Most At Risk Populations and Healthcare Workers Perspectives On Existing Services For Hepatitis C Care And Support In Malaysia

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INTRODUCTION

380K Patients are living with Hepatitis C (HCV)

2,000 New cases reported every year

1,500 HCV patients treated (year 2018)

MAR 2018 Government started providing 12 weeks generic Direct Acting Antivirals (DAAs) treatment

4 Malaysian states participated in the Focus group discussions (FGD)

53 Total Number of Participants

BACKGROUND

In Malaysia, 380,000 patients are living with Hepatitis C (HCV), 2,000 new cases reported every year and 1,501 HCV patients treated (year 2018). Government started providing 12 weeks generic Direct Acting Antivirals (DAAs) treatment in March 2018. As government seeks to improve its policies, it is essential to hear from Hepatitis C patients and at-risk populations like people who inject drugs (PWID) and HCV Healthcare Workers (HCW) to ensure that there is a good understanding of the reality which patients face in seeking information, getting diagnosis and receiving treatments.

METHODS

Malaysia represents one of the six-sites study for which Coalition PLUS has presented a multi-country study abstract at INHSU 2018. 4 Focus group discussions (FGD) with 9 to 15 PWIDs each were organized to hear directly from HCV patients and/or at-risk populations PWID. 11 Healthcare Workers (HCW) providing HCV services were interviewed one-on-one. Through these, MTAAG+ aimed at finding out what are the key bottlenecks experienced by patients along the HCV treatment pathway. Additionally, the critical barriers currently restricting efforts to progress in HCV elimination were documented.

RESULTS

53 PWIDs from 4 Malaysian states participated in the FGD, age ranging from 20 to 60 years old and either from private or government funded rehabilitation centers. 11 HCWs of various disciplines were recruited, age ranging from 20 to 50 years old, either from community base organization, private or government healthcare facility at different cities in Selangor and Federal District.

EPIDEMIOLOGY OF HCV IN MALAYSIA (YEAR 2018)

2,000	1,501	380,000	31.2 MILLION
Incidence / Year	Treated	Estimated Number of PLHCV [2]	POPULATION

PATIENTS' PERSPECTIVES

Total Number of Participants **53**

PROFILE OF FOCUS GROUP PARTICIPANTS BY AND AGE GROUP AND RISK GROUP

Focus Group	FGD #1	FGD #2	FGD #3	FGD #4
Number of Participants	14	15	9	15
Age	Early 20s to 40s	Early 20s to 40s	Early 30s to 40s	30s to 50s
Risk Group	PWID in rehabilitation at initial screening stage.	PWID in rehabilitation at pre-screening stage.	PWID, with 2 of the group confirmed HIV+, and the rest mainly confirmed diagnosis & seeking treatment.	PWID, with 13 of the 15 screened, and 1 who completed treatment.

CONCLUSION

Both at-risk populations and healthcare workers indicated that they have some knowledge, but it became clear during the focus groups and interviews that other than very specific specialist doctors, all the other persons interviewed – whether patient or provider – lacked key knowledge and were very eager to address this problem.

While healthcare workers perceived that information was clearly provided on where to go next and how to get diagnosed or treated, at-risk populations identified this as a barrier, mainly in terms of accessing treatment.

The diagnostic and treatment steps need to be simpler, and should be made available at more decentralized levels of service provision. Both patients and healthcare workers expressed concern at how few people currently have access to DAAs and called for DAA treatment to become more widely available.

This study is a snapshot of the Malaysian access to HCV treatment situation and continued research will be needed as the national program evolves.

HEALTHCARE WORKERS' (HCWs) PERSPECTIVES

Total Number of HCWs **11**

PROFILE OF HCWs BY PROFESSION

Profession	Hepatologist / Gastroenterologist	Medical Doctor / Family Medicines Specialist	Nurse	Social Worker / Counsellor
Number of HCWs	2	4	1	4

RESULT

KEY FINDINGS

Topics	Focus Group Participants	Healthcare Workers
1/ Awareness	1. Recognized need to increase awareness on Hepatitis C among HCWs and at risk populations. 2. Highlighted that HCV information is shared through channels such as informal sources (social network, social media) or organized information sessions run by NGOs.	1. All are engaged in some form of health education activities targeting both at-risk populations and other HCWs. 2. Only 1 out of 11 believed that the lack of awareness was the result of low government prioritization of HCV.
2/ Prevention and Risk Reduction		2 out of 11 HCWs engaged in providing harm reduction services, and would like more accessible good needles exchange programs.
3/ Diagnosis	1. Acknowledged long delays in linkage to confirmatory testing and subsequently to treatment 2. Highlighted diagnosis costs as an important barrier to progress along the continuum of care.	1. All recommended that every Malaysian should get tested for HCV to remove the taboo and stigma of testing. 2. All the facilities offered initial screening, and subsequent tests were offered in half of the facilities. 3. Tests had to be offered by a specialist such as Hepatologist or Gastroenterologist; for tests beyond initial screening (e.g. viral load confirmation, fibrosis testing), 20-30% of the facilities could order these tests.
4/ Treatment	1. Expressed lack of clarity about treatment access and noted a lack of a dedicated approach to key populations and absence of easily understandable information. They indicated that treatment was very expensive (prior to arrival of generic DAAs) and that the cost of treatment had caused some patients to drop out of treatment. 2. Noted that drop-outs usually happen between completion of the diagnosis process and start of treatment, where many participants think peer support groups are important. 3. Highlighted that drop-outs are mostly due to the inconvenience of getting to healthcare services (time and cost).	Less than half indicated that their facility provides treatment.

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DISCLOSURE OF INTEREST

No interests to be declared.

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