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Towards Shared and Effective Self-Care: A User-Centric Framework for Enhancing HIV Prevention

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ABSTRACT

Background: Despite a declining trend in Human immunodeficiency virus (HIV) prevalence across sub-Saharan Africa, specific vulnerable groups continue to be disproportionately impacted (29.9% for sex workers, 12.9% for gay men having sex with men (MSM) vs 5.9% for adults). In the face of this challenge, it is critical to tailor demand creation for prevention, in particular self-care, for maximum impact and cost-efficiency. This study seeks to provide a behavioral understanding towards HIV prevention that shape the efficacy of prevention strategies among priority populations (female sex workers, MSM and adolescent girls and young women) in southern and eastern Africa.

Methods: This study involved a literature review of 110 articles, focusing on HIV prevention in priority populations, behavioral interventions, and policy priorities from governments and funders. Additionally, insights were gained from 11 in-depth interviews and a workshop with 10 experts at the AIDS Impact 2023 conference. Participants included behavioral researchers and program leaders from Global Fund, United States Agency for International Development (USAID), U.S. President's Emergency Plan for AIDS Relief (PEPFAR), Bill and Melinda Gates Foundation, FHI360, Population Services International and Genesis Analytics. A user-centric behavioral framework was devised to identify actionable drivers and barriers in HIV prevention during the consultation exercise.

Results: The study highlights the importance of shared and effective self-care in enhancing HIV prevention, particularly in vulnerable groups. The behavioral framework integrates the decision-making contexts and the health ecosystem layers to inform research and demand strategy. Key findings include: (1) effective self-care is not the same as continuous use of Pre-exposure prophylaxis and therefore, programs and policies need to measure them differently; (2) users exercise choice through a combination of prevention products and focus on a few may be sub-optimal, and (3) perceived risk is transient and hence risk-based messaging lacks sustained relevance.

Conclusion: Effective self-care strategies extend beyond overcoming access and availability issues. Examining the underlying factors causing the barriers is essential. The behavioral framework presented here suggests that: (a) Self-care is a shared responsibility between the user and healthcare system and (b) demand creation should be de-medicalised, away from products and towards meeting the needs and preferences of users.

Introduction

Approximately 20.8 million acquired immunodeficiency syndrome (AIDS)-related deaths have been averted between 1996 to 2022 due to antiretroviral therapy. There were 1.3 million (approximately) new Human immunodeficiency virus (HIV) incidences in 2022, marking a 59% decline from its peak in 1995.[1] Five countries have already achieved 95-95-95 targets. The success seen in HIV programs over the years underscores the importance of strong commitments to public health. Be it evidence-based policy making, scaling up of HIV services, or increased focus on prevention programs.

The advancements made in HIV treatment and prevention over the past few decades have been remarkable, be it in biomedical products or service delivery, leading to a substantial reduction in AIDS-related deaths and new HIV infections globally. Advancements such as the development of antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP), the implementation of treatment as prevention (TasP) strategies, the dapivirine vaginal ring, rapid HIV tests, differentiated delivery and home-based HIV testing kits have transformed HIV from a fatal disease to a chronic manageable condition. Breakthroughs in diagnostic technologies and community-based testing initiatives have enhanced early detection and linkage to care, further reducing the spread of the virus. These achievements have underscored and continue to show the effectiveness of collaborative efforts between researchers, healthcare providers, policymakers, and affected communities in addressing the HIV/AIDS pandemic.[2-3]

However, amidst these achievements, significant challenges persist, hindering our progress towards ending the HIV/AIDS pandemic. Despite efforts to scale up HIV prevention programs and improve access to treatment, millions of individuals continue to acquire HIV each year, with disparities and inequities exacerbating the burden among marginalized populations. Disparities in access to HIV services persist, particularly among key populations such as sex workers, men who have sex with men (MSM), and transgender individuals. Structural barriers, stigma, and criminalization further impede efforts to reach those most in need of HIV prevention and treatment services.[4,5]

The 1.3 million infections that were reported, which is significantly above the target of "fewer than 370,000" new HIV infections by 2025.[6] HIV programming has also not been able to achieve the 90-90-90 target of testing and treatment. Even though the new incidences have dropped by more than 40% among adolescent girls as well as boys, 4000 adolescent girls and young women (AGYW) acquire HIV every week.[7] And only 42% of districts with very high HIV incidence in sub-Saharan Africa are being catered by dedicated prevention programs for AGYW.[8] The inequities get amplified for key populations and other at-risk populations. In a gap analysis, significant gaps against the target for condom use in the last high-risk sex, HIV prevention programs coverage, and sexually transmitted infection (STI) screening were registered among at-risk populations.[9] The HIV pandemic continues to impact key populations disproportionately. Limited access to or scarcity of HIV and other health services for people from key populations still exists. Laws that criminalize people from key populations or their behaviors remain on statute books across much of the world. 168 countries criminalize some aspect of sex work; 67 countries criminalize consensual same-sex intercourse; 20 countries criminalize transgender people; and 143 countries criminalize or otherwise prosecute HIV exposure, non-disclosure, or transmission. In 2022, HIV prevalence was 11 times higher among gay men and other men who have sex with men, four times higher among sex workers, seven times higher among people who inject drugs, and 14 times higher among transgender people as compared to individuals from the general population.[10]

These challenges warrant international action to address the gaps in HIV prevention efforts and to explore innovative strategies to enhance the effectiveness and efficiency of our responses. President's Emergency Plan for AIDS Relief (PEPFAR) strategic framework, along with ones for other donors and national strategic plans for South Africa and Kenya on AIDS, have reinforced their vision of ending the pandemic with their strategic focus on promoting health equity for key populations through health rights, removing barriers to access and stigma, driving system's strengthening by with a primary focus on partnerships, policies, financial sustainability, and health security, encouraging evidence-based programming and implementation, innovation in service delivery towards integration and differentiated care, and continuing focus on prevention products including condoms, oral PrEP, long-acting injectable cabotegravir (CAB LA), Voluntary medical male circumcision (VMMC), and Dapivirine ring.[11-14]

For such collective action, it is pertinent that focus on HIV prevention continues, one that centers around primary transmission and not just secondary transmission.[15] That is, it is important to stop incidence to HIV-negative persons as compared to just viral suppression to restrict secondary transmission from HIV-positive persons. The effectiveness of prevention efforts depends on their accessibility and acceptability by the people most at risk of acquiring HIV (primary prevention).

The failure to meet global targets for reducing new HIV infections and achieving treatment goals highlights the limitations of current approaches to evaluating and analyzing prevention programs' design and implementation. One such approach that has been pivotal is the cascade-based approach. The cascades have been able to understand programmatic decision-making, observable inefficiencies, and gaps in implementation, which bring in a linear-unidirectional approach to understanding prevention decision-making.[16-17]

This paper presents a user-centered behavioral approach to HIV prevention that can complement a cascade-based approach as prevention decision-making varies from programmatic decision-making. The behavioral framework integrates the decision-making contexts and the health ecosystem elements to inform HIV prevention research and demand strategy.

Our user-centered approach promotes *shared and effective self-care for HIV prevention* as a lens to understand and design for HIV prevention programs. Developing an understanding of self-care can help us

build an understanding of the user needs and decision-making involved in prevention-related decisions. Addressing the current shortcomings and adopting self-care-driven approaches can help us move towards a more comprehensive and inclusive approach to HIV prevention that addresses the diverse needs of all individuals at risk of or living with HIV.

HIV Prevention: Cascade-based approach

Treatment cascades (usually representing a unidirectional series of steps ranging from diagnosis, linkage-to-care, engagement/retention in care, ART initiation and adherence, and viral suppression)[16] have provided a pragmatic and unifying framework for policymakers, program planners, advocacy, and civil society groups, and researchers, driving the impressive global scale-up of HIV treatment services. There has been success achieved through HIV treatment, and vertical transmission cascades in driving appropriate programming in those areas.[18]

This has led to analogous efforts in developing prevention cascades to inform prevention programs. The appeal of cascades lies in their simple sequential illustration that helps concerned stakeholders understand losses in engagement and identify gaps in program implementation.[19]

But unlike treatment, HIV prevention is more challenging as it involves multiple interventions, does not involve a pressing need on the user's end due to the absence of any health challenges, varies in usage protocol due to the periodicity of risk, and caters to a more heterogeneous population with varying needs, risks, and vulnerabilities.[20] This presents program planners, policymakers, and funding bodies with the difficult task of driving effective prevention programs.

The cascades in prevention provide funders and programs with information that identifies major gaps in programming and intervention effectiveness. In short, they help understand the “what” aspects of the challenge a program may be facing. But to drive both programmatic effectiveness and efficiency, we also need to understand the reasons that underlie these gaps, i.e the “why” and “how” aspect of the challenge.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) operational guidance emphasizes the primary aims of the HIV prevention cascade are program management, monitoring, and gap identification. It entails a thorough examination of the services provided and utilized by the target population, pinpointing existing gaps to facilitate programmatic enhancements.[21] Several other prevention cascades have also been tested. These have been either key population-based or a method-centric or a combination of both. For example, in Kenya, a prevention cascade, focused on female sex workers (FSW) helped in identifying gaps in program outputs and outcomes, providing valuable insights for program monitoring and improvement.[22] Cascades at both the national and sub-national levels indicated the percentages of FSWs who were not retained at each stage of program implementation, as well as the differences in program success rates. The intention was to see which of the program stages had more drop-offs. The Avahan program in India too used a prevention cascade to track consistent condom use where it followed the sequence baselined on people at risk of HIV followed by individuals who feel at risk of HIV, succeeded by those who have access to condoms and then people who use condom[23]. Researchers in Zimbabwe used separate provider-centric and user-centric cascades differing in starting point of the cascade to monitor gaps in program implementation [24]. A Lancet study by Schaefer et al. in 2019 proposed a unifying framework for cascade with an aim to integrate biomedical, behavioral, and structural approaches to HIV prevention. The starting point of this cascade lay in motivation to take up prevention services, there on progressing into access, and then effective use[25]. However, challenges persist in developing cascades due to the complexity of prevention programs and inconsistent data availability. Challenges persist in obtaining accurate data to measure motivation, access, and effective use of prevention methods, with key indicators often lacking in routine collection efforts. In their analysis of a condom cascade in Zimbabwe, the authors encountered difficulty in accessing specific data on motivation to use condoms, relying instead on individuals' perceptions of HIV risk.[26] Moreover, the authors acknowledge the exclusion of additional steps, such as estimating the number of HIV infections averted, due to data collection complexities. These challenges highlight the necessity for innovative methodologies and improved data collection strategies to optimize the utility of prevention cascades for monitoring and evaluating HIV prevention programs.

The cascade approaches to prevention play an important role in monitoring programs and helping planners address implementation challenges. Though cascades such as one proposed by Schaefer R[25], do take into consideration the cognitive aspects such as motivation and one proposed by Garnett GF[24] putting the user at its core, there is a need for a different behavioral framework to understand decision-making that can supplement the existing ones focused on monitoring of program and help funding bodies and policy planners understand the factors underlying the gaps.

However, prevention cascades do not track the complex interplay of behavioral factors that influence individuals' decisions regarding HIV prevention. These cascades typically track programmatic aspects such as service uptake and adherence but may not delve deeply into the underlying psychological, social, and cultural determinants that shape individuals' behaviors. To enhance the effectiveness of HIV prevention strategies, there is a critical need for a behavioral framework that goes beyond programmatic metrics and comprehensively examines the decision-making processes of at-risk populations. Such a framework should consider factors such as risk perception, social norms, stigma, access to resources, and individual agency in shaping preventive behaviors.

Shifting Towards Shared and Effective Self-Care: A New Paradigm for HIV Prevention Demand Strategy

As more people benefit from HIV-related investments and there is a drop in overall incidence and prevalence rates[1], it will become essential for public health practitioners to reach hard-to-reach and at-risk populations with prevention services to restrict primary transmission. This underscores the necessity for a prevention approach, one that not only identifies implementation gaps in targeting and reaching hard-to-reach and at-risk populations but also delves into the root causes of gaps to provide funders and policy planners with research into the barriers resulting in ineffective implementation and drop-offs.

Traditionally, HIV prevention demand strategies have centered on promoting the uptake of prevention products and services, often through a top-down, product-focused approach.[27] This operates under the assumption that users primarily require access to a variety of preventive options to mitigate HIV risks. It has been based on the linear progression of individuals from awareness to uptake of preventative measures, assuming that spreading awareness about these measures will automatically lead to their adoption.[28] The emphasis of demand strategies has been on maximizing awareness and facilitating access and availability to ample products to facilitate prevention.

However, there is a growing recognition of the limitations of this approach, particularly its inability to address the diverse needs and behaviors existing within populations and in particular among at-risk populations, and not being agile enough to keep up with the dynamic context.[29-31] In the dynamic landscape of HIV prevention, decisions must continuously adapt to evolving circumstances, including shifts in the epidemic and the introduction of new prevention products and services. Individuals must assess their own risk of HIV transmission based on factors such as sexual behavior, substance use, and exposure to high-risk environments. They must also identify available prevention opportunities, such as access to condoms, PrEP, and HIV testing services. Moreover, individuals must make informed choices about how to use these prevention options effectively, considering factors such as adherence to medication regimens, consistent condom use, and engagement with healthcare providers for regular testing and follow-up.

Recognizing this, we view self-care as an individual's ability to assess their risk, identify prevention opportunities, and use them effectively, can emerge as the new vantage point to guide prevention decisions. More recently, there has been a shift in the HIV prevention paradigm with a focus on self-care, defined by the World Health Organization as the ability of individuals, families, and communities to promote health, prevent disease, and cope with illness and disability independently or with minimal support from healthcare providers.[32] However, bringing in a self-care lens makes it evident that prevention isn't solely the responsibility of individuals; it entails collaboration with the healthcare system. This collaborative approach ensures that individuals receive the necessary support, guidance, and resources to make informed decisions about their health. It fosters shared accountability between users and healthcare professionals, aligning efforts toward achieving optimal health outcomes.

Achieving the goals of self-care warrants a shift from mere product delivery to a more integrated approach involving multiple stakeholders. It requires empowering individuals to accurately assess their HIV risk, identify prevention opportunities, and take appropriate actions. Self-care can then be viewed as a shared responsibility and a common objective among users, communities, and the healthcare system at large. In this context, we propose a behavioral framework rooted in driving "*Shared and Effective Self-care*," aiming to augment the existing user-level product-based and cascade-based demand strategy.

To achieve this goal, we suggest a user-centric behavioral framework for HIV prevention. Our framework consists of three key behavioral layers, each representing a decision context for users - Risk Assessment, Opportunity Evaluation, and Effective Use. Risk assessment includes accurately identifying risks and the level of risk one faces and the need to mitigate this risk. Opportunity evaluation aims at taking appropriate actions aligned with the risk assessment. This can mean that users who accurately identify themselves are at zero risk of HIV and respond with no particular product uptake. It can also mean that users accurately identify themselves to be at risk of HIV and respond by using the relevant prevention method. Whereas effective use is built on both risk assessment and opportunity evaluation. The shared aspect embedded in the framework does not make effective self-care just user-centric or user-driven but equally supported and involved providers. Importantly, the framework translates behavioral goals for each decision context into individual goals for both users and providers, emphasizing collaborative decision-making and support.

Figure 1: The Behavioral Layers involving the 3 Decision-Contexts

The multiplier effect of all these 3 decision contexts coming together leads to "effective self-care". Research suggests that user decision-making for HIV prevention is a continuous dynamic process and does not end with the uptake of a product or a service.[33-35] Accurate assessment of risk and prevention opportunities constantly get updated based on vulnerabilities, cognitive factors, interactions, systems and changing socio-economic factors. And in turn affect a user's prevention response.

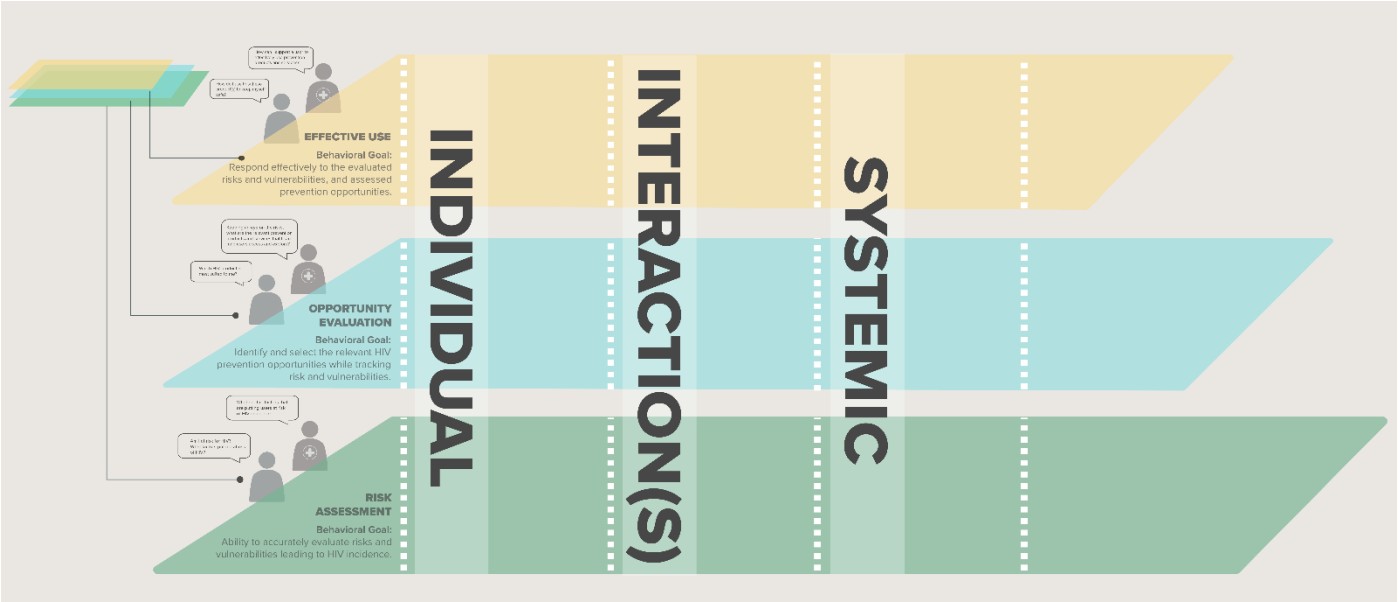

Figure 2: The 3 ecosystem levels

Surrounding these decision-making contexts are the three ecosystem levels: Individual, Interaction(s), and Systemic. These levels encompass the broader socio-ecological context within which HIV prevention decisions are made, encompassing cognitive, behavioral, structural, and cultural factors. By considering the interplay between individual behaviors, interactions with the healthcare system, and systemic influences, the framework aims to facilitate a more nuanced understanding of HIV prevention behaviors. Interactions represent the user-level engagements within their ecosystem while accessing HIV prevention services, while systemic factors encompass structural elements such as culture, political institutions, and policies that significantly influence the dynamics within the ecosystem. The combined impact of these decision contexts and ecosystem levels contributes to the demand for HIV prevention.

Implications

While the prevention cascade framework supports program monitoring and evaluation efforts, the behavioral framework can be used to identify research gaps, design innovations, and facilitate capacity-building efforts. Our approach diverges from traditional linear

models of the user journey towards uptake of prevention products and firmly situates HIV prevention decisions within a multi-layered ecosystem framework. Such an approach allows programmers and funders to better understand prevention decisions at the user-product-policy level and identify program gaps to inform future programming.

In a previous study, the ecological model was leveraged to organize enablers and barriers to the uptake of prevention among at-risk populations at the individual, interaction, and systemic levels. It identified factors (Figure 3) that influence the uptake of HIV prevention products and services.[36] The approach discussed in this paper can be juxtaposed to unpack these enablers and barriers both at the ecological levels as well as in terms of the behavioral layers. This sort of organization can help programs apply the user-centric behavioral framework in driving self-care strategy. We provide some illustrative scenarios to show the implications of applying the user-centric behavioral framework.

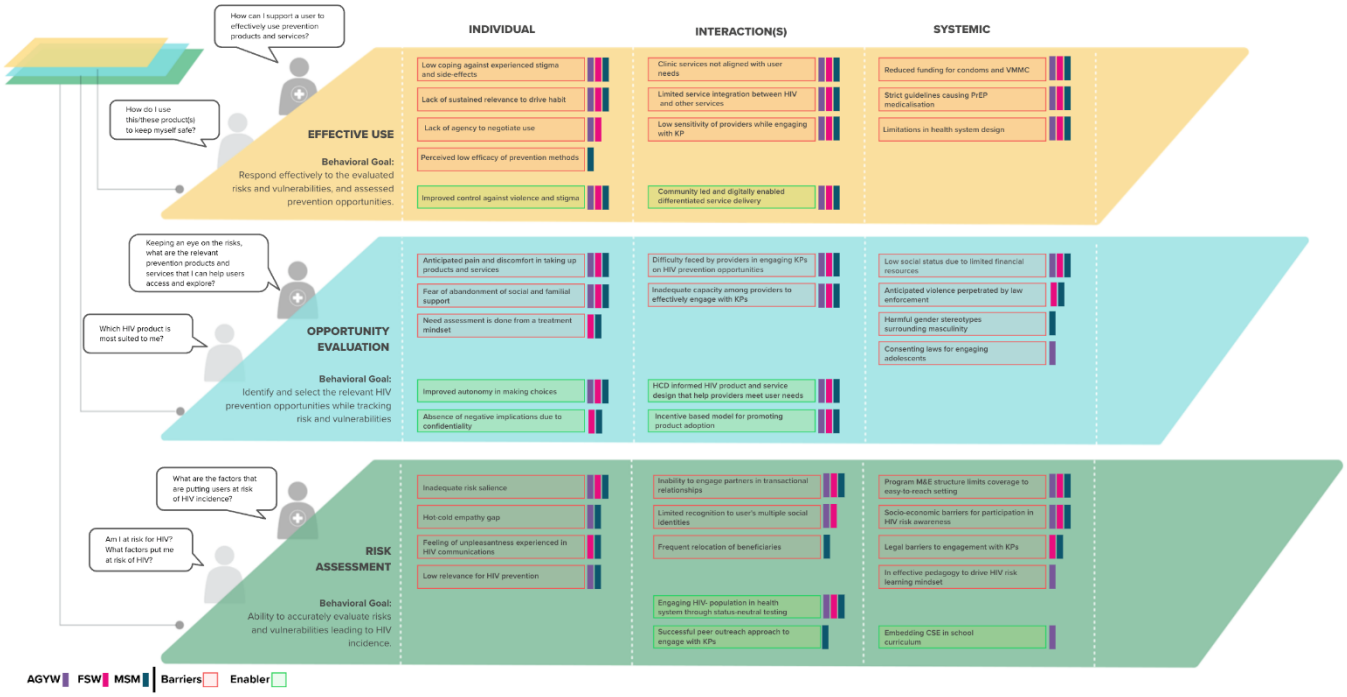

Figure 3: The HIV Prevention Behavioral Framework

Firstly, let's consider a program that is trying to improve risk literacy and risk coping among at-risk populations. First, the framework identifies barriers present at different levels - 1. individual barriers, such as inadequate risk salience and limited relevance for HIV prevention, 2. interaction barriers, such as limited recognition of a user's multiple social identities, and 3. systemic barriers of limited education on HIV prevention. The framework can then help a program situate these barriers in relevant user decision contexts. Inadequate risk salience and relevance can be better understood as barriers emanating from users assessing the risk while they indulge in various high-risk transactions. Similarly, one then acknowledges that limited recognition of user needs is anchored while users evaluate prevention opportunities and product experience fails to cater to multiple user identities. Thus, promoting shared and effective self-care can mean a programmatic intervention to develop predictive models to identify determinants of risk by healthcare care workers for tracking risk or one that is aimed at designing product communication aligned to the myriad identities of a user belonging to an at-risk population.

Similarly, let's consider that a program is facing challenges in the delivery of PrEP. First, the framework identifies 1. individual barriers, such as lack of sustained relevance and limited coping against anticipated stigma, 2. interaction barriers, such as misaligned clinical services, and 3. systemic barriers, such as impractical PrEP guidelines that prevent effective use of biomedical interventions. Each of these barriers can be further understood in the relevant decision contexts. Building such a matrix understanding places a program to both understand the decision-making contexts as well as identify the level most appropriate for implementing the intervention. For the delivery of PreP, this can mean building coping for users beyond confidentiality at an individual level, capacitating healthcare facilities with tools to help them deliver differentiated and de-stigmatised delivery of services at an interaction level, and developing guidelines for effective use and not continuous use at the systemic level.

Conclusion

Effective self-care strategies are not merely about onboarding individuals onto platforms and facilitating access and availability of prevention options. Examining the dynamic environment surrounding a prevention relevant decision can help identify underlying factors causing the barriers to uptake. Additionally, it is critical to start informing programs for effective self-care by defining it as a shared responsibility. One where both the individual as well as the healthcare system are aligned

on mutually compatible goal of HIV Prevention. And where demand creation is de-medicalised, away from products and towards meeting the needs and preferences of users.

The behavioral framework provides a powerful tool to examine prevention behaviors by bringing together an individual level decision-making mechanism and the circle of influence through the ecological levels. This can be leveraged to understand the barriers driving implementation bottlenecks and thereby informing interventions at individual or at interactional or at a system level.

Conflicts of Interest Statement

The authors have no conflicts of interest to declare.

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