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‘Everything is okay’: The influence of neoliberal discourse on the reported experiences of Aboriginal people in Western Australia who are HIV-positive

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Abstract

While Australian Aboriginal conceptions of health have been described as holistic and collective, contemporary approaches to health services and health research are often premised on the rational, reflexive subject of neoliberal discourse. This paper considers how neoliberal conceptions of health and subjectivity arose and were negotiated in the context of a qualitative research project on Aboriginal experiences of HIV in Western Australia. Questions about ‘coping’, ‘future’ and ‘life changes’ stood out in the interview transcripts as examples of neoliberal discourse. This paper explores the reflexive, contextual and deflective responses to these questions and suggests they demonstrate how neoliberal discourse can produce the impression that ‘everything is okay’ despite the difficult social and economic conditions of everyday life experienced by many Aboriginal people. Aboriginal people with a chronic and serious infectious disease such as HIV may utilise the language of self-management and responsibility when talking about HIV with a non-Aboriginal researcher for pragmatic and utilitarian reasons. In this way, the responses of the Aboriginal participants in this study provide a valuable opportunity for exploring new approaches to both research methodology and health service delivery.

Résumé

Alors que les conceptions de la santé chez les Aborigènes d’Australie ont été décrites comme holistiques et collectives, les approches contemporaines des services de soins et de la recherche sur la santé sont souvent construites autour du sujet rationnel et individualiste du discours néolibéral. Cet article examine comment les conceptions néolibérales de la santé et de la subjectivité ont émergé et ont été négociées dans un projet de recherche qualitative sur l’expérience du VIH chez les Aborigènes d’Australie Occidentale. Les questions sur la ‘capacité de faire face’, le ‘futur’ et les ‘changements de vie’ ressortent des transcriptions des entretiens comme des ‘exemples’ de discours néolibéral. Cet article explore les réponses réfléchies, contextuelles et détournées à ces questions, et suggère qu’elles démontrent comment le discours néolibéral peut produire une impression que ‘tout va bien’ en dépit des difficultés socioéconomiques quotidiennes auxquelles beaucoup d’Aborigènes sont confrontés. Les Aborigènes qui vivent avec une maladie infectieuse chronique et grave comme le VIH peuvent employer le langage de l’autogestion et de la responsabilité lorsqu’ils parlent du VIH avec un chercheur non aborigène, pour des raisons pragmatiques et utilitaires. Ainsi, les réponses des participants aborigènes à cette étude offrent une occasion importante d’explorer de nouvelles approches des méthodologies de recherche et de la délivrance des services de santé.

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Resumen

Si bien los conceptos de salud entre indígenas australianos han sido descritos como holísticos y colectivos, los enfoques contemporáneos sobre servicios de salud e investigaciones sanitarias con frecuencia dependen del argumento racional y reflexivo del discurso neoliberal. En este ensayo hemos analizado en qué medida surgían los conceptos neoliberales de salud y subjetividad y cómo se negociaban a través de un proyecto de investigación cualitativa sobre las experiencias de los indígenas de Australia occidental afectados por el virus del sida. En las transcripciones de las entrevistas destacaron preguntas sobre el futuro, cambios en la vida y la superación como ejemplos del discurso neoliberal. En este artículo estudiamos las respuestas reflexivas, contextuales y deflectivos a estas preguntas que demuestran cómo los discursos neoliberales pueden dar la impresión de que ‘todo va bien’ pese a las dificultades en las condiciones sociales y económicas de la vida diaria que experimentan muchos indígenas. Los indígenas que padecen una enfermedad infecciosa crónica y grave, por ejemplo el VIH, podrían utilizar, por razones pragmáticas y prácticas, el lenguaje de la autoadministración y responsabilidad al hablar sobre su enfermedad con un investigador que no sea indígena. De este modo, las respuestas de los participantes indígenas en este estudio brindan la valiosa oportunidad de explorar nuevos planteamientos para la metodología de investigación y el suministro de los servicios de salud.

Keywords: *Australia, Aboriginal health, living with HIV, health service delivery, neoliberal discourse*

Introduction

‘Nothing wrong with my future. Nothing wrong with my activities and work around the house. Nothing wrong with that. Everything is okay.’ (Bonnie)

In recent decades health research in Australia has exposed an inequitable burden of disease in Aboriginal people, linked to ongoing conditions of social and economic marginalisation (Australian Bureau of Statistics and the Australian Institute for Health and Welfare [ABS and AIHW] 2005). Complicating this issue are perceived differences between ‘western’ and ‘indigenous’ concepts of health and illness (Maher 1999, Wiseman 1999, Boulton-Lewis *et al.* 2002). One of the enduring achievements of the National Aboriginal Health Strategy Working Party, established in December 1987, was the articulation of a more holistic definition of Aboriginal health than is evident in the western biomedical model. This definition includes: ‘Not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life’ (National Aboriginal Health Strategy Working Party 1989: ix). The challenge for both Aboriginal and non-Aboriginal people in Australia, therefore, is to embrace this definition in the context of the contemporary healthcare system, which has been shaped by the rise of neoliberalism as a political discourse.

Neoliberalism, or what Nikolas Rose (2000: 337) has described as ‘advanced liberalism’, can be characterised by:

‘The emphasis upon creating active individuals who will take responsibility for their own fates through the exercise of choice, and the organization of socio-political concerns around the management and minimization of risks to lifestyles of contentment and consumption.’

In a similar vein, Kelly (2001: 29) argues that the ideology of neoliberalism ‘attempts to reconfigure the practices of government by conceiving the subject as rational, autonomous, choice making and responsible’. In relation to health, neoliberal discourse promotes the idea that individuals should take personal responsibility for health and make behavioural and lifestyle choices that maximise current health states and reduce the potential for future

disease, in consultation with a range of sources of expert knowledge (Rose 2001). Petersen (1997: 194) has argued that 'neoliberalism calls upon the individual to enter into the process of his or her own self-governance through processes of endless self-examination, self-care and self-improvement'.

In many western societies, neoliberal discourse has been mainstreamed across various public sectors, including the financial (Aldridge 1998), justice (Andersen 1999), education (Kelly 2001) and urban planning (Gleeson and Low 2000) systems, with a common focus on shifting responsibility for care and support away from the state and onto individuals, families and communities. Yet for a great many people, the neoliberal privileging of rationality, autonomy, choice and responsibility does not reflect their understandings of self, nor offer desirable or achievable ideals to aspire to in their everyday lives.

This paper examines how neoliberal discourse was produced and negotiated in a qualitative research project on the experiences of Aboriginal people who are HIV-positive in Western Australia. By drawing attention to the cultural complexities of the research encounter, we hope to identify some of what Michael Bury (2001: 278) has described as the 'linguistic and symbolic repertoires which allow and constrain what is said and how it is expressed' in health service contexts. While this approach aims to improve cross-cultural understanding, it also informs current debates on how to develop approaches to health research and service delivery that embrace diverse linguistic, social and cultural contexts. In this way, the paper contributes to the interdisciplinary literature on living with HIV, the sociological critique of neoliberalism and the cultural politics of Aboriginal health. This analysis is not intended to reduce or to fix the cultural complexities of 'Aboriginality'. Rather it hopes to inspire a range of questions about the relationship between language, subjectivity and health in contemporary Australia.

Project background

In 2003, a qualitative study was conducted with Aboriginal people who are HIV-positive and living in urban and rural areas of Western Australia (Bonar *et al.* 2004). This was the first project of its kind and the twenty participants represented almost half the total number of Aboriginal people known to be living with HIV in Western Australia at the end of 2002 (Giele 2003). The project was endorsed by the Western Australian Aboriginal Sexual Health Advisory Committee who also supported a funding request to enable the study to occur.

The broad project design was developed in conjunction with key stakeholders, including HIV-positive Aboriginal people and their Aboriginal and non-Aboriginal health service providers, following the ethical guidelines for the conduct of research in Aboriginal communities (Aboriginal and Torres Strait Islander Research Agenda Working Group 2002, National Health and Medical Research Council 2003). Representatives of both groups were engaged at each stage of the research process, including the development of the research aims and design. Before the research began, an Aboriginal researcher met with five rural Aboriginal women who were attending a positive women's retreat to consult with them regarding the project aims. An HIV-positive Aboriginal man from the metropolitan area was also consulted, ensuring both male and female and rural and metropolitan input.

The project had the principal aim of providing participants with an opportunity to tell their stories, with a secondary interest in exploring their experiences of social, geographic or other barriers to effective healthcare and quality of life. As the project was developed in a health services context, the interview guide was designed to be open and responsive while

remaining focused on achieving practical outcomes in improving health services for Aboriginal people. The interview guide was developed in consultation with the project Steering Committee and Reference Group, including representatives from public health and health services, HIV social research centres and Aboriginal communities. The differing input provided a range of perspectives on how the research could be both methodologically rigorous and culturally appropriate.

Participants were asked about their lives prior to diagnosis, the circumstances around their diagnosis and the social, economic and health impact of living with HIV. The questions were provided as a semi-structured guide rather than as a questionnaire to be strictly adhered to. Although a few participants required considerable prompting to elicit detailed responses on some topics, this could usually be attributed to factors such as their youth, shyness or the difficult and highly personal nature of the topic being discussed. Nonetheless, a few of the questions did elicit somewhat more awkward responses. Following the theoretical interests of this paper, three of these questions in particular can be seen to typify the expression of neoliberal discourse: (1) What things helped you cope when you first knew you had HIV? What things help you cope now, (2) Can you tell me how HIV has changed the way you think about the future and (3) In thinking over the whole experience of living with HIV, what has been the most important change that has taken place in your life? These are not unusual questions in qualitative research on chronic illnesses such as HIV (see, for example: Ezzy 2000, Ciambone 2001, Moskowitz and Wrubel 2005) and they draw upon ideas that are familiar in the context of health services. But there are significant implications of introducing concepts of coping, future and life changes into the research encounter (Holt and Stephenson 2006). Following a synopsis of the project background, we will examine how research participants responded to these questions, organised into reflexive, contextual and deflective responses.

The research project received ethics approval from the Western Australian Aboriginal Health Information and Ethics Committee and both The Royal Perth Hospital and Fremantle Hospital Ethics Committees. To be eligible for inclusion in the study, participants had to be Aboriginal, HIV-positive and living in Western Australia. Eligible individuals were approached, generally through their health service provider, and invited to participate in this study. One rural health service facilitated the recruitment of participants from a cluster of Aboriginal cases, mostly women. Interviews took place in a setting chosen by the participants to ensure adequate privacy and familiarity in an environment in which they were comfortable. These settings included the researcher's office, rural health clinics, participants' own homes, hostels and one in a prison setting. Participants chose or were given pseudonyms for the purpose of confidentiality throughout the study. Interviews were recorded and transcribed (17) or written down verbatim (three) and transcripts checked with participants where possible.

While it had been hoped an Aboriginal person could be appointed to the role of project senior research officer (and principal interviewer), the Steering Committee agreed it was most important this person be skilled in establishing and maintaining trusting relationships with research participants. As there were no Aboriginal applicants, a non-Aboriginal woman who had considerable experience in working with Aboriginal people and an established relationship with many of the potential research participants was appointed to the position. She was also experienced in dealing with the many challenges faced in living and working in rural and remote Western Australia, including travelling across long distances, living in hot conditions and hurdling the logistical and cultural barriers to

conducting interviews with research participants who may be difficult to contact or unsure about taking part.

The characteristics of the twenty participants demonstrate the different patterns of HIV infection in Aboriginal people in Western Australia (see, for example: Wright *et al.* 2005, Newman *et al.* 2007). As a comparison with other people living with HIV/AIDS in Western Australia (Grierson and Misson 2002) or other Aboriginal and Torres Strait Islander people in Australia who are HIV-positive (Willis *et al.* 2002), this group was more likely to be young, female, heterosexual, in receipt of government welfare benefits and living in a rural area. Sixteen women and four men aged between 22 and 54 years took part in the research. Four lived in metropolitan areas and the rest in rural or regional parts of Western Australia. The high number of female participants may reflect the larger number of women in the rural cluster, the closer contact with health services of women compared with men and the use of a female interviewer.

All participants were in receipt of very limited income, with one working in a community employment scheme, one dependent on an employed partner and the remaining eighteen receiving a variety of government benefits, pensions or social security payments. All participants were literate and had attended high school to at least the end of the first year, while two had attended post-secondary college or TAFE courses and one was attending a degree course at university. Most named a specific Aboriginal linguistic or skin group affiliation, while three identified as Aboriginal only. Two of the men believed they had contracted HIV through male sexual contact and the rest of the participants reported heterosexual modes of transmission.

None of the participants reported any major illnesses resulting from HIV and most believed HIV had not made a great difference to their health apart from minor complaints, with depression and fatigue being the most common health problems. Participation bias may have influenced this finding, as it is likely that individuals who were unwell did not agree to be interviewed. All participants also had access to good quality HIV healthcare and there was a high level of satisfaction with the health services provided. This may be partly due to the large number of participants living in one particular rural area who had access to a psychosocial health service that is unique in Western Australia. This service provides ongoing health and medical care, support, counselling, transport, home assistance, advocacy, food vouchers, access to temporary accommodation, HIV-positive women's retreats and assistance with travel to other regions. However, most of the research participants live in conditions of poverty, with few opportunities for employment or increased income and often with personal or family histories of homelessness, alcoholism and mental illness. For many of the participants, HIV had led to a kind of 'normalisation' of lifestyle through the increased care and support of holistic and personalised health services.

While it is recognised there are two Indigenous populations in Australia—namely Aboriginal and Torres Strait Islander peoples—no Torres Strait Islander people were involved in this project. In addition, the Aboriginal members of the project Steering Committee and Reference Group advised that in some Aboriginal communities the phrase 'people living with HIV/AIDS' could be interpreted as including the carers and families of individuals infected with HIV. To avoid ambiguity, therefore, the phrase 'Aboriginal people who are HIV-positive' has been used wherever possible. The names of participants have been changed to protect their privacy and locations discussed in general terms so communities are not identified. As far as possible, participants were contacted to give them the opportunity to make changes or corrections to their stories.

Neoliberal discourse and health research

The Australian health system is shaped by a legacy of conceptualising Aboriginal subjectivity through the cultural logic of the colonisers (Smith 1999). In research contexts, as John Fielder *et al.* (2000: 353) have warned, ‘dealing with this legacy involves an intellectual struggle for both the researcher and the participant of the study’. Although the past decade has witnessed the ‘exploration of models of consultative, empowering and culturally sensitive research’ (Humphrey 2001: 201), there are enduring challenges in developing research methods as well as models of service delivery that are more inclusive of Aboriginal people. One of the key challenges lies in accommodating the many diverse cultural conceptions of health and subjectivity that may be valued and shared in Aboriginal communities. This may be increasingly challenging as health becomes progressively more shaped by neoliberal discourse. The following sections examine how Aboriginal research participants responded to those questions that were particularly reliant on neoliberal ideas, organised into reflexive, contextual and deflective responses.

Reflexive responses: Rationality and optimism

Several interview participants provided ‘reflexive’ responses to questions about coping, future and life changes. While they may not have done so deliberately, these participants articulated descriptive responses that were closely engaged with these concepts. This can be seen in an extract from the interview with Jayme, who had been living with HIV for nine years, had one child and had been in a relationship for several years. Despite other longstanding health problems unrelated to HIV, Jayme consistently represented her life story in the language of rationality and optimism:

‘What things helped you cope when you first knew?’

‘I just tried not to think about it a lot and just kept doing the normal thing like going to college, going back to school, work experience. I just didn’t really let it pull me down because it’s something I can’t change and something that’s not going to get better. So you either have to live with it or just let it pull you down altogether.’

‘Sounds like you’ve got a good philosophy then, eh?’

‘Well I had to think about it really carefully and what am I going to do? I don’t really want to let myself go downhill. I was just the same as I’ve always been but it was like I had a...I considered myself as a time bomb, you know. But I’m just trying, you know? I mean I wake up every morning ever since I found out I was positive, wake up every morning thinking, “Okay, I’ve got this day, I’m looking forward to it, see what it brings for me”.’

Jayme’s response can be interpreted as a reflexive narrative of the self, implying that her everyday experience of health and illness can be directly influenced by her frame of mind. In a study of how cancer patients talk about their illness experiences, Sue Wilkinson and Celia Kitzinger (2000: 809) argue that:

‘In describing how they “think positive”, the women in our focus groups are implicitly (sometimes explicitly) constructing themselves as not responsible for their illness. The claim to be thinking positively is made, in part, to protect themselves against accusations of complicity in the onset and progression of their cancer—of having brought their suffering upon themselves.’

Along these lines, Jayme’s response also represents her experience of illness as one that she can effectively self-manage with a positive mental attitude.

A second example is drawn from the interview with Nick, who identified as gay and had been living with HIV for around eight years. Nick had experienced continued fatigue and tiredness forcing him to give up work and making it difficult for him to socialise and complete university assignments on time. Nonetheless, Nick described himself as being 'more focused' and having a greater sense of purpose since diagnosis. Nick described the way that he coped with his HIV diagnosis as follows:

'The only time I really thought about it was in the mornings when I'd wake up. The first thought would be HIV on my mind straight away. But then I would push it to the back of my memory, my mind, and just get on with normal work...it was like information overload and it was like getting...'

'Took your mind off it?'

'Yes. Yes it was like this amount of information on HIV and everything else took my mind off being HIV-positive myself.'

Nick was one of the few research participants who had regular contact with an HIV/AIDS support and advocacy organisation, where he also provided volunteer peer support and public speaking services. This extract indicates that Nick believed it was important for him to reflect upon his own thought processes and to become equipped with the knowledge required to self-manage life with HIV. This is a highly individualistic narrative, arranging the world according to resources available to the 'responsibilised' (Kelly 2001: 23) subject.

Together, Nick and Jayme's responses demonstrate how some research participants make use of neoliberal discourse to show they are responsible, rational and able to cope with life changes and to make plans for the future with relative ease. But since these concepts were introduced by the researchers, we can also question whether the research process is itself at least partly complicit in the production of this discourse. It seems pertinent to consider whether — in the words of Damien Riggs (2005: 90) — a neoliberal reflexivity is here being 'researched because it is performed, or is it performed because it is researched?' Similar questions can be asked of the health service encounter, in which a clients' performance of 'coping' is more likely to achieve the desired response from the service.

Contextual responses: Self-care and family

Other research participants engaged with these interview questions quite differently, reworking the concepts to suit the context of their own life story. The first of these themed responses is here described as 'looking after yourself' and can be seen in the interview with Karina, who had been living with HIV for seven years at the time of interview. Karina acquired HIV from her former husband, who subsequently left her for another woman. Although she had not disclosed to anyone, others in her community guessed her status because her ex-husband's status was assumed. As a result, she kept to herself and tended to socialise only with close friends and family, including her children. In this interview, Karina interprets a question about 'the biggest change in your life' into one that focuses instead on 'the changes you have made to improve your health':

'In thinking over the whole experience of living with HIV, what has been the most important change that has taken place in your life?'

'I don't know.'

'What's the biggest change?'

‘Biggest change is that I stopped drinking for a while. I slowed right down.’

‘Why did you do that?’

‘Cause I’m looking after my self now.’

‘Looking after your health?’

‘Yeah. Everything else is the same. No big changes.’

‘Looking after yourself’ has become a familiar — although contested — theme of popular and public health cultures, complementing neoliberal imperatives for taking personal responsibility for health (Newman 2005). As Carlos Novas and Nikolas Rose (2000: 489) put it, ‘the patient is to become skilled, prudent and active, an ally of the doctor, a proto-professional — and to take their own share of the responsibility for getting themselves better’. Looking after yourself was a common theme in this project, with many participants describing a kind of ‘responsibilisation’ in the period after their HIV diagnosis. Some ceased or reduced alcohol and drug use, while others sought permanent accommodation after being intermittently homeless or began to actively seek out more nutritious food. In these narratives, HIV infection is conceived as a turning point in the ‘journey’ of taking greater responsibility for your health.

Contextual responses also evoke more collective models of care than just care for the self. One of the best examples can be seen in the theme of ‘strengthening family’. For example, Shona was a young mother who had been living with HIV for around five years at the time of interview. Her partner was employed but earning a minimum wage, and the whole family lived with relatives. Shona found it a relief to be able to talk to those close to her about her HIV: [note: the following extracts are not consecutive]

‘What things helped you cope when you first knew?’

‘Um, I think it was just helping my partner cope with it too, making him think that he is not the only one, he had been in denial. We just pulled through together, we supported one another.’

‘How have you changed how you think about the future because of HIV?’

‘Um, I haven’t changed a lot. No, I’m just looking forward to bringing my kids up now, yeah.’

‘In thinking over the whole experience you know of living with HIV what has been the most important change that has taken place in your life?’

‘Maybe, I think now that I am getting older, because I was like young, I am understanding more and not being scared or lonely, yeah and the kids keeping me well and calm and on my feet!’
(Laughs)

Similarly, Charlie also referred to family in her response to these questions. Charlie had been living with HIV for around nine years and believed that the most important change that HIV had made in her life was the strengthening of family, particularly her relationship with her eldest daughter. She explained that: ‘having my two daughters mainly...helped me to keep strong...in myself’. Both Shona and Charlie respond to questions about their personal experience of HIV by referring to the impact on family members: coping becomes helping others to cope, future involves caring for others and the notion of an individual life course is replaced with an image of the perpetual business of mothering. These responses indicate that HIV plays only a minor role in the everyday lives of many people living with HIV/AIDS, who may be more concerned with practical issues such as maintaining relationships, feeding and clothing children and so on. In this way, contextual responses can be seen to re-focus individual needs within the more complex and immediate environment of social and cultural context. Participants may not be consciously reworking the concepts but their responses point to more collectivist systems of meaning than those established by the initial research questions.

Deflective responses: Confusion and resistance

The final set of responses evident in these interviews are here described as deflective ‘non-answers’, because they indicate a confusion about, or resistance to the concepts of coping, future and life changes. This can be seen in the following example from the interview with Karina who, as mentioned previously, had been living with HIV for seven years at the time of interview and kept to herself after facing some discrimination from others in her community:

‘What things have helped you cope when you first knew you had HIV?’

‘I don’t know.’

‘Did you have anybody to talk to about it or to give you a bit of support?’

‘No. I kept it all inside myself. Didn’t tell nobody.’

Karina’s response — first a deflection, then a resistance to the examples provided — points to the uncomfortable fit between social context and what ‘coping’ is taken to mean in a health research or service delivery context. For Karina, what seems to be important is making sure HIV does not impact negatively on her day-to-day life. In Aboriginal community contexts, it may be particularly important to keep on with normal activities, because health is ‘performed’ by taking part in usual, everyday routines so as to not appear different or changed. This is quite different from health service contexts, in which ‘coping’ is usually understood as acknowledging illness and finding ways to deal with it in partnership with a range of health and social services.

Karina also deflected a question about whether HIV had changed the way she thought about her future, answering: ‘I don’t think too much about it’. Karina’s answer suggests she tries not to think about HIV at all if she can help it but also not to spend time worrying about her future. Karina may be avoiding a difficult subject but this may also indicate that the very concept of future does not ‘fit’ with Karina’s conception of what is important in her life. Several other participants provided similar answers to questions about the future. For example, Charlie offered a rich description of her life during the rest of her interview, except in relation to a question about her future:

‘Can you tell me how HIV has changed the way you think about the future?’

‘In some ways. I can’t explain it.’

‘You can’t explain it? Do you have any worries about the future or anything?’

‘No.’

Another example of this comes from Tanya, who had been living with HIV for six years at the time of interview, since she was a teenager. In the course of the interview, Tanya explained that she had stopped drinking and smoking cannabis, believing ‘the virus will be rising, so I don’t drink no more to protect my health’. Tanya had one child and was expecting another, and yet the concept of future did not figure in her explanations of why she no longer used alcohol or drugs or about her role as a mother:

‘Can you tell me how HIV has changed the way you think about the future?’

‘No difference. I don’t worry for it.’

Tanya’s response to a question about life changes also indicated her reluctance to articulate a vision of the ‘future’:

‘In thinking over the whole experience of living with HIV, what has been the most important change that has taken place in your life?’

'I don't know.'

'What's the biggest change?[Lengthy pause]

'It's still the same. All I can see is still the same.'

In relation to the concept of future, both Tanya and Charlie's explanations demonstrate how it is shaped by culture and context. For example, in a recent UK study, Julia Lawton (2002) observed great variation in how people of different ages 'imagine' their futures, with a particular difference between older and younger people. Louise Farnworth (2003: 120) has observed that 'in some Nations of Aboriginal people in Australia, such as traditional Wiradjuri, there is no word for time as an abstract concept...[and] a future time perspective may have no relevancy.'

There are also cultural differences in making sense of HIV in relation to present day conceptions of self. For many Aboriginal people, present day life is characterised by significant social and economic disadvantage, with limited access to income, employment and educational opportunities, information technology or permanent accommodation (ABS and AIHW 2005). While the interviews examined in this paper provided rich descriptions of the everyday challenges facing Aboriginal people who are HIV-positive, the concepts of coping, future and life change did not elicit these descriptions. This may be partly because neoliberal conceptions of the subject are too preoccupied with individual behaviour to represent these structural and contextual realities. In Tanya words, 'all I can see is still the same.'

New approaches to health research and service delivery

This paper has examined how participants responded to the concepts of coping, future and life changes: articulating reflexive, contextual or deflective responses. Taken at face value, each of these responses contributes to the overarching impression that 'everything is okay', as participants offer either highly optimistic or socially valued responses such as positive thinking or strengthening family, or avoid delving into difficult subjects altogether. Many of the participants in this research have been given access to psychosocial health services that would not otherwise be available to them but which means they benefit from better healthcare and more focused support than many other Aboriginal people. Indeed, for these participants, things may be pretty good, or even better, than before their diagnosis with HIV.

Given the means by which participants were recruited and the person-centred support that they had received following their HIV diagnosis, it is not surprising that many had adopted the language of self-management and responsibility which is typical of health service settings. In fact, welfare and holistic support are provided only to those participants who continue to engage with health services and fulfil their part of what can be conceived of as a transactional encounter. However, in terms of the language expressed in these interviews, the narrative of 'everything is okay' is also shaped by a variety of other factors: it is carried out against the backdrop of a highly stigmatised disease, associated with secrecy and shame, concerns about HIV transmission of infection and highly intimate behaviours.

This concluding discussion is intended to locate the main analysis in the context of wider debates about the socio-linguistic dynamics of the research interview and the historic and contemporary conditions that shape the public response to Aboriginal health. The aim is to consider some potential new approaches to both health research and service delivery that can be directed towards improving health outcomes for Aboriginal people.

Several factors may shape the narrative expression that ‘everything is okay’ in an interview context. The research participant may wish to legitimate their position to the interviewer; to demonstrate that they have a right to speak and to be heard. The speaker may want to avoid appearing as ‘a potential malingerer, or even a habitual complainer’ (Radley and Billig 1996: 226). This is particularly important in neoliberal discourse, where the moral distinction between good and bad health behaviours produces what Rose Galvin (2002: 108–109) has described as: ‘A new culture of victim blaming [in which]...chronic illness is increasingly viewed as culpability in the face of known risks, an instance of moral failure’. Wanting to resist the sick role may also be influenced by the ‘shame’ (Morgan *et al.* 1997) associated with HIV in both Aboriginal and non-Aboriginal contexts.

In addition, there may be a cultural preference for ‘indirect’ communication in some Aboriginal communities. Alan Cass *et al.* (2002: 468) observed in a study of communication between Yolngu language patients and English language healthcare workers that ‘it is generally considered impolite to directly contradict or to respond negatively, particularly in encounters of unequal power’. Diana Eades (1994: 105) has also suggested that, for many Aboriginal people, when ‘their views on a topic [are found] to be at odds with others in a conversation, they will tend to understate their own’. As Cass *et al.* found (2002: 468) Aboriginal people may simply give the responses they believe researchers want to hear. Strategies such as positive thinking may be expressed, therefore, so that, as Wilkinson and Kitzinger (2000: 805) have observed, ‘the speaker can bring her troubles talk to an “upbeat” end, relieving her listeners of a potential conversational burden’. These factors are also likely to contribute in a much wider sense to the reproduction of neoliberal concepts such as coping and future in both health services and health research and to their increasingly normative presence in those contexts.

This paper has suggested that neoliberal discourse is not necessarily effective in representing the complexity of Aboriginal experiences of health and illness (Maher 1999). This is likely to be true of many other social and cultural contexts also, beyond Aboriginal health. For example, Barry Adam (2005: 344) observed the following in a study with gay and bisexual men in Toronto:

‘The neoliberal view constructs human actors as rational, adult, contract-making individuals in a free market of options. It does not account for the much more complex motivators and vulnerabilities that characterize real human interaction and it denies the vulnerabilities, emotions and tough dilemmas faced by people in their everyday lives.’

The stories from this project remind us that, as Stephen Buetow and Ngairé Kerse (2001: 77) have argued, ‘health and ill-health are not binary opposites. They describe our ability as individuals to function in our own environment by developing physical, psychological, social and spiritual resources for living’. Aboriginal people — like most people — may be simply more interested in finding ways to live a well life than in dwelling on stories of illness. The narrative of ‘everything is okay’ is a testimony to the resilience of Aboriginal people in developing resources for living with HIV as just one of a multitude of daily challenges. Thus, it is critical that the design of both research methods and service delivery reflect the everyday experiences of Aboriginal people so that they can, in the words of Julia Lawton (2002: 729), ‘tap into an existing corpus of meaning’. Each arm of the response to Aboriginal health inequities can benefit from a better recognition of how language and culture interact in research and service delivery contexts, including the medical consultation (Cass *et al.* 2002).

It is not an easy task, however, to design research methods, models of service delivery and medical consultation guidelines that can support the development of ‘resources for living’ without privileging neoliberal discourse. In the context of health research, methods can be developed that are more focused on the immediate present tense and the more collective contexts of everyday life. Following Diana Eades’ (1994: 113) description of the social and cultural context of Aboriginal people in southeast Queensland, this may include a recognition of ‘the importance of responsibilities to kin, the priority of social relationships, and the need for indirectness in interactions’. In the context of health services, there is also potential to develop new models of service provision and intervention. One of the findings of this research project was that participants who had access to a holistic psychosocial approach to health service delivery were better supported. Their individual health needs were being addressed in relation to everyday social and contextual issues such as housing, transport, income, mental health, legal advice, familial relationships and so on. However, making use of this kind of service nonetheless still requires participants to engage with the language and culture of that service, which is inevitably shaped by neoliberal discourse, as suggested in this paper.

These new approaches to health research and service delivery continue to face significant challenges in accommodating divergent models of health and subjectivity. Some of the immediate issues faced in a service delivery context include how to negotiate the limits of care and support in the context of extensive family and kinship networks. How can a holistic health service provide effective care for the ‘whole’ person without also caring for the other people embedded within those networks? How can privacy and confidentiality be maintained while embracing those kinship networks? How best can we understand and explore the role of shame in relation to HIV and sexual health while building trust in the open flow of communication between clients and their health and other support service providers? And how can we care for the whole person in the context of the broader organisation of healthcare within regulated appointment systems and separate health specialisations?

Conclusion

This paper has explored some of the challenges and tensions associated with the expression of neoliberal conceptions of health and subjectivity in a research project on Aboriginal experiences of HIV in Western Australia. While innovative health services have been developed to accommodate more holistic approaches to care in the context of Aboriginal health, both service delivery and research methodology are increasingly shaped by neoliberal discourse. Although interpersonal communication is often fraught with misunderstanding, this analysis suggests that concepts such as ‘coping’, ‘future’ and ‘life change’ may be particularly problematic in the context of HIV and Aboriginal health. Therefore, it is vital to focus a critical lens on the ways in which health research is conducted, and how this may relate to the development of new models for service delivery. While this paper has been focused on the particular stories of the twenty people interviewed for this project, these also contribute to ways of conceptualising the relationship between language, subjectivity and health in other contexts.

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