THE PRO-CARE STUDY

Amager og Hvidovre Hospital

People living with HIV's perspectives on Patient Reported Outcome (PRO) use in Danish HIV care
A qualitative focus group discussion and interview study

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BACKGROUND

Incorporating patient-reported outcomes (PRO) into clinical HIV care can better align healthcare practices with the needs and preferences of people living with HIV (PWH)[1].

It is crucial that the selected PRO measures address the specific concerns of PWH and maintain clinical relevance[2].

This study is part of a combined research and implementation mixed methods research project about PRO usage (The PRO-CARE Study).

AIM

To explore concerns of PWH and their views and experiences on the use of PRO in clinical HIV care.

"[HIV] is on my mind every day, because you are seen as a healthy and well person, and you are not - mentally. You may see me as physically okay, but on the inside or mentally, I am not. I am not well."

Lydia

METHODS

A Danish, single-centre, qualitative focus group and interview study.

One focus group discussion and seven individual interviews were held between June and September 2023.

We included 11 PWH: Four in a focus group and seven in individual interviews.

The interviews followed an interview-guide with open-ended questions and were conducted by one member of the study team.

Interviews were audio recorded and transcribed verbatim.

Data were thematically analyzed following Interpretive Description framework: An applied, inductive research methodology emphasizing the significance of performing research arising from clinical practice to generate new insights[3].

"So, if the physician broaches [a topic], he must be able to see it through. And must demonstrate safety – everything that's required to dare to open up to a stranger, actually, even though it might a physician that you have known for any years, you know? So, there is a great responsibility, if [the physician] opens up for these [sensitive topics]. Because if [physicians] create this kind of questionnaire, [they] must be willing to talk about all the topics in it, right."

James

RESULTS

We identified three main themes:

1) Does living with HIV make one ill?

HIV was for the participants both and illness and not an illness. On one hand, it was merely an undetectable virus they were living with. On the other hand, the social circumstances of living with HIV, including societal ignorance and stigma, impacted their daily lives negatively.

2) The psychosocial aspects of living with HIV can be difficult to discuss with HIV health care providers (HCPs)

HCPs were thought to do their best given the circumstances to view their patients holistically. But were also thought to be limited by a biomedical focus. PWH themselves also had difficulties bringing up sensitive topics.

3) PRO could be helpful for psychosocial support, but PRO also had limitations and potential challenges

PROs were considered a valuable tool that could bring attention to the psychosocial aspects of living with HIV. PRO could also help both PWH and HCP prepare for consultations and place responsibility on HCP to initiate sensitive discussions.

However, PWH highlighted that they preferred more time allocated to consultations rather than PRO questionnaires. They also emphasized that HCPs must be well-equipped to address psychosocial and sexual issues raised by PRO.

"[PRO] could have been useful for me. Because there have been several times, after I have left the doctor and am just sitting in my car and [think]: Oh shit, now you forgot to ask about this, and you also forgot to ask about that. Because you enter [the consultation], [and] you have little time, I think."

Paul

"But I think the idea [of PRO] is very good, as a starting point, but I think that it requires a lot from the healthcare providers you'll be meeting. So, they really have to be properly prepared somehow and must dare to have these [sensitive] conversations."

James

CONCLUSIONS

For the interviewed PWH, HIV and related concerns were often stressors in their daily lives, despite being well-treated for HIV. PRO could help bring these issues to light, but HCPs must be well-prepared to address the sensitive topics PRO raise.

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