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Citation for the published version:

Clifford, G., Craig, G., & McCourt, C. (2018). "Am iz kwiin" (I'm his queen): Combining Interpretative Phenomenological Analysis with a feminist approach to work with gems in a resource-constrained setting. Qualitative Research in Psychology. DOI: 10.1080/14780887.2018.1543048

Link to the final published version available at the publisher:
This is an Accepted Manuscript of an article published by Taylor & Francis Group in Qualitative Research in Psychology. Published on 28/12/2018, available online: https://doi.org/10.1080/14780887.2018.1543048

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"Am iz kwiin" (I'm his queen):

Combining Interpretative Phenomenological Analysis with a feminist approach to work with gems in a resource-constrained setting

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Abstract:

This paper focuses on working with gems using a feminist approach to Interpretative Phenomenological Analysis (IPA) in a resource-constrained setting. The research explores the experiences of maternal disclosure of HIV to children of HIV positive mothers in Kingston, Jamaica. A feminist approach helps to recognise power imbalances within research relationships and the women's lived experiences. We present three "gems" which illuminate women's lived experiences and explore how popularised representations of women's sexuality and mothering influence disclosure discourses. We use emotion work as a conceptual resource to structure the women's narratives and challenge existing policy discourses, which, arguably represent disclosure within a binary, rationalist, decision-making framework. This paper adds to global literature on maternal HIV disclosure and problematises policy discourses by bringing into relief the emotion work women engage in when deciding if and how to communicate their HIV status to their children. It adds to the body of research using IPA, particularly in resource-constrained settings where IPA has thus far had little application.

Keywords:

Feminist Interpretative Phenomenological Analysis, IPA, disclosure of maternal HIV to children, resource-constrained, emotion work, Jamaica

1. Introduction

This paper focuses on the use of a feminist approach to Interpretative Phenomenological Analysis (IPA) in a resource-constrained setting to work with “gems”. Smith (2011:6) defines gems as “the relatively rare utterance that is especially resonant and offers potent analytical leverage to a study […by providing] strong insight to the experience for the individual and often for the group of participants as a whole.” Smith (2011:10–14) proposes a spectrum of gems, from the shining gem, which is clearly apparent, to the suggestive gem, which requires some investigation and interpretation, to the secret gem, which requires a great deal of investigation and interpretation. The examples presented here are suggestive gems which serve to highlight and clarify particular themes within individual interviews and the research as a whole.

Our research explores Jamaican HIV positive mothers’ experiences of talking to their children about maternal HIV. IPA provides rich, detailed information, which illuminates lived experience. We employ feminist reflexivity (Burman, 2006) to examine power and difference within research relationships. Using a critical feminist lens we reflect on our position as white middle-class women researching the experiences of poor black mothers in a resource-constrained country. A feminist approach complements the key elements of IPA, including the focus on individual experience and sense-making, and the emphasis on interpretation by both researchers and participants (Smith, Flower and Larkin, 2009). Combining a feminist approach with IPA helps recognise difference and power imbalances and acknowledges the impact of wider structural factors on the research process as well as on the women’s lived experiences. Although IPA has not yet been used extensively in resource-constrained settings, its focus on lived experience and researcher interpretation of participants’ interpretation of their experience (the ‘double hermeneutic’, Smith and Osborn, 2003) lends itself well to work with disadvantaged groups. This paper presents our research as an example of how combining a feminist approach with IPA in a resource-constrained setting can support the uncovering of gems. This paper adds to the global literature

on maternal HIV disclosure and problematises WHO (2011) policy discourses by bringing into relief the emotion work women engage in when managing their HIV, thus challenging the assumed binary (*i.e.,* disclosure/non-disclosure) implicit in normative, disclosure decision making models.

This research is based on single interviews with 15 Jamaican HIV positive mothers with at least one seronegative child (*i.e*., children who do not have HIV) aged over 10 years, recruited from one HIV clinic and one HIV NGO in Kingston, Jamaica in 2012. Interviews were carried out by one of the authors (Clifford) as part of a doctoral study. Participants were aged between 32 and 57 years and had between one and 4 children ranging in age from two to 32 years; participants were encouraged to reflect on their disclosure experiences for all of their children. Additionally, three of these participants had one HIV positive child. Participants were diagnosed 1–17 years prior to the interviews. The interviewees had all completed primary education and five had completed secondary education; a further 3, despite not taking their exams (equivalent to GCSEs) went on to further education or training. The majority of participants were unemployed or in low paid, insecure jobs, such as 'higgling' (Senior, 2003:230–231), selling small items on the streets. Eleven of the 15 women had become mothers for the first time aged 20 or under; of these, four were aged 15–16 years. As is common in Jamaica, most of the women were unmarried (Jamaican National AIDS Committee, 2002) and were in 'visiting' relationships, where they were responsible for childcare and the majority of income generation. The majority of the women had multiple "biebifaadas" (babyfathers), a term which implies a merely biological relationship (Turner, 2006). The interviewer spoke standard English and the participants spoke standard English, Jamaican Creole or a combination of the two. Where necessary, the interviewer translated Jamaican Creole into standard English. Ethical approval was received from two review boards in Jamaica (University of the West Indies, Faculty of Medical Science and the Jamaican Ministry of Health) and one in the UK (City, University of London, School of Health Sciences). Informed consent was discussed with and obtained from all participants. Pseudonyms are used throughout.

2. Methodological considerations

2.1. Interpretative Phenomenological Analysis

IPA, a recognised and established methodological approach to analysing qualitative data (Willig, 2001), developed by Jonathan Smith (Smith, 1996), draws on three long-established areas of philosophical knowledge: phenomenology, hermeneutics and idiography. IPA research focuses on detailed interpretation of the lived experiences of a small group of participants who share a similar experience. IPA prioritises the views of the participant, considering the participant, rather than the researcher to be the expert, making IPA, alongside other qualitative approaches, a ‘bottom up’ approach. IPA explores the meaning-making process of individuals, exploring not just the experience, but the significance of that experience to the participant. Attention is also paid to the language and emotions surrounding the experience for the participant.

2.2. Feminist research

We understand feminism to be a collection of intellectual, social and political movements whose aim is the equality of women. These movements challenge existing institutional and social structures, which, through tradition and attitude, can disempower and subordinate women (Shefer, 2004). We argue that feminist research is feminist because of the focus, approach and purpose that the researchers bring to the work and these are characterised by particular principles, though these also vary, according to different authors. We adhere to the definition proposed by Ollivier and Tremblay (2000) who believe that feminist research has three key elements. Firstly, they believe that feminist research both constructs new knowledge and seeks to create social change, particularly in relation to challenging the multiple forms of social oppression that women face. Secondly, Ollivier and Tremblay (2000) believe that feminist research

is grounded in feminist values, which guide the entire research process and inform all decisions. Thirdly, they see diversity as a key element of feminist research (Ollivier and Tremblay, 2000). It is both inter- and trans-disciplinary, utilises multiple methods and methodologies and is constantly evolving and developing. It therefore incorporates a recognition of diversity and antiracist perspectives and has a focus on empowerment of all women, including those who are traditionally marginalised.

2.3. Feminist IPA, emotion work and gems

There are few articles which use feminist IPA and those which exist are generally situated in the Global North (*e.g.,*Lorasdagi, 2009; Kastrani, Deliyanni-Kouimtzi and Athanasiades, 2015). Leve, Rubin and Pusic (2011), writing about the risks and responsibilities associated with elective cosmetic surgery in the USA, include a detailed explanation of how they combine a feminist approach with IPA. They identify a tension in previous work between voice-centred (Tarule, 1996) or 'agency' perspectives (Pitts-Taylor, 2007) and culture-centred (*e.g.,* Bordo, 1997) or 'structure' perspectives (Pitts-Taylor, 2007). In their research, they seek to address this tension by simultaneously exploring women's experiences of cosmetic surgery whilst also situating these narratives within wider social, cultural and political contexts.

Our research focuses on women's experiences, voices, and sense-making, whilst acknowledging that the world and institutions within which the research is conducted remain predominantly patriarchal. By linking women's experiences to the wider feminist literature on women's sexuality and mothering (*e.g.,* Ussher, 1989) and emotion work (Hochschild, 1979, 1983), we aim to challenge policy imperatives (*e.g..,* WHO, 2011) which draw on research conducted in the Anglo-North and assume disclosure to be beneficial. Ussher (1989:15) refers to the Madonna/whore dichotomy: a woman "cannot be a good mother and a sexual person at the same time…women's sexuality is dangerous and threatening and… at odds with the stereotype of the 'good mother' ". The 'good' mother in her most extreme (and unrealistic) form is represented by the Madonna: pure, virtuous, clean and virginal. In contrast, the whore is immoral,

promiscuous and diseased.

Paterson (2008:76), in a meta-synthesis of qualitative HIV disclosure research, reported that gay men who did not disclose their HIV status to sexual partners were portrayed as "cowardly, irresponsible, in denial and/or immoral", whereas mothers who chose not to disclose to their children were seen as "protective and strategic". More recently, Madiba and Matlala (2012) identify keeping parental HIV secret from children as protective and Tiendrebeogo *et al.* (2013) found that both concealing and disclosing parental HIV was carried out with the intention of protecting children. We suggest that the policy imperative to disclose has begun to shift the representation of the non-disclosing mother in similarly negative ways, so that her parenting is called into question for failing to safeguard the mother-child relationship characterised by honesty and openness or failing to prepare her child for the possibility of maternal illness. In short, she is positioned as a 'bad' mother who is not adequately protecting her child's emotional wellbeing. Accordingly, the belief that Jamaican mothers generally do not tell their children about their HIV, is also imbued with judgment.

We use IPA and gems to open up a space to explore these constructions and assumptions further. By situating our work within the Jamaican context we aim to recognise women's choices and agency within the constraints of their daily lives. A feminist approach allowed us to challenge policy assumptions that it is "good to talk" and develop a more nuanced picture of women's experiences that is sensitive to the wider issues of gender, women's sexuality and power. Emotion work (Hochschild: 1979, 1983) describes the work, often unrewarded and unrecognised, which people (often women) do to manage their own and other people's emotions. Emotion work explores not only how people think and feel about an experience, but how they think they should feel and how they think others think they should feel, as well as what they do about any disconnects among these feelings, which Hochschild (1983) terms the "pinch". We use emotion work as a conceptual resource to highlight the "work" women engage in when managing their illness and communicating their HIV, albeit in ways not anticipated by policy discourses. We highlight

ways in which mothers engage in emotion work, such as what we refer to as 'protective mothering' (mothering activities which aim to protect children, the mother-child relationship and/or maternal identity), as a rationale for full, partial and non-disclosure of their HIV.

2.4. Working as an outsider in a resource-constrained setting: the role of feminist reflexivity

Interviews were conducted by one of the authors (Clifford), who, as a white, British HIV negative woman, was an "outsider" in the Jamaican context, bringing additional considerations to the interview, interpretation and analysis processes. The women interviewed were marginalised as a result of their gender, race, socioeconomic and HIV status. We employed feminist reflexivity (Burman, 2006) as a process to better understand power and difference in research relationships. Burman (1994) proposes that it is the focus on power and difference in research relationships which distinguishes feminist reflexivity from other forms of reflexivity. Burman (2006:324), whilst noting the increasing popularity of reflexivity and the participation agenda within health, education and development, urges caution. She identifies the risk that reflexivity can "educate[s] the emotions, and normalise[s] some subjective accounts while pathologising or silencing others" whilst the drive for increased participation risks "producing a reified, homogenised and consensual model of 'communities' under investigation (in ways that reinforce colonial paternalism and privilege) and of reducing structural issues to personal ones." Burman (2006:327) suggests that this can be addressed by "locat[ing] reflexive analysis within institutional relationships that precisely interrogate and challenge the constitution of the narrative position of the accounter, rather than explore their identity." Resolving these issues is beyond the scope of this paper; however, we sought to keep these concepts in mind. In her examination of feminist reflexivity, Burman (2006) links reflexivity to emotions and extends the definition to include emotional geographies: "the location of emotion in both bodies and places, the emotional relationality of people and environments, and representations of emotional geographies" (Bondi, Davidson and Smith, 2005:4). This perception of reflexivity has particular resonance in view of the interviewer's (Clifford) position as an outsider researcher in the

Jamaican context.

We acknowledge the potential challenges for researchers from different backgrounds from their participants, who may fail to understand the impact of “structural and social constraints” on the views and choices of participants (Tufford and Newman, 2012:91). At different stages in the research process we endeavoured to use memos (Cutcliffe, 2003), separate interviews with outside sources to highlight preconceptions (Rolls and Relf, 2006) and a reflexive journal (Ahern, 1999) to support reflexivity. Without careful attention to reflexivity there is the risk that the experiences of poor, urban, HIV-positive Jamaican women could be simplified by our perspectives as white, middle-class, HIV-negative British women and through our potential feelings of shock, guilt, empathy, pity or judgment (Marshall, 1996:88; Letherby, 2003: 109–113) into narratives of victimhood, helplessness or hopelessness (Mohanty, 2003), thus obscuring (or glorifying) the also-present stories of strength, resilience, determination and overcoming adversity. We also wanted to recognise the impact of wider contextual factors, which have long been recognised in feminist work (*e.g.,* Harding, 1986) such as race, gender, poverty, the legacy of colonialism and the inevitable impact that these factors have on the day to day experiences of women’s lives (Mohanty, 2003:4–5), all of which are particularly evident within a resource-constrained setting.

3. Three gems which illuminate the experiences of HIV positive mothers in Jamaica

3.1. “Am iz kwiin” (I’m his queen)[i]: Protecting the maternal image

Here we focus on the gem (“I’m his queen”) which gives our paper its title and demonstrate the ways in which this gem illustrates the “good mother”. In response to the interviewer’s question about how she felt about the possibility of talking to her children about her HIV, Sandra replied:

> *Maybe the big one would cry and the second one would cry too. ‘Cause he is saying that I am his*

> *angel, so…**I'm his queen**. So I don't know—if his queen messed up—Having that [HIV], I don't know how he would feel.*

Sandra talks about her middle son's characterising her as an angel, a queen, and fears that knowing her HIV status would challenge his sense of her as a perfect, infallible, almost divine figure. Sandra silences herself (Jack and Ali, 2010) to protect her relationship with her children and preserve their image of her as pure and regal. She prioritises their emotional health over her own, later acknowledging that, although she doesn't want them to know about her status, telling them might result in some benefits: " because… I don't know. Maybe I would get more support…but, then again, I don't want them to know." It can be easier for women to live up to social mothering expectations and display culturally appropriate emotions if they do not discuss their HIV with their children. In the face of the challenges of reconciling their own and cultural images of the 'good' mother, with the reality of their positive HIV status, they chose instead to avoid confronting this disconnect, even in the face of pressure from professionals to tell their children their status.

The imagery evoked by Sandra's son's words draws on wider popularised representations of women's sexuality and mothering in cultural arenas. His words are simple and yet very powerful in their evocation of the special, regal role held by mothers in Jamaican society. This view is echoed by Adisa (2013:40), reflecting upon her Caribbean childhood: "Mothers, married or unmarried, wore a crown; and children were said to be a woman's insurance in old age". In contrast, the mother with HIV challenges this representation, due to the association of HIV with immorality (Sontag, 1991) and tainted mothering. Accordingly the 'good' mother is seen as being asexual (the Madonna/whore dichotomy identified by Ussher, 1989 and discussed further in the next section).

Women's accounts suggested that a 'good mother' was characterised as strong— both physically and emotionally. This strength allows mothers to be physically present for their children as well as capable of caring for them, supporting them emotionally and financially by earning money. The concept of a 'good

mother' is based on a culturally specific ideal which can be difficult to live up to and particularly challenging for women with a stigmatised condition such as HIV. When women's mothering fails to reach this unattainable ideal, their parenting is found wanting (Craig and O'Dell, 2010). Sandra fears her children will "scorn" her:

> *I don't want to tell my children anything because I don't know if they would scorn me or… you know?*

In the Jamaican context, 'scorn', in addition to its more commonly understood meaning of disdain or contempt, also carries connotations of dirtiness, particularly powerful in view of the associations of HIV with promiscuity and immorality (Sontag, 1991).

Sandra articulates her sense of responsibility, her desire to protect her image in her children's eyes as a pure and regal mother figure, encapsulating the range of emotion work she carries out to protect her children from the distress she thinks would accompany the disclosure of her HIV. Her focus on protecting her maternal identity in the eyes of her children illuminates the stories told by other participants as they strove to present themselves to their community, their families and to the interviewer as responsible and respectable. They worked to counter images of HIV positive women as deviant, shameful, promiscuous or immoral (Sontag, 1991), but they also acknowledged the challenge in this, as demonstrated by Maria:

> *Maria: […] I was like 'I don't want my worse enemy to have this' because of – it's not like xxx [one word] a lot of pain but because of the shame bout it? […]*
>
> *Gayle: So talk to me about shame. Tell me what that means to you.*
>
> *Maria: Oh – that's the part that you just don't want nobody to say you have AIDS. You HIV positive….because…it's like they like — people make it looks like it's the worst thing and they make it look like you're you had to be a promiscuous person to get it or an — and it's not true so when like you — people talk about other people and AIDS and so? It kind of make you draw back and go in the shadows.*

Maria provides a powerful description of feeling ashamed, alienated and excluded as a result of social

assumptions concerning HIV.

3.2. Responsible mothering and the fear (or reality) of 'downfallment'

Just under half of the women talked explicitly about their fears that their children had HIV and addressed these fears by ensuring they were tested, sometimes repeatedly, and usually without the children’s full understanding. For Cupcake, her anxiety about her children having HIV was deep-rooted and not alleviated by receiving a negative HIV test result. Cupcake’s anxiety is focused on her youngest son, aged 11 at the time of the interview:

> *… I would always have it in di back a mi head? /— that the baby is HIV./ But he wasn’t. He did the test two times.*

We have argued that policy unproblematically advises women with HIV to disclose to their seronegative children with little understanding of the risks and challenges to maternal identity, particularly in a setting where motherhood is highly valued. We suggest that in the same way female sexuality is represented within a discourse of difference between the Madonna and the whore (Ussher 1989)—the latter commonly used to characterise women with HIV through accusations of promiscuity and deviance (Sontag, 1991:159)— the disclosure/non-disclosure binary also invokes constructions of the good/bad mother.

Women spoke of the fear (or reality) of a child having HIV; several women referred to a child’s diagnosis with HIV as ‘downfallment’. Mothers using this word to describe their child’s HIV status are implying that they see (or believe others see) the child as permanently ruined or spoiled, and that they have lost status and the future possibility of power and prosperity. This is a particularly damaging prospect in the context of a culture which places such emphasis on the importance of education and a mother’s

responsibility to safeguard and promote access to education (Clark, in Craig and O'Dell, 2010). Similarly, 'downfallment' may reflect the position of women themselves, indirectly as "fallen" women and mothers. The consequences of disclosure not only present a challenge to their idealised maternal identity, but can have material effects, such as loss of income through loss of work. Women then experience further challenges to their identity as a good mother and breadwinner.

> *I went to the clinic and I said "Excuse me um, […] I did a HIV test when I was five months pregnant and I don't get the result. What's the problem? And now I'm hearing that I am HIV positive." When they check it out they say "Oh" but I said "That's slackness! That's stupidness! I mean you let me give my child HIV."/ They didn't get the result —/— until after my baby was born. And they didn't even call me back to say "Um, Tracy…" — just nothing at all./ Did not do anything at all like that. So that was where, she got it so she was at the – the* ***downfall.*** *She was the first…who got* ***downfall****. (Tracy)*

> *And by breastfeeding him, that is his* ***downfallment****. Because he was born as a healthy baby and seven months later, he just got sick. Everything you give him, he just passed it out. And when I brought him, they ran tests on him, they said he is HIV positive…Because looking at the pictures when he was a baby, you can see how he looked so healthy and fat and nice? An' that— looking fat and nice still doesn't mean that you don't have it […] So looks are deceiving. (Sarah)*

Both women use the word 'downfall' or 'downfallment' with echoes of contagion. Tracy blamed the clinic that failed to give her the results of her antenatal HIV test. She believed that had she known about her HIV status before delivery she would have been able to protect her child. She felt very angry about what happened, as she felt it was entirely preventable. Sarah, on the other hand, believed that it was her doing, her decision to breastfeed which led to her 'healthy' baby getting HIV. However, she also acknowledged the impossibility of her knowing that she or her son had HIV, due to their appearance of

good health.

Women whose children have acquired HIV stand to be doubly judged: not only should ‘good’ mothers be healthy (and in particular free from a sexually transmitted disease carrying connotations of immorality) but, in passing HIV on to their children (or being seen to have put their children at risk of acquiring HIV), they can be perceived as having failed in their motherly duty to safeguard the health (emotional and physical) of their children. A young child receiving a positive HIV test result, or ‘downfallment’, carries an implicit challenge to the mothering identity. This occurs in several ways. Firstly, as it is extremely unlikely that a young child has acquired HIV other than perinatally, a mother may fear judgments of promiscuity or immorality. These assumptions often accompany an HIV diagnosis and help to explain women’s determination to present themselves as respectable, responsible and clean. Secondly, in a country like Jamaica with free HIV treatment and a successful record of preventing maternal transmission of HIV to children, an HIV positive child implies that the mother failed to obtain a diagnosis or treatment for herself and her child or that she behaved contrary to medical advice by, for example, breastfeeding her child. There are a myriad of reasons which might explain a child becoming HIV positive (including, for example, medical negligence) but the assumption is that it is indicative of a failure of a mother’s duty to protect her child. In addition to feelings of sadness, guilt and anger which a mother might experience upon receiving a positive HIV diagnosis for her child, she is likely also to encounter additional practical and financial challenges in caring for that child’s health. These women’s choice of the word ‘downfallment’ highlights the powerful physical and emotional consequences of a child’s actual or potential HIV positive diagnosis, not just for the child, but for the mother and her mothering identity.

The experience of mothering a ‘downfallen’ child or testing a child for potential HIV serves to intensify the mothers’ emotion work in presenting themselves as ‘good’ and ‘responsible’ mothers as they work to counter the negative imagery conjured by the word ‘downfall’. Mothers struggle to present themselves as ‘good’ mothers in the face of a stigmatised disease associated with promiscuity and irresponsibility; the

possibility or reality of transmitting this disease to their children ('downfallment'); and the judgement incurred as a result of having been seen to have put their children at risk. Not disclosing their HIV status can similarly position women in negative ways, for example as an irresponsible and "bad" mother. Disclosure policy may fail to consider the risks associated with disclosure in the Jamaican context including a loss of employment and income as well as emotional and practical support. .

The participants in this study used various strategies to manage feelings of guilt, blame or judgment and to present themselves as 'responsible mothers' (Lupton, 2011), thus resisting the concept of the 'fallen women'. Women deflected negative characterisations of HIV positive women by presenting images of themselves as faithful, supportive wives (Sontag, 1991), as healthy, capable women (Rhine, 2016), and as 'responsible' mothers (Craig and Scambler, 2006; Lupton, 2011). For mothers with HIV, who risk judgment and loss of emotional, financial and practical support if their (or their children's) HIV status becomes known, protecting their maternal identity may be considered especially important. Although not discussed as gems, the research also identified that individuals, other than the mothers might disclose the woman's HIV status (*i.e.* where children were not living with the mother) or that mothers might disclose to one child and not another (discussed in future papers) suggesting that disclosure is neither a discrete event nor seen as the responsibility of the mother. Moreover, there was evidence that children knew their mother had HIV without a disclosure moment.

3.3. Protective mothering: " [it] is my mistake so I won't sacrifice the kids"

Cupcake relates a conversation with a friend, also HIV positive and with children of a similar age, highlighting her sense of responsibility for acquiring HIV and her focus on protecting her children, a theme which recurs across the women's interviews:

> *'Cause we [my HIV positive friend and I] talk about it. We always say that we [are] not going*

sacrifice the kids…for our mistake. ‘Cause I think ***is my mistake so I won’t sacrifice the kids****./ And I think God have them here for a reason because he could have let them be HIV but he didn’t…because they were born from an HIV mom.*

Cupcake did not want her children to suffer for something she saw as her fault, demonstrating her feelings of guilt for having acquired HIV, with the words “my mistake”. Cupcake identified the potential “sacrifice” of her children’s happiness because of her “mistake” as fundamentally wrong. She presented herself as a passive recipient of God’s kindness and presented her children as special, chosen and protected. Regardless of your position on religion, this is at most only partially true as, despite medical pressure and Jamaican cultural norms, she made certain that she did not breastfeed her children, demonstrating her determination and agency:

At first — because I always know that um…not giving them breastfeed —all when I was in the hospital and the nurse was like telling me to breastfeeding them I would ask my mom to take the formula and the bottle – hide it and bring because I just had it in the back of my head but my mother was wondering why — /— but I didn’t tell anybody but I just knew I was HIV.

In Jamaica, HIV positive mothers are advised not to breastfeed and are provided with free formula for six months (Harvey and Thame, 2004), so mothers whose HIV status is known should not experience financial challenges associated with formula feeding. However, there may be significant practical and social challenges in a culture where, particularly amongst poorer sectors of society, breastfeeding is considered the norm (Harvey and Thame, 2004). Additionally, in much the same way as taking ‘vitamins’ has come to be understood as code for ‘HIV medication’, refusing to breastfeed can be seen to signify HIV infection; hence, Cupcake’s request for her mother to hide the formula and bottle.

Cupcake described how she convinced her sons that she doesn't have HIV, by testing the whole family for HIV and allowing them to believe that all of the results were negative:

No, they came back for their result. I came back with them and then when the lady told us that they are negative then I called them inside and give them the paper./ So they all think that we

> *[are] all negative./ But they don't know about my status.*

She took deliberate action to ensure that her sons felt certain she did not have HIV and felt proud that she had fulfilled her maternal duty to protect her children from what she saw as her "mistake" in getting HIV. She has very thoroughly and effectively silenced herself (Jack and Ali, 2010) in her determination to protect her sons' happiness. The link between self-silencing and depression has been clearly identified (Jack and Ali, 2010) and Cupcake, who has silenced herself almost completely, also provided explicit descriptions of feeling depressed: "[….] Sometimes – sometimes I lay down you know and I think about it and I cry to myself. A lot of times I go through depressions. And I lie down and I cry about it [….]"

Unlike many mothers, who emphasised a feeling of closeness as a reason to tell their children and a lack of a close bond as a barrier to telling them, Cupcake feels that the close bond she shared with her children was a reason not to tell them:

> *[…] we just have this bond together. [...] yesterday, I was very sick as I had the flu./ So he was like "Mommy, I don't like when you sick" […] So I don't want to tell them and just –I think that it is gonna have a very big impact on them. So I just don't want nothing to [affect their] happiness./ So I just try not to tell them. Until the day come – the sickness times come?/ I think that's the time they should know.*

Cupcake saw her role as caretaker of her children's happiness. She was concerned about the "very big impact" their knowing her status would have on them, and although she was clear that she will tell them when the time comes, she was unable or unwilling to describe this in detail: "…cause they really love me. They don't have a father right now. It's just me alone./ They don't have nobody. But me." There was a sense of pressure here, that she felt a burden in being the sole parent, single-handedly responsible for all practical and emotional issues.

Cupcake described how she "tricks" her sons into thinking that her medication is for a previously existing condition, a "burst" in her head. Despite the complications involved in managing these discussions, Cupcake still valued the practical support her sons provided.

> *They know I have a sickness but they don't know it's HIV. Because I have to take the meds and because sometimes when I take the medication? it will like block me out for a little while? so what I do I tell them? I just trick my son and tell him that because of the burst I have in my head, I'm sick with my head […] because I take the medication out of the bottle, keep them in something else? and they would give it to me every night before I go to my bed. That's their duty because I will forget to do it.*

Cupcake described dispensing her medication as her children's "duty", demonstrating her desire for their support and involvement. She devised a strategy to ensure they did this without knowing about her HIV, by decanting the medication into different bottles and telling them it was for a pre-existing condition. For her, this involvement was linked to the close relationship she felt with her children, particularly her younger son, and also to the side effects: 'block[ing]' out after taking her medication required some kind of explanation.

The example of Cupcake's gem demonstrates the way in which a simple phrase can act as a window into an entire experience. The extract illuminates the decisive actions that she has taken to protect her children physically and emotionally, despite personal emotional cost, including not breastfeeding, convincing her children that she is HIV negative, and concealing her HIV medication. Throughout the interviews the women sought to present themselves as 'good': good mothers, good wives, good people, good patients, and good interviewees. As mothers with HIV, they are aware of potential judgment and so seek to counteract the negative discourses (Sontag, 1991) of HIV positive women as promiscuous, deviant, unclean, passive victims, or unfit to parent (Alldred, 1996). HIV can create multiple challenges for

mothers: physical (illness, fatigue, medication side effects); emotional (depression, fear for the future, secrecy); and practical (finding time and money to attend appointments and collect medication). In attempting to live up to the unrealistic concept of the idealised mother (Craig and O'Dell, 2010), HIV positive mothers must work extra hard to overcome these challenges and present themselves as healthy and responsible.

4. Conclusion

In this paper we have described how we combined IPA with a feminist approach in a resource-constrained setting to bring into relief women's lived experiences of disclosure and given examples of gems which aim to problematise the policy imperative to disclose. These gems demonstrate HIV positive mothers' focus on protecting their children and preserving their maternal and sexual identity. Although women may not tell their children about their HIV, they engage in considerable emotion work to develop and protect their children and their maternal identity, to live up to cultural expectations of the mother as protector and provider, to present themselves as responsible mothers and to maintain close relationships with their children. Using a feminist approach to IPA has identified the role of wider discourses of female sexuality and mothering in determining whether and how women talk about their HIV to their children. The research challenges policy recommendations (*e.g.*, WHO, 2011) that assumes that disclosure is necessarily good, and will add to the increasing body of research on maternal disclosure globally and, more specifically, in resource-constrained settings.

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[i] This quote is written in Jamaican Patois, transcribed using the Cassidy-Le Page system of written Jamaican Patois (Cassidy and Le Page, 1980) and translated by Author 1.

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