Thus, while the MPT remains valuable, this study suggests that its application in multiethnic LMIC contexts like Malaysia requires adaptations that more fully integrate structural determinants, health system fragmentation, and the non-linear nature of patient journeys. Our findings offer empirical support for this broader conceptualization, helping to advance ongoing efforts to refine pathway models for cancer care in resource-constrained settings.

From a practical standpoint, the findings point to linked interventions across the pathway to treatment. During appraisal, limited NPC awareness, ambiguous symptoms, and familiar explanations such as "heatiness" or work fatigue reduced the perceived urgency of seeking care. Public health campaigns should therefore combine clear guidance on red-flag symptoms and when persistent symptoms require medical assessment with locally meaningful explanations of illness. Developing these messages with community leaders, employers, and traditional practitioners may improve their cultural acceptability and encourage earlier presentation [30-32].

Once patients sought care, delays were often sustained by clinical misjudgment. Continuing medical education for primary-care practitioners should focus on NPC's non-specific presentation, thorough assessment of persistent red-flag symptoms, and clear criteria for re-evaluation, diagnostic escalation, or ENT referral. These clinical measures need to be supported by better system-level referral coordination. District-level care coordinators or centralized referral pathways could track patients across facilities, reduce repeated investigations, coordinate appointments, and shorten waits for specialist care, particularly for rural patients.

The findings also show that timely care depends on whether patients can afford to leave work, travel for appointments, and remain engaged in treatment. Protected medical leave, income-replacement mechanisms, transport assistance, and early financial navigation would directly respond to the income loss, travel costs, and difficulty sustaining care reported by informal, low-income, and rural participants.

These barriers are not unique to Malaysia and may offer transferable insights for improving early cancer diagnosis pathways in other resource-constrained, multiethnic health systems [9,33].

**Limitations and future research**

This study has several limitations. First, participants were recruited from a single tertiary cancer center in Northern Malaysia, which may limit transferability to other regions or private healthcare settings. Second, the sample included only patients who had completed treatment; experiences of individuals who disengaged from care or experienced fatal delays were not captured. Third, reliance on retrospective accounts may introduce recall bias. Finally, the sample was predominantly Malay, limiting ethnic comparison but addressing an underrepresented group in NPC research.

Future studies should include more ethnically diverse and multi-site samples to examine variation in delay mechanisms across contexts. Mixed-methods and intervention-focused research is also needed to evaluate strategies such as culturally tailored education, primary care training, and care navigation systems.

## CONCLUSION

This study explored barriers contributing to diagnostic and treatment delays among Malaysian patients with nasopharyngeal carcinoma using the Model of Pathways to Treatment. Delays accumulated across appraisal, help-seeking, diagnostic, and pre-treatment intervals, driven by symptom misinterpretation, occupational and geographic barriers, diagnostic misjudgment, and financial toxicity. While the Model of Pathways to Treatment offered a valuable framework, our findings highlight the need to adapt this model to better capture the socioeconomic, systemic, and nonlinear dynamics that shape cancer care pathways in multiethnic LMIC contexts.

Addressing these complex barriers requires not only patient education and clinical capacity-building, but also broader policy interventions targeting the structural vulnerabilities that constrain patients throughout their diagnostic journey.

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**Ethics approval**
This study was approved by the Human Research Ethics Committee, Universiti Sains Malaysia (Jawatankuasa Etika Penyelidikan Manusia, JEPeM-USM) under approval code USM/JEPeM/22040243.

**Data availability**
The deidentified data generated during the current study are available from the authors on reasonable request.

**Declaration of competing interest**
The authors declare no potential competing interest with respect to the research, authorship, and publication of this article.

**Authorship contributions**
C.Y. led the conceptualization of the study, curated and analyzed the data, and wrote the initial draft of the manuscript. H. C. provided supervisory and methodological guidance, secured funding for the study, and contributed to reviewing and editing the manuscript. Both authors jointly contributed to the development of the study methodology, interpretation of findings, and refinement of the manuscript.

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