Values and preferences – maternal and child health summary
Consultation for the development of the WHO Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection

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Introduction
The World Health Organization (WHO) is in the process of developing updated 2013 Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. Within this development process, the WHO Guideline Review Committee supports the involvement of key stakeholders, including end-users. To ensure end-user input, it is important to assess the values and preferences of potential guideline recommendations. Consultations were undertaken to facilitate this participation.

This consultation addresses the key values and preference related to antiretroviral therapy (ART) in maternal and child health. For children’s health, it specifically assessed (a) the challenging and supportive factors to starting and maintaining children on ART, (b) suggested strategies that assist in improving a child’s adherence to ART and (c) perceived preference of when to start ART in children and what ART regimen to start on. For maternal health, this consultation specifically assessed (a) the challenging and supportive factors for taking ART during pregnancy, (b) the challenging and supportive factors for engaging in care, (c) suggested strategies to improve adherence and engagement in care and (d) perceived preferences of starting lifelong ART during pregnancy.

Method
In November 2012, a series of eight workshops was conducted in KwaZulu-Natal (KZN) and Gauteng (GAU), South Africa. Four workshops involved parents and caregivers of children receiving ART and four pregnant women living with HIV. The workshops were based on participatory learning and action approaches.

Local partner organizations from both rural and urban areas invited participants to attend the workshop. Khayelisha Care (KZN), Philisani (KZN) and Let us Grow (GAU) assisted in recruiting parents and caregivers. Mothers 2 Mothers (KZN) and the Chris Hani Baragwanath Hospital (GAU) assisted with pregnant women living with HIV.

The transcriptions of voice recording and field notes were condensed and divided into subthemes and overall themes using qualitative content analysis. For each area, themes are presented in the order of being most frequently voiced.

Key findings from parents and caregivers of children receiving ART
Overall, 47 parents and caregivers of children receiving ART took part in the workshops. 51% resided in townships, 60% were caregivers, 85% had the child in their full-time care, 62% had children receiving ART longer than two years and 64% had children who were still on their first ART regimen.

Challenging factors
- Challenges directly associated with the medication: taste, storage, strict 12-hourly timing, side effects especially on starting ART, number of tablets, especially for those with comorbidities, and changing formulations.
- Not knowing the reason and not understanding the need for taking ART were identified as significant challenges to adherence. Parents and caregivers expressed anxiety about telling their child the truth about their status. Particularly older children “begin to ask questions”, and these are often left unanswered or lies are told instead.
- Especially for those from rural areas, the financial burden of attending hospital greatly affected access to ART. Many stated not having enough money for transport and food to take the ART. Challenges in receiving assistance from the government were as a result of not being able to obtain the child’s birth certificate and prove legal guardianship.
- Long distances to hospitals, no access to ART in local clinics and frequent appointments were raised as barriers. Within the hospital, waiting time to be seen or collect ART, negative staff attitudes and lack of confidentiality were also viewed as barriers.
- Participants felt the impact looking after a child receiving ART had on their own life as a result of the extra financial strain, expectation of clinic appointments and the responsibility of ensuring that their child takes their ART. A number of participants told of having to “quit their jobs to look after their child” and rely on other family members to help.

Supportive factors
- Looking after a child receiving ART was seen as a collective effort. Support in ensuring that ART is taken and that the child attends appointments from other family members, friends, neighbours and health care workers was viewed as a necessity.
- Observing the dramatic improvement to the health of their child and other children was felt to be a key motivator in continuing to support their child to take their ART.
- Several parents and caregivers told of the positive effect that being open with their child about their status and the need for ART had on their adherence. Continuing conversation after disclosure was also viewed to be helpful.
Ensuring their own understanding of ART assisted parents and caregivers in recognizing the importance of adherence. Attending treatment classes, having discussions with other parent and caregivers and the ability to ask questions of health care workers were identified as ways that improve their understanding.

Encouraging autonomy and independence with their ART and addressing adherence as a joint effort between child and caregiver, especially among older children, was viewed as an important and highly supportive.

A few participants gave examples of how having less-frequent appointments, a longer supply of medication and free transport to clinics greatly reduced health service barriers.

Suggested strategies for improving adherence
- To overcome financial barriers that are affecting access to ART, participants suggested the providing income-generating projects, providing free transport to clinics, improving the grant structure, especially for caregivers, and providing food parcels.
- Health service changes included: decentralizing ART to improve access, less-frequent appointments, having other parents and caregivers living with HIV as health care workers, providing family clinics (where everyone can receive care and collect ART at the same time), improving the appointment structure and the possible delivery of ART.
- Increased support through parent and caregiver support groups, improved access to counselling and social worker involvement.

Responses on “when to start” and “what to start on”
- All participants indicated that all children should be started on ART “when they are younger” at “an early age”. It was felt that this would assist children in getting used to taking ART. They also conveyed that children should be started at diagnosis even if they are well, since this would prevent them from ever becoming sick and to help them to remain healthy.
- Participants suggested that children be started or changed to ART regimens taken once a day, which can be taken in the evening, taste better and do not require refrigeration.

Key findings from pregnant women living with HIV
In total, 46 pregnant women or recent mothers (child ≤1 year old) living with HIV were involved in the workshops. 59% were 25–34 years old, 46% had tested HIV positive during this pregnancy, 59% were taking ART for preventing mother-to-child transmission and 63% started ART during this pregnancy.

Challenging factors
- For women who have been diagnosed during pregnancy, the initial challenge is dealing with the shock and accepting their status. This often made it difficult to cope with all the information given. Some reported not being happy with how they were told their results and that health personnel were brutal or insulting.
- Participants reported problems in disclosing their status, especially to family and partners. Several women choose to hide their status because of fear. Some particularly found the requirement of having a treatment buddy too stressful, since it involved having to disclose to someone.
- Nondisclosure led to lack of support and isolation, with many having no one to talk to. Many women complained of a complete lack of support from their families and boyfriends or partners. The women who do disclose, willingly or unwillingly, are faced with many issues around stigma and discrimination, especially within their communities.
- Some participants expressed limited understanding of the importance of ART, with many having questions especially concerning how ART would affect their unborn baby and confusion around feeding choices.
- Other challenges participants faced were the side effects of ART. Many women reported nausea and vomiting and difficulty with the number of tablets.
- Health service challenges included: frequent appointments, travel costs to the clinic, negative staff attitudes, waiting times, ART availability, including reports of stock-out, and difficulty in re-engaging in care postpartum.

Supportive factors
- Many women find that accepting their status and support from others are extremely helpful. They found visiting the clinic to be an opportunity for support and were also grateful for the chance to talk about HIV freely in support groups.
- Most women stated that they were happy they knew their status and were grateful they had found out. Health improvement due to taking ART and having a baby who was HIV free made them feel stronger and confident about taking ART.
- Women who had disclosed to others sometimes saw this as providing opportunities to be supported. Participants with another family member living with HIV found this easier to talk about their status and challenges.
- Understanding more about antiretroviral medicines and how they help protect them motivated participants to take their medication. Such information received was from the clinic, counsellors and workshops as well as other sources, including the Internet. Counselling at the clinic was mentioned a number of times as a positive thing that has helped them.
- Many women stated that family members and partners helped them to take their medication on time and reminded them. Other women used the alarm on their mobile phones and reminders in diaries.
Suggested strategies for improving adherence and engagement in care

- Many women stated the importance and need to accept their status and move on. They felt it was important that women get diagnosed early before pregnancy so there is less to cope with when pregnant.
- Participants requested greater access to services through appointments and medication collection being available after work or college and available from mobile clinics. They also highlighted the preferences for having less frequent appointments with the ability to choose their clinics. Others called for more training of health care workers, private counselling areas and family clinics that made it possible for mother and child to receive care in the same clinic.
- Having support groups in the community and being able to discuss HIV issues freely were popular concepts. However, some women preferred that support groups just be for women living with HIV and some preferred to be able to bring their partners.
- Participants also felt that providing more information, including on positive living, would be useful, not just for the women themselves but for their families and the community.

Responses to option B+

- Views toward starting lifelong treatment in pregnancy regardless of CD4 count were equally split among the participants.
- Those who supported option B+ felt that it would:
  - have benefits for their own health
  - increase the likelihood of having a HIV-negative baby
  - be less confusing and more straightforward
  - encourage ongoing engagement in care.
- Those who opposed option B+ felt that it would:
  - create extra strain on current clinics and government finances
  - be too much to cope with
  - cause further problems with adherence especially if not feeling unwell
  - increase the chances of having medication side effects
  - cause anxieties about having lifetime commitment to ART.
- Participants voiced additional considerations:
  - requirement of further information and advice on the options and consequences of each;
  - potential added benefit of being counselled by women and mothers living with HIV;
  - the need for time to decide – with some suggesting a week;
  - ultimately the decision on which option should be theirs;
  - that having to go to different clinics to their children for medication would decrease acceptability – with a call for one-stop family clinics; and
  - a warning that pressure to choose B+ could result in defaulting.

Conclusion

Parents and caregivers of children receiving ART

- Based on the feedback among caregivers of children living with HIV, caregivers are expected to accept well the early initiation of ART among young children, regardless of clinical condition. However, adequate support is needed to ensure adherence and retention in care. These findings highlight the preference for once-daily dosing and the challenges of administering syrups (such as lopinavir/ritonavir), confirming the importance of balancing effectiveness and acceptability when choosing first-line ART regimens.

Pregnant women living with HIV

- The development of option B+ recommendations should consider challenging and supportive factors to enhance pregnant women living with HIV to engage in care and the community acceptability of option B+.

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