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Rebooting resilience: Shifts toward dynamic, multi-level, and technology-based approaches for people living with HIV

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Abstract

Resilience research has often been characterized by a static conceptualization of resilience that focuses on individual-level factors that help people living with HIV (PLHIV) adapt to HIV-related challenges and overcome other life adversities. Early conceptualizations often depicted resilience as a static, stable construct, with limited attention paid to the social context and broader systems that may foster or discourage resilient adaptation across time and place. This special issue seeks to challenge these conventional views by highlighting innovative HIV resilience research across the globe. Far from ignoring socio-cultural contexts, studies presented in this issue directly address systemic stigma and discrimination against PLHIV, as well as sexual and gender minority individuals, and identify unique opportunities to promote resilience through building strong “villages” (i.e., social networks), reducing structural inequities, and enhancing HIV treatment and care systems. In addition, papers included in this issue address the promise and challenges of utilizing mobile Health (mHealth) technology to build resilience for PLHIV through improving psychosocial and clinical outcomes.

Formal conceptualizations of human resilience emerged in the published scientific literature in the 1970s. However, interest in humans’ ability to “rebound” or “spring back up”—translations of the Latin “resilire” from which resilience is derived—appears universal (Fleming & Ledogar, 2008). Stories of individuals who defy odds and persevere through hardship are familiar collective narratives across time and place. While our understanding of resilience has shifted with its scientific study, the construct continues to garner interest and may have particular utility within the HIV field, given the multiple adversities (e.g., health-related, psychosocial, socio-economic) that people living with HIV (PLHIV) frequently encounter. The articles presented in this special issue draw attention to the progress that has been made in our understanding of resilience for PLHIV, highlight unique opportunities to build resilience, and identify future directions for HIV-related resilience research.

Initially characterized as a stable personality trait, resilient individuals were seen as being in possession of key internal characteristics that enabled them to thrive despite hardship (Vanderbilt-Adriance & Shaw, 2008). This conceptualization spurred early efforts to identify protective factors—with a focus on early childhood—that could make one invulnerable or invincible to life’s challenges (Anthony, 1974; Fleming & Ledogar, 2008; Pines, 1975). Emphasis was placed on traits such as intelligence and personality (e.g., easy temperament, secure attachment style) that could equip an individual to cope with challenges and that would also evoke positive responses from others in the environment (e.g., peers, caregivers)

(Werner, 1995). By the early 2000s, resilience was increasingly viewed not as a trait, but instead as a dynamic process of positive adaptation despite the experience of adversity (Luthar, Cicchetti, & Becker, 2000; Luthar & Zelazo, 2003). In addition, resilience shifted from being viewed as an extraordinary process to an ordinary one that can be accomplished when human adaptive systems and processes are protected and nurtured (Masten, 2001). Current directions in resilience research devote more emphasis to environmental and structural influences (e.g., social, economic, cultural, and political) that interact with and influence individual responses to hardship, as well as call for increased specificity in the definition and measurement of resilience (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014).

This special issue is anchored by a thoughtful and comprehensive review by Dulin and colleagues (2019) that traces the definition and study of resilience among PLHIV, beginning with initial work in the 1990s that identified links between individual personality characteristics (e.g., “fighting spirit”, active coping style) and positive clinical and immunological outcomes (Solano et al., 1993). Dulin’s (2019) review confirms that current gaps in HIV-related resilience research largely mirror the broader field. A majority of studies that examine resilience among HIV populations continue to focus upon individual-level factors, and formal definitions of resilience remain scarce within the HIV literature (Dulin, 2019). While 14 of the 54 articles reviewed address at least one or more interpersonal resilience factors—most notably social support—only one study could be identified that examined broader neighborhood and community-level resilience resources (Zachariah et al., 2007). This lack of attention to social context and broader socio-cultural, political, and economic systems is highly problematic given their profound influences on HIV outcomes.

Some scholars have made significant efforts to highlight the social context of HIV. Notably, Parker and Aggleton (2003), drew attention to limitations in how HIV stigma had previously been conceptualized—highlighting the need to move beyond a conceptualization of stigma that focused on individual attitudes and beliefs and move toward a deeper understanding of the ways in which HIV-related stigma “feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality” (Parker & Aggleton, 2003, p. 13). This ushered in a greater understanding of the structural and power-related dimensions of discrimination against PLHIV. We hope for a similar shift in our understanding of resilience and believe that paying greater attention to ways that social systems may promote or discourage resilience for PLHIV will be a welcome step forward.

Broadening the conceptualization of resilience to address social and structural factors also aligns with the recently proposed modified socioecological model of health (Baral, Logie, Grosso, Wirtz, & Beyrer, 2013), which examines multi-level risks associated with HIV and has drawn increased attention to the roles that social networks, communities, and public policy play in shaping HIV-related risk. Similarly, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has also increasingly recognized the role that communities play in improving individual outcomes for PLHIV and pushing for the “broader social transformation, which is paramount to halt and reverse the HIV epidemic” (UNAIDS, 2012 p. 58). Communities that are mobilized, engaged, and equipped with resources can be a powerful force for resilience. More study is needed to understand that ways in which HIV-

affected communities interact with social and political processes, as these interactions may either promote social change or undermine individuals' ability for collective social agency (Kippax, Stephensen, Parker, & Aggleton, 2013).

Thus, we are excited to draw attention through this special issue to work by Dale and Safren (2019) that highlights the unique role that communities can play in fostering resilience for Black women living with HIV (BWLWH) in the United States. This paper highlights the role of diverse "villages", including those of kinship, choice, and circumstance, that BWLWH identify as critical to their ability to overcome adversities across the lifespan. Dale and Safren's (2019) findings, informed by 45 in-depth qualitative interviews with BWLWH and community stakeholders, extend previous research (e.g., Dale, Pierre-Louis, Bogart, O'Cleirigh, & Safren, 2018; DeMoss, Bonney, Grant, Klein, del Rio, & Barker, 2014) in suggesting that social networks can help BWLWH better cope with HIV-related challenges. In particular, women reported about their positive experiences with communities that supported them in being their authentic selves, healthcare providers who prioritized empathy and compassion, and family members who provided "safe havens" from HIV-related stigma and adversity.

Another paper in this special issue moves beyond merely defining community resilience to addressing the mechanisms through which communities enhance the resilience of their members. Barry and colleagues (2019) present innovative findings from the evaluation of *HealthMpowerment*, an online, mobile phone optimized intervention with the dual aims of reducing HIV risk and strengthening community ties among young Black gay, bisexual, and other men who have sex with men (GBMSM). There is increasing interest in developing mobile Health (mHealth) interventions that are tailored to the needs of HIV populations. Such interventions offer promise for improving behaviors related to the HIV care continuum, and may also be effective tools for building social support and enhancing psychosocial wellbeing (Muessig, Nekkanti, Bauermeister, Bull, & Hightow-Weidman, 2015; Muessig, LeGrand, Horvath, Bauermeister, & Hightow-Weidman, 2017; Schnall, Bakken, Rojas, Travers, & Carballo-Diequez, 2015). The *healthMpowerment* intervention was created in partnership with young Black GBMSM and provides them with an anonymous online space where they—regardless of HIV status—can build supportive relationships (Hightow-Wediman et al., 2015; Muessig, Baltierra, Pike, LeGrand, & Hightow-Weidman, 2014).

In their creative and insightful piece, Barry and colleagues (2019) push us to think about how new technologies can facilitate the development of resilience and also make us think about resilience in new ways. They reconceptualize Harper's (2014) framework to highlight the dynamic inter-workings of four key resilience processes identified by young Black GBMSM living with HIV (i.e., exchanging social support, engaging in health-promoting cognitive processes, enacting healthy behavioral practices, empowering other gay and bisexual youth). The authors then use this framework to analyze a diverse collection of 322 conversations generated on the *healthMpowerment* platform (Barry et al., 2019; Harper, Bruce, Hosek, Fernandez, & Rood, 2014). In doing so, the piece calls attention to the dynamic and interactive nature of resilience and pushes for an enhanced understanding of community resilience—one that expands beyond merely viewing communities as a place for

social support to one in which communities, whether virtual or in vivo, foster resilience through empowerment, affirmation, and authenticity.

The process of developing resilience is also explored in an article that details what we believe to be the first behavioral resilience intervention tailored to the needs of HIV-positive men who have sex with men in China (Yang, Simoni, Dorsey, Lin, Sun, Bao, & Lu, 2019). In this piece, Yang and colleagues (2019) report promising findings from a pilot hybrid effectiveness-implementation trial of a brief cognitive-behavioral therapy (CBT)-based intervention designed to reduce distress and promote adaptive coping and resilience among newly diagnosed individuals (Yang et al., 2018). We hope this contribution will spur more efforts to develop culturally-tailored, resilience-based interventions and also suggest that the promising intervention could be enhanced by adding components that galvanize interpersonal and community resources (e.g., peers, caregivers, healthcare providers, community members) (Albarracin, Rothman, Clemente, & Del Rio, 2010; Kaufman, Cornish, Zimmerman, & Johnson, 2014; Li, Chi, Sherr, Cluver, & Stanton, 2015).

Two other papers within this special issue also make contributions to our understanding of resilience among Chinese HIV populations. First, Huang, Zhang, and Yu (2019a) utilize a systems framework of resilience to examine the interplay between external and internal resilience factors for rural PLHIV in China. Specifically, they explore the protective effects of positive marital and family relationships on individual wellbeing, with findings suggesting that the protective effects of positive relationships are mediated by individual resilience resources. Identifying opportunities to strengthen family and individual resources for residents of rural regions of China may be especially important given the economic challenges and paucity of high quality healthcare services in these areas.

Secondly, the authors examine resilience among serodiscordant couples in China—specifically, whether “we-ness” or a close couple identity has protective benefits for psychosocial and physical wellbeing (Huang, Zhang, & Yu, 2019b). Findings align with what has long been recognized—healthy, supportive relationships foster resilience (Cohen & Syme, 1985; Lakey & Cohen, 2000; Reblin & Uchino, 2008). Interestingly though, the positive effects of “we-ness” were significantly diminished within high-stigma environments—drawing attention again to the urgent need to consider context in our efforts to build resilience. Failure to address broader socio-cultural challenges for PLHIV (e.g., widespread stigma and discrimination, social inequities) may significantly diminish the impacts of even the best laid plans for resilience building.

One context that remains relatively understudied in HIV-related resilience research is that of the healthcare setting. For that reason, we are excited to share new findings by Logie and colleagues, presented on behalf of the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (i.e., CHIWOS) research team, that examines the effects of women-centered care and community social support on resilience-related outcomes among a national cohort of women living with HIV in Canada. Women-centered care for women living with HIV adopts a person-centered and strengths-based approach and has been suggested to be associated with enhanced self-worth, advocacy skills, empowerment, and self-management (Carter et al., 2013, O’Brien et al., 2017). The multi-level approach to

resilience employed by Logie and her team (2019) is a welcome addition to the literature, and their findings that structural factors (i.e., models of service delivery, economic insecurity) impact resilience for women living with HIV underscore the key role that policies and programs can play in improving outcomes for vulnerable populations (Logie et al., 2019).

Two final papers in the issue highlight some current efforts to build resilience among PLHIV in sub-Saharan Africa. First, Kunzweiler and colleagues present findings from the *Anza Mapema* (i.e., “Start Early” in Kiswahili)—a longitudinal cohort study investigating an HIV prevention and care program that is tailored to the needs of GBMSM in Kenya. Despite receiving a high level of support, only 62.7% of GBMSM living with HIV who were enrolled in the study were virally suppressed 12-months after ART initiation—a rate that is far below current UNAIDS 90-90-90 targets. Investigators found that coping self-efficacy was associated with higher odds of achieving viral suppression. Men who reported adopting receptive or versatile sex positions during anal sex were significantly less likely to achieve viral suppression—a concerning finding that requires more study. Socio-cultural norms regarding gender and sexuality, as well as high levels of stigma and discrimination against sexual and gender minorities, may play a role in this, and more efforts are needed to understand the particular challenges encountered by this group of Kenyan GBMSM.

In the second study, Musiimenta and colleagues (2019) explore resilience-related challenges associated with the conclusion of a technology-based intervention. Specifically, they assess the post-study experiences of individuals enrolled in the *Wisepill Intervention*—a pilot randomized controlled trial conducted in rural Uganda that examined the effects of a technology-based adherence support intervention. A challenge of such interventions that is largely unexplored is the impact of removing access to the technology after the intervention concludes. This has particular impacts for resource-limited settings and economically vulnerable individuals. The study found that many participants of the *Wisepill Intervention* were resilient after withdrawal of the real-time adherence monitoring device. Many reported feelings of self-efficacy and self-esteem, as well as the use of adaptive coping strategies (e.g., positive thinking, seeking social support, use of alternative methods for daily medication reminders). This study has important implications for behavioral interventions, particularly given the current interest in mHealth technologies.

The studies included in this special issue are expansive in terms of study population, geographic focus, and methodology. However, they coalesce around current opportunities and challenges in resilience-related HIV research. We hope this issue will yield increased rigor in the definition and measurement of resilience for HIV populations. Further research should recognize and work to overcome structural inequities and socio-cultural contexts that challenge PLHIV’s capacity for resilience. Doing so, we believe, will quicken the pace at which we move beyond an individual-centric view of resilience, and help to foster positive outcomes across the life course for PLHIV.

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