The Case for Family-Centered Differentiated Service Delivery for HIV

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Abstract: Differentiated care, or differentiated service delivery (DSD), is increasingly being promoted as one of the possible ways to address and improve access, quality, and efficiency of HIV prevention, care, and treatment. Family-centered care has long been promoted within the provision of HIV services, but the full benefits have not necessarily been realized. In this article, we bring together these two approaches and make the case for how family-centered DSD can offer benefits to both people affected by HIV and the health system. Family-centered DSD approaches are presented for HIV testing and antiretroviral therapy (ART) delivery, referencing policies, best practice examples, and evidence from the field. With differentiated family-centered ART delivery, the potential efficiencies gained by extending ART refills can both benefit clients by reducing the frequency and intensity of contact with the health service and lead to health system gains by not requiring multiple providers to care for one family. A family-centered DSD approach should also be leveraged along the HIV care cascade in the provision of prevention technologies and mobilizing family members to receive regular HIV testing. Furthermore, a family-centered lens should be applied wherever DSD is implemented to ensure that, for example, adolescents who are pregnant receive an adapted package of quality care.

Key Words: differentiated care, differentiated service delivery, differentiated ART delivery, differentiated HIV testing, family-centered, service delivery

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INTRODUCTION

For the first time in the history of the HIV response, more than half of the people living with HIV (PLHIV) are accessing life-saving antiretroviral therapy (ART).[1] However, with the recommendation that all PLHIV should be on treatment, significant gaps remain. In acknowledgment of the diversity of needs of PLHIV, there is a realization that different packages of prevention, testing, treatment, and care are required.[2] Differentiated service delivery (DSD), or differentiated care, puts the client at the center of care, focusing on meeting the needs and expectations of people living with and at increased vulnerability of acquiring HIV.[3] Although DSD has only been recently articulated, a family-centered approach to HIV is not new[4]; however, its application has been limited. The introduction of DSD into national programs provides an opportunity to readdress how family-centered HIV care may be implemented and scaled up within national programs. Furthermore, a paradigm shift from recognizing that people are in families to leveraging the fact that people can receive services through families is necessary to scale up family-centered DSD.

Although DSD has been well defined and is increasingly recognized by different stakeholders,[5] it is also critical to define "family" in the current social and epidemic contexts. Many "family-centered" interventions are limited to assessing the outcomes for mothers and children. Husbands and fathers of children, who may or may not be living with HIV, should be encouraged to test for HIV and be engaged in accessing ART as part of a family unit. "Family" should also be more broadly defined to reflect the large number of people living in "non-traditional families," or "families of choice," made up of some traditional family members, partners, and friends.[4] This is particularly important as we seek to "leave no one behind" in the HIV response and provide services for the most vulnerable groups of people.[6] For example, members of key populations—men who have sex with men, sex workers, people who inject drugs, and transgender people—are also part of families as parents, siblings, and spouses. Failure to acknowledge them as families will only limit their opportunities for quality care. Although many lessons can be gleaned from the implementation of Option B+ in the prevention of mother-to-child transmission, we would be remiss to ignore the family members beyond the mother and infant if we are to scale up quality family-centered care.

In this article, family-centered DSD is described across the HIV care continuum from prevention through to viral suppression. Available data and best practice examples are outlined to make the case that scaling up this approach is particularly critical to reach the global goals for HIV.

DISCUSSION

Family-Centered Differentiated HIV Testing

HIV testing services may also benefit from applying a family-centered DSD approach. The 2016 World Health Organization (WHO) "Guidelines on HIV self-testing and partner notification" presents new recommendations that will

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require a family-centered approach to have maximum impact.[7] With the new evidence available, the recommendation that "voluntary assisted partner notification services should be offered" builds on the existing recommendations to support testing of family members. It is an additional approach that comes with a strong recommendation based on data showing increased testing among those who received voluntary assisted partner notification services. Furthermore, self-test kits can be used in secondary distribution to test family members who are not home during home- or community-based testing initiatives.[8]

Using index client testing through invitation not only of partners but also of children to the facility has also enhanced uptake of HIV testing using a family-centered approach.[9] Expanding index client testing to other members of the community (often within an integrated health screening approach) may further increase uptake of HIV testing services among family units.[10]

Integration of HIV testing into maternal and child health (MCH) clinics and expanded program on immunization (EPI) services also supports a family-centered approach, optimizing the opportunity of mothers and children attending simultaneously. When early infant HIV diagnosis was integrated within EPI in rural Zambia, the proportion of both infant and maternal HIV testing increased.[11]

The addition of HIV self-testing also presents a unique opportunity to support higher uptake of testing among families.[12] Data are now available to support that HIV self-testing that is voluntary, not coercive or mandatory, can increase testing rates among primary male partners of pregnant or postpartum women,[8] sex workers,[13] and men who have sex with men.[14]

Barriers to Differentiating Art Delivery for Children and Adolescents

The WHO 2016 recommendation to reduce the clinical frequency of ART visits to three to six months and increase the ART refill duration to three to six months for clinically stable clients did not define the age of the client to whom it applied, leading many countries and clinicians to be hesitant to expand DSD policies to children and adolescents. For example, the National AIDS Control Programme in Kenya, which was one of the first countries to include DSD in the national guidelines for HIV in 2016, excludes people aged less than than 20 years from DSD models and defines them as "unstable patients."[15]

In recognition of the exclusion of children, adolescents, pregnant and breastfeeding women, and key populations from differentiated ART delivery, WHO, along with Centres for Disease Control and Prevention, PEPFAR (the United States President's Emergency Plan for AIDS Relief), the United States Agency for International Development, and the International AIDS Society published "Key considerations for differentiated antiretroviral therapy delivery for specific populations: children, adolescents, pregnant and breastfeeding women and key populations," emphasizing that these populations can benefit from and should not be excluded from differentiated ART delivery models.[16] Previous concerns regarding weight increases have led to clinicians continuing monthly appointments for all children until on adult doses. These concerns are addressed by highlighting that only three dosage changes will occur in children between the ages of two and years. This document clearly outlines the frequency of clinical visits and ART refill visits according to age. For children between the ages of two and four years, "considerations should be given to seeing them every three months" and ART refills can be every three to six months. For children aged five years and older, the frequency of clinical consultations is every three to six months with a recommendation to align with school holidays.

Part of the argument for expanding DSD to families is that any efficiency gains from DSD for adults will not be realized if children are still required to attend facilities at such frequent intervals. For example, if an HIV-infected parent/caregiver collects his or her ART at a community delivery point on a three-month basis, but must still travel to a facility each month to collect ART for their HIV-infected child, the benefits of the alternative models are "diminished for the family as a whole, putting adherence and retention in care at risk."[17]

Field Experience of Family-Centered Differentiated Delivery

Family-centered DSD is appropriate across the care continuum, but most data and examples are from ART delivery. Differentiated ART delivery has been defined into four service models: (1) health care worker-managed groups, (2) client-managed groups, (3) facility-based individual models, and (4) out-of-facility individual models.[18] Increasingly, these models are being adapted for families.[19]

For both HIV testing services and ART, service delivery can be built around the "when," "where," "who," and "what" of the model. Regarding the "where" of family-centered care, one important decision is whether care is delivered to the family within the MCH service up to a prescribed age versus within the ART or out-patient department. In Zimbabwe, the Ministry of Health and Child Care Operational and Service Delivery Manual (OSDM) advises that children and their parents be followed up in the MCH unit until the child reaches five years of age, after which they are all transferred to the adult ART clinic.[20] Second, the principles of integration, providing services on the same day, by the same health care provider, in the same clinic space, are essential to the concept of many family-centered service delivery models.

There is increasing evidence that longer ART refills for clinically stable children and adolescents through facility-based individual models can yield improved outcomes. Data from six countries in the Baylor International Pediatric AIDS Initiative highlight that good outcomes (adherence, retention in care, and viral suppression) were maintained among clinically stable children and adolescents (0–19 years) when they were provided with longer ART refills (greater than one month) or multi-month prescriptions.[21] Similar outcomes have been observed in Tanzania from the standardized pediatric expedited encounters for ART drugs initiative (SPEEDI) where clients are fast-tracked to receive two-three monthly refills.[22] However, to ensure that this is within a family approach, visits must be aligned for all family members.

In South Africa, Adherence Clubs, a health care worker-managed group model, have been adapted to cater for families. In Family Adherence Clubs, families (defined as children and at least one caregiver) attend the club meetings for ART refills and child disclosure support. The clubs include a number of families and both HIV-positive and HIV-negative caregivers. Pilot data show high rates of retention (>85%) and low rates of viral rebound (<20%) after 36 months for both children and caregivers.[23] Adherence Clubs are also being adapted for HIV-positive mothers. This entails forming postnatal clubs are formed after delivery to support women to remain in care and maintain viral suppression while integrating care of the exposed infant, including provision of HIV testing, prophylaxis, and other child health services, such as growth monitoring and EPI.

For adolescents, a family-centered lens may also be relevant. To appropriately support adolescents during this period of transition and growth, a balance should be struck between engaging the family of adolescents in care and treatment while fostering independence and self-management. This is exemplified by the transition of adolescents from a Family Adherence Club to being part of a Youth Club.[24] In the Youth Clubs, there is a strong emphasis on psychosocial support that compliments the clinical consultations and ART refill components of the model.

Client-managed group models, such as Community ART Refill Groups (CARGs), have also been modified to support family-centered ART provision. In Zimbabwe, family CARGs are included within the MoHCC OSDM.[20] Where multiple family members require ART, one member is nominated to collect the ART refills for the others. For clinical consultations, all family members are seen together. Care must be taken to ensure that children are seen frequently enough for clinical review, dose modification, and disclosure counseling. The WHO recommendation to provide three- to six-monthly clinical and refill visits for children older than two years supports integration of ART delivery for the child and parents within such differentiated models of ART delivery.

A family approach is also observed within mobile outreach models, an out-of-facility intervention where clinical services are brought closer to rural communities. In northern Namibia, the community-based ART outreach model has observed high rates of retention and adherence.[25] Primary care facilities provide mobile outreach to fixed points in hard to reach rural communities four to six times a year. Family units are managed together at this service. Children and adolescents and their adult family members are seen for clinical review every three to six months (depending on their being defined as stable), with ART refills for up to three months.

Family-Centered DSD for Clients with Advanced HIV Disease

WHO classifies all children aged younger than five years as having advanced HIV disease.[26] Until two years of age, monthly visits are still recommended to identify clinical problems and adjust ART doses. Family member appointments must still be aligned and may be booked on the same day to encourage caregivers of infants with HIV to access peer support.

Clients previously stable on ART may become unstable with a detectable high viral load. Where family-centered care is provided, such patients may benefit from family member support while receiving a period of more intensive clinical and psychosocial follow-up.

Family-Centered DSD Across the HIV Care Continuum

A family-centered DSD approach applies a family lens to the way in which all services are provided. There are few examples of doing so across the care continuum, but where it has been done, benefits are evident for both the clients and the health system. In Kenya, the HIV program is designed around the family unit. "Family members are booked for joint appointments, their files are kept together, couples and family counseling is provided, and family treatment buddies and partner involvement are encouraged."[27]

In Mozambique, a pilot program of the Ariel Glaser Pediatric AIDS Healthcare Initiative implemented a family approach across the care continuum. The program included index case finding with same-day family consultations and disclosure support. Follow-up visits were designed as a family CARG with ART refills collected on behalf of all family members. More than 1000 families were part of the pilot program. Adults (18 years and older) in the family approach were 68% less likely to be lost to follow-up (LTFU) after four years [adjusted hazard ratio (aHR) 0.32, 95% confidence interval (CI) 0.25 to 0.41] compared with the control arm after adjusting for education and marital status.[28] Similarly, after four years, the pediatric patients in the family approach were 72% less likely to be LTFU compared with the control arm after adjusting for age (aHR 0.28, 95% CI: 0.21 to 0.39).

CONCLUSIONS

Adopting family DSD models across the continuum of HIV care will support programs to reach the 90-90-90 targets. ART programs that have previously focused on differentiated ART delivery for stable clients should now think beyond this client population and consider implementation of family-centered differentiated ART to further support retention and virological suppression. Where family-centered DSD models have been endorsed in ART programs, clients should always be offered the choice equal to receive their ART through either a family- or individual-focused model, respecting the client's wishes to disclose to family or nonfamily members.

DSD for families must be sensitive to the specific needs of the different family members. Services should be provided within an integrated approach with care by the same clinician (who), at the same time (when), and within the same clinic (where). Countries and ART programs that are including DSD in their strategic planning to reach their 90-90-90 targets should conduct a situation analysis to assess how families are currently being offered HIV testing and ART services and look to adapt or build family service delivery models that address specific challenges identified in their program's

outcome data (for example poor retention in postpartum prevention of mother-to-child transmission programs or for adolescents on ART) for clients accessing services (multiple visits for a stable adult who needs to bring a child to care monthly) or for health care workers delivering care.

By including this analysis in the strategic planning of DSD, it can be ensured that family-centered models are included and funded in the scale-up of DSD, allowing clients to benefit from the range of interventions shown to increase testing uptake and improve retention and adherence.

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