# My world felt smaller when I was diagnosed with hepatitis:

## UNDERSTANDING PEOPLE'S LIVED EXPERIENCES & CARE JOURNEY FOR VIRAL HEPATITIS

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### BACKGROUND

Chronic viral hepatitis remains a major public health concern in the Western Pacific, including the Philippines [1,2].

National health sector strategies have proliferated but services are not yet reaching many people who need them.

In order to accelerate progress, it is critical to understand the experiences of people living with hepatitis when accessing and navigating care from first diagnosis through to continuing care or recovery.

#### **OBJECTIVE**

This study is part of a larger project which aims to develop a primary care integrated model of care for hepatitis B and C. The scope of work being presented here is part of the baseline phase dedicated in exploring people's care journey for hepatitis B and C in the Philippines and offer insights on facilitators and barriers to people-centered care from their lived experiences of managing the condition.

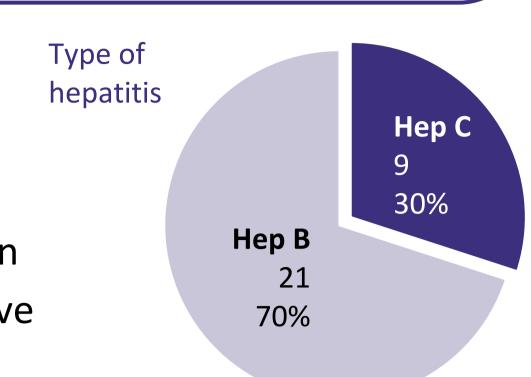
Analysis: Rapid deductive qualitative approach [3] was used to analyze interviews, streamlining knowledge generation which will subsequently feed into the co-designing process for the model of care. A coding matrix was developed to document key experiences happening at each stage of the care journey with attention to the facilitators and barriers at each step, perceptions of the treatment, and impacts of hepatitis in their quality of life.

#### METHODS & ANALYSIS

### WHAT IS PATIENT JOURNEY MAPPING?

Used in this study to enable a deeper understanding of the patient experience with the health system throughout their care

Design: Retrospective in-depth interviews were conducted to surface patient journeys of 30 people living with hepatitis B or C in Region 3 of the Philippines, an active demonstration site for hepatitis.



Sampling strategy and recruitment:

purposive and quota-based,
reached through health facilities
and so those who completed or
currently enrolled in treatment
may be overrepresented.

Status at recruitment

On or recently completed treatment

22

73%

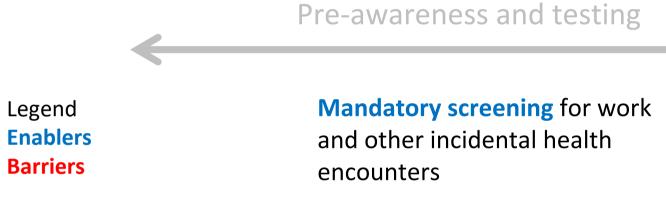
Quit treatment

0
0%

Analytical framework: Adopted from previous studies applied in non-communicable diseases [4,5] and accounted for three overarching steps in the care cascade.

Ongoing care and recovery

## PATIENT JOURNEY MAPPING FOR PEOPLE LIVING WITH HEPATITIS B/C IN THE PHILIPPINES



Strong family support – financial, logistical and emotional

Free medication within the public health system (only in demonstration sites and not nationally)

High motivation to eliminate virus, remain employable, protect family



Blue and red arrows

represent points of

departure or re-entry.

Barriers experienced

different stages but only

and eventual outcomes

disrupted and inactive

possible journey

are similar and

overlapping across

vary in their intensity

(i.e., fragmented,











Linkage and initiation of care







Exposure

Screened

counseling

**Inadequate posttest** 

**Emotional burden** from

exclusion and feelings

self-stigma, social

of hopelessness

Re-engage
opportunistically –
becoming aware of the
hepatitis services in

Re-engage unintentionally – acquiring HIV

public health facilities

**Tested positive** 

**High cost** of viral load testing, other tests

**Diagnosed & Linked to Care** 

**Difficult access** to health facilities and **complex navigation** 

Hepatitis deprioritized due to other pressing health conditions

## Started Treatment/ Long-term monitoring

**High cost** of medication for those accessing private care

## Continuing Treatment/ Fully Treated

Cured or Controlled

High cost of medication for those accessing private care

Inconvenience of going back to facilities for antiviral medication refill and monitoring affecting adherence

**Emotional burden** from institutional stigma, uncertainty on employability, future transmission risk to family

## 4 KEY FINDINGS

People living with hepatitis B/C may drop in and out of the care pathway at any point in time and be impacted differently.

Several care journeys became prominent such as **fragmented**, **disrupted and inactive care patterns**. These divergences from the ideal clinical care pathway are primarily influenced by several personal, social and health system factors aspects.

Family co-construct the care journey. They emerged as a strong source of financial, emotional and logistical support. Personal motivations also served as enablers to treatment such as desire to eliminate the virus to remain employable and prevent transmission to protect family members.

Outside of clinical care, people living with hepatitis still had to contend with multiple forms of stigma associated with their condition and live with the health and social consequences of the disease.

## 3 PROMINENT JOURNEYS

Fragmented care pattern - experienced timely care but with social & economic vulnerabilities due to inaccessible health facilities, high cost of treatment and testing, and recurring emotional burden attached to a stigmatized illness like hepatitis.

Disrupted care pattern - exited the care pathway at any point due to overlapping reasons such as inadequate counselling, affordability and accessibility concerns but have now re-engaged with hepatitis treatment opportunistically because of free to minimal cost of services provided by public health facilities (as part of the demonstration project) or unintentionally due to HIV co-infection for others.

Inactive care pattern - expressed interest to treat hepatitis but there are trade-offs such as preoccupation with other serious health conditions, affordability and accessibility issues.

## CONCLUSION

factors affect people's movement along the care pathway, often complicating their journey with hepatitis.

Our study underscores the importance of prioritizing people's lived experiences of hepatitis care and its value in constructing locally contextualized and people-centered health care services.

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