Using narratives to boost care: HIV in pregnancy

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Receiving a diagnosis of HIV infection during pregnancy constitutes a major trauma for women and their families. This article summarises the findings of a qualitative research study conducted with women diagnosed during pregnancy, who were interviewed shortly after diagnosis and again after the birth of their baby. It highlights the role of narrative care in helping people to reconstruct their personal narrative during difficult life transitions or trauma.

Narratives play an important role in human experience. Our personal stories help to shape our sense of self and identity, and orientate us towards the future. However, as we are constantly making sense of everyday and major events in our lives, our personal story must be continuously revised, if it is to continue to help us hold things together. Narratives, therefore, have a particular resonance for individuals who need to reframe their lives after a particular crisis or trauma and, therefore, have a key role in nursing practice (Holloway and Freshwater, 2007).

This article, adapted from an unpublished thesis, focuses on the disruption felt by four pregnant women on discovering they had tested positive for HIV infection during routine antenatal screening. It presents a composite narrative from all four women’s experiences, capturing the essence of the disruption to their lives caused by a diagnosis of HIV during pregnancy. It then draws on the work of American anthropologist Gay Becker (1997), as a framework for understanding how the women created continuity out of the disruption. Finally, it considers the therapeutic imperative of paying attention to, and facilitating the rewriting of, personal stories as part of nursing practice.

Methodology
The four women in this study were taking part in a larger prospective qualitative study in Northern Ireland, a relatively low sero-prevalence area for HIV, and one of the last regions of the UK to introduce antenatal HIV screening (in 2003).

The women were interviewed twice, once after HIV diagnosis and again after their babies were born. The interviews used an unstructured and conversational style, and the women were invited to tell their story from any starting point in their life. Analysis uncovered “characteristic plotmarks” (Bleakley, 2005) in the women’s narratives. Six key themes contributed to their lived experience:
- The chaos of diagnosis;
- The experience of otherness;
- The threat to their relationships;
- Concerns for the baby;
- Pregnancy as saviour;
- Creating continuity out of the disruption of diagnosis.

The narrative in Box 1 is a composite developed from direct quotations from the four women in the study.

Discussion
What do we hear in the women’s narrative? The starting place for all four women’s

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stories was their excitement about being pregnant and their commitment to doing all the right things that pregnant women are expected to do, such as attending for antenatal screening. None of the women gave much thought to the screening process, never considering they were at risk of HIV. One week and one phone call later and their lives would be disrupted.

Becker proposes that stories of disruption are cultural in nature and invariably stories of difference because, regardless of the nature of the disruption, it is felt most acutely when people view themselves as being at odds with what they and others view as normal for their gender, age and circumstances (Becker, 1997). The women experienced the greatest distress at times when the experience they were living through clashed with dominant cultural narratives about how life should be. A diagnosis of HIV constituted a major threat to their health, their relationships and their social identity. As pregnant women, however, the threat posed by HIV was experienced most significantly in relation to their unborn child.

Most of the women’s narratives conveyed their initial belief that HIV happened to other people. Being diagnosed as HIV positive themselves, therefore, forced them into an experience of “otherness”. Renegotiation required them to present moral or normalising accounts of their lives in order to reconcile the experience of becoming the other. In order to distance themselves from “others”, the women presented evidence of their moral selves as “good people”. Then, to present their behaviour as “normal” – and therefore “normal” – they were required to distance themselves from the behaviours they associated with HIV.

Ultimately, through a process of revision and renegotiation all four women managed to create continuity after the disruption. They found solace in the medical benefits to be gained for themselves and their babies, from timely knowledge of their HIV status. While their HIV diagnosis constituted a disruption to their biographies, their role as mother provided a focus for regaining continuity in their lives – their babies became a metaphor for hope and orientation towards the future.

The findings of this study also highlight the healing nature of narratives. Through the reconstruction and telling of their stories, the women were actively resisting the threat posed by HIV. Sociologist Arthur Frank (2007) reminds us that people can be thrust into becoming patients with terrible suddenness, and that health professionals who have had some preparation and training must therefore recognise “discoveries of meaning”. Hence, “narrative care”, as defined by Frank (2007), requires “help(ing) people who have fallen out of the story of which they were part to find a new story of which they can be part”.

While the four women came from very culturally diverse backgrounds, their experiences of disruption were strikingly similar, underscoring the universality of prevailing normalising ideologies attributed to women, pregnancy and motherhood. Repositioning the crisis as a beginning, rather than an end, required them to reread all those discourses on normalcy, allowing them to rewrite themselves into their own life story.

References

BOX 1. COMPOSITE NARRATIVE FROM STUDY PARTICIPANTS

Receiving the news
When I knew I was pregnant, I was so excited. I received a letter from the hospital that was an appointment for the scan and antenatal tests. After two weeks, the hospital called me to say that there was a problem.

They called me in as quick as possible. I knew that they were really concerned and that they didn’t know how to tell me. And then [the doctor] told me, “You are HIV,” and just everything going on in my head [sobs].

The chaos of diagnosis and experience of otherness
I just thought in my head, “Maybe there is something wrong, there is a mistake, it is not my result, it is impossible”.

I had all these questions and all I thought was I am going to die and that is it. I will have to get rid of the baby and I knew nothing. I do not know what next. I want to kill myself, how do I kill myself? Where, where do I go?

Every day you stay at home and then you worry, maybe you will die tomorrow, or next year or two years. I just want, I just hope, that God will give me 20 years more because my baby will be 20 years old [sobbing].

Ah it was a nightmare. I swear to God. It was just one thing after another.

Threat to relationships and concern for the baby
“How did you get this?” He [partner] is not blaming, he is panicking. “What about the baby? What is going to happen to the baby?” He was just panicking and he was shaking and we were both crying. I was feeling worse because I didn’t know which way it came from so he had to have a blood test. I was praying that he would be negative. Also afraid of the way he could react if he could be positive.

It is all the time going round and round, why? What I become? Why it happen to me? I just tell myself it is unlucky. I just tell myself, why it is so unfair? Like I have so many friends and they go out with different men or something. Why they do not transmit HIV?

The part of holding it in is worse, it’s a killer, it’s a killer. You would do anything to cover it up and not let on at all. I don’t want them acting any differently. I don’t want them looking at me any different or judging me or having their own opinions on things when they don’t know anything about it.

Pregnancy as saviour
The only thing that is supporting me, that is my baby. If I am not pregnant I don’t know what I would do. Because there are times when you think, “I don’t want to even be here” but then that just completely went away because I was pregnant like.

Being diagnosed in time, when you are pregnant is brilliant as far as I’m concerned. You do not know how much happy when the antenatal doctor [was] saying, “This is the baby’s head, it is nice and strong” or “This is the baby’s heart and everything seems to be well”. It makes you happy and have much hope that the baby will be fine.