

Palliative Care Need for HIV Adolescents Using Maxwell Model: A Qualitative Study

Iqbal Pramukti, M.Sc

Professor Ko, Nai-Ying, Ph.D

Ai Mardhiyah, M.Kes

Ahmad Yamin, M.Kes

Background

- Human immunodeficiency virus (HIV) infection people poses tremendous challenges to health globally. Over 90 percent of the estimated 38 million with HIV infection in 2003 lived in resource poor settings (Rajasekaran, Jeyaseelan, Raja & Ravichandran, 2009).
- According to WHO (2015), HIV continues to be a major global public health issue, having claimed more than 34 million lives so far. In 2014, 1.2 million people died from HIV-related causes globally. Thus, there were approximately 36.9 million people living with HIV at the end of 2014 with 2.0 million people becoming newly infected with HIV in 2014 globally

- Adolescence is a distinctive developmental period for young people characterized by biological, psychological, physiological, and cognitive changes. These changes in essence make adolescent and young adult HIV medicine both different and unique from pediatric and adult HIV medicine (Katusiime, 2012)
- Respond of adolescent with HIV is subjective, so therefor it needs a comprehensive approach in delivering care
- Caring for children and young people with life-limiting conditions is as an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond.

Prevalence of HIV in Asia

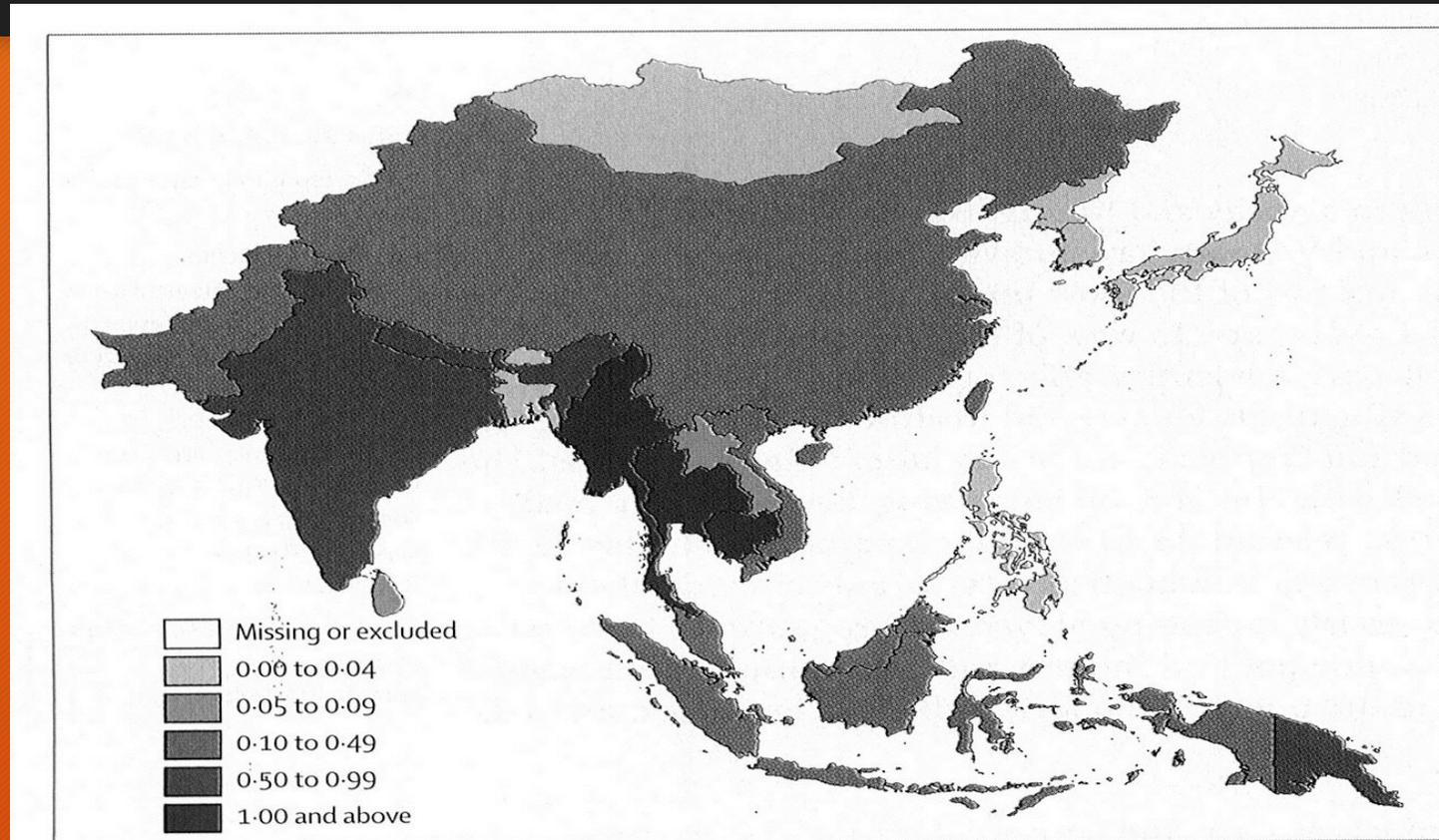


Figure 1: HIV infection in Asia at the end of 2001⁵

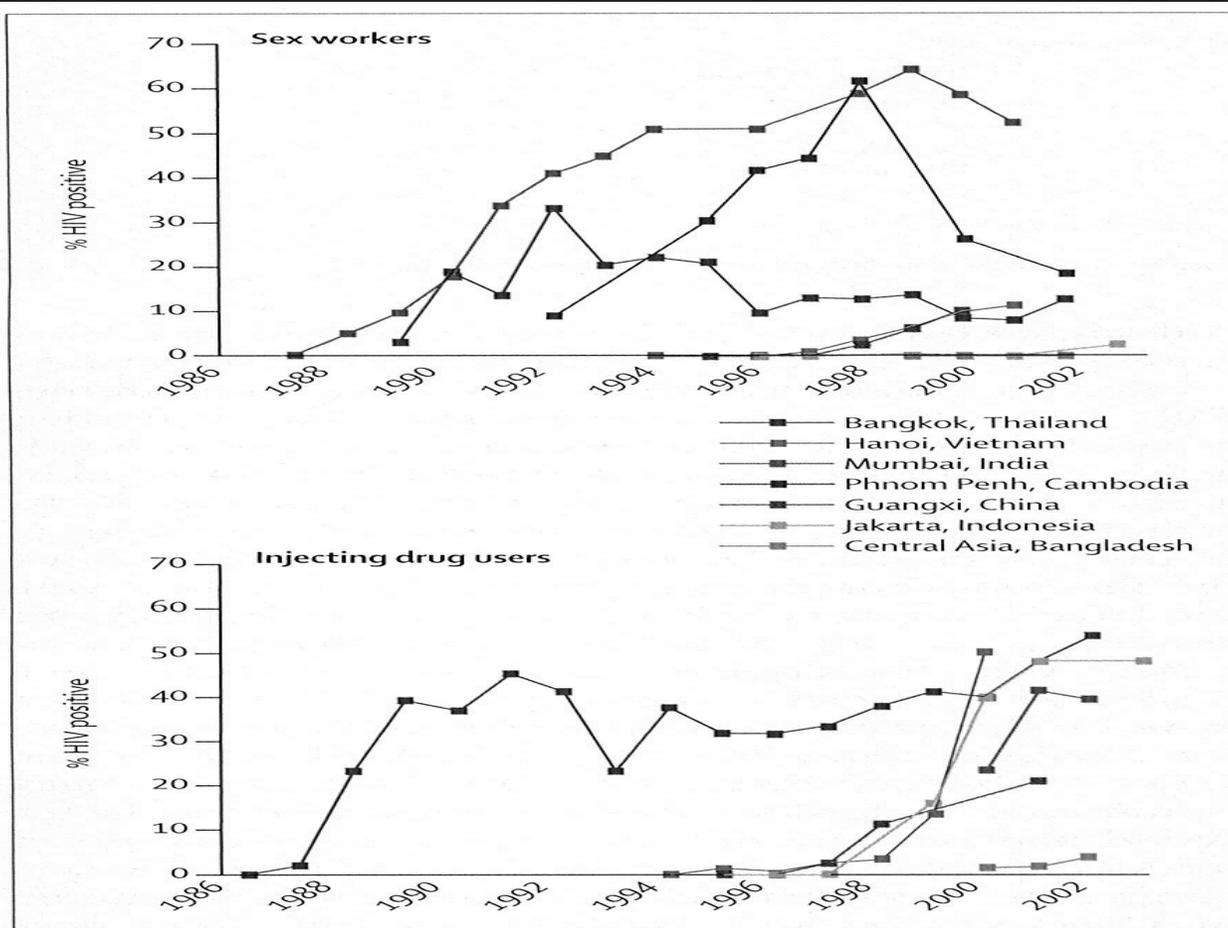


Figure 2: Growth of HIV prevalence in different Asian surveillance populations¹⁷⁵

Significance of Study

This study will contribute to the finding of new issues related to HIV among adolescent which can finally influence the framework of conducting further reseach in enhancing HIV problem among adolescent

The study will benefit patients, health care providers, academics and clinicians through the development of appropriate research strategies involving service users.

The study will also benefit national policy in term of how to develop a guidance of caring people especially adolescent with HIV

Aim of Study

This study aimed to gain comprehensive view on need of palliative care for Adolescent with HIV from service user and service provider

Research Question

What actually the need of palliative care for Adolescent with HIV in improving quality of health care by Service user and service provider perspective?

Research Design

- A qualitative approach is adopted to capture the complex nature of the palliative care needs of adolescent with HIV/AIDS.
- The interview will use the Maxwell model as the guideline. This model has consist of 6 components, there are: access, equity, relevant to need, acceptability, efficient, and effective.
- The views of service users and providers will obtained through semistructured focus groups or individual tape-recorded interviews, according to individual preference. The researcher will conduct all the interviews and focus groups.

Setting and Place

- This study was conducted in Public Health Centre in Bandung West Java, Indonesia. This public health center has a group of community who concern on HIV called “kader kesehatan”

Data Analysis

- A thematic analysis had conducted on the transcriptions by the researcher who conduct the interviews. The transcripts are open coded and then organized in themes by using the qualitative data analysis software package. The themes identified were then reviewed by assessing their goodness-of-fit to Maxwell's six dimensions of quality care

Result

Access

Patients described persistent and troublesome access to health care services. In addition, extreme poverty and worries about the financial implications of accessing medical care meant that most patients only sought this at a very late stage of their disease:

Equity

The equity had become the classical problem. Many patient with poverty received worst treatment. The need of this equity is very urgently needed. Health care provider should not be influenced by stigma in the society which could lead them into a subjective condition in delivering care to the patient.

Appropriateness

The health care services for HIV adolescent is sometimes not relevant to need. The services mostly concern on “curing” aspect rather than caring. Palliative care often delivered inaccurately. The patients are not only need “cure” but also “care”. So therefore support from health care provider is very needed.

Acceptability

Health services for adolescent with HIV is need to be acceptable. The service delivered by the health provider will determined quality of patient's life. This is influenced by the level of complexity of the regimen given. The easier the treatment given, the more consistent in undergoing the procedure.

Efficiency

Palliative care services for HIV adolescent need to be efficient since this services will be a long term service. Otherwise, it will waste the time and energy.

Effectiveness

Some participant described first going to informal health care before eventually seeking help from more formal sector. For example, they went to traditional medicine practitioner. In delivering care for HIV patient, the service often given inaccurately due to insufficient tools.

Conclusion

- The need of palliative care among HIV adolescent is not easy as predicted. It due to the transition process by the adolescent themselves which could lead into a different responds even have the same disease.

References

- Ardon, D, & Kendall, M 2010, 'Patient and public involvement in health research: what is it, and why is it so important?', *International Journal Of Palliative Nursing*, 16, 4, pp. 160-162 3p, CINAHL Plus with Full Text, EBSCOhost, viewed 10 February 2016.
- Armes, P. J., & Higginson, I. J. (1999). What constitutes high-quality HIV/AIDS palliative care? *Journal of Palliative Care*, 15(4), 5-12. Retrieved from <http://search.proquest.com/docview/214202976?accountid=25704>
- Auckland S: Involving Users in the research process, A how to guide for researchers:. National Institute for health research; Biomedical Research Centre: London 2010, Version 1.
- Avert. (2016). History of HIV and AIDS Overview. Retrieved from <http://www.avert.org/professionals/history-hiv-aids/overview>
- Beedham H, Wilson-Barnet J. (1995), HIV and AIDS care: consumers' views on needs and services. *J Adv Nurs*; 22: 677-686. Department of Health. Equity and Excellence: Liberating the NHS. London: Department of Health; 2010. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf. Accessed July 2014.

- Gupta, I., & Guin, P. (2010). Communicable diseases in the South-East Asia Region of the World Health Organization: towards a more effective response. *Bulletin Of The World Health Organization*, 88(3), 199-205. doi:10.2471/BLT.09.065540
- Ha, T. H., Liu, H., Li, J., Nield, J., & Lu, Z. (2012). Psychometric assessment of scales measuring HIV public stigma, drug-use public stigma and fear of HIV infection among young adolescents and their parents. *AIDS Care*, 24(1), 39-45. doi:10.1080/09540121.2011.592820
- Hirst, J., & Hewison, J. (2001). Pakistani and indigenous "white" women's views and the donabedian-maxwell grid: A consumer-focused template for assessing the quality of maternity care. *International Journal of Health Care Quality Assurance*, 14(6), 308-316. Retrieved from <http://search.proquest.com/docview/229602643?accountid=25704>
- Katusiime, C. (2012). Palliation in adolescent and young adult HIV medicine--an emerging need. *Journal Of Palliative Medicine*, 15(11), 1167-1168. doi:10.1089/jpm.2012.0318

- Lavy, V. (2007). Presenting symptoms and signs in children referred for palliative care in malawi. *Palliative Medicine*, 21(4), 333-9. doi:<http://dx.doi.org/10.1177/0269216307077689>
- Lewis, I 2014, 'Highlights from the 2013 National Cancer Research Institute Conference', *Ecancermedicalscience*, 8, 381-412, pp. 1-7, Academic Search Complete, EBSCOhost, viewed 10 February 2016.
- Lyon, M. E., Garvie, P. A., Briggs, L., He, J., McCarter, R., & D'Angelo, L. J. (2009). Development, feasibility, and acceptability of the Family/Adolescent-Centered (FACE) Advance Care Planning intervention for adolescents with HIV. *Journal Of Palliative Medicine*, 12(4), 363-372. doi:10.1089/jpm.2008.0261
- Mathie E, Ford N: 'Peer Education for Health'. Edited by: Topping K, Ehly S.

- Morrow E, Boaz A, Brearley S, et al. *Handbook of Service User Involvement in Nursing and Healthcare Research*. Chichester: Wiley-Blackwell; 2011.
- Nakawesi, J., Kasirye, I., Kavuma, D., Muziru, B., Businge, A., Naluwooza, J., & ... Mukasa, B. (2014). Palliative care needs of HIV exposed and infected children admitted to the inpatient paediatric unit in Uganda. *Ecancermedicalscience*, 8(474-494), 1-7. doi:10.3332/ecancer.2014.489
- Nkosi, B. (2014). Palliative care for children living with HIV/AIDS. *Nursing Update*, 39(11), 24-25 2p. Peer-Assisted Learning, London: Lawrence Erlbaum Associates; 1998:203-218.

- Piper, K., Enah, C., & Daniel, M. (2014). Black southern rural adolescents' HIV stigma, denial, and misconceptions and implications for HIV prevention. *Journal of Psychosocial Nursing & Mental Health Services*, 52(6), 50-6. doi:<http://dx.doi.org/10.3928/02793695-20140210-01>
- Porteous C, Rea D. *Involving People/Cynnwys Pobl: an internal evaluation of infrastructure support for active involvement in health and social care research in Wales*. Cardiff: Involving People/Cynnwys Pobl; 2009.
- Rajasekaran, S., Jeyaseelan, L., Raja, K., & Ravichandran, N. (2009). Demographic & clinical profile of HIV infected children accessing care at Tambaram, Chennai, India. *The Indian Journal Of Medical Research*, 129(1), 42-49.

- Richter, L. M., Rochat, T. J., Hsiao, C., & Zuma, T. H. (2012). Evaluation of a Brief Intervention to Improve the Nursing Care of Young Children in a High HIV and AIDS Setting. *Nursing Research & Practice*, 1-8. doi:10.1155/2012/647182
- Richter, L. M., Sherr, L., Adato, M., Belsey, M., Chandan, U., Desmond, C., & Wakhweya, A. (2009). Strengthening families to support children affected by HIV and AIDS. *AIDS Care*, 21 Suppl 13-12. doi:10.1080/09540120902923121
- Ruxrungtham, K., Brown, T., & Phanuphak, P. (2004). HIV/AIDS in asia. *The Lancet*, 364(9428), 69-82. Retrieved from <http://search.proquest.com/docview/199043905?accountid=25704>
- WHO (2015), HIV/AIDS. Retrieved from <http://www.who.int/mediacentre/factsheets/fs360/en/>
- Wilson, J. S. (2004). HIV/AIDS in Indonesia. AIDS in Asia. Y. Lu, M. Essex and E. Stiefvater. Boston, MA, Springer US: 91-98.



Thank You