‘When you have children, you’re obliged to live’: Motherhood, Chronic Illness and Biographical Disruption

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Abstract

Recent work on biographical disruption has emphasised the critical importance of timing and context to the understanding of the effects of illness on identity. This paper takes a different approach by examining the inter-relationship between illness and key sources of identity, in this instance HIV infection and motherhood. It is argued that, viewed in this light, biographical disruption remains a powerful analytic framework with which to explore the intense threat which may be posed to key identities by chronic, potentially fatal illnesses, and the fundamental re-working of such identities occasioned by such threats. With reference to the empirical study on which this paper draws, it is shown that, the respondents’ emphasis on their need to survive and to protect their children, represented a fundamental re-formulation of their identities as mothers and, therefore, a type of biographical disruption while paradoxically also containing elements of biographical reinforcement. It is further argued that the incorporation of such key identities into the analysis problematises work that suggests that biographical disruption is less relevant to those who have experienced difficult lives, while also highlighting the need to take greater account of gender and caring responsibilities in further work in this field.

Key Words: motherhood, identity, biographical disruption, HIV infection

Introduction

In an important review of the literature on biographical disruption, Williams suggested that:

> *greater attention to the timing, context and circumstances within which illnesses are 'normalised' or 'problematised', and the manner in which identities are threatened or affirmed is [..] central to any future development in this area (2000: 62).*

Rather than focusing on the destructive effects of illness *on* identity, this paper responds to this challenge by examining the inter-relationship *between* illness and key sources of identity, in the context of motherhood and HIV infection. It is argued that viewed in this light, biographical disruption remains a powerful analytic framework to explore the way in which a key identity, such as motherhood, may be fundamentally threatened by incapacitating or potentially fatal illness, while paradoxically also forming a reason for continuity of identity and source of self-worth.

In focusing on the inter-relationship between illness and identity, this paper, like several influential articles (Pound et al. 1998, Ciambrone 2001, Faircloth et al. 2004), rejects any universal expectation of biographical disruption. However, in contexts where key identities are threatened, it also problematises these writers' suggestions that biographical disruption is less relevant to the illness experiences of older people or of those who have experienced hardship. By exploring the importance of a key identity, motherhood, and surrounding moral discourses, this paper also highlights the need for analysis of the experience of illness that takes gender and caring responsibilities into greater account.

The first part of this paper will set the scene by examining the literature on biographical disruption, chronic illness and motherhood in the light of concerns relating to identity, gender and context and briefly introduce the empirical study with HIV-positive mothers on which it draws. The main body of the paper will focus on three main elements of the inter-relationship between illness and identity in the respondents' accounts: their emphasis on establishing and maintaining identities as good mothers; the threat posed by HIV infection and their potential mortality to this identity; and the respondents' concern to prevent the disruption of their children's lives. These findings will be used to interrogate further the literature on biographical disruption and motherhood in the final discussion section.

Situating the Argument: Biographical Disruption and Motherhood

The source of the ideas for this paper was a study of HIV-positive mothers' service use. Out of concern for sensitivity, the study included no direct questions on mothering. However, the women's narratives were suffused by motherhood. It seemed that their identities as mothers were hugely significant to their perception and experience of their illness. Motherhood was equally present in their accounts of everyday practices, including treatment adherence and service use. The respondents' narratives further pointed to the complexity of their identities as mothers, incorporating elements of both fragility and strength. Trying to situate initial findings within the literature on biographical disruption proved challenging, however, and reinforced the need for a greater attention to gendered roles in this area (Bendelow and Williams 1995, Ciambrone 2001).

Work on the concept of biographical disruption has highlighted the destructive effects of illness on identity: notably, the ‘crumbling self-image’ (Charmaz 1983: 168), the disruption of relationships, material and practical affairs and undermining of assumptions about the body and life course (Bury 1982: 175). Here, however, the respondents placed great emphasis on a pre-existing identity, motherhood, in presenting their lives with HIV infection. This suggested the potential relevance of Carricaburu and Pierret’s idea of ‘biographical reinforcement’ (1995), a notion formulated to express how aspects of identity may be reinforced post-diagnosis, to the interpretation of their accounts. In addition, further work, including some with disadvantaged HIV-positive women like those interviewed here, has questioned the relevance of biographical disruption to the chronic illness experience of those who have lived less privileged lives (Pound et al. 1998, Ciambrone 2001).

At the same time, however, the respondents’ narratives conveyed a strong sense of HIV infection as a moral and existential threat to their identities as mothers, suggesting the potential role of biographical disruption in interpreting their accounts. They also suggested the advantages of employing a more reflexive approach to the inter-relationship between illness and identity than that which has perhaps animated work focusing on the physical effects of illness itself, associated losses and the incorporation of illness into identity (Bury 2001, Mathieson and Stam 1995).

In the light of the relative inattention to motherhood and gender in literature on biographical disruption, I reviewed sociological, cultural and anthropological work on motherhood to try to situate its importance to the women's identities. An ambiguous picture of the significance of motherhood to women themselves, and of societal perceptions of mothers, emerges from this literature. Some explorations of 'ordinary' white women's experience of becoming mothers revealed much ambivalence, and a sense of identity loss in their own eyes or those of others (Oakley 1979, Boulton 1983). Further, writers have posited a contemporary devaluation of the cultural status of mothers, illustrated by the promotion, in much UK government policy, of work (Rake: 2001), and the substitution of gender-neutral terms, such as 'parent', for 'mother' (Smart 1996: 33). Equally, however, researchers have highlighted the potential significance of motherhood to women's identities, presenting motherhood as a 'far-reaching' 'social transformation' (Kitzinger 1992: 1). Of particular interest in a study with a disadvantaged group is Woodward's suggestion that 'essentialist' identities, such as motherhood, may be particularly attractive to marginalised women (1997: 12).

At the same time, however, the pervasive moral and cultural discourses attached to Western motherhood, influenced by the figure of the Virgin (Rich 1977, Warner 1985), have been associated with expectations of self-reliance and self-sacrifice:

> *Regardless of her own needs, socio-economic conditions or husband-partner, the mother must always subject herself to the ideal (Silva 1996: 10, Bell 2004).*

Several writers have analysed the influence of these discourses, and the fear of being perceived as a 'bad mother' indifferent to these ideals (Woodward 1997: 251), over women's negotiation of their identities as mothers. Ribbens, for example, memorably analyses her own 'continual self-monitoring' as a mother (1998: 24). Murphy examines the intersection of discourses around risk, responsibility and motherhood in relation to women's anticipatory accounts of breastfeeding, concluding that professional advice in this sphere:

> *sets the moral context within which women negotiate their identities as good mothers (2004: 207).*

Motherhood and Illness

While a relaxation of cultural expectations of mothers might be expected in the context of illness, a review of the small body of relevant work suggested otherwise, at least where HIV infection is concerned. Much of the HIV literature has focused on the effects of stigma (Feldman and Crowley 1997, Ingram and Hutchinson 1999, Green and Sobo 2000). For example, Doyal and Anderson (2005) analyse its impact on HIV-positive African women in London in terms of biographical disruption, but do not incorporate motherhood into this aspect of their analysis. These and other authors have explored the stigmatisation of HIV-positive mothers in terms of the potential for vertical transmission, as well as the association of HIV infection with sex and injection drug use, activities considered incompatible with good motherhood. As Barlow puts it:

> *[d]rug injecting women have gone against society's perceived role of women as nurturers (1992: 26).*

Empirical research has suggested that many HIV-positive women feel the stigma attached to their pregnancies keenly and for long periods thereafter (Pierret 2000).

A review of literature relating to HIV-positive mothers further suggests that much research has been framed less in terms of mothers' own experience than public health priorities. For example, many researchers, particularly in the US, have examined whether HIV-positive mothers have conformed with best practice in disclosing their diagnosis to children (Letteney and LaPorte 2004, Murphy et al. 2003, Scrimshaw and Siegel 2002) or planning for their children's care in the event of their own death (Lightfoot and Rotheram-Borus 2004, Jones 2004).

Moving Beyond Stigma

Beyond this focus on stigma in the HIV literature, little work has explored motherhood in the context of illness, however. A small number of articles have examined serious illnesses, notably cancers, in parents, but, again, have focused primarily on the effects on children of their mother's condition (Pretter and Raveis 2005, Hoke 2001). As Radtke and Mens-Verhulst conclude:

> *Although contemporary scholarship […] has recognised the significance of motherhood for women, this positioning has received little attention from researchers interested in women and chronic illness (2001: 379).*

An examination of the small number of articles on mothers' experience of illness reveals very different approaches. On the one hand, Thomas, focusing on institutional approaches to illness in pregnancy, argues strongly that illness and pregnancy and should be treated as 'separate, but co-existent career paths' (2000: 383). In contrast, some short research reports, primarily in the nursing literature, have suggested the importance of understanding women's experience of illness in the context of motherhood. In a study of three middle class women with asthma, Radtke and Mens-Verhulst identified a concern with 'good motherhood' as central to their accounts of everyday life (2001: 385). Billhult and Segesten's analysis of interviews with mothers with breast cancer emphasised mother's determination to survive (2003: 124), a concern Wood et al. relate to HIV-positive women's treatment adherence (2004). None of these articles, however, provide a sustained analysis of the inter-relationship between identity, motherhood and illness and, with some exceptions, this is also the case with respect to the growing literature on parents whose children have cancer (Boman et al. 2005, Clarke 2005).

One very interesting exception draws on the literatures on motherhood, childhood and caring, and chronic illness, to suggest that the mothers themselves, although not ill, experience biographical disruption as carers (Young et al. 2002). In their view:

> *Being a mother of a child in crisis required a fundamental redefining of mothers' self-identities and the work of motherhood (2002: 1837).*

This paper aims to build on this approach, exploring the inter-relationship between identity and illness with reference to an empirical study with HIV-positive mothers, and examining the concept of biographical disruption in this light. It aims to outline a concept of biographical disruption which reflects the insights of recent work on factors which may mediate the experience of illness, but which views them as potential influences, among others, on identity in the context of illness. This concept of biographical disruption will also incorporate a greater sense of those identities with which illness may interact, including the way such identities may be both threatened and reinforced by illness, as well as the influence of these identities on the experience of illness itself. In doing so, this paper will focus on motherhood, a source of identity, important to many women, which is under-explored in the literature on illness. The following sections will introduce my study before exploring the inter-relationship between motherhood and HIV infection in the findings.

Methods

The main focus of the study on which this paper is based was service use, not motherhood. The aim of exploring the social processes, contexts and meanings underlying the use and non-use of services suggested the appropriateness of qualitative methods (Miles and Huberman 1994, Hughes 1996), primarily semi-structured interviewing. Twelve women were recruited purposively (Robson 2002) to reflect different levels of service use through a variety of voluntary services, and interviewed about their service use in the context of practical issues such as finances and accommodation. The topic guide also included several open-ended questions, relating, for example, to changes in the women's lives since diagnosis.

The potential sensitivity of the interviews was an important consideration, and influenced a decision not to ask questions about being mothers.[i] In practice, however, the respondents raised many potentially sensitive issues themselves. They seemed to use the interviews as a 'safe space' in which to talk with someone who had no formal authority over their family's lives, and whom, it is suggested, was positioned by some as a kind of 'respectable companion' (Riessman 2002: 16-18). Anna, for example, reflected that she tried not to discuss painful issues with family members to avoid worrying them, but:

> *It helps me talking [...] you put the past in the past, but sometimes it doesnae do any harm to go over it and […] hopefully realise how lucky I am.*

Where possible, each respondent was interviewed twice, after an interval of several months, to reflect the uncertainty of their condition (Backett 1990), generate a rapport between interviewer and interviewee (Cornwell 1984), and produce some longitudinal data. This strategy facilitated a dynamic, iterative relationship between data and methods (Backett 1990), and embryonic themes identified through intermediate analysis were incorporated into the second interviews.[ii]   The success of this strategy in building rapport with interviewees affected by a stigmatised condition is reflected in field notes detailing a more relaxed atmosphere in the second interviews. For example, the interviewer felt that refusing the offer of a drink would not be misinterpreted. Further, several respondents seemed to be more trusting: HIV-positive friends were mentioned by name, rather than in general terms, and several interviews took place while other people were present in the home. In one instance, a niece who was unaware of her aunt’s condition, was in a bedroom, and the interview stopped each time she entered the interview room. Several respondents’ homes, while still tidy, appeared less clinically so than for the first interviews, suggesting a confidence that the interview did not involve scrutiny of their children’s living conditions.

Five respondents preferred to meet at voluntary organisations. This decision often reflected frequent use of the organisations, but one respondent seemed ashamed of her home in a deprived area, associated with drugs. Two of these interviews took place in communal spaces. In one, a worker was present, at the respondent’s request, which may have influenced her reflections on the services provided, and accentuated her concern to present herself in a good light. Seven respondents chose to be interviewed at home, several commenting that this would make them more at ease. However, all took care that the interview could not be overheard. The intensity of this concern was illustrated by one respondent’s horrified reaction when she thought, wrongly, that the young son of her neighbours had been listening through the letterbox. All of the interviews were carried out, tape-recorded and transcribed verbatim including pauses and changes of mood by the author. A broadly grounded theory approach, as distilled by Seale (1999: 104) informed much of the analysis. The respondents’ accounts of motherhood were analysed as performative and moral narratives (Bury 2001: 273).

Aged between 26 and 44 at the time of the first interviews, the respondents had been diagnosed between 1985 and 1990, and had known of their diagnoses for between 7-13 years. Their health varied: six respondents were being prescribed HAART (highly active antiretroviral therapy or 'combination therapies'), four described themselves as having AIDS, while four had never experienced any HIV-related illnesses. Although none reported current street drug use, six respondents had histories of injection use, three of whom were receiving substitute prescription. The other six respondents, were often critical of drug use and emphasised having been infected by partners, who had not always revealed their history of drug use. All but three women were brought up in peripheral, deprived housing schemes, associated with Scottish injection heroin use in the early 1980s, and several had experienced multiple bereavements among family and friends. Hazel reflected:

> *There was 23 of us [..] who was brought up together, [..] got into drugs in [area], and there's three of us left…a couple committed suicide, but the majority [..] died with AIDS.*

All of the women, none of whom were working, were in receipt of varying levels of social assistance, from the lowest levels of means-tested benefits to relatively generous disability benefits. These benefits had enabled some of the respondents, none of whom were homeowners, to move into private tenancies in less deprived areas, reinforcing their concern that landlords should not learn of their condition.

Seven of the respondents had one child, four respondents had two children and one, three children. The children's ages ranged from 7 to 22, and all but four were minors. Like the majority of HIV-positive mothers in Europe (ECS 2004), all but two respondents had full-time custody of all their children, and all were in regular contact with them.

In relation to the study of HIV infection specifically, this sample does not reflect current UK conditions in two main respects. First, the respondents were of white British or other European origins and did not face the difficulties of immigration status, racism and familial and cultural dislocation affecting African women (Doyal and Anderson 2005) who constitute an increasing proportion of the HIV-positive women in the UK (Health Protection Agency 2006) and Europe as a whole (ECS 2004). Secondly, all of the women were diagnosed before the introduction of HAART in the mid-1990s improved survival rates dramatically (Health Protection Agency 2006). They had been told that their condition was fatal, and several, perhaps influenced by multiple bereavements, resisted any reclassification of HIV infection as a 'chronic' illness.

It is argued, however, that this paper's findings remain relevant to HIV-positive mothers, including those with access to HAART (among whom the numbers having children is likely to rise (Cree et al. 2004)), since HIV remains a potentially fatal condition. Its findings are also relevant to a broader group of mothers (and potentially fathers) affected by other chronic, life-shortening conditions, including various cancers.

Exploring the Inter-relationship of Identity and Illness in Relation to HIV-Positive Mothers

The main body of this paper will explore the inter-relationship between HIV infection and their identity as mothers in respondents' accounts of their post-diagnosis lives. The following three sections will focus on different elements of this inter-relationship: the importance of establishing and maintaining identities as good mothers in spite of HIV-related stigma; the threat posed to this identity by the potentially fatal nature of their condition; and their attempts to minimise the impact of their diagnosis on their children.

Establishing and Maintaining an Identity as a Good Mother in the Context of a Stigmatised Condition

Although they were not asked about motherhood directly, the interview transcripts were permeated by the respondents' accounts of their lives as mothers. They seemed to use the interviews to establish and reinforce their claims to be good mothers, by emphasising their determination to place their children's interests before their own.

In constructing their identities as good mothers, the respondents displayed an acute awareness of the stigma attached to HIV-positive motherhood. Many respondents recounted being diagnosed while pregnant, counselled to have late abortions and instances of gross insensitivity by maternity staff. While the events recollected occurred several years previously, there was no mistaking the raw emotion they still evoked. Kerry, a non-drug user, reflected on the long-term effects of the punitive and indiscreet actions of midwives:

> *The medical staff played a big part in how I felt in my whole being regarding HIV […]. I was 19, [..] still pretty naive […] Staff make it very clear that they have an opinion towards you […] basically scum,.. handing the baby over to me with gloves, in open ward […] I had to give birth […] in an auditorium, [..] workmen working next door, no sign, no bell, no nothing […] Everybody's entitled to the feeling that you've had a child, and they took that away from me.*

Several respondents' accounts further suggested an internalisation of this stigma. One woman commented that her children would be better off without her. Years later, several women found certain issues difficult to negotiate, suggesting continued discomfort. Notably, although they were not asked about it, several respondents' interviews contained contradictions as to whether or not they had given up street drugs when pregnant.

Respondents also attempted to negotiate the threat posed to their identities as good mothers by the association of HIV transmission with drug use and sexual activity in other, more direct, ways. Although not asked about drug use, those respondents who had never used drugs, emphasised this fact, whereas previous drug use hung heavily over the narratives of those who had. To defend their identities as good mothers, these respondents often emphasised their efforts to transform their lives and return to 'normality', a concept writers have associated with living a good and responsible life (Crawford 1994). Orla, who had spent 15 years living a transient life, related:

> *It's been hard, it has been hard [….]. One time I went [back] on the street but it only lasted a week, and then I thought […] I'm going to have to start stealing*

> *again, and it took me a long time to get the respect from my family back [..] to be able to walk past dealers….[…] but I had to do it for my daughter.*

Changing for the sake of their children formed an intrinsic part of these narratives. Nina, for example, contrasted her previous drugs lifestyle with her current determination to preserve a 'normal' environment for her daughter:

> *She's seen stuff in her early years. […] It's been a big change from like the drugs years to straight living, even paying the TV licence, ken […] back to normality again and I like it that way.*

In addition, all but one respondent emphasised their willingness to sacrifice personal relationships in the interests of their children. Within the context of a long-term, HIV-discordant relationship, Hazel expressed the importance of self-sacrifice in relation to the dangers of sexual transmission:

> *I've really [had] nae sex life at all […] for the last years.. […] because [..] my partner's no positive and he really has to be there for the bairns at the end of the day.*

Most respondents were single, however, and pointed to their wariness of new relationships, emphasising the potential danger to their children from violent or indiscrete (see Melvin 1996: 227) partners. Marina, whose previous boyfriend had scrawled 'AIDS-riddled scum' on her door, explained:

> *I'd have to explain to them that I was HIV. And if it was to be a short relationship then they would tell someone else [….]. I need to protect it for my daughter because people are gonnae say 'your Mum's got AIDS', 'your Mum's this'.*

Anna extended this 'duty of care' to the children of potential partners, further emphasising her willingness to self-sacrifice:

> *it's hard to bring new people into my life because then they're just gonnae get hurt […] I knew a lad years ago […] He wanted to start a relationship but he had two small boys. And I says no […] the thought of having to tell [them] or for [them] to get attached to me.*

The respondents' accounts therefore illustrated the importance they attached to establishing and reinforcing post-diagnosis identities as good mothers. Since motherhood often preceded diagnosis in chronological terms, this concern might be interpreted as an element of continuity in the respondents' post-diagnosis identities, perhaps reflecting a type of 'biographical reinforcement' (Carricaburu and Pierret 1995). However, it seemed that this post-diagnosis formulation of a moral identity as a good mother was carefully constructed to take account of the threat or risks (Green and Sobo 2000) posed by the stigmatised nature of their condition. The next section will continue this exploration of the inter-relationship between illness and identity, by focusing on the threats posed to the respondents' identities as good mothers by diagnosis with a life-threatening condition.

Preserving an Identity as a Good Mother in the Context of Potentially Fatal Illness

The potentially fatal nature of HIV infection seemed to pose an even greater threat to their identities as good mothers than its associated stigma. As Melvin puts it, an HIV-positive mother:

> *[has] to think not only about [..] her own mortality but also about losing or sharing the parenting role (1996: 226).*

Thomas' work suggests widespread ambivalence towards pregnancy among women with such conditions (2003: 393), who, as Campion points out, are not normally permitted to adopt (1995: 45).

This threat to their identities as good mothers permeated the respondents' accounts. Like studies with mothers affected by cancer (Billhult and Segesten 2003) and HIV infection (Doyal and Anderson 2005), and in contrast with research exploring the narratives of HIV-positive single men (Ezzy 2000), these women highlighted the importance of surviving for their children's sake. The central importance of survival to the respondents' identities as good mothers will be further illustrated in this section by their difficulty in re-thinking their identities once their children reached adulthood.

Throughout the interviews, the respondents' rarely spoke of periods of illness in exclusively individual terms, often attributing their determination to look after themselves, comply with arduous treatment regimes, and, in some cases, resist suicidal thoughts, to being mothers:

> *Last year when I was ill [….], I would have committed suicide cos it was that bad….. I needed a blood transfusion, [..] an oxygen mask on four times a day, [..] a drip on for 18 hours a day [….]..If it wasnae for my daughter I would have gave up (Ella).*

Orla was to be discharged from hospital the day after her interview, following serious illness. The precariousness of her health was a recurrent, poignant theme of her interview:

> *I'm like a cat with nine lives…it's the third time I've been ill with chest problems. I'm fully blown AIDS now. So that's it…that's me.*

On several occasions however, almost within the same breath, she exhorted herself to keep going until her daughter reached 16, and mentioned plans to stop smoking as part of making sure she succeeded.

All but one respondent highlighted their determination to survive, an aim which, like Orla, they expressed in terms of surviving until their youngest child's sixteenth birthday. For example:

> *My future has been from the day I found out, my hope has been that I make it to [daughter]'s 16. Then I've done my duty as a mother (Nina).*

> *My daughter that worries me….I just think so long as I can still be here when she's 16 (Ella).*

This aspiration reflected a strong cultural perception that this age marks the end of childhood, and, consequently, of children's need for their parents:

> *Once they're 16, […] it's like you've done your best […] in the most important points of their life. […] Like you bring them up and teach them right from wrong, show them the way if you like (Tracey).*

> *[Sixteen is] when they're responsible for themselves [….] They dinnae need anyone else to be their guardian or anything […] It's like cutting the umbilical cord (Kathy).*

The importance of this aim to their identities as good mothers was further underlined by the difficulties several respondents encountered in re-working their identities once their youngest child reached this milestone age. As Kathy explained:

> *When they turned 16 I got a bit paranoid, you know, cos I thought 'have I lived to this age for that reason, and now am I gonnae die?' you know, because my* ***quest*** *is over (emphasis added).*

Nina’s youngest daughter turned 16 in between her two interviews. In her first interview, she recounted her concern at this approaching milestone, and how she intended to cope with it:

> *[It] is worrying in a way, because that’s when my hopes went to […]. A friend […..]when [her youngest] came 16 she just went seriously ill thinking she was gonnae die now [….]. But I’ve learnt now to make it when she gets to 16, to make it 21. And to do it that way, because that’s what’s keeping me going.*

By her second interview, she had been told that her combination of drugs no longer seemed to be working and her daughter’s birthday had become a major source of anxiety:

> *all these years, you’ve been going to 16,[..] well me 13 years going 16, 16, 16 and it’s now fucking here and it’s like oh wow.. you never think for a minute that you’re still gonnae be here! […] You hope you [are] but with all the people that have died on the way you think chances are….*

Her deteriorating health seemed to reinforce a perception that her self-definition as, primarily, a mother, would no longer be credible and her survival no longer necessary.

These findings further underline the importance of motherhood to the respondents’ identities and self-worth. Indeed, being the mother of a minor child appeared to provide a moral justification for their continued existence, while potentially no longer being needed as a mother seemed to provoke fears of no longer serving any useful purpose. Influenced by cultural ideas relating to the duration of childhood, the process of identity re-negotiation in which the respondents engaged when their children reached the age of 16, also illustrates the reflexive nature of their identity construction. All of these elements seemed important to understanding the threat occasioned by their potentially fatal diagnosis. Before discussing these ideas in relation to the concept of biographical disruption, however, the following section will explore a further, linked, element of the inter-relationship of illness and identity in the respondents' accounts.

Shielding Children from the Implications and Effects of Potentially Fatal Illness

The respondents' accounts of their everyday lives, including their service use, further illustrated their understanding of their HIV infection in terms of motherhood. This section will explore the emphasis in the respondents' narratives of good motherhood on minimising the impact of their condition on their children, and the dilemmas this posed, for example, in trying to ensure that their children could both live 'normally' but also cope with early independence, if necessary. It will start, however, by raising the thorny issue of children caring.

Periods of acute illness, during which the respondents could not care for their children, posed a further threat to the women's identities as good mothers. Particularly difficult to assimilate into this identity were any experiences of being cared for by their children (also see Aldridge and Becker 1994). The respondents who discussed this issue expressed profound ambivalence. Marina, for example, seemed uncomfortable with receiving help from her children, but was touched by their concern, and felt they had wanted to be involved:

> *they're too grown up. It's wrong for kids to be carers […] They like to help me. 'have you taken your pills today?' When I was very ill, I didn't like it that the kids were helping me but…. they were there for me.. taking me to the loo and when I needed a drink at three in the morning.*

This issue was particularly upsetting for Barbara, who was both ill and socially isolated at the time of her interview. She preferred to emphasise her use of a respite agency which allowed her pre-teenage son, who often made his own meals and on whom she relied for company, to:

> *be a child as opposed to a child carer.*

In contrast, many respondents highlighted their efforts to ensure their children enjoyed a 'normal' childhood in spite of their illness and the dilemmas they encountered in trying to fulfil this aim. One such dilemma was posed by the chronic fatigue associated with their condition. For example, in response to a question probing what she had found most difficult since her diagnosis, Tracey emphasised:

> *finding the energy to keep up with my son, […] all day and all night. [….] There is some days like he won't settle down and he is hyper ehm and [..] I want to go to my bed and I can't because with a kid you can't do that.*

Since tiredness is a common parental complaint, it seemed that raising this issue did not undermine the respondents' identities as good mothers. However, the respondents did point to ways in which they tried to reconcile their concern that their children should experience normal childhoods, with their need, discussed previously, to survive. Barbara's account of her consistent efforts, in spite of her fatigue, to allow her son to enjoy 'normal' home activities highlights this difficulty:

> *It's scary for him […]. They're looking for signs that you're [..] not being normal […..] I've had to try and be normal for the kids. Be there [..] make the teas, [..] entertain their pals […] Make a good pretence of it, but it's a lot of front.*

Like other respondents, she recounted trying to resolve this conflict by sleeping while her son was at school and taking up services for her son, such as a buddy:

> *[he'll have] a male role model to go go-karting etc…all these things I just don't have the energy to do. I've got the enthusiasm but [..] by the time I get to the bus-stop I'm exhausted [..] freezing […] It's better if he's got his own person to do that sort of thing.*

Tracey described how she used an HIV playgroup for a similar purpose, viewing this service as a unique space in which her young son could feel 'normal' in spite of his mother's diagnosis:

> *He thinks 'wow this is great! You can relax and talk about HIV, everybody's in the same boat one way or another'.*

The potentially fatal nature of their condition posed further dilemmas for the respondents in terms of this aim of ensuring a ‘normal’ childhood for their children. As discussed, much of the HIV literature has emphasised the importance of ‘permanency planning’, through the formalisation of fostering plans and making wills. Some respondents had completed the emotionally difficult process of making a will and used bereavement counsellors to try to prepare their children emotionally for their potential death. For others, however, such an approach could only shatter any sense of a ‘normal’ childhood. These women preferred to emphasise less formal preparations for the future, such as educating their children to look after themselves.

Several respondents’ own early experiences of drug use and sexual activity intensified their concern to protect their children from potential pitfalls. For example, Hazel, who also emphasised her determination to move from an area associated with drug-dealing, commented:

> *I’m really hoping that they dinnae go the same way as me [..] They’ve been brought up real different […] I was really strict with them [….] I dinnae want them to do anything that I done.*

Mothers whose children were older, were concerned to educate their children. Asked what had changed for her since diagnosis, Rhona said:

> *Life’s been more important to me since then ehm..just wanting my kids to know all the facts of life.*

This response to a very general question illustrated the importance of this aim to her concept of good motherhood. Similarly, when asked what she had found most difficult since her diagnosis, Kathy emphasised:

> *Teaching them and making them independent- that was the hardest thing […] for me as a mother. Knowing that I had something and I felt so guilty ….my kids were gonnae be without two parents because of my stupidity as a teenager [..] taking drugs.*

With hindsight, however, her children having reached adulthood, she was concerned she had over-emphasised this aim, suggesting the difficulty of reconciling this concern with that of protecting her children's childhood:

> *They missed a fair bit of their young lives [..]. I forced things on them about sexual issues.*

These findings therefore illustrate the way in which the respondents were concerned to limit the effects of their condition on their children, and to protect them from biographical disruption. They also highlight the respondents' understanding of their diagnosis in collective rather than individual terms. In the final discussion section, these findings will be used to revisit the concept of biographical disruption.

Discussion: Motherhood, Identity and Biographical Disruption

This paper has traced the intimate relationship between motherhood and HIV infection in the accounts of a group of HIV-positive women. Despite the fact it was not the focus of interview questions, motherhood permeated these women's reflections on living with HIV infection. The interview transcripts contained many examples of their careful construction of identities as good mothers in the light of the stigma attached to their particular condition. They also strongly reflected concerns potentially shared by mothers with other life-threatening conditions, notably their determination to protect their children by surviving until their children reached adulthood and by ensuring that their children experienced 'normal' childhoods. Common to the construction of these different elements of their post-diagnosis identity was an intense sense of threat. This section will explore implications of these findings for the literature on motherhood, and interrogate the concept of biographical disruption in their light.

Analysis of the transcripts drew upon sociological and anthropological work on motherhood. Returning to this work subsequently prompts several thoughts. For example, reflecting on the literature on HIV-positive mothers suggests that it has been the stigma associated with their condition, rather than their experience as mothers, which has captured, and perhaps legitimated, much research interest. The lesser attention paid to mothers with other conditions in the literature on chronic illness as a whole suggests that such scrutiny might usually be considered too sensitive. The respondents' emphasis on motherhood in their interviews suggests, however, that mothers with such illnesses may not perceive research attention as intrinsically intrusive.

Some of the findings further suggested that explorations of the experience of mothers with chronic illness might contribute to an understanding of how notions of good motherhood, and the self-reliance expected of mothers (Bell 2004), might subtly be re-negotiated. This study, for example, provides some examples of mothers involving services in their childcare, but presenting this choice in terms of their determination to ensure a normal childhood for their children.

Overall, however, given the lack of attention paid to motherhood in work on chronic illness, this body of work was invaluable, not only in pointing to the importance of motherhood to identity, but also in suggesting how motherhood might represent a key source of identity. For example, the respondents’ determination to establish and defend identities as good mothers throughout their interviews recalled several writers’ work on women’s negotiation of this identity in a variety of contexts, including that of the research interview, in the light of strong moral discourses surrounding motherhood (Murphy 2004, Bell 2004). These discourses seemed to restrict the ways in which these women could legitimately speak about their illness. However, recalling Woodward’s analysis of an ‘essentialist’ interpretation of motherhood as an attractive identity for marginalised women (1997), motherhood also seemed to provide these respondents with a strong moral narrative justifying their continued existence.

These findings suggest the potential significance of this notion of key identities, and motherhood specifically, to understanding the experience of chronic illness. For example, in the context of illness, when other sources of identity, such as work, may have been undermined, they suggest that the importance of maintaining such key identities may be accentuated. Such morally-loaded identities might be viewed, therefore, as a further challenge to notions of 'chronic reflexivity' as a symptom of modern life, to add to those of age and socio-economic class (Williams 2000, 59-60). That these women perceived their possibilities for personal reinvention as moral beings to be limited, was poignantly illustrated by their difficulties in re-negotiating their identities once their children reached the culturally accepted threshold of adulthood.

The relevance of biographical disruption to an interpretation of these findings might not be so immediately obvious, however. Bury's initial formulation of biographical disruption emphasised the assault of *illness on* previously-held and often cherished conceptions of self and life course, prompting a 'fundamental re-thinking of the person's biography and self-concept' (1982, 169) *in the light of the illness*. Since in chronological terms, several respondents were already mothers at the time of their diagnosis, the emphasis on motherhood in their accounts might be analysed as a weak form of 'biographical reinforcement', a notion developed precisely to explain how post-diagnosis biographical reconstruction may reinforce previously-existing components of identity (Carricaburu and Pierret 1995: 65).

On reflection, however, the respondents could not draw on their past as mothers in the same collective sense, bolstered by political movements, as the gay and haemophiliac men interviewed by these authors (1995: 80). Further, they did not emphasise elements of continuity in their lives. Rather, their narratives were permeated by an almost physical sense of threat to their identities as mothers, both from HIV-related stigma and their potential mortality, which has been analysed in this paper as a form of biographical disruption. This notion of biographical disruption emphasises the fundamental re-formulation of a key identity in the light of illness and focuses greater attention on the critical nature of identities which may be threatened by illness.

Several examples of the potency of such threats to identity, and their importance with respect to the respondents' post-diagnosis re-formulation of identity, have been analysed in this paper. The threat posed by the stigma attached both to HIV infection because of its means of transmission, and to motherhood in the context of HIV, is reflected in the respondents' careful construction of their identities as good mothers. The experience or fear of HIV-related stigma has previously been analysed as a form of biographical disruption. Doyal and Anderson, for example, flirt with this interpretation (2005, 1734), while Green and Sobo present a strong case for a constant process of social 'identity risk management' or the protection of important social identities against the risks presented by stigma (2000, 37-8). The findings presented in this paper, however, suggest that there is a need to move beyond this focus on stigma to explore the full range and intensity of threats to identity experienced by HIV-positive women as mothers, and, in particular, the threat posed by the potentially fatal nature of their condition. The determination of HIV-positive mothers to survive has been noted elsewhere (Doyal and Anderson 2005). In this paper, however, the significance of this threat has been explored further, through various recurrent narratives of protecting their children from the implications of their diagnosis.

This conceptualisation of biographical disruption, suggesting the importance of a greater focus on the relationship *between* identity and illness, rather than only the effects of illness *on* identity, also has implications for recent critiques of Bury's concept and for research into the experience of illness more generally. For example, recent work on biographical disruption has called for greater attention to be paid to the timing and context of chronic illness, and notably the age (Pound et al. 1998), and previous experience of hardship (Ciambrone 2001), including illness (Faircloth et al. 2004), of the person affected.

The findings discussed in this paper suggest, however, that such 'mediating factors' cannot be seen in isolation from identity. On reflection, this point is also suggested, although not explored, in several of these articles. For example, Pound et al. mention that the stoic post-stroke narratives employed by older, white working-class respondents, were not shared by their Asian-origin counterparts, many of whom were likely to have had equally, if not more, difficult lives (1998: 501-2), perhaps reflecting different cultural perceptions of old age. Similarly, although Ciambrone's respondents often downplayed the impact of HIV infection on their lives in the light of multiple other difficult experiences (2001: 517), several of these women did allude to the importance of children, or their absence, to their experience of HIV infection. Indeed, although her analysis focuses on mothers who do not have custody of their children, and who can, therefore, distinguish easily between issues relating to motherhood and illness, her central argument hints at the potential importance of motherhood to the experience of illness where custody is retained:

> *Illness, especially one that has not yet compromised women's functional ability, is easier to incorporate into their biographies than separation from their children [and] the [resulting] feelings of failure and guilt (2001: 524).*

Taking a more reflexive approach to identity in the context of illness, and viewing older age or the experience of hardship as potential influences on identity, might also avoid the development of assumptions that older or disadvantaged people may be less affected by illness, and somehow expected to be more stoic.

Focusing on the respondents' identities as mothers specifically, further reinforces a point made by several authors as to the absence of gender from the literature on biographical disruption (Ciambrone 2001: 520), and on the experience of illness more generally (Bendelow and Williams 1995). This paper has highlighted that the respondents did not see their condition and its implications in individual terms. In contrast, however, the effects of illness have often been explored with respect to aspects of life which best reflect the concerns and priorities of single individuals. For example, Bury's seminal (1982) article on biographical disruption was based on interviews with young women, recently diagnosed with rheumatoid arthritis. Many of these women were mothers. Yet his analysis, like that of many other writers, took an individual approach, focusing on the effects of illness on work-related, rather than on caring responsibilities. The study on which this paper draws, like that of Young et al. (2002), which examined the effects on mothers of potentially terminal illness in a child, suggests the limitations of such an individual approach. It points to the importance of incorporating the ‘cognitive and emotional significance’ (Bendelow and Williams 1995: 150) of motherhood and of caring responsibilities more generally into sensitive explorations of the effects of illness, as well as the interest in identifying further key identities through which the experience of illness may be refracted.

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[i] Ethical supervision was provided by PhD supervisors and PhD panel examiners in accordance with BSA ethical guidelines, and the topic guide was discussed with all voluntary agencies involved in the study. Particular emphasis was placed on the process for obtaining written informed consent and on the safe storage and destruction of any identifying material. In this paper I have employed different pseudonyms to those employed in my thesis and altered some potentially identifying information in the quotations used.

[ii] The first interviews took place between October 1997 and April 1998, and the second interviews, with all but two respondents, in April and May 1998. They lasted for between 45 minutes and two hours but nearly all tended towards the longer end of this spectrum.