

# Ethical decision-making with regard to children born HIV-positive in Kinshasa City, Democratic Republic of the Congo: Experience and expectations of those involved in the prevention of mother-to-child transmission

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## ABSTRACT

### Introduction

HIV infection is a formidable pandemic with an incalculable impact. Pregnancy and HIV infection together create an immunobiological risk duo and a myriad of ethical conflicts throughout gestation and the birth of an exposed baby who may be HIV-positive.

### Purpose

This study aims to understand the ethical decision-making process used by those involved in the Prevention of Mother-to-Child Transmission (PMTCT) of HIV.

### Methods

An exploratory study based on grounded theory involved semi-structured interviews with twenty-one participants at Saint-Joseph General Hospital and Kintambo Maternity Hospital.

### Results

The study identified two value conflicts experienced by the participants: interpersonal conflicts and intra-personal conflicts. Ethical decision-making involved not sharing information, stopping the maternity project, and analysing facts and possible decisions. Major factors influencing ethical decision-making included internal factors (lack of experience, personal values, non-exposure to ethical conflicts, attitude of silence) and external factors (economic aspects, non-existence of an ethics committee, and ignorance of ethical decision stages). Participants described levers such as sharing experiences, raising personal values, and peer education. Their expectations included male partner involvement, zero HIV-positive babies, access to inputs and medicines, open exchanges with others, state support, literacy campaigns, and better health for people living with HIV and their babies.

### Conclusion

Ethical decision-making among PMTCT actors is predominantly individual rather than collective. The analysis reveals common points and underscores the need for ethical reflection among the actors.

## INTRODUCTION

To contribute to the improvement of ethical decision-making (EDM) in the implementation of the Prevention of Mother-to-Child Transmission (PMTCT) policy of Human Immunodeficiency Virus (HIV) in the Democratic Republic of the Congo (DRC), this initial study was conducted to understand the experiences and expectations of PMTCT actors regarding EDM when faced with value conflicts generated by the occurrence of children born seropositive (ENS). Pregnancy, in the context of HIV risk, remains the main route through which the products of conception become infected with HIV during gestation, childbirth, and breastfeeding (World Health Organization [WHO], 2017). Mother-to-child transmission (MTCT) is very high (25 to 40%) without antiretroviral treatment (ART), especially in countries with limited resources, making PMTCT of HIV a priority intervention in HIV/AIDS programs worldwide (WHO, 2019). Despite progress made in PMTCT, around 17.5% of children in the DRC are still infected with HIV through MTCT (Programme National de Lutte contre le SIDA [PNLS], 2019), which adds to the ethical issues surrounding the dilemmas or value conflicts that increase when a baby is born HIV-positive.

PMTCT is a setting where providers and HIV-positive women often experience heightened value conflicts, especially when an ENS occurs, requiring necessary ethical decisions to be made (EDM). During our research, mothers living with HIV expressed overwhelming jubilation when faced with negative Polymerase Chain Reaction (PCR) results from their exposed babies. However, when the results were positive, silence, remorse, and guilt prevailed, often unshared and intertwined with dilemmas or value conflicts. The principle of non-maleficence, which imposes an obligation to ensure that the benefits of an action like PMTCT outweigh its harms, becomes critical (Hottois & Missa, 2001). Is the newborn's positive HIV status not a failure of PMTCT?

Healthcare providers also face ethical dilemmas when their clients refuse to disclose their HIV-positive status to their sero-ignorant sexual partners due to fear of the consequences. This situation pits the principles of non-maleficence and autonomy against each other. Autonomy requires that any action affecting others be subject to the

consent of the involved individual (Hottois & Missa, 2001). Providers often face value conflicts when diagnosing HIV/AIDS in patients who are unable to cope with the diagnosis. Should they inform their patients or hide the truth to avoid potential harm? The duty to tell the truth, however, clashes with the principle of beneficence (Hirsch, 1997).

In PMTCT, the values of honesty and family solidarity frequently conflict. Hiding one's HIV status from a partner may seem dishonest, while disclosing it could break up the family. PMTCT interventions present numerous ethical challenges, such as balancing the right of an individual not to know their serostatus against the community's right to protect unborn children and serodivergent partners. The autonomy of patients may seem opposed to utilitarianism. Is being informed of one's HIV-positive status and disclosing it to a partner in the best interest of all, particularly when women in developing countries are vulnerable to social rejection due to their precarious status? Furthermore, PMTCT services aim to promote the birth of healthy babies from healthy mothers (WHO, 2019). The survival of infants is often linked to the survival of their mothers. If HIV-positive mothers die early, the likelihood of their children receiving continuous therapy decreases, leading to the recurrence of the disease and possibly early death in the children. Ethical theories, such as Kantianism and ethical egoism, may justify procreation despite the biological risks, while other theories, such as utilitarianism, Christian ethics, and natural law, argue against it when an HIV-positive child is born.

Thus, ethical theories and principles serve as fundamental guidelines in influencing ethical decision-making (Townsend, 2010).

### *Ethical Decision-Making Frameworks*

Ethical decision-making is conditioned by value conflicts (Mercer, 2005). However, the literature is often silent on ethical decision-making in the context of PMTCT and ENS. Value conflicts and the resulting workplace suffering have significant organizational consequences. Compatibility between personal and organizational values positively impacts both workers and the organization's well-being (Posner & Schmidt, 1993). Ethical behavior is more likely

to thrive when the organization's code of ethics aligns with personal values (Hudon, 2013).

Decision-making models suggest that the process involves exploration, incubation, decision-making, and evaluation. During the exploration phase, all elements of the situation are analyzed, leading to the identification of ethical dilemmas (Laurier, 1994). Incubation allows for assessing the pros and cons of various options, often accompanied by ambivalence (Larivey, 2000). Eventually, a decision emerges, bringing relief and a sense of resolution. Various models, both prescriptive and descriptive, provide steps for reaching ethical decisions, such as those proposed by Lefkowitz et al., McDevitt et al., and Vroom & Jago (Deschênes-Beaulieu, 2014).

Townsend (2010) outlines an ethical decision-making model similar to the nursing approach, involving data collection, problem definition, planning, action, and evaluation. Nilles (2018) suggests that quality decisions can be verified through three tests: transparency, exemplarity, and reciprocity.

#### Research Questions

In light of the above, the primary research question is: *How do PMTCT workers make ethical decisions in the face of value conflicts generated by the birth of HIV-positive offspring?* Three additional questions follow:

1. How do PMTCT workers become familiar with value conflicts experienced in Kinshasa hospitals?
2. How can ethical decision-making be improved in hospitals regarding PMTCT?
3. What are the expectations of healthcare workers and patients concerning HIV-positive offspring?

## METHODS

### Materials

The research sites selected for this study are the HGR St. Joseph and the Kintambo Maternity Hospital in the city of Kinshasa, Democratic Republic of Congo (DRC). These sites were chosen because they are among the qualified general referral hospitals that receive a high frequency of pregnant women living with HIV in Kinshasa. Additionally, their Prevention of Mother-to-Child Transmission (PMTCT) services have been operating for more than a decade.

### Methods

This study employed an exploratory design based on grounded theory. Semi-structured, in-depth interviews were conducted with 21 participants at the HGR St. Joseph and the Kintambo Maternity Hospital.

### Population and Samples

The target population for this study consists of all PMTCT actors involved in the procreation of people living with HIV (PLHIV), including healthcare providers and female PLHIV who attended the two hospitals between January 22 and April 30, 2022. A total of 57 participants were identified: 8 healthcare providers and 23 female PLHIV at HGR St. Joseph, and 6 healthcare providers and 20 female PLHIV at Kintambo Maternity Hospital.

To participate in this study, participants were required to meet the following inclusion criteria: having experienced the phenomenon under study (i.e., the occurrence of a baby found to be HIV-positive), being able to clearly express their experiences, and freely and voluntarily consenting to participate. Additionally, PLHIV mothers needed to have been aware of their HIV status for at least six months before the procreation project, be monitored in a qualified centre by qualified providers, and have given birth to at least one child who had become HIV-positive. They were also required to have at least a baccalaureate level of education. For healthcare providers, the inclusion criteria required them to be doctors, midwives, or nurses caring for PLHIV through the PMTCT program.

The exclusion criteria included any participant who did not meet the inclusion criteria, any PLHIV mother who had given birth to an HIV-negative child, individuals who did not speak French, and those with cognitive, behavioural, or mood disorders. Sampling was based on data saturation, which began with the 17th participant and was reinforced until the 21st participant. Sampling principles were governed by achieving redundancy and reinforcing information saturation (Polit & Beck, 2007).

### Technique and Data Collection Instrument

Semi-structured interview techniques were used, employing two interview guides (one for healthcare providers and one for mothers), a logbook, and a dictaphone to record the interviews. Additionally, the researcher served as a data collection instrument (Santiago

& Carral, 2017), tasked with collecting both verbal and non-verbal information, transforming it, and seeking to understand the meanings behind the participants' experiences. Verbatim transcripts of the interviews were produced and coded using in vivo coding, where codes are drawn from participants' language to stay close to the raw data (Luckerhoff & Guillemette, 2012). Themes, sub-themes, categories, and sub-categories were then identified and supported by verbatim quotes.

#### *Data Processing and Analysis*

Data collection and analysis were carried out simultaneously, starting with the first participant and continuing until theoretical saturation was reached with the 21st participant. Concepts and categories were generated through this process. The recordings were listened to in full, and the information was transcribed verbatim. Key statements were identified and meanings were formulated for each statement, with redundancies eliminated. The meanings were then grouped into themes, and these themes were analysed according to the research objectives. The final analysis was integrated into a comprehensive description of the phenomenon, corroborated with theoretical elements from the literature review (Depelteau, 2011).

#### *Ethical Issues*

Since the study involved human participants, approval was obtained from the National Health Ethics Committee (n°89/CNES/BN.PMMF/2021) on January 19, 2021. Free and informed consent was obtained from all participants, and their privacy was assured. Informed consent, defined as an agreement given freely after receiving relevant information about the nature, purpose, and risks of participation, was secured (Townsend, 2010). Participants were free to withdraw from the study at any time without consequences.

In terms of benefits, the study's only direct benefit was its contribution to improving ethical decision-making during the implementation of the national PMTCT policy in the DRC. Two disadvantages were noted: the time spent in interviews (approximately 45 minutes) and the emotional distress caused by recalling personal events. To compensate for the time, participants received a \$5 token after the interview, which did not influence the study

results. Additionally, participants were morally supported during the interview process.

To ensure confidentiality, all collected data were anonymised through coding (e.g., Pn for healthcare providers and Gm for mothers), preventing the identification of participants. Research results, disseminated in articles, papers, and a doctoral thesis, will not include any identifying information about the participants.

## RESULTS

### *Socio-demographic Portraits of the Study Subjects*

Two categories of subjects were studied: eleven healthcare providers and ten mothers living with HIV. The portraits are as follows:

- **Healthcare providers:** The age range of the providers was 25 to 46 years. Five were female and six were male. Educational levels were distributed as follows: five graduates, four medical doctors, and two bachelor's degree holders. The professional categories included five doctors, two midwives, and four nurses. The positions held were: four heads of department, three consultants, and four operatives. Interviews lasted between 30 and 60 minutes, with an average duration of 45 minutes.
- **Mothers living with HIV:** The ages of the mothers varied between 24 and 45 years, with an average of 34.5 years. Their professional categories included three shopkeepers, one government employee, one teacher, one peer educator, one student, and one unemployed woman. Educational levels were represented by six bachelor's degree holders, two graduates, and two state graduates. The duration of Prevention of Mother-to-Child Transmission (PMTCT) ranged from six to nine months. Regarding marital status, five were married, three widowed, and two divorced. The number of children born HIV-positive ranged from one to three per mother, for a total of fourteen children. The duration of interviews ranged from 30 to 60 minutes, with an average duration of 45 minutes.

*Presentation of Sub-themes, Categories, Sub-categories, and Verbatim of the Central Theme*

**Central Theme:**

"Experience of Ethical Decision-making in the Face of Conflicts of Values Generated by the Birth of HIV-positive Children."

The thematic analysis of this central theme highlighted eight sub-themes, including:

**Sub-theme 1:** Stakeholders' understanding of value conflict, dilemma, and ethical decision (Box 1)

Three categories emerged from this box:

- **Category 1:** Conflicting values, with five sub-categories:
  1. Contrast with expectations, unexpected outcomes
  2. Non-respect of ethical principles
  3. Remorse, ethical suffering, internal malaise about the contaminated baby
  4. Contradiction with personal beliefs
  5. No quality, no need for work
- **Category 2:** Ethical dilemma, with one sub-category:
  1. Competing values and principles
- **Category 3:** Making ethical decisions, with five sub-categories:
  1. Ethical conflict resolution process
  2. Resolution after ethical conflict
  3. Choices to make
  4. Key to the success of PMTCT practices
  5. An excellent way of avoiding value conflicts

**Sub-theme 2:** Key personal values of stakeholders (Box 2)

Seven categories emerged from this box, namely:

- **Category 1:** Vital values, with three sub-categories:
  1. Respect for life and health
  2. Safety and protection
  3. Pleasure
- **Category 2:** Affective values, with three sub-categories:
  1. Love of neighbour, concern for others
  2. Emotional sensitivity

3. Self-sacrifice for others

- **Category 3:** Intellectual values, with four sub-categories:
  1. Ambition
  2. Motivation
  3. Just listening
  4. Optimism
- **Category 4:** Economic values, with two sub-categories:
  1. Efficiency
  2. Work, material well-being
- **Category 5:** Aesthetic values, with two sub-categories:
  1. Harmony
  2. Beauty, coquetry
- **Category 6:** Legal and social values, with four sub-categories:
  1. Equity, justice, uprightness
  2. Team spirit
  3. Authority, power, prestige
  4. Honesty, integrity, loyalty
- **Category 7:** Religious values, with two sub-categories:
  1. Empathy
  2. Faith

**Sub-theme 3:** Ethical principles advocated in PMTCT (Box 3)

- **Category 1:** Fundamentals of bioethics, with four sub-categories:
  1. Autonomy
  2. Caring and well-being of patients
  3. Justice
  4. Non-malevolence, children's happiness
- **Category 2:** Fundamentals of screening, counselling, and care for PLHIV, with two sub-categories:
  1. Free and informed consent
  2. Professional secrecy or confidentiality

**Sub-theme 4:** Types of value conflicts experienced by PMTCT stakeholders (Box 4)

- **Category 1:** Conflicts of values with others or the group, with five sub-categories:
  1. Conflicting ideas

2. Conflicts of interest
  3. Conflicting positions
  4. Marital conflicts
  5. Conflict of competence
- **Category 2:** Intrapersonal value conflicts, with two sub-categories:
    1. Conflict inherent in the person
    2. Pseudo-conflict

**Sub-theme 5:** *Ethical Decision-making by Stakeholders in the Face of Conflicts of Values Generated by the Birth of HIV-positive Offspring in PMTCT Programmes (Box 5)*

From this sub-theme, five categories emerged:

- **Category 1:** Absence of a rational ethical approach, with one sub-category:
  1. Missing the ethical decision-making procedure
- **Category 2:** Information not shared, with three sub-categories:
  1. Remaining silent
  2. Relying on divine providence
  3. Avoiding the person who caused the conflict
- **Category 3:** Maternity ward project halted, with two sub-categories:
  1. Supporting the baby
  2. Giving advice and understanding others
- **Category 4:** Fact analysis phase, with two sub-categories:
  1. Identifying the facts
  2. Raising awareness
- **Category 5:** Decision phase, with one sub-category:
  1. Possible options for decision-making

**Sub-theme 6:** *Factors Determining Whether or Not Ethical Decisions Are Made (Box 6)*

Two categories emerged from this sub-theme:

- **Category 1:** Internal influence factors, with nine sub-categories:
  1. Lack of experience in value conflicts
  2. Value conflict as a critical offence
  3. Personal values

4. Personal circumstances
5. Ignorance of ethical conflicts and the ethical decision-making procedure (EDP)
6. No third-party exposure of ethical conflicts
7. An attitude of silence that can lead to forgetting the conflict
8. Fear of being charged
9. Gravity of the situation

- **Category 2:** External influence factors, with three sub-categories:

1. Economic and political issues
2. Absence of ethics committees
3. Ignorance of the steps in ethical decision-making

**Sub-theme 7:** Remedial Measures (Box 7)

One category with six sub-categories emerged:

- **Category:** Corrective measures, with six sub-categories:
  1. Acquisition and exchange of experience
  2. Increased self-worth through peer education for PLHIV
  3. Setting up an ethics committee and publicising ethical principles
  4. Improving economic, social, and political conditions
  5. Emergency ethical decision-making in serious situations
  6. Distancing oneself from situations that lead to conflicts of values

**Sub-theme 8:** PMTCT Workers' Expectations of Children Born HIV-positive (Box 8)

From this sub-theme, three categories emerged:

- **Category 1:** At the level of the structure, with five sub-categories:
  1. Implication or support for male partners
  2. Zero HIV-positive babies
  3. Accessibility of inputs, medicines, and care structures
  4. Open exchanges with other players
  5. Qualified personnel

- **Category 2:** At the central level, with two sub-categories:
  1. Government support
  2. Combating illiteracy

- **Category 3:** Among people living with HIV, with two sub-categories:
  1. Good health for babies and mothers living with HIV
  2. Miraculous cure

Eight sub-themes were examined and highlighted in the following sections:

**BOXES**

**Box 1:**  
Stakeholders' understanding of value conflict, dilemma, and ethical decision.

**Question:**  
"What do you mean by value conflict and ethical decision?"

Sub-topic	Category	Subcategory	Verbatim
Stakeholders' understanding of the value conflict, ethical dilemma and ethical decision.	Conflicting values	Contrasts with expectations, unexpected	P1, « ... is everything that happens in contrast to the expectation. You expect a child to be exposed and unharmed, but when the PCR test is carried out, the exposed baby becomes seropositive. ... ». P2, « ... conflict of values? That in itself is quite unexpected».
		Non-respect of ethical principles	P1,3,4,5,6,9,10, G6,7 « ... is the failure to respect ethical principles, ...»
		Remorse, ethical suffering, internal malaise about the contaminated baby	G1, « ..., despite everything I did to ensure that my baby was born free of the germ, to no avail, when we did the test at 12 months, the baby was already contaminated. I have internal remorse about my baby being contaminated every day since he was put on the lifelong care programme,». P4, « ..., when a provider is aware of being at the root of a baby's contamination because he didn't manage the birth properly, even if the baby and other people don't know about it, it creates internal remorse when I see this child, it creates an internal conflict in my conscience,». P5,9 « ..., I understand it as ethical suffering, felt when one is called upon to do something contrary to one's own values, or as a state of malaise felt by a person, in the case of guilt. »
		Contradiction with his personal beliefs	P3 « ..., the fact of contradicting my personal convictions, that's the conflict of values ». P4 « ..., this may be when the work required conflicts with personal convictions,...». G5 « ...,when my aspirations are stymied,...»
		No quality, no need for work	P4 « ..., in PMTCT, if the activity can be botched, it is a quality that is prevented. ». G8 « ..., futile effort, pointless work,» P10 « ..., the discrepancy between what is done and what is expected, useless work, that's the conflict of values understood in this way. »
Ethical dilemmas	Competing values and principles		P1,2,5,G7 « ...,Situations where values and principles conflict, or where values conflict with each other,...» P6 « ..., For example, one day I hid from my colleagues a serious error committed during the delivery of a PLWHA, I don't like talking about it...I regret it,..., I think I was dishonest in this case ; if I had admitted that too, I'd have been sacked and lost my job,..., so my values of honesty and truth clash...». G2 « ..., The doctor who diagnosed my husband with HIV didn't want to tell him, given his state of depression, fearing that he wouldn't be able to cope with the diagnosis. He had a duty to inform him of his condition, which conflicted with his duty not to destroy his hope for life... ». G4 « ..., My husband ran away from me without saying a word after I told him my HIV status, and went to Angola. I had to stay away from him, I would keep my husband. I also thought that my child could come out HIV-negative after testing, but unfortunately he's HIV-positive too. I'm always tormented by his questions when he says to me : "Mum, why do I have to take the medication every day? Should I tell my child the truth about being infected by me?, .. »
		Ethical conflict resolution process	P3, « ...,I understand it as any process leading to a decision, i.e. to the resolution of a conflict or dilemma,...». P4,5,9,10,11, « ...,ethical conflict resolution process,... » ;G1,2,3 « ...,is all we do to resolve ethical conflicts».
		Resolution best after ethical conflict	P1 « ..., any resolution is best, even after an ethical conflict, ...».
		Choices to make	G7 « ..., I see this as a choice to be made when faced with several alternatives,... » G9 « ..., it's a choice faced with several dilemmas,... »
Making ethical decisions	Ethical conflict resolution process	Key to the success of PMTCT practice	P2 « ..., I think that ethical decision-making is the key to success in PMTCT practice, because there are several situations that need to be decided on,...».
		An excellent way of avoiding value conflicts	P9 « ..., I think that ethical decision-making remains an excellent way of avoiding the conflicts of values mentioned,..., it's with caution that we approach a rocky path, in the same way that in PMTCT we can avoid conflicts of values by being careful in everything we do and say ».

**Box 2:**  
Key personal values of stakeholders.

**Question:** "Could you tell us about your own values?"

Subtopic	Category	Subcategory	Verbatim
Types of player values	Vital values	Respect for life and health	P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> «...respect for human life,.. » P <sub>4,6,7</sub> «...health ... »
		Safety and protection	P <sub>4,11</sub> «...the safety of the patient and myself...". G <sub>4</sub> "... protect my child,... »
Affective values	Love of neighbour, concern for neighbour,	Pleasure	P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> G <sub>3,4,6,8</sub> «...the pleasure,... »
		Love of neighbour, concern for neighbour,	P <sub>3,10,11</sub> , G <sub>5,7,9,10,11</sub> « .... love for neighbour,... » P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> G <sub>1,2,3,4,5,6,7,8,9,10</sub> , « .... concern for one's neighbour,... »
		Emotionality, Sensitivity,	P <sub>1,2,5,6,7,8</sub> , G <sub>1,2,3,5,6,7,9,10</sub> « ... emotional,... sensitivity. »
		Self-sacrifice for others, abnegation	P <sub>3,5,9,10</sub> , G <sub>1,4,5,6,7,8,9</sub> , « ... self-sacrifice for others,... » « ...abnegation, »
Intellectual values	Ambition, Motivation	Ambition,	P <sub>1,2,7,8</sub> , G <sub>4,7,9,11</sub> « ...ambition,... »
		Motivation	P <sub>3,4,5,6,9</sub> G <sub>1,2,3,4,5,6,10</sub> « ...motivation,... »
		Just listen,	P <sub>1,2,3,4,5,7,8,9,10,11</sub> G <sub>1,2,6,7,8,9</sub> « .... listening,... »
		Optimism	P <sub>1,2,6,7,8,11</sub> G <sub>2,3,6,7,8,9,10</sub> « ... optimism,... »
Economic values	Efficiency Work, material wellbeing	Efficiency	P <sub>2,3,4,5,6,7,8,9</sub> , G <sub>3,4,5,7,8,10,11</sub> « .... efficiency,... » «... sensitivity,»
		Work, material wellbeing	P <sub>1,10</sub> , « ... work, » G <sub>9</sub> « ...material well-being,... »
Aesthetic values	Harmony Beauty, coquetry	Harmony	P <sub>2,8</sub> «... I love harmony,... »
		Beauty, coquetry	G <sub>4</sub> «...beauty, .. » G <sub>3</sub> «... coquetry,... »
Legal and social values	Equity, Justice, Uprightness Team spirit	Equity, Justice, Uprightness	P <sub>1,3,4,5,6,7,9,11</sub> , G <sub>3,4,5,9,10,11</sub> « ....equity,... » « ...justice,... »
		Team spirit	P <sub>1,2,3,4,5,6,7,8</sub> , « Team spirit» G <sub>2,8</sub> , « ... family spirit»
		Authority, power, prestige,	P <sub>1,2,3,4,5,11</sub> , G <sub>1,2,10</sub> « ... je suis autoritaire,...le pouvoir ....., » G <sub>6,7,9,10</sub> P <sub>16</sub> , « ... prestige,... »
		Honesty, Integrity and Loyalty	P <sub>1,2,3,4,5,6,7,8,9,10</sub> G <sub>1,2,3,4,5,6,7,8,9,10</sub> , «... Frankness or honesty», « ... integrity,... » «...loyalty»
Religious values	Empathy Faith	Empathy	P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> , G <sub>3,4,5,6,7,8,9,10</sub> « ...empathy, ... »
		Faith	P <sub>4</sub> , «... faith in God,... » G <sub>1,2,3,4,5,6,7,8,9,10,11</sub> «... faith, »

**Box 3:**  
Ethical principles advocated in PMTCT

**Question:** "Could you tell me more about the ethical principles advocated in PMTCT?"

Subtopic	Category	Subcategory	Verbatim	
Types of principles advocated for PMTCT	Fundamentals of bioethics	Autonomy	P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> the autonomy of the pregnant woman to take the test or not and even to share her result ... » G <sub>10</sub> « ... , at the ANC, we were told that we were free to accept the test or even the result. »	
		Caring and well-being of patients	P <sub>10,11</sub> « ... Benevolence, » G <sub>9,10</sub> « ... Patient wellbeing,... »	
			Justice	P <sub>7,8</sub> « ... there are also the principles of bioethics: justice,... »
			Non-malevolence, children's happiness	P <sub>10,11</sub> « ... non-monitoring,... » P <sub>3</sub> « ... happiness of the unborn child,... »
		Fundamentals of screening, counselling & care for PLHIV	Free & informed consent	P <sub>5,9,10,11</sub> « ... we insist on free and informed consent,... »
			Professional secrecy or confidentiality	P <sub>1,2,3,4,5,6,7,8,9,10,11</sub> « ... here in PTME, we advocate professional secrecy,... confidentiality, ... » G <sub>1,2,3,4,5,6,7,8,9</sub> « ... confidence, and confide in the person who can keep my results secret»
			Faithful to the promise	P <sub>1,11</sub> « ... , hold firm to the promise»

**Box 4:**  
Types of Value Conflicts Experienced by PMTCT Stakeholders

**Question:** "Can you tell me in broad terms about the difficult situation(s) linked to conflicts of value on an ethical level that you have experienced when a baby with HIV was born in the PMTCT program?"

Subtopic	Category	Subcategory	Verbatim
Types of value conflicts in		Conflicting ideas	P <sub>1</sub> «... , very often we encounter resistance from PHAs who don't want to respect the therapeutic principles. For example, instead of taking their medication at the right time, or avoiding multiple relationships, I'm often angry with certain clients who oppose my ideas, even though they're beneficial. So there's a conflict of ideas here,».
			P <sub>4</sub> «... , at the start of the pregnancy, I kept talking to a woman living with HIV about the risks she was running with her pregnancy if she didn't follow my advice to the letter ; even when the worst happened, the woman never wanted her partner to come. What can you do, corner her, denounce her ? She is protected by the law, because for



PMTCT		<i>her, treatment alone is not enough. »</i>
Conflicts of values with others or the group	Conflicts of interests	G3 « ..., the situation I'm in is leading me to look for all kinds of solutions, including fasting and prayer, but the nurses are forcing me to take the medicines even when I should be praying and fasting... »
		G1 « ..., my main concern since I found out I had HIV was to leave the world with a living memory, especially with PMTCT, everything was going to go better. But unfortunately, my only son is also HIV-positive. Can't you see that my interests conflict with those of the child ?,... ».
		P2 « ..., I wanted to say that PMTCT provides all the assistance to pregnant PLHIV, but as long as the baby is HIV-positive, the interests of PMTCT and the beneficiary are at stake,... »
		G4 «..., I've been in a difficult situation since my son was found to be ill, I can't see anyone to whom I can entrust my child's problems, his father is gone forever, my health doesn't allow me to, in the event that I'm no longer here who will look after my child, even though I really wanted this pregnancy....., today, is my interest also that of the child,.... I don't think so, .... »
Conflicting positions		G2, «...I have very bad memories of the midwife who told me the result, she took advantage of her position as provider to humiliate me in the rain, telling me: you're here, you've got AIDS, you're going to die, she really hurt me, taking advantage of her position as provider. I've been alive for 10 years now... and my child is sick too,...».
Marital conflicts		P11 « ..., PLWHIV are often stubborn, taking primary responsibility for the baby's seropositivity, not only because they are the parents, but above all because they do not follow our recommendations,... »
Conflict of competence		P6 « ... yes, when the announcement of the status is not well managed, it can lead to marital conflict for the partners, leading to a breakdown in the relationship. It's difficult, that's what happened to me with my client,... »
Intra-personal conflicts of values		P7 « ...an army officer once came here with a gun, accusing his wife of being the cause of his contamination. Yes, marital conflicts are the cause of break-ups or divorce, leading to a breakdown in therapy for the child. It's just sad. » G5 «..., my child's positive diagnosis has shattered the hope I had in PTME. Until then, my husband never knew that my child was HIV-positive, because he had already warned me that if my child tested positive, he would divorce me.» G8 « ... at the beginning of my engagement, my husband and I swore never to hide the truth from each other, whatever the problem. When the diagnosis was revealed to me, the nurse advised me to tell my husband. I trusted my husband too, and it was at 5 o'clock in the morning that I told him. He didn't reply, so when he left the house to go to work, he never came back. He sent me a message to take everything and go home. He's in Angola, he's not coming back. You can see why I'm saying this... silence, then tears... »
Conflict inherent in the person		G7 « ..., so while I was hesitating to tell my husband because I was afraid of the risk of misunderstanding and divorce, the lady had told him, and I'll be surprised if he's gone forever, leaving me in the maternity ward. Imagine the rest,... »
Pseudo conflict		P3 « ...It's true that as we're hired here, we don't have the same level of study or understanding, there are even providers who haven't had PMTCT training like us, especially the new recruits, who make mistakes". P5 "...., the churches or prayer groups don't make it easy for us, instead of encouraging PLHIV to take ARVs, they first subject them to fasting and prayer sessions for a very long time, and when they realise that the disease is advanced, that's when the patients come back to us, there's a real conflict of competence. We haven't forgotten the traditional healers either,...».
		G9, « ..., of course ! When the baby was born, I had the consolation of saying, well, even if I died, there's my child, there's the energy, although the fear was there, but I had more regret, bitterness and anguish when after testing my baby was declared HIV-positive,..., there's an inherent conflict within me,... »
		G10 «..., When I see my son suffering, it hurts a lot, especially several times, he's asked me why he was taking medicine every day, should I tell him the truth or lie? I know he's innocent in all this, ... silence .... crying ... »
		P9 « ..., One day I found myself alone on duty, very tired because I was alone, the birth I had directed that day, I was afterwards very convinced that I had made a lot of mistakes, the principles of childbirth had not been properly respected, I was not surprised by the positive result of this child. And when I saw him come to collect the medicines, my eyes were honestly filled with tears... it was because of me that this child was contaminated,... »
		P8 « ..., PHAs often exaggerate, especially as their disease progresses, especially for those who take ARVs irregularly, falsely accusing providers after a misunderstanding, and when I check, there's nothing, so it's a pseudo conflict certainly linked to their state of mind. »
		P10 «..., the woman I was following was ill, she gave me the impression that she was less convinced despite the test that she was HIV positive, she so often believed in family witchcraft, despite the fact that she was following the treatment, her child's positive diagnosis made her situation worse..., she's too attached to her culture and believes in it. It's a problem, what should we do?... »
		G6 « ..., personally, I think that this disease is still a curse cast by those who are angry with me, because I've never understood how I caught this disease and above all how my child came to be HIV-positive despite everything I did by following all the PTME recommendations,...»

**Box 5:**  
Ethical Decision-making by Stakeholders in the Face of Conflicts of Values Generated by the Birth of HIV-positive Offspring in PMTCT Programmes

**Question:** "What were the different phases in your ethical decision-making process to resolve this conflict of values generated by the implementation of the PMTCT policy that led to the birth of HIV-positive offspring?"

Subtopic	Category	Subcategory	Verbatim
Ethical decision-making process for PMTCT stakeholders	Absence of a rational ethical approach	Missing the ethical decision-making procedure	P1,2,4, «...I don't know,...", P10,11, "...I don't know how to go about making an ethical decision..." G4,6,8,10 «...I don't know how to go about making an ethical decision... »
	Information not shared	Remaining silent	P1 « ..., Phew ! What am I supposed to do if someone doesn't feel sorry for me ? That's my problem, because if you insist too much you risk being stigmatised ! » G2 « ..., nothing to be done, we have to avoid problems, I've resolved that the husband doesn't know about it ...» G3 «..., silence, ...crying...I really don't know what to do, please help me»

*P9 « ..., I've never spoken to anyone, maybe in time I'll be able to forget, but it's difficult, should you speak to your mother or to whom?, which is why I've always avoided looking at that child with the eyes »*

Relying on divine providence	on	G1 « ..., what would you have me do, I only suffer, I trust in God ... » P2 « ..., sigh..., silence ... » G7 « ..., I do what is good for me, which is prayer »
Avoid the person who caused the conflict	the person who caused the conflict	G2 « ..., in any case, I never wanted to see that midwife again,... » P11 « ..., what should you do with a stubborn person? unless you entrust her to someone else »
Maternity ward project halted	Supporting baby	G2 « ..., not to give birth again, to support my baby » G9 « ..., I stopped with the maternity ward. »
	Giving advice & understanding others	P3 « ..., I continue to give them advice and I understand their condition,... which is what I do, because I often talk to them and explain the reality of their condition, making them see that the healthcare staff have nothing to do with it,... » P8 « ..., I try to get the service provider to understand his mistakes,... »
Fact analysis phase	Identifying the fact	P6 « to avoid a repeat offence, I do everything I can to identify the fact beforehand » P7 « ..., I tried to verify,... »
	Raising awareness	P7 « ..., my brother I became aware to avoid future remorse,... »
Decision phase	Possible options	P5 « ..., sometimes I decide to go and see the pastor and make him understand that his sick follower must be given life-long medication every day, ... on one occasion we even initiated a meeting with our partners, involving the church authorities, and this option made a real difference. » P6 « ..., and then I see the possibilities,... »

**Box 6:**  
Factors Determining Poor or Non-existent Ethical Decision-making

**Question:** "Could you explain to me why you were unable to make sufficiently ethical decisions?"

Subtopic	Category	Sub-category	Verbatim
Factors determining whether or not ethical decisions are made		lack of experience in value conflicts	P1 « ...a lot of things happen because of a lack of previous experience, because similar realities also lead to similar previous decisions, so we can evaluate the previous result, which can lead to very good decisions,... » G1 « ...,I have no idea how to make an ethical decision,... »
		value conflict, as a critical offending	P3 « ..., most ethical conflicts are not known to third parties, as they are considered a quasi-crime,... » G2 « ..., I wonder if it's worth sharing this gnawing fault under penalty of criticism ?... »
		personal values	P1 « ... If you are here for long, you will understand that there is a problem with the personal values of many PTME & or CPN users because many are illiterate, low socio-cultural level is at the root of many ills. Not to mention the harmful influence of prayer groups,... » P2 « ...,the big problem is the women who come to ANC, many of whom have not studied and are illiterate, so they often don't understand, » P4, « ...,the language problem is also a factor, ..., for example, when our Luba sisters come from Kasai, many of them speak only their language, fortunately there are PAFs here to help us with translation,... » P5 « ..., I think that the basic education and even the age of our customers may explain this ... » G4 « ..., I think the fact that I didn't push myself with my studies may explain that,... »
		Personal circumstances	P1 « ...,so often when a PLWHIV realises that his or her status is known to an old relationship provider, there is often a loss of sight, which is why most of the PLWHIV who arrive here are those who have come from far away in other towns; they are afraid of being identified » P4 « ..., In my experience, PLWHA are only treated where they are not known to be, and very few of them remain attached to the centre where they receive treatment » P6 « ..., P6 "..., the fact that women are not accompanied by their husbands to PMTCT sessions is largely to blame ».
		Ignorance of ethical conflicts and the EDP procedure	P7 « ..., were it not for this interview, I wouldn't know that ethical conflicts exist, because I've never learned about them. » G2,3,10 « ..., I don't know what exactly is an ethical conflict and how do you make an ethical decision? » G7 « ..., I think that ignorance of the very process of ethical decision-making has a lot to do with it,... »
		No third-party exposure of ethical conflicts	P5 « ...,service providers who feel they are in an ethical conflict often don't admit it, because they don't want the consequences to fall on their shoulders ». G2 « ...,which can expose the gnawing in the heart that can lead to consequences,... » P4,5 « ..., most ethical conflicts are not exposed or shared. ».
		An attitude of silence that can lead to forgetting the conflict	P2 « ..., I believe that with time, you can forget, so I maintain an attitude of silence whatever the anguish ». G1,3,8 « ..., but it's an attitude of apparent silence, because it shines in the heart » G5 « ..., silence is my resolution, because I hope that with time, everything will turn out all right,... » G8 « ..., it so often happens that we don't talk about a situation with a third party, and over time we forget, but it's an attitude of apparent silence, because it shines in the heart ».
		Fear of being charged	P11 « ..., the fear of being charged leads a service provider not to share his problem ... »
		Gravity of the situation	P2 « ..., Another reason may be the seriousness of the situation. If the conflict is benign, there is no urgency, and it is trivialised. But when faced with a serious situation of guilt, there is a profound silence. How can you make a decision if you don't know whether there is a serious situation to blame?... ».
	External influencing factors	Economic and political issues	P1, « ...,the economic, financial and even political influence of the decision cannot be ignored. Providers don't have the means.... Once we ventured to hand over the transport money to invite the husbands to come and take the voluntary PMTCT test. The results were spectacular, but when we stopped, the husbands no longer came with their wives to the ANC sessions,... ». P3 « .... The country's bad policy is at the root of many of our problems. Today, we are taken care of by international

NGOs, but their actions are temporary. Once their contract is terminated, there is a serious problem in sustaining these actions because the budget allocated to health is mediocre...».

No ethics committee	<i>P<sub>5</sub></i> «...there is no hospital ethics committee to resolve ethical problems,...». <i>G<sub>2,4,7,8,9,10</sub></i> « I don't know if there is a "G1,3,5,6" ethics committee ..., it's the midwives who can find out» . <i>P<sub>10</sub></i> « ... yes, in all the time I've been here, I've never seen a meeting called by the ethics committee for ethical problems in PMTCT»
Ignorance of the stages of an ethical decision	<i>P<sub>5</sub></i> «...we still need more in-depth study to learn how to make an ethical decision. However, we are governed by PMTCT standards,...» <i>P<sub>9</sub></i> « ... , but for there to be an ethical decision, the problems have to be identified. Who is exposing these kinds of realities?,... » <i>G<sub>1</sub></i> «...I don't know how you make an ethical decision,...»

**Box 7:**

Appropriate Measures to Combat Weak or Non-existent Ethical Decision-making

**Question:** "How then can we eradicate weak or non-existent ethical decision-making?"

Subtopic	Category	Verbatim
Remedial measures	Acquisition and exchanging experience	<i>P<sub>2</sub></i> «... , I believe that care providers should be encouraged to acquire the experience and skills they need to provide care to their patients,... » <i>P<sub>3</sub></i> « ... , if we develop an environment where experiences are shared, we will also be able to acquire experience, as we say that the testimonies of some are a source of experience for others,... » <i>P<sub>1</sub></i> «... , of course ! The lack of dialogue between service providers and users leads to conflict. We need to break the silence to alleviate what we have called the malaise. This requires the team to be good listeners,... »
	Increased self-worth Peer education PLHIV	<i>P<sub>5</sub></i> «... , we need to combat illiteracy, which requires everyone to make an effort, and organise upgrading of service providers, which can raise personal standards» <i>P<sub>7</sub></i> « ... good awareness of PMTCT among partner staff and all pregnant women at ANC sessions». <i>G<sub>2,5</sub></i> «... ,we need to be informed about how to make ethical decisions,... »
	Setting up an ethics committee and publicising ethical principles	<i>P<sub>8</sub></i> «... , set up an ethics committee of well-trained people to rule on ethical issues. This committee should also encourage people to share ethical conflicts to combat silence, ignorance and anxiety» <i>P<sub>6</sub></i> «... also popularise the concepts and/or principles of ethics, because personally I don't know what they are»
	Improving economic, social and political conditions.	<i>P<sub>9</sub></i> «... , Improving the living conditions of both the service provider and the general population remains essential, and this depends on political will. The Congolese government must make the activities of one-off providers (NGOs) sustainable ». <i>P<sub>10</sub></i> « Acknowledging the facts or conflicts of values can lead the hierarchy to make every effort, whether human, material or financial, to mitigate the sources of conflict,.. ».
	Emergency ethical decision-making in a serious situation	<i>P<sub>11</sub></i> «... ethical decisions must be taken as a matter of urgency and the number of people affected must be known, to avoid prolonging the conflict of values,...» <i>P<sub>2</sub></i> «... ; in view of the seriousness of the situation, that it needs to take urgent ethical decisions,...»
Distancing yourself from situations that lead to conflicts of values	<i>G<sub>1</sub></i> «... if we can manage to distance ourselves in a calm and considered way from any seeds of conflict, it can be interesting to reduce conflicts of values, unfortunately there are some realities that we can't do without».	

**Box 8:**

PMTCT Workers' Expectations of Children Born HIV-positive

**Question:** "Could you tell me at length about your expectations regarding the birth of an HIV-positive child?"

Sub topic	Category	Sub-category	Verbatim
Expectations of PMTCT actors	At the structure level	Implication or support for male partners	<i>P<sub>1,9</sub></i> «... involve men, male partners in ... supporting their wives,...» . <i>P<sub>2,11</sub></i> «... ,that all women receiving PMTCT services be accompanied by their husbands». <i>P<sub>4, 10</sub></i> « ... involve the male partner in supporting his wife. This ensures that the HIV status of the partner is well known and that the pregnancy is safe » <i>G<sub>2</sub></i> « ... see how my husband can be persuaded to come with me, so that he can also follow the PMTCT advice, if he could also accept and get involved that would be good,... » <i>G<sub>10</sub></i> ... « .... involving the husband is a problem, that's better, but you have to avoid problems,... » <i>P<sub>8</sub></i> « ... , The involvement of husbands in ANC or PMTCT is highly desirable,... » <i>G<sub>5</sub></i> « ... , As responsibility for the pregnancy is shared, husbands should get involved - that would be good,... » <i>P<sub>7, G<sub>6</sub></sub></i> « ... , the government to make it compulsory for husbands to take part in ANC activities ... »
		Zero HIV positive babies	<i>P<sub>1,2,5, G<sub>1</sub></sub></i> «... Our expectation is that zero HIV-positive babies will be born in the near future. With PMTCT, this is possible because there are those who have healthy children, so why not us too ? » <i>G<sub>1,4,6,7, P<sub>10</sub></sub></i> « ... that one day HIV/AIDS will be defeated, that sufferers will be cured and no more people will be HIV-positive,...»
		Accessibility of inputs, medicines & care structure	<i>P<sub>2,3</sub></i> «... Accessibility ! means availability of inputs, medicines and healthcare facilities». <i>G<sub>1,2,3,4,5,6,7,8,9,10</sub></i> « ... availability of medicines is our survival ... »
	Open exchanges with other players	<i>P<sub>1,5,9</sub></i> « ... encourage frank exchanges in the service with other service providers as partners» <i>G<sub>7</sub></i> « ... I really need to have a chat with my husband, as long as I have the courage, because I'm afraid»	

	Qualified personnel	P <sub>9</sub> « ... PMTCT care providers need to be brought up to standard, because we end up with two types of provider : those who have received PMTCT training and those who have not... »
At the central level	Government support	P <sub>2</sub> « ..., first of all, at central level, we want the State to do its job, to relay everything that the partners are doing »
	Combating illiteracy	P <sub>9</sub> « ... Most of the women who come here for PMTCT, even if they're well dressed, have a very low level of literacy, and the consequences are very serious. So the authorities need to fight illiteracy»
Among people living with HIV	Good health for babies and mothers living with HIV,	P <sub>2,3</sub> , my expectation is that the mother who is HIV-positive should be in good health to protect the child first and foremost,...»
	Miraculous cure	G <sub>1,2,3,4,5,6,7,8,9,10</sub> «...,that the baby is in good health,... »
		G <sub>5</sub> «..., we are waiting for testimonies of miraculous healing, why not also my child one day, »

**DISCUSSION**

*Experience of Ethical Decision-Making in the Face of Conflicts of Values Generated by the Birth of HIV-Positive Offspring Stakeholders' Understanding of Value Conflicts and Ethical Decision-Making*

*Conflict of Values*

The study participants attributed five meanings to the conflict of values. Firstly, the conflict of values was understood as a contrast with expectations, particularly the unexpected. From P1, this perception evokes reflection: "the contrast is striking and reminds us that we shouldn't always take for granted the clichés we can find on the web" (Victor, 2019). This illustrates how value, as hope, expectation, or wish, can clash with reality, leading to disappointment for pregnant people living with HIV (PLHIV) in relation to HIV-positive babies.

Secondly, value conflicts were seen as a failure to respect ethical principles. This perspective was shared by P1, P3, P4, P5, P9, P10, G6, and G7. However, Article 41 of Law 08/011 of 14 July 2008 on the protection of the rights of people living with HIV/AIDS and those affected in the Democratic Republic of Congo (DRC) states: "On pain of being subject to the provisions of Article 45 of this law, any person who knows he or she is HIV-positive must immediately inform his or her spouse and sexual partners of his or her HIV status. However, if the patient refrains from disclosing his or her serological status to his or her spouse, the doctor may, in exceptional circumstances, waive professional confidentiality" (Kabila, 2013). Thus, the values of confidentiality and free consent advocated in PMTCT can clash with the principle of protecting the community.

Thirdly, value conflicts were described as remorse and suffering, or an internal state of unease about the contaminated baby. P4 stated, "Among the main

consequences of the conflicts of values that a person may experience are momentary demotivation and targeted bitterness" (Hudon, 2013). This state of malaise is secondary to demotivation and associated with the bitterness of life. The conflict of values refers to the discomfort experienced by the worker facing disappointment. This remorse leads to moral suffering, which is understood as affliction, pain, or a trial (Le Robert Plus, 2011). The conflict of values may arise when the purpose of work or its side effects clash with the worker's convictions or when the worker has to act against their professional conscience (Fo-Santé, 2011).

Fourthly, value conflicts were seen as contradictions with personal convictions, as noted by P3. This meaning aligns with the assertion: "Contradiction can therefore strengthen a follower's convictions or generate doubts" (Guy, 2009). Conviction helps build both individual and social identity and is a significant value for individuals and social groups. Fifthly, value conflicts were viewed as impeded quality or useless work, as described by P4 and P10. This is in line with the statement: "Prevented quality is the cause of suffering; a lot of capacity and commitment are wasted, employees' psychological and social resources are wasted, their energies are wasted" (Lamarque, 2018). When quality is not achieved, the work becomes futile. Albert Camus, in the 1960s, remarked, "There is no punishment more terrible than useless and hopeless work" (Roche, 2016). Value conflicts, in this context, are understood as the gap between set objectives and expected results.

The question of understanding the conflict of values did not only give rise to different interpretations but also to silence from some respondents. This silence echoes the assertion: "Faced with a value conflict, individuals can behave in different ways: they ignore the conflict or pretend to ignore it (this is avoidance). But they can also deny the facts (denial)" (Potin, 2009). It emerged from

interactions that care providers perceived the conflict of values as a contrast with expectations, a failure to respect ethical principles, and a contradiction with personal convictions, while mothers spoke of remorse, suffering, and unease regarding the contaminated baby.

#### *Ethical Dilemmas*

A single meaning derived from respondents' comments defines ethical dilemmas as conflicts between values and principles. P1 and P5 noted: "A dilemma means choosing between contradictory proposals. The difficulty of choosing often lies in the fact that our decision will force us to accept both positive and negative consequences" (Legault, 2003). Faced with dilemmas, individuals are compelled to make mutually exclusive choices (Malherbe, 2000). Dilemmas highlight conflicts of values or principles, exemplified by the opposition between honesty and truth. For example, hiding a mistake leads to dishonesty, while telling the truth may result in job loss. Dilemmas are perceived as existing oppositions between values and principles, with fear for personal safety and that of relatives often blurring emotional and egocentric values (Brogon, 2023). Thus, a value is what PMTCT actors morally prefer, influencing their decisions.

The respondents' understanding of ethical dilemmas converged on the notion of opposing values and principles.

#### *Ethical Decision-Making*

Five meanings emerged from the respondents' views on ethical decision-making. Firstly, it was understood as a process for resolving ethical conflicts, as noted by P4, P5, P9, P10, P11, G1, G2, and G3. This understanding aligns with Dion and Fortier (2011), who described ethical decision-making as a process for resolving ethical conflicts. Ethical decision-making is also perceived as a deliberate process (Townsend, 2010). Respondents viewed it as involving various steps to resolve ethical dilemmas or value conflicts in professional life.

Secondly, ethical decision-making was understood as finding the best resolution to an ethical conflict, as observed by P1. This interpretation is consistent with Dion and Fortier (2011), who argued that a well-considered ethical decision leads to the best possible resolution of a value conflict.

Thirdly, ethical decision-making was seen as a choice to be made, noted by G7. This perception aligns with the view that ethical decisions rarely have a single "right answer" (Anonymous, n.d.). In a problem-solving process, multiple alternatives may be presented to allow for the best decision.

Fourthly, ethical decision-making was seen as the key to successful PMTCT practice, as noted by P2. This view is consistent with Perreault (2015), who described ethics as a tool for reflection and decision-making, considering the legal, ethical, and personal contexts involved.

Lastly, ethical decision-making was perceived as a preventive tool to avoid value conflicts, as described by P9. Many ethical decisions are spontaneous, but resolving dilemmas requires a deliberate process that includes assessing the situation's ethical aspects, clarifying values, and engaging in reasonable decision-making and dialogue with stakeholders (Legault, 2003). The service provider viewed ethical decision-making as preventive, enabling deeper reflections on the underpinnings of ethical conflicts within any organisation. Parents, on the other hand, focused on the choices to be made. Both groups, however, acknowledged the process for resolving ethical conflicts.

#### *Main Values of the Players and Principles Advocated in PMTCT*

These two sub-themes, taken together, guide us in answering our first specific research question: "How do PMTCT workers immerse themselves in the conflicts of values experienced in hospitals in the city of Kinshasa?" To achieve this, we first sought to pinpoint the main values of PMTCT actors, followed by the principles advocated in PMTCT, as values and principles are the pivotal points that generate conflicts of values in cases of opposition (Dion & Fortier, 2011). Secondly, we aimed to identify the conflicts of values experienced in PMTCT.

#### *Respondents' Main Personal Values*

Seven categories, subdivided into sub-categories, emerged from the values expressed by the respondents. These values are grouped into categories that indicate the major orientations of human action (Morazain & Pucella, 1998). The seven categories of values are: vital, affective, intellectual, economic, aesthetic, legal, and religious. All these values are beliefs inextricably linked to emotions.

This means that, when values are 'activated,' they combine with feelings and relate to desirable goals that motivate action. Values serve as standards or criteria and are ranked hierarchically in relation to each other, a hierarchy that is characteristic of the individual. The relative importance of values guides action, as any attitude or behaviour necessarily implies more than one value (Meier, 2016).

Values are the foundation of human action; they underlie and motivate the conduct of individuals. As opposed to what is factual, value designates what should be, what should be promoted or rejected, and is the subject of an attitude of adherence or rejection (Morazain & Pucella, 1998). Value lies at the borderline between ethics and morality, which is why it is so ambiguous (Simn, 1993). A value is therefore what is morally preferred by those involved in PMTCT.

#### *Ethical Principles Advocated in PMTCT*

These principles clash with the personal values of the players, leading to conflicts of values. The categorical analysis shows that respondents mentioned two categories as principles of PMTCT: the fundamental bioethical principles advocated in PMTCT and those advocated in screening, counselling, and care for PLWHA.

The fundamental principles of bioethics advocated in PMTCT, mentioned by the respondents, include autonomy (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11; G10), benevolence (P10, P11; G9, G10), justice (P7, P8), and non-maleficence (P3, P10, P11). The WHO and its healthcare stakeholders insist on patient autonomy (Flaskerud & Ungvarski, 2011). Benevolence encompasses care, compassion, empathy, sympathy, altruism, kindness, grace, love, friendship, and charity (Johnstone, 2009). Healthcare professionals who act to protect the interests of their clients demonstrate beneficence, promoting the patient's well-being (Beauchamp & Childress, 1993). Justice involves the fair use of limited resources and rejects any notion of discrimination between care providers and clients (Ball & Bindler, 2010). Non-maleficence consists of refraining from actions whose consequences would harm others (Laufman, 1989); it is the will not to harm or cause harm (Ball & Bindler, 2010).

Respondents also mentioned ethical principles fundamental to testing and care for PLWHA: free and

informed consent (P5, P9, P10, P11; G9), professional secrecy and confidentiality (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, P11; G1, G2, G3, G4, G5, G6, G7, G8, G9), and fidelity to promises (P1, P11). Free and informed consent covers the entire carer-care receiver relationship, not forgetting research involving humans. The decision to test must be taken by the person concerned. Professional secrecy is understood as confidentiality (Sicard, 2009). Ethical principles can be used to justify actions or policies aimed at protecting people's rights, maximising their well-being, and avoiding harm (ONUSIDA, 2018). Confidentiality of information given in confidence is a contract, a promise, and, in some cases, an obligation to others. The person receiving the information is expected to protect it faithfully, use it appropriately, and keep promises, as this generates trust (Verdier, 2007).

Understanding the values of the players and the principles governing PMTCT is crucial to exploring the types of value conflicts experienced by PMTCT workers. These actors hold common and specific values which, when confronted with the principles advocated in PMTCT, generate conflicts of values experienced collectively or individually. Our personal values are the basis of every decision we make in any area of life (Vallet, 2019).

#### *Types of Conflicts of Values Experienced in PMTCT Conflicts of Values Between Individuals or Groups*

Five sub-categories of conflicts were explored: conflicts of ideas (P1, P4, G3), conflicts of interest (G1, G4, P2), conflicts of position (G2, P11), marital conflicts (P6, G5), and conflicts of competence (P3, P5, G7). Conflicts of ideas arise when there is disagreement over different opinions or points of view (Audrey, 2015). Respondents indicated that conflicts of ideas were generated by non-compliance with instructions or clashes of ideas. For example, P1 highlighted personal values such as ambition, authority, power, uprightness, and emotionalism, which may clash with clients' failure to respect therapeutic principles. For G3, the conflict lies in balancing religious obedience and medical recommendations. This dilemma places the client and service provider in a situation of value conflict.

Conflicts of interest arise when competing interests clash. For instance, G1 expressed a conflict between her desire for offspring to carry her memory and the unexpressed

interest of the baby to be born healthy. G1's values of authority, power, prestige, and self-sacrifice influenced her choice of maternity in the context of HIV risk, leading to a conflict of values: motherhood vs. HIV risk for the baby.

Conflicts of position, such as G2's experience, involve clashes between the provider's approach and the client's expectations. G2 felt that her positive result was communicated in a discriminatory way, contrary to the principles of benevolence and non-maleficence.

Marital conflicts, according to respondent P6, arise when the announcement of HIV status leads to suspicion, anxiety, or even homicide. Not sharing the results creates tension between honesty, transparency, and the desire to maintain marital harmony (Cornerotte, 2019).

Conflicts of competence occur when organisational demands exceed an individual's abilities (Girard, 2009). The need to exercise religious faith in the face of an incurable disease can conflict with medical demands, such as fasting vs. regulated medication.

#### *Intra-Personal Value Conflicts*

Two sub-categories were explored: conflicts inherent in the person (G9, G10, P3) and pseudo-conflicts (P8, P10, G6). Values such as ambition, integrity, and respect can create internal conflict when the individual faces moral dilemmas. Hope for a baby, coupled with the fear of HIV, presents a precarious situation, as expressed by G9. Pseudo-conflicts, as described by Matteoli (2014), are perceived but not actual conflicts, which can persist and become real if not addressed.

Interpersonal and intra-personal value conflicts reveal the complex nature of these experiences for PMTCT players, affecting providers and clients differently throughout various stages of procreation.

Ethical decision-making in the face of value conflicts in PMTCT involves five categories that emerge from ethical decision-making frameworks. Firstly, the absence or ignorance of a rational ethical approach due to a lack of ethical decision-making procedure (EDP) is noted (P1, P2, P4, P10, P11, G4, G6, G8, G10). Bayard (2016) asserts that "ignoring the existence of something may be detrimental to a good analysis or decision of any significance." After a reminder, it became evident that respondents were

unaware of procedures for making ethical decisions in the face of value conflicts. The reasons were twofold: on the one hand, the absence of an ethics committee in one of the hospitals where the study was conducted, and on the other hand, the inaction of ethics committees, even where they existed, due to stakeholders failing to raise ethical issues (P1, P2, P3, P4, G1, G2, G5, G6, G7). As one respondent noted, "...we don't have the ethics committee here at home to teach us about this..." (P1). Additionally, even when ethics committees existed, there was a lack of action, as noted by another respondent: "...most ethical problems remain in the realm of conscience, which can expose it to third parties" (P11). Habimana and Cazabon (2013) explain that "the occasional lack of a person who is unable to meet his or her obligations on a momentary basis leads to a lack of willingness to make decisions and set goals." The absence of a rational ethical approach is linked to a lack of initiation into the ethical decision-making process, leading to inertia.

Secondly, the non-sharing of information (P1, P9, G2, G3) leads providers, when faced with value conflicts, to remain silent, avoid the person who is the source of the conflict, or rely on divine providence. The silent attitude is classified as "professional confidentiality" (Sicard, 2009), even if it is a silence born of fear. The attitude of avoiding the source of conflict for social harmony is supported by Habimana and Cazabon (2013), who suggest that "conflicts of values are an integral part of life at work. It would be an illusion to think that they will disappear" (Half, 2016). The reliance on divine providence, as noted by G1 and G7, is linked to religious values, with G7 showing empathy. "Religious values are energies to be capitalised on in the face of an appalling reality" (Artus, 2016).

Thirdly, stopping maternity projects, raised by G2, G9, P3, and P8, in order to support the HIV-positive baby was a concern for mothers, while giving advice and understanding the other person was a concern for providers. Supporting the HIV-positive baby and refraining from further childbirth was noted by G2 and G9. This decision was seen as an effective precaution to avoid further HIV-positive cases. "By choice of the best option, we mean the moment of making decisions that are fair, reasonable, and balanced, taking into account possible consequences and circumstances" (Dion & Fortier, 2011).

Fourthly, the fact analysis phase, mentioned exclusively by care providers, raises the ethical decision-making process, subdivided into two stages: fact analysis and awareness (P6, P7). Respondents highlighted identifying ethical facts and discussing conflicts of values, or ethical dilemmas, as central to ethical approaches (Sgreccia, 1999). Awareness, as noted by respondent P7, is an essential stage in ethical conflict resolution, often preceded by de facto awareness (Townsend, 2010). Cherré (2013) suggests that "this knowledge of oneself and of what is going on around us is a prerequisite for recognising what is at stake and then proceeding to analyse the moral situation."

Fifthly, the decision-making phase was noted exclusively by care providers (P5, P6). One respondent shared, "...sometimes I decide to go and see the pastor and make him understand that his sick follower must be given medication for life, every day...once we even initiated a meeting with our partners, involving the church authorities, and this option made a difference..." (P5). Ethical problem-solving generally follows the process of recognising ethical dilemmas, gathering information, formulating the dilemma, consulting on intervention options, determining advantages and disadvantages, setting objectives, implementing an action plan, and evaluating the results (Dion & Fortier, 2011).

#### *Factors Determining Whether or Not Ethical Decisions Are Taken*

By identifying the factors influencing ethical decision-making, it is possible to better describe measures to increase ethical decision-making. According to Agence Française (2017), an "influencing factor" acts directly or indirectly on the state of an issue, and its analysis helps determine long-term objectives. Two categories of influencing factors emerged: internal and external.

Nine internal influencing factors were identified. Firstly, the lack of experience in value conflicts (P1, G1) leads to an absence of ethical decision-making approaches. "Experience is the origin, foundation, and guarantor of all our knowledge" (Agence Française, 2017). Secondly, conflicts of values as quasi-crimes generating criticism were identified (P5). A quasi-crime, as explained by Genouvrier et al. (2012), is a fault that causes harm without intention and gives rise to a right to reparation (Le

Petit Larousse, 2010). Thirdly, personal values, such as illiteracy and low socio-cultural levels, were seen as reasons for not making ethical decisions (P1, P2, P4, P5, G4). According to UNESCO (2009), "literacy empowers people and helps improve their livelihoods, becoming a driving force behind sustainable development."

Fourthly, personal circumstances, such as the failure to provide care or follow-up consultations (P1, P4, P6), also influence decision-making. Ethical decision-making requires the involvement of all stakeholders, yet personal circumstances such as fear of being discovered can hinder ethical decisions (PNLS, 2017). Fifthly, ignorance of ethical conflicts was another internal factor influencing poor decision-making (P7, G2, G3, G7). Bayard (2016) asserts that "ignoring the existence of something...can be detrimental to a sound analysis or decision." Sixthly, the non-exposure of ethical conflicts was noted (P5, G2), as sharing experiences can prevent blockages (Robert & Favaro, 2013).

Seventhly, silence can exacerbate conflicts. While silence may appear professional, it can hide anguish and conflict (P2, G1, G3, G5, G8). Le Figaro (2007) suggests that "the brain tries to forget bad memories," but time may not always resolve conflicts. Eighthly, the fear of being overwhelmed or burdened was noted (P11). Clouzard (2014) refers to this as "the hyper-responsibility syndrome," where fear of commitment prevents ethical decisions. Ninth, the seriousness of the situation affects decision-making (P2), as urgency and the number of people affected can influence ethical action (Coaclica, n.d.). Three external factors were identified. Firstly, economic and political aspects were barriers (P1, P3). As noted, "the lack of funding is one of the barriers to involving sexual partners in PMTCT activities" (P1). Secondly, the absence of ethics committees in hospitals was a significant barrier (P5, G1, G3, G5, G7, G9). Sgreccia (1999) asserts that ethics committees facilitate dialogue with healthcare professionals, helping them make informed decisions. Lastly, ignorance of the ethical decision-making process was also identified (P5, G1), as many conflicts are not shared, limiting the opportunities for ethical decision-making.



### *Appropriate Measures to Combat Poor or Non-Existent Ethical Decision-Making*

This sub-theme enables us to answer our second specific research question: "How can ethical decision-making on the reproductive policy for people living with HIV (PLHIV) in hospitals (PMTCT) be improved?" Seven proposals for appropriate measures were put forward by stakeholders.

Firstly, the acquisition and exchange of experience were emphasized by participants P1, P2, and P3. This corrective measure is aligned with Bouvard's (2016) assertion that "Experience is one of the fundamental components of professionalism. It transforms general or specific knowledge into practical skills. It integrates the sources of material and human contingency that theory cannot contain" (p. 34). Acquiring experience, Bouvard (2016) notes, means accepting that experience is a true principle of knowledge, even if, in many cases, we think and act according to principles that we have not experienced ourselves. This knowledge structures our system of representations and guides our decisions, actions, and interpersonal skills, often unconsciously. Respondents propose creating spaces for ethical reflection between care providers and clients.

Secondly, stakeholders, including P5 and G2,5, advocated for increased self-worth and peer education among PLHIV. Vallet (2019) highlights that "personal values are the foundation of every decision we make in every area of our lives" (p. 89). Literacy and skills training, as well as raising awareness of ethical issues among PMTCT users, are seen as key pillars of an Ethical Decision Process (EDP).

Thirdly, the establishment of ethics committees was recommended. Sgreccia (1999) describes an ethics committee as "a body for the protection of autonomy and respective responsibilities, where members discuss ethical problems and seek solutions consistent with basic values" (p. 112). In the DR Congo, such committees are notably absent from most medical training programs.

Fourthly, the improvement of economic, social, and political conditions was highlighted by P9 and P10. This measure seeks to improve people's quality of life and remove barriers associated with poverty.

Fifthly, stakeholders, including P11 and P2, emphasized the need for emergency ethical decision-making in serious situations. Bertin et al. (2013) explain that "emergency situations often clash with personal values, sometimes leading to ethical dilemmas for the caregiver" (p. 56). In such cases, the urgency of care leaves little room for ethical reflection (Vallet, 2019).

Finally, G1 suggested distancing oneself from situations that may lead to conflicts of values. Bertin et al. (2013) observe that "conflicts of values are often unresolvable because our values are ingrained" (p. 78). However, Becky and Dotson (2016) note that opening up to new perspectives can help address such conflicts.

### *Expectations of PMTCT Workers Regarding Children Born HIV-Positive*

This theme addresses the question: "What expectations do stakeholders have for offspring born HIV-positive?" Three categories of expectations emerged: structural (hospital level), central (State level), and among PLWHA.

At the hospital level, respondents including P1,9, P2,11, G2, and G10 emphasized the importance of involving male partners in the care process, a strategy supported by the National AIDS Control Program (PNLS, 2017). The PNLS (2017) advocates for improving strategies to involve male partners in maternal, newborn, and child health (MNCH) and family planning.

Secondly, respondents including G1,4,6,7, and P10 expressed the expectation of zero HIV-positive babies. According to the World Health Organization (WHO, 2017), several countries have significantly reduced mother-to-child transmission of HIV (MTCT). This expectation can be achieved by improving indicators such as the number of HIV-exposed children on ARV prophylaxis and early testing.

Thirdly, P2,3, and G1,2,3,4,5,6,7,8,9,10 pointed to the need for accessible medicines and care structures. Socio-economic conditions, as highlighted by the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2018), play a significant role in limiting access to essential resources.

### *Expectations at the Central Level*

At the central level, respondents, including P2 and P9, expressed the need for stronger government support. The

Ministerial Order No. 1250 (2012) outlines the roles of key players in the development and monitoring of the MTCT plan. The fight against illiteracy, particularly among women, was also highlighted as a critical issue (UNESCO, 2014).

#### *Expectations of People Living with HIV*

Two main expectations emerged from the respondents' comments: the good health of pregnant PLHIV and their babies, and the hope for miraculous recovery. The PNLS (2018) recommends screening pregnant women for HIV, treating sexually transmitted infections, and providing ARV therapy for HIV-positive individuals. The possibility of miraculous healing, though scientifically unproven, remains a powerful hope for many, as evidenced by accounts such as that of Dr. Pete Du Toit (Vatican, 2001).

#### *Partial Conclusion*

Our research suggests that there is still a lack of ethical decision-making in PMTCT, which can lead to conflicts of values when an exposed baby is found to be HIV-positive. This hypothesis is supported by four sub-hypotheses:

1. There are two types of value conflicts experienced by PMTCT workers: interpersonal conflicts (conflicts of ideas, interests, and competence) and intra-personal conflicts (conflicts within the individual).
2. Internal and external factors contribute to poor ethical decision-making in PMTCT. Internal factors include lack of experience, personal values, and ignorance of ethical conflicts, while external factors include economic and political challenges, and the absence of ethics committees.
3. Measures to improve ethical decision-making in PMTCT include acquiring experience, peer education, establishing ethics committees, improving socio-economic conditions, making urgent ethical decisions, and distancing oneself from value conflicts.

Expectations regarding children born HIV-positive include the involvement of male partners, the health of HIV-positive mothers and their babies, the goal of zero HIV-positive babies, accessible healthcare, and government support. Among PLWHA, there is also hope for miraculous recovery.

#### *Theorising Ethical Decision-Making in PMTCT*

The experience that leads to ethical decision-making in the face of the conflicts of values experienced in PMTCT, which are heightened by the occurrence of HIV-positive offspring, depends firstly on the meanings that each actor has of the unifying concepts of ethical decision-making. The conflict of values is understood by the providers as a discrepancy between the objectives set and the results expected, and by the mothers as remorse for their suffering and their state of ill-being in the face of the contaminated baby. The common perception is in terms of ethical dilemmas, conflicting values and principles, and ethical decision-making being the process of resolving ethical conflicts (Dion & Forter, 2011).

Secondly, personal values of the actors are often in opposition to the principles advocated in PMTCT, as well as the ethical theories involved. Vital, affective, intellectual, economic, aesthetic, religious, legal, and social values conflict with the fundamental principles of bioethics—autonomy, beneficence, non-maleficence, and justice—or with the fundamentals of screening, counselling, and care for PLHIV, such as free and informed consent, confidentiality, and fidelity to the promise (Artus, 2016). Ethical theories such as utilitarianism, Kantianism, Christian ethics, the theory of natural law, and ethical egoism are essential guidelines influencing ethical decision-making. These theories can explain both the acceptance of procreation in the context of HIV/AIDS risk, the presence of ethical conflicts, and the lack of ethical decision-making (Dion & Forter, 2011).

Thirdly, ethical decision-making is influenced by the stakeholders involved. These may include the care provider versus self or others (another provider or progenitor) or the progenitor versus self or each other. The experience of caregivers is generally different from that of mothers, though there is some overlap, particularly concerning the categories of value conflicts. Therefore, these are described as conflicts of values experienced by PMTCT actors (Dion & Forter, 2011). There are two types of conflict of values: communicational conflicts, which are interpersonal or group conflicts (conflicts of ideas, interests, position, marital order, or competence), and intrapersonal conflicts (inherent personal conflicts or pseudo-conflicts). Conflicts of values are integral to work

life, yet there is often the illusion that they will disappear (Artus, 2016). Ethical decision-making, therefore, must be both spontaneous and continuous.

Fourthly, the timing of the conflict is critical, and this may occur during gestation, postpartum while awaiting a definite diagnosis, or after the baby has tested positive for HIV. These conflicts of values can intensify when the baby tests positive or diminish after a negative test (Artus, 2016). Fifthly, the ethical decisions made by PMTCT actors depend on these moments. Faced with ethical conflicts, the actors take an individual approach characterised by the absence of a rational ethical framework due to the lack of a procedure (Dion & Forter, 2011).

Finally, there are bottlenecks to ethical decision-making, including internal factors such as lack of experience and personal values, and external factors like economic and political constraints and the absence of an ethics committee (Dion & Forter, 2011). Measures to mitigate these bottlenecks include gaining and exchanging experiences, raising personal values, educating peers, establishing ethics committees, disseminating ethical principles, improving socio-economic conditions, and distancing oneself from situations that cause these conflicts (Artus, 2016).

#### *Study Strengths, Limitations, and Biases*

As a qualitative study, its strength lies in the validity of the data, which were collected through in-depth interviews that reflect the reality of the participants, providing rich descriptions. The study is also bold in its empirical approach, particularly in its recruitment of participants (care providers and PLHIV parents). However, two major limitations are noted: the small sample size, which may affect representativeness, and the lack of random selection, which limits the generalisability of the results. These limitations were mitigated by using theoretical sampling and conducting interviews until data saturation was achieved. Two biases were also identified: biases related to the interviewer-interviewee relationship, which were addressed through neutrality, and biases due to the absence of responses, which were mitigated by using follow-up questions and ensuring data saturation (Dion & Forter, 2011).

## CONCLUSION

The study reveals that PMTCT workers face silent interpersonal and intrapersonal conflicts of values. Their ethical decision-making approach is individual rather than collective, deviating from existing models. To counter bottlenecks, the measures described by participants can enhance ethical decision-making. Expectations regarding HIV-positive babies remain high, and this study does not claim to be exhaustive. There is a need for reflection, re-examination of values, and ethical analysis among all subjects, which requires an ethical initiation. The differing existential dimensions of care providers and mothers contribute to potential tensions and ethical issues, with intersections between their experiences and expectations revealed through categorical analysis.

## Implications

In maternal and child health, promoting the birth of healthy babies to healthy mothers is crucial. Exploring the experiences and expectations of those involved in PMTCT highlights conflicts of values related to procreation and HIV/AIDS. This study emphasizes the need for a comprehensive ethical decision-making approach in PMTCT.

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