



Blog of the Month

AMPJ Blog of the Month: March 2022 Edition

Dr Nuala Hurst Marshall is a foundation doctor currently working in the North East London region. For this month's APMJ blog post, we share Dr Hurst Marshall's piece on HIV and Palliative Care. Thank you and congratulations Dr Hurst Marshall!

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The Role of Palliative Care in the Care of Patients with HIV

Dr Nuala Hurst Marshall

In the early days of the AIDS epidemic, all care for People Living With HIV (PLWH) was palliative. Without any effective treatment, HIV transformed inexorably into AIDS and care focused on helping the patient “struggle day after day with the symptoms of AIDS.”¹ Due to limited provision of hospital care, as facilities were still being developed, much of this palliative care was informally provided, by friends, relatives and other members of the LBGTQI community. Community members stepped up to provide “hospital visits, [help with] social security forms, befriending and so on.”² With the introduction of effective antiretroviral therapy (ART), for those patients with access to treatment and who remain compliant with their medication, HIV has been transformed from a terminal diagnosis to a chronic disease. Nevertheless, HIV remains a condition with a significant disease burden and one where early introduction of palliative care may be beneficial. This article will discuss the synchronous model of palliative care, whereby palliative care is delivered alongside disease-modifying treatments, before discussing the ongoing disease burden of a HIV diagnosis. Finally, it will discuss the specific roles

¹ Schietinger, S. (1986) A Home Care Plan for AIDS. *The American Journal of Nursing*. 86 (9), pp.1021-1028

² Lister K. (2020) The lesbian ‘blood sisters’ who cared for gay men when doctors were too scared to. *i news* [online] 21st Aug. Available from: <https://inews.co.uk/opinion/comment/the-lesbian-blood-sisters-who-helped-save-gay-mens-lives-235100>

palliative care may have in the treatment of PLWH, namely symptom management, specifically pain and fatigue; decisions around discontinuation of medication at the end of life and support of family members and next-of-kin (NOK).

Traditional palliative care was delivered in a “dichotomous” way wherein disease modifying treatments were initially trialled, and palliative care was introduced only after these treatments had failed.³ However, this absolute distinction between disease modification and palliation does not always align with the treatment of many conditions or serve the best interests of patients. For instance, the use of diuretics in exacerbations of heart failure, serves both to improve symptoms and prolong life.⁴ There is increasing evidence that early introduction of palliative care improves outcomes for patients, including enhancing quality of life, reducing unnecessary hospitalisations, reducing prolonged grief among family members and possibly even increasing survival.⁵ Therefore, for chronic conditions with a significant disease burden, palliative works best alongside, rather than after, active treatment.

Despite the introduction of safe and effective ART, HIV remains a condition with just such a disease burden, both in terms of mortality and morbidity. One analysis of mortality among PLWH using data collected by Public Health England and the Office of National Statistics between 1997 and 2012, demonstrated that all-cause mortality was six times higher in PLWH than in the general population.⁶ 58% of deaths among PLWH were AIDs-related with the most common causes of non-AIDS deaths being cancer, CVD/stroke, infections and liver disease.⁷ Risk factors for mortality were low CD4 count at diagnosis, late diagnosis and limited interactions with health services.⁸ As well as an increased mortality rate, PLWH have a higher symptom burden and rates of comorbidity than the general population. Common symptoms reported by PLWH include pain, fatigue, sweats and cough, as well as psychological symptoms such as worry, insomnia and irritability.⁹ PLWH also have higher rates of comorbidities such as hypertension, diabetes, renal failure and fractures than age-matched controls in the general population, hypothesised to be due to “direct toxicity from the virus, chronic inflammation, chronic immunosuppression, toxicity related to ART, and elevated rates of high-risk health behaviours in this population”.¹⁰ In addition, PLWH have higher rates of psychiatric comorbidities and higher rates of substance misuse.¹¹ All of this demonstrates that, notwithstanding the significant improvement in

³ Meier D et al. (2020) Benefits, Services and Models of Subspecialty Palliative Care. *Up to Date* [online]. Available at <https://www.uptodate.com/contents/beenfits-services-and-models-of-subspecialty-palliative-care/print>

⁴ Meier D et al (2020)

⁵ Meier D et al (2020)

⁶ Croxford S et al. (2017) Mortality and causes of death in people diagnosed with HIV in the era of highly active antiretroviral therapy compared with the general population: an analysis of a national observational cohort. *The Lancet Public Health*. 2(1)

⁷ Croxford S et al (2017)

⁸ Croxford S et al (2017)

⁹ Pahuja M et al (2021) Issues in HIV/AIDS in adults in palliative care. *Up to Date* [online]. Available at <https://www.uptodate.com/contents/issues-in-hiv-aids-in-adults-in-palliative-care>

¹⁰ Pahuja M et al (2021)

¹¹ Pahuja M et al (2021)

life expectancy due to ART, PLWH continue to be a cohort with a significant burden of disease who could benefit from early introduction of palliative care.

Two specific symptoms common amongst PLWH are pain and fatigue. One study looking at data collected from PLWH attending a dedicated HIV outpatient clinic, found that 95% of referrals to the clinic were due to pain.¹² Other studies have suggested that chronic pain affects “25 to 85 percent of individuals with HIV infection”.¹³ This pain is thought to be due to a number of factors, including a direct effect of the virus, consequences of the virus such as infections and malignancy, the impact of ART and other medications, and comorbid conditions.¹⁴ In their assessment of the role of palliative care for PLWH, the World Health Organisation (WHO) advised that this pain should be managed with a combination of pharmacological and non-pharmacological methods, including the WHO pain ladder and interventions such as “psychological support and relaxation techniques”.¹⁵ PLWH also report higher rates of fatigue than the general population. Studies have estimated that fatigue affects “30 to 80 percent,” of PLWH and is likely, as with pain, to be multifactorial.¹⁶ The presence of physical comorbidities such as liver disease, anaemia and hypothyroidism are likely to contribute, as well as psychiatric comorbidities such as depression, anxiety and post-traumatic stress disorder.¹⁷ In their analysis of the role of palliative care in the treatment of PLWH, Pahuja et al suggest this fatigue should be managed with an attempt to locate and treat modifiable factors, advice about sleep patterns and sleep hygiene, and recommendations for moderate exercise where tolerated.

One role of palliative care in patients with all conditions is in facilitating patient-centred decisions about withdrawal of treatment and discontinuation of disease-modifying therapies at the end of life. This decision is often centred around the symptom control these therapies give and where symptom benefit is achieved with the treatment, it may be continued. Pahuja et al discuss the complex decision for PLWH and their care providers of when to stop ART at the end of life. Continuing ART may have a number of possible benefits, they argue, such as preventing a sudden viraemia in patients who have previously had an undetectable viral load, which may have associated symptoms, and sustaining cognitive functioning.¹⁸ However, they also highlight possible negatives to continuing ART, such as that it may create anxiety in patients who are struggling to take medications, produce confusion in patients and relatives about the aims of treatment and the patient’s prognosis, and that it may interact with other important palliative medications such as opioids.¹⁹ Given that this decision is likely to be

¹² Pahuja M et al (2021)

¹³ Pahuja M et al (2021)

¹⁴ World Health Organisation Palliative Care for People Living with HIV: Clinical Protocol for the WHO European Region. Available at https://www.euro.who.int/_data/assets/pdf_file/0019/78121/E90840_Chapter_3.pdf

¹⁵ WHO

¹⁶ Pahuja M et al (2021)

¹⁷ Pahuja M et al (2021)

¹⁸ Pahuja M et al (2021)

¹⁹ Pahuja M et al (2021)

emotionally charged and complex, it may be best conducted with assistance of both HIV physicians and palliative care clinicians, given their expertise in end-of-life discussions.

One final important role in the care of PLWH that palliative care clinicians may be well suited for is the care of the patient's relatives and NOK. The World Health Organisation, in their document on the role of palliative care for PLWH, argues that deaths of HIV positive patients have the potential to have an additional burden of grief compared to other deaths due to a number of factors including "the relatively young age at which most patients die...the stigmatized nature of the disease, which may complicate the grieving process; and the possibility that other family members have already died from HIV/AIDS, or that survivors may be HIV-infected and at risk for dying from it."²⁰ These factors increase the risk of complicated grief for those left behind and the potential for long grieving periods. Palliative care clinicians, with their experience and ability in supporting relatives and NOK through the deaths of their loved ones, may be appropriate to guide relatives through the death of PWLH.

The discovery of safe and effective ART has radically altered the prognosis of HIV. Nevertheless, as this article has demonstrated, PLWH have a consideration disease burden and risk of early mortality. As such, they fit into the "serious illness paradigm"²¹ in which palliative care is appropriate. This palliative care should be delivered alongside, rather than after, active, disease-modifying treatment, with the balance between the two being determined by the cause of the patient's symptoms and the possibility of improving these symptoms through disease-specific and/or palliative interventions."²²

²⁰ WHO

²¹ Pahuja M et al (2021)

²² WHO