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Promoting patient-centered care within HIV care settings in sub-Saharan Africa

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Abstract

Purpose of the review: Patient centered care (PCC) in HIV care systems in sub-Saharan Africa (SSA) may improve outcomes for persons with HIV (PWH). We review the progress the region has made in promoting PCC and highlight some of the implementation challenges and potential areas of research.

Recent findings: Studies show growing interest in promoting PCC across HIV care programs in SSA. Effective implementation of PCC, however, is hampered by: 1) lack of consensus on the conceptualization of PCC, including definition, frameworks, measures and implementation strategies; 2) limited regional studies on the adoption and sustainability of PCC interventions; and 3) healthcare structural challenges including limited capital and human resources, poor provider-patient dynamics, high provider turnover and lack of continuity in care. Recent studies in the region have focused on identifying key PCC domains addressable in resource limited settings, understanding the PCC experiences and expectations of PWH and their providers, and testing innovative interventions. We highlight the need for additional studies to address the existing gaps.

Summary: We discuss the progress and challenges of implementing PCC in HIV care settings in SSA as well as the need for additional research to ensure that proposed PCC interventions have optimal impact.

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Patient-centered care; HIV; healthcare systems: sub-Saharan Africa								

Introduction

Globally, there are calls for healthcare systems to embrace patient-centered care (PCC). [1*,2] PCC has been defined as "care provision that is consistent with the values, needs, and desires of patients and is achieved when clinicians involve patients in healthcare discussions and decisions".[3] The overall goal of PCC is to encourage patients to take an active role in clinical decision making. PCC is necessarily a broad set of processes including: (1) empathy, (2) respect, (3) engagement, (4) relationship, (5) communication, (6) shared decision-making, (7) holistic focus, (8) individualized focus, and (9) coordinated care.[1*,4**,5]

PCC has been advocated as standard of care, globally, [1*,2,4**,5] and has been supported by the WHO, the President's Emergency Plan for AIDS Relief (PEPFAR) and UNAIDS [6,7**]. Strong evidence shows that PCC promotes patient education, linkage, adherence, retention and satisfaction with care across a number of chronic diseases.[7**–12] There is increasing interest in understanding patients' experiences and preferences, while acknowledging the heterogeneity among them.[13,14] There is also an increasing appreciation that PCC should embrace families and caregivers.[5,11]

Research on PCC has focused on chronic conditions, for which appropriate patient behaviors are essential for good clinical outcomes,[4**] such as HIV. Despite effective HIV treatment and interventions, sub-Saharan Africa (SSA) continues to bear the greatest disease burden worldwide. In addition, persons with HIV (PWH) now have concerning rates of other non-communicable diseases (NCDs), such as hypertension and diabetes. Healthcare systems are therefore challenged to respond to these evolving patient needs.[4**,15,16]

Challenges in implementing PCC in HIV care systems in SSA

The conceptualization of PCC remains a challenge. PCC has been mostly studied in high-resource settings, and there is still no clear definition that is acceptable and applicable across different socio-cultural contexts and healthcare systems.[1*,2,4**,7**,17*] PCC is sometimes referred to as person-centered, person-directed care, or person-focused care.[2,5] These terms have been used interchangeably across various diseases and healthcare settings, [2] yet their goals have been shown to differ.[5] Despite efforts to identifying the key PCC elements or domains,[2] consensus has been elusive. Furthermore, the absence of consensus on PCC frameworks, measures and implementation strategies[2,4**,7**,17*] makes it difficult to assess the impact of PCC interventions.[2,11,17*] Conceptual work that clarifies and sharpens our understanding of PCC and that explores the ways in which core concepts might be adapted to better align with local or regional history and culture, are needed.

Implementing PCC practices is complex and time-consuming, requiring the support and commitment of health management teams, and patience.[1*] Few studies have focused on how to implement PCC processes and approaches. Literature on how to address the system-level barriers that hinder the adoption and sustainability of appropriate PCC interventions is limited.[2] A recent systematic review proposed an integrated conceptual framework

that identified attributes of successful PCC pathways within healthcare systems, while considering professional experience, organizational constraints, and social dynamics.[1*]

The majority of PCC studies have been conducted in high-income countries.[1,4,17*] Existing definitions, frameworks and measures have been primarily been developed and validated among those populations. Few studies[7**] provide carefully developed and validated measure of PCC domains in SSA. Well-tailored frameworks and validated measures that incorporate the diversity of PWH across different socio-cultural settings in SSA are needed.[7**]

Healthcare systems in SSA have structural challenges that hamper the effective implementation of PCC. They include limited capital and human resources, high patient volume, long queues, high provider turnover, paternalistic care, poor provider-patient dynamics, lack of continuity in care, and stigma associated with HIV facilities, among other system-level barriers.[18] The rise of NCDs among PWH and the COVID pandemic further burden already constrained health systems.[15,16] These system issues have the potential to negatively influence patients' and providers' expectations, experiences, and interactions, and reduce the capacity of HIV programs to promote PCC. The region would therefore benefit from studies that explore the implementation of PCC in disease-burden health systems.

Lesson learned from PCC in SSA

Despite these challenges, an increasing number of studies examine PCC in SSA.[4**,7**–10,19**–21] A systematic review of 31 studies from 12 SSA countries identified three major domains to incorporate in defining PCC practices in HIV care facilities: 1) staffing, 2) service delivery standards, 3) direct client support services.[7**] Another systematic review identified cross-national domains that could be adopted in limited resource settings. [4**] These domains were interdependency and collectivism, bringing care into the home and community, equity and non-discrimination, addressing health and illness, and workforce well- being.[4**] These studies provide a roadmap for developing effective PCC frameworks for region.

Our studies in Kenya revealed that PWH desire active participation in their HIV care, but may not always know how to take up this role. HIV providers have their own expectations of how PWH should interact with the healthcare system, and may not be accustomed to patients who desire an active role in their care.[22] HIV providers in the region lack adequate training on the key components of PCC, including patient-provider communication and shared decision making.[4**,22] Yet PWH who perceive more patient-centered communication are more likely to be satisfied with care.[9] This suggests that all levels of HIV providers would benefit from training in implementing the principles of PCC. Appropriate training interventions would ensure that the existing healthcare workforce is well equipped to implement PCC in SSA.

Efforts to introduce some of the elements of PCC into HIV care delivery in SSA have included adolescent friendly clinics, fast track antiretroviral therapy (ART) initiation, differentiated care models, peer support, financial incentives, task shifting, health system

quality improvement and mobile health (mHealth) programs.[21,23*–27] Unfortunately, the majority of these interventions do not address a combination of system-level barriers, perhaps limiting their effectiveness. Our group in Kenya recently conducted a successful and cost-effective intervention to improve PCC that addressed a combination of PCC system-level barriers. The intervention included provider training on patient-clinician communication, continuity of care, shared-decision making and convenient clinic appointment scheduling.[8**,20] Clinician training on patient-clinician communication that incorporated motivational interviewing, had a significant impact on patient viral suppression. [8**] Continuity of care has also been shown to promote ART adherence.[10] These positive findings notwithstanding, more work is needed in SSA on the definitions, measures, frameworks, and implementation strategies for PCC to ensure that health systems have the tools to successfully implement it.

As PCC interventions move ahead in SSA [7,21], careful and continuous evaluation will be essential as many questions remain. For example, does addressing one domain of PCC compromise another? Differentiated service delivery (DSD) is an approach that promotes PCC by minimizing frequency of clinic visits, promoting convenient location of service delivery, and coordinating healthcare packages for varying PWH needs.[23*,24] DSD may improve opportunities for integrated HIV-NCD care[23*] with great potential for sustainability,[24] but does DSD limit and/or negatively impact patient-provider relationships?

The impact of mHealth in SSA on PCC is unknown. The majority of the mHealth interventions in the region involve offering clinic and medication reminders, social support, improving HIV care knowledge as well as access to telemedicine.[25–27] Other mHealth interventions have focused on promoting HIV self-management including personal monitoring of health status.[28] As SSA embraces mHealth, we need to acknowledge that it is changing how providers and patients interact.[29*] On the one hand, providers have been reported to spend many clinical hours entering health information in the electronic health record systems, limiting the interaction time with patients.[29*] On the other hand, patients may feel less actively engaged during a clinical encounter, and may not always have the funds or technological support including smart phones and internet connectivity to effectively participate in beneficial clinical discussion. Innovative approaches are needed to ensure that as we implement certain dimensions of PCC, we do not compromise on others.

Moving forward, the research agenda for SSA could therefore focus on: 1) Conceptual research that enhances our understanding of the core concepts of PCC, aligning with the regional diversity, 2) Development and validation of regional frameworks and measures, 3) Identification of effective PCC implementation strategies for disease-burden and financially challenged health systems, 4) Provision of appropriate PCC training to equip the existing healthcare workforce with adequate knowledge and skills, 5) Continuous evaluation of the impact of proposed regional interventions on the different dimensions of PCC. Execution of this research agenda may be key in developing effective PCC policies for the region.

Conclusion

In conclusion, our review highlights the value of PCC in HIV care systems in SSA as well as some of the key implementation challenges including lack of consensus in the conceptualization of PCC, limited regional studies on the adoption and sustainability of PCC interventions and structural challenges within the HIV care system. These challenges notwithstanding, there is increasing interest in examining PCC in the region. Recent studies have focused on identifying key PCC domains for resource limited HIV settings, understanding patients and providers' experiences and expectations of PCC, as well as identifying effective interventions. We propose the need for additional research to provide contextual definitions, measures, frameworks, and implementation strategies. There is also need to continuously evaluate how proposed PCC interventions affect the different domains of PCC.

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Key points:

- Effective implementation of PCC in SSA has been hampered by: 1) lack of consensus on the conceptualization of PCC, including definition, frameworks, measures and implementation strategies; 2) limited regional studies on the adoption and sustainability of PCC interventions; and 3) healthcare structural challenges including limited capital and human resources, poor provider-patient dynamics, high provider turnover and lack of continuity in care.
- There is growing interest in promoting PCC across HIV care programs in SSA, focusing on identifying key PCC domains addressable in resource limited settings, understanding the PCC experiences and expectations of PWH and their providers, and testing innovative interventions
- We highlight the need for additional studies to address the existing gaps and the need to continuously evaluate how proposed PCC interventions affect the different domains of PCC.