

Sexual and reproductive health service use and resilience among adolescents attending a teen club clinic in urban Blantyre, Malawi.

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ABSTRACT

Background

HIV/AIDS remains exceptional in the age of treatment, characterised by huge flows of medication, health information, education, resource supports, technologies, and people across cultures. Such dynamics and complexity raise questions about the everyday lives of people living with HIV (PLHIV), particularly adolescents living with HIV (ALHIV). This thesis is concerned with how these young people, born with HIV and those horizontally infected, manage to maintain their sexual reproductive health (SRH) and well-being despite the blame and adversity associated with the condition. This is known as resilience. An understanding of SRH, service use and resilience is critical to recognise the capacity of individuals, families and communities to navigate available resources and to collectively negotiate for resources to be provided in culturally meaningful ways. Reflecting on resilience places emphasis on the factors and processes in relation to risks and protective supports along a continuum that is complicated by individual, relational, contextual, institutional and cultural issues. Yet little is known about ALHIV service usage, SRH and resilience in Malawi.

I adopt a constructionist interpretive approach to inquire into how ALHIV navigate complexity and negotiate and ensure health, wellbeing and resilience. I attempt to take a critical position, drawing on the in-depth meanings and experiences of ALHIV as they strive to do well. Such applications resonate with resilience -- a concept employed as a heuristic tool centring on a strength-based perspective on processes and experiences that enhance positive outcomes. I utilise a socio-ecological framework to capture the multilevel links and interactions that influence resilience and functional outcomes among ALHIV. In my research, I explored ALHIV experiences, including by attending ART (antiretroviral therapy) and teen club clinics, which were part of the institutional framework designed to foster resilience. Understanding the relationships

between service usage and resilience is of great importance to Malawi to understand the varied pathways ALHIV negotiate for health care, SRH and relational supports.

Methods

In this study, I used a mixed-method approach in a cross-sectional, exploratory sequential design. This is a two-phase method to inform and allow for the modification of the questionnaire and qualitative guides and tools. A qualitative pilot survey was conducted with 42 ALHIV, using cognitive interviews and analysis to ensure that 15-19 year old youth were able to understand and could respond to the questionnaire and qualitative interview guides as intended. This pilot phase was followed by a survey with 406 purposefully selected ALHIV to determine factors associated with resilience and to validate the psychometric properties for the Child Youth Resilience Measure (CYRM-28) tool for ALHIV attending the teen club clinic. To describe and analyse an institutional enabling environment, particularly the adolescent-centred teen club clinic (TCC) model in fostering service use and resilience, I conducted a survey with ALHIV (406), involved 35 health workers in a workshop, and interviewed seven key informants and 144 adults, both “PMKs” (Persons Most Knowledgeable, as identified by young people), and parents/caregivers. Using a case study approach, I illuminated multiple and unexpected pathways that ALHIV took to do well despite experiencing adversity. In-depth interviews were conducted with 26 ALHIV, from which four case studies were selected to present in this thesis to highlight diverse pathways to service users and supports. The 'ecomaps' were added to understand what 'doing well' meant to young people in nuanced ways. The ethnographic approach of this study highlighted how physical and social spaces, places, and discourses enabled ALHIV to embrace the complexities of their experiences, including in relation to SRH, over time. Descriptive and inferential statistics were used to analyse the quantitative findings from the survey, while the framework and thematic analysis were used to guide the analysis of the qualitative data.

Findings

Resilience related constructions are multiple and layered and evolve not only to influence individual capacity but also to enhance family, community and institutional support. Collectively, common elements influence resilience and service use among ALHIV, but the ways they are grouped vary. At the individual level, using a Child Youth Resilience Measure (CYRM-28), I ascertained the three-factor structure and unique components (personal and social skills,

caregivers' support, spiritual and cultural support) that inform resilience for ALHIV and appear to influence their attendance at a teen club clinic in Malawi. However, the factorial model challenged the individual and ecological perspective of resilience as dimensions on peer support and education showed low loadings for ALHIV. These observations confirmed that across sub-populations, there are common resilience elements, but the ways they are grouped differ, suggesting the value of further qualitative research.

In line with enhancing our understanding of resilience as a multidimensional and complex construct influencing SRH, service usage and health outcomes, I considered multiple perspectives (ALHIV, caregivers and health-workers, and researcher's roles). This includes an institutional enabling environment, the adolescent-centred teen club clinic (TCC) model, which influences complex interactions and dynamics in fostering resilience among ALHIV. The TCC underscores the potential of institutional factors, processes and policy-enabling environments to ensure positive developments among ALHIV. I also captured ALHIV as multiple service users, who accessed education, community teen club, youth-friendly centres, SRH, HIV care and traditional healing. In analysing this, I stressed ALHIV layers of interest, differing needs, and place interactions for their health and wellbeing. Prioritising the ART and teen club clinic is not unexpected, given the needs for ALHIV and adolescent-centred care. Further analysis using structural equation modelling not only offered unique insights on gendered service use experiences but demonstrated the complex network of correlates and factors that influence the interactions between risks, resilience service use frequency and satisfaction. The desire of ALHIV to reproduce at an early age complicated their adoption of safe sex negotiation skills, intimacy and SRH care, and likely influenced their lower utilisation of SRH, family planning and sexually transmitted infection services.

Using a case study approach, I reflected on living with HIV as a reference point to understand how young people navigate and negotiate a complex mix of needs. I illuminated multiple and unexpected pathways, including opting for strategic relationships and silence, that ALHIV used to maintain their support systems and not undermine their resilience. The 'ecomaps' were added to personalise ALHIV experiences and strengthen the diagrammatic representation of social and health service utilisation over time. Despite the encouragement of disclosure, openness and the

development of self-efficacy as informing resilience, in this current study, 'strategic relationships and silence' were considered to be especially valuable for 'doing well despite adversity'.

Finally, I explored the multiple enabling spaces and places that influence dialogues and positive SRH experience over time. I highlighted the multiple roles of different physical and social spaces and discourses at homes, schools, church, and community and institutional settings, which showcased SRH complexities (informed choices, communication, physical satisfaction, sexual readiness and reproductive preparedness) as ALHIV navigated their status to live positively. ALHIV, parents/caregivers and health workers strive for more open, honest and explicit knowledge sharing and relationships to ensure safety, privacy, choices, pleasure and the provision of SRH services. All acknowledge ASRH as a normative issue that occurs and is influenced by the capacity of young people to negotiate. Diversity norms, values and power relations transformed SRH experiences for ALHIV.

Conclusion

This study stresses the context-specific, multi-layered, multidimensional nature of resilience, SRH and service use which are critical for ALHIV wellbeing. I used a public health lens to infer risk and protection factors influencing the outcomes of ALHIV. Living with HIV, even if one is doing well on antiretroviral treatment (ART), is still experienced as exceptional. I subscribe to a transformative lens and a strength-based approach, and view adolescence as providing space for health exploration and learning.

In this thesis, I note disparities between resilience measures, SRH service usage, frequency and satisfaction among ALHIV, health workers and parents/caregivers, emphasising the need to strengthen collaborative efforts for ALHIV health. ALHIV are multiple service users with variable knowledge of service provision vis-à-vis access and utilisation in practice. Where knowledge and awareness are strong, there is potential for ALHIV to navigate multiple settings for resource and service supports. This reflects an improvement in accessing services, particularly SRH service use and care, revealing the complexity and fulfilment that ALHIV seek. This is critical for their sexuality. Such recognition accounts for ALHIV as sexual beings, ultimately leading to more open discussions to meet the sex-positive and reproductive needs of both genders. The teen club clinic continues to transform ALHIV biological and social lives, and this ultimately affects their informed choices, empowerment and a sense of belonging.