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# Role of Community-Level Factors Across the Treatment Cascade: A Critical Review

Carol Underwood, PhD,\* Zoé Hendrickson, BA,\* Lynn M. Van Lith, MPA,†  
John Eudes Lengwe Kunda, PhD,‡ and Elizabeth C. Mallalieu, MPH‡

**Abstract:** Addressing community-level factors (CLFs) is integral to the ongoing effort to design multilevel, effective, and sustainable interventions to address each element of the HIV/AIDS treatment cascade. This review, the first critical review of this topic, identified 100 articles that (1) assessed CLFs in relation to the HIV/AIDS treatment cascade, (2) had been peer-reviewed, and (3) were based on studies conducted in low- or middle-income countries. Social support and social networks, cultural norms, gender norms, and stigma were the key CLFs associated with treatment and care. This extensive review found only 5 evaluations of interventions designed to affect CLFs, reflecting a major gap in the literature. All were communication interventions designed to create a more positive environment for HIV testing and access to treatment and care, thus pointing to some of the potential extraindividual effects of communication interventions. The qualitative data are rich and vital for understanding the context; yet, more quantitative analysis to provide evidence regarding the distribution of these factors is essential, as only 19 of the studies were quantitative. There is a pressing need to (1) collect community-level data, (2) validate social and gender norm scales, and (3) better use available data regarding social norms, gender norms, and other CLFs. These data could be aggregated at the cluster, neighborhood, or community levels and incorporated into multilevel analysis to help clarify the pathways to enhanced outcomes across the treatment cascade and thereby mitigate HIV sequelae.

**Key Words:** community-level factors, HIV/AIDS, treatment cascade

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From the \*Department of Health, Behavior & Society, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD; †Center for Communication Programs, Department of Health, Behavior & Society, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD; and ‡Department of Public Health & Policy, London School of Hygiene and Tropical Medicine, Lusaka, Zambia.

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Correspondence to: Carol Underwood, PhD, Department of Health, Behavior & Society, Bloomberg School of Public Health, Johns Hopkins University, 111 Market Place, Suite 310, Baltimore, MD 21202 (e-mail: [carol.underwood@jhu.edu](mailto:carol.underwood@jhu.edu)).

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## INTRODUCTION

Studies regarding factors associated with the HIV treatment cascade, including access to testing and loss to follow-up during adherence to pre-antiretroviral therapy (pre-ART), ART initiation, and ART treatment, often focus at the individual or clinic levels.<sup>1–4</sup> Importantly, the role of structural determinants has been acknowledged increasingly over the past decade.<sup>5–8</sup> Yet, the arena where social relations are constructed and reconstructed and where social change occurs—namely, the community—is still relatively ignored.<sup>9</sup> Recent highlighting by the Joint United Nations Program on HIV/AIDS<sup>10,11</sup> of the importance of community across the treatment cascade underscores how essential community-wide systems are for motivating use of HIV diagnosis and treatment services and argues for expanded research in this direction.<sup>12</sup> Coates<sup>12</sup> points to the potential role of community-level interventions in creating an enabling environment for prevention as well as for testing, treatment, and care.

To date, no review of the literature on community-level factors (CLFs) and the treatment cascade has been published. A better understanding of CLFs in HIV treatment and care would contribute to the larger effort to design multilevel, effective, and sustainable programs and interventions. This review, which seeks to address that gap, was guided by the understanding that CLFs could be assessed from both a contextual and a compositional perspective.<sup>13</sup> Contextual factors, such as the number of community groups providing care and support, are integral to the community and measurable only at that level. Compositional factors, such as the proportion of the population that has been tested, are aggregated from individual-level variables and consequently are much more readily available. This review covers articles addressing both compositional and contextual CLFs. The articles included in this review use the term “community” to refer to people living in the same geographic area.

This critical review of the literature sought to answer the following research questions:

- What CLFs promote/inhibit HIV testing, encourage/discourage uptake of appropriate treatment, or support/undermine adherence and care in low- and middle-income countries?
- What CLFs have HIV-related interventions addressed? How and with what effect?

## METHODOLOGY

### Overview

Informed by the literature, the research team developed complex search strings to search for CLFs “AND” for

each phase of the HIV/AIDS treatment cascade. The detailed search protocol is available as Supplemental Digital Content (see **Appendix A**, <http://links.lww.com/QAI/A539>). A search hedge developed by research librarians at the Johns Hopkins Welch Medical Library limited the search to low- and middle-income countries. This search strategy was adapted for and executed in PubMed, Embase, Scopus, CINAHL, and Global Health. The only citations included were those regarding low- and middle-income countries, published before January 8, 2014 in English, Spanish, or French, and with abstracts available.

These search terms located a total of 5279 articles. After the removal of duplicates, conference papers, and dissertations, 2809 articles remained for initial review. Two reviewers independently reviewed all titles and abstracts and chose 324 articles that explicitly or implicitly referred to CLFs. A third reviewer reread the 324 abstracts and, if needed, the relevant article, to determine whether CLFs were actually addressed; 197 articles were deemed relevant. An additional 11 articles were added from a previous literature review because of their relevance. Overall, 208 articles were assessed for inclusion in this document (Fig. 1).

A team of 5 reviewers read the articles. Each article was read by 2 randomly selected reviewers who independently made a further selection based on the following inclusion criteria: (1) CLFs had been assessed in relation to the HIV/AIDS treatment cascade, (2) the articles had been peer-reviewed, and (3) the study was conducted in a low- or middle-income countries. On completion of that step, all readers discussed articles with discordant assessments. These discussions led to consensus on 100 articles that would be included in this literature review.

## RESULTS

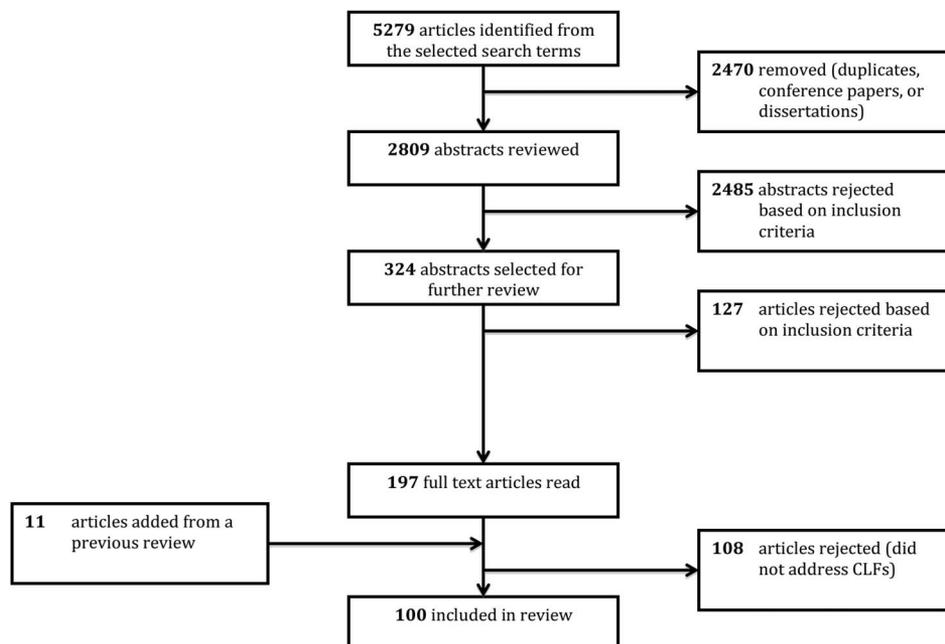
### Overview

Following a brief discussion of health system factors, findings are presented according to the individual elements of the treatment cascade: testing, pre-ART, ART adherence, and care.<sup>3</sup> Within each element, the associated CLFs and whether their effects are negative or positive effects are discussed (Fig. 2).<sup>3</sup>

Health care system factors that aid or impede access throughout the treatment cascade are typically structural in that decisions are generally made at the national or provincial level rather than in communities. Nonetheless, both human and material resource allocation can manifest differently in different communities. Health care systems factors that were identified in this review as potentially subject to community-level intervention included distance, cost, lack of confidentiality, and inconvenient hours associated with testing,<sup>14–17</sup> pre-ART<sup>18,19</sup> timely initiation of ART,<sup>20</sup> adherence,<sup>21–24</sup> and care.<sup>15</sup> This search, however, found no articles that explored community-specific aspects of health systems on treatment or care.

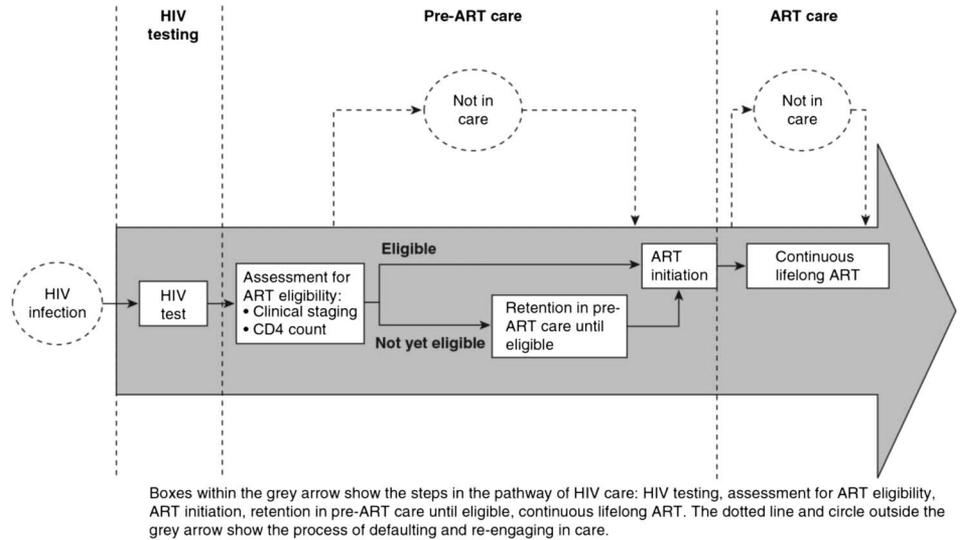
### HIV Counseling and Testing

An analysis of community factors in 8 African countries found that living in communities with relatively high community levels of HIV knowledge, male employment, and primary school completion by both men and women were all positively associated with men's uptake of HIV counseling and testing (HCT). In communities where more women were employed, and there were a higher number of sexual partners in the community, men were less likely to be tested for HIV.<sup>25</sup>



**FIGURE 1.** Flow chart of literature search on CLFs and the HIV treatment cascade.

**FIGURE 2.** The care pathway for HIV-positive individuals. Adapted from Kranzer et al.<sup>3</sup> Adaptations are themselves works protected by copyright. So in order to publish this adaptation, authorization must be obtained both from the owner of the copyright in the original work and from the owner of copyright in the translation or adaptation.



### Social Support and Social Networks

Social influence and support are important to people’s health decisions, including whether one should test for HIV. Living in communities that have low testing rates are un-supportive, place blame, or associate HCT with immorality is associated with low HCT uptake.<sup>26,27</sup> The fear of social exclusion, stigma, and loss of social support caused many to avoid HCT.<sup>16,27–30</sup>

In many countries, membership in community organizations (eg, women’s groups, people living with HIV [PLHIV] groups, burial societies, sports clubs, political groups) is positively associated with uptake of HCT.<sup>28,31,32</sup> Organizational membership increases social capital and support and can give members a feeling of belonging. In Malawi, male and female members of community groups (16.2% and 10.5%, respectively) were twice ( $P < 0.05$ ) as likely as non-members (8.5% and 4.6%, respectively) to have had an HIV test.<sup>32</sup> In Zimbabwe, rates of uptake by both men and women were higher among community organization members (15% and 35.6%, respectively) than among nonmembers (9.2% and 29.6%, respectively).<sup>31</sup> Group membership aggregated at the village level was also positively associated with higher HCT rates over 3 years.<sup>31</sup>

The Health Communication Partnership Zambia sought to strengthen community-based systems as part of a larger effort to encourage positive health behaviors. The project evaluation found that the intervention was able to build community capacity, which was associated with community action to improve health behaviors. Respondents from communities with high levels, rather than low levels, of community action were twice as likely to have undergone HCT and know the results (odds ratio = 2.00,  $P < 0.001$ ).<sup>33</sup>

### Cultural and Gender Norms

Gender, social, and cultural norms in a community can influence HCT uptake. Multiple studies have found that men associate HCT with diminished masculinity.<sup>16,25,34</sup> South African men reported fear of becoming a burden and no longer being

able to fulfill their provider role as reasons for not seek testing.<sup>34</sup> A study in Zambia found that men felt their position in intimate relationships would be undermined if they agreed to HCT at the urging of a wife or other partner.<sup>27</sup>

Some communities and cultures require the wife to obtain her husband’s permission to be tested, possibly placing the woman in a dangerous situation if her partner suspects her request for testing arises from either her infidelity or suspicion of his.<sup>16,26</sup> Gender norms that restrict women’s access to financial resources also make it difficult for them to receive HCT.<sup>16</sup>

### Stigma

Although often measured at the individual level, stigma is a social construct that frequently manifests itself at the community level.<sup>35</sup> Therefore, accounts of stigma are intrinsically linked to CLFs across the treatment cascade. Both perceived and actual stigma in communities leads to lower levels of HIV testing.<sup>15,16,26,29,30,36–54</sup> A study in Nigeria found that men from communities that reported a medium level of stigma (on a tripartite scale of low, medium, and high stigma) were 43% less likely to report readiness for HCT than men living in communities with low levels of stigma (odds ratio = 0.57,  $P < 0.001$ ).<sup>36</sup>

### Pre-ART

The period between testing and treatment is often perilous, with loss of patients at each step of the cascade, beginning with patients who never collect their CD4 count results and ending with those who, although eligible, do not initiate ART.<sup>2</sup> A systematic review and meta-analysis of 12 countries in sub-Saharan Africa demonstrated high pre-ART attrition and losses twice as high among those not yet eligible for ART.<sup>1</sup> According to another systematic review, among clients testing positive for HIV who are not ART-eligible at diagnosis, less than one-third are retained continuously in care.<sup>2</sup> Poor rates of referrals following diagnosis are reported in Ethiopia, indicating a need to strengthen linkages and

retention in care and address patient-identified barriers, including fear of stigma and lack of community support.<sup>55</sup>

The care pathway is not a simple linear process, as clients enter and leave, and losses occurring throughout, particularly before ART initiation.<sup>3</sup> Although much of the literature focuses on addressing these losses through clinical improvements, such as point-of-care CD4 count testing or improved referral systems, far less attention has focused on CLFs that may also influence the pre-ART period.

### Social Support and Social Networks

Following HCT, a largely private and individual decision, many PLHIV depend on social support networks to help them navigate the pre-ART period.<sup>56</sup> Those without reliable or trusted networks are at high risk of dropping out. Social support, including physical, spiritual, or financial support, is vital for promoting pre-ART care and timely ART initiation.<sup>18,57</sup> Support from community-based organizations and networks of PLHIV also has the potential to increase utilization of HIV-related services.<sup>17,58,59</sup> Likewise, a review of community-based support services points to a positive association between the availability of such services and expanded access to, and increased coverage of, ART programs in resource-limited settings, whereas acknowledging that most studies included in the review did not quantify the mean effect of community-support initiatives.<sup>60</sup>

Social support may hinder or reinforce care-seeking behavior and ART uptake among sex workers and men who have sex with men (MSM). Fear of losing fellow sex workers' social support and client referrals hindered care-seeking behavior in India; the feared repercussions of rejection and social isolation led women to postpone ART initiation until they were symptomatic.<sup>61</sup> This has been found true also for MSM and transgender women, who feared social rejection if seen taking ART.<sup>62</sup> However, when collective efficacy, agency, and social support are high, both service utilization and consistent condom use improve among both sex workers and MSM.<sup>63</sup>

### Cultural and Gender Norms

Prevalent gendered attitudes and norms can lead to delay in seeking pre-ART care and in loss to care. A study in Malawi found that widely held concepts of masculinity and femininity strongly inhibit willingness to seek care.<sup>56</sup> In Burkina Faso, gendered values attached to femininity motivate women to seek care, whereas gender norms inhibit men from seeking care early,<sup>64</sup> which also places their partners at risk of HIV infection. Likewise, in Thailand, more women initiate treatment than men, although men are more likely to be infected with HIV.<sup>65</sup>

### Stigma

Stigma remains a formidable challenge throughout the pre-ART period. Fear of the stigma attached to being seen at an ART facility is prominent in several countries including Uganda, South Africa, Ghana, and Swaziland.<sup>66-69</sup> Key populations, including sex workers, MSM, and people who inject drugs, often face formidable barriers when entering treatment. Stigmatizing attitudes and behaviors of health workers remain

pervasive, discouraging linkage and retention in HIV care.<sup>15,70,71</sup> These negative provider attitudes could be addressed through training programs that address stigma-related barriers.<sup>72</sup>

Stigma can vary between urban and rural setting. As the effect of antiretrovirals became visible and the health status of PLHIV began to improve in Zimbabwe, broader acceptance and greater social cohesion were evident in rural areas, whereas in urban areas, less cohesion and delayed care seeking emerged.<sup>73</sup> In South Africa, a higher proportion of PLHIV from rural than from urban communities sought services, with the largest percentages seen in rural communities with active HIV support groups.<sup>74</sup>

### Adherence

Adherence to ART is essential for viral load suppression, which is correlated with a steep reduction in HIV transmission at the population level.<sup>75</sup> Several studies have found that community-level HIV/AIDS knowledge, which can decrease misconceptions and enhance support for PLHIV, is positively associated with adherence.<sup>76,77</sup>

### Social Support and Social Networks

Social support is critical in encouraging PLHIV to normalize their lives and adhere to treatment.<sup>27,76-80</sup> A study in Zimbabwe found that social networks can enhance adherence among children through increased support for PLHIV, mitigation of stigma, improved access to health services, and disclosure.<sup>76</sup> Networks of family members, friends, teachers, community-based organizations, and employers are important in supporting adherence and retention in care.<sup>17,56,59,76,77,79,81-88</sup> A systematic review found that patients with community support had better virological and immunological outcomes as well as increased levels of retention and rates of survival.<sup>60</sup>

Although social networks often play a positive role in adherence, they can prevent adherence if PLHIV avoid disclosure for fear of rejection. Conversely, in other cases, PLHIV adhere because they fear that nonadherence could jeopardize support from significant others and family.<sup>79,81,85,89</sup>

### Cultural and Gender Norms

In Zimbabwe, a study found that many men struggle to adhere because they avoid clinics identified as "AIDS clinics" by their community.<sup>79</sup> Women also struggle to adhere, particularly when their husbands refuse to provide money for transport or clinic fees.<sup>79</sup> Women who are financially dependent on their husbands may choose to remain sick when adherence is associated with the possibility of divorce.<sup>79,85</sup>

### Stigma

A qualitative study conducted in Mexico found that discrimination in access to public services hindered adherence.<sup>90</sup> A qualitative study of children on ART and their caregivers highlighted stigma at school as an impediment to adherence.<sup>91</sup> Similarly, a study in western Kenya found that 16% of children living with HIV were lost to follow-up because of discrimination by the family or community, and 30% were lost to follow-up because of caregivers' fears of

stigmatizing by family or community.<sup>92</sup> Several studies have found that participants' fear of stigma and discrimination constituted a common barrier to adherence.<sup>3,8,12,13,22,93–98</sup> Stigma was also cited as a reason not to accept home-based DOT (Directly Observed Therapy) with antiretroviral medication in Vietnam.<sup>99</sup>

Yet, at least 1 study found that anticipated stigma was an inadvertent motivator of adherence, as PLHIV took their medications to avoid a sickly appearance and the anticipated negative community reaction.<sup>100</sup> Similarly, a study in South Africa found that, despite the negative climate occasioned by stigma, study participants noted the positive effects of ART and their ability to improve their health and accommodate their HIV status.<sup>101</sup>

### HIV/AIDS Care

HIV/AIDS care is the final step of the HIV/AIDS treatment cascade. Care includes engagement in, and outcomes of, treatment and services for PLHIV, with the ultimate goal of viral suppression.<sup>102</sup> An extensive search of the literature found only 10 articles that addressed CLFs and HIV/AIDS care.<sup>15,35,58,103–109</sup>

### Social Support and Social Networks

In Malawi, individuals living in areas with community support had decreased risk of death, decreased loss to follow-up, and increased adherence to ART compared with those in areas lacking community support.<sup>105</sup> A qualitative study in Uganda found that community support, community groups, and networks were vital to palliative care delivery, treatment support, and bereavement support. Leadership, capacity building, partnerships with community members, and supportive policies facilitated community participation in the provision of palliative care.<sup>103</sup>

A home-based care intervention in Ethiopia worked with community-based organizations (CBOs) and nongovernmental organizations through community mobilization to train community members to provide basic palliative care.<sup>104</sup> The study found a reduction in opportunistic infections and mortality and concluded that the intervention improved the health and well-being of PLHIV while reducing HIV-related stigma.

Finally, a cross-sectional survey in Nigeria found that CBO engagement in the community, as measured contextually by the number of CBOs per 100,000 people, was associated with better odds of both the availability and the utilization of prevention or care services.<sup>58</sup>

### Stigma

Stigma has been found to impede HIV/AIDS care delivery in multiple countries.<sup>35,110</sup> A study in Serbia exploring PLHIV perspectives found that the limited availability of state-funded HIV treatment has interacted with structural forces to create new forms of stigmatization that limit empowerment and employment opportunities.<sup>106</sup> Prisoners reentering mainstream society in Malaysia who perceived that public attitudes were highly stigmatizing toward PLHIV faced more challenges, including difficulty in obtaining HIV care, compared with

those reporting low HIV stigma.<sup>107</sup> Female sex workers, MSM, transgender, and peer educators in southern India reported fear of and experiences of discrimination from family and community members (eg, neighbors, school, and government), as well as perceived and actual discrimination from health care providers, as barriers to care and support services, particularly at government-run facilities.<sup>15</sup> Both a qualitative study in Grenada and Trinidad and Tobago<sup>108</sup> and a cross-sectional study in Nigeria<sup>109</sup> found that providers' stigmatizing acts of neglect and refusal of services were barriers to care for PLHIV.<sup>45,46</sup>

### Limitations

As this was a critical and not a systematic review, articles that might have been included may have been overlooked. For example, studies from the gray literature were not included because the type of review process to which they were subject, if any, is unknowable. Studies from high-income countries were also excluded given the dominant role that economics play in reducing obstacles to, and creating opportunities for, treatment and care. Finally, this review did not assess the quality or strength of the evidence presented in the articles. This is clearly an aspect that requires further attention and should be undertaken in future research.

### CONCLUSIONS

This review has sought to highlight CLFs identified in the literature as associated, whether positively or negatively, with the stages in the HIV treatment cascade in low- and middle-income countries. Positive social norms and social support organized around HIV treatment and care were widely discussed in the literature and are areas where programmatic interventions might have high impact. In particular, equitable gender norms, cultural norms to enable appropriate treatment of key populations, and stigma reduction were identified as areas that should be addressed with communities to reduce dropout along the treatment cascade. At the same time, community-level interventions alone are not sufficient. Many articles note the importance of structural-level change, including changes in policies, access to health care services, and broader economic factors.

The second aim of this review was to identify evaluations of interventions relevant to the topic at hand. Thirteen articles about CLF interventions were identified; of those, 7 were purely descriptive so were not included in this review. The 5 interventions that were evaluated were communication interventions designed to influence or alter CLFs. The interventions worked with social networks, community leaders, and clinic staff to increase access across the treatment cascade, including community-based care, which points to the potential for communication programs in the HIV trajectory. In particular, the articles point to the need to work with a broad swathe of community members over a period of time to enable and allow changes to take place. The dearth of relevant evaluation articles suggests several possibilities. One is that assessments of interventions designed to address individual-level factors have failed to examine potential

community-level change, whether contextual or compositional. Another possibility is that some articles were overlooked because of search term or search engine limitations, which would suggest the need to conduct a further search in this area. Most likely, however, this study reflects the fact that few interventions designed to have community-level effects have been evaluated. Such evaluations are crucially needed.

Context really does make a difference. It not only defines individuals' abilities to reduce their risk and vulnerability to HIV,<sup>12,111</sup> but it also serves as the middle ground<sup>9</sup> in which collective action plays out and where social change occurs. Yet, too often research remains at the individual level. As this review demonstrates, compared with hundreds of articles about individual-level factors and the HIV care pathway, relatively few articles actually measure or evaluate the associations between the community-as-context and continuation in the HIV treatment and care cascade. Even fewer explore the causal pathway between community factors and HIV outcomes. Furthermore, of the 100 articles reviewed, only 19 were quantitative. Qualitative research is crucial to understanding context and the need for such studies has not been exhausted as we are still in the early stages of understanding how context affects HIV outcomes. Yet, qualitative research alone is not sufficient, particularly to better understand the pathways to improved treatment and care. At the same time, there is a clear need to standardize, at least at the subregional level, and validate social and gender norm scales so that comparisons of these important CLFs can be rigorously assessed over time and place, if relevant. Although community contexts were described and discussed in the articles reviewed, no clear theoretical model of the causal linkages was presented. The qualitative studies could contribute to such a theoretical model, but would need to be tested with quantitative data.

Moreover, there is a vast body of data that is underutilized and could help us better understand community factors. Data regarding social norms, gender norms, and other such factors could be aggregated at the cluster, neighborhood, or community levels and incorporated into multilevel analysis; this would help elucidate pathways to better treatment and care. Research that rigorously assesses the role of CLFs is urgently needed to help us reach the still-elusive goal of minimizing loss to follow-up across the treatment cascade.

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