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Title:

Expert perspectives on the contribution of HIV general practice nursing to the 'extraordinary story' of HIV medicine in Australia

Running title:

HIV general practice nursing

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Abstract:

Aim: This paper explores cultural and professional dynamics of HIV general practice nursing in Australia. It highlights specific contributions that HIV general practice nurses make to HIV medicine and considers how nurses' clinical practice has been shaped by past experiences of the AIDS crisis and subsequent developments in HIV medicine. **Background:** In international contexts, nurses in HIV medicine commonly work as part of shared-care teams. In recent years, HIV general practice nursing has become a prioritised area for primary health care in Australia. **Methods:** Data for this analysis were drawn from 45 in-depth, semi-structured interviews conducted with nurses and general practitioners (GPs) who provide HIV care in general practice, and key informants who work in policy, advocacy or education and training of the HIV general practice workforce. **Findings:** Viewed through a socio-ecological framework of social capital, descriptive content analysis highlights a unique and strong HIV health professional identity, which emerged out of the adverse conditions experienced by nurses, GPs and allied health professionals during the 1980s AIDS crisis. Participants reported that today, HIV general practice nursing includes information provision, HIV treatment side-effect management, teaching patients methods to increase adherence to HIV treatments and capacity building with allied health professionals. Participants reported that HIV general practice nurses can reduce the clinical burden on GPs, ameliorate patients' exposure to HIV health care-related stigma and discrimination and facilitate the emergence of a comprehensive and personalised model of shared primary health care based on trust and rapport, which is desired by people with HIV. This study's findings support the future expansion of the role of HIV general practice nurses in Australia and internationally. General practice nursing will become increasingly important in the scaling up of HIV testing and in caring for increasing numbers of people living with HIV.

Key words: nursing; culture of HIV medicine; general practice; medical professions; primary health care; Australia

Introduction

In recent years, shared-care models that enable people living with HIV to access care in a diverse range of community settings have become increasingly prioritised in Australia. One such model is that of the medical practitioner who provides care to people living with HIV in private 'general practice' settings (Newman et al., 2012). This model includes general practitioners (GPs) who are specially trained and accredited to prescribe HIV medications and GPs who share patients' HIV treatment and care with other specialist clinicians. Nurses have been a part of the general practice approach to HIV treatment and care since the beginning of the HIV/AIDS epidemic. While there is much debate about the most viable and accessible way to facilitate shared-care arrangements, the role of the nursing workforce in contributing to the general practice HIV care team has received less attention.

In international contexts, the roles of HIV general practice nurse, nurse practitioner, physician assistant and community-based nurse have contributed to high levels of patient satisfaction and favourable patient health outcomes (Hekkink et al., 2005; Wilson et al., 2005; Valenti, 2006; Vervoort et al., 2010; Fairall et al., 2012). Nurses and allied health professionals are perceived to support the achievement of comprehensive and co-ordinated primary health care for people living with HIV, including the management of HIV treatment regimens (Savage et al., 2009). While there are significant risks associated with any fragmentation of care (Kidd et al., 2006), particularly with a condition as clinically complex as HIV infection, a shared-care model of HIV treatment and care in general practice is generally viewed as an effective response to HIV clinical needs (Van Der Weyden, 2008).

In Australia, research has begun to explore the workforce issues around providing HIV treatment and care in general practice settings (Newman et al., 2011; Newman et al., 2012). Included as part of this research was an examination of the roles and contributions of HIV general practice nursing. The HIV general practice nursing workforce in Australia usually comprises experienced generalist nurses who have an interest in HIV medicine and nurse

specialists, typically a registered nurse who has completed special courses in HIV medicine and undergone on the job training (Savage et al., 2009). Nurses work with general practitioners who are accredited to prescribe HIV medications in private practice, providing a range of services to support a GP's care plan. These nursing professionals are distinct from nurse practitioners who are registered nurses with post-graduate qualifications that enable them to perform additional clinical duties (Savage et al., 2009). Unlike some countries in Europe and North America, Australia is still debating the costs and benefits of a widespread roll-out of nurse practitioners (Van Der Weyden, 2008).

Despite the rich, complex and diverse roles that nurses continue to play in HIV care in community settings, little attention has been paid in research to the culture of HIV nursing and the contribution nurses have made to HIV medicine, both in Australia and internationally. The present analysis aimed to explore the cultural and professional dynamics of HIV general practice nursing, and to consider how nurses' clinical practice has been shaped by past experiences of the AIDS crisis and subsequent developments in HIV medicine. The analysis sought to highlight the major issues affecting HIV general practice nurses in Australia, and the specific contributions that these nurses continue to make to HIV medicine by drawing on a wide range of health and policy professionals' perspectives. The findings of this analysis can inform health policy relating to comparable primary health care settings in international contexts where nurses contribute to HIV treatment and care.

Method

The HIV General Practice Workforce Project was a three-year study funded by the Australian Government's National Health and Medical Research Council to explore barriers and incentives to pursuing training and accreditation for Australian GPs to prescribe HIV medications. Ethics approvals were received from the National Research and Evaluation Ethics Committee of the Royal Australian College of General Practitioners and the Human Research Ethics Committees of participating universities.

For a detailed account of the study's method, please refer to Newman and colleagues (2011). In brief, a total of 71 participants ranging from 32 to 69 years of age with almost half aged in their fifties were interviewed for this study. Not all participants discussed HIV nursing, so the analysis presented in this paper draws upon a sub-set of these data in which HIV nursing was explored. These data comprised 45 in-depth, semi-structured interviews with GPs who are accredited to prescribe HIV medications (n=18), GPs who have ceased prescribing (n=3), GPs who provide other (non-prescribing) forms of HIV care (n=5), key informants (KIs) working in policy, advocacy or education/training of the HIV general practice workforce (n=16), and nurses who provide HIV care in general practice (n=3). While only three general practice nurses participated in this study, all 45 participants commented on nursing in HIV primary health care during interviews. All participants either previously or currently worked in health policy or HIV primary health care settings in Australia.

For this paper, a descriptive content analysis centred on identifying and categorising interview content regarding HIV general practice nursing. Our analysis was able to examine a broad range of viewpoints on HIV general practice nursing in Australia. The analytical process was informed by best practice guidelines for content analysis in qualitative research (Minichiello et al., 2000). Analysis involved recognising recurring words, concepts and sentences in the data, counting their frequency and categorising similar conceptual content across the whole data set. Data were analysed for both their manifest and latent content; interpretation of the data was informed by the symbolism underlying the words, concepts and sentences articulated by interviewees as well as the semantic content of their narratives. The manuscript was then workshopped by the writing team, drawing on the areas of expertise of each author. Rigour was established through an iterative process of discussion and revision, both within the writing team and in consultation with members of the study's expert advisory committee including representatives of Australia's peak HIV and general practice organisations. All interview extracts have been reproduced with a code to protect participant confidentiality. The following content analysis examines both the culture of HIV general practice nursing and the contribution that nursing continues to make to HIV medicine in general practice in Australia, as perceived by a broad range of experts.

Findings

1. The early HIV nursing workforce: forging professional identity through adversity

Data about the early years of the HIV nursing workforce are important to present because currently the social history of health professionals during the early AIDS epidemic is largely invisible in the HIV literature despite this period foreshadowing developments in the HIV-related workforce. In this study, HIV nurses' narratives articulated the difficulties health professionals experienced in caring for highly stigmatised patients, with previously unseen illnesses, and the impact these difficult experiences had in forging a professional identity and building links with researchers, policy-makers and the affected community. To begin exploring the cultural and professional dynamics underpinning HIV general practice nursing, the three nurses interviewed for this study were asked to comment on what originally attracted them to the care of people living with HIV. Each said they had identified a growing demand for nurses in the early years of the HIV/AIDS epidemic, which included the promise of significant career opportunities. They were curious about what it might be like to work in the emerging field of HIV medicine and all were concerned about the palpable unease demonstrated by many health professionals in relation to treating people with AIDS.

I came into nursing because I wanted ... it sounds really idealistic doesn't it ... I wanted to make a difference. And not, you know, not in a 'Florence' sense but in the reality of the basic nursing premise that people need care because [HIV] is something they cannot manage for themselves. (Nurse 1)

I got involved in [HIV] as a nurse [because] I saw an advert saying, "We're looking for somebody who is willing to ... look after patients with AIDS." And, of course, the implication was that there were loads of people who weren't willing ... So I applied and, not surprisingly, I got the job quite easily because I don't think many people actually went forward! (Nurse 2)

A third nurse interviewed for this study was offered an opportunity to work with HIV patients in general practice after being involved in HIV clinical trials. Although the nurses in this study had worked with HIV patients in a variety of settings including hospitals, home care, education, and general practice, in Australia involvement in clinical trials is one common pathway into HIV general practice nursing. All nurses characterised their peers in HIV medicine during the earlier stages of the HIV/AIDS epidemic as being imbued with a strong sense of common purpose; they were responding to an immediate public health crisis, which affected an already marginalised population of gay men, who because of misinformation, prejudice and fear of contagion, often died a solitary death.

... [A]nd it wasn't just the dying, it was the way that people died was so often out of control and so difficult ... [t]he patients were struggling to breathe with diseases, they had skin infections, they had, you know, relentless diarrhoea, they were going blind ... for the nurses it was really, really difficult. (Nurse 2)

During interviews, HIV general practice nurses, GPs and key informants independently gave a socio-historical account of the development of a unique and strong HIV health professional identity, which they believed had emerged out of the adverse conditions endured by nurses, GPs and allied health professionals during the 1980s. Their independent accounts were strikingly similar. Participants reported that, in part, nurses and GPs shared their patients' marginalised status; they were at times ostracised by other health professionals who did not wish to be associated with the HIV affected population, their stigmatised practices and disease. This burgeoning sense of a common professional identity led over time to HIV health professionals forming strong bonds. These bonds were formed between nurses, as well as with workers from other HIV-related health care disciplines. Bonds were cemented by learning about HIV medicine on the job, mentoring newer nurses, teaching each other recently acquired skills, and coping with a constant loss of patients throughout the most medically challenging and emotionally confronting public health crisis of the twentieth century. These bonds continued to be acknowledged and celebrated in the accounts of participants today.

... [I]t was like a war. You know, it was like that sort of crisis: you're just in crisis mode all the time. You'd be out every night looking after sick patients. You'd be getting phone calls all night. You'd spend all day trying to get people into hospital, driving people to hospital yourself. Doing home visits in the daytime. We had ... a very small core of nursing support from the community nursing organisations ... and that made a huge help. Like there was like a little band of doctors and nurses, and volunteers ... it was like you just were on the go all the time and, you know, that went on for a number of years. (GP 29)

For many years I worked with the same colleague ... In fact, we were together for fourteen years. We were very close, still are good friends, but we were a great support for one another ... that grief and loss was a big part of our work. So there was a lot of acknowledgment around that, which in one sense helped. (Nurse 1)

GPs and nurses who were employed in HIV care worked collaboratively and collegially throughout this period to address a spectrum of conditions, some of which were previously unseen by clinicians. The nurses interviewed for this study had witnessed significant developments in HIV medicine during their relatively short careers, and their narratives evoked a sense of awe about the immensity and the implications of these changes for health professionals and affected communities.

It's an extraordinary story, I think, the medicine of HIV. Really extraordinary.

(Nurse 2)

From the early years of the HIV/AIDS epidemic grew a common sense of professional purpose shared by nurses and allied HIV health professionals. Some thirty years later,

participants acknowledged that the early years were important to the evolution of HIV general practice nursing and shared-care in HIV medicine today.

2. HIV nursing in general practice today: the benefits of investing in a practice nurse

The role of HIV general practice nursing today was described by participants in this study as emotionally less confronting and clinically less challenging than prior to the advent of antiretroviral therapy, which turned the tide of AIDS-related mortality during the mid to late 1990s. It was reported that in contrast to earlier times, HIV general practice nursing today requires a clinical skill set that is much more explicitly orientated toward chronic disease management. Participants said that HIV general practice nursing today is mostly concerned with the management of treatment-related tasks, which are prescribed by a GP, as well as information provision and the management of patients' psychological and psychosexual wellbeing.

When asked to elaborate on the specific contributions that nurses make to general practice, participants reported that HIV general practice nurses: provide information to HIV patients; assist patients who experience side-effects from antiretroviral therapy; teach methods to increase adherence to treatment; mentor newer HIV general practice nurses; and participate in capacity building with allied health professionals. Nurses in HIV general practice also performed blood tests, wound care and vaccinations. General practice nurses were described by participants as particularly effective in managing 'challenging' patients, and as being well placed to provide home visits and follow-up for HIV-positive patients with more complex needs. General practice nurses also acted as a 'checks and balances' memory back-up for some GPs.

... [T]here's times when I will remind the doctor that this [test] hasn't been done for three months and maybe we ought to do an annual fasting lipids and glucose because of the antiretrovirals that [a patient] is on. And they might sort of say, "Let's

wait for another three months.” That’s fine. I’ve brought it to their attention. (Nurse 3)

Former-HIV GP prescribers and key informants reported that general practice nurses were viewed by some younger patients as less ‘scary’ than GPs and that a nurse’s presence in general practice could help to break down barriers in medical consultations. It was implied that younger patients were often less experienced in negotiating medical contexts and may feel more at ease with a nurse than with a GP. Similarly, former-HIV GP prescribers and key informants reported that because general practice nurses can reduce some of the clinical demands on GPs, they are becoming quite critical in HIV medicine and GPs typically want to be able to fund nursing roles in their practices. All participants agreed that HIV general practice nurses can offer GPs an opportunity to provide a ‘linked-up’ or comprehensive HIV primary health care service.

[H]aving a nurse I think adds a lot to providing a service ... It’s a much more holistic service ... They have time basically ... And bring up issues or advocate for patients that [patients] may not feel comfortable talking to a doctor about. I think ... sometimes people say the right things to doctors. They want to [say] what doctors want to hear! [laughter] So, I think [practice nurses] add another ... layer of comprehensiveness. (GP 15)

Participants reported that while GPs are viewed in Australia as the central point of coordination of HIV care, general practice nurses, and possibly nurse practitioners, have the potential to redefine HIV primary health care in the future, making GPs less central. Key informants in particular felt that when looking to the future, innovation would be essential in redefining models of HIV care.

Given all our difficulties with the health workforce, I think we need to look at ways of trying to provide non-traditional ways of providing services. And I actually think that having a team approach and getting GPs to delegate some of the things that they've done traditionally, is a really good idea. (KI 7)

So the more complex HIV cases, definitely, should be managed by a doctor, but I very much think that nurse practitioners should be carrying a patient load of their own, very much in concert with a GP. And ... to me that's a good part solution to the workforce issue around GPs. (KI 8)

Participants in this study unanimously supported an increased use of general practice nurses in HIV medicine and several participants also supported the idea of nurse-led models of HIV treatment and care that have been trialled in pilot programmes in some Australian states (Van Der Weyden, 2008). Only two participants were resistant to nurse-led models, based on their concern that quality of care might be compromised. One GP and a key informant implied that the difference in training that GPs and nurses traditionally receive would result in a poorer standard of care for HIV patients if they were exclusively cared for by nurses.

I don't favour a, in Australia, a nurse practitioner model for HIV ... I do favour responsibilities being given to nurses ... [however] I wouldn't want to see nurse practitioners prescribing drugs and things like that ... I'm probably happy to see that in developing countries because there aren't a lot of other choices. But I don't see why we would be lowering our standards to do that here. (KI 20)

I think there will always be division between doctors and nurses in the same way that males and females are different. And yet if they work together, the minds of both of them can come up with greater solutions. (GP 3)

Participants were also concerned about the impact of structural changes in general practice on people living with HIV. This includes the emergence of large, de-personalised mainstream primary health care clinics. Compared with treatment and care in HIV general practice, participants believed that HIV-positive patients in mainstream general practice settings were more likely to be triaged by a GP and treated by a nurse who may have little or no knowledge of and experience in HIV medicine. Participants felt that a primary health care setting with a low HIV-caseload might provide a poorer standard of care.

So we're very positive about general practices but [what] we're not positive about is the system in which they're having to operate. And ... the idea of these sort of mega clinics or corporate owned medical centres, as well as super clinics, we just think is going in a really bad direction. (KI 19)

Over a relatively short time-frame, HIV infection has gone from acute care to chronic disease management, which is creating new opportunities for HIV health professionals such as nurses. One dynamic that has changed very little over the decades however is HIV-related stigma and discrimination in health care.

3. The social benefits of HIV general practice nursing: building trust, reducing stigma

These data explicitly and implicitly highlight the benefits of HIV general practice nursing for inculcating trust and building rapport between people with HIV and clinicians. Trust in the clinical expertise of medical staff and rapport with nurses and GPs are important to people living with HIV, not least because of the medical complexity associated with HIV regimens and the potential high cost to a patient of getting this management wrong. While this study did not interview people living with HIV, our participants believed that patients valued highly the close ties they developed with nurses and GPs in general practice settings. Participants said that patients accepted shared-care within general practice if patients knew and trusted all of the health professionals involved. On the other hand, sharing care in less

personalised tertiary health care environments and large mainstream practices was seen as problematic because of the perceived difficulty in building trust within therapeutic relationships.

And I think part of the challenge ... [is that] generally people with HIV ... historically have a very high level of trust for their GP and often quite a solid relationship with their GP, and would only go to that GP for anything ... (KI 8)

I think HIV-positive people, because they experience the health system much more intensively, start to see some effects from [a trend toward large general practices] ... the [HIV] positive population's sometimes ... is very reticent to go down that [path]. Because as I said, a lot of people don't want more people to deal with, they want less. (KI 22)

Underpinning the issue of trust in therapeutic relationships were participants' concerns about HIV-related stigma and discrimination. More than thirty years after the first cases of AIDS, participants believed that HIV remained a highly stigmatised condition and that patients were still vulnerable to discrimination from health professionals in a variety of health settings.

I think the issue that's probably still out there is still around stigma. It's still around how people treat gay men ... [A]s much as I'd like to say all doctors and nurses will deal with people from the gay community or transsexuals without a problem, I don't believe that is yet true, sadly. (Nurse 2)

[S]ay "HIV" and usually the first question [people ask is] "How did you get it?" And then the blame game starts or, you know, unspoken look. (Nurse 1)

Throughout the study, participants readily described what they perceived to be the persistence and ubiquity of HIV-related stigma, their patients' experiences of HIV-related discrimination, as well as their own experiences of being stigmatised by colleagues in health care. An account, below, from a GP exemplified the experiential-chasm and uneasy dynamics that can arise between people living with HIV and health professionals during a routine consultation in mainstream health care environments.

I had one guy who went to see a gastroenterologist because he's having problems with faecal incontinence. And the gastroenterologist was aghast that he'd had anal intercourse ... he couldn't handle it, and he had to leave the consultation because ... this is a gastroenterologist, for God's sake! ... And it was a gastroenterologist that I'd used previously ... and to find out what he was actually like was quite horrifying, that I'd sent other people to him. So yeah, there is still a lot of prejudice out there amongst doctors. Nurses as well. I don't know that I can quantify who's worse but they're both bad. (GP 16)

Participants reported that the model of shared-care for managing HIV in general practice settings reduced the likelihood that patients would be exposed to HIV-related stigma and discrimination. They did not suggest that the HIV general practice nursing workforce is somehow immune from holding prejudiced beliefs and attitudes, but nurses were viewed as making an additional and welcome contribution to the general practice team, which helped to create an environment that could facilitate inclusiveness and trust.

I just think that if you're dealing with a disease that still is marginalised, you don't want to be feeling that when you go to the doctor, from anybody in the clinic. It needs to feel like a place where all comers are welcome and yeah [at our practice], all comers are welcome. (GP 24)

Discussion

All participants in this study agreed that nurses in HIV general practice make a substantive contribution to the management and co-ordination of HIV care in the community. The present analysis shows how HIV general practice nurses are well situated to build links to community services and organisations, ameliorate patients' exposure to HIV-related stigma, enculturate and mentor newer nurses into the HIV workforce and act as a clinical 'back-up' for GPs. HIV general practice nurses in this study were said to reduce the clinical burden on GPs and to facilitate the emergence of a comprehensive and personalised model of shared-care, which is desired by people living with HIV. The content areas described in the findings point to the substantial progress made in HIV medicine over the last thirty years. As well, these data implicitly and explicitly highlight the HIV nursing workforce's adaptation despite adversity, the importance of trust and rapport in therapeutic relationships, and the impact of HIV-related stigma on the experience of HIV treatment and care.

The study findings closely align with previous international and Australian research into nursing in multidisciplinary teams of HIV health professionals (e.g., Crock and Butwilowsky, 2006; Valenti, 2006; Phillips et al., 2009). In particular, the findings are consistent with the six roles of (non-HIV related) general practice nurses in Australia identified by Phillips and colleagues (2009). In their study, the role of general practice nurses included patient care, organising, problem solving, quality control, educating patients and connecting patients with allied health professionals and other practice staff. While much of the earlier literature is from the United States where HIV nurse practitioners and physician assistants are common, all models of HIV nursing in community-based medical practice were described as beneficial for HIV patients and their doctors (Wilson et al., 2005).

One of this analysis' main findings regarded bonding amongst nurses, and between nurses and health professionals, in the HIV workforce. A socio-ecological concept of social capital explains the development of strong bonds and linkages between people who work in health

care organisations (Hofmeyer and Marck, 2008) such as the HIV workforce, which for many years functioned in a permanent state of crisis. Bonding social capital was expressed in nurses' accounts of a shared identity, affiliation and solidarity that developed from wanting to make a difference, dealing with the 'difficult' early years of AIDS, learning HIV medicine on the job, of coping with dying patients, and the watershed moment of antiretroviral therapy. These shared experiences fostered a common professional identity, solidarity and trust in the values, beliefs and work practice of other nurses in HIV, as well as with allied health professionals. As several participants highlighted HIV general practice nurses have also played an important role in linking people and organisations across the entire HIV health, advocacy, research, and community service sectors. Bonding also acknowledges the shared risks and vulnerabilities experienced by the HIV workforce, such as marginalisation by non-HIV health professionals and the phenomenon of 'burn-out' among HIV health workers (Saag, 2006). These findings indicate that bonding social capital underpins the evolution of the HIV workforce in Australia; it has been a potent force for building and maintaining professional unity and identification, and it is the cement that continues to bind many HIV-related health professionals together.

Another finding of this analysis pertained to the importance of trust and rapport in HIV-related therapeutic relationships. At the semantic level, these data highlight participants' overwhelmingly positive views of HIV general practice nursing. Underpinning participants' reticence regarding shared-care in hospitals and large mainstream general practices is an implicit acknowledgement of the important role of trust in HIV patient-practitioner relationships. This trust is broadly defined as the expectation that health professionals will act in ways to protect their patients' best interests (Graham et al., 2010). In an Australian context, little research has examined the issue of trust between HIV patients and health professionals. However a recent US literature review of HIV patient-provider trust found that greater trust in HIV health professionals is associated with a greater access to care and an increased likelihood of people with HIV remaining in care (Graham et al., 2010). Participants in this current study also reported that exposure to stigma and discrimination in health care is reduced when HIV patients can access treatment and care in general practice settings because trusting therapeutic relationships are more able to develop in the often

smaller, more intimate and specialised environment of general practice. Increasing the profile of the HIV general practice nursing workforce might be a particularly effective way of challenging HIV-related stigma because HIV general practice nurses can enhance a culture of participation and inclusion in HIV medicine.

A descriptive content analysis was employed in this study. While there are limitations inherent to all analytical approaches, such as researcher bias, care was taken throughout analysis to remain consistent with the intent of the situated accounts of phenomena presented by participants. Further, while the number of nurses in the sample was small, the validity of the analysis was strengthened by inclusion of a broad variety of HIV health professionals' perspectives on HIV general practice nursing. Nonetheless, the findings may not be fully generalizable to other HIV general practice nursing contexts. Our study did not explore in detail future potential roles for HIV nurses in general practice, and we acknowledge that a sample of younger nurses schooled in a more interdisciplinary paradigm might express different views to those of our mostly middle-aged participants.

We recognise that resources are needed to fund the role of HIV nurses in general practice settings, and as earlier research has cautioned (Kidd et al., 2006) the long-term cost-effectiveness of general practice nursing remains unclear. Funding is complex and important and 'requires unique approaches to planning, financial support and investment' (Kidd et al, 2006: 21). Recently in Australia, the Practice Nurse Incentive Programme (PNIP) was introduced to improve GPs' capacity to fund nursing in private practice and early indications are the programme is having a positive impact (Eccles, 2012). As HIV treatments have become increasingly central to the clinical management as well as *prevention* of HIV (i.e., HIV treatment-as-prevention) (e.g., Garnett et al., 2012; Kippax and Stephenson, 2012), the role of the general practice nurse will become increasingly important in both enabling a scaling up of HIV testing and for supporting the care of increasing numbers of people with HIV around the world.

While further studies are needed to critically evaluate different models of HIV nursing in general practice and other primary care settings, the findings of this analysis acknowledge nurses' important contribution to managing the increasing complexity of HIV health care, such as bridging general practice with affected communities and in circumventing HIV-related stigma. These findings support the future expansion of the role of HIV general practice nurses in Australia and internationally.

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References

Crock, E., and Butwilowsky, J. (2006). The HIV resource nurse role at the Royal District Nursing Service (Melbourne): Making a difference for people living with HIV/AIDS in the community. *Australian Journal of Primary Health*, 12, 83-89.

De Moor, K. (2003). The doctor's role of witness and companion: Medical and literary ethics of care in AIDS physicians' memoirs. *Literature and Medicine*, 22, 208-229.

Diedrich, L. (2005). AIDS and its treatments: Two doctors' narratives of healing, desire, and belonging. *Journal of Medical Humanities*, 26, 237-257.

Eccles, K. (2012). PNIP brings success to general practices. Medical Observer, St Leonards: UBM Medica. Article accessed August 16, available at:
<http://www.medicalobserver.com.au/news/pnip-brings-success-to-general-practices>

Fairall, L., Bachmann, M. O., Lombard, C., Timmerman, V., Uebel, K., Zwarenstein, M., Boule, A., Georgeu, D., Colvin, C. J., Lewin, S., Faris, G., Cornick, R., Draper, B., Tshabalala, M., Kotze, E., van Vuuren, C., Steyn, D., Chapman, R., and Batemena, E. (2012). Task shifting of antiretroviral treatment from doctors to primary-care nurses in South Africa (STRETCH): A pragmatic, parallel, cluster-randomised trial. *The Lancet*, DOI: 10.1016/S0140-6736(12)60730-2

Garnett, G., Becker, S. and Bertozzi, S. (2012) Treatment as prevention: Translating efficacy trial results to population effectiveness. *Current Opinions in HIV and AIDS*, 7, 157-163.

Graham, J. L., Giordano, T. P., Grimes, R. M., Slomka, J., Ross, M., and Hwanf, L. (2010). Influence of trust on HIV diagnosis and care practices: A literature review. *Journal of the International Association of Physicians in AIDS Care*, 9, 346-352.

Hekkink, C. F., Wigersma, L., Yzermans, C. J., and Bindels, P. J. E. (2005). HIV nursing consultants: Patients' preferences and experiences about the quality of care. *Journal of Clinical Nursing*, 14, 327-333.

Hofmeyer, A., and Marck, P. B. (2008). Building social capital in healthcare organizations: Thinking ecologically for safer care. *Nursing Outlook*, 56, 145-151.

Kidd, M. R., Watts, I. T., Mitchell, C. D., Hudson, L. G., Wenck, B. C., and Cole, N. J. (2006). Priniciples for supporting task substitution in Australian general practice. *Medical Journal of Australia*, 185(1), 20-22.

Kippax, S., and Stephenson, N. (2012) Beyond the distinction: Between biomedical and social dimensions of HIV: prevention through the lens of a social public health. *American Journal of Public Health*, 102, 789-799.

Minichiello, V., Aroni, R., Timewell, E., and Alexander, L. (2000). *In-depth interviewing: Principles, techniques, analysis [2nd edition]*. Longman: Sydney, Australia.

Newman, C. E., de Wit, J. B. F., Kippax, S. C., Reynolds, R. H., Canavan, P. G., and Kidd, M. R. (2012). The role of the general practitioner in the Australian approach to HIV care: interviews with 'key informants' from government, non-government and professional organisations. *Sexually Transmitted Infections*, 88, 132-135.

Newman, C. E., Kidd, M. R., de Wit, J. B., Reynolds, R. H., Canavan, P. G., and Kippax, S. C. (2011). What moves a family doctor to specialise in HIV? Interviews with Australian policy key informants. *Culture, Health and Sexuality*, 13, 1151-1164.

Phillips, C. B., Pearce, C., Hall, S., Kljakovic, M., Sibbald, B., Dwan, K., Porritt, J., and Yates, R. (2009). Enhancing care, improving quality: The six roles of the general practice nurse. *Medical Journal of Australia*, 191, 92-97.

Saag, M. S. (2006). Burn-out among HIV care providers. *AIDS Patient Care and STDs*, 20, 385-390.

Savage, J., Crooks, L., and McLean, S. (2009). *Models of Access and Clinical Service Delivery for People with HIV in Australia: final report*. Australasian Society for HIV Medicine. Sydney, NSW.

Available at: http://www.ashm.org.au/default2.asp?active_page_id=168

Valenti, W. M. (2006). Providing quality HIV care: Role of nurse practitioners and physician assistants. *The AIDS Reader*, 16, 236-238.

Vervoort, S. C. J. M., Dijkstra, B. M., Hazelzet, E. E. B., Grypdonck, M. H. F., Hoepelman, A. I. M., and Borleffs, J. C. C. (2010). The role of HIV nursing consultants in the care of HIV-infected patients in Dutch hospital outpatient clinics. *Patient Education and Counseling*, 80, 180-184.

Van Der Weyden, M. B. (2008). Doctor displacement: A political agenda or a health care imperative? *Medical Journal of Australia*, 189, 608-609.

Wilson, I. B., Landon, B. E., Hirschhorn, L. R., McInnes, K., Ding, L., Marsden, P. V., and Cleary, P. D. (2005). Quality of HIV care provided by nurse practitioners, physician assistants, and physicians. *Annals of Internal Medicine*, 143, 729-736.