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A Role for Health Communication in the Continuum of HIV Care, Treatment, and Prevention

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Abstract

Health communication has played a pivotal role in HIV prevention efforts since the beginning of the epidemic. The recent paradigm of combination prevention, which integrates behavioral, biomedical, and structural interventions, offers new opportunities for employing health communication approaches across the entire continuum of care. We describe key areas where health communication can significantly enhance HIV treatment, care, and prevention, presenting evidence from interventions that include health communication components. These interventions rely primarily on interpersonal communication, especially individual and group counseling, both within and beyond clinical settings to enhance the uptake of and continued engagement in care. Many successful interventions mobilize a network of trained community supporters or *accompagnateurs*, who provide education, counseling, psychosocial support, treatment supervision and other pragmatic assistance across the care continuum. Community treatment supporters reduce the burden on overworked medical providers, engage a wider segment of the community, and offer a more sustainable model for supporting people living with HIV. Additionally, mobile technologies are increasingly seen as promising avenues for ongoing cost-effective communication throughout the treatment cascade. A broader range of communication approaches, traditionally employed in HIV prevention efforts, that address community and sociopolitical levels through mass media, school- or workplace-based education, and entertainment modalities may be useful to interventions seeking to address the full care continuum. Future interventions would benefit from development of a framework that maps appropriate communication theories and approaches onto each step of the care continuum in order to evaluate the efficacy of communication components on treatment outcomes.

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INTRODUCTION

Public health efforts to reduce the spread of HIV have undergone a major shift from separate models for prevention and treatment to the current focus on combination prevention strategies, which simultaneously address biomedical, behavioral, and social/structural levels.¹⁻⁴ Particularly with the recent finding that antiretroviral therapy (ART) significantly reduces the rate of HIV transmission among HIV discordant couples,⁵ expanding treatment access and improving adherence have become essential components of any HIV prevention strategy. High-quality evidence has been rapidly accumulating for effective implementation strategies that could be incorporated into the combination prevention paradigm,⁴ including evidence from large trials that take such interventions to the population level.⁶ Three randomized controlled trials (RCTs) are underway to test the efficacy of combination prevention packages.⁷⁻¹⁰

Numerous investigators have argued for better integration, within combination prevention, of the contributions of the social and behavioral sciences to improve access to HIV-related services and the delivery of services to people living with HIV across the entire continuum of care^{2,3,11-13} from voluntary counseling and testing (VCT), through linkage to care, retention in care, adherence to antiretroviral therapy (ART), and, ultimately, viral suppression.^{14,15} The aim of this paper is to explore the role of health communication, an approach within the social and behavioral sciences, across the treatment continuum. The integration of health communication and other social behavioral interventions as part of combination prevention is particularly important given the growing emphasis on the early provision of ART to reduce HIV transmission and the consequent push to enroll and maintain an increasing number of people living with HIV on treatment. These social and behavioral interventions can play a crucial role in addressing the significant losses at each stage of the continuum of care, which constitute a key barrier to achieving these goals.¹⁶⁻²⁰

Health communication, broadly defined as “the study and use of communication strategies to inform and influence [...] decisions that enhance health,”²¹ has played an important role in the prevention response since the onset of the epidemic.²² Some of the key functions of health communication include the provision of relevant health information, persuasion to help motivate behaviors that improve health outcomes, and the facilitation and maintenance of social connections and a supportive social environment for these desired health behaviors.²³ Historically, communication methods can be divided into one of five categories: intrapersonal, interpersonal, organizational, community and public/mass communication.²⁴ While earlier models viewed health communication as a “one-time one-way communication ‘act’”²⁵ primarily comprised of messages targeting individual behavior change, recent theoretical models consider health communication as a social process that operates on multiple social ecological levels.²³ Since communication is an integral part of

interventions that seek to address individual, community, and social and political factors,²⁶ it can have a significant impact at multiple levels of implementation in each step of the continuum of care.^{23,27} Communication can be used to create health-seeking behavior, on the demand side, and as a means to increase quality and support, on the supply side, at the clinic and community levels. In the context of HIV, communication can motivate people to get tested and obtain their results, promote access to treatment, link people living with HIV to medical and psychosocial care, support continued retention in care, and help reduce stigma that may prevent individuals from taking these actions.²⁸

Although health communication has played an important role in HIV prevention efforts, its potential to improve outcomes across the continuum of care has not been fully realized, in part due to the lack of a framework that translates health communication theories and practices into specific interventions to address each step in the treatment cascade. In this paper we provide illustrative examples of the specific roles that health communication can play in bolstering the continuum of care in low and middle income countries, where limited resources present considerable barriers to accessing HIV care and treatment. In this process we draw on recent reviews of the HIV treatment literature and highlight studies that provide high quality evidence for interventions that incorporate health communication components. The selected examples focus primarily on interpersonal communication, in individual and group settings, and mobile communication technologies, reflecting the bulk of the interventions discussed in the literature. Many of the high quality studies cited in the literature originate from Sub-Saharan Africa, reflecting researchers' attention to the acute HIV epidemic in this region, but we also include examples from other regions of the world in an effort to broaden the scope of discussion and to highlight the versatility of specific intervention strategies. While we follow the World Health Organization's approach in highlighting the similarities in the challenges across the treatment continuum that result from resource limitations,¹⁵ successful interventions clearly tailor these programs to the specific needs of local populations. Finally, we make recommendations for future research on health communication in support of the full continuum of HIV, including treatment, care, and prevention.

From Positive Test Results to Treatment Initiation

A considerable challenge in improving outcomes of HIV treatment is to ensure that those who have tested positive can be, and are, linked to HIV care and treatment. While the number of people over the age of 15 who received an HIV test in low- and middle-income country settings had risen to over 118 million in 2012, many do not receive their results, undergo CD4 testing and clinical staging, enroll in pre-ART care, or initiate ART.¹⁵ According to recent estimates, in some settings only one-fifth of those with a positive diagnosis undergo CD4 count testing, and nearly one-quarter of those eligible for ART may die before initiating it.²⁹ This loss is more pronounced among men than women.^{15,30}

Key barriers to linkage to care in low- and middle-income countries include lack of integration in health care systems of the various service from testing to treatment, coupled with significant limitations in equipment, personnel, and training, stock-outs of essential drugs, high transportation and out-of-pocket costs for patients, as well as social barriers,

including stigma and lack of social support.¹⁵ People living with HIV who are asymptomatic may not perceive a need for care or maintain the motivation to continue clinical monitoring in the face of these constraints.³¹

A number of promising interventions have been employed to address these structural, social, and personal barriers, some of which have significant health communication components. Current research underlines the importance of interpersonal communication in linkage to care through counseling, both in clinical settings and at patients' homes. For instance, a randomized controlled trial in Uganda found that enhanced post-test counseling coupled with home visits and continued counseling support from trained volunteers significantly improves the uptake of pre-ART care.³² Counselors in the intervention arm received additional training emphasizing disclosure of HIV status and the importance of pre-ART care leading to enrollment in ART. Subsequently, a community support worker reinforced these messages during monthly home visits. Those who received the enhanced counseling and home visits were almost twice as likely as those in the standard counseling group to return for pre-ART care within 5 months. Wanyenze et al.³³ tested a similar intervention in Uganda, in which participants who tested HIV-positive in a hospital-based setting were randomized to receive standard post-test counseling on linkage to care or to receive enhanced counseling that included facilitated disclosure, introduction to HIV clinic staff, appointment reminder phone calls, and home visits for appointment reminders if needed. Over follow-up of more than 1 year, they found that the intervention improved HIV clinic attendance by women, but not by men, and reduced the time to initiation of ART for those eligible for men, but not for women.

Improving ART Adherence

After an individual has initiated therapy, other formidable barriers arise, as many struggle with taking prescribed medications and must overcome the challenges of taking medications with potentially serious side-effects each day for the rest of their lives, in the face of substantial barriers of supply disruptions, out of pocket expenses related to visits for medication refills, social stigma, and declining motivation over time.^{34,35} Suboptimal adherence to ART compromises optimal treatment outcomes.³⁵ Recent estimates suggest that there are wide variations in adherence, ranging from very poor adherence to nearly optimal.³⁶ Specifically, clinics with educational materials and food rations available were significantly associated with lower attrition compared with clinics without these services, while clinics with available peer educators, support groups, and adherence reminder tools were associated with lower rates of measured death compared to clinics without these services.³⁶

As in interventions focusing on linkage to care, health communication has played an important and positive role in adherence outcomes through interpersonal communication and counseling. For example, Chung and colleagues³⁷ compared adherence counseling provided by trained counselors to counseling with the added use of an alarm, an alarm on its own, and the absence of counseling or an alarm in Kenya. Those assigned to the counseling interventions had significantly higher levels of adherence and lower rates of virologic failure, while the use of an alarm had no effect on these outcomes. In a meta-analytic review

of RCTs examining the relationship between behavioral interventions and adherence, Simoni and colleagues concluded that behavioral interventions such as counseling can improve adherence in diverse settings.³⁸ For example, a 4-session comprehensive intervention for couples, delivered by a nurse practitioner, demonstrated some success in increasing adherence.³⁹ Group counseling and education has also been demonstrated to improve adherence in a variety of settings, including Brazil and India.^{40–42} An important factor affecting the impact of counseling on adherence is its quality. Three cohort studies in sub-Saharan Africa that trained counselors to improve their skills found higher levels of adherence at the study's end than at baseline.^{43–45}

The caseload of many health care workers in low- and middle-income countries is overwhelming; this significantly constrains the quality of counseling. Task shifting, decentralization, and employment of lay health care workers have emerged as promising interventions to address this problem in low- and middle-income settings around the world, including India, Malawi, South Africa and Uganda.^{15,41,46–48}

Mobile communication technologies offer a promising new approach to enhancing ART adherence. For instance, a recent systematic review by Horvath and colleagues⁴⁹ found that two randomized trials in Kenya^{50,51} provided high-quality evidence that mobile telephone short message service (SMS) consisting of medication reminders, motivational messages or questions that required a response could improve adherence. Lester and colleagues'⁵⁰ trial, in which nurses or clinical officers sent SMS messages to inquire about participants' well-being and called unwell patients and non-responders for additional support, found that SMS support also improved rates of viral suppression. At the same time, in the Cameroon mobile phone SMS study, standardized motivational text messages did not improve adherence outcomes compared with usual care without text messages,⁵² suggesting that additional research and the tailoring of messaging to specific populations are necessary to achieve consistently improved outcomes.

Enhancing Retention in ART Care

Retaining patients in care once they have started ART presents another significant problem in the treatment cascade. The World Health Organization (WHO) reported that cohorts from 28 low- and middle-income countries retained on average 86%, 82%, and 72% of individuals in HIV care at 12, 24, and 60 months after treatment initiation.¹⁵ Factors associated with attrition from care have included transport costs, distance to clinic, shortage of health care workers, and patients' low levels of education.²⁹ The "test and treat" paradigm poses new challenges to retention in ongoing HIV care, as patients initiate treatment at higher CD4 cell counts and therefore may feel healthier and less motivated to continue care.

Health communication may play several roles in enhancing retention in care, ranging from improved overall provider-patient communication in the context of patient-centered case management to enhanced interpersonal communication, psychosocial and organizational support from a community member ("patient navigators" or guides) accompanying the patient to health care visits and through counseling by community health-care workers.^{53,54} Communication interventions to help people living with HIV stay in care synergize with

efforts to improve adherence, as both emphasize the importance of ART for long-term survival and prevention of secondary transmission.

Successful retention in care has been demonstrated in observational cohort studies of comprehensive community-based programs that include interpersonal communication components. For example, a community-based ART program in Rwanda achieved 92.3% retention in care after 24 months from 2005 to 2008.⁵⁵ This multi-faceted combination community-based program enrolled patients in education and support groups that met the same day as clinic appointments and included daily visits by trained community health workers who directly observed therapy and offered psychosocial support. In an additional analysis of the same program, Franke et al. found a higher retention rate with suppressed viral load (85% versus 79%) in one of the community-based accompaniment programs than in an ongoing clinic-based ART program, as well as greatly reduced hazard of loss-to-follow-up (0.17) among those with community-based accompaniment.⁵⁶ Munoz et al. found a greatly increased proportion retained in treatment (90% versus 65% at 1 year following treatment initiation) when comparing a pilot intervention of community-based accompaniment with supervised antiretrovirals (CASA) with a matched control group in Lima, Peru, and also observed improved psychosocial outcomes in the intervention group.⁵⁷ In the CASA program volunteers and field supervisors observed medication ingestion, provided social and emotional support to patients and family members during home visits, accompanied patients to health-care visits, and reported patient issues to health care providers. An ongoing trial that will contribute evidence regarding the role of communication to improve retention in care is WelTel Retain, a randomized clinical trial that will assess the impact of weekly SMS messages on retention at 1 year in Nairobi, Kenya.⁵⁸

DISCUSSION

In today's era of HIV prevention, there is a growing need and demand to deliver effective behavioral interventions that work to achieve results in concert with biomedical and structural interventions. As more people living with HIV become eligible to receive ART due to new WHO recommendations to initiate therapy earlier, these efforts will have a significant impact on how many patients will link to care, initiate treatment, adhere to their treatment regimen, and remain in treatment in order to achieve and sustain viral suppression. Within this continuum of care, interventions rely heavily on increasing the frequency and quality of interpersonal communication in clinical settings as well as in homes and communities. Individual and group counseling has played a particularly important role in these efforts throughout the continuum of care, from post-test counseling in HIV testing and counseling services to adherence counseling provided by lay health workers in the community. Interpersonal communication also plays an important role in integrated models of treatment provision that rely on decentralization of care, patient navigators or *accompagnateurs*, and community health workers who offer support, education, and treatment supervision to patients at all stages from testing through sustained treatment. The employment of lay health workers and volunteers offers a model for reducing the otherwise prohibitive personnel costs of these interventions and engaging community members in providing cost-effective and sustainable support for people living with HIV. Mobile

technologies present another cost-effective means to enhance treatment outcomes at various points of the continuum of care, and may be used as a bridge to activate additional support for struggling patients that offer other kinds of interpersonal communication modalities, such as telephone- or clinic-based support.^{59–61}

This paper considered studies that offered high quality evidence for interventions that included substantial health communication components within the context of the treatment cascade, which limited our discussion of the communication modalities to those represented within the pool of available studies. Other health communication modalities that address community and societal levels, including mass media, school- or workplace-based education, or entertainment modalities (e.g. street theater) in addressing specific steps in the treatment cascade, have been traditionally used in HIV prevention efforts^{62–64} and may not yet be fully integrated into interventions that link these communication strategies to treatment outcomes. These modalities may provide additional possibilities for the incorporation of health communication into interventions. For instance, there is preliminary evidence from Malawi that provision of a workplace-based clinic and support group can increase the uptake of HIV testing and care, and provide good ART outcomes,⁶⁵ but the communication aspects of this intervention were not clearly developed.

Although many behavioral intervention efforts clearly incorporate health communication components, a framework that explicitly draws on health communication theories and practices is rarely identified as part of an intervention to improve ART. Such a framework would need to map specific communication theories, proximate determinants, and interventions to specific purposes at each step along the continuum of care in both clinical and non-clinical settings, resulting in a hands-on toolkit for program design. The development of this framework would also facilitate clearer assessment of the health communication components that might be applied within comprehensive models of care.

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