HIV Cure Research: A Survey of Australian People Living with HIV on Perspectives, Perceived benefits and Willingness to Participate in Trials

Reported by Jules Levin
IAC Durban 2016

Authors
Jennifer Power1 Anthony Lyons1 Graham Brown1 Gary W Dowsett1 Jayne Lucke1
1The Australian Research Centre in Sex, Health and Society, La Trobe University

"Willingness to participate in HIV cure trials
The majority of respondents (82%) indicated they would be willing or very willing to participate in a clinical trial related to HIV cure research. However, of these:
• 87% would be less willing to participate if it would increase their susceptibility to illness
• 79% would be less willing to participate if it risked developing resistance to current antiretroviral treatment combination
• 63% would be less willing to participate if it resulted in an unpredictable viral load for up to one year
• 40% would be less willing to participate if it involved weekly visits to a medical clinic for several months
• 31% would be more willing to participate if it would help future generations but offer no personal benefit."

Introduction

In 2015, there were over 100 HIV cure related clinical trials operating worldwide [1]. Participation in current, and future, trials may pose health risks for people living with HIV (PLHIV), while being unlikely to deliver therapeutic benefit. Alongside this, there has been widespread public and media attention on HIV cure research [3], likely raising interest in (if not optimism about) the possibility of HIV cure among the community, people living with HIV (PLHIV) and potential trial participants. For these reasons, there is an ethical imperative to understand the motivations, decision-making, expectations and comprehension of potential trial participants [1-3].
Aims
This paper reports on a survey of Australian PLHIV which aimed to identify:

- familiarity with HIV cure research and optimism regarding achieving a cure
- anticipated benefits of cure
- socio-demographic and health-related characteristics of PLHIV who indicate willingness to participate in HIV cure trials
- factors that moderate willingness to participate in a trial.

Method
Data were derived from the HIV Futures 8 study, a cross-sectional survey of PLHIV in Australia conducted in 2015/2016 using a self-complete instrument. There were n=895 valid responses. Analysis involved univariate and multivariate logistic regression to identify factors associated with greater willingness to participate in trials. Ethics approval: La Trobe University Science, Health and Engineering College Human Ethics Subcommittee (S15-100).
Results

Awareness and optimism about HIV cure research

57% indicated they were aware of recent scientific research related to HIV cure.

40% indicated they believed a cure for HIV would become available in their lifetime, while 27% did not and 33% were unsure.

Willingness to participate in HIV cure trials

The majority of respondents (82%) indicated they would be willing or very willing to participate in a clinical trial related to HIV cure research. However, of these:

• 87% would be less willing to participate if it would increase their susceptibility to illness
• 79% would be less willing to participate if it risked developing resistance to current antiretroviral treatment combination
• 63% would be less willing to participate if it resulted in an unpredictable viral load for up to one year
• 40% would be less willing to participate if it involved weekly visits to a medical clinic for several months
• 31% would be more willing to participate if it would help future generations but offer no personal benefit.
Correlates of willingness to participate in trials

There were no socio-demographic characteristics clearly associated with greater willingness to participate in trials.

Perceived benefits of HIV cure

Not wanting to transmit HIV to others was the most desirable ‘cure scenario’, followed by health-related factors – not being at risk of ill-health and not using medication (Table 1).

Conclusions

The majority of participants indicated they would be willing to participate in a HIV cure trial. This was understandably moderated by concerns about risks to health, treatment efficacy or unpredictability of viral load. There is a need for more research in Australia about the acceptability of analytical treatment interruption that may be part of future trials.

There were no demographic or socio-economic characteristics associated with greater willingness to participate in trials. This confirms previous research that suggests targeting particular sub-groups for recruitment would not necessarily be beneficial unless it is necessary for particular study or trial [4].
Not wanting to pass the virus to others was a more desirable ‘cure scenario’ than health benefits, perhaps indicative of ongoing stigma associated with the transmissibility of HIV. However, this may also give us some insight into what people may assume or expect when we talk about a ‘cure’ for HIV. Not passing the virus onto others potentially points toward expectations for a sterilising cure, which current research suggests is less likely than long-term viral suppression, which may not guarantee against onward HIV transmission. Ongoing discussion about the language of ‘cure’ will be important.

<table>
<thead>
<tr>
<th>Table 1. Perceived Desirability of HIV Cure Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenarios</td>
</tr>
<tr>
<td>Not passing the virus on to others</td>
</tr>
<tr>
<td>Not be at risk of ill-health due to advanced HIV disease</td>
</tr>
<tr>
<td>Stopping using HIV medications</td>
</tr>
<tr>
<td>Being considered a person who is not infected with HIV</td>
</tr>
<tr>
<td>Not getting HIV again for a second time</td>
</tr>
<tr>
<td>Stop visiting the doctor for regular visits to monitor HIV</td>
</tr>
<tr>
<td>Rank</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>6</td>
</tr>
</tbody>
</table>

References