HEADSUP!

Using a modified DEPICT model for participatory analysis in a qualitative study of neurocognitive difficulties among people living with HIV

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BACKGROUND

Despite the high prevalence of HIV-associated neurocognitive disorder (HAND), limited information exists about how people with HAND view, cope with, and speak about cognitive impairments.

PURPOSE

Despite the high prevalence of HIV-associated neurocognitive disorder (HAND), limited information exists about how people with HAND view, cope with, and speak about cognitive impairments.

METHODS

Study design. We conducted a cross-sectional qualitative study using face-to-face interviews to explore the experience of living with HAND.

Procedures. HEADS UP! used a team-based participatory analysis approach and included five Peer Research Associates (PRAs), four clinicians, four academics, and two students. PRAs received approximately 20 hours of training using the blended eLearning model designed by Universities Without Walls (www.universitieswithoutwalls.ca).

Participants. 25 adults recently diagnosed with HAND were interviewed by the Research Coordinator and Principal Investigator in Toronto (n=8 Casey House; n=8 St. Michael's Hospital) and Vancouver (n=9 Dr. Peter Centre).

Interview schedule. Questions prepared by study investigators and trained peer researchers focused on: (1) the trajectory of HAND; (2) HAND's effects on self-confidence, mood and resilience; and (3) the role of HAND in interactions with friends, family and healthcare providers.

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ANALYSIS AND INTERPRETATION

Using a modified Nixon & Flicker's (2014) DEPICT model for participatory qualitative analysis, interviews were transcribed verbatim and processed as follows: the first available set of 10 transcripts from Toronto participants was coded by one academic and one PRA. In a day-long meeting in Vancouver with the research team (including only Vancouver PRAs to avoid deductive disclosure) following a grounded theorizing approach, we generated 25 descriptive codes, subsequently distilling these into 10 primary codes with 25 secondary codes. For example, the primary code "Actions taken over time to deal with HAND" was separated into secondary codes of immediate tactics (e.g., "laughing it off") and medium/ long-term strategies (e.g., sticking to helpful habits and avoiding potentially embarrassing situations). The aggregation of each code was summarized and used to guide an additional full-team analysis and interpretation meeting in Toronto.

LESSONS LEARNED

Integrating PRAs' storytelling into the analysis and interpretation is crucial to grounded theorizing and triangulation with existing clinical literature on HIV and HAND and to achieving descriptive and interpretive validity. The DEPICT model helped balance clinical/academic authority with the patient's common sense and eagerness for action. PRAs are crucial to a grounded knowledge to action process, and helped to build content for a website, video and flyers.

Benefits for Peer Researchers.
- Increased PRAs' understanding of HAND
- Had a lasting positive emotional impact on PRAs
- Increased PRAs' ability to recognize and process their own cognitive concerns
- Helped alleviate feelings of isolation regarding their own cognitive concerns
- Fostered GIPA (the greater involvement of persons living with HIV) in this area

Improving the process for future studies.
- Provide periodic one-on-one support to PRAs throughout the research process
- Increase training for coding transcripts
- Offer neuropsychological assessment to PRAs prior to study involvement

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