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Putting people at the center: methods for patient journey mapping of viral hepatitis services across two LMICs in the Asia Pacific

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Abstract

Background To ensure that health services are high-quality, trusted and used by the population, their design and improvement should start from the perspective of what matters to people. Patient journey mapping (PJM) is one research method that centers the experiences of individuals living with health conditions and follows their pathways through care and recovery. This paper describes a novel, qualitative PJM methodology used in Vietnam and the Philippines to inform the co-design of a people-centered viral hepatitis screening, care and treatment pathway for individuals living with chronic hepatitis, which is a significant public health concern in the Asia-Pacific region.

Methods Data collection involved in-depth interviews with a purposive sample of 63 people living with hepatitis (demand-side) and focus group discussions with healthcare providers working in the same geographical areas (supply-side). Rapid deductive qualitative analysis was used to identify typical journeys, and related barriers and enablers. The methodology was implemented over 8 weeks, adapting the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Results This paper demonstrates how a PJM methodology that incorporates patient and HCP perspectives can be feasibly implemented in two LMIC contexts, while fulfilling many of the criteria identified by the COREQ guidelines. Sharing such methods and associated instruments may help to enable broader uptake and application in other LMIC settings, providing health systems practitioners with a critical tool to identify and overcome barriers in and promote the delivery of people-centered health services globally.

Conclusion Despite limited uptake, especially in resource-limited contexts and at the primary healthcare level, PJM is a novel research method with the potential to make promising contributions to people-centered health service design.

Keywords Patient journey mapping, People-centered care, Hepatitis, Philippines, Vietnam, Health system strengthening

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Background

Chronic viral hepatitis is a condition of global public health significance. Deaths due to viral hepatitis are expected to exceed deaths due to HIV, TB, and malaria combined by 2040 [1]. Vietnam and the Philippines are among the Asia-Pacific countries with the highest burden of viral hepatitis. In Vietnam, an estimated 1 million individuals have hepatitis C (HCV) and among people who inject drugs (PWID) the prevalence is as high as 60% [2, 3]. In the Philippines, active HCV is estimated to affect approximately 600,000 people, and up to 90% of PWID [3, 4]. Hepatitis B (HBV) is more prevalent in the general population, estimated to affect 8 to 25% of Vietnamese people [2] and 4 to 18% of Filipinos [4, 5].

In recent years, research has led to new advances in the diagnosis and treatment of Hepatitis B (HBV) and Hepatitis C (HCV). However, less attention has been paid to how patients navigate care and the barriers they encounter. Both HCV and HBV are associated with significant psychosocial consequences, including fear and distress, stigma and discrimination, social withdrawal, and societal exclusion [6–8]. These health and social consequences of viral hepatitis are disproportionately borne by vulnerable populations, including groups with a higher risk of transmission (e.g., people living with HIV (PLHIV), men who have sex with men having sex with men (MSM), sex workers, people who inject drugs (PWIDs), and/or people living in poorly resourced settings without access to high-quality, affordable healthcare. This alarming situation may be in part the result of health system constraints, as well as social and cultural dynamics, that create high barriers to entry for people to be screened, diagnosed and treated for viral hepatitis. One approach to elucidate these barriers is through patient journey mapping.

Patient journey mapping (PJM) is a relatively new research method that has evolved out of multiple disciplines, including health systems research, health service re-design and improvement, and private consumer industries. Rather than focusing on a single step in a care pathway/cascade, PJM maps the patient's experiences across the entire continuum of care and treatment, from pre-awareness to management and treatment, documenting key events both inside and outside the formal health system [9, 10]. A recent global scoping review determined eight distinct justifications for doing PJM [9]. These include documenting patients' entire journey through the health system and how they navigate care, evaluating the continuity and/or comprehensiveness of care and identifying gaps and delays to inform health service improvements [10].

One challenge with PJM is the large degree of heterogeneity in the methods, instruments and visual representations presented by articles incorporating PJM in their study design [9]. This may be due to a lack of standardized protocols or terminology [9, 11]. Other closely related methods include process mapping [12] or patient pathway analyses [13, 14]. PJM can be distinguished from such approaches because health system users are the key source of information rather than the passive subjects or beneficiaries of research. Additionally, while quantitative data sources might be used, PJM emphasizes qualitative data to elucidate deeper insights about peoples' experiences.

PJM can provide information on what works well, where gaps exist, and what might be done to improve healthcare delivery, from users' perspectives. Specifically, it explores how access to care is complex, and modified by the sociocultural factors and the everyday realities of people, alongside local health system delivery contexts. However, unlike other qualitative research methods that explore a broader range of lived experiences, PJM focuses more specifically on the framework of a clinical pathway. It systematically maps people's lived experiences within this framework, generating contextualized, actionable insights that facilitate rapid implementation and application towards service improvements [9, 11, 15]. When used to develop health system interventions, PJM can support key stakeholders (i.e. users and healthcare providers) to empathize with one another, and collaboratively identify and have ownership over improvement efforts [10, 16]. However, certain gaps in the literature exist which our paper seeks to address. First, most PJM studies do not report against accepted quality standards for qualitative research, making it difficult to appraise and raising validity concerns from some more traditionally trained researchers [9]. Second, a recent scoping review found that low- and middle- income countries (LMICs) are under-represented in PJM studies, and an even smaller subset of these studies mapped experiences within primary healthcare settings [9].

This paper seeks to contribute to the expanding PJM literature by addressing the gaps mentioned above. By documenting our experience in Vietnam and the Philippines specifically in the context of HBV and HCV, we seek to offer insights about the generalizability and implementation of PJM tools, in resource-limited primary care settings within LMICs, and potentially across other disease areas. Additionally, we aim to demonstrate how PJM can facilitate the development of people-centered interventions which place patients' experiences and contexts at the center of healthcare delivery. Finally, by assessing our PJM methods against a standardized quality, we offer how PJM qualitative studies can be strengthened to enhance transparency and transferability.

Methods

Our PJM approach applies qualitative data collection and analysis methods. Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guidelines [17] were utilized to ensure methodological consistency and promote transparency and replicability for other PJM studies. We detail the PJM methodology used according to the COREQ structure. A point-by-point assessment is detailed in Additional file 1.

Study design

Conceptual framework

People are influenced by many factors when accessing healthcare. This includes knowledge and socio-culturally informed perceptions about a disease, socioeconomic status, previous experiences with the healthcare system, and the health system itself [18]. This is particularly true for diseases requiring extended treatment, like viral hepatitis. Care continuity and coordination is essential as there are many points at which patients may choose or be forced to interrupt care.

This PJM methodology draws upon a framework devised by Braithwaite and colleagues as the result of a systematic review of patients' care pathways for hypertension management in LMICs. Devi and colleagues' proposed five stages in a patient's journey with chronic disease care in LMICs [19], which Braithwaite et al. condensed into three for simplicity and broader applicability: 1) first contact/entry/diagnosis; 2) start of treatment/referral; and 3) follow up/retention. In addition, Braithwaite et al. also derived six domains of barriers and enablers 1) demographic and socioeconomic factors; 2) knowledge and beliefs about the disease; 3) health status and comorbidity; 4) trade-offs; 5) social relations and traditions; and 6) health system resources and processes) which were further adapted into this PJM methodology to further understand viral hepatitis [18], as shown in Fig. 1.

Study setting

Within Vietnam and the Philippines, two sub-national sites were chosen as study sites in collaboration with government authorities. Key factors considered included the political willingness of subnational leaders to support the research and health system readiness to design and implement a new people-centered viral hepatitis screening, care and treatment pathway based at the primary care level. Thai Binh province in northern Vietnam and Tarlac province in Central Luzon/Region III in the Philippines were selected, each with a population of 1.5 to 2 million people (see Table 1). Specifically, the PJM research described in this paper focused on the catchment areas of two district hospitals and at the nearby community-based clinics (called commune health stations (CHS) in Vietnam, and screening and assessment facilities (SATFs) or Rural Health Unites (RHUs) in the Philippines) within each province. Together these facility networks were referred to as a primary care unit (PCU). In the Philippines, an additional PCU included the primary care clinic (TPH Cares) located within Tarlac Provincial Hospital.

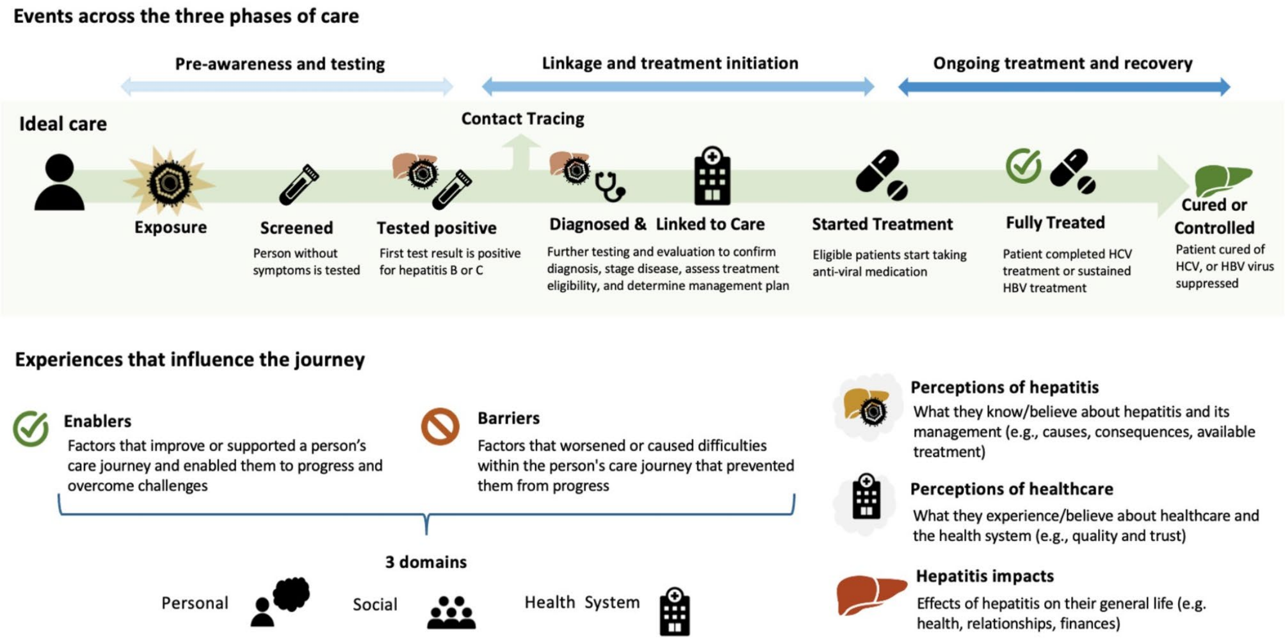


Fig. 1 PJM conceptual framework for viral Hepatitis B and C showing the ideal care pathway and the types of experiences that can influence the patient journey

Table 1 Geographic and demographic details of selected provinces

	Thai Binh, Vietnam	**Tarlac, the Philippines**
Geography	Coastal province in the Red River Delta of Northern Vietnam	Landlocked province north of Central Luzon Island, the largest in the archipelago
Total population	1.88 million (2022)	1.50 million (2020)
Population density (person/km2)	1,188 3.6x higher than national average	506
% of the population in rural areas	88% (2022)	74% (2020)
Main industry	Agriculture	Agriculture
Unemployment rate at working age	1.13% (2022)	8.8% (2021)
Household poverty[a]	1.82% (2023)	9.4% (2023)
% people with health insurance	87.1% (2023)	No data available

References: Vietnam Poverty Standard 2021–2025 (Decree 07/2021/NĐ-CP of Vietnam Government), Vietnam General Statistics Office [20, 21], Philippine Statistics Authority, Labor Force Survey [22], Official Poverty Statistics of the Philippines [23], Province classifications [24]

[a] The proportion of families/individuals with per capita income less than the per capita poverty threshold (set at PhP13,797 or $245USD per month in the Philippines (amount required to meet basic food and non-food needs for a family of 5), VND 2,000,000 per month for urban and VND 1,500,000 per month for rural in Vietnam)

Data collection and sample selection

Several qualitative methods were used to explore peoples' journeys with hepatitis. First, this included retrospective, in-depth individual interviews with patients using a semi-structured guide aligned to the conceptual framework (see Additional file 2). The semi-structured guide identified key events, locations, and timing of care received by participants as shown in Fig. 1. Within each of the three phases of the care cascade, the guide contained open-ended questions exploring barriers and enablers, people's perceptions of viral hepatitis and their experiences with the healthcare services they encountered, and the impacts of viral hepatitis on their lives. The guide was piloted with six individuals living with hepatitis B/C (three from each country) living outside the catchment area who were not included in the final analysis. The semi-structured guide was subsequently modified based on feedback from piloting prior to full implementation.

These study participants were drawn primarily from health facility registries within the selected PCUs of each chosen province. Health facilities were asked to identify retrospective people living with HBV and HCV from their registry within the last 5 years prior to the commencement of recruitment and data collection for the patient journey mapping. In the Philippines, recruitment was slower due lower rates of screening and diagnosis, and so supplemental sources were added, including facility registers of two neighboring provinces (Bataan and Bulacan). Once study participants were identified, healthcare providers contacted them to introduce the research and screen for interest in participating. A list of interested participants was provided to the research team. The research team then contacted participants to confirm their interest, obtain informed consent and schedule the interview in their preferred location/format.

A total of 63 individual participants were enrolled in the interview component of the study (30 in Philippines and 33 in Vietnam), which falls in the range that is usually required in qualitative research to arrive at 'data saturation' or the point at which no new information emerges [25, 26]. A purposive, quota-based sampling strategy was applied. This was designed to maximize the range of experiences among participants, provide longitudinal insight across the patient journey, and be current and contextually relevant. It sought to recruit a balanced representation across type of hepatitis (2:1 HBV to HCV) and gender (1:1 male to female) and cover the range of possible treatment outcomes (i.e., never started treatment, taking or completed antiviral treatment, quit treatment). Additionally, quotas were placed on specific risk factors (co-infected with HIV, intravenous drug use, and advanced/complicated disease). Pregnant women and children under the age of 19 years old (legal definition in the Philippines) were excluded. Table 2 and Fig. 2 summarize the final sample characteristics in terms of demographics and treatment status respectively.

The second data collection method involved focus group discussions (FGDs) with healthcare providers (HCPs). A discussion guide was developed that focused on HCPs perceptions and experiences on barriers and enablers of care provision for viral hepatitis. For subject selection, a purposive sample from the same PCUs as the patient participants was recruited. Each session was participated by a mix of doctors and nurses from management and service delivery roles, and of varied seniority. This diversity elicited a range of perspectives and experiences within a limited data collection timeframe, enriching the discussion and allowing for similarities and differences to naturally emerge. Given many of the primary care level providers had limited experience in managing people with hepatitis to date, informants were also

Table 2 Demographic characteristics of interview participants

Characteristic	Vietnam			Philippines		
	HBV	**HCV**	**Total**	**HBV**	**HCV**	**Total**
Participants, ***n***	25	9	33*	21	9	30
Age, ***mean (SD)***	52 (14)	52 (16)	51 (14)	35 (12)	41 (10)	36 (11)
Male, ***n*(%)**	12 (48)	9 (100)	20 (61)	14 (67)	6 (67)	20 (67)
Rural area, ***n*(%)**	20 (80)	6 (67)	26 (79)	18 (86)	7 (78)	25 (83)
Employed, ***n*(%)**	22 (92)	7 (78)	29 (91)	14 (67)	4 (44)	18 (60)
Living with HIV, ***n*(%)**	1 (4)	1 (11)	2 (6)	5 (24)	0 (0)	5 (17)
Any IV drug use, ***n*(%)**	1 (4)	3 (67)	4 (15)	0 (0)	2 (22)	2 (7)

HBV hepatitis B virus, *HCV* hepatitis C virus

*Total adds to less than sum of HBV and HCV because one participant had both conditions

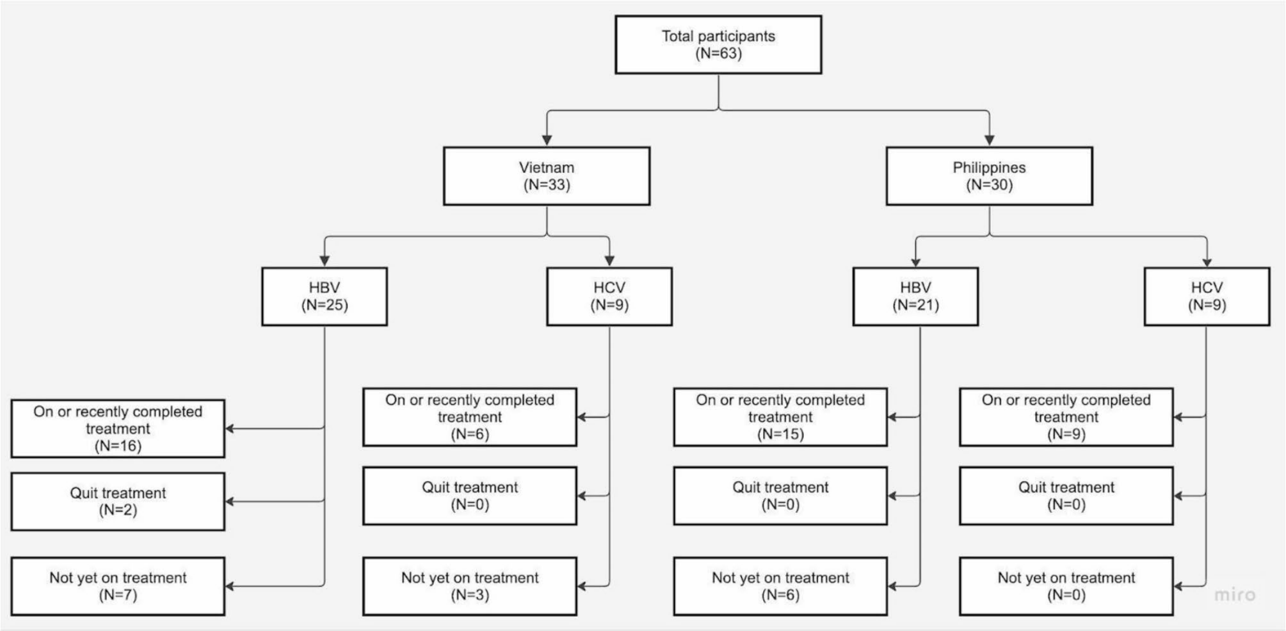


Fig. 2 Final participant sample characteristics by treatment status (per health facility records)

recruited from the closest higher level referral hospitals (Thai Binh Provincial General Hospital, Tarlac Provincial Hospital, and its neighboring provincial hospitals). In Vietnam, two focus groups of 12 participants each were held (10 from PCUs and 2 from reference hospital); in the Philippines, four sessions with 4 to 8 participants were held.

A hybrid approach consisting of virtual or face-to-face platforms was used to conduct participant interviews and HCP focus groups, based on research team comfort and patient choice. In the Philippines, there was a preference for virtual platforms, and in Vietnam for face-to-face. A variety of mobile applications suited to participant preferences were utilized for the virtual mode (i.e., Facebook Messenger, Viber, Zoom, WhatsApp, etc.). In-person patient interviews and HCP focus groups were conducted either in the clinics or in a quiet and comfortable space of participants' choosing (e.g., home or community spaces). All were conducted in the local language (Vietnamese and Tagalog) and audio recorded. Each individual interview was conducted by a team of two researchers, and ran from 45 to 75 min in duration. Each FGD was facilitated by one researcher and took from 60 to 120 min to conduct. Written or verbal consent was always sought or confirmed from participants prior to commencement. Monetary compensation in accordance with local norms was provided to participants.

Data management

The digital files were stored in a private and secured cloud platform which only core research team members had access to. Physical copies were secured in a locked cabinet in each country's institutions. Personal information that can risk the anonymity of participants were not collected (i.e., names and home address). Each participant was assigned anonymized identifiers to ensure privacy.

Analysis

Qualitative analysis

A rapid deductive qualitative approach (RDQA) was adopted for the analysis of the participant interviews and HCP FGDs. This streamlined the production of actionable insights for intervention. The RDQA process was adapted from a prior validation study [27]. In this deductive approach, a directed content analysis [28] was employed wherein a code book and data extraction matrix were derived, a priori, from the conceptual framework (see Additional file 3). Codes included barriers and enablers of progression in care occurring at three levels (personal, social, and health system), perceptions of hepatitis and the healthcare received, and impacts of the disease on everyday life.

The rapid process required preliminary analysis to be immediate or simultaneous with data collection. To enable this, interviews were not transcribed from the audio recordings, but coded and summarized in real-time using the specifically designed data extraction tool in MS Excel. This tool was adjusted following the pilot interviews and iteratively refined as the data collection commenced. Specifically, this required two researchers per interview; one conducted the interview, and one took detailed notes. Immediately after completion, the pair completed the coding matrix together. If required for specific quotations, snippets from audio recordings were listened to when creating each individual participant summary. The data extraction tool also required interviewers to record observations of the interview environment and non-verbal cues from participants throughout the interview or focus group discussion. This process meant that a maximum of five interviews could be conducted each day.

A detailed quality assurance procedure was developed to ensure the RDQA was replicable and feasible in both countries, and to harmonize efforts with limited time and resources (see Fig. 3). A team of four local researchers from each country underwent training in interview techniques and RDQA prior to data collection and analysis. At the end of each day of data collection, the team would meet and review all five completed matrices to identify any gaps in information that should be considered in the next round. All data extraction matrices were first completed in the local language (Vietnamese and Tagalog) and then translated into English. A sample was back-translated to ensure accuracy, and key terms with no English equivalent were retained. Additionally, one lead researcher from each country reviewed and validated each data extraction matrix before finalizing for thematic analysis, checking for accuracy, logic and consistency of the data provided. Finally, the first 5 interviews were simultaneously transcribed and translated, and a coding matrix completed based on these transcripts by the independent cross-country researcher. The resulting summary was compared to the translated summaries from the field, and demonstrated few significant differences. The RDQA methodology was also used for the HCP

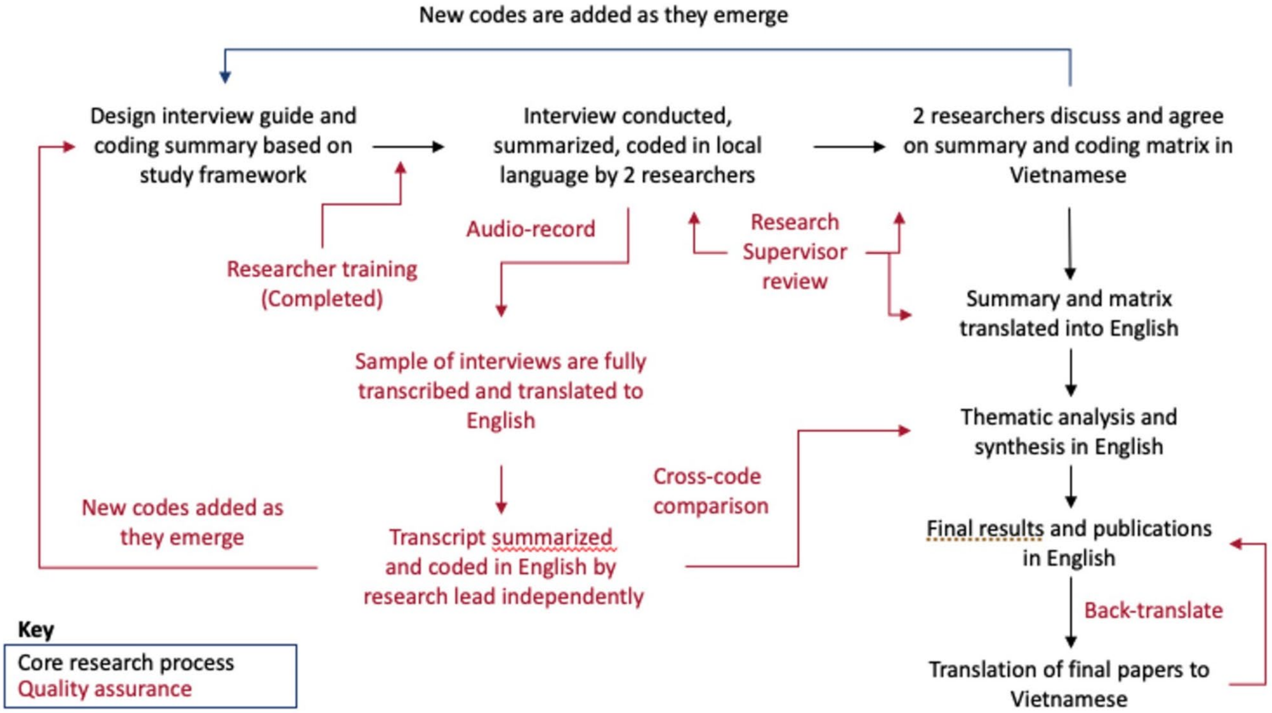


Fig. 3 Illustration of RDQA and quality assurance process

focus groups, with summaries focused more simply on describing the barriers and enablers identified across the cascade of care from the HCP perspective.

Thematic analysis was conducted directly on the individual participant summaries, continuing until the point of data saturation was reached. This step was performed by a smaller team of three researchers; the lead from each country, and one overall research lead. Simultaneously, key data was extracted into a set of aggregate tables. Collated data included the relative frequency of qualitative themes, as well as discrete variables used to characterize the participant sample (e.g., demographics, presence of comorbidities, baseline health utilization) and construct the journey (i.e. times and locations of each step in the care cascade and outcomes of care). Thematic analysis identified patterns in the completion, timing and location of care, and major and minor themes among the barriers and enablers of care, and perceptions and impacts of hepatitis. Initial findings were analyzed by in-country research leads and staff, followed by iterative discussions to explore similarities and differences between the two countries. Subsequently, the findings were synthesized across both countries and validated through discussions with the wider cross-country project team in virtual meetings.

Presentation of key findings

Findings were presented in narrative and visual formats. This included a summary of five typical journeys, as well as a range of key barriers and enablers from personal, relational and health system domains within each of the three phases of the care cascade. These findings have been published in a separate paper [29]. Anonymized illustrative quotes were provided to support the key findings. Quotes contain only the high-level information including the kind of hepatitis, country, and a few key characteristics such as gender, and age range. Additionally, current employment status and line of work were also added in the quotes as a proxy for income level. They were collected during the interviews to provide context for healthcare utilization and capacity to pay as some participants' health insurance depends on employment. All these details were incorporated into the presentation of illustrative quotes to provide personalized context for each participant.

Data dissemination

The preliminary findings of the research were initially shared with a group of local multi-sectoral stakeholders in each country as part of a research validation workshop. This group included representatives from public, private, and civil society organizations, and included HCPs and people living with viral hepatitis. Study findings were subsequently used and disseminated during a series of workshops which aimed to design health systems interventions to improve viral hepatitis care and treatment and improve patient experience and clinical outcomes across the cascade of care.

Research team

Team membership

The research team was composed of international members from diverse academic and professional backgrounds including clinical medicine, epidemiology, anthropology, public health, biostatistics, data science, and allied health. All the team members are either working in a research academic setting, providing direct patient care or a combination of both. There was a balanced representation based on gender and age differences.

Reflexivity

Over the course of the data collection and analysis, reflexivity and quality assurance were maintained through regular meetings among the overall and country research leads and trained local researchers. As part of the quality assurance procedure, regular meetings were used to troubleshoot issues and discuss emerging themes; revise the instruments, data extraction tool and recruitment strategy as needed; and evaluate the point at which data saturation was reached or the point where no new findings emerged, particularly about enablers and barriers to care. Key results were collaboratively identified among all the research leads with attention to convergences from both countries while also distinguishing country-specific themes. Key findings were finalized among the whole research team and a broader set of stakeholders through the virtual meetings and in-person country workshops described above.

Patient and public involvement

Prior to data collection, the research team engaged with stakeholders and community representatives, including people living with viral hepatitis and government authorities, to situate the study within the existing landscape of efforts for viral hepatitis care interventions. After data collection and analysis, findings were disseminated and validated through workshops with public, private, HCPs, and civil society sectors as well as people living with viral hepatitis themselves, as described above. Research subjects, both HCPs and patients, were invited to participate in the data dissemination event in each country; while most of the HCPs involved in FGDs attended these events, most patient subjects chose not to.

Results and discussion

Methodological insights

Patient journey mapping

This article contributes to the nascent PJM literature focusing on the primary healthcare system in LMICs, and it is one of few on viral hepatitis [30–32]. There is a significant body of research from LMICs that uses PJM, in general, to understand peoples' experiences living with stigmatized and/or chronic conditions (for example, HIV and tuberculosis) [33–36]. There are also a growing number of experimental and observational studies that examine the cascade of care for people living with HCV [37–42] and, to a lesser extent, HBV [41, 43–45]. The PJM methodology described in this paper allows researchers to retrieve rich insights about peoples' lived experiences and perceptions of care which underpin health-related behaviors, and document where and when they received each step in the care pathway. It also captures more nuanced understandings in care delay, drop-out and re-entry as compared to other studies of the cascade of care.

Another strength of this PJM methodology is that it intentionally includes demand (users)- and supply (healthcare provider)- side insights from within the same health system catchment area. This helps to systematically identify service delivery gaps and contextually specific improvements to health services [46–48]. For example, HCP insights about the impacts of COVID-19 redirecting health systems resources were helpful to contextualize patient's observations about sudden stock-outs in medications and testing kits in this PJM study. The comparison also helps to flag areas of discordance between patients and HCPs, which are important to address in any interventional design and improvement efforts. In this study, HCPs attributed patients' unwillingness to be tested or treated for hepatitis simply to lack of knowledge or lack of financial resources. Patients, by contrast, identified a broader range of contributing factors, such as the presence of competing co-morbidities, and expressed more complex trade-offs underlying a decision not to seek care. The juxtaposition of the interactions between HCPs and patients has been identified as an underexplored dimension of PJM studies [11]. Our study demonstrated how incorporating is feasible and can produce a more comprehensive picture of the patient journey.

Importantly, this paper also responds to the lack of a standardized approach in reporting PJM studies to date [9]. This oversight may contribute to the asymmetry of PJM studies between HICs and LMICs [49]. Given use of qualitative data collection and analysis, the COREQ framework represents an appropriate tool for objective assessment. As shown below, most criteria were met during the methodology implementation (see Table 3 and Additional File 1). Other studies have highlighted the benefits of using a checklist to enhance the transparency and transferability of methods and findings in qualitative research. However, acknowledged limitations remain in the COREQ as an assessment tool including insufficient attention to ethics adherence, data management and dissemination, and the public impact of research [50, 51]. These aspects have been incorporated into our version of the PJM protocol as additional domains.

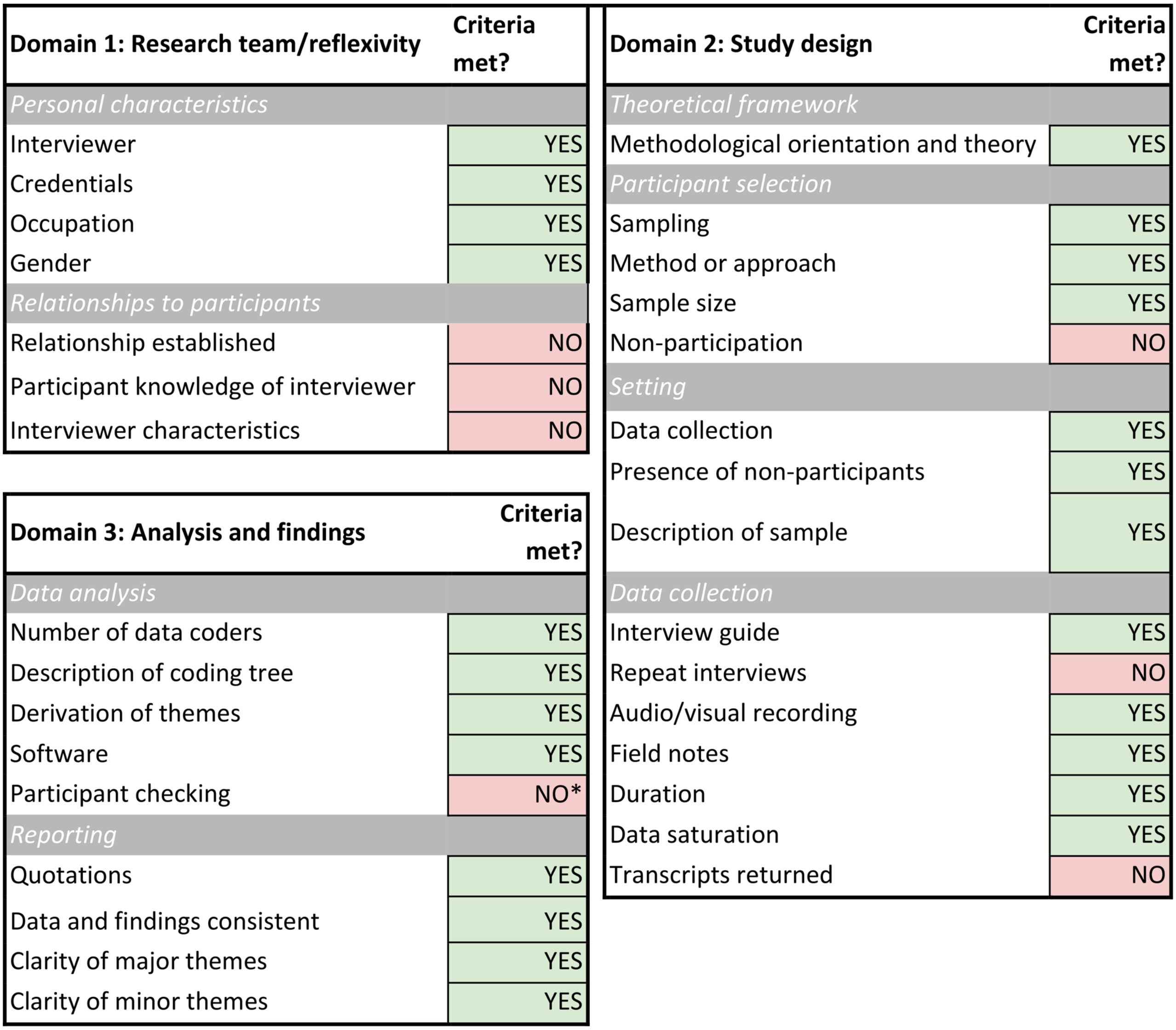
Our methodology purposely deviated from the COREQ guidelines in three domains: we did not (1) pre-establish participant-researcher relationships, (2) involve participants in checking the results and returning their matrices, or (3) repeat interviews with individual participants. These choices were made in part to protect participant confidentiality given the stigmatizing nature of hepatitis B and C [52–54]. It also enabled the research to be completed within a timely manner given limited resources. Involving participants in the analysis of data, using a new research method, in multiple languages, would have been time- and resource-intensive. Instead, the decision was made to involve patients/ people with lived experience receiving and delivering care within the research validation and data-dissemination workshops. However, as noted above, it was rare for individual patients who had been part of the research to accept the invitation, perhaps due to fear of stigma. To address this, established patient advocates were also invited to attend.

Limitations in participants' involvement in research design and evaluation of results is a common pitfall even within qualitative health research adopting co-design or co-production frameworks [55]. Scholars have emphasized the value of "slow co-production" [56] to create meaningful patient and public involvement in research and knowledge production. This approach emphasizes carefully building a foundation of trust between the researchers and community while ensuring continuity beyond the research process. However, the prevalence of cost-effective paradigms may view the slow process as less convincing than having predictable deliverables within limited time frames and resources [57]. Future studies will benefit by carefully considering the extent of participant involvement and in what phases of the project, resourcing it appropriately in order to offer a pragmatic approach.

Value of rapid qualitative analysis

In this study the RDQA approach produced timely, useful results within a shorter time frame than might have been expected using traditional qualitative research methods. This is in large part due to the elimination of the transcription step. The lower time and financial burden has been highlighted in other studies [27, 58–60]. However, given researchers' lack of familiarity with RDQA, the methodology still required considerable time and effort

Table 3 Assessment against COREQ guidelines



Domain 1: Research team/reflexivity	**Criteria met?**
Personal characteristics	
Interviewer	YES
Credentials	YES
Occupation	YES
Gender	YES
Relationships to participants	
Relationship established	NO
Participant knowledge of interviewer	NO
Interviewer characteristics	NO

Domain 2: Study design	**Criteria met?**
Theoretical framework	
Methodological orientation and theory	YES
Participant selection	
Sampling	YES
Method or approach	YES
Sample size	YES
Non-participation	NO
Setting	
Data collection	YES
Presence of non-participants	YES
Description of sample	YES
Data collection	
Interview guide	YES
Repeat interviews	NO
Audio/visual recording	YES
Field notes	YES
Duration	YES
Data saturation	YES
Transcripts returned	NO

Domain 3: Analysis and findings	**Criteria met?**
Data analysis	
Number of data coders	YES
Description of coding tree	YES
Derivation of themes	YES
Software	YES
Participant checking	NO*
Reporting	
Quotations	YES
Data and findings consistent	YES
Clarity of major themes	YES
Clarity of minor themes	YES

*Participants were invited to validation workshops but only HCPs accepted and attended

to implement. Even with training prior to data collection, our experience suggests it may take longer than anticipated to validate the coding performed by new researchers. This was mitigated by scheduling a pause in the data collection period after a small sample of interviews (five per country). During this time, the senior researchers cross-checked each individual coding matrix for accuracy, by re-listening to interview audio recording, and holding a feedback session with the research team to improve the process. Future PJM studies would benefit by dedicating additional time in equipping researchers with necessary skills to perform RDQA, incorporating a similar pause with feedback, and strengthening QA overall with specific, tested validation tools.

Of course, RDQA may not be appropriate to all settings and research questions. Effective use depends on appropriate case selection, ensuring a single research question supported by a structured framework for coding. Indeed, this was the case for our research, but a limitation is that some more nuanced themes and dynamics may have been missed in the first round of coding. Additionally, the accuracy of quotations was at times difficult to determine. This was especially the case with multi-sited research settings and different languages. One strategy identified was to have two versions of the summary coding for each interview, a local language, and a translated English version. Specific phrases were also retained where they had cultural significance or no accurate English equivalent could be identified.

Implementation insights

Participant recruitment

Participant recruitment emerged as the leading challenge for implementation. From the outset, country-specific challenges emerged. In the Philippines, existing hepatitis services were not widely implemented in the chosen province, meaning very little screening was performed, and case numbers were very low at baseline. This required the study team to supplement the sample with participants from two neighboring provinces' health records. The opposite situation emerged in Vietnam. The abundance of existing patients known to participating health facilities - including those who were screened in surgical and obstetric as well as the HIV program - made it difficult to narrow the selection from hundreds to 30 individuals. This required adjustment of the quota-based sampling strategy to provide narrower guidance. To provide clearer guidance, priority was given to individuals diagnosed with HBV or HCV within the last two years since the start of data collection. As seen in Table 2, it was also not possible to achieve perfect gender balance, especially for people with hepatitis C in Vietnam for which only male participants could be recruited. Female participants were identified, but either could not be contacted or refused to participate. It has been noted that the context and stigma surrounding hepatitis make recruitment for research studies difficult [61], and this was likely a contributing factor. Unfortunately, the non-participation rate was not documented to explore patterns any further.

The recruitment strategy also had some inherent limitations. First, the decision to exclude pregnant women meant that the experiences of an important sub-population (especially for hepatitis B which is largely transmitted from mother to child) were largely not captured. However, women who had previously been pregnant were part of the sample, potentially mitigating this gap. Second, retrospective interviews introduced a risk of recall bias. Repeated, real-time interviews with newly diagnosed patients were intended to mitigate this but could not be completed within the time and resource constraints.

In both countries, health facilities were utilized for recruitment, which was the most practical mechanism available to the team. However, this may have introduced participation bias, as patients were more likely to agree to participate when recruited by their healthcare providers. Additionally, selection bias may have occurred, as recruited patients were more likely to already be engaged in healthcare. The consequence is that the sample likely over-represents the proportion of patients who successfully complete or maintain treatment, as opposed to never beginning or quitting treatment (see Fig. 2). In addition, challenges experienced by vulnerable populations may not be captured. However, analyzing a higher proportion of "successful" experiences (i.e., completed or retained in care) provided insights on the successful enablers of the care journey, which is valuable to inform health systems interventions. Devising a careful recruitment plan and diversifying patient sources where possible is especially important for rapid qualitative research [62].

Given the multiple challenges that emerged in this research, future studies may benefit from regularly reviewing the inclusion and exclusion criteria against the project objectives and conceptual framework and assessing if any adjustments (to the sampling strategy or timeline) are required. As with any research, there was a need to balance both rigor and available resources.

Relational considerations

Core to qualitative interviewing is safeguarding confidentiality and building trust among participants, especially in the case of vulnerable populations [63, 64]. During pilot interviews, volunteers expressed fear associated with divulging sensitive information related to hepatitis. This was addressed by providing participants with the choice of format/location of the interview and assuring them that only de-identified data would be analyzed and shared. With such safeguards in place, the in-depth, one-on-one interviews provided a foundation on which people's experiences of illness, otherwise difficult to share in service delivery, are given space so they can be articulated, listened to, and acted upon [65]. This PJM methodology attempted to make these experiences prominent, despite a limited window of time for mutual trust to be built, with only a single interview. Strategies to address this included creating a safe environment and private settings and using the local, informal language, allowing participants to openly express their stories and emotions, often without prompts or further probes.

Continuous attention to researchers' positionality was also important during the data collection process [66]. The majority of the data collectors had a healthcare background, which risks influencing how a question is asked and answered [67]. For example, a participant may choose not to provide truthful answers due to fear of being corrected or reprimanded by a physician- or nurse-data collector. This potential conflict was addressed by continually underscoring to researchers that their healthcare worker role ends where their data collector role starts and vice versa. An informal, subjective assessment after each interview was also conducted, intended to self-critique their performance and determine any undue influence over the process.

Conclusion

PJM is a novel research method with the potential to make promising contributions to people-centered health service design. However, it still has limited uptake, especially in resource-limited contexts and at the primary healthcare level. This paper has demonstrated how a PJM methodology that incorporates patient and HCP perspectives can be feasibly implemented in two LMIC contexts, while fulfilling many of the criteria identified by the COREQ guidelines. Sharing such methods and associated instruments may help to enable broader uptake and application in other LMIC settings, providing health systems practitioners with a critical tool to identify and overcome barriers in and promote the delivery of people-centered health services globally.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-025-12543-w.

Additional file 1. COREQ point by point assessment.

Additional file 2. Participant Interview and Note-taking Guide.

Additional file 3. Interview summary Coding Matrix and Codebook.

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Authors' contributions

BH, JM, HN, DD, TD, DBD have made substantial contributions in the conceptualization, data analysis, and writing of the manuscript. DD, THN, TB, MF, MG, VN have made important contributions in data collection, analysis and reviewing the draft. LDD, GH, BNL, BN, TMP, JO, JS, PT, DBD have all critically reviewed the manuscript.

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Data availability

The dataset supporting the conclusion of the current study is included within the article and its additional files.

Declarations

Ethics approval and consent to participate

Ethics approvals were obtained from the Ethical Review Board for Biomedical Research Hanoi University of Public Health (Vietnam), the University of the Philippines Manila Research Ethics Board Panel 2 (Philippines), and the Mass General Brigham Institutional Review Board (USA). The study was conducted in accordance with the Declaration of Helsinki. Written informed consent was secured from all research participants. Alternatively, audio-recorded verbal informed consent was secured from research participants during online or mobile interviews.

Consent for publication

Not applicable.

Competing interests

Gilead Sciences Inc., and its representative author (Boon-Leong Neo) provided input from a technical perspective in study design and final manuscript edits but otherwise had no role in data collection and analysis, manuscript drafting, or decision to publish. There are no other conflicts of interest to disclose.

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