



HIV Complex Care and Ageing in NSW

February 2013

HIV Complex Care and Ageing Health Care Forum

HIV Complex Care and Ageing Forum Terms of Reference:

The South Eastern Sydney Local Health District and ASHM are working in partnership to bring together a range of key informants to explore how both the private and public health sectors can most effectively respond to the care and treatment needs of an ageing population of people with HIV living with a chronic and complex disease profile

AIM

To explore the health care needs of HIV positive people living with a chronic co-morbid diseases, with a focus on developing effective and sustainable models of integrated care. In particular this discussion will:

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- ⇒ **Assess the current mainstream clinical response to identified needs of the patient group in the primary care, community and tertiary treatment settings**
 - ⇒ **Consider effective future models of care for people with HIV involving a range of health care practitioners and treatment settings**
 - ⇒ **Explore the roles of service providers and the frameworks that will promote effective communication and decreased barriers to better patient management**
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Some key questions for consideration by participants:

- How can HIV services and mainstream services position themselves in the future to respond to the care based needs of HIV positive people with chronic disease profiles/ neurocognitive impairment/complex health conditions?
- What are the gaps in current service provision – in either primary or tertiary treatment settings, in research, in policy development – and how can these be overcome to improve health care for people with HIV with complex care needs?

Background

During the last decade, clinicians and researchers have become interested in the issue of HIV, co-morbidities and ageing. They have tried to better understand what, if any, links might exist in the causal relationships between these issues. Research conducted into the clinical and social circumstances of people who are ageing with HIV and with co-morbidities has steadily increased, both internationally and within Australia.

We know that the effects of ageing may be accelerated by HIV and that age related diseases can be made more complex by HIV treatment. The clinical management of HIV will therefore increasingly require a focus on co-morbidities. Apart from accelerated ageing, there are other long term effects of ARV treatment that some people with HIV experience, including metabolic disorders, neurological complications, malignancies,

cardiovascular disease and kidney and liver dysfunction. Co-morbidities can include hepatitis B and hepatitis C infection¹.

However, the majority of people with HIV require only regular health monitoring (rather than specialist treatment and care). It is a minority of people with HIV who have more complex needs because they have mental health issues, drug and alcohol misuse, or other service needs² related to the management of co-morbid conditions.

Community organisations such as The National Association of People with HIV Australia (NAPWHA) and Positive Life NSW have tracked emerging health issues and the evolving clinical and social research. They have advocated for a multidisciplinary discussion of the issues and for future service planning. The development of the SESLHD – ASHM *HIV Complex Care and Ageing Working Group* and the proposed Forum are part of an ongoing involvement and commitment from SESLHD HARP Unit and ASHM to explore and promote discussion on this issue.

This discussion paper has been developed by Positive Life NSW and SESLHD HARP Unit as a background discussion tool, to assist forum participants to better understand and focus on the clinical and service needs of people with HIV who are ageing with complex care needs. The evidence cited includes research into the ageing process of HIV-infected individuals and the causal relationships between HIV and other medical conditions. It also lists research into the social and economic circumstances of people with HIV.

The information and references to the published literature are by no means comprehensive but constitute a starting point to facilitate and promote further discussion in the Forum and after the event.

A way forward

To effectively respond to the care based needs of an unknown number of HIV positive people with co-morbidities and limited family and support structures, the future service requirements of this population need to be better understood.

Despite research being undertaken on the clinical and social needs of people with HIV who are ageing and have co-morbid conditions in Australia, more data may be required that fills gaps in our knowledge and permits service providers and policy makers to effectively respond to the known and emerging needs of this population group.

¹ NSW Health (2012) *NSW HIV Strategy 2012-2015 A New Era*, Co-morbidities and HIV p29

² Ibid



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Appendix

HIV and ageing

Literature review

Population of people with HIV is growing proportionally older and larger (Wilson, 2010)

- An estimated 24,731 people were living with diagnosed HIV infection in Australia at the end of 2011.³ By 2020, the total number of people living with diagnosed HIV in Australia is predicted to be 28,422 (that is a 38% increase on 2010 figures). This does not account for the 10-25% of HIV infections that are thought to be undiagnosed.⁴
- NSW is the state with the highest population of people living with diagnosed HIV.⁵ In 2012, *The NSW HIV Strategy 2012-2015 A New Era* estimated the number of people who know they are living with HIV (70-80% of all people living with HIV in NSW) to be 10,170.⁶
- The population of people living with HIV has aged substantially. In 1985 the proportion of the population aged over 55 years was 2.7%. By 2000 it was 11.2%. In 2010, it was 25.7% and by 2020, it is expected to be 44.3%.⁷ By 2020, more than half of all people living with HIV in Australia will be over the age of 50 years.

Prevalence of HIV Associated Dementia (HAD) will increase as the HIV population ages (Cysique et al, 2011)

³ Annual Surveillance Report (2012) HIV, viral hepatitis and sexually transmissible infections in Australia, Kirby Institute, Summary, HIV infection p7

⁴ Wilson, D (2010) *Mapping HIV Outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*. National Centre in HIV Epidemiology and Clinical Research, key findings, p5,

⁵ Ibid, p5

⁶ NSW HIV Strategy 2012-2015 – A New Era, Fig 2: The NSW HIV Treatment Cascade, unpublished analysis by the Kirby Institute for infections and immunity in Society

⁷ Wilson, D (2010) *Mapping HIV Outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*. National Centre in HIV Epidemiology and Clinical Research, key findings, p5

- The projected increase in the general size of the population with HIV as well as the ageing of the HIV population itself will impact on the prevalence of neurocognitive disorders in these groups⁸
- The study estimated that the numbers of people with HAD will increase from 1457 people in 2009 to 2625 people with HAD in 2030.⁹
- The costs of treating people with HIV affected with HAD by 2030 will increase to \$50 million for full time residential care and exponentially larger costs for the larger numbers of affected people requiring care in the community setting¹⁰

Pitts (2005) reported on a group of Australian PLWHA aged 50 years and over. They were compared to younger PLWHA on a range of indicators. Key findings include:

- Older PLWHA were significantly less likely to rate their health and well-being as good or excellent.
 - A significantly larger percentage of older PLWHA reported additional health conditions (47.2% versus 35.5%), of which the most common was cardiovascular disease (12.2%).
 - PLWHA were markedly less likely to be in contact with services, both those that were HIV related and those that were not.
 - The financial circumstances of older PLWHA were significantly worse than for younger PLWHA
 - Personal support through a regular relationship was also significantly less.
 - The clinical and community needs of this group of PLWHA are likely to be of increasing concern.¹¹
- Tietz (2006) research on older adults with HIV was conducted by the *AIDS Community Research Initiative of America* in 2006. The study surveyed 914 people with HIV over the age of 50 years in New York City. Six primary areas of information were surveyed: demographic profile, health status, sexual behaviors, social networks, stigma and psychological resources. Respondents included White, Black and Latino populations with HIV.

Key findings include:

- Most participants experienced one of the listed comorbidities (91.4%) and (77%) have two or more comorbidities. The most common comorbidities were depression (52%), arthritis (31%), hepatitis (31%), neuropathy (30%) and hypertension (27%).
- Life events such as retirement, illness, relocation and death of family and loved ones can result in shrinking social networks. It was found that as people aged, their social networks were transformed into social care systems and composed of family, friends and formal support services (e.g. community and government agencies, hospitals, and home care services).
- Unlike the general population, who rely upon spouses, partners and family, many older adults with HIV rely on friends as the primary source of informal support. Many of these friends are also living with HIV and may not be able to function as caregivers. Ageing adults with HIV who receive marginal

⁸ Cysique, L., Bain, M., Brew, B., and Murray, J., (2011) The burden of HIV-associated neurocognitive impairment in Australia and its estimates for the future, *Sexual Health*, (8) Pg 548

⁹ Cysique et al, Pg 548

¹⁰ Cysique et al, Pg 549

¹¹ Pitts, M, et al (2005) *Growing Older with HIV: A study of Health, Social and economic Circumstances for People Living with HIV in Australia over the Age of 50 Years*. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Victoria Australia. *AIDS Patient Care and STDs*, Volume 19, Number 7, 2005.

- social support report feelings of isolation and a decreased ability to cope with the rigors of disease management.
- Research found that loneliness is not related to frequency of contact or the social network size, but to the quality of the support provided.¹²

Ageing of the immune system

- Desai et al (2010) found that non-AIDS-defining co-morbidities occur despite viral suppression and immune reconstruction using antiretroviral therapy. Immune activation coupled with lack of anti-inflammatory responses likely results in a process of accelerated ageing in HIV disease.¹³ Accelerated ageing in people with HIV is characterized by a number of the typical co-morbidities associated with ageing, but in people with HIV they typically occur at a younger age and with greater frequency.
- Deeks (2010) research into *HIV Infection, Inflammation, Immunosenescence, and Ageing*¹⁴ and his presentation at the ASHM Conference in 2008 increased the profile of HIV and ageing in Australia.
 - Although antiretroviral therapy for HIV infection prevents AIDS-related complications and prolongs life, it does not fully restore health
 - Long-term treated patients remain at higher than expected risk for a number of complications typically associated with ageing, including cardiovascular disease, cancer, osteoporosis, and other diseases
 - The potential effect of HIV on health is perhaps most clearly exhibited by a number of immunologic abnormalities that persist despite effective suppression of HIV replication. These changes are consistent with some of the changes to the adaptive immune system that are seen in the very old (“immunosenescence”) and that are likely related in part to persistent inflammation.
 - HIV-associated inflammation and immunosenescence have been implicated as causally related to the premature onset of other diseases.
 - Novel therapeutic strategies aimed at preventing or reversing these immunologic defects may be necessary if HIV-infected patients are to achieve normal life span.”

Medical conditions associated with HIV and ageing – co morbidities, risk factors and medical care

- Guaraldi G et al (2010) found that diseases of ageing occur in patients 10 – 15 years earlier. The prevalence of a range of comorbid conditions was approximately equivalent to prevalence observed in members of the public who were 10 to 15 years older. By showing the premature onset of poly-pathology among HIV-infected patients, the authors believe that they have contributed to the characterization of an emerging description of an HIV-specific ageing phenotype.”¹⁵ (See Fig 1).

¹² Tietz D. (2006) *Research on Older Adults with HIV*, AIDS Community Research Initiative of America.

¹³ Desai, S (2010) *Early Immune Senescence in HIV Disease*, Department of Immunology/Microbiology, Rush University Medical Centre, Chicago USA

¹⁴ Deeks S,J (2010) *HIV Infection, Inflammation, Immunosenescence, and Aging* Annual Review of Medicine, Vol. 62: 141-155 (Volume publication date February 2011) First published online as a Review in Advance on November 17, 2010, DOI: 10.1146/annurev-med-042909-093756

¹⁵ Guaraldi G et al. *Premature age-related comorbidities among HIV-infected persons compared with the general population*. Clin Infect Dis, online edition, doi: 10.1093/cid/cir627, 2011. Capeau J. *Premature aging and premature age-related comorbidities in HIV-infected patients: facts and hypotheses*. Clin Infect Dis, online edition, doi: 10.1093/cid/cir628, 2011.

- Justice (2010) reported that people with HIV who are successfully treated with ARV and ageing, may experience a widening spectrum of non-AIDS diseases and require new paradigms of patient care. Concurrently, AIDS-defining conditions are becoming less common. However, the spectrum of disease experienced by those ageing with HIV remains strongly influenced by HIV, its treatment, and the behaviours, conditions, and demographics associated with HIV infection. The authors stated that the focus must shift from narrow interest in CD4 counts, HIV-RNA, and AIDS-defining illnesses, to determining the optimal management of HIV infection as a complex chronic disease in which the causes of morbidity and mortality are multiple and overlapping. A new paradigm of care to maximise functional status, minimise frailty, and prolong life expectancy is needed.¹⁶

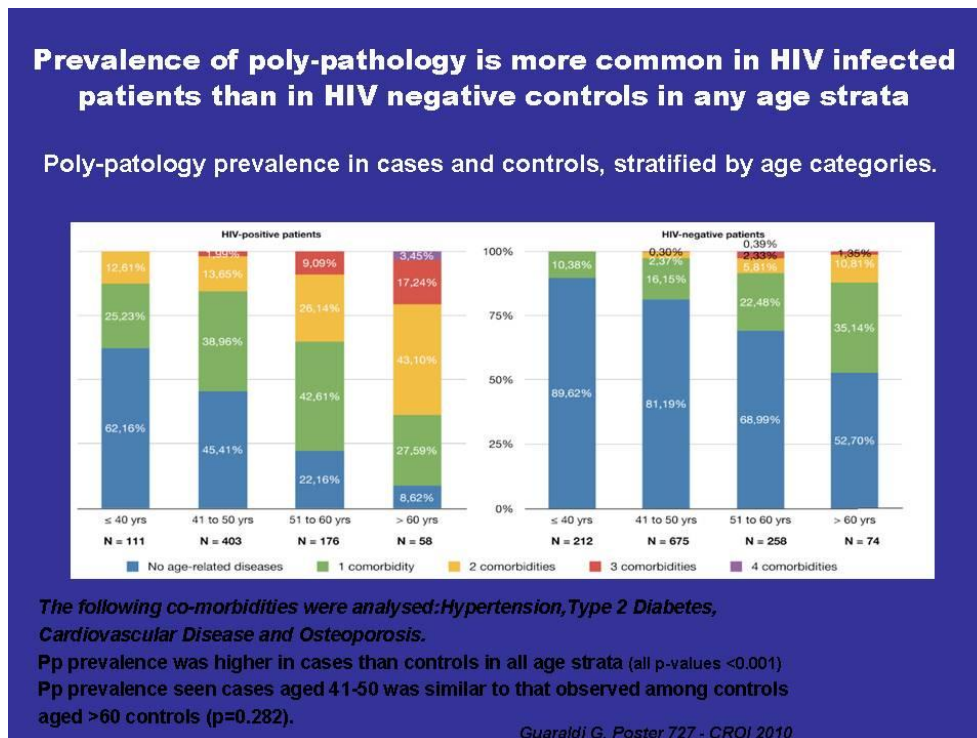


Fig 1 Guaraldi, G Poster 727 – CROI 2010

- In December 2011 the Australian journal - *Sexual Health*, volume 8, Issue 4, December 2011, published by the CSIRO, produced a special edition on *HIV and ageing*.

The issue included 15 papers by different authors and attempted to come to grips with both the immediate and underlying causes of the premature onset of age-related conditions in people with HIV.

Slavin S, (2011) states in the introductory paper:

HIV and Ageing: an overview of an emerging issue, that the collective wisdom of the papers present a complex set of answers to this question of 'do people with HIV age more rapidly? 'The biological argument that HIV causes immunosenescence, which is a

¹⁶ Justice, A. (2010) *HIV and Aging: Time for a New Paradigm*

characteristic of older individuals, is persuasive. However, we can only be sure that T-cells are affected. Evidence is more limited when it comes to the innate immune system. So at this stage, the evidence is unable to answer the question of whether HIV in its own right accelerates the ageing process. What is clear, though, is that certain diseases of ageing, most notably CVD and dementia, are occurring at a higher rate and at an earlier age among PLHIV. Whether this is wholly explained by lifestyle factors or contributed to by additional ageing processes specific to HIV and its treatment is not known. Future research that explains this process will be important for developing effective interventions. Although the causes for these high rates of chronic disease are being elucidated, prevention and management of adverse disease outcomes through lifestyle modification, screening for early disease, and pharmacological intervention are now at the centre of management of older patients with HIV'.¹⁷

Australian papers in the edition include:

- HIV and ageing: an overview of an emerging issue¹⁸
 - HIV and Aging: a personal perspective¹⁹
 - HIV infection and ageing of the innate immune system²⁰
 - HIV infection, ageing and cardiovascular disease: epidemiology and prevention²¹
 - Vascular stiffness and ageing in HIV²²
 - HIV-associated kidney disease in the context of an ageing population²³
 - HIV infection and bone disease: implications for an ageing population²⁴
 - Sexual function and dysfunction in older HIV-positive individuals²⁵
 - Sexually transmissible infections in ageing HIV populations²⁶
 - Liver disease, HIV and ageing²⁷
 - HIV, cancer, and ageing²⁸
 - Life expectancy of HIV-positive adults: a review²⁹
 - Optimal antiretroviral therapy for ageing³⁰
 - The burden of HIV-associated neurocognitive impairment in Australia and its estimates for the future³¹
 - Comorbidities and depression in older adults with HIV³².
- High K et al (2012) reported that there is an emerging consensus that HIV and/or its treatment affects the process of ageing and/or the development of illnesses typically

¹⁷ Slavin S et al. *HIV and aging: an overview of an emerging issue*, Sexual Health, 2011, 8, p449-451

http://www.publish.csiro.au/?act=view_file&file_id=SH11110.pdf

¹⁸ Slavin S et al (2011) Editorial: HIV and ageing: an overview of an emerging issue, Sexual Health Volume 8 Issue 4, December 2011, www.publish.csiro.au/journals/sh

¹⁹ Menadue D (2011) HIV and Aging: a personal perspective

²⁰ Heaps A. et al (2011) HIV infection and aging of the innate immune system, Sexual Health, 2011, p453-464

²¹ Petoumenos K (2011) HIV Infection, aging and cardiovascular disease: epidemiology and prevention Sexual Health, 2011, p 465-473

²² Chan W et al, (2011) Vascular stiffness and aging in HIV, Sexual Health, 2011, 8 p474-484

²³ Naftalin C et al, (2011) HIV-Associated kidney disease in the context of an aging population, Sexual Health, 2011, p485-492

²⁴ Cotter AG. et al, (2011) HIV infection and bone disease: implications for an aging population, Sexual Health, 2011, p493-501

²⁵ Russell D. et al (2011) Sexual function and dysfunction in older HIV-positive individuals, Sexual Health, 2011, p502-507

²⁶ Poynton M. et al (2011) Sexually transmissible infections in aging HIV populations, Sexual Health, 2011, p508-511

²⁷ Falade-Nwalia O. et al (2011) HIV disease, HIV and aging, Sexual Health, 2011, p512-520

²⁸ Grulich A. et al (2011) HIV, cancer, and aging, Sexual Health, 2011, 8, p521-525

²⁹ May M. et al (2011) Life expectancy of HIV-positive adults: a review, Sexual Health, 2011, 8, p526-533

³⁰ Cordery D. et al (2011) Optimal antiretroviral therapy for aging, Sexual Health, 2011, 8, p534-540

³¹ The burden of HIV-associated neurocognitive impairment in Australia and its estimates for the future, Sexual Health, 2011, 8, p451-550

³² Havlik R. et al (2011) Comorbidities and suppression in older adults with HIV, Sexual Health, 2011, 8, p551-559

associated with advanced age: when compared with behaviorally and demographically similar HIV-uninfected individuals, people with HIV infection, even those receiving effective ART with suppression of virus to levels below typical detection limits, experience excess morbidity and mortality. On average, a 20-year old initiating ART may have already lost one-third of the expected remaining years of life compared with demographically similar HIV uninfected persons. Although AIDS-defining illnesses are increasingly rare in those with ART-suppressed HIV, the list of HIV-associated non-AIDS (HANA) conditions is growing. A common theme among currently identified HANA conditions is their association with advancing age and chronic inflammation. These include cardiovascular disease, a number of infectious and noninfectious cancers, osteopenia/osteoporosis, liver disease, renal disease and neurocognitive decline. It is uncertain whether people with HIV infection develop these conditions earlier in their life course because the ageing process is itself accelerated (i.e. is HIV speeding pathways ageing in every organ?) represents a cohort effect, or whether HIV is an additional risk factor (i.e. is HIV similar to high cholesterol which does not make one 'age' faster but increases the risk of cardiovascular events.³³

- Obel N et al (2011) reports that patients taking HAART have the same mortality risk as individuals in the general population, according to Danish research. However, this was only the case when patients responded to treatment and did not have other factors that increased the risk of serious illness and death, such as co-infections or co-morbidities, or drug and alcohol misuse. Mortality in HIV-infected patients with no identifiable risk factors was almost identical to that of the general population with no risk factors. The authors conclude that future management of the HIV-infected population should focus on early diagnosis, timely and effective HAART, and treatment of co-morbidity and alcohol/drug abuse. The authors also believe that it is important to give patients optimistic and accurate information about their prognosis. Stressing the impact of HIV on mortality after HAART initiation may severely hamper the patient's quality of life and be at odds with data. Evidence from the SMART trial and other observational studies suggest that HIV infection and ART influence morbidity and mortality through the effects on inflammation, treatment related toxicity (which includes abnormal fat distribution, renal and kidney dysfunction, and neuropathy), interactions with other chronic viral infections, and co-morbid diseases typically associated with advanced age. This complex and often subtle pathophysiology also interacts with prolonged substance use and other psychosocial and health behaviors more commonly experienced by those with HIV infection. As a result, ageing with HIV-infected persons exhibit an excess burden of co-morbid symptoms and syndromes that are often associated with advanced ageing, multi-morbidity, poly-pharmacy, limited reserve, and functional (physical and cognitive) decline.³⁴
- Justice AC (2012) professor of medicine and public health at the Yale School of Medicine is a leading researcher on ageing and HIV and the lead investigator of the Veterans Aging Cohort Study (VACS). The study of 7,400 people matched HIV-positive against HIV-negative individuals who otherwise have extremely similar characteristics (such as age, location, race, income, access to health care). The study then followed these people over time and recorded when they developed various health complications. The VACS study found that HIV-positive people develop kidney failure four years earlier, they develop lung cancer about two years earlier, they develop cardiovascular disease as much as six years earlier, but do not begin to experience heart attacks earlier, develop liver cirrhosis about one year earlier and fracture a bone due to bone weakness one year later than those who were HIV-negative. Justice says that "there certainly is more of a trend for HIV-positive people to be a bit younger when they develop certain health

³³ High KP, 2012. *HIV and Aging: State of Knowledge and Areas of Clinical Need for Research. A report to the NIH Office of AIDS Research by the HIV and Aging Working Group*, executive Summary p1-3

³⁴ Obel N, et al. 2011. *Impact of non-HIV and HIV risk factors on survival in HIV-infected patients on HAART: a population-based nationwide cohort study*. PLoS One 6 (7):e22698.

problems, but when I say a bit younger, we are talking about somewhere between one and six years...we are not talking about 20 or 30 years".³⁵

(This paper is based on an original discussion paper developed by Lance Feeney Senior Project Officer, Systemic Advocacy, Positive Life NSW and has been adapted with permission as a Discussion Paper for the HIV Complex Care and Ageing Forum partnership project between ASHM NSW and SESLHD)

³⁵ Justice AC, et al (2012) *Veterans Aging Cohort Study (VACS)* <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3049942/>
<http://www.thebody.com/content/69122/premature-aging-and-hiv-dispelling-myths-and-calcu.html>