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Authors

Tuthill, Emily L Maltby, Ann E Odhiambo, Belinda C et al.

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Resilient mothering: An application of Transitions Theory from pregnancy to motherhood among women living with HIV in western Kenya

Emily L. Tuthill, PhD^{1,§}, Ann E. Maltby, MIDA¹, Belinda C. Odhiambo, BA², Eliud Akama, MPH³, Carol Dawson-Rose, PhD¹, Sheri D. Weiser, MD⁴

¹Department of Community Health Systems, School of Nursing University of California, San Francisco, CA, USA

²Global Programs, University of California, San Francisco, CA, USA

³Kenya Medical Research Institute- Center for Microbiology Research, Nairobi Kenya

⁴Division of HIV, Infectious Disease, and Global Medicine, Department of Medicine, University of California San Francisco

Abstract

Efficacious strategies can now prevent the transmission of HIV from mother to child. However, transmission rates remain unacceptably high, especially in sub-Saharan Africa. Understanding women's perinatal transitions can inform interventions to support adherence to preventative strategies. Therefore, we applied Transitions Theory in a longitudinal qualitative study to explore perinatal transitions among women living with HIV in western Kenya. We conducted in-depth interviews with 30 women living with HIV at 3 key timepoints and, using our findings, described the theory's concepts in terms of participants' experiences. We then proposed theory-based interventions which could support smooth transition processes and positive outcomes.

Keywords

perinatal transition; HIV; Transitions Theory; food insecurity; financial insecurity; exclusive breastfeeding; Prevention of Mother to Child Transmission of HIV (PMTCT); motherhood

INTRODUCTION

Highly efficacious strategies now exist for the prevention of mother to child transmission of HIV (PMTCT), which can reduce HIV transmission rates to less than 2% versus 45% without PMTCT strategies. ^{1, 2} In low resource settings, like Kenya, these strategies include life-long antiretroviral therapy (ART) for women and prophylactic antiretroviral medications for HIV exposed infants from birth until the end of the breastfeeding period. Exclusive breastfeeding (EBF) for the first 6-months postpartum is also associated with reduced

[§]Corresponding author: Emily L. Tuthill, 2 Koret Way, San Francisco, CA 94143, USA, 415-476-1504, Emily.tuthill@ucsf.edu. Conflicts of Interest: The authors have no conflicts of interests to declare.

mother to child transmission ^{3, 4} and provides optimal nutrition and health benefits for infants and their mothers. Despite these advances and support from National Ministries of Health rates of mother to child transmission of HIV remain high. In Kenya, where this study takes places, vertical transmission rates were 8.92% in 2021⁵. Furthermore, these strategies are largely dependent on women's behaviors, and they all come with their own set of challenges including financial and food insecurity, especially in the setting of limited resources. In addition, pregnant and postpartum (perinatal) women living with HIV (WLWH) must strive to adhere to PMTCT strategies while experiencing life changing health and developmental transitions. We therefore sought to understand the challenges WLWH face in adhering to PMTCT strategies across the perinatal period.

The aim of our study was to apply the concepts of Transitions Theory to the transition from pregnancy to postpartum for WLWH in western Kenya to better understand women's experiences and identify areas for intervention. To accomplish this aim, we conducted a longitudinal qualitative study among perinatal WLWH to explore women's perinatal experiences in the context of PMTCT. We then used Transitions Theory as a framework for our data analysis to identify when and how interventions are needed to improve transition conditions, support transition processes or achieve better outcomes.

Theoretical Background

Transitions Theory is a middle-range nursing theory developed over the last four decades under the leadership of Afaf I. Meleis, a nurse-researcher and medical sociologist. As a nurse, Meleis recognized transitions as a challenging and vulnerable time for patients amenable to targeted nursing interventions. Transitions Theory⁶ provides a framework for describing the experience of transition, whereby transition is defined as, "a passage from one life phase, condition, or status to another". The theory posits, transitions are complex processes which occur across time as opposed to change which may occur as a single event (e.g., birth, a new job, a surgery), often initiating the transition process. The theory was developed not only to explain experiences and responses to change, but also to identify preventative or therapeutic interventions which could improve the conditions under which transitions occur and promote healthy behaviors (see Figure 1 for a model of Transitions Theory and Table 1 for concept definitions). Transitions Theory has been applied to guide research design and analysis as well as to inform the development of interventions to support a variety of transitions including, patients transitioning between levels of care, 8-12 immigrants or refugees adjusting to life in a new country. ^{13, 14} In addition, it has been used to better understand certain disease and developmental transitions, 6, 15, 16 including the transition to motherhood in a variety of contexts. ^{17–20} As a middle-range theory, Transitions Theory has been used to develop a number of situation-specific theories.²¹

METHODS

Setting

Our study took place at a Family Aids Care and Education Services (FACES) clinic within a public sub-county hospital in Kisumu, Kenya. Kisumu is the third largest city in Kenya

situated on Lake Victoria where about one third of the population lives in poverty 22 and the prevalence of HIV is 16.3%. 23

Population

Clinic staff assisted our Research Associate (RA) to identify a convenience sample of women who met eligibility criteria and were willing to participate. We aimed to recruit 30 women, at least 18 years old and between 28–38 weeks pregnant, who were living with HIV. Exclusion criteria were: a high-risk pregnancy for reasons other than HIV status, self-reported participation in another study, the inability to understand the consent process, or imminent plans to relocate. This sample size was determined based on our knowledge of the literature, sample sizes used for similar qualitative designs²⁴ and our prior qualitative work with the target population while ensuring our in-depth, collaborative longitudinal analysis remained feasible.

Design

From April 2019 to January 2020, we conducted a series of three in-depth, semi-structured interviews with each participant during pregnancy and at approximately 6-weeks and 5–7 months postpartum. We used a semi-structured interview guide with questions and probes related to the concepts from Transitions Theory (see Table 2 for sample questions and corresponding concepts). Our qualitative interview guide was developed and evaluated by our study team, including our Kenyan RA, our locally based Kenyan site Principal Investigator (PI) and UCSF-based Research Coordinator and PI to ensure questions were understandable to our target population, and that our translated guides expressed items with the intended meaning in the local context and languages.

Data collection

A female RA from Kisumu, fluent in Dholuo, Kiswahili and English, conducted the interviews in a private office within the hospital The interviews lasted approximately 60–90 minutes, were audio recorded, transcribed, translated, and quality checked.

Ethical considerations

All procedures performed received institutional ethical approval from UCSF Human Research Protection Program (IRB# 18–25134) and Kenya Medical Research Institute Scientific and Ethics Review Unit (Protocol # 3723).

Data Analysis

We utilized a deductive longitudinal analysis approach²⁵ using matrices to organize our data according to the theories concepts and then a series of framing questions.²⁶ First, we created an analysis matrix for each participant in which the Transitions Theory concepts and their working definitions were listed in the first column with three subsequent columns, one for each interview/time point (see Supplemental Table 1 for an example of our phase 1 analysis matrix). Two members of our research team, including our on-site Kenyan PI, then read the series of three interviews for one participant and independently populated the matrix with descriptions of how the concepts manifested themselves in the narratives at each time point.

These descriptions included salient or exemplar quotes to support findings or to illustrate certain concepts as experienced by our participants.

After completing the matrix our research team, including our on-site Kenyan PI and the RA who conducted the interviews, discussed discrepancies in the application of the concepts including when and how they did or did not appear in the transcripts. We continued the process of filling in the matrix and discussing our findings for ten participants until we had a well-developed common understanding of the concepts relevant to this transition and were no longer seeing discrepancies in our matrices.

Two team members then independently reviewed and synthesized the matrices describing the theory's concepts into a second analysis matrix (phase 2) with a row for each participant whereby the columns addressed following questions: 1) What were described by women as the most impactful (either facilitating or inhibiting) transition conditions? 2) What were the healthy and unhealthy behaviors described by women during the transition process? 3) What positive or negative outcomes could be identified by the time of the 3rd interview? (see Supplemental Table 2 for an example of phase 2 analysis matrix).

We then held several team discussions where we presented and discussed our findings. We took turns presenting a brief summary of each participant's experience and then discussed at length the answers to the three questions posed above. Through our discussions we reached consensus on the completeness and accuracy of the summaries for each participant. Furthermore, we reduced the sixteen personal and community level conditions considered during our analysis to just seven transition conditions which meaningfully impacted this transition. In some cases, conditions were closely linked and we merged them, for example we found disclosure of HIV status was directly tied to HIV related stigma. In other cases, we eliminated conditions mentioned by women that did not markedly influence women's experiences or behaviors. For example, although we noted a few women mentioned praying about their difficulties, women's faith did not clearly facilitate nor impede their perinatal transition. We then described these conditions and the patterns of response (process and outcomes) in detail. In the final TT analytical step, we posed and discussed the following questions with regards to each participant: What preventative or therapeutic interventions could have supported a healthier transition across time? What supports were already in place that could be maintained, strengthened or expanded to help other women going through this transition? Answers to these questions along with our main findings provide data which justify the targeted preventive and therapeutic interventions we propose.

Trustworthiness

We ensured rigor and trustworthiness²⁴ in the following ways: 1) We use a collaborative multinational, interdisciplinary team approach to analysis, including locally based RAs to collect, transcribe, translate and quality check data (i.e., credibility and confirmability). 2) We used a sufficient sample size and a series of in-depth interviews at key timepoints to capture a wide range of perinatal experiences (i.e., transferability). 3) We provided a detailed description of our methods and specifically our analysis procedures (i.e., dependability).

FINDINGS

Participant Characteristics

We recruited a total of 30 pregnant women, almost all of whom (i.e., 29 of 30) were from the Dholuo ethnic group, to which the majority of Kenyans in Kisumu belong (the remaining woman belonged to the Kisii ethnic group). Women ranged in age from 18–37 years with seven women having their first baby and 9 women having received their HIV diagnosis during this pregnancy (see Table 3 for participant characteristics).

Applying Transition Theory Concepts to Perinatal Transitions Among WLWH

See Meleis' Transitions Theory Model (2019) and Table 1 for definitions of Transitions Theory concepts.

Transition Change Triggers (Developmental, Situational, Health-illness, Organizational)

The change trigger present for all women in our study was pregnancy, triggering both health-illness and developmental transition processes as women moved through the physical changes of pregnancy, birth and postpartum recovery as well as the developmental changes associated with entering or re-entering motherhood. Henceforth, we will refer to this complex transition as the perinatal transition, to include both the health-illness and developmental aspects of the experience. In addition to pregnancy, we noted many women experienced simultaneously occurring change triggers. Nine women discovered their HIV diagnosis at their first prenatal care appointment and ten women separated from the father of the baby during pregnancy or early postpartum.

Transition Properties (Timespan, Process, Critical Points)

Timespan.—In many cases perinatal transitions arguably begin before pregnancy, as women mentally prepare for motherhood. Yet, a majority of participants had unplanned pregnancies, thus, we identified the starting point for this transition as the time at which women discovered their pregnancy. For most women, this was early pregnancy. Several women who were using long-acting contraception (and therefore not considering pregnancy a possibility) discovered they were pregnant later, including some who were well into their second trimester.

While pregnancy ends abruptly with childbirth, the perinatal transition continues as women initiate breastfeeding and begin their physical recovery from the birth. As is often the case, the timespan for this transition does not have a clearly defined endpoint as a mother's identity, role and the skills and abilities required of her across time are fluid and everchanging with the growth and development of her child.²⁷ However, previous studies on the transition to motherhood in other contexts have established 2–6 months postpartum as a reliable endpoint for understanding the perinatal transition.^{27, 28} Furthermore, accomplishing specific goals and achievements or reaching certain milestones may also mark the end of a transition.⁶ Thus, we estimated that the perinatal transition lasted until around 6-months postpartum, the end of the recommended EBF period and the timepoint of the infants second HIV test, both major milestones for women in terms of adhering to the PMTCT strategies.

Our final interview took place when women were 5–7 months postpartum and we found this to be a point at which we could indeed make an assessment of women's transition outcomes.

Process (Phases).—Since Transitions Theory is not specific to any one type of transition, other theories or information are inevitably needed to understand the specific characteristics, processes and outcomes of the transition of interest. Along with our in-depth interview data, we used Mercer's theory of Becoming a Mother (BAM) to inform the development of the phases of this transition²⁷. We identified five phases composing the transition to motherhood including, *1) early pregnancy, 2) late pregnancy, 3) birth, 4) early postpartum, and 5) late postpartum* (See Figure 1 for our adapted perinatal transitions model).

Early Pregnancy (<28 weeks).: Women largely described early pregnancy as a very difficult time in the transition process with the primary reasons being that the pregnancy was unplanned that they were simultaneously abandoned by the father of the baby or that they were grappling with a new diagnosis of HIV, as expressed by this participant (025):

"I had it rough, I thought that it would be better if he had only left me pregnant but now, he leaves me pregnant and HIV positive at the same time, and he knew that he was doing it intentionally."

Of the 9 women who were newly diagnosed with HIV during this pregnancy, several described struggling to accept their diagnosis including feeling extremely sad, being in denial or being reluctant to engage in HIV care and initiate ART.

Late Pregnancy (>28 weeks).: By late pregnancy women had come to terms with their HIV status. They reported good adherence to ARTs and were imminently preparing for the birth of their babies. They were generally well informed about the PMTCT guidelines including EBF and were highly concerned with adhering to these guidelines after birth. Also, during this phase, many women had stopped working and were therefore highly concerned with their household's food and financial insecurity.

<u>Birth.:</u> Birth was a significant (albeit short lived) phase which posed considerable challenges for women, including transport to the clinic or hospital for delivery, the initiation of breastfeeding (sometimes while sharing a bed with other new moms and babies) and the process of giving babies the first doses of prophylaxis medications.

Early Postpartum.: Early postpartum was a time of physical recovery for women who were balancing multiple competing demands, including sustaining EBF, caring for other dependent children, household duties, medication adherence for themselves and their baby and remaining engaged in HIV/postpartum care. Food and financial insecurity remained at the forefront of the women's daily challenges. Many women were relieved the birth was now behind them and were looking forward to resuming some form of gainful employment.

<u>Late Postpartum.:</u> The final phase of this transition was still ripe with challenges including ongoing worries related to food and financial insecurity. Yet, 6-months postpartum marked the end of a challenging period critical to PMTCT, as the recommended period for exclusive breastfeeding ended. At this time, most women re-engaged or planned to re-engage in

income generating activities. Women expressed feelings that things were returning to their pre-pregnancy state or that they had adjusted to this new normal.

Critical Points.—Within each phase of the perinatal transition, we identified critical points or milestones characteristic of this transition (see Figure 1 for our adapted Transitions Theory model). Critical points included being diagnosed with HIV, women's departure from the workforce, the initiation of breastfeeding and prophylaxis medications for infants, infant HIV tests (at 6-weeks and 6-months), and the end of EBF/ the beginning of complimentary feeding.

Transition Conditions (Personal, Community)

Personal Conditions.

Level of Planning.: For the majority of women this pregnancy was unplanned, and many reported they were using some form of long-acting contraception (either an implant or monthly injection) at the time they became pregnant. Unplanned pregnancy was troubling for women in various ways. Women reported they did not have the resources to support another child or that pregnancy and the obligation to EBF after birth would interfere with their work and therefore the income needed for meeting basic needs. Unplanned pregnancy also disrupted relationships for some women who were abandoned or mistreated by their partners after discovering their pregnancy. Women believed their partners left because they were not prepared to be fathers or because the women were no longer able to work/ earn income during their pregnancy and the early postpartum period. One young woman simply recounted (019),

"He told me that he was not ready to be a father... that is the reason we broke up."

Past Experiences.: Past experiences, or a lack thereof, emerged as a condition influencing most women's perinatal transition. For example, women who had been living with HIV (and adhering to ART) before becoming pregnant had fewer worries about transmitting HIV to their infants than those who were newly diagnosed during this pregnancy. Likewise, women who had previously experienced a pregnancy while living with HIV expressed fewer worries about facing this transition again. We also noted that younger women (<24) more often reported struggling to accept their HIV diagnosis, disclose their status to support people and initiate treatment than women who were slightly older (>32). Finally, women's past experiences often included a previous miscarriage or the death of a child (either related HIV or to a number of other illnesses). For some women, the loss(es) seemed to increase their resolve to adhere to the PMTCT guidelines while for others it seemed to be a continued source of sadness.

Personal Financial Stability/ Resources.: Access to basic resources such as food, water and shelter was a nearly universal problem for women as expressed here (012):

"P: When I was pregnant, I would think about how we would get food, sometimes there is no food and sometimes my husband has not got anything, so this made me sad."

Undeniably, this impacted women's transitions in a number of ways including inability to pay for transportation to the clinic, debilitating side effects from taking medications when hungry, and for many, inadequate breastmilk production. One woman explained (025):

"It is hard because you breastfeed the baby the whole day without food, sometimes the baby suckles and gets nothing and this hurts me."

Worries about meeting their basic needs and the needs of their dependent children was a major source of stress which was exacerbated by increased financial insecurity during the period when women's employment was interrupted by pregnancy and the commitment to EBF postpartum.

Community Conditions.

<u>Relationships with Primary Partners.</u>: Most women described inadequate material support (e.g., money, food, housing) from their partners as a result of their partner's unwillingness or inability to provide (either because their income was insufficient or because they had another wife and family to provide for). One-third of women interviewed were separated from or were abandoned by their partners during or shortly after pregnancy (026):

"I have had so many challenges, my husband left me and sometimes he can only send me 400 shillings in a week and sometimes he does not send; I decided not to be sad about it and not to depend on him I have to look for a way to be independent."

Women also reported other problems with their partners including rejection, abuse, mismanagement of finances, alcohol abuse, pressure to stop breastfeeding and pressure to conceal their HIV status leading to difficulty with medication adherence in the presence of others. In addition, a lack of emotional support from partners was reported by nearly all women with associated challenges such as feeling stressed or isolated. Despite "relationships with primary partners" being a personal condition which inhibited the transition process for most women, several women credited their partners with providing critical support after their initial HIV diagnosis. Support included encouraging women to engage in care and take their ARTs, providing fare for transportation to clinic appointments as well as being tested for HIV and disclosing their own status.

Support from Healthcare Providers.: Women interacted with doctors, nurses, and mentor mothers (community health workers) during their transition. Overall, they reported receiving good care and had a high level of confidence in these providers. Women also credited healthcare providers with educating them about PMTCT, with the vast majority demonstrating adequate basic knowledge of PMTCT strategies including the importance of adherence (for both mother and child) and EBF for the first 6-months (024):

"The doctors here talk to people nicely and when it is almost two days to your appointment day you are reminded that you are supposed to come to the clinic and that makes you feel better ... the way they teach people makes me feel that taking the drugs is easy."

Women also described provider support and counseling as instrumental in terms of accepting their initial HIV diagnosis and initiating and maintaining HIV treatment. Healthcare providers supported women throughout this transition in a number of ways including, calling or text messaging to remind women of their appointments, paying for clinic fare when women had no other means to arrive at the clinic, helping women to resist pressure to prematurely stop or supplement breastfeeding, supporting women with disclosing their HIV status to their partners and supporting women to ensure continuity of HIV care when they chose to relocate.

Some women also explained that providers encouraged them to resist engaging in unsafe traditional medicines or practices. One traditional practice, in particular, mentioned by many women is referred to as "plastic teeth removal". This practice, carried out by a traditional healer, involves slicing open the infant's gums and may include the removal of the infant's incisor buds. ^{29, 30} The practice is thought to cure various common ailments including general crying/ fussiness, fever or poor feeding and may be carried out as early as a few days after birth.

Women did not give birth at the same facility where they received HIV care and some were less satisfied with the care they received while in labor and during and immediately after delivery. Most of the women's complaints were related to lack of resources within the hospitals, including overcrowded wards, sharing beds or poor-quality food. Only a few women reported being treated poorly by providers or receiving inadequate provider support, including a lack of information and support for initiating EBF.

Social Support.: Sisters, parents and mothers-in-law were the most frequently mentioned sources of social support. They provided emotional support, food, money and/or shelter. This support was critical to women's ability to provide for herself and her children and to maintain good mental health as well as engagement in HIV care. Women who lacked social support from family suffered both mentally (sadness, stress, isolation) and physically (hunger, inadequate shelter/clean water). They were forced to meet basic needs by borrowing/ taking things on credit from local shops and/or pleading with landlords to accept late or partial payments, all of which was extremely stressful for women and their children. As one woman explained (020),

"I am worried because sometimes I spend time in the house with the children without anything. Sometimes I send them to the shop to go and get things on credit and that I will pay back later so that they can get something to eat."

<u>Disclosure/Stigma.:</u> Although most women (even those newly diagnosed with HIV) had come to terms with their own HIV status by the time of the initial in-depth interview, there were still many women regardless of the length of time they had been living with HIV who feared stigma and who therefore feared others knowing their HIV status or who simply believed it was something that should be kept private (022):

"I feel ashamed and it is not easy for me to tell them."

The main difficulty associated with this was administering the infant's prophylaxis medications. Women (and in some cases their partners) believed that if anyone saw them giving medicine to their babies, that person might ask what the medicine was for or simply presume that it was related to the mother's HIV status. Yet, most women reported that this only occasionally impacted their baby's adherence.

Among women who disclosed their HIV status to their support people, including their partners, many were received positively, often receiving support for their HIV care after disclosure. However, a few women reported a negative reception by partners or support people after disclosing their status and some simply chose not to disclose their status to their partners or support people for fear of their response. In both of these scenarios, women suffered from the resultant lack of emotional and material support and often isolated themselves as a way to avoid disclosing their status to anyone. This was challenging for women both in terms of remaining engaged in HIV care and in terms of getting support to meet their basic needs.

Patterns of Response (Process, Outcomes)

Process: Behaviors during the phases of the transition.

Engaging and Finding Solutions.: Women demonstrated engagement through active participation in the perinatal transition including questioning the process, working towards goals or making efforts to understand and follow the guidance or directions of providers and support people. More specifically, the majority of women engaged in the transition process by initiating and/or maintaining their perinatal and HIV care, to include their efforts to adhere to the PMTCT guidelines.

Women also described efforts to address to their food and financial insecurity, which were major challenges during the transition period. Some women worked for as long as possible during pregnancy and/or returned to work bringing the baby along soon after birth. Many women also reported searching for work that could be done very close to home or with their babies in tow to allow for continued breastfeeding. Women found balancing the need to work and infant care difficult and many women reported a lack of start-up capital or the need to EBF for the first six-months as major barriers to returning to their income generating activities (007):

"...staying at home made me spend the money I used to trade with and now I am without any, so it is not easy to look for money and start up again."

When unable to afford fare to the clinic, women reported borrowing money from friends/ neighbors, negotiating with motorists to pay later, changing their appointment date, asking someone else to pick up their medicines for them, or walking long distances (up to 5 kilometers) to avoid missing their appointment both when pregnant and then carrying their baby with them postpartum. Some women even walked to the hospital when in labor and one woman, who was unable to make it to the hospital before giving birth, carried her newborn baby to the hospital the next day so she could receive her first vaccines. Another woman gave birth by the roadside with the help of her neighbor while trying to make it to the hospital.

In addition to food and financial insecurity, women described efforts to overcome significant challenges related to EBF, including feeling their milk supply was insufficient because of inadequate access to food or facing pressure from friends and family members to feed the baby other things such as porridge, water or traditional medicines. As one participant explained (022):

"Sometimes he wants to breastfeed and there is nothing coming, sometimes he does not get satisfied so he just cries, and the greatest challenge is that you cannot go anywhere and leave him behind."

Women used various strategies to overcome these challenges including turning to providers for support and reassurance, explaining to friends and family the importance of EBF for the baby's health, and by carrying their baby with them at all times. Despite their efforts, some women reported introducing supplemental feedings or traditional medicines prior to six-months, or ongoing struggles with insufficient breastmilk related to food insecurity and no plausible solution beyond suffering through.

Several women also struggled to address the issue of their babies' "plastic teeth." Women who had their babies' "plastic teeth" removed believed it was a necessary risk to ultimately improve their babies' health with some reporting the practice was recommended to them by friends or family as participant 005 notes here:

"I was a first-time mom, I did not understand why she was crying. When my neighbor heard, she came and told me that we should look at her mouth and on checking, she had plastic teeth and I left immediately to go get them removed."

Finally, an important issue many women struggled with was effective postpartum family planning. By six weeks postpartum, nearly half of the women had yet to access family planning despite not wanting more children. Several barriers to using family planning emerged, including women's uncertainty about effective contraceptive options available to them after their previous long-acting contraception failed and the unavailability of monthly injections, which was the preferred method for some.

Locating and Being Situated.: Recognizing how the current experience of pregnancy, birth and motherhood differed from previous experiences was a primary way woman demonstrated "locating" themselves and "becoming situated" in the present (and distinct) transition process. For example, women who had their previous children before being diagnosed with HIV, pointed out things they did differently, such as having a skilled delivery in the hospital or EBF for a longer period (most had previously EBF to 3 months or less). Likewise, first time mothers reflected both on their new status as a "mother" and on their new responsibilities—namely to provide for their child. We found the concept, "locating and being situated" also applied to the way women managed and understood their changing positions in various relationships. Women were inevitably more dependent on the supportive people in their lives during late pregnancy and early postpartum. As a result, some women reported feeling uncomfortable depending on others or that relationships were strained by their increased need for support leaving them feeling unsettled (025):

"...right now I don't sit with friends because when you talk to a friend, she may want to brag while you are going through a tough time so I prefer to sit in the house and sleep. I am always in the house; I cannot spend time with my friends whom I used to be free with."

Throughout this transition, a number of women also reflected on negative changes in their relationships or their perceived position in society related to their HIV status. For example, one woman reported a lack of sexual intimacy with her husband after disclosing her status to him and another believed her husband was justified in seeking a second wife because of her HIV status.

Seeking and Receiving Support.: We found both "engaging and finding solutions" and "locating and being situated" were closely tied to "seeking and receiving support". This is because seeking or receiving support was often the means by which women addressed their primary challenges of food and financial insecurity and trouble with EBF. Furthermore, the extent to which women had "located and become situated" impacted their perceived needs and willingness to solicit support.

For some women, disruptions in their relationships related to unplanned pregnancy or a new diagnosis of HIV, created barriers to seeking support. For example, several women were abandoned by their partners and others were hesitant to seek support because they feared the friends or family might disapprove of their unplanned pregnancy. In addition, many women noted a lack of finances during the transition further impacted relationships with their primary support people. Women believed supporters grew tired of their repeated requests for financial support. One participant describes her sister's response when she asks for help (019):

"She complains saying that supporting someone with a baby is hard and that I should look for means of getting a job."

Notably, some women simply lacked social support and described having no one to turn to.

There were also barriers to seeking and receiving support from providers including limited time for interaction in the setting of the busy hospital (especially during labor, delivery and immediately postpartum). In addition, women's fear of disappointing or being reprimanded by providers led to a reluctance to report their difficulties with challenges such as medication adherence, plastic teeth removal or their decision to practice mixed feeding (026):

"I could tell because if I gave him breast milk he would cry and if you put him to sleep he would wake up immediately but when I introduced cow's milk he would take and sleep without waking up, so when I come here and I'm asked what I am giving him I would just say breast milk."

Acquiring Confidence.: Despite numerous challenges faced by women throughout this transition, the majority of women described gaining confidence in their abilities as a mother and as a woman engaged in HIV care. They naturally assumed their maternal role, including bonding with their babies and understanding their babies' needs as expressed here (004):

"When she wants to breastfeed, at times you can see her sucking her fingers, then she wants to suckle or sleep, so I will test her, if she does not breastfeed then she will sleep, or at times she cries."

The majority of women also reported being knowledgeable about their HIV care and confident in their abilities to access the resources available to them (primarily healthcare services) as well as to adhere to the PMTCT guidelines as expressed by participant (008):

"I usually just give breast milk but people normally tell me to boil [cow's] milk for her, but I still want to follow the doctor's instructions."

And participant (013):

"I thought that if a mother is HIV positive, she shouldn't breastfeed but since I was told that people are nowadays 'digital' [Meaning enlightened] I will breastfeed for six months then stop. I had the courage now since it's the doctor who said."

Outcomes: Behaviors at the End of the Transition.

Mastery.: At 5–7 months postpartum, we found the processes of "engaging and finding solutions" as well as "acquiring confidence" culminated in the women's mastery of her role as a new mother living with HIV. Although women continued to struggle to address their food and financial insecurity, we found most women demonstrated the resourcefulness and confidence associated with "mastery" of their new role (016):

"I have a high level of confidence because you know that I, as the woman, I have to be the one to look after the child, so I have to just set my mind on looking after the baby."

Women were highly capable mothers who reported successfully balancing their household duties, along with breastfeeding and caring for their new baby, caring for their other children and remaining engaged in HIV care despite substantial structural, community and relationship-level barriers. As evidenced by this participant's description of an interaction with her partner (029):

"He was feeling that the baby is breastfeeding too much and if she was given milk then maybe she would stop breastfeeding that way, I had to explain to him that babies who breastfeed exclusively for six months develop a good immunity and they don't often get sick."

None of the women reported difficulty bonding with their babies or feeling they were overwhelmed, inadequate mothers or lacking confidence as a mother. Women were well-informed and largely adherent to the PMTCT guidelines including taking their own HIV medications, EBF for the first six-months and administering prophylaxis medications to their infants as relayed here by participant (029):

"We were taught that you have to breastfeed the baby for six months then after six months you can now introduce other foods so I followed that instruction."

As well as (004):

"I know that when I take my medication as recommended then she cannot get infected with HIV, and I also give her medication as recommended, so I can breastfeed her until 2 years, she will have been well developed by then."

At 5–7 months postpartum, all 28 women (2 women were lost to follow-up) remained engaged in HIV care and the infants' first HIV tests (completed at 6-weeks) were negative for all 28 infants. Thus, by a variety of measures, the majority of women mastered their role as a mother living with HIV. There was only one woman who did not demonstrate the confidence and ability to utilize resources that we associated with mastery. This young woman reported not taking one of her medications because of the side effects and not giving HIV prophylactic medication to her child because of her husband's fear that others might see her doing it and discover her HIV status (something he did not want anyone to know about). Although, with support from providers, she overcame pressure from her husband to prematurely stop breastfeeding, she never addressed the issues of medication adherence for herself or her baby, both critical to PMTCT.

Fluid Integrative Identity.: As women reached the end of the transition process, they came to accommodate several different identities. Yet, shifting between identities or integrating these different identities was not always fluid. Mother, first-time mother, single mother, wife, daughter, breadwinner, dependent and woman living with HIV were the identities we found women had integrated into their daily lives by the end of the transition period. Many women were able to move smoothly from one "way of being" (mother) to another (employee/entrepreneur) or even comfortably integrate multiple identities at once, for example working while carrying their babies along (023):

"I work and she is next to me and when she cries, I will breastfeed her then I continue with my work or she plays, I give her things to play with and then I continue."

By 5–7 months postpartum, the majority of women reported having an important role in generating income for the family and had returned to work or were making plans to return to work. Yet, of the women who had already resumed work, several reported difficulties balancing between being mothers and breadwinners. For example, one woman described difficulties when her customers were put off by her breastfeeding her baby in between preparing and serving food.

The majority of women found it difficult to move seamlessly between the reality of living with HIV and their other identities. Specifically, most women continued to consider their HIV status something that should not be disclosed to anyone beyond their closest support people, with the main reasons cited being embarrassment, guilt and fear of stigma. We assessed that keeping one's personal health information private does not mean that a part of one's identity has failed to be integrated. In fact, many people prefer to keep their chronic and even life-threatening health conditions private. Nonetheless, there were continued difficulties for women who chose to keep their HIV status private, including added stress from hiding appointments and medications, navigating infant feeding, and a tendency to limit participation in social activities.

<u>Healthy Interaction.</u>: Despite the noted challenges women faced when seeking and receiving support, women who began this transition with good social support were generally able to maintain good relationships throughout. Nevertheless, many women hoped resuming gainful employment postpartum could ease some of the tensions placed on their relationships during the transition (006):

"Let me say like right now I am just begging for help, begging is not good, if I can get some little capital, I can start a business and I can carry my baby with me and go with him to my work place, and I can do my work without giving people a burden."

Women who started out with a limited social support network made little progress in the way of expanding their network but were most often able to maintain relationships with their one or two close supporters.

Perceived Well-being.: Women's sense of well-being improved across time as the women moved from a stressful and uncertain period following the first knowledge of their pregnancy (and in some cases their initial HIV diagnosis) to a more stable postpartum state (025):

"...right now [6 months postpartum] is not as before. I may not be able to pay the rent, but we can get food- we can get porridge and at times we take black tea and maize and sometimes when the maize dries, we can take it to the flour mill then make ugali."

As women accepted their unplanned pregnancies, adjusted to living with HIV, became accustomed to being separated from their partners and/or took actions to prevent the transmission of HIV to their babies, they were comforted by reduced levels of stress. However, even by the end of this transition, the sense of well-being for many women was negatively impacted by ongoing problems with food and financial insecurity. Despite women's successes in mastering their new role, integrating their identities and maintaining supportive relationships, nearly all women still struggled to meet their families most basic needs, and this was detrimental to their sense of well-being even as they reached other milestones marking a successful end to this transition period. Furthermore, unsupportive relationships with partners and a generalized sadness about living with HIV continued to impede the mental well-being of many women. Thus, for the majority of women their sense of well-being remained sub-optimal by the end of the transition.

DISCUSSION

The aim of our study was to apply Meleis' Transitions Theory⁶ to describe the transition from pregnancy to postpartum among WLWH in western Kenya using a longitudinal qualitative design. We describe our findings of the perinatal transition in terms of its timespan, phases and critical points. We also identify the perinatal transition conditions that women reported as having the greatest influence (both positive and negative) on their experience and describe the healthy behaviors as well as challenges women reported across the phases of transition and by the end of the transition period. To our knowledge, this is the first study to comprehensively use the concepts of Transitions Theory as a framework

for longitudinal qualitative research design and analysis. This is also the first application of Transitions Theory to the perinatal transition for WLWH. Moreover, our study takes an important step towards bridging the gaps between nursing theory, research and practice. We do this by conducting research which is deeply rooted in theory, provides in-depth findings on perinatal women's experiences and simultaneously facilitates an understanding of the theory's concepts in practical terms as well as the implications for practice (see Figure 1 for our adapted Transitions Theory model).

Proposed Interventions to Support Perinatal Transitions among WLWH

Our findings reveal key points for interventions, which could support women during this transition and specifically support the behaviors known to prevent the transmission of HIV from mothers to their infants.

First of all, while it may seem to fall outside of the Transitions Theory model, we found there is clearly a place for interventions to prevent unwanted pregnancy and/ or prevent the transmission of HIV to women prior to pregnancy and in effect, prevent or delay this transition from happening altogether. The large number of unplanned pregnancies and challenges accessing family planning postpartum indicate an unmet need for access to safe and effective family planning options. Furthermore, a number of women reported discovering their HIV status during this pregnancy. Given the high prevalence of HIV in this community, ²³ there is a continued need for interventions which can support a cultural shift to normalize HIV testing and disclosure of status for couples as well as provide guidance for discordant couples after testing, including support for the uptake of preexposure prophylaxis. Such actions could increase the number of women who engage in HIV care and achieve viral suppression prior to pregnancy.

In terms of interventions specific to WLWH, although all women were engaged in care prior to joining our study, many cited major difficulties accepting their HIV status at the time of their initial diagnosis, with several women describing delaying engagement in care until well after their initial diagnosis. Many women also struggled with ongoing fear of stigma or sadness about their HIV status even long after their initial diagnosis. Several women credited counseling and support from providers with allowing them to rapidly engage in care, disclose their HIV status to their partner and/or accept their HIV diagnosis. Thus, there is a need to expand HIV counseling and services focused on supporting the initial engagement in care when emotional support and coping skills are being established and critical to sustained care across time. We further noted the timespan included a wide range in age and experiences among our participants, and observed that younger women generally struggled more to engage in care and accept their HIV status, meanwhile older, single, women were more comfortable identifying themselves as a WLWH to others and less fearful of stigma. This could point to life experience or maturity as being a supportive factor and/or the behavior or attitudes of partners (e.g., blame, pressure to hide status, etc.) as being a barrier to the fluid integration of this identity. Given these findings, whenever feasible, counseling should be tailored to the individual and the possibility of including primary partners should also be considered.

The personal condition posing the largest threat to women's ability to adhere to the PMTCT guidelines across time was severe financial insecurity (and related food insecurity), which made processes of engagement in care, medication adherence and EBF increasingly difficult. Previous studies similarly identified economic strain/ insecurity ^{17, 18, 20} as a key inhibitor of this transition in other settings. Additionally, hunger (a measure of severe food insecurity) was associated with early EBF cessation among a similar population in western Kenya. ³¹ Thus, interventions which reduce women's financial insecurity and increase women's access to food during pregnancy and postpartum would markedly reduce challenges and ensure better outcomes associated with engagement in care, medication adherence, EBF and mental well-being. These interventions might include, food and financial support, access to capital for small scale entrepreneurs, assistance resuming employment or finishing school postpartum and support for breastfeeding mothers who return to work.

In addition to food and financial support, we noted women also needed other types of support and reassurance throughout the EBF period. The majority of women worried about the adequacy of their milk supply. Thus, in addition to the information about the importance of EBF that women received, women needed confirmation that their infant was adequately nourished, support in understanding their infant's hunger and satiety cues, information about how to optimize their milk supply and a clear understanding of the range of infant feeding options as well as the risks and benefits of each option (rather than just reinforcement of the idea that EBF was the best and only option). We specifically noted two critical points where individualized infant feeding support and counseling would improve women's experiences: immediately postpartum when EBF was initiated and at around 6-months postpartum when women started introducing complimentary foods.

Interventions targeting problems with primary partners is another key intervention area we identified. Indeed, social support, including support from partners, was previously identified as a key facilitator of the transition from pregnancy to postpartum in a variety of other contexts. ^{17, 19, 20} Furthermore, a lack of family and partner support has also been shown to negatively impact this transition. ^{17, 19, 20} We expand on these findings by showing partners, who primarily provided poor quality or non-existent support during the perinatal transition, were a major source of stress for women across the perinatal transition. During pregnancy, women described being abandoned and/or fear about disclosing their HIV status to their partner. Meanwhile, postpartum, stress related to partners centered on inadequate financial and food support. Thus, interventions to improve and expand women's social support networks including strengthening and improving the quality of relationships with partners when feasible, are essential to improving women's wellbeing across this transition period. In addition, many women also reported contracting HIV from their partner who knowingly or unknowingly infected them. This is further evidence pointing to the need for interventions to support HIV testing and disclosure for couples. Supporting engagement in care and adherence for men is also clearly of paramount importance.

Finally, we identified a need for interventions which would prevent women from engaging in unsafe traditional practices, such as having their infant's "plastic teeth" removed. Nearly a third of the women still opted to have their baby's "plastic teeth" removed by traditional healers in the community. As discussed above (see community conditions), this practice puts

infants at risk for bleeding and infection. The large number of women still engaging in the practice, despite information about the dangers, indicates this issue might best be addressed through community-based and culturally sensitive interventions which engage stakeholders at multiple levels.

Limitations

Our findings provide a comprehensive application of Transitions Theory to better understand the perinatal transition. Data from the in-depth interviews we conducted illuminated personal and community level conditions more so than societal or global level conditions. There is a need to incorporate data from other sources that can elaborate on the aspects of these higher-level conditions impacting this transition. These findings may be limited in their transferability to high resource settings.

We have identified several limitations in the Transitions Theory. First, WLWH experiencing perinatal transitions experienced one or more simultaneously occurring transitions. For many women, this was the transition to living with HIV or the transition triggered by the relationship with the father of the baby coming to an end. Consequently, the perinatal transition experience of WLWH involved several overlapping transitions at various stages across time. For the purposes of this study, we focused primarily on the perinatal transition while incorporating some elements of the transition to living with HIV, however, there is a need to fully understand and incorporate the phases of the other ongoing transitions. Secondly, Transitions Theory does not account for interactions between conditions or the changing significance of the different conditions to individuals across time. For example, the unplanned nature of many pregnancies, and women's severe financial insecurity undoubtedly impacted their relationship with their partners. Similarly, we noted a relationship between women's age and her fear of stigma (older women being less fearful of HIV related stigma). Thus, there is a need to understand the interactions between transitions conditions and variations in how these interactions impact the transition across time.

CONCLUSIONS

Multiple conditions challenged the perinatal transition among WLWH in western Kenya including unplanned pregnancy, severe food and financial insecurity and unsupportive partners. Meanwhile, previous experience with PMTCT, being older (and presumably having more life experience), good social support and support from healthcare providers facilitated a smoother transition process. By the end of transition, all 28 women successfully prevented the transmission of HIV to their infants and remained engaged in HIV care. Many women also fully incorporated the knowledge, skills and experiences needed to succeed in their new roles. Despite these successes, most women ultimately described a sub-optimal sense of well-being and our in-depth exploration of this experience reveals the many challenges perinatal WLWH in western Kenya face as well as the immense efforts women are making to rise to these challenges and protect their infants from contracting HIV. Based on our comprehensive application of Transitions Theory, we propose several interventions which could support women during this transition and improve transition outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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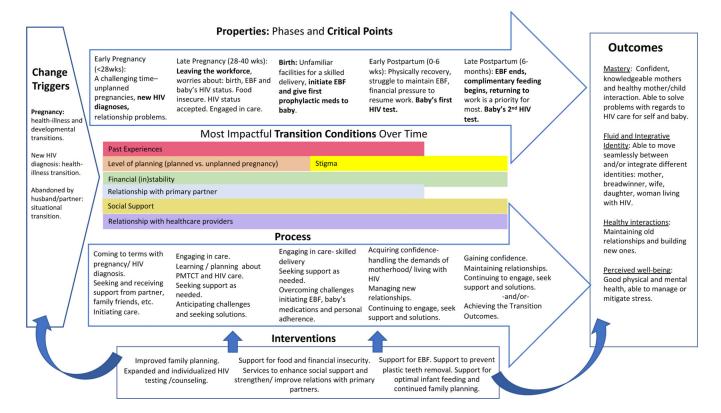


Figure 1: Adapted Transitions Theory Model: From Pregnancy to Postpartum among Women Living with HIV in western Kenya.*

*In order to visually represent the transition as something occurring across time, we stretched the transition properties horizontally along a timeline with the critical points and milestones bolded within the different phases. We then placed the transition conditions, and the "patterns of response: process" parallel to the timeline of the phases of the transition. We did this to emphasize that different transition conditions may be more or less relevant during different phases of the transition and the behaviors indicative of a healthy transition process also vary depending on the phases of transition. We maintained the other elements of the model with the change trigger being the starting point for transition, the "patterns of response: outcomes" being the ending point and the possibility for interventions being considered at any point from start to finish.

Table 1:

Transitions Theory Concepts Defined

Concept	Definition				
Change Triggers	Transitions Theory proposes that every transition begins with a "change trigger" or an event that causes a change to occur and sets the transition process in motion. Change triggers can lead to one or more types of transitions including, 1) health/illness, 2) developmental, 3) situational (e.g., discharge from hospital, a floor nurse becoming a manager) and 4) organizational (e.g., a new leader, a different charting system, use of new technology). ⁵				
Properties of Transitions	The characteristics of the transition. How long does it take? —usually the starting time is distinct while the endpoint may be more fluid. What are the phases or steps involved? How does one disconnect from the familiar way things used to be to enter uncertainty and make way for the new way of being? How aware is the person experiencing transition of what is happening and what is to come? What are the critical timepoints, events or milestones along the way? ⁵				
Transition Conditions	Transition "conditions" describe the context in which the transition occurs and can be understood as factors influencing (positively or negatively) the transition at the personal, community, societal, or global level. ⁵				
Patterns of Response- Process and Outcomes	Transitions Theory also explains one's reaction to a transition using the concept "patterns of response." "Patterns of response." refers to the actions, thoughts, feelings and behaviors of the individual(s) experiencing the transition. Literally, how are they responding? These "patterns" are divided into "process", the responses observed during the course of the transition and "outcomes", the responses that indicate the person has reached the end of the transition. Notably, the concepts that fall under both "process" (engaging and finding solutions, locating and being situated, seeking and receiving support and acquiring confidence) and "outcomes" (mastery, fluid and integrative identity, resourcefulness, healthy interaction and perceived well-being) are indicators of a <i>healthy</i> progression through transition and of a positive transition outcome respectively. The idea being that when these concepts are not observed, or when one is struggling with the behaviors associated with these concepts, they are at risk for an unhealthy transition process or a sub-optimal outcome.				

 Table 2.

 Examples of Interview Questions and Corresponding Transitions Theory Concepts

Baseline Interview—late pregnancy						
Concepts	Questions					
Level of planning and awareness Past experiences Relationships	I'd like to begin by asking you a bit about your pregnancy. Is this your first pregnancy? • If so, what are some things about your pregnancy that you didn't expect? How does your pregnancy compart to what you thought it would be like? • If not first pregnancy, is your experience of this pregnancy any different from your previous pregnancy/pregnancies? How so? • What is your relationship like with the father of your baby? • Are other important people in your life, such as your mother or sister, who have or have not expressed their support of your pregnancy? Tell me more about that.					
2 nd Interview—around 6-week postpartum						
Concepts	Questions					
Engaging and finding solutions Seeking and receiving support Locating and Being Situated Acquiring confidence	Are you currently breastfeeding, formula feeding, or doing both? • Who has helped you learn about breastfeeding your baby? What did they tell you or show you? • Do you feel you know when your baby is hungry? How do you know? • Who would you go to if you were having problems breastfeeding? What is your role in your family? In your household? • How do you feel about your role in the family/ household? • Are you satisfied with your living situation? Why or why not? Tell me all the ways mothers can prevent their babies from getting HIV? • What are your concerns about your baby's health?					
3 rd and final interview—around 6-month postpartum interview						
Concepts	Questions					
Mastery Perceived well-being	With all the roles you're playing (breastfeeding, caring for baby and other kids, HIV care, relationships) tell me how you are managing? • What is going well or what isn't? • Tell me about your level of confidence in your ability to care for your baby. • What would you need to make this go better? Tell me about how you're feeling these days.					

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Table 3: Sociodemographic characteristics of participants (n=30)

	Before pregnancy	Pregnancy	6 weeks	5–7 months
		(n=30)	(n=30)	(n=28)
Employment				
Employed	25 (83%)	6 (20%)	4 (13%)	12 (43%)
Unemployed	5 (17%)	24 (80%)	26 (87%)	16 (57%)
Employment Type				
None/housewife	5 (17%)			
Office work	3 (10%)			
Trader	13 (43%)			
Day Laborer	9 (30%)			
Ethnic group				
Luo		29 (97%)		
Kisii		1 (3%)		
Education				
None		17 (57%)		
Primary		5 (17%)		
Secondary		5 (17%)		
College		3 (9%)		
Unknown				
Time engaged in HIV care				
2 years		9 (30%)		
> 2 years		21 (70%)		
Children living at home				
None		7 (23%)		
1–3		18 (60%)		
> 3		5 (17%)		
Relationship status				
Living with partner		17 (57%)*	16 (53%)	14 (50%)
Not living with partner		13 (43%)	14 (47%)	14 (50%)
Disclosed HIV status to partner				28 (93%)
Aware of partner's HIV status			23 (77%)	

 $[\]ensuremath{^{\ast}}$ Four women reported polygamous relationships at pregnancy timepoint