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Community Engagement in Health Status Instrument Development: Experience With the HIV Disability Questionnaire

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Abstract

Background: People with HIV face a variety of health-related challenges from HIV, concurrent health conditions, and side effects of treatment. These health-related challenges may be termed *disability*. Community involvement in conceptualizing and understanding disability is essential to developing appropriate measurement tools.

Objective: To describe a community-academic partnership in the development of a new self-administered health status instrument, the HIV Disability Questionnaire (HDQ), using a community-engaged approach.

Methods: With a Community Advisory Committee, we used categories from the *Episodic Disability Framework*, a conceptual framework developed in an earlier stage of research, as a foundation for item generation.

Results: The purpose of the 70-item HDQ is to characterize the presence, severity, and episodic nature of disability experienced by adults with HIV. The Community Advisory Committee suggested items beyond those in the *Episodic*

Disability Framework, refined item phrasing, order, response options, and questionnaire instructions to enhance feasibility and relevance of the HDQ to adults with HIV, advised on how to structure the questionnaire to capture the episodic nature of disability, and suggested next steps for testing and implementation.

Conclusions: The HDQ is the first HIV-specific questionnaire to describe disability experienced by adults with HIV. Engaging community research partners in the development of the HDQ enhanced the questionnaire's relevance, feasibility, and face and content validities. This approach may be considered by others interested in health status instrument development.

Keywords

HIV, questionnaires, self-report, disability evaluation, community-based participatory research

People living with HIV infection face a variety of health-related challenges from HIV, concurrent health conditions, and side effects of treatment.¹⁻⁸ These health-related challenges, considered in aggregate, may be termed *disability*. Herein, we focus on a new instrument to measure disability experienced by people living with HIV, the HIV Disability Questionnaire (HDQ). Throughout the development of the HDQ, a community advisory committee has been an active partner in the research enterprise. Although

details of the HDQ have been published elsewhere,⁹ the role of community research partners has not been fully described.

In an earlier phase of research, we partnered with community members to develop a conceptual framework to describe disability experienced by adults living with HIV. Participants characterized disability as multidimensional and episodic, with unpredictable periods of wellness and illness. The *Episodic Disability Framework* consisted of fluctuating dimensions of disability (such as symptoms and impairments,

Figure 1. Components of the Episodic Disability Framework

Components include dimensions of disability, contextual factors that may exacerbate or alleviate disability, and triggers that may spark a major or momentous episode.

difficulties with daily activities, challenges to social inclusion, and uncertainty about the future), contextual factors that may exacerbate or alleviate disability, and triggers that indicate momentous or major episodes of disability (Figure 1).¹⁰ This framework offers a new way to conceptualize disability, specifically derived from the perspective of adults living with HIV.

Measuring disability in the context of HIV is important for determining the impact of the disease and for evaluating the effectiveness of interventions that might reduce disability. Although a multitude of health status instruments exist, none capture the breadth and depth of disability experienced by adults living with HIV. Many existing health instruments were developed before the advent of combination antiretroviral therapy and specifically lacked items related to social inclusion and uncertainty, which we found to be very important from the perspective of people living with HIV.¹¹ Thus, there was a need for a new instrument that specifically incorporated the experiences of people living with HIV.

Patients and clinicians are often consulted as research participants through qualitative focus groups or interviews during the initial phases of an instrument's development, focusing on item generation and reduction.¹² However, little has been published that describes the role of community members in other aspects of health measurement research, such as item phrasing, developing response options, or questionnaire instructions. Furthermore, community input can enhance the contextual relevance, comprehensiveness, and understandability of an instrument. Our aim was to describe our community-academic partnership in the development of a new self-administered instrument, the HDQ, using a community-engaged approach.

METHODS

Generating Items

To generate items for the HDQ, we used detailed categories from the four disability dimensions in the Framework: 1) Symptoms and impairments, 2) uncertainty, 3) difficulties with day-to-day activities, and 4) challenges to social inclusion in addition to our content analysis of existing HIV-specific health status instruments¹¹ (Table 1). We identified 72 detailed categories, 50 from the Framework and 22 from existing instruments. Forty-four categories represented symptoms and

impairments (such as physical, mental, and emotional health-related challenges), 22 represented difficulties with day-to-day activities (such as difficulties with walking, activities of daily living, and carrying out household chores), four represented challenges to social inclusion (such as challenges fulfilling roles as a parent, difficulties engaging in work and school, and personal relationships), and two represented uncertainty (worrying about the future and the impact of uncertainty on life decisions such as buying a house or returning to work; Table 1). We used these categories as the primary source for items in the HDQ. This research was approved by Research Ethics Boards at McMaster University, Hamilton, Ontario, and St. Michael's Hospital, Toronto, Ontario, Canada.

Community Partnership

The development of the HDQ was a community-academic partnership. All aspects of this project were conducted in collaboration with a community advisory committee. The role of the community advisory committee was to provide advice and guidance throughout all phases of this research to ensure successful implementation, interpretation, and dissemination of the HDQ to relevant stakeholders in the HIV community. We defined community as "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings."¹³ All members of the community advisory committee reviewed and agreed on terms of reference that outlined the research goals and objectives, guiding principles, membership of the committee, roles and responsibilities, and access to data.

The community advisory committee was composed of two adults living with HIV, an employee of an AIDS service organization, and a representative of the Ontario Ministry of Health and Long-Term Care with varying expertise in HIV and disability research. We specifically sought multi-stakeholder representation to enhance the relevance, feasibility, and future translation of the HDQ across individual, program, and policy perspectives. Two members collaborated with the lead author in the earlier development of the Episodic Disability Framework. The other two members were new to HIV and disability research and were recommended by members of the investigative team to enhance geographic and gender diversity on the advisory committee. Although we did not

Table 1. Prespecified Categories Within Dimensions of Disability in the Episodic Disability Framework

Dimensions of Disability and Detailed Categories (n = 72)	
Physical Symptoms and Impairments (n = 31 detailed categories)	Shame/blame and embarrassment, guilt, regret, feeling alienated
Fatigue; feeling tired; exhaustion; decreased energy level	Loneliness
Diarrhea; bladder	Grief/bereavement*
Nausea and vomiting	Adjustment difficulty*
Headaches	Feeling unsafe*
Rashes and skin sores, ulcers or discoloration	Frustration/temper/agitated/anger/discouraged*
Ulcers and upset stomach – GI symptoms	Upset/distress/despair/hopelessness*
Pins and needles & numbness and tingling (may or may not be secondary to neuropathy)	Un-acceptance/not feeling loved*
Pain (aches and pains)	Uncertainty (n = 2 detailed categories)
Speech and swallowing problems	Worrying about the future
Decreased libido	Impact of uncertainty on decision making
Cardiovascular effects (secondary to stroke, myocardial infarction)	Difficulties With Day-to-day Activities (n = 22 detailed categories)
Cardiorespiratory impairments such as dyspnea, cough	Difficulties with day-to-day activities (global)
Secondary to pneumonias	Standing (indoors and outdoors)
Decreased endurance; activity tolerance	Walking (indoors and outdoors)
Decreased balance	Negotiating stairs
Fever and sweats	Transfers (moving from bed to chair, standing)
Weakness	Dancing (and other leisure and recreational activities/vigorous activities e.g. exercise)
Cramps (muscle and stomach)	Activities of daily living – eating
Body composition changes (weight loss and gain may or may not be secondary to lipodystrophy)	Activities of daily living – bathing/hygiene
Decreased appetite	Activities of daily living – dressing
Sleep loss; difficulty sleeping	Household chores – cleaning
Hair loss	Household chores – dishes
Forgetfulness; difficulty focusing attention	Household chores – laundry
Shaky hands; tremor*	Household chores – cooking
Change in handwriting*	Grocery shopping
Bruising; bleeding*	Getting out paying bills (errands)
Dry mouth; mouth pain*	Attending doctor's appointments
Vision loss*	Reaching*
Hearing loss*	Gripping*
Dizziness*	Bending or lifting*
Swollen lymph or glands or feet*	Sexual activity*
Genitals; menstruation *	Balancing checkbook, paperwork for bills*
Symptoms and Impairments Related to Stress, Anxiety, and Depression (n = 2 detailed categories)	Driving*
Stress, anxiety and depression (and nervousness)	Challenges to Social Inclusion (n = 4 detailed categories)
Stress, anxiety and depression – suicide ideation*	Parental roles
Symptoms and Impairments Related to Emotions (n = 11 detailed categories)	Work and school
Emotions (global)	Personal relationships (difficulty initiating or maintaining relationships either casual or intimate in nature with friends, family or partners)
Fear	Difficulty engaging in other social or leisure activities (e.g., travel)
Decreased self-esteem/confidence	

Note: Categories derived from the Episodic Disability Framework.

* Indicate new categories derived from existing instruments in a previous content analysis [11].

predetermine the size of the community advisory committee, our aim was to ensure that the committee was small enough to promote meaningful engagement of members in the HDQ development.

The community advisory committee advised on all aspects of HDQ development. The committee worked with the lead author, who presented suggestions for HDQ content and wording at face-to-face meetings followed by questions for consideration in HDQ development. We met twice with our community advisory committee to discuss the content, phrasing, order, and response options of each item, and the questionnaire instructions. We also sought feedback on how to measure the episodic nature of disability. In the first meeting, we presented 72 items based on the categories in the Episodic Disability Framework. The committee combined some items to minimize redundancy and also generated additional items. In the second meeting, we refined the item phrasing, domain order, response options, and questionnaire instructions; determined the timeframe; and established a way to capture the episodic nature of disability. After each meeting, recommendations from the community advisory committee pertaining to item generation, phrasing, order, and response options, questionnaire instructions, and the episodic nature of disability were relayed back to the research team via the lead author for decision. Item generation and reduction were iterative between investigators and the community. Individual consultation with community advisory committee members occurred between formal meetings with the lead author via email and phone to seek further guidance and clarification on the HDQ development. Investigators and community advisory committee members reviewed and revised three versions of the HDQ. Members of the community advisory committee were offered a one-time honorarium for their engagement in the development of the HDQ.

RESULTS

Item Generation

The community advisory committee in collaboration with the lead investigator determined that categories of symptoms and impairments ($n = 44$) and difficulties with day-to-day activities ($n = 22$) were detailed enough that each could

represent an item on the initial draft HDQ (Table 1). We then separated double- and triple-barreled categories into multiple items. For example, we separated the “body composition changes” category of the framework into two items that addressed weight loss and weight gain (items 15 and 16), and the “forgetfulness; difficulty focusing attention” category into three items that addressed remembering, thinking clearly, and concentrating (items 19–21; Table 2). Also, the community advisory committee identified categories from the previous content analysis of HIV-specific health status instruments that were important to include in the HDQ, such as vision (item 22), hearing (item 23), dizziness (item 24), feeling discouraged (item 34), and not feeling accepted (item 35; Table 2).

The community advisory committee suggested that some aspects of disability were incompletely captured by the preliminary list of items. Accordingly, we generated additional items pertaining to social inclusion and uncertainty dimensions of disability, including items about “worrying about the future” in the uncertainty dimension to address worrying about laboratory test results (item 37), side effects of treatments (item 41), body appearance (item 46), the ability to remain or return to the workforce (item 44), and financial security (item 42). Similarly, we added items to the social inclusion dimension to capture difficulty initiating new friendships (item 66) and intimate relationships (item 67; Table 2).

The community advisory committee also helped to establish a way to capture the episodic nature of disability. The community suggested asking about fluctuations in the past week was an optimal timeframe so that respondents could recall the potential episodic nature of their health challenges.

Item Reduction

We combined or removed categories that the community advisory committee considered redundant or less relevant. For example, we reduced the three categories related to “activities of daily living” (eating, bathing and hygiene, and dressing) and the four categories related to “household chores” each into one item collectively addressing these activities (items 53 and 54; Table 2). We removed “transfers,” because community members felt that this item would result in a large floor effect with few participants having difficulty with this activity (Table 1).

Table 2. HIV Disability Questionnaire (HDQ) Items (Version 1)

Symptoms and impairments (35 items)	Uncertainty (15 items)
1. I feel too tired to do my usual activities.	36. I worry about my future health living with HIV.
2. I have diarrhea.	37. I worry about my numbers (CD4 count and viral load) with HIV.
3. I feel nauseous.	38. I worry about having a serious illness living with HIV.
4. I have headaches.	39. I worry about when my next even of illness might be living with HIV.
5. I have numbness or tingling in my hands.	40. I worry about what the outcome of my next episode of illness might be living with HIV.
6. I have numbness or tingling in my feet.	41. I worry about the side effects of HIV treatments.
7. I have aches or pains.	42. I worry about my income or financial security living with HIV.
8. I have difficulty swallowing food.	43. I worry what might happen to my family and friends if I have an episode of illness with HIV.
9. I have decreased interest in having sex (decreased libido).	44. I worry about my ability to remain in the workforce or return to the workforce.
10. I experience shortness of breath.	45. I worry about dying.
11. I am unsteady on my feet.	46. I worry about my bodily appearance living with HIV.
12. I experience fever, chills, or sweats.	47. I worry about the legal issues of telling others about my HIV status.
13. I feel weakness in my muscles.	48. I am worried about what others such as family and friends might think of me if they knew I was HIV positive.
14. I have muscle or stomach cramps.	49. I worry about transmitting HIV to others.
15. I am experiencing weight loss or a decrease in my body composition.	50. I have put certain life decisions on hold (such as buying a house, returning to work or school, or starting a family) because of my uncertainty living with HIV.
16. I am experiencing weight gain or an increase in my body composition.	
17. I have a lack of appetite.	
18. I have difficulty sleeping.	
19. I have difficulty remembering things.	
20. I have difficulty thinking clearly.	
21. I have difficulty concentrating.	
22. I have problems with my vision.	
23. I have problems with my hearing.	
24. I feel dizzy.	
25. I feel anxious or worried.	
26. I feel sad, down or depressed.	
27. I am fearful of my future living with HIV.	
28. I feel a lack of confidence around others.	
29. I am uncomfortable with the appearance of my body living with HIV.	
30. I feel alienated by those around me (OR I feel that I don't belong) (OR I feel isolated even when I'm around others).	
31. I feel embarrassed around others due to my illness.	
32. I feel a sense of guilt in relation to my illness.	
33. I feel lonely living with my illness.	
34. I feel discouraged about my future life options living with HIV.	
35. I do not feel accepted by my friends and family.	
	Difficulties with day-to-day activities (8 items)
	51. I have difficulty walking.
	52. I have difficulty climbing stairs.
	53. I have difficulty carrying out daily activities such as eating, bathing, hygiene and dressing.
	54. I have difficulty carrying out household chores such as cleaning, doing dishes, laundry and cooking.
	55. I have difficulty carrying out leisure or recreational activities, such as exercise, dancing.
	56. I have difficulty getting out to do errand such as grocery shopping, getting to the bank or attending doctor's appointments.
	57. I have difficulty keeping track of my finances.
	58. I have difficulty getting around (either driving or taking public transportation).

table continues

Table 2. *continued*

Domains of Disability in the HDQ	
Challenges to Social Inclusion (11 items)	
59. I have difficulty meeting the needs of those I am responsible caring for (i.e., children, parents, grandparents, and partners).	
60. I have difficulty fulfilling my role as a family or community members living with HIV.	
61. I feel a loss of community in relation to my HIV status.	
62. My ability to work (either volunteer or paid work) or attend school is limited because of my illness.	
63. I feel that my performance in the workforce is hindered because of my illness.	
64. I have difficulty talking with others about my illness, including my family, children, or friends.	
65. I have difficulty asking others for assistance when I am experiencing an episode of illness.	
66. I have difficulty initiating new friendships.	
67. I have difficulty initiating new intimate or sexual relationships.	
68. I tend to isolate myself from others because I am HIV positive.	
69. I have difficulty taking part in recreational or leisure activities due to my illness.	
Health classification (1 item)	
70. Individuals living with HIV sometimes refer to having 'good days' and 'bad days' that represent the fluctuating ups and downs or periods of wellness and illness. How would you classify your overall health today living with HIV?	

HDQ

The resultant HDQ was a 70-item, self-administered questionnaire describing the presence, severity, and episodic nature of disability experienced by adults living with HIV. The HDQ was composed of four domains: Symptoms and impairments (35 items), uncertainty about future health (15 items), difficulties with day-to-day activities (8 items), and challenges to social inclusion (11 items; Table 2). A typical item presents a statement about a health-related challenge (e.g., "I feel too tired to do my usual activities") and has both an ordinal response scale asking how the respondent rates the challenge on the day of administration (from "not at all" to "extremely") and a nominal response scale asking whether the challenge fluctuated (improved or worsened) over the past week ("yes," "no," or "don't know"). A final item asks the respondent to classify his or her health on the day of HDQ completion as either a "good day" or "bad day" living with HIV. Additionally, a cover sheet includes the definition of disability, purpose of

the HDQ, explanation of how responses will be used, and instructions for how to complete the questionnaire.

HDQ Implementation

The community advisory committee suggested ways in which the HDQ may be used in clinical and community-based practice. People living with HIV may use the HDQ to articulate their health challenges to their health care provider. Health providers may use the HDQ to identify areas of disability experienced by their clients and identify interventions that may help to mitigate dimensions of disability experienced by adults living with HIV. AIDS service organizations can use the HDQ to assess the profile of disability experienced by clients, which may help to identify areas in which they might implement programs, services and interventions to either prevent or reduce disability among adults living with HIV.

DISCUSSION

To our knowledge, the HDQ is the first HIV-specific instrument developed to describe the presence, severity, and episodic nature of disability and one of the few instruments to actively involve the community in its development. Community-based participatory involvement in instrument development is useful for ensuring surveys and questionnaires are culturally relevant, sensitive, and applicable to the population of interest.¹⁴ We feel community representation, ranging from the lived experience to the program and policy sector, combined with the clinical and measurement expertise of the research team, will help to ensure that the HDQ is comprehensive, feasible, and contextually relevant to people living with HIV and other stakeholders.

The community advisory committee was integral to generating new items relevant to disability. For example, community members identified worrying about the criminalization of HIV transmission as an important item to include in the uncertainty domain. This item was not represented in the Episodic Disability Framework, possibly because the framework was derived from data collected before criminalization of HIV transmission emerged as a highly profiled issue in Canada.^{15,16} This emphasizes that the role of community to ensuring the HDQ is relevant to the current health-related challenges faced by adults living with HIV.

The community advisory committee also was central in

determining item selection and refining and revising the HDQ. Involving people with first-hand knowledge of the domains under study in item selection and refinement can enhance the content validity and, particularly, the interpretability of an instrument.¹⁷ Community members ensured items were short, simple, easy to understand, and culturally sensitive. They contributed to decisions on phrasing the items in the first person and as HIV-specific or generic. Specifically, the community advisory committee felt that there were important aspects of uncertainty or social exclusion that should remain specific to HIV (such as those related to criminalization of HIV transmission, disclosure of HIV status, and stigma associated with HIV positivity). Researchers and community members agreed on almost all elements of HDQ development. However, we did not reach consensus on the final wording for item 30. We decided to retain two possible options for this item, noting that this question requires further refinement in the next stage of sensibility assessment with adults living with HIV.

Our community-engaged approach was integral to the development of the HDQ. Our research adhered to key principles of partnering with the community in research, such as recognizing the community possessed unique contributions to dedicate to the HDQ development, integrating research and experiential knowledge for the benefit of all partners, and ensuring sustainable collaborative partnership throughout all stages of the research.¹⁸ Having terms of reference for the community advisory committee helped to formalize the structure of the partnership and clarify roles and expectations of researchers and community members.¹⁹

We faced some challenges in our community-engaged approach to HDQ development. First, we struggled with the tendency to continue to generate items that were important or related to disability, but were beyond the construct. For example, the community advisory committee raised stigma, social support, coping strategies, and causes of disability as concepts to consider including in the HDQ. Health challenges represented in the HDQ can emerge from multiple sources that are difficult to determine. In the Episodic Disability Framework, dimensions of disability comprise the construct of interest represented in the HDQ, whereas stigma, social support, and living (or coping) strategies are considered extrinsic and intrinsic contextual factors that may influence and interact with disability. Hence, although important to

the broader contextualization of disability, contextual factors are beyond the scope of the HDQ.²⁰ In the situation where contextual factors were raised as potential items to include in the HDQ, the research team articulated their rationale to the community advisory committee for retaining the scope of the HDQ to items that purely comprised (rather than influenced) the construct of disability, making final decisions surrounding item inclusion. However, this emphasized the importance of considering HDQ administration in combination with other instruments that measure contextual factors that exacerbate or alleviate disability, such as stigma, social support, and coping questionnaires. Another challenge involved balancing our enthusiasm to immediately implement the HDQ into community-based practice with the need for further measurement property assessment. Since the development of the HDQ, we pilot tested the questionnaire with 22 adults living with HIV and 5 clinicians who work in HIV care. Results indicated that the HDQ possessed sensibility, including face and content validity and ease of use for adults living with HIV.⁹ Findings from this sensibility assessment were integral in providing feedback on the HDQ content, item wording, terminology, and format.⁹ The HDQ also demonstrated construct validity among adults living with HIV.²¹ Nevertheless, the process of comprehensively assessing the measurement properties of a new instrument including validity, internal consistency reliability, test-retest reliability, interpretability, and responsiveness is essential for future research and requires a multi-staged and time-intensive approach.¹⁷ This can be frustrating for community who are eager to implement a new measure into practice. Hence, in collaboration with the committee advisory committee, we established a clear plan for further measurement property assessment with goals for HDQ implementation in the future. Ongoing knowledge translation and community engagement throughout this process will be integral to ensure the successful next steps of HDQ property assessment and implementation. Third, we surpassed our originally proposed timelines for HDQ development. This may be attributed to the time-intensive nature of community-engaged (or participatory) research that requires ongoing communication and collaborative decision making between community and academic partners.¹⁴ Nevertheless, we feel this process enhanced the relevance, applicability and feasibility of the HDQ, which will lead to the successful imple-

mentation of the HDQ into future practice. Finally, during the course of HDQ development, we had two community advisory committee members resign, one owing to staffing changes at an AIDS service organization; another relocated to a geographical location outside of Ontario. Nevertheless, one member remains engaged with HDQ academic researchers in the field of HIV and disability research and recently rejoined the community advisory committee upon moving back to Ontario (RA). Furthermore, a new AIDS service organization representative and person living with HIV recently joined the community advisory committee and will be involved in the next stages of HDQ measurement property assessment.

Our approach has some potential limitations. Our community advisory committee was small and may not have fully represented the diversity of perspectives from the HIV community. For instance, community members were primarily men from Toronto or Hamilton, Ontario, Canada, and it is unclear whether engaging more women and additional community members from rural or northern regions would broaden the applicability of the HDQ. Similarly, greater representation of individuals from the employment or insurance sectors could potentially strengthen the validity of the HDQ for use in the labor force. The Episodic Disability Framework and HDQ were derived within the Canadian context; hence, the HDQ may not possess similar relevance to adults living with HIV in resource poor settings. Broadening the diversity of the community advisory committee will be important to consider for future phases of HDQ research.

We do not wish to confuse our community-engaged approach with community-based research.²²⁻²⁴ Community-based research is a “collaborative approach to research that equitably involves community members, organizational representatives, and researchers.”¹⁸ The role of community in HDQ development was in an advisory capacity rather than as full members of the research team.²⁵ Although the community guided the process, final decisions related to the HDQ development were made by the research team. Hence, we use the term “community-engaged research” to more accurately describe the relationship between community and researchers throughout the research process.¹⁹ Nevertheless, the committee was involved in all aspects of the HDQ development in a collaborative process with researchers.²⁶ We will continue to

use this community-engaged approach in the next steps of measurement property assessment and revision to enhance the face and content validity, and feasibility of the HDQ for use in the clinical research setting.

IMPLICATIONS FOR FUTURE RESEARCH AND PRACTICE

As individuals live longer and age with HIV, they may be living with multiple concurrent health conditions, adding further severity and complexity of disability experienced with HIV. Hence, measuring disability is increasingly important for determining the impact of the disease and its comorbidities. The HDQ has the potential to become the first HIV-specific disability questionnaire used in HIV clinical research developed to assess the spectrum of disability experienced by adults living with HIV. Upon measurement property assessment, researchers may broadly use the HDQ to document the presence, severity and episodic nature of disability experienced by adults living with HIV. After interpretability assessment, the HDQ may be considered for use by clinicians and AIDS service organizations to assess the profile of disability experienced by their clients, particularly those dimensions that may not have been previously well captured in existing health status instruments such as living with uncertainty. This may help to identify areas in which clinicians and AIDS service organizations might implement programs, services, and intervention to reduce disability experienced by their clients with HIV.

CONCLUSIONS

To our knowledge, the HDQ is the first HIV-specific questionnaire developed to describe the presence, severity, and episodic nature of disability. All aspects of the HDQ development were done in collaboration with a community advisory committee. We believe engaging the community is a valuable method for health status questionnaire development that will enhance the face and content validity and feasibility of the HDQ for use in HIV research and has potential implications in other health contexts. This community engaged approach may be a useful approach for researchers and clinicians conducting other forms of health measurement research.

COMPETING INTERESTS

The authors declare that they have no competing interests.

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