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From Pregnancy, to Baby and Beyond:
Preliminary Findings from an Evaluation of the Pilot Programme

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Introduction

For all women, pregnancy can be an anxious time, demanding exploration of all the joys and challenges inherent in the experience. But for women living with HIV, the prospects of pregnancy and parenthood may be particularly daunting. Perhaps the most apparent difference for HIV-positive women is the risk of transmitting a potentially life-threatening illness vertically from mother to child, a possibility that claims its own set of biomedical and moral concerns. Whether diagnosed before conception or antenatally, in the context of pregnancy, HIV-positive women must negotiate a multitude of unique medical and psychosocial issues.

In the United Kingdom, women constitute 26,000 of the estimated 85,000 people living with HIV (Health Protection Agency, 2010). At present, approximately 1,200 infants are born annually to HIV-positive mothers, and of all women who give birth, about 1 in 500 is HIV-positive (Health Protection Agency, 2010; UNAIDS, 2010). For the UK population of HIV-positive women, the clinical setting offers promising opportunities to achieve healthy pregnancy outcomes.

The availability of interventions to reduce the risk of vertical transmission in the UK has repositioned pregnancy as a clinically supported option for women with HIV. Subsequently, new information about the possibilities and risks of pregnancy has transformed antenatal and postpartum management (Vogler, Singh, & Wright, 2011). These clinical changes, along with advancements in assisted reproductive technologies, have diversified the experience of pregnancy for HIV-positive women. As a result, women must now negotiate a new set of choices throughout pregnancy, from conception to delivery. To ensure the full realisation of their reproductive rights, HIV-positive women must be aware of all their options and supported at every stage of pregnancy. As women with HIV face continuously changing protocol and possibility, the introduction of services tailored specifically to support them in pregnancy is both relevant and critical.[1]

In response to this need, the London-based organisation Positively UK developed the From Pregnancy, to Baby and Beyond (FPBB) programme, which seeks to enable HIV-positive women to cope with the multidimensional issues they face and to promote women's reproductive rights. By providing education and tailored peer support throughout ante- and postnatal care to women living with HIV, the programme aims to empower women to navigate the complexities of pregnancy and living with HIV, as well as to challenge stigma in the wider social context.

While the pilot programme has shown many signs of success, no formal evaluation has been conducted. In response, this work aims to assess the preliminary effectiveness of FPBB by addressing the following two research questions: (1) What are the needs of HIV-positive women in the UK who are pregnant or planning a pregnancy? (2) To what extent does the From Pregnancy, to Baby and Beyond programme support women and enable them to fulfil their needs for an optimal experience of pregnancy?

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[1] For a full review of the literature contained in the author's MSc dissertation, please send an email to E.A.Knudsen-Strong@lse.ac.uk.

Description of the Programme

From Pregnancy, to Baby and Beyond aims to compliment clinical care through the provision of education and tailored peer support to HIV-positive women throughout each stage of pregnancy. The programme offers one-to-one peer support from Mentor Mothers to women who are currently pregnant or desiring children. In addition, Mentor Mothers deliver "Pregnancy Journey Workshops" to women throughout the UK, providing information ranging from safe conception, to delivery, to childcare. A group of healthcare professionals work in partnership with programme leaders to develop the workshop content and train Mentor Mothers, as well as to promote the delivery of comprehensive support to HIV-positive women in pregnancy. During its pilot year, the programme aimed to develop an effective and sustainable model of Education, Information and Support and to achieve the following outcomes:

- Recruit and train Mentor Mothers
- Establish one-to-one and group support
- Facilitate workshops at Positively UK and nationally
- Provide and publish information and resources
- Sustain reduced onward transmission
- Improve access to healthcare services
- Improve healthcare for mothers and their babies
- Promote leadership by positive women
- Inform policy

At the end of the programme's pilot phase, FPBB had made contact with 49 women and received referrals for an additional 15 potential clients. Furthermore, 17 women were referred to The Food Chain through their involvement with FPBB. Eight Mentor Mothers were trained, 2 of whom were based in Scotland. Additionally, a second round of Pregnancy Journey training was attended by 11 people. Eleven workshops were facilitated nationally, which were attended by 115 people and averaged approximately 10 attendees per workshop. Eight men attended workshops, and 2 engaged in one-to-one mentoring with their partners. In addition to the workshops, FPBB facilitated group support for clients to discuss pregnancy-related issues. Finally, programme leaders and health professionals collaborated to produce an informational leaflet to be distributed in clinics and other organizations. To explore the impact of these accomplishments on clients and assess the preliminary effectiveness of FPBB to support them in pregnancy, a qualitative evaluation was conducted toward the end of the programme's pilot phase in the spring of 2011.

Methodology

Study design and sampling

This study was conducted over the course of a four-month period in London, from March to July of 2011. A qualitative mixed-methods approach was employed to explore the needs of HIV-positive women in pregnancy and assess the impact of programme participation. The sample was drawn to represent the diversity of opinions among the people directly involved in the programme. Three key groups of actors in the project were identified: clients, Mentor Mothers, and health professionals who helped to guide the programme design. Through convenience sampling, a total of 18 participants were recruited for interviews: 6 clients, 5 Mentor Mothers, 6 health professionals, and the Programme Manager. Participation was voluntary, though clients received a small voucher from Positively UK in appreciation for their time. Clients ranged in age from mid-twenties to early-thirties. Three clients were currently pregnant, 2 had recently delivered babies, and 1 was trying to conceive with her partner. Four of the Mentor Mothers had children, and 1 was currently pregnant. All of the health professionals currently worked in the UK and served as members of the project's Steering Group.

Ethics

This study was conducted under the approval of the Institute of Social Psychology at the London School of Economics, in accordance with the guidelines for research with human subjects. In addition, Positively UK approved this study as compliant with the ethical research guidelines of the organisation.

Data collection

Data was collected through 18 semi-structured interviews and 1 focus group. Thirteen interviews were conducted in London, either at the Positively UK office or at an alternate location chosen by the participant. The other 5 interviews were conducted over the phone at the participants' request. A small focus group was conducted in early July between a Mentor Mother and the Programme Manager to explore perceptions of programme impact through facilitated group discussion. Informed consent was obtained from each participant prior to beginning the interviews and focus group. The interviews produced textual data in the form of transcribed audio recordings or in-depth notes. The focus group was audio recorded and transcribed to produce additional textual data.

Analysis

All transcripts were imported into the qualitative software programme ATLAS.ti, and the steps for thematic network analysis were followed (Attride-Stirling, 2001). The first step was to devise a coding framework, which was guided partially by two conceptual

frameworks. First, to identify HIV-positive women's needs in pregnancy, data was organised across four conceptual dimensions: material, symbolic, relational, and institutional (Campbell & Cornish, 2010; Skovdal, Campbell, Nhongo, Nyamukapa, & Gregson, 2011). Second, the assessment of programme outcomes was organised by the conceptualisation of the "AIDS-competent community," which structures the effectiveness of health promotion initiatives by their ability to facilitate six key psychosocial resources: (1) knowledge and skills, (2) safe social spaces, (3) ownership and responsibility, (4) confidence in local strengths, (5) solidarity, and (6) bridging partnerships (Campbell, Nair, & Maimane, 2007). Each of these elements was adapted to evaluate the impact of From Pregnancy, to Baby and Beyond.

After the framework was devised, the text was coded accordingly through the assignment of interpretive labels to text segments. Next, a set of prevailing "basic themes" was abstracted by interpreting the relationships between codes. These basic themes were then grouped into "organising themes," which were informed by the conceptual frameworks. The organising themes were then grouped into two "global themes," each corresponding to one of the two research questions: "Needs" and "Programme Impact."

Findings

Needs experienced by women living with HIV for healthy pregnancies

As a developed and affluent country, the United Kingdom is equipped with a highly evolved healthcare system, characterised by specialist services, provider expertise, and widespread availability of medication to manage HIV. The clients, Mentor Mothers, and healthcare providers spoke positively about the clinical opportunities for HIV-positive women seeking care in the UK. However, all of the participants acknowledged a range of obstacles and challenges shaping their multidimensional needs.

All participants emphasised financial problems as a primary concern in pregnancy. Insufficient financial resources led to the following *material* deprivations experienced by several clients: lack of adequate housing, inadequate quantity and quality of food, and lack of transportation. Women explained that these problems adversely affected self-care and their ability to seek support during pregnancy.

> "Some people – they live with this problem. Not having food makes them not take medication. Because when you take medication, if you don't have food, you're going to feel bad. Sometimes you feel like you are fainting" (Client)

Several women identified *symbolic* challenges that complicated their management of HIV and pregnancy, including fear of disclosure, the impact of stigma, and a lack of awareness of HIV in society.

> "If I tell them – my friends – even they don't want to meet me forever! You don't know their reaction after…so I don't want to tell them. I prefer to stay at home alone" (Client)

Clients, Mentor Mothers, and healthcare providers all emphasized women's need for support to help navigate—and to challenge—these symbolic obstacles encountered in HIV and pregnancy.

Access to social support, support from healthcare providers, and supportive relationships with their partners emerged as women's *relational* needs for a healthy pregnancy.

> "There's something about being pregnant. There's an inevitability about it. You're pregnant, you will give birth. But there's a question of whether you do that feeling despondent, or whether you do that feeling a bit supported" (Mentor Mother)

The presence of supportive relationships can alleviate a woman's stress as she struggles with the challenges of pregnancy and HIV, encourage her adherence to precautionary interventions, and bolster her confidence throughout the uncertainties of pregnancy and motherhood.

Finally, the extent to which the *institutional* context facilitates healthy pregnancies for HIV-positive women influences their needs, such as through the consistent quality of healthcare services, which can vary across geographic settings.

> "I've been caught out sometimes when I've left London and forgotten my medication and phoned a local hospital to try and get some meds. And they don't even know what you're talking about. And these are professional people working in a hospital. And they're like, "We don't have a department." Of course you don't, it's just a small hospital, isn't it. A small, local hospital. I've got to go back to London and sort myself out" (Mentor Mother)

Collaboration across service sectors to mobilise support represents an additional institutional need. In the absence of effective cross-sectoral interaction, women may never gain access to critical resources to support pregnancy.

Impacts of programme participation

Concurring with the "AIDS-competent community" framework, the following six psychosocial resources emerged from the data as programme outcomes (Campbell, et al., 2007):

Building knowledge and skills

Through engaging in workshops and one-to-one mentoring, clients developed the knowledge they needed about a number of HIV- and pregnancy-related issues: safe conception, the role of medication in reducing the risk of MTCT, self-care during and after pregnancy, delivery options, caring for their babies, the availability of support services, as well as their own reproductive rights. Several women explained that an enhanced understanding of their medical and social care options improved their communication with healthcare providers. Likewise, women developed skills to negotiate difficult social

situations, such as the ability devise plausible explanations when faced with uncomfortable questions about breastfeeding.

> "If there are any issues that you want to discuss, you bring it up...for example, breastfeeding. I've got some friends that are not positive and if they see me, they keep asking me, 'Why are you not breastfeeding?' If I hadn't gone there I wouldn't have known what to say" (Client)

In addition, Mentor Mothers expressed their enthusiasm for participating in the training sessions; several women who had delivered their babies years ago described learning the current guidelines and possibilities for HIV-positive women in pregnancy as an enlightening experience, and they were eager to discuss this new information with others.

Provision of safe social spaces

Both workshops and one-to-one mentoring sessions functioned as opportunities for women to address issues with peers that they felt unable to discuss with anyone else.

> "…I just talk this kind of things with my doctors, with my nurse, and this Positively UK thing – just them. The other one, I can't tell. So, I just need help from someone that knows" (Client)

> "If you haven't a forum to discuss all those decisions with, if you feel like you can't tell your girlfriend or you can't talk to your family, you're doing all of that in your head. That's like the worst case scenario for minimizing stress which affects your health" (Mentor Mother)

Supported within the safety and confidentiality of these safe spaces, women collectively reinterpreted new information about conception, transmission prevention, and childcare into everyday terms.

Promotion of acceptance and proactive responses

Programme participation promoted women's acceptance of their diagnosis and subsequent willingness to make proactive choices in pregnancy. Sharing experiences in one-to-one mentoring and group workshop settings normalised living with HIV, thus encouraging women to pursue safe and supported pregnancies.

> "If I'm positive, I'm positive. That's done and I can do nothing…Women's lives are with husbands, babies and families…For me, HIV is normal. My immune system is still high. I'm not scared from HIV. I want to have more babies…If I go for another pregnancy, I'm going to go see the women in the organisation and attend all the events, talk to everyone, even in other organisations…" (Client)

Developing confidence in strengths

Women described a unique characteristic of the mentor-mentee relationship, in which Mentor Mothers exemplified the strength to overcome the challenges currently experienced by clients. Mentor Mothers offered living proof that the obstacles within HIV

and pregnancy are not insurmountable, thus inspiring women to recognize their own capacities.

> "The first time I was really stressed and upset and hungry, but when I saw [Mentor Mother] and I talked to her, and she gave me advice. I said, 'Oh, look there are women and they are positive…so I can be positive and positive in my life like this woman" (Client)

Moreover, Mentor Mothers expressed the feeling of empowerment they gained from knowing they had exercised their own strengths to provide emotional as well as tangible support to their mentees.

Building solidarity

Through forging connections with other HIV-positive women and relating over the common experiences of seropositivity and pregnancy, participants generated the mutual trust and supportive relationships that characterise community solidarity. All of the women expressed a desire to help and support one another, demonstrating their emerging sense of connection and commitment to building a community.

> "With my experience, I want to share with another woman because now I need someone…maybe if someone needs someone's experience, I will be very happy to help some woman and tell how I passed with this" (Client)

Mentor Mothers likewise developed solidarity in supporting each other as community leaders, and some clients even hoped to serve as mentors in the future. These intentions indicated the potential for the programme to be sustained through women's continued participation and emergent leadership as peer mentors.

Developing partnerships across sectors

One of this programme's most impacting achievements was its establishment and mobilisation of partnerships between the social support and clinical sectors. The development of networks between programme leaders and external agencies, such as hospitals, clinics, social support organisations, food provision services, and a nursery, facilitated clients' access to medical and material resources.

> "You know you're able to go back to the different organizations and apply for a grant to enable them to buy the starter things for their baby. They get it…And from there at least they're able to move on and stuff like that. It's just working with other people who could help the situation has been quite helpful" (Programme Manager)

Additionally, the involvement of healthcare professionals was key in the training process for Mentor Mothers, as doctors and midwives worked in partnership with mentors to provide the information delivered to clients through workshops and one-to-one mentoring.

Conclusions and Recommendations

Through developing an understanding of HIV-positive women's multidimensional needs in pregnancy and assessing the preliminary impact of participation in FPBB, this evaluation seeks to demonstrate the effectiveness of the pilot programme in enabling clients to experience healthy pregnancies. The findings indicate that in its pilot phase, the programme has achieved six key outcomes in the form of psychosocial resources that promote the health of HIV-positive women who are pregnant or desiring children. Looking toward the future, there is much opportunity to expand the programme and to refine the provision of support. In addition to the programme's successes, interviews highlighted a number of recommendations for improvement.

Several clients expressed a desire for continued support while they transition from pregnancy to motherhood, indicating the potential benefits to be gained from extending FPBB to support women longer into their postnatal care. Additionally, clients demonstrated a strong interest in attending additional Pregnancy Journey workshops, which suggests a need to deliver more workshops in the future. In order to facilitate women's ability to attend these events, another recommendation is to assist with transportation, as several clients cited limited access to transportation as a primary barrier to their participation in support services. For those cases in which women are unable to access services in person, a dedicated phone line for pregnancy-related issues would function as an inexpensive and effective alternative. Furthermore, establishing an interactive website for women to safely pose questions and discuss issues would improve access to support and provide another "safe space" for women to communicate about HIV and pregnancy.

Moreover, programme outreach can be extended through increased provider referrals. To effectively manage the influx of additional referrals, a greater cohort of Mentor Mothers would be necessary. A larger group of Mentor Mothers would demand better facilitated and streamlined coordination with programme management to ensure regular follow-up with clients. Keeping mentors up-to-date on current medical guidelines through routine training will also be necessary for the most accurate, effective, and beneficial delivery of services to clients.

Only time well reveal the self-sustainability of the programme, though the majority of clients expressed a strong desire to provide peer support in the future. To facilitate programme expansion to other locations, it will be necessary to maintain flexibility within the support model, so as to ensure adaptability to settings with low patient pools. This would require a refinement of the training approach to guarantee effective mentoring in settings where very few HIV-positive women present to the healthcare system.

Finally, the burgeoning promise of FPBB uncovered in this early assessment of programme success suggests that an in-depth, longitudinal evaluation would be a valuable future undertaking. Such a project would need to include additional outcome indicators, such as questionnaires to track clients' progress throughout different stages of participation, in addition to an increased sample size.

The findings of this pilot evaluation illustrate the effectiveness of a model combining education and tailored peer support to compliment clinical care for women living with HIV. Indeed, a comprehensive programme to support and enable HIV-positive women in

pregnancy necessarily involves collaboration across practical, clinical, and social support sectors. These recommendations emphasize the sustained mobilisation of this team support approach. The dedicated and motivated leadership behind this project, combined with a strong interest among clients for future involvement, demonstrates the potential for this growth.

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