



People Living With HIV Experiences During Transition From Nevirapine to Dolutegravir-Based Antiretroviral Therapy in Indonesia: A Qualitative Study

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HUMAN IMMUNODEFICIENCY VIRUS (HIV) IN THE WORLD



**HIV is an epidemic that
has existed for over 40
years**



**Currently, total ±38
million people living
with HIV (WHO)**



**Antiretroviral therapy (ART)
as main treatment to reduce
morbidity and mortality**



COMBINATION OF 3 DRUG REGIMENS



2 nucleoside reverse transcriptase inhibitors (NRTI)

One of the following: non nucleoside reverse transcriptase inhibitors (NNRTI), integrase strand inhibitor (INSTI), or protease inhibitor (PI)

An NNRTI-class ART approved by FDA and used since 1996 : Nevirapine



WHO

The presence of NVP resistance in $>10\%$ of the population using it as first-line therapy.



SIHA HIV UNIT CIPTO HOSPITAL

97.5% of HIV patients on NVP-based ART achieve suppressed viral load → **NVP is still effective for use.**



The increasing resistance rate to NVP → **a strong reason to fast-track the transition from NVP to DTG.**

BACKGROUND: ART TRANSITION



The transition to DTG is a new thing for healthcare facilities



Information on user experiences & side effect management, as well as risk communication, is important for optimizing usage



Qualitative studies related to the transition to DTG → help program designers, implementers, and policymakers better understand patient experiences during the implementation of the new treatment policy

WHO. HIV Treatment: update of recommendations on first and second line antiretroviral regimens [e-book]. Switzerland: World Health Organisation; 2019 [cited 2024 May]. Available from: <https://iris.who.int/bitstream/handle/10665/325892/WHO-CDS-HIV-19.15-eng.pdf?sequence=1>

Alhassan Y, Twimukye A, Malaba T, et al. Engendering health systems in response to national rollout of dolutegravir-based regimens among women of childbearing potential: a qualitative study with stakeholders in South Africa and Uganda. BMC Health Services Research [Internet]. 2020 Aug 1 [cited 2024 May];20(1):1-12. <https://doi.org/10.1186/s12913-020-05580-0>

Giralt AN, Nostlinger C, Lee J, et al. Understanding the acceptability and adherence paediatric antiretroviral treatment in the new formulation of pellets (LPV/r): the protocol of a realist evaluation. BMJ Open [Internet]. 2017 [cited 2024 May];7(3):e014528. doi: 10.1136/bmjopen-2016-014528



WHO recommends transitioning from nevirapine to dolutegravir, The transition from NVP to DTG began in Indonesia in March 2023



There has been no qualitative research on the experiences of HIV patients undergoing the transition from nevirapine to dolutegravir-based antiretroviral therapy.

Research Question



What are the experiences of HIV patients undergoing the transition from Nevirapine to Dolutegravir-based ARV therapy?

General Objective

To describe the experiences of HIV patients undergoing the transition from nevirapine-based antiretroviral therapy to dolutegravir.



Specific Objective

- **To describe patients' perceptions of the effectiveness of dolutegravir as a new drug.**
- **To identify patients' experiences related to side effects that arise during the transition to dolutegravir.**
- **To explore the challenges of patient adaptation during the transition process, including difficulties encountered, uncertainties regarding side effects, and patients' readiness to face sudden changes in treatment regimens.**





Time & Place

The study will be conducted at the **HIV Integrated Service Unit, Cipto Mangunkusumo General Hospital, Jakarta**, in October 2024.

This study is part of the research: "**Profile of Side Effects of Dolutegravir-Based Antiretroviral Therapy in HIV Patients Undergoing the Transition Program from Nevirapine-Based Antiretroviral Therapy at Cipto Mangunkusumo Hospital,**" with the principal investigator Prof. Evy Yuniastuti, which has been ongoing since March 2023.

conducted on **People Living with HIV**

The study sample includes patients who previously received **Nevirapine-based treatment** and have undergone the **treatment transition to Dolutegravir**.

Using **in-depth interview** methods, patients are asked to **describe their experiences related to the treatment transition**.





Subject Recruitment Flow

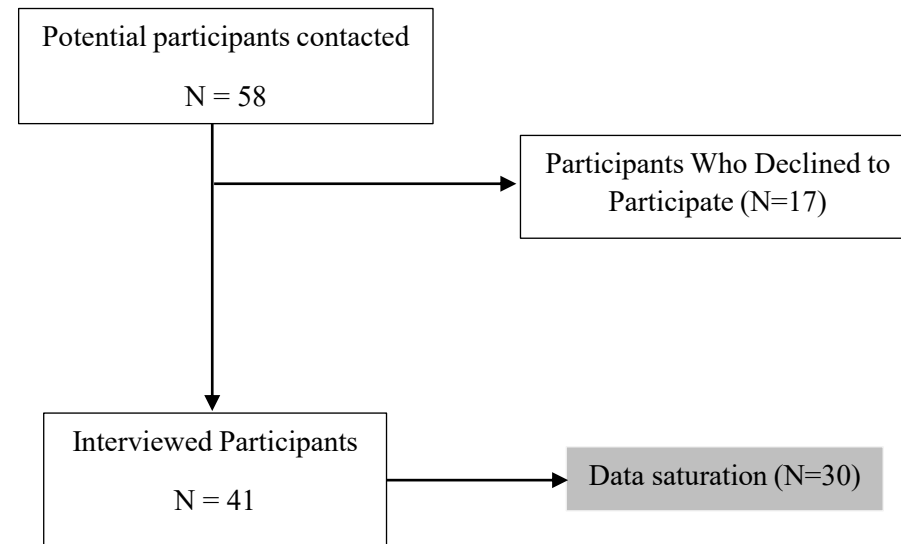


Figure 4.1 Subject Recruitment Flow

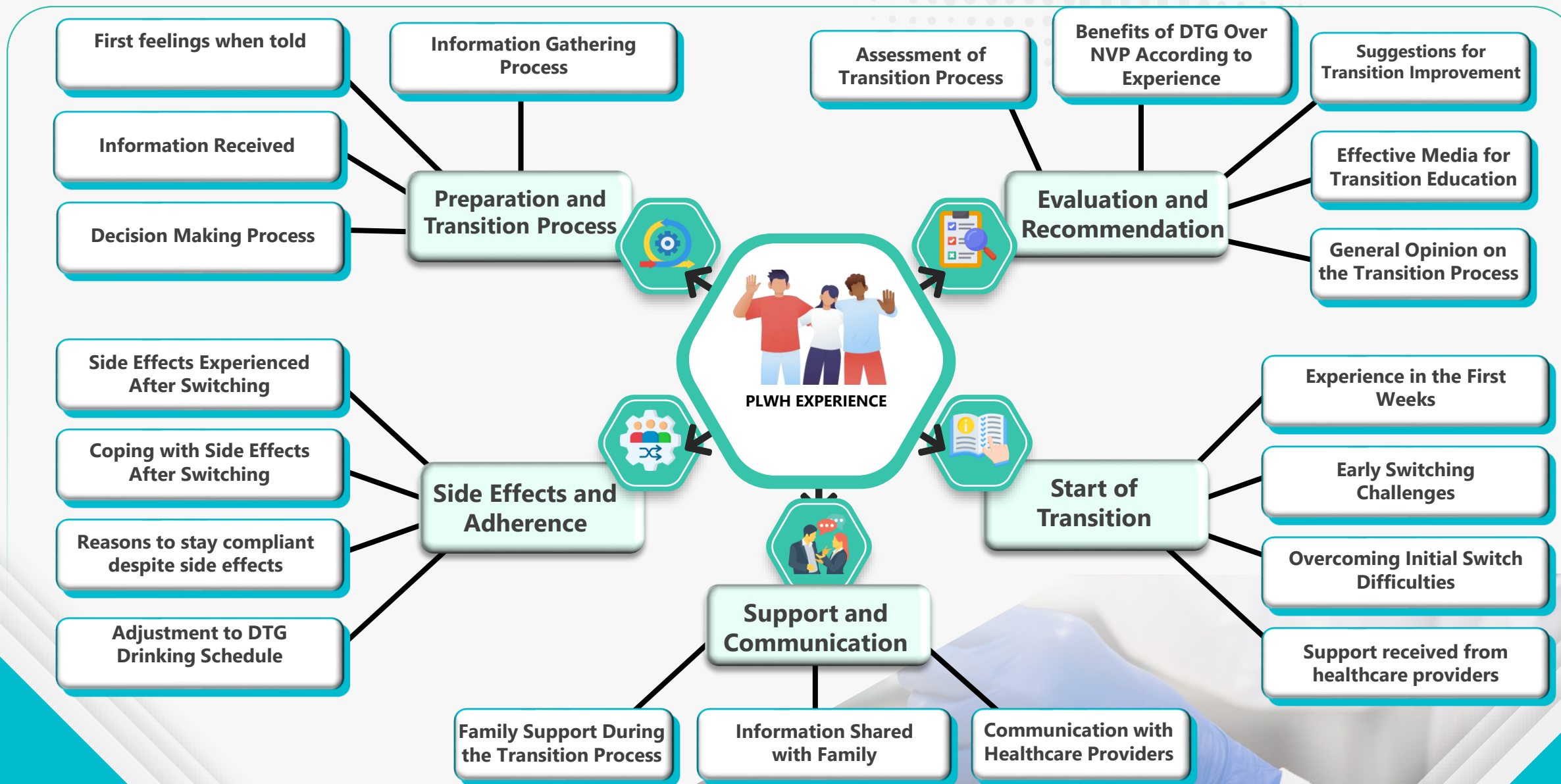
Table 4.1 Demographic and clinical characteristics of 30 patients who switched to DTG

Characteristic	N (%) or Median (IQR)
Age, Year	46 (20-55)
Biological Sex	
Female	14 (47)
Male	16 (53)
Last Education	
Elementary School	2 (6,7)
Middle School	5 (16,6)
High School	15 (50)
University/College	8 (26,7)
Current employment status	
Working	24 (80)
Risk Factors	
PWID	19 (63)
Seropositive Husband	6 (20)

Perinatal	2 (7)
Bisexual promiscuity	2 (7)
Opportunistic Infection	
Oral candidiasis	2 (7)
Chronic diarrhea	2 (7)
Ocular syphilis	1 (3)
Toxoplasmosis	1 (3)
Comorbidity	
Hepatitis C	11 (37)
Hypertension	5 (17)
Dyslipidemia	2 (7)
Liver cirrhosis	2 (7)

Table 4.2. Participants category based on biological sex

Participants Category	Interview participants	
	Male	Female
Participants without side effects	6	5
Participants with side effects		
Neuropsychiatric	5	5
Kidney dysfunction	5	4
TOTAL	16	14

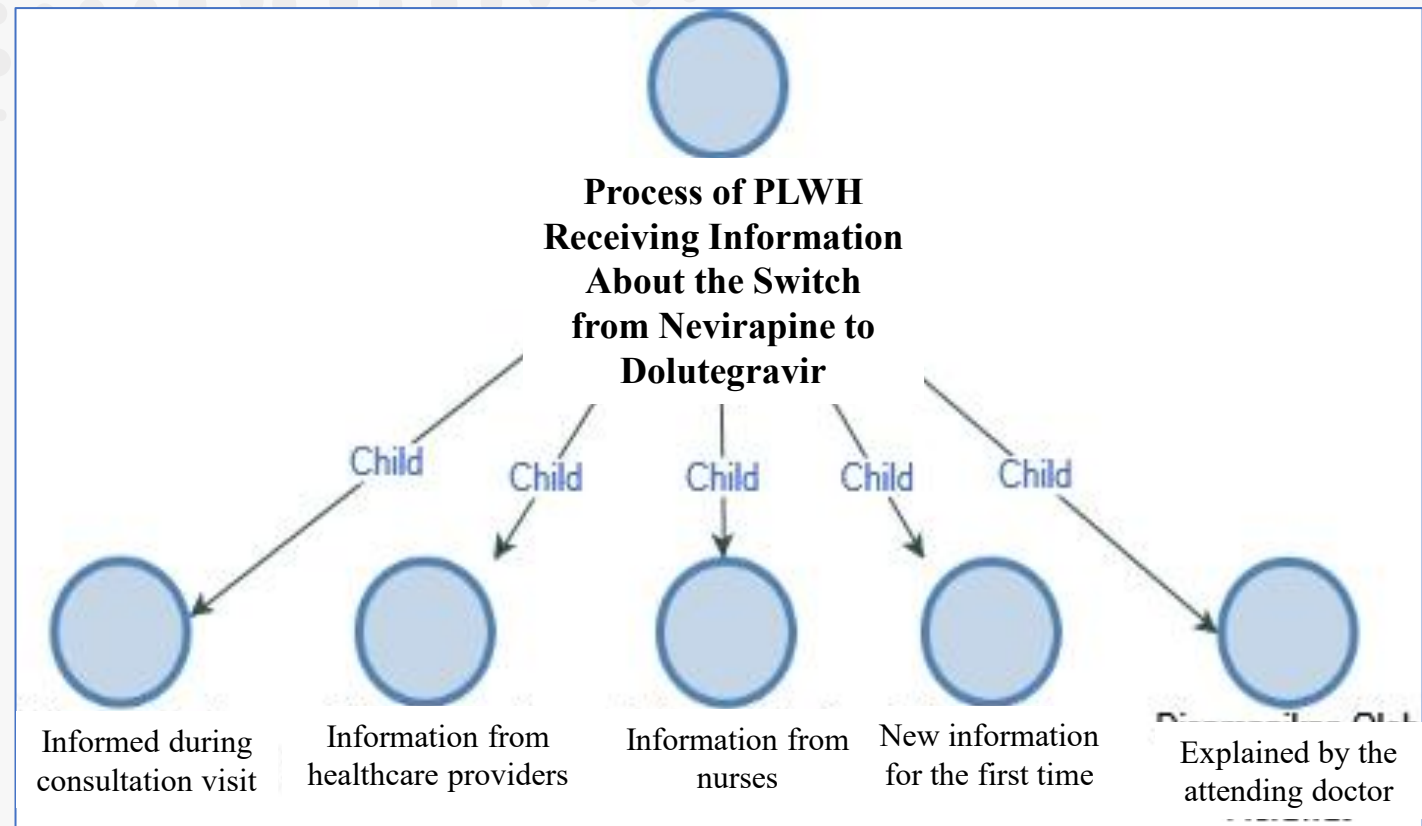


1. Transition Preparation and Process

Process of PLWH Receiving Information About the Switch from Nevirapine to Dolutegravir

- Most participants received transition information from their healthcare providers through direct communication. Initial reactions varied from apprehension to acceptance. “At first I was worried... but after they explained everything, I felt okay with it.” (Participant_9_B1)
- Reaction to the switch depends on the method of communication and the patient's level of understanding
- Information was received at different times
- Some participants forgot the details of the information provided

Comprehensive information → increases patient trust in medical decisions, making it easier to adapt to the new regimen. **(Krist et al.)**

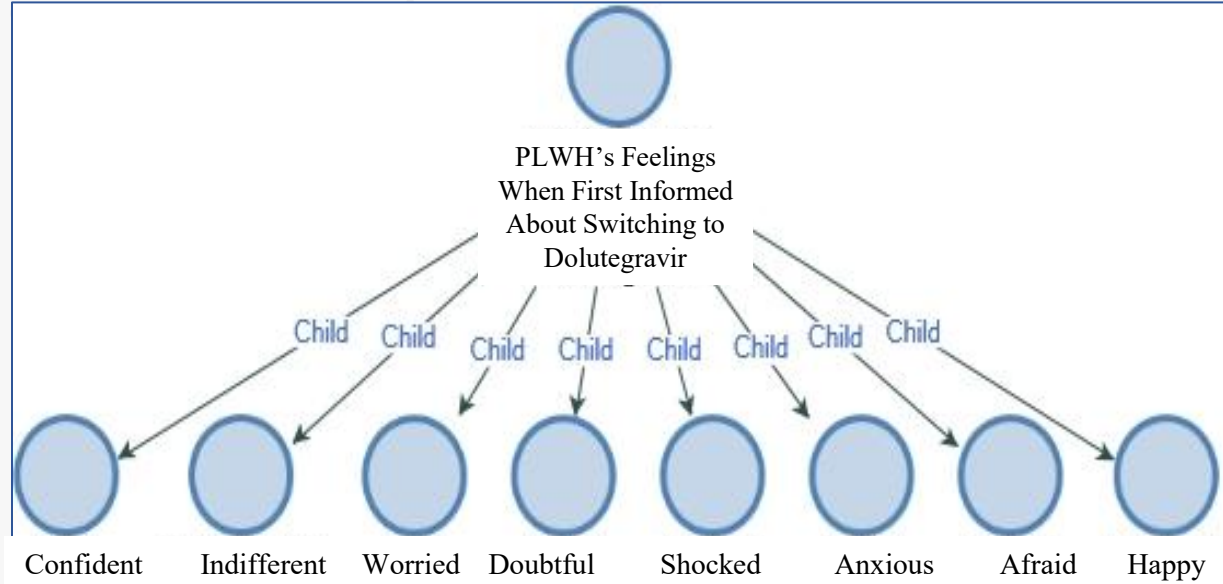


1. Transition Preparation and Process

PLWH's Feelings When First Informed About Switching to Dolutegravir

- Common reaction → Worried, Doubtful, Shocked, Anxious, Afraid, Happy, Indifferent, Confident
- Worried
- Felt worried when first told about the medication change
- *“....Eh, I'm also nervous since I'm used to Duviral and Neviral...”*
(participant_9_B1)
- PLWH accepted the switch after receiving explanations

Uganda → most participants had no problem when first informed about switching to DTG.



Phillips AN, Venter F, Havlir D, Kuritzkes D, Wensing A, Lundgren JD, et al. Risks and benefits of dolutegravir-based antiretroviral drug regimens in sub-saharan africa: a modelling study. Lancet HIV [Internet]. 2019 Feb [cited 2024 May];6(2):e116–27. doi: 10.1016/S2352-3018(18)30317-5

1. Transition Preparation and Process

Information Received by PLWH from Healthcare Providers Before Switching to Dolutegravir

- **Once-daily dosage welcomed as practical**

"Yes, they said this TLD medicine only needs to be taken once a day..." (participant_23_B1)

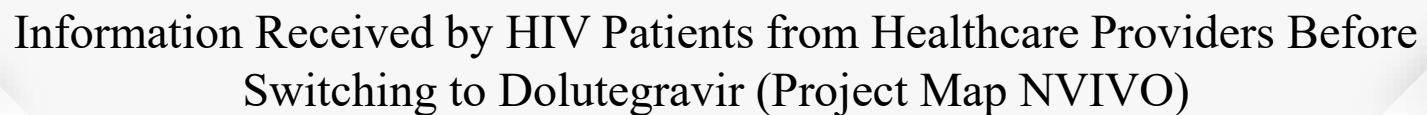
- **Information on potential side effects provided**

"...Um, what else, mostly what I understood were the side effects..." (participant_28_C1)

- **Acceptance of new drug despite possible side effects**

"Yes, even though there are side effects, like it or not, I have to accept it..." (participant_28_C1)

- Clear communication about side effects is essential in shaping PLWH expectations.
- **Stewart et al.:** PLWH who understand the risks and benefits of therapy are more likely to remain adherent, even when facing side effects.



1. Transition Preparation and Process

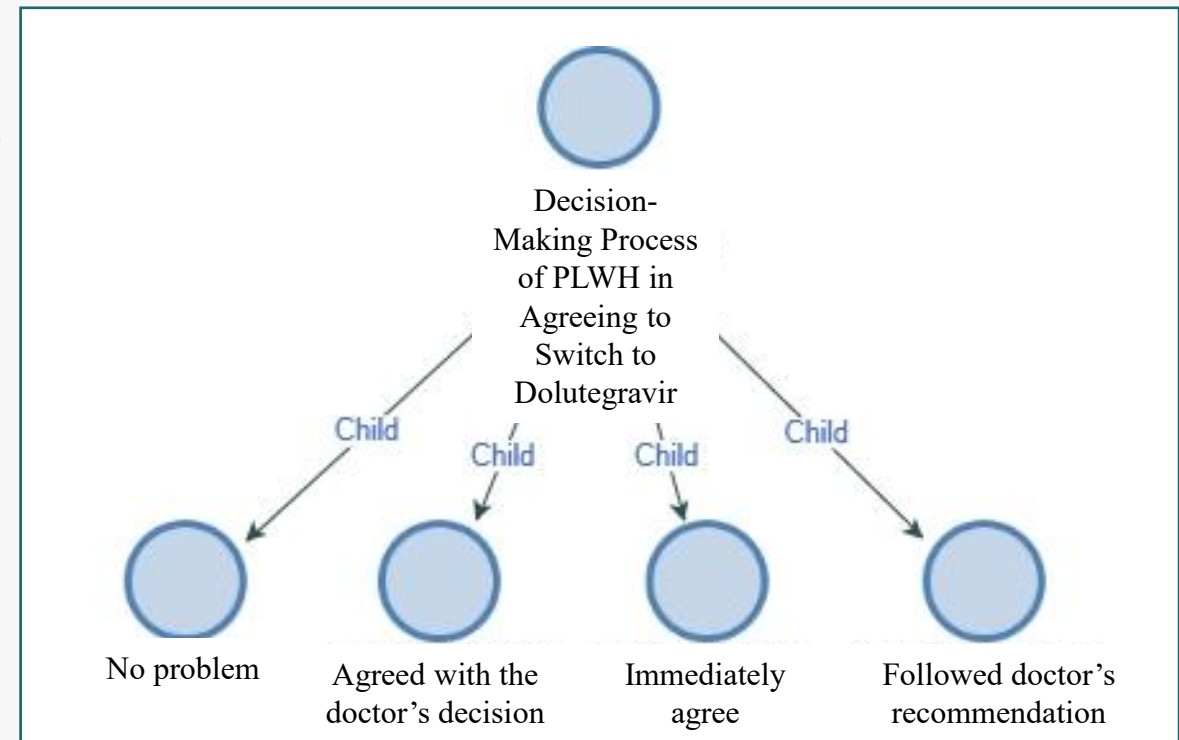
Decision-Making Process of PLWH in Agreeing to Switch to Dolutegravir

- Most PLWH agreed to the switch due to trust in doctors

*"Yes, I just follow the doctor's advice..."
(participant_28_C1)*

- Minimal hassle in undergoing the new treatment
- Perceived convenience and belief that the new regimen would not be burdensome

Quick agreement by PLWH → indicates high level of trust → **Wu et al.** : Trust in doctors plays a key role in treatment adherence among PLWH



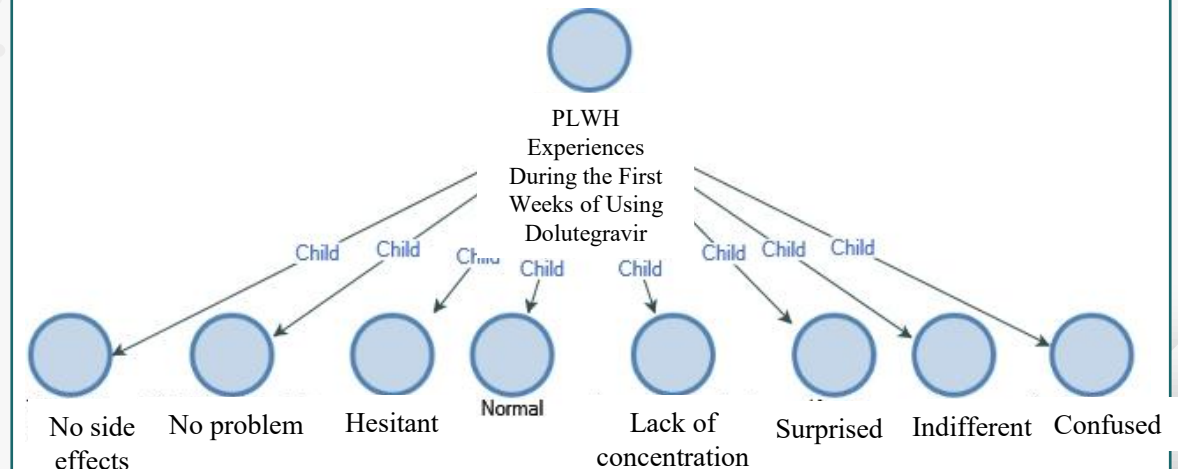
2. Start of Transition

PLWH Experiences During the First Weeks of Using Dolutegravir

- Most reported no side effects or significant changes

"In the first week, I didn't feel anything, just normal, nothing at all." (participant_28_C1)

- Confusion about adjusting medication schedule
 - Doubt and anxiety at the start, even without any actual issues
 - Mild discomfort: difficulty concentrating, slower information processing
 - Surprised by the larger tablet size
 - Appreciation for the practicality of the new regimen
-
- Switching regimens requires both physiological and psychological adjustment
 - **Brown et al.** → Transition to DTG is generally well tolerated



Brown JA, Nsakala BL, Mokhele K, Rakuoane I. Dolutegravir in real life: self-reported mental and physical health outcomes after transitioning from efavirenz- to dolutegravir-based antiretroviral therapy in a prospective cohort study in lesotho. *Hiv medicine* [Internet]. 2022 Jun 22 [cited 2024 Dec 3];24(2):153-62. doi: <https://doi.org/10.1111/hiv.13352>

Watkins CC, Treisman GJ. Cognitive impairment in patients with AIDS - prevalence and severity. *HIV/AIDS* [Internet]. 2015 Jan 29 [cited 2024 Dec 16];7:35-47. doi: 10.2147/HIV.S39665

Jakimiuk A, Piechal A, Drapalo AW, Nowaczyk A, Guzel DM. Central nervous system disorders after use of dolutegravir: evidence from preclinical and clinical studies. *Pharmacol rep* [Internet]. 2023 Aug 21 [cited 2024 Dec 16];75(5):1138-51. doi: 10.1007/s43440-023-00515-y

B. Challenges Faced by PLWH During the Initial Transition to Dolutegravir

- experienced no challenges

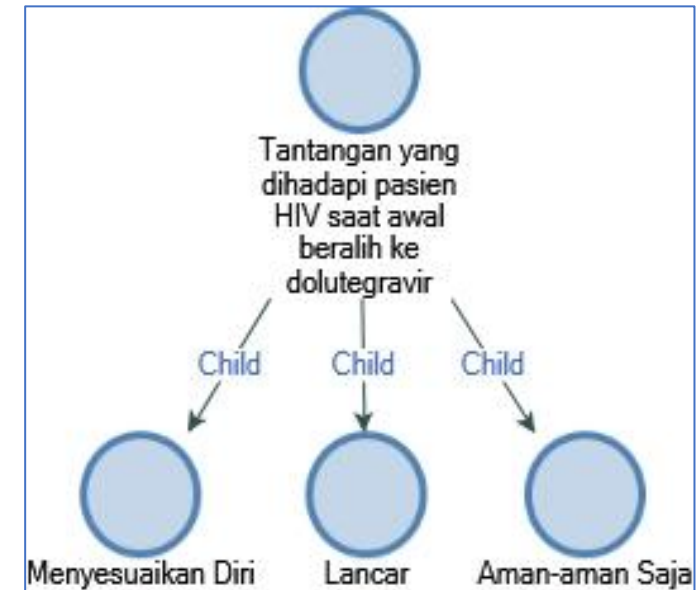
"Actually, there were no challenges, everything went smoothly..." (participant_11_A1)

- Need adaptation mainly related to dosing frequency
- Reduced concentration

"...That's it really. Just a bit of trouble concentrating, that's all." (participant_14_B2)

- Adjustments were mostly practical (habitual) rather than physiological (pharmacological)
- Education and support are essential during the transition period

2. Start of Transition

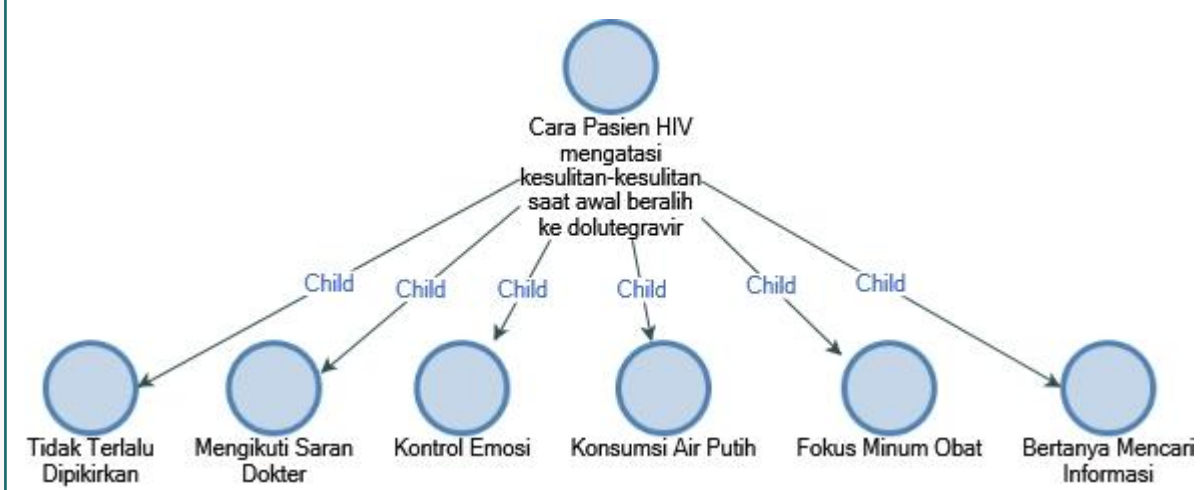


Solution: Involving family members, partners, and/or caregivers to help optimize the transition process for PLWH.

2. Start of Transition

How PLWH Cope with Challenges During the Initial Switch to Dolutegravir

- Maintaining a healthy diet & regular exercise
“Well, I keep my diet under control, doc. Monitoring, maintaining a good diet, and don’t forget to exercise...” (participant_8_A2)
- Taking supplements & vitamins
- Following doctor's advice & eating healthy food
- ↑ focus & repetition of certain activities to manage emotions



Zanganeh et al. → adopting a healthy lifestyle helps reduce side effects and improve quality of life in PLWH.

A holistic approach emphasizes the importance of non-pharmacological interventions.

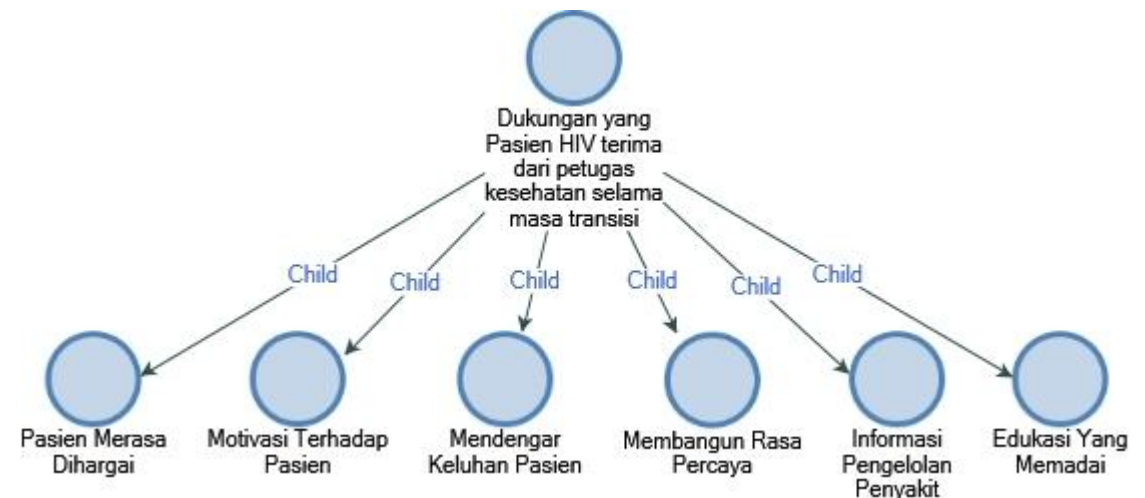
2. Start of Transition

Support Received from Healthcare Providers

- Desire for More Information regarding possibility of cure and illness management

“As patients, we want to know... Can we recover from this illness with the new medication or what about this new medication...” (Participant_11_A1)

- Motivational support to avoid feeling burdened by their condition
- Open communication builds trust and ensures PLWH understanding at every stage of treatment
- PLWH who feel heard and respected tend to be more adherent.



- **Cook et al.:** PLWH who received adequate emotional and educational support from healthcare providers have a better ability to overcome challenges during ART transition.

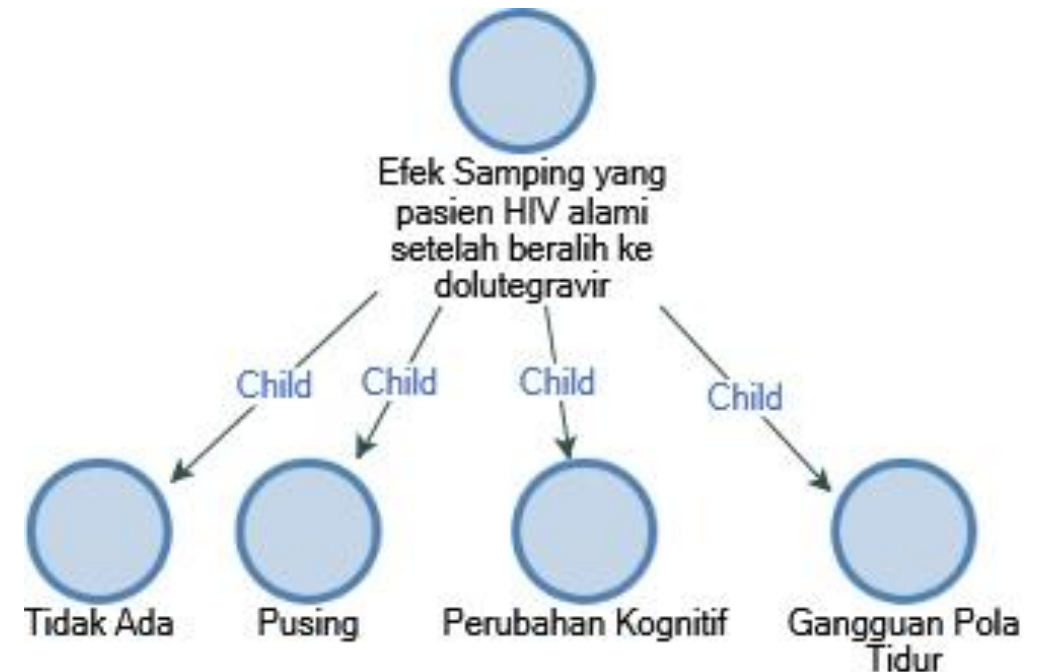
3. Side Effects & Adherence

Side Effects Experienced PLWH After Switching to Dolutegravir

- Sleep Disturbances → Difficulty falling asleep or staying asleep after waking up
- Dizziness

“At first, I felt kind of dizzy...” (Participant_11_A1)

- Cognitive impairment
- DTG shows better tolerability compared to previous antiretroviral regimens.
- Mild neurological side effects (e.g., insomnia, dizziness) are common but temporary during the transition phase

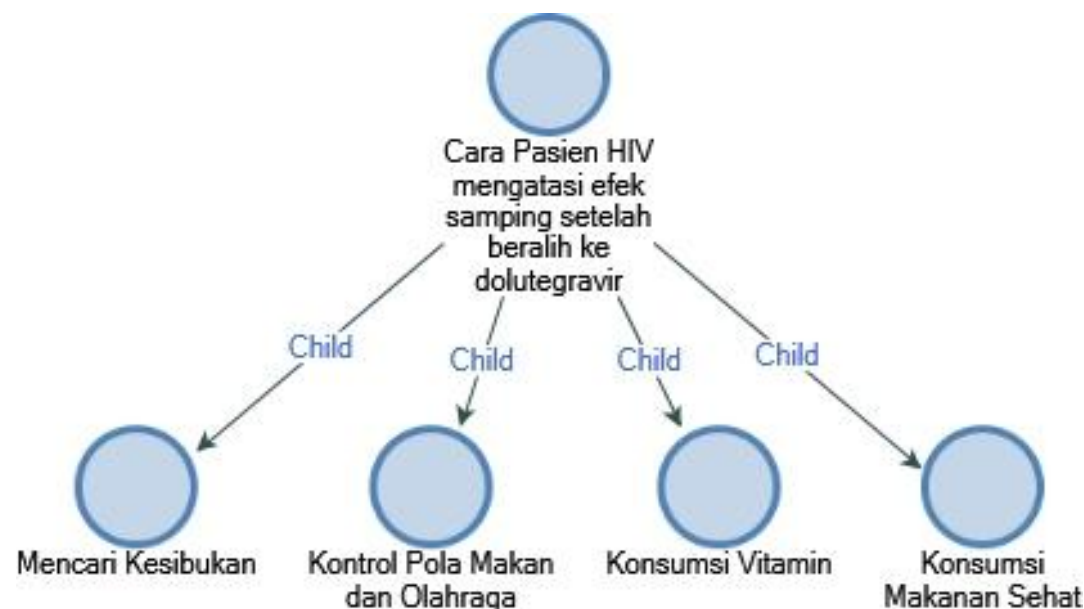


3. Side Effects & Adherence

How PLWH Manage Side Effects After Switching to Dolutegravir

- Medication Timing → Improved focus on when to take medication
- Hydration & Nutrition → Increased fluid intake and Maintaining a healthy diet
“*Mostly I just drink lots of water...*” (Participant_18_C2)
- Mental Health → Managing emotions, staying calm
“*Stay calm, you know, to control emotions and such...*” (Participant_16_C2)
- Following doctors’ advice and sticking to recommended healthy routines

Botros et al: Lifestyle interventions help reduce ART side effects and enhance quality of life



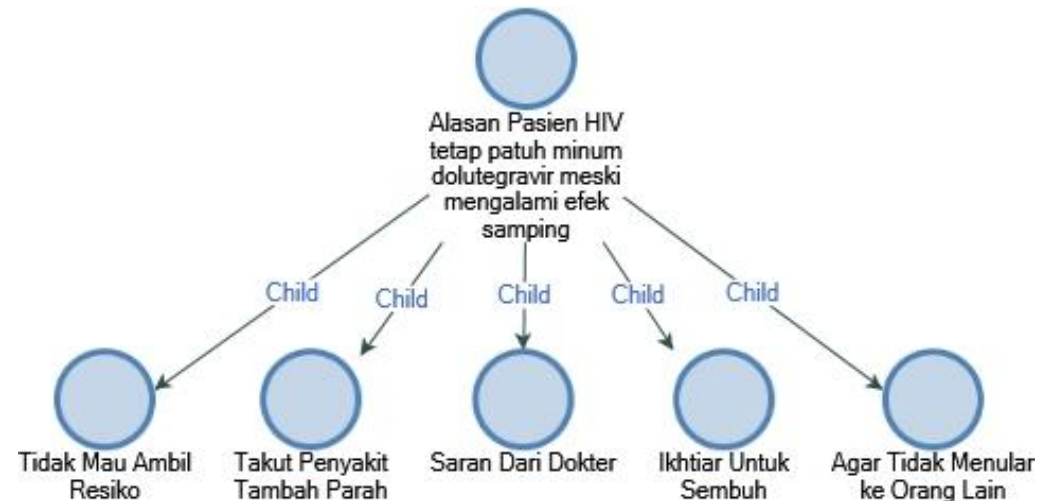
3. Side Effects & Adherence

Reasons PLWH Remain Adherent to Dolutegravir Despite Side Effects

- Trust in Medical Advice → Belief that doctors provide the best guidance
- Effective Therapeutic Communication → Helps maintain adherence even when side effects occur → key factor in successful treatment transition
- Fear of Health Deterioration → Concern that skipping medication may worsen their condition
- Fear of Transmitting the Virus

“So I don’t infect others” (Participant_29_B2)

Lirri E et al.: Side effects usually occur early after starting new treatment and tend to improve over time



- Many PLWH feel they have no other option but to continue the treatment to maintain their health and minimize risks.

Lirri E. Uganda switches to HIV super drug dolutegravir. In The East African. Nation Media Group: Nairobi, Kenya;2018.

Botros D, Somarriba G, Neri D, Miller TL. Interventions to address chronic disease and HIV: strategies to promote exercise and nutrition among HIV-infected individuals. Curr HIV/AIDS Rep [Internet]. 2012 Dec [cited 2024 Dec 3];9(4):351-63. doi: 10.1007/s11904-012-0135-7.

Pavlova S. Therapeutic communication in clinical practice. Journal of imab [Internet]. 2024 Jun [cited 2025 Jan 9];30(2):5509-11. <https://doi.org/10.5272/jimab.2024302.5509>

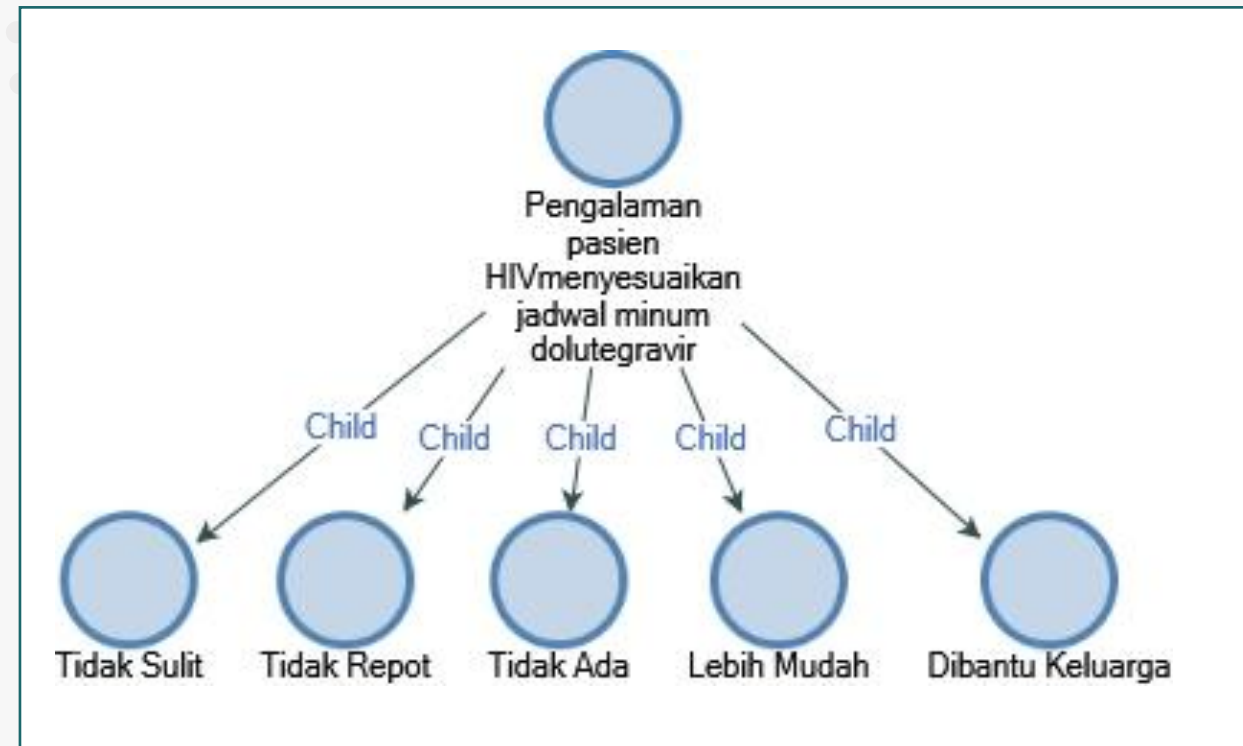
Effendy H, Virginia R, Asfar D, Syahrani A, Daeng A. Being survivors: therapeutic communication for people living with hiv/aids (plwha). Jurnal studi komunikasi [Internet]. 2021 Nov 3 [cited 2025 Jan 11];5(3):584-99. e-ISSN: 2549-7294

3. Side Effects & Adherence

PLWH Experience Adjusting to Dolutegravir Schedule

- No Major Difficulty in Scheduling
“It’s easy. I’ve always taken it around 8 o’clock...”
(Participant_27_A1)
- Medication Timing Based on Medical Advice → PLWH followed recommended timing from healthcare providers
- Supportive Tools & Environment → Technology and family support made it easier to stick to the schedule
- Once-Daily Regimen is Convenient → PLWH found once-daily dosing simpler and more manageable

Twimunkye et al.: Once-daily regimens are preferred due to greater comfort and flexibility in daily life

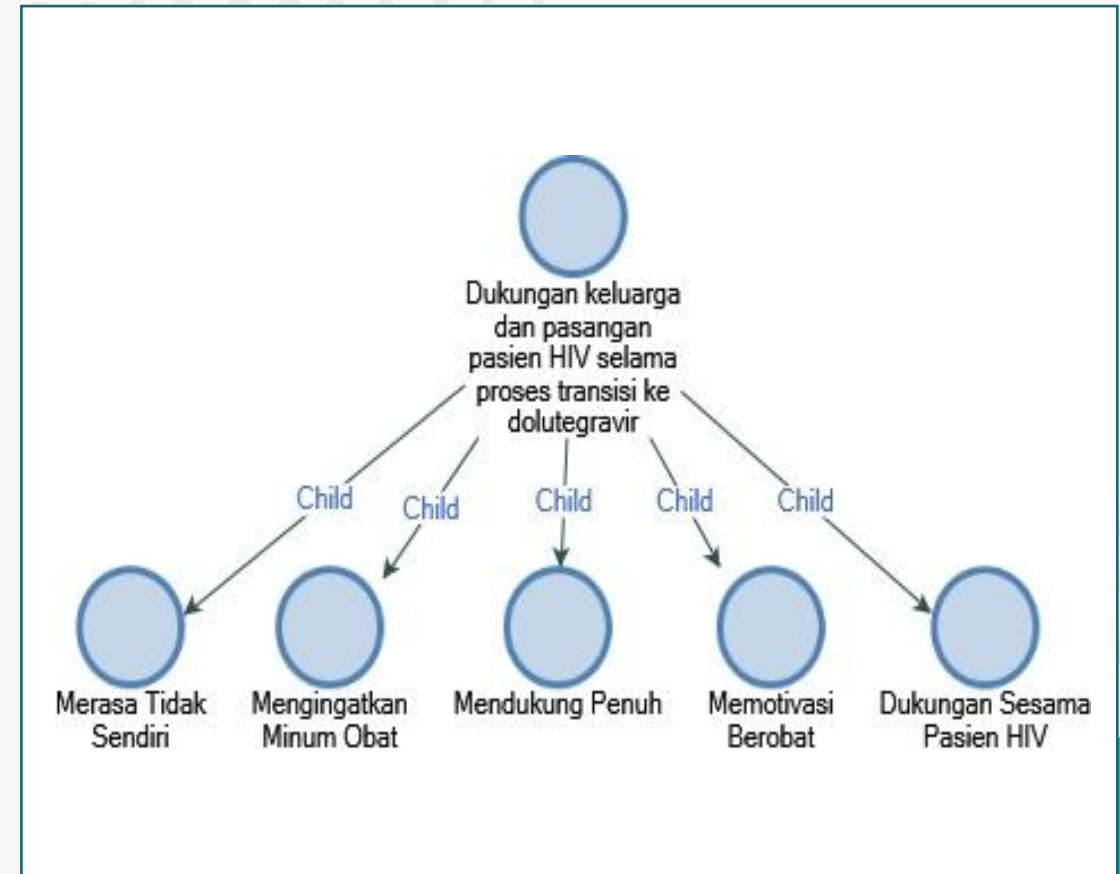


4. Support and Communication

Support from Family & Partners during Transition Process

- Family and partners help ensure treatment adherence
“They just accept it because they don’t feel it themselves. What matters is that we stay healthy and try to stay healthy.”
(*participant_28_C1*)
- Trust in Medical Decisions → Families/partners fully support medical decisions
- some family members even take the same medication to shows support

Fang Xu et al: family support is one of the key factors that improves quality of life and increases treatment adherence (enhances understanding of treatment and reduces anxiety related to new medications)

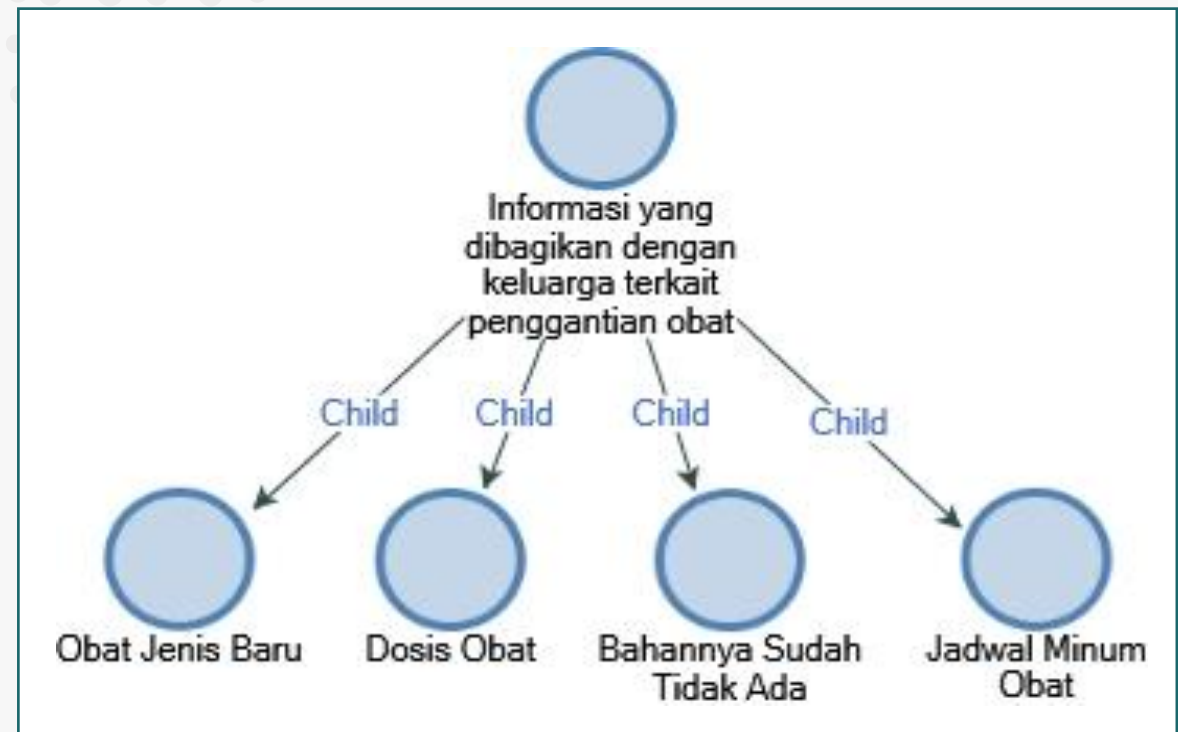


4. Support and Communication

Information Shared with Family Regarding Medication Switch

- Reason for the Switch → The previous medication will no longer be produced
“Umm, yes, the information was that ingredient is no longer available.” (participant_21_C1)
- Details about the benefits of switching to Dolutegravir
- Change in medication schedule
- The switch is part of a better and more controlled treatment plan

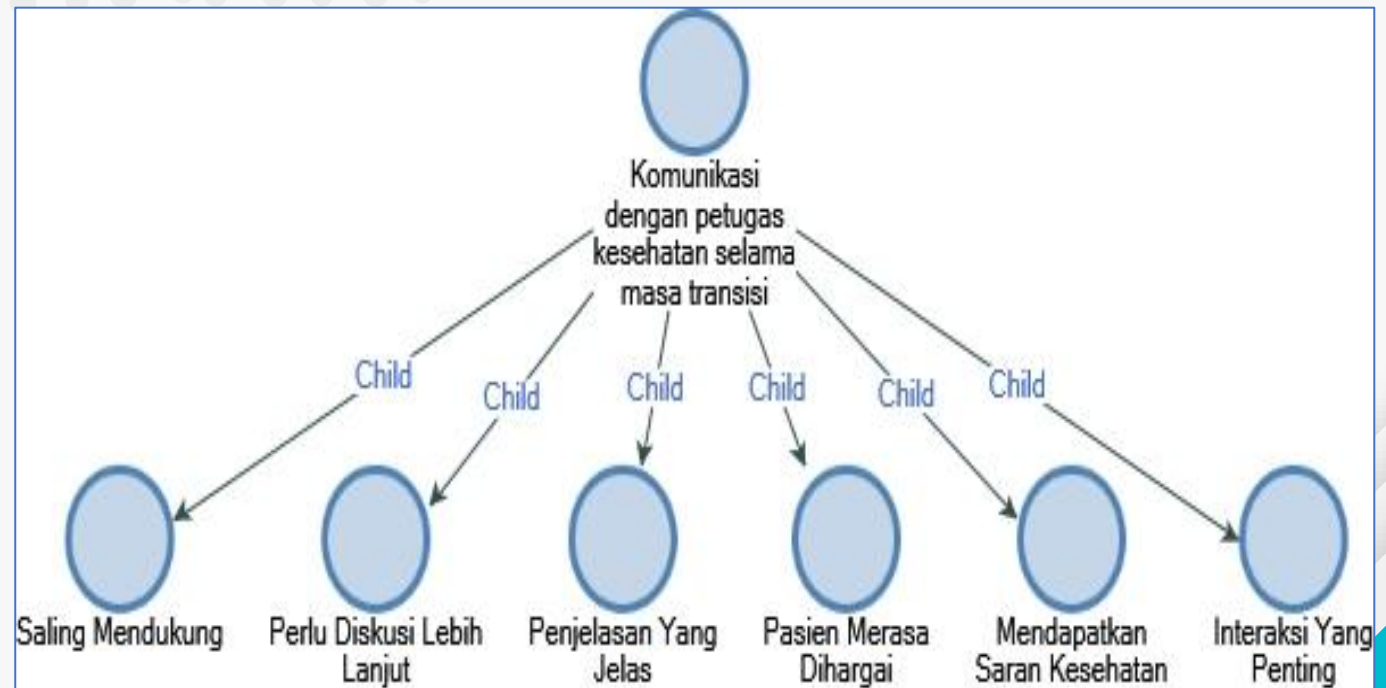
Mestre et al.: informational and emotional support from family is considered a key pillar in managing chronic illnesses.



4. Support and Communication

Communication with Health Providers During the Transition Period

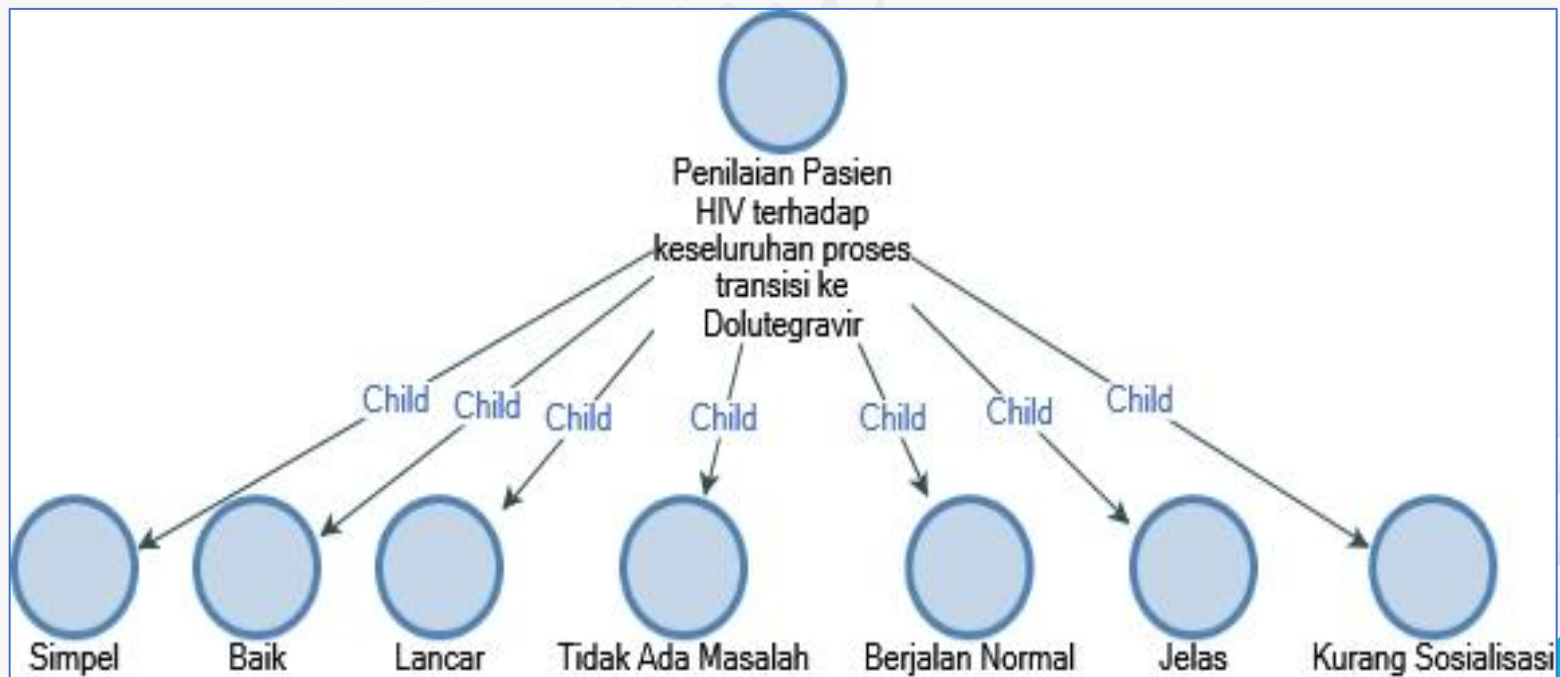
- Most PLWH reported good and encouraging communication with medical staff
“The communication was good, I felt very supported by the healthcare providers...”
(Participant_17_A1)
- PLWH expressed a need for more guidance on how to maintain health during the transition process
- Effective communication between PLWH and healthcare providers → ↑ trust and a sense of security
- Clear and empathetic communication → ↑ adherence and reduces anxiety related to side effects



5. Evaluation & Recommendation

PLWH Evaluation of the Transition to Dolutegravir

- No significant side effects experienced
“It was good. I didn’t experience any side effects.” (Participant_27_A1)
- Smooth and clear transition process
“The transition process was good... clear... and very informative.” (Participant_20_B1)
- Insufficient information or outreach about the medication change
- Overall, the transition to DTG was considered relatively easy and not burdensome



Zanganeh A, Khademi N, Ziapour A, Farahmandmoghadam N, Izadi N, Saeidi S, et al. Lifestyle in people living with HIV: a study of patients in kermanshah, iran. Inquiry [Internet]. 2023 Jan-Dec [cited 2024 Dec 3];60:469580221150567. doi: 10.1177/00469580221150567.

5. Evaluation & Recommendation

Benefits of DTG Over NVP According to PLWH Experiences

- Simpler treatment management

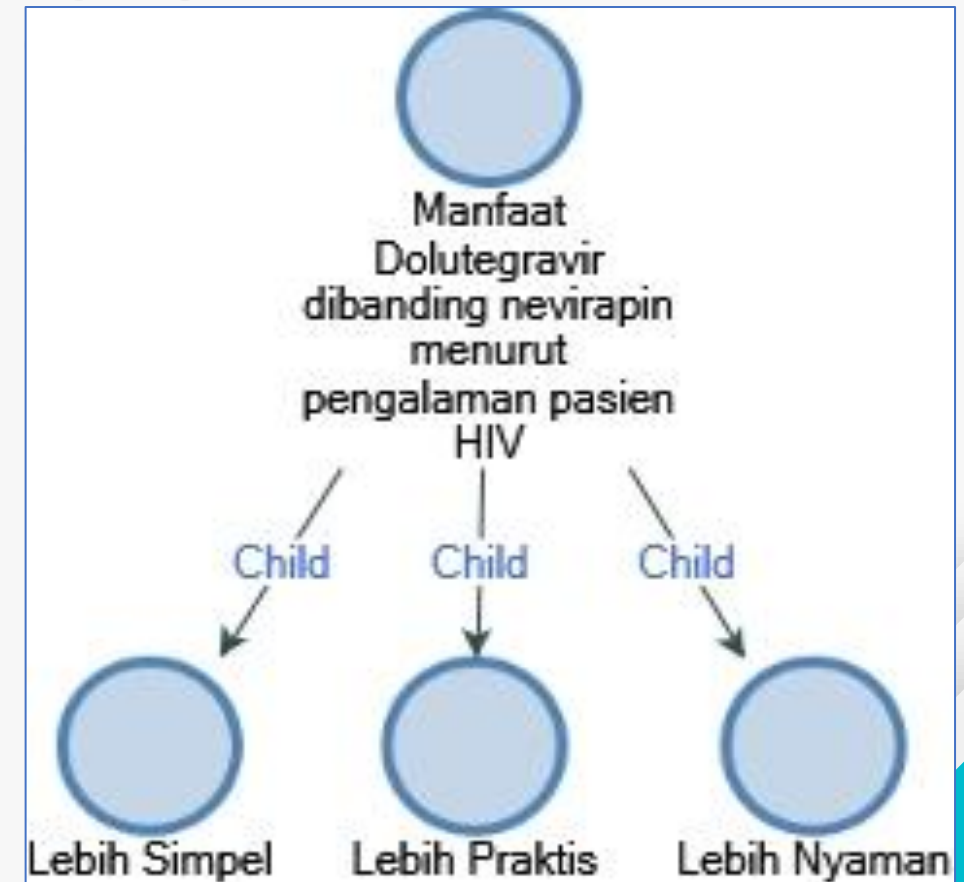
“It’s simpler, Doc.” (Participant_10_A1)

- More convenience in daily life

“I don’t need to carry a lot anymore. Usually three pills, now just one — it’s more practical.” (Participant_9_B1)

- Simplicity of a once-daily pill

- Pill burden (bigger number or size of tablets) → can reduce adherence
- **Choudhary et al.:** Single-dose regimens improve treatment adherence among PLWH

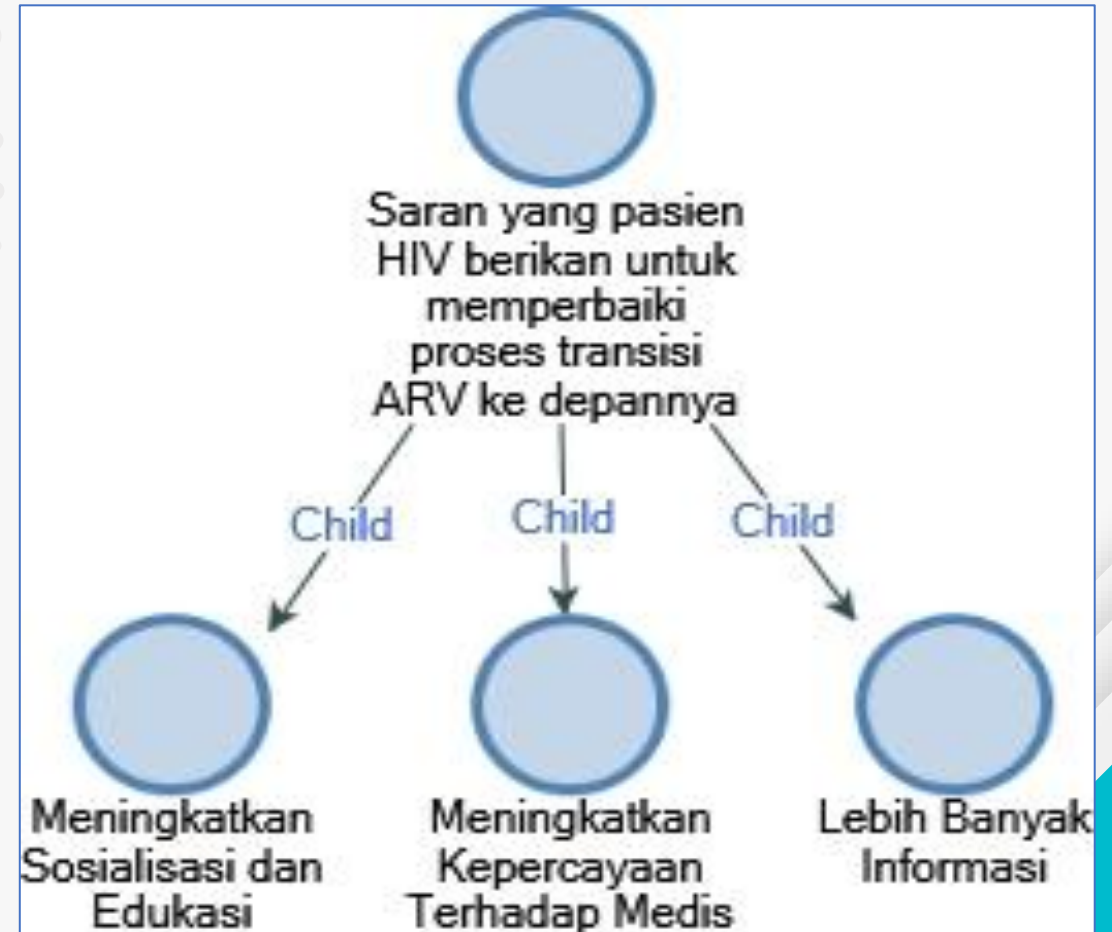


5. Evaluation & Recommendation

Recommendations from PLWH to Improve Future ART Transition Processes

- Follow doctors' advice
“My suggestion is just to follow the doctor’s advice.”
(Participant_26_A2)
- Monitor possible side effects during the transition process
- Continue DTG treatment as long as it remains effective and causes no significant issues
“If possible, just stick with this medication.”
(Participant_21_C1)
- Improve access for more comprehensive information

Ibrahim et al.: Technology and social media-based communication strategies have proven effective in increasing PLWH knowledge about HIV and ART

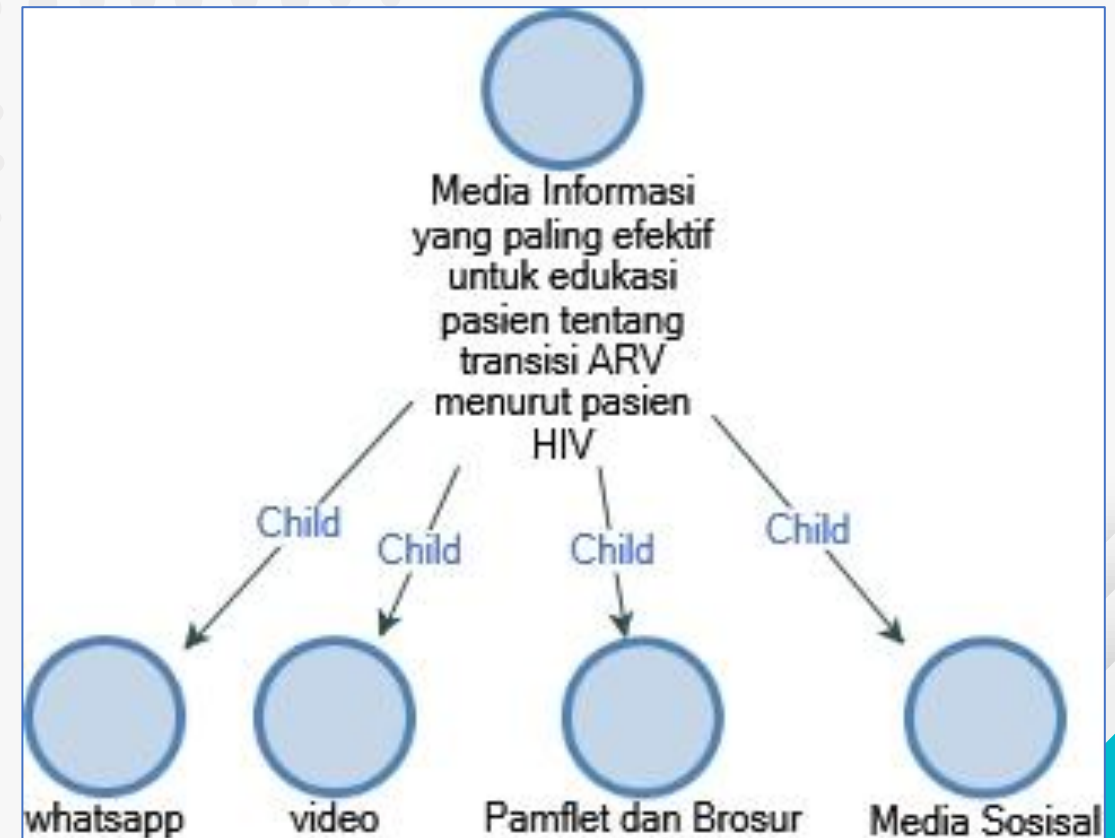


5. Evaluation & Recommendation

An Effective Media for Educating PLWH About ART Transition

- Recommending the use social media and digital communication platforms
- WhatsApp is considered sufficient for sharing information
“I think it’s better through WhatsApp, Doc.” (Participant_9_B1)
- Face-to-face sessions or seminars
- Educational videos
“Maybe a video would be enough...” (Participant_16_C2)

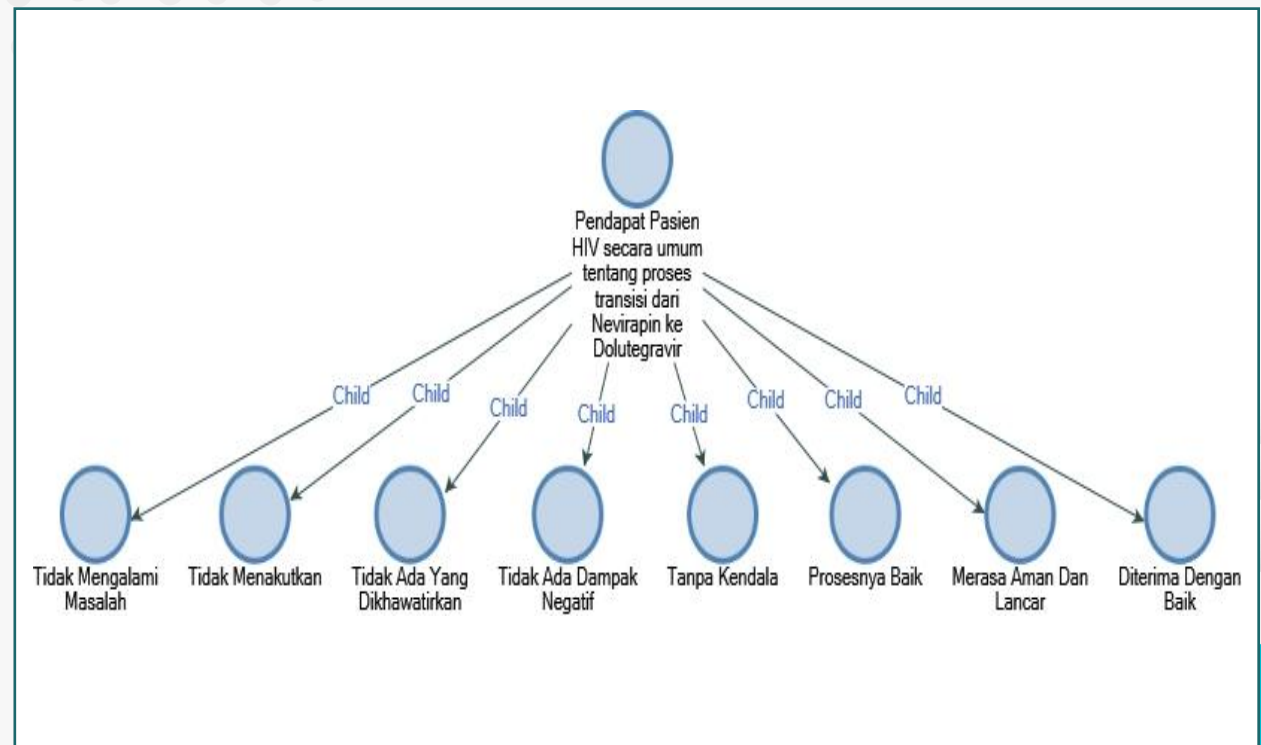
- **Digital-based education** → ↑ patient understanding of ART, especially in areas with limited access to healthcare facilities.
- Person-to-person communication → essential in building trust between patients and healthcare providers.

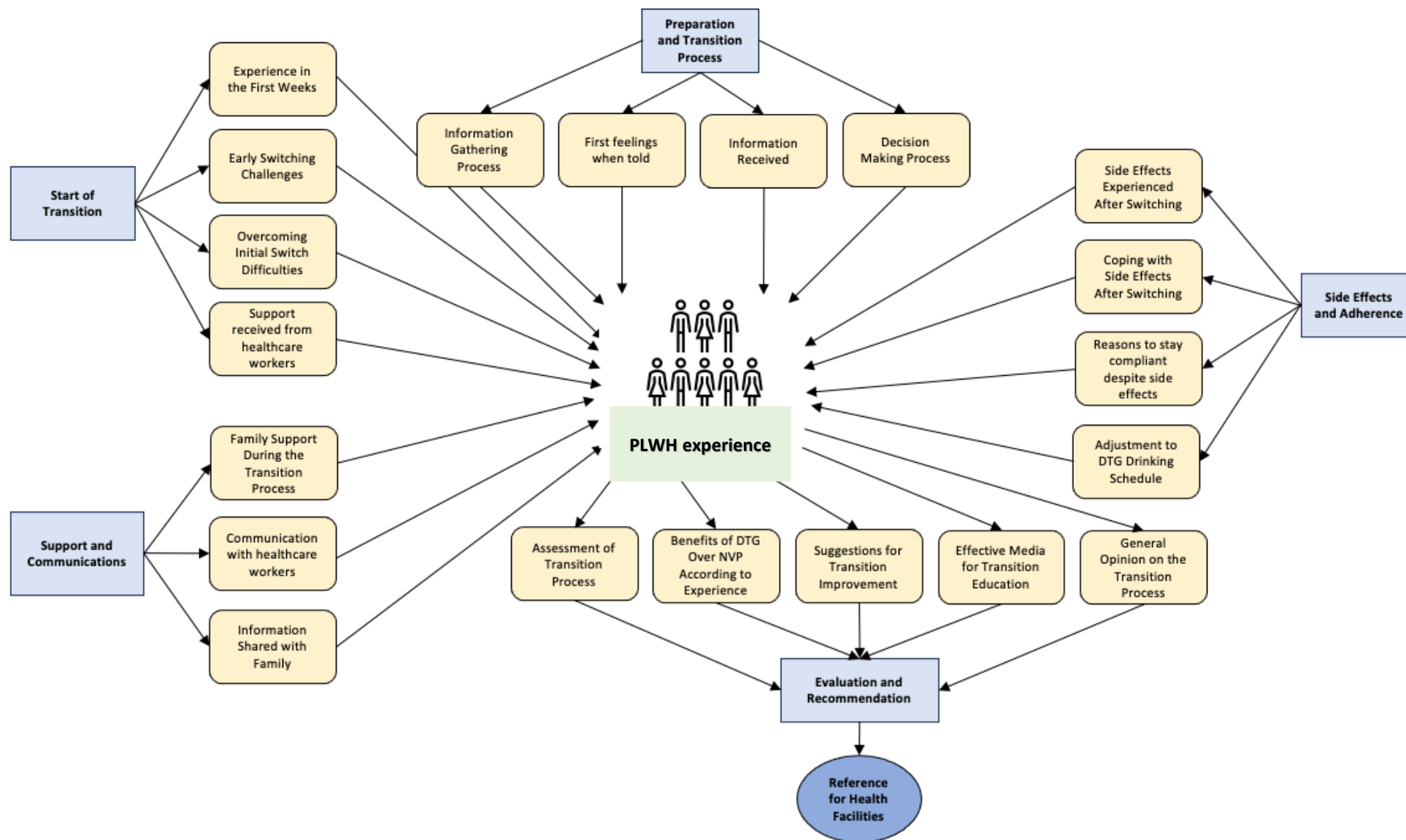


5. Evaluation & Recommendation

General Perceptions of PLWH on the Transition from Nevirapine to Dolutegravir

- Felt safe and experienced no concerning changes
“Yeah, I felt fine, like nothing happened. So it was all good.” (Participant_27_AI)
- Smooth process without any major issues
“Overall, I think it went well.” (Participant_24_AI)
- Clear communication about DTG’s side effects and benefits provided psychological reassurance
- holistic communication approach, adequate planning, and preparation by healthcare providers are needed during the transition





Strengths & Limitations

Strength

- The first qualitative study in Indonesia exploring the experiences of PLWH transitioning from Nevirapine to Dolutegravir.
- Focus on subjective aspects → provides in-depth insights into the psychosocial and emotional experiences of patients during the transition.

Limitation

- Study location limited to Cipto Mangunkusumo General Hospital → restricts generalizability of findings.
- Disparities in healthcare facilities may affect implementation.
- Hawthorne effect

Implementation

- Healthcare facilities with strong psychosocial support tend to be more effective in helping patients adapt.
- Importance of trained healthcare providers → risk communication & clear information on side effects.
- Access disparity between remote and urban areas.
- Standardized service protocols are needed to ensure optimal support and equal access to information and services.
- Strategic Recommendations for ART Transition Programs
 1. Develop guidelines for ART transition.
 2. Aim to improve the overall quality of life for PLWH

1. Positive Perceptions Towards Transitions

Most PLWH had a positive perception of the transition from nevirapine-based antiretroviral therapy (ART) to dolutegravir → **Effective communication with healthcare providers, trust in the effectiveness of dolutegravir, simplified dosing schedule that is more practical**

2. Mild & Manageable Side Effects

- Side effects experienced during the transition to DTG were generally mild and manageable
- Support from healthcare providers and lifestyle adjustments helped PLWH cope effectively

3. Minimal Barriers During the Transition Process

Challenges during the transition were minimal. PLWH were able to adapt well through support from healthcare providers and effective communication.

Overall: The transition from nevirapine-based therapy to dolutegravir-based therapy went smoothly.

- During transition → Conduct regular monitoring to detect potential side effects.
- Provide structured and personalized information.
- Use social media, WhatsApp, and educational videos to effectively reach more patients.
- Offer psychological counseling services for patients experiencing anxiety related to therapy changes.
- Educate families about their role in supporting the patient to improve treatment adherence.



THANK YOU