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## Scaling Up Information Sharing on HIV-Associated Neurocognitive Disorder: Raising Awareness and Knowledge Among Key Stakeholders

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# Scaling Up Information Sharing on HIV-Associated Neurocognitive Disorder: Raising Awareness and Knowledge Among Key Stakeholders

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## Abstract

Although the majority of specialists and researchers in the field of HIV/AIDS are aware and knowledgeable about HIV-associated neurocognitive disorder (HAND) as a condition that affects as much as 50% of people living with HIV/AIDS (PLWH), research has documented that many health care and service providers who work directly with PLWH are either unaware of HAND or believe they do not know enough information about HAND to effectively support their clients experiencing neurocognitive challenges. Based on the findings of a qualitative study that interviewed 33 health care and service providers in HIV/AIDS services to identify and examine their awareness and knowledge on HAND, this article argues for utilizing a combination of Public Health Informatics principles; communication techniques, propagation strategies, and recognized approaches from Implementation and Dissemination Science; and social media and online discussion platforms, in addition to traditional Knowledge Mobilization strategies, to scale up information sharing on HAND among all relevant stakeholders. Increasing information sharing among stakeholders would be an important step to raising awareness and knowledge on HAND, and consequently, improving care, services, and support for PLWH and neurocognitive issues.

## Keywords

HIV-associated neurocognitive disorder, information sharing, Public Health Informatics principles, Implementation and Dissemination Science strategies, social media

## Introduction

HIV-associated neurocognitive disorder (HAND) is an all-inclusive designation assigned to a spectrum of conditions that causes cognitive, motor, and/or behavioral impairment in HIV infection (Watkins & Treisman, 2015). HAND includes three subdisorders: asymptomatic neurocognitive impairment (with no apparent functional impairment), mild neurocognitive disorder (with apparent mild functional impairment), and HIV-associated dementia (with apparent marked functional impairment; Antinori et al., 2008; Sanmarti et al., 2014). People living with HIV/AIDS (PLWH) may develop and experience mild to severe decline related to memory, concentration, complex attention, information processing, communication, learning, decision-making, problem-solving, and other executive functioning (Elbirt et al., 2015; Moore et al., 2006; Woods et al., 2009) because of HAND.

Research has shown that even in its mildest form, HAND is associated with higher rates of virological failure, poorer adherence to medication and treatment regimen, challenges in performing instrumental activities of daily living and making crucial life decisions, unemployment and underemployment, increased risk for mental health issues, lower

quality of life, and access barriers to health care and social services (Elbirt et al., 2015; Heaton et al., 2004; Nightingale et al., 2014; Sanmarti et al., 2014; Trepanier et al., 2005). Studies have estimated that between 30% and 50% of PLWH are or will be affected by some form of neurocognitive impairment in their lifetime even with the use of combination antiretroviral therapy (cART) as prescribed (Mind Exchange Working Group et al., 2013; Nightingale et al., 2014; Sanmarti et al., 2014; Watkins & Treisman, 2015). Despite the profound effect of cART on the treatment of HIV/AIDS since it was introduced in the mid-1990s, its impact on preventing and reducing HAND remains uncertain (Elbirt et al., 2015). Although it has been reported that there has been a significant decrease in the incidence of HIV-associated dementia with the use of cART (De Cock

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et al., 2012), the prevalence rates of the less severe forms of HAND have correspondingly increased over the last decades (Mind Exchange Working Group et al., 2013).

More recently, researchers and specialists in the HIV/AIDS sector have come to recognize HAND as a major public health issue not only in resource-poor settings but also in industrialized countries with easy access to cART (Nightingale et al., 2014). With a prolonged life expectancy of PLWH and estimated prevalence rates of neurocognitive decline remaining consistent in recent years (Watkins & Treisman, 2015), it is reasonable to anticipate that PLWH will progressively need to avail themselves of services that will help them address the impact of HAND on their lives.

Unfortunately, despite the high prevalence rates of HAND, health care and service providers in the community may not routinely receive appropriate education and training to address HIV-related neurocognitive impairments and their resultant mental health issues. They may find these neurocognitive impairments and confounding mental health issues difficult to distinguish from cognate conditions such as anxiety disorders, major depression, medication side effects, problematic substance use, and accelerated aging due to HIV/AIDS (Foley et al., 2008; Watkins & Treisman, 2015). Notwithstanding laudable efforts of researchers through published academic literature, community reports, and other more accessible public avenues to share relevant information about HAND that could be useful to frontline health care and service providers in the community caring for HIV-positive clients with neurocognitive challenges (Canadian AIDS Treatment Information Exchange [CATIE], 2018; Eaton et al., 2017; Ontario HIV Treatment Network [OHTN], 2018), it appears that there is still a need to improve the levels of awareness and knowledge of providers on HAND in real-world settings (Liboro et al., 2017, 2018, 2019).

Based on the main findings of the qualitative study described in this article, the aim of the discourse in this article is to present a proposal for utilizing a combination of (a) Public Health Informatics (PHI) principles; (b) communication techniques, propagation strategies, and recognized approaches from Implementation and Dissemination Science (IDS); and (c) social media and online discussion platforms (e.g., email listservs, webinars, messaging apps, mHealth, blogs, and other discussion boards), in addition to traditionally used Knowledge Mobilization strategies and tools, to scale up information sharing on HAND among HIV/AIDS specialists, researchers, health care and service providers, and PLWH. Increasing information sharing among relevant stakeholders would be an important step to raising awareness and knowledge on HAND, and consequently, improving services and support to PLWH and neurocognitive issues.

## Method

Utilizing a community-based research approach (Israel et al., 1998), the research team of the study described in this article

worked in close collaboration with their community partners from the OHTN to conduct a qualitative study that was dedicated to identify and examine the levels of awareness and knowledge of health care and service providers in the community on HAND, as well as the factors that affect these levels of awareness and knowledge. Together, the research team and their community partners established a community advisory board for the study that would provide essential input on all the aspects and stages of the research process from the very beginning of their project. The aims, procedures, and planned conduct of the study were approved by the Research Ethics Board (REB) of the Centre for Addiction and Mental Health of Toronto, Ontario, Canada.

## Participants and Procedure

A purposive sampling approach (Palys, 2008) was used to recruit participants for the study's interviews. Community-based health care and service providers were purposively recruited to participate in the interviews if their work involved in-person interaction with PLWH and was based at either an AIDS service organization or nonprofit agency that provided support services to PLWH in Southwestern and Central Ontario, Canada. This would include providers with intermittent but significant in-person interaction with clients as part of their daily responsibilities (e.g., executive directors, program managers), as well as providers with prolonged in-person interaction with PLWH for most of their day-to-day work (e.g., social workers, support workers, public health counselors). The prospective participants' levels of awareness on HAND were not determined prior to their participation in the study interviews.

Using an REB-approved recruitment script sent out by email, 39 providers from across Southwestern and Central Ontario were purposively invited to join the study interviews. From those who were invited, 33 providers with diverse characteristics (Table 1) agreed to participate. The participants took part in hour-long, semi-structured, audio-recorded, one-on-one interviews, which were conducted at the participants' offices by the article's first author. They provided informed consent prior to the start of their interviews and were compensated with CAD\$25 gift cards for their time and participation in the study. Their interviews were transcribed verbatim by two research assistants and were subsequently cross-checked for verification by the first author who conducted the interviews.

## Analysis

Thematic analysis (Braun & Clarke, 2006) of the interview transcripts was conducted by the first author and the research assistants. Before thematic coding was started, the first author reviewed all the transcripts to become more familiar with the interview data. The first author then chose eight of the 33 transcripts that would be representative of the

**Table 1.** Participant Characteristics ( $n = 33$ ).

Characteristics	$n$ (%)
Gender	
Female	18 (55)
Male	15 (45)
Age range (years)	
<25	1 (3)
25–34	11 (34)
35–44	10 (30)
45–54	7 (21)
55–64	4 (12)
Race/Ethnicity	
Aboriginal	1 (3)
African/Caribbean/Black	4 (12)
Hispanic/Latinx	2 (6)
Asian/Pacific Islander	6 (18)
White	20 (61)
Location of organization	
Downtown Toronto	21 (64)
Greater Toronto Area	6 (18)
Southwestern Ontario	6 (18)
Years working in HIV/AIDS services	
1–2	6 (18)
3–5	16 (48)
>5	11 (34)
Services provided predominantly to	
Aboriginal clients	1 (3)
Racialized clients	14 (42)
White clients	18 (55)
Participant's job title	
Caseworker	4 (12)
Counselor	9 (27)
Outreach worker	2 (6)
Social worker	6 (18)
Executive director	4 (12)
Program supervisor/manager	8 (25)

interview data set in terms of participant characteristics and perspectives for the research assistants to read and also gain greater familiarity. As individual coders, the first author and research assistants separately identified initial codes, themes, and subthemes from the eight representative transcripts. Then, they met to compare their initial codes, themes, and subthemes, and together, collaboratively finalized the codes, themes, and subthemes to subsequently establish a codebook for analyzing the remainder of the transcripts. The first author used the codebook to thematically analyze the remaining 25 transcripts.

## Findings and Discussion

Several themes were identified during the thematic analysis of the study's interview data. For this article, the discourse is going to primarily focus on the authors' proposal on how to

address the study's main findings. One of the main findings that was determined from the study was despite the vast information about HAND that is known to HIV/AIDS specialists and scholars, many community-based, frontline health care and service providers who support PLWH on a day-to-day basis readily acknowledged their lack of awareness on HAND, and the limited knowledge and skills they had to support PLWH experiencing neurocognitive challenges. About 25% of the participants revealed that they had never heard of HAND prior to their participation in the study, while nearly 75% of them claimed they did not know enough about HAND to feel adequate to provide support to clients experiencing neurocognitive challenges. Another main finding the study revealed was that not only did providers find it difficult to parse and distinguish signs and symptoms attributable to HAND from other neurocognitive manifestations, conditions, and client complaints, they also recognized their limited access to pertinent information about HAND that prevented them from effectively addressing it in their work with supporting PLWH. The other themes and subthemes that were generated from the thematic analysis of the interview data (Tables 2 and 3) are discussed in separate publications (Liboro et al., 2017, 2018, 2019).

## Theoretical Framework

The main findings of the study call attention to the urgent need to raise the levels of awareness and knowledge of community-based health care and service providers on HAND. To address this need, the authors of this article propose the adoption of the World Health Organization (WHO, 2017) Strategic Communications Framework, which recognizes that effective, integrated, and coordinated communication is integral to carrying out objectives that promote healthier futures for everyone. The WHO (2017) Strategic Communications Framework underscores the value of developing specific strategies to include communications that are more actionable, accessible, relevant, timely, understandable, and credible for predetermined objectives such as raising levels of awareness and knowledge on emerging public health concerns (e.g., HAND). The framework openly incorporates different principles, strategies, products, and platforms that are contextualized to meet predetermined objectives, and ultimately, seeks to meet the common primary goal of providing information, advice, and guidance to key audiences to prompt action that will address health issues. The framework focuses on communicating to and with key audiences such as individuals who make decisions about their own health, health care and service providers, policymakers, communities, and various organizations and stakeholders, as health decision-makers (WHO, 2017). By proposing to adopt this theoretical framework, the authors are able to explore and present principles, strategies, products, and platforms in this article that would not only be able to best communicate information about HAND to community-based health care and service

**Table 2.** Barriers to Addressing HAND at Work.

Types of barriers	Specific barriers
Personal barriers	Limited experience addressing HAND at work
Service access barriers	Lack of local primary care, mental health, and other services for referrals Limited access to services with adequate expertise working with PLWH Stigma toward PLWH in agencies outside of dedicated HIV/AIDS services
Systemic Barriers	Lack of capacity (i.e., resources) to provide appropriate services

Note. HAND = HIV-associated neurocognitive disorder; PLWH = people living with HIV/AIDS.

**Table 3.** Strategies Providers Use to Support PLWH Experiencing Neurocognitive Issues.

Types of strategies	Specific strategies
Intrapersonal strategies	Researching and learning about HAND Staying informed about HAND
Interpersonal strategies	Providing information on diet, exercise, and medications to clients Providing practical advice on memory aids and doctor consults to clients Providing professional/peer counseling to clients
Organizational strategies	Partnering with other organizations to share resources Creating dedicated support groups for PLWH with neurocognitive issues Advocating for greater capacity for the province

Note. PLWH = people living with HIV/AIDS; HAND = HIV-associated neurocognitive disorder.

providers, as well as the PLWH experiencing neurocognitive challenges they serve, but also prompt them to take action that will address the impacts of HAND on their work and personal lives. In the discourse that follows, arguments will be made for utilizing a combination of PHI principles; communication techniques, propagation strategies, and recognized approaches from IDS; and social media and online discussion platforms, in addition to traditional Knowledge Mobilization strategies, to scale up information sharing on HAND among all relevant stakeholders.

### PHI Principles

PHI is the application of information science and technology into public health research and practice (Yasnoff et al., 2000). By leveraging information technology solutions, it aims to capture, manage, analyze, and share information to support the mission of emphasizing disease prevention and health promotion over treatment, as well as achieving more specific public health goals effectively, efficiently, and inexpensively (Aziz, 2017; Coleman & Delea, 2013). Historically, PHI has been used primarily to deliver targeted information to clinicians, monitor public health, and evaluate and improve delivery of public health practices (Dixon et al., 2013). PHI

adherents have worked toward accomplishing these goals by creating usable systems, improving interoperability of technology solutions, establishing clear governance in practice, and improving communication infrastructure, which include organizations, personnel, procedures, facilities, and networks employed to transmit and receive information through electrical and electronic means (Dixon et al., 2013).

As the reach and impact of PHI has increased in the last two decades, it has extended its focus and efforts to expeditiously sharing practice-specific and specialized health information to service providers as well as users (Brennan, 1999; Vatalaro, 2014). Providers in different primary health care and service delivery fields and disciplines, patients, and clients who avail of social and support services, including those who have been affected by HIV/AIDS and its neurocognitive sequelae, have also become recipients and beneficiaries of valuable health information in recent years through advances in information technology (Hightow-Weidman et al., 2015; Maksud et al., 2015; Young & Chiu, 2014). Building capacity for public health information technology to translate and transfer information on effective prevention programs and interventions to a wider audience has become incorporated within the goals of PHI (Kraft et al., 2000).

Increasingly, proponents of PHI have paid more attention to public sentiment and activity regarding health issues, and the communication needs not only of HIV/AIDS specialists and researchers but also of primary health care and service providers, patients, and laypersons from the community (Brennan, 1999; Joshi, 2019). These changes in PHI principles and goals have become particularly evident in PHI practitioners' greater efforts over the years to integrate data from various sources, and include timely and accurate information from diverse relevant stakeholders (Aziz, 2017; Coleman & Delea, 2013). In the case of applying these principles to sharing pertinent information on HAND, perspectives of community-based health care and service providers in the HIV/AIDS sector have revealed in the study that the application of these principles could require the need to derive detailed but accessible information on definitions, classifications, signs and symptoms, assessments, differential diagnoses, treatment options, prognosis, and updates related to HAND from HIV/AIDS specialists and researchers; work experiences, questions, and viewpoints on barriers and strategies to identifying, addressing, and managing HAND of primary



health care and service providers (e.g., family physicians, nurses, social workers, counselors, case and support workers, and providers who work in AIDS service organizations); and concerns, feedback, and lived experiences of PLWH experiencing neurocognitive challenges (Liboro et al., 2017, 2018, 2019).

Other new principles discussed in more recent PHI academic research literature that would be paramount to consider for the purposes of sharing relevant information on HAND in concerned communities are intersectoral collaboration and multidirectional communication (Brennan, 1999; Dixon et al., 2013; Edmunds et al., 2014; Joshi, 2019). PHI scholars have put forward the importance of valuing collaborations between public and private sectors (Edmunds et al., 2014). Interestingly, health care and service providers in our study also expressed the value of collaborations in increasing open communication and sharing of resources among HIV/AIDS specialists, researchers, policymakers, providers, patients, and laypersons from both sectors (Liboro et al., 2019). They emphasized that increasing open communication and sharing resources through collaborations could improve health care and service delivery, and health and service outcomes, particularly those related to HAND, by making current evidence- and values-based information, diverse perspectives from work and lived experiences, and timely feedback available and accessible to everyone in the public and private sectors who are working toward the same goals. PHI researchers have pointed out that promoting multidirectional communication among multiple stakeholders would likely be more time-saving, cost-effective, and productive as opposed to using the traditional unidirectional, or even bidirectional forms of communication, which have been more commonly used to share health information in the past (Joshi, 2019). In the case of applying these principles to sharing pertinent information on HAND, this would mean that all relevant stakeholders could potentially be communicating and providing one another knowledge, perspectives, and feedback in real time, or at least in a much timelier manner. The emphasis of promoting multidirectional communication is on the potentially significant impact of the interaction among key stakeholders that cannot be obtained from the delivery of information going only in one direction, customarily from HIV/AIDS experts and academic researchers to primary health care and service providers, and then to patients and service users. Multidirectional communication could potentially help overcome personal and professional barriers to gaining greater awareness and knowledge about HAND that health care and service providers encounter (Liboro et al., 2017, 2018, 2019), and prospectively, benefit all stakeholders involved. Timely information from HIV/AIDS specialists and scholars can help providers develop their practice guidelines and address issues of PLWH experiencing neurocognitive challenges within the scopes of their practice. Conversely, input from providers, patients, and service users can help inform HIV/AIDS specialists and health care and service

delivery about day-to-day challenges related to addressing HAND, improve health and service outcomes related to care for PLWH, and add valuable information to the body of knowledge on HAND based on their valuable work and lived experiences.

### *IDS Techniques, Strategies, and Approaches*

IDS is the study of techniques, strategies, and approaches to promote the integration of research findings and evidence into health care policy and practice (Gonzales et al., 2012). It seeks to understand the behavior of health care practitioners and other stakeholders as an important variable in the purposeful distribution of information and intervention materials to specific clinical or public health practice audiences, and the sustainable uptake, adoption, and implementation of evidence-based interventions (Bodison et al., 2015; Clifford et al., 2009; Gonzales et al., 2012). Within IDS, there is a diversity of elements that value the engagement of stakeholders, organizations, and health care and service delivery systems, as well as research that is cyclical, iterative, and collaborative (Bodison et al., 2015; Gonzales et al., 2012). Several communication techniques, dissemination strategies, and recognized approaches have been evaluated and used in IDS literature to guide protocols for conducting systematic reviews of the effectiveness of health care programs (McCormack et al., 2013). These techniques, strategies, and approaches could potentially be valuable to efforts to scale up information sharing about HAND and raise greater knowledge among key stakeholders.

*Communication techniques.* Multiple systematic reviews in IDS academic literature have explicated key communication techniques that could prove useful to disseminating and implementing pertinent information about HAND. These communication techniques include (a) tailoring the message, (b) targeting the message to audience segments, (c) using narratives, and (d) framing the message (Clifford et al., 2009; McCormack et al., 2013).

Tailoring the message is a multistep and multidimensional process that involves assessing individual characteristics, creating individualized messages, and delivering these messages using a variety of appropriate channels (Clifford et al., 2009; McCormack et al., 2013). In the case of sharing information about HAND, a message could be tailored, for example, to specifically reach the individual who has been newly diagnosed with HIV so that the individual could learn to value the idea of remaining cognizant about the possibility of experiencing cognitive challenges in the future.

Targeting (also referred to as audience segmentation) involves the development of an intervention approach for a defined population subgroup that considers characteristics that are shared by the subgroup (e.g., age, sex, race, ethnicity; Clifford et al., 2009; McCormack et al., 2013). Once a subgroup is segmented, the messages should be designed in

a way to be maximally effective for that target subgroup. From the perspectives of the community-based health care and service providers in our study, creating a specific message about where to access support groups dedicated to supporting HIV-positive older African Caribbean Black women who are experiencing memory challenges would be a good example of targeting a message (Liboro et al., 2017).

Using narratives that provide appealing detail, characters, and a plot, which could serve as models for emulation and learning (McCormack et al., 2013), is proven to be particularly useful for reaching audiences who retain messages that are personally more meaningful to them. For example, a message that tells the story of a newcomer struggling to make sense of his immigrant experience while dealing with difficulties related to his new HIV diagnosis and making important life decisions about his health is a narrative that becomes very relatable to people experiencing similar challenges.

Finally, framing the message is a technique that conveys the same message in different ways (McCormack et al., 2013). Describing what is gained or lost by making the decision to get psychometrically tested for HAND could be beneficial as a technique to convince two people who think differently and in opposite ways the value of undergoing an initial neurocognitive assessment.

**Dissemination strategies.** Certain dissemination strategies that have been evaluated and supported by the Agency for Healthcare Research and Quality (AHRQ; McCormack et al., 2013) could be seriously considered for the purposes of improving stakeholder awareness and knowledge about HAND. Such dissemination strategies that have been described by the AHRQ in prior IDS literature include (a) improving reach of evidence, (b) motivating recipients to use evidence, (c) enhancing abilities to use evidence, and (d) utilizing two or more of the above strategies simultaneously or successively (Gonzales et al., 2012; McCormack et al., 2013). Distributing evidence widely to different types of audiences and across many settings increases the reach of information. This strategy supports the PHI principles of intersectoral collaboration and multidirectional communication in the sense that, the wider the reach established to share information about HAND, the greater the potential for collaboration between sectors and interactive communication between multiple stakeholders could be. The second strategy seeks to promote interest in using pertinent evidence. In this case, it would be to draw greater interest to information about HAND among all key stakeholders. This could mean examining possible factors that may motivate stakeholders to use information about HAND, such as the curiosity of PLWH to learn more about risks and consequences related to HAND, the drive of providers to learn more about ways to support PLWH experiencing neurocognitive challenges in their work, and the inclination of HIV/AIDS specialists and researchers to learn more about the different barriers providers and PLWH experience related to addressing HAND day-to-day (Liboro et al.,

2017, 2018, 2019). The third strategy involves providing additional resources to enhance stakeholders' abilities to use new information, such as resources that highlight how new information about HAND can be incorporated into providers' current practice (CATIE, 2018; Eaton et al., 2017; OHTN, 2018). This strategy may be particularly useful in the development of practice guidelines, or the delineation of different scopes of practice among clinicians and providers. Finally, the fourth strategy promotes the concurrent use of more than one of the strategies described. Combining multiple dissemination strategies is likely going to be more effective than using only single strategies for enhancing information adoption (McCormack et al., 2013).

**Recognized approaches.** In order for the above communication techniques and dissemination strategies to be employed, IDS has recognized the merits of using diverse approaches to deliver information to targeted recipients (McCormack et al., 2013). Information about HAND as a condition, for example, can be shared widely via human carriers delivering hard copies of academic journals, brochures, pamphlets, and community reports (e.g., postal service, for-profit mail delivery system); mass media (e.g., television, radio, print newspapers and magazines, billboards); phone (e.g., voice calls/messages, text messages, apps); and large meetings (e.g., conferences, symposiums, summits). These approaches are inherently useful for improving reach of evidence, and prospectively, increasing intersectoral collaboration and multidirectional communication among many stakeholders.

Ensuring the involvement of key opinion leaders, champions, and other people who have a visible stake in the issues related to the information provided is an approach that would help motivate stakeholders to use the information they receive (McCormack et al., 2013). The involvement of key opinion leaders, champions, and other people who have a visible stake in the issues related to the information provided could help endorse the validity and relevance of the information conveyed because of their recognized credibility or commitment to public health. Their involvement could also enhance stakeholders' abilities to use information, particularly if skills training is provided to stakeholders at the same time (McCormack et al., 2013). Community-based health care and service providers in HIV/AIDS services, in particular, rely on and greatly appreciate pertinent information on HAND provided by experts, scholars, and advocates from the HIV/AIDS sector through products and platforms such as consensus and evidence reports, facts sheets, information brochures, conferences, interactive seminars and forums, workshops, and accessible websites of AIDS service organizations and other community-based agencies (Liboro et al., 2017, 2018, 2019).

### *Social Media and Online Discussion Platforms*

With the exception of the recent surge in peer-reviewed publications on the topic in the last 3 years (Garret et al., 2017;

Hall et al., 2017; Iribarren et al., 2018; Jones et al., 2017; Krueger et al., 2016; Nielsen et al., 2017; Noble et al., 2017; Schwartz & Grimm, 2017), there has been relatively scant prior literature on HIV/AIDS message dissemination using social media and online discussion platforms (Huang et al., 2016). Although some investigators outside of HIV/AIDS research have asserted that the impact of social media-based methods does not confer additional benefits over print, email, and internet-based methods in increasing stakeholder awareness and knowledge (Narayanaswami et al., 2015), there are researchers from the HIV/AIDS sector who have conducted studies that support the usefulness of social media and online discussion platforms as important tools for information dissemination and uptake among clinicians, researchers, providers, and PLWH, particularly if immediacy and convenience are main considerations (Garret et al., 2017; Hall et al., 2017; Iribarren et al., 2018; Jones et al., 2017; Krueger et al., 2016; Nielsen et al., 2017; Noble et al., 2017; Schwartz & Grimm, 2017). Notwithstanding the fact that the usefulness of social media has been questioned by skeptics who find its knack for spreading rumors and false information problematic (Dosemagen & Aase, 2018), HIV/AIDS researchers have recently documented that social media and online discussion platforms are not only effective for scaling up information sharing (Hall et al., 2017; Iribarren et al., 2018; Jones et al., 2017; Krueger et al., 2016; Nielsen et al., 2017) but also very useful for timely misinformation management and countering stigmatizing narratives (Schwartz & Grimm, 2017). In addition, social media and online discussion platforms have been reported to be efficient tools for promoting HIV/AIDS prevention and intervention campaigns (Garret et al., 2017; Hall et al., 2017; Huang et al., 2016; Iribarren et al., 2018), evidence-based continuing education (Garret et al., 2017; Huang et al., 2016; Schwartz & Grimm, 2017), clinical and study recruitment (Huang et al., 2016; Jones et al., 2017), stakeholder behavior change (Huang et al., 2016; Krueger et al., 2016; Nielsen et al., 2017; Noble et al., 2017), and specialized information (Huang et al., 2016; Nielsen et al., 2017). This makes social media and online discussion platforms potentially ideal tools to be utilized for scaling up HAND information sharing in addition to traditional Knowledge Mobilization tools that have been conventionally used to provide unidirectional communication of specific messages from scholars and experts to knowledge users (Iribarren et al., 2018; Noble et al., 2017). Case in point, in our own research study, none of the 33 community-based health care and service providers we interviewed who were aware of and had some knowledge about HAND obtained their information from social media and online discussion platforms; their awareness and knowledge on HAND were exclusively gained from more traditional sources such as conference and community presentations, fact sheets and information brochures, and AIDS service organization websites (Liboro et al., 2017, 2018, 2019).

Some studies have proposed that social media and online discussion platforms could be utilized as viable alternatives to traditional Knowledge Mobilization tools because unlike social media and online discussion platforms, traditional Knowledge Mobilization tools may not comprehensively cover current influential factors and trends present in the community by the time they disseminate information (Hannaford et al., 2018; Noble et al., 2017). Social media and online discussion platforms could not only deliver messages with similar credibility (Hall et al., 2017; Jones et al., 2017) but also offer greater convenience, speed, discretion, and confidentiality for stakeholders who transmit and receive information (Iribarren et al., 2018; Jones et al., 2017).

However, it seems that the greatest advantages that social media and online discussion platforms could have over traditional Knowledge Mobilization tools for scaling up information sharing and raising awareness and knowledge about HAND involve their ability to tailor messages for different audiences in a rapid or timely fashion (Garret et al., 2017; Huang et al., 2016; Iribarren et al., 2018) and their unlimited capacity to actively engage stakeholders from relevant communities in interactive and multidirectional communication and dialogue (Huang et al., 2016; Krueger et al., 2016; Martens, 2010; Newman et al., 2006). Social media and online discussion platforms have the ability to expeditiously promote PHI principles (e.g., multiple stakeholder involvement, intersectoral collaboration, multidirectional communication) and implement empirically recognized IDS communication techniques (i.e., tailor the message, target the message to audience segments) and strategies for raising awareness and knowledge (e.g., improve reach of evidence, motivate recipients to use evidence) on HAND and services dedicated to PLWH experiencing neurocognitive challenges. For example, social media and online discussion platforms could be used to provide customized messages to health care and service providers about the availability of much needed housing services specifically created for PLWH simultaneously experiencing both neurocognitive challenges and homelessness or insecure housing. Once providers receive these customized messages, they would have opportunities to ask more about the requirements for utilizing these services, inquire about the strengths and limitations of the services, and relay pertinent information about the housing services to appropriate clients who may not have access to social media, online discussion platforms, and the messages they receive.

The auspicious capacity to actively engage relevant stakeholders in interactive, multidirectional communication and dialogue in real time (Martens, 2010; Newman et al., 2006) is perhaps the most critical advantage social media and online discussion platforms have over traditional Knowledge Mobilization tools. Unlike peer-reviewed journal publications, community reports, brochures, pamphlets, TV/radio/billboard ads, and websites, which have been conventionally used by HIV/AIDS nonprofit agencies to



deliver messages as one-way communication with audiences instead of dialogic interactions (Huang et al., 2016), Facebook, Twitter, Instagram, webinars, messaging apps, and other online discussion platforms could be used not only to generate interest on information about HAND among key stakeholders, they could also be used to raise and answer questions, parse and explain details, increase relevant knowledge, separate fact from fiction, and accomplish many goals that only real-time (or at least much more timely) active engagement could.

Research has documented that the production and sharing of knowledge about medicine and HIV/AIDS in media is likely best served by valuing engagement between clinicians, researchers, and communities (Newman et al., 2006). Studies have shown that when stakeholders are actively engaged online, they are more likely to take on pertinent information and adhere to practice guidelines and recommendations dedicated to promote the health of PLWH (Iribarren et al., 2018; Jones et al., 2017; Krueger et al., 2016; Nielsen et al., 2017; Noble et al., 2017; Schwartz & Grimm, 2017). These studies have also contended that social media-based tools should be able to encourage ongoing discussions and dialogue, particularly around HIV testing and HIV stigma (Huang et al., 2016; Krueger et al., 2016; Newman et al., 2006). It would be reasonable to presume that such online discussions and dialogue could also prove just as beneficial to efforts to scale up information sharing for raising levels of awareness and knowledge on HAND among HIV/AIDS specialists, scholars, health care and service providers, and PLWH experiencing neurocognitive challenges.

Public health agencies and community-based organizations can use social media and online discussion platforms to further disseminate time-sensitive health information, promote information sharing to encourage behavioral changes, allow the public to provide useful feedback, provide venues for important conversations between agencies and clients, and manage misinformation around emerging public health issues or during health crises (Huang et al., 2016; Krueger et al., 2016; Nielsen et al., 2017; Noble et al., 2017; Schwartz & Grimm, 2017). Social media and online discussion platforms are already currently being used by some scholars to facilitate information sharing, particularly for sharing HIV-related information (Krueger et al., 2016; Nielsen et al., 2017). Because social media and online discussion platforms could deliver information with equal credibility, and more convenience, speed, discretion, and confidentiality (Hall et al., 2017; Iribarren et al., 2018; Jones et al., 2017), it is highly possible that they could play a vital role in scaling up information sharing in efforts to raise levels of awareness and knowledge on HAND in relevant communities. Although there has been no research studies to date that would empirically support the notion that social media and online discussion platforms would actually be superior alternatives to use over traditional Knowledge Mobilization tools for this task,

it could be justifiably argued that there is enough scholarly evidence available to assert that social media and online discussion platforms should be used in addition to traditional Knowledge Mobilization tools to scale up information sharing in efforts to raise levels of awareness and knowledge on HAND among all relevant stakeholders; actively engage and encourage stakeholders to share their own information, perspectives, challenges, and experiences; and promote collaborations among them.

## Conclusion

This article extends the current academic literature on HAND by examining and discussing the levels of awareness and knowledge on HAND of community-based health care and service providers who deliver care and services to PLWH experiencing neurocognitive challenges. Based on the main findings of the study discussed in this article, the need to scale up information sharing for the purpose of raising the levels of awareness and knowledge on HAND among community-based health care and service providers in HIV/AIDS services has become of critical concern. Utilizing the WHO (2017) Strategic Communications Framework, a proposal to promote communications that are actionable, accessible, relevant, timely, understandable, and credible for this specific purpose was described in this article. The proposal involves the use of fundamental PHI principles; established IDS communication techniques, propagation strategies, and recognized approaches; and social media and online discussion platforms as additional tools to complement traditional Knowledge Mobilization strategies for scaling up information sharing on HAND (Table 4).

For researchers, policymakers, key opinion leaders, advocates, PLWH, and other relevant stakeholders in the HIV/AIDS sector who are ardent to draw attention to the importance of raising the levels of awareness and knowledge of community-based health care and service providers on HAND, the proposal presented in this article is worth giving due consideration. By adhering to PHI principles and IDS techniques, strategies, and approaches, which have been empirically documented in extant academic literature as elements that successfully support information dissemination and uptake, these relevant stakeholders in the HIV/AIDS sector could potentially utilize social media and online discussion platforms to help effectively raise levels of awareness and knowledge on HAND among community-based health care and service providers in the future. In addition, they could also prospectively design new empirical research studies, prevention services, intervention programs, advocacy documents, and organizational policies focused on information sharing on HAND based on the principles, techniques, strategies, approaches, and tools described in the proposal.

**Table 4.** Proposal for Scaling up Information Sharing on HAND.

Elements	Types	Examples
Public Health Informatics principles	Earlier principles	Capture, manage, analyze, and share information to emphasize disease prevention and health promotion Deliver targeted information to clinicians, monitor public health, and evaluate and improve delivery of public health practices
	Later principles	Share practice-specific and specialized health information to service providers and users Build capacity for public health information technology to translate and transfer information on effective prevention programs Pay more attention to public sentiment and activity regarding health issues, and the communication needs of providers and patients Promote intersectoral collaboration and multidirectional communication
Implementation and Dissemination Science	Communication techniques	Tailor the message Target the message to audience segments Use narratives that resonate with the audience Frame the messages in different ways
	Dissemination strategies	Improve the reach of the evidence Motivating recipients to use the evidence Enhance the abilities of the audience to use the evidence Utilize two or more of the above strategies
	Recognized approaches	Use traditional tools (e.g., academic journals; community reports; mass media; conference presentations; town halls; lunch and learns) Ensure the involvement of key opinion leaders, champions, and other people who have a visible stake in the issues related to HAND
Social media	Social networking	Facebook, LinkedIn, ResearchGate, Academia.edu
	Microblogging	Twitter, Tumblr
	Photo sharing	Instagram, Pinterest, Snapchat
	Video sharing	YouTube, Vimeo, Periscope
Online discussion boards	Email listservs	Human Resources and Services Administration HIV/AIDS Bureau
	webinars	AIDS Education and Training Center Program, CATIE, OHTN
	Messaging apps	WhatsApp, Facebook Messenger, Viber
	mHealth	HIVSmart!

Note. HAND = HIV-associated neurocognitive disorder; CATIE = Canadian AIDS Treatment Information Exchange; OHTN = Ontario HIV Treatment Network.

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