

THESIS

HIV AMONG OLDER ADULTS IN SUB-SAHARAN AFRICA

HIV AMONG OLDER ADULTS: QUALITY OF LIFE AND DISABILITY
EXPERIENCES IN SUB-SAHARAN AFRICA

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Abstract

In 2014, UNAIDS published the *Gap Report* that identified adults aged 50 years and older as a vulnerable group being left behind in HIV treatment and prevention efforts (UNAIDS, 2014). This manuscript thesis is composed of two data chapters that aim to address the gap in the HIV, aging, and disability literature by exploring what is known about the quality of life and disability experiences of older adults aged 50 years and older living with HIV in sub-Saharan Africa (SSA). The purpose of the scoping review was to map out published literature on quality of life among older adults living with HIV in SSA. Following Arksey & O'Malley's framework for conducting scoping reviews, 6 databases were searched resulting in 1021 titles and abstracts that were screened for inclusion resulting in a total of 8 articles included for review and synthesis. The review confirmed a dearth in research literature on older adults living with HIV in SSA as included studies were only conducted in 2 out of 47 countries in the region. The qualitative study addressed this gap in knowledge by exploring the disability- related experiences of 10 older men and women living with HIV in Zambia. The qualitative study identified 5 major themes: 1. Multiple Symptoms and Impairments: Variation in Onset and Duration; 2. Daily Activities and Participation: Shaped by Gender Roles; 3. HIV Status Disclosure: Hindered by Stigma, Driven By A Purpose; 4) Poverty and Food Insecurity: Precarious Employment; and 5) Managing An Altered Uncertainty: Changes Resulting From A Prolonged Life. These findings demonstrated that while participants were benefiting from antiretroviral therapy, many still experienced disability. The component studies in this thesis complement one another and advance dialogue about the quality of life and experiences of disability in older adults living with HIV in SSA and points to a need for further research so that fewer people are left behind.

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List of Abbreviations

AIDS- Acquired Immune Deficiency Syndrome

ART- Antiretroviral Therapy

EDF- Episodic Disability Framework

HIV – Human Immunodeficiency Virus

ICF- International Classification of Functioning, Disability and Health

SSA- Sub-Saharan Africa

UNAIDS- Joint United Nations Programme on HIV/AIDS

UNCRPD- United Nations Convention on the Rights of Persons with Disabilities

WHO- World Health Organization

WHOQOL- World Health Organization Quality of Life Assessment Tool

WHODAS-II World Health Organization Disability Assessment Schedule-II

Declaration of Academic Achievement

The following is a declaration that the content of the research in this document has been completed by Samantha Cheuk and recognizes the contributions of Dr. Patty Solomon, Dr. Stephanie Nixon, and Dr. Christy Gombay in both the research process and completion of the thesis.

Thesis Overview

The following thesis is considered a manuscript-based thesis. The thematic objective of this thesis is to understand the quality of life and disability experiences of older adults living with HIV in sub-Saharan Africa, and more specifically in Zambia. The first chapter of this thesis is a general overview to provide the reader with relevant background information to understand and support the overall thesis. The second chapter is considered a data chapter and is a scoping review used to identify the extent of knowledge in the published research literature on older adults living with HIV in sub-Saharan Africa. The third chapter is also a data chapter and is a qualitative study of the experiences of 10 men and women aged 50 years and older living with HIV in Zambia. Finally, the thesis will end with a discussion about the significance, implications, limitations, and future research directions based on the synergy of the two data chapters. All tables, figures and lists contained within this thesis can be found in Appendix A for the scoping review and Appendix B for the qualitative study.

Chapter 1: Introduction

Chapter 1 Overview

The purpose of this chapter is to provide an overview of background information relevant to the two manuscripts contained within this thesis. As this is a manuscript thesis, there will be repetition between components of this introduction and the two manuscript chapters (Chapters 2 and 3). However, this introduction will provide a detailed understanding of key terms, concepts, and fields needed to situate the thesis within the wider literature and academic milieu.

To provide context and background information, Chapter 1 begins with a description of the global and regional burden of HIV elaborating on the impact that access to antiretroviral therapy (ART) has on mortality, prevalence, aging and associated comorbidities. More specifically, background on HIV among people over the age of 50 will be described in both resource-rich and resource-limited regional settings as a core element of this thesis. A combined definition of quality of life along with an outline of different disability frameworks will be provided as key concepts discussed later in Chapters 2 and 3. Finally, this chapter ends with an emphasis on the pressing need for research to be conducted on the extent of knowledge on older adults living with HIV in sub-Saharan Africa and the contributions that a study on disability experiences of older adults living with HIV in Zambia can offer.

HIV Among People Over Fifty

Human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) have been characterized as one of the worst public health threats in recent history (Fauci, 2003). Despite a decline in AIDS-related deaths since 2005, in 2013 an estimated 35

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. million people were living with HIV worldwide (UNAIDS, 2014) and sub-Saharan Africa was the most severely affected region of the world with 1.5 million new infections that year (United Nations, 2015).

Advances in HIV treatment have reduced mortality rates (Mocroft et al., 2003; Palella et al., 1998) and increased the number of people living with HIV. Between 1995 and 2014, 13 million people living with HIV had received ART allowing for 7.6 million deaths to be averted (United Nations, 2015). Sub-Saharan Africa had the largest increase in the number of people receiving ART with 4.8 million deaths averted since the introduction of ART in the region (United Nations, 2015).

Despite improved efforts, the 2014 UNAIDS *Gap Report* listed twelve different groups of HIV infected people who have been largely ignored in efforts to address the HIV/AIDS epidemic (UNAIDS, 2014). People aged 50 years and older were identified as one of the groups left behind in HIV treatment and prevention campaigns. The *Gap Report* estimated that 4.2 million people aged 50 years and older were living with HIV globally with 120,000 people in this age group acquiring HIV every year. The report stated that people aged 50 years and older required specialized care for HIV as infections are often compounded by chronic health conditions associated with aging. However, research on older adults with HIV has been unevenly distributed globally with the bulk of studies generated in high-income countries while data from low-income countries remain sparse.

The success of available treatment has prompted some researchers to inquire about the impact of HIV on an older and aging adult population (Boon et al., 2010; Emlet, 2008; Emlet, 1997; Martin, Fain, & Klotz, 2008; Mutevedzi & Newell, 2011; Savasta, 2004; Siegel, Dean, & Schrimshaw, 1999). However, a scoping review on HIV, aging and health revealed that of the 451 studies identified for categorization, a majority (95.6%) were conducted in

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. high income countries with 160 studies conducted in the United States (US) (Chambers et al., 2012). Researchers in the US were the first to recognize and study an older cohort of people living with HIV (Knodel, Watkins, & Vanlandingham, 2003). As people aged with or acquired HIV later in life, those aged 50 years and older became the fastest growing segment of people living with HIV in the US (Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011). Researchers found that HIV-positive patients experienced several co-morbidities at an earlier time than their HIV-negative counterparts (Gebo, 2008), were more frequently symptomatic at diagnosis and experienced rapid infection progression, but were more likely to adhere to ART (Avelino-Silva, Ho, Avelino-Silva, & De Sousa Santos, 2011).

Due to earlier access to ART in high-income countries, much of what is known about HIV among older adults comes from data outside of sub-Saharan Africa. Qualitative studies conducted in the US focused on the benefits and challenges of aging with HIV while on ART (Siegel et al., 1999; Siegel, Raveis, & Karus, 1998). Researchers studied social support networks and found that older adults in the US experienced HIV-related stigma, ageism, and had challenges with disclosure (Emlet, 2006, 2007, 2008; Foster & Gaskins, 2009; Gosselink & Myllykangas, 2007). In Europe, Lazarus & Nielson projected that older adults will experience additional adversities due to co-morbid conditions, uncertain drug to drug interactions, and stigma (Lazarus & Nielsen, 2010). Researchers in Asia Pacific found that the effects of age have been demonstrated to cross over between resource-rich and resource-limited settings (Han et al., 2015). As such, aging with HIV in sub-Saharan Africa is anticipated to have many of the same aging effects on the body as seen in the global North but with different contextual and environmental factors that contour those experiences. Researchers in Thailand called for further expansion of studies on older persons in resource-limited settings around the world (Knodel et al., 2003) Resource-limited settings are

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. experiencing the fastest growth of an aging population and there will likely be substantial social implications for individuals and their wider global communities (Samman & Rodriguez-Takeuchi, 2013).

More than 2.5 million HIV positive adults over the age of 50 live in sub-Saharan Africa, accounting for more than half the people infected in this age cohort around the globe (UNAIDS, 2014). Sub-Saharan Africa experiences the greatest HIV burden, yet delay in free access to treatment and a lower life expectancy leaves a gap in both research attention and knowledge (UNAIDS, 2014). Many studies relate to older HIV positive adults serving as caregivers to their HIV-positive dying or ailing children or as the primary caregivers of their AIDS-orphaned grandchildren (Baylies, 2002; Ezeh, Chepngeno, Kasiira, & Woubalem, 2006; Munthree & Maharaj, 2010; Phiri, 2004; Rutakumwa, Zalwango, Richards, & Seeley, 2015; Schatz & Seeley, 2015; Simpson & Bond, 2014). Therefore, much of the research on older adults in sub-Saharan Africa has centered on how they are affected rather than infected by HIV. Yet with access to ART, the number of HIV infected people in older age groups is expected to grow in the coming decades (Mutevedzi & Newell, 2011; UNAIDS, 2014).

In resource-rich settings, the HIV and aging literature has brought attention to treatment effects of ART, co-morbidities, and changes in social experiences for those living with HIV. It is expected that the increasing prevalence of HIV among an older age cohort in sub-Saharan Africa will parallel similar complex challenges observed by researchers in the global North. A number of health challenges, including disability, are anticipated to affect overall quality of life. However, to date there has been no systematic effort to synthesize research examining quality of life in older adults living with HIV in sub-Saharan Africa. This gap in knowledge leads to the rationale and purpose for the manuscript in Chapter 2 where a

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. scoping review is conducted to determine what is known about the quality of life of older adults living with HIV in sub-Saharan Africa.

Quality of Life and Disability: Broad Definitions and Conceptual Overlap

Quality of life and disability are important to understand as major concepts in this thesis. Below, an outline of the definitions of each concept will be provided as well as how they are conceptualized and used in the context of this thesis.

Quality of Life

Quality of life is an ambiguous and contextually fluid phrase that has been used widely in colloquial language and holds multiple meanings that vary from one person to the next (Warren & Manderson, 2013). Ferrans questioned:

“But what is quality of life? The literature contains a bewildering array of characterizations. The term “quality of life” is commonly used to mean health status, physical functioning, symptoms, psychosocial adjustment, well-being, life satisfaction, or happiness...because the terms have meaning in everyday language, they are frequently used without explicit definition” (Ferrans, 2005, p. 14).

As suggested by some scholars, even the best current tools of measuring and understanding quality of life will remain only as an approximation as efforts are made to quantify an inherently qualitative term that requires subjective judgment (Barofsky, 2012). More specifically, Barofsky suggested that to set a content-based definition on an abstract concept such as quality of life would “unavoidably be an approximation” (p.628) and will have some limitations.

In this thesis, quality of life is understood by combining the definition from the World Health Organization (WHO) with Lorenz and colleagues’ definition of health-related quality of life (Lorenz, Shapiro, Asch, Bozzette, & Hays, 2001). Although the definitions

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conceptually overlap, they also include distinct components that allow them to be

complementary. The WHO defines quality of life as:

"[An] individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (World Health Organization, 1997, p. 1).

This definition takes into consideration the cultural context and values as well as the subjective nature of individuals' perceived goals and expectations which generate their understanding of their position in life, and ultimately a perceived satisfaction and quality of life. To further enhance an understanding of quality of life, health-related quality of life places the added dimension of ability to function in everyday tasks and offers self-assessment on life satisfaction. Lorenz and colleagues' succinctly define health-related quality of life as "how well people are able to perform daily activities and how good they feel about their lives" (Lorenz et al., 2001, p. 854).

Given this understanding, components of quality of life will be operationalized for the scoping review in Chapter 2. Quality of life is an important component of chronic conditions and is often used to measure and understand the impact of interventions. Instruments developed to measure quality of life can be adapted and validated in culturally appropriate ways to capture contextual differences. For example, when adapting a health-related quality of life questionnaire to a Ugandan context, researchers found that standard questions describing physical activities such as "running and participating in sports" needed to be modified to relatable activities such as "fetching water from a well" (Mast et al., 2004). Warren & Manderson (2013) have argued the instruments used to measure quality of life are unable to account for "how local cultural, economic, social, and political contexts profoundly

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. shape people's lived experiences" (p.4). It is therefore important to consider utilizing qualitative methods to understand factors that shape the lived experiences of people living with chronic disabilities whether these disabilities are HIV or aging-related. This leads to the purpose of the manuscript in Chapter 3 where an analysis of cross-sectional qualitative data aims to understand contextual factors that shape the quality of life and experiences of 10 older adults living with HIV in Zambia.

Disability

HIV infection, ART side effects and associated co-morbidities not only impact quality of life, but may also lead to experiences of disability. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) takes a human rights perspective on disability. With recognition that disability is "an evolving concept", the UNCRPD defines disability as the "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (UNCRPD, 2006, p.5). Historically, the term "disability" has had a number of meanings and applications. In a medical model of disability, disability is perceived as the result of an individual's functional deficiency whereas in a social model of disability, it is perceived as a result of the environment in which an individual belongs (Hanass-Hancock, 2009).

The International Classification of Functioning, Disability and Health (ICF) produced by the World Health Organization in 2001 provides a conceptual overlap between the medical and social models of disability (Hanass-Hancock, 2009). The framework outlines three levels at which disability can present itself: 1) impairment in body function and structure (i.e. pain) that can lead to 2) limitations in activities (i.e. difficulty walking) and 3) restrictions in participation (i.e. leisure activities) (World Health Organization, 2001). By

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. incorporating personal health conditions (i.e. disease) with environmental factors (i.e. stigma), the ICF serves as a bridge between the medical and social models of disability.

A similar framework for understanding disability that also merges personal and environmental factors is the Episodic Disability Framework (EDF). The EDF is similar to the ICF but has an added dimension of uncertainty because an episodic disability occurs when periods of good health is interrupted unexpectedly by periods of illness, a hallmark of HIV (O'Brien, Bayoumi, Strike, Young, & Davis, 2008). The EDF was designed to describe disability-related experiences specific to people living with HIV (O'Brien, Davis, Strike, Young, & Bayoumi, 2009). The EDF has only been used in North American settings, but the environmental component of the framework allows for transferable application and takes into consideration the local context where research in other settings can take place.

Advancing age is associated with health deterioration whereby disability becomes more frequent and prevalence of comorbidities are amplified (Maharaj, 2013). As adults with HIV grow older, they experience a decline in function associated with 'normal' aging (Onen et al., 2010). With evidence that being HIV positive while on ART alone can generate experiences of disability and with health deteriorating with advancing age, it may be possible that a combination of the two conditions may exacerbate experiences of disability. Further still, these aging experiences in a low-income and hyper-endemic setting such as Zambia has yet to be illuminated. Thus, this thesis integrates these factors to explore disability experienced by older adults aging with HIV in Zambia.

The Zambian Context

Chapter 3 will present findings from a qualitative study conducted in Zambia. The following description of the Zambian context is provided as additional information on the country that may enhance understanding of the burden of HIV among older adults in the

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. country. Zambia is one of the most severely affected countries in sub-Saharan Africa and has been considered a hyper-endemic country with high rates of HIV. In 2013, an estimated 1,100,000 people were living with HIV in Zambia (UNAIDS, 2013). Prevalence estimates vary widely by province, rural/urban settings, gender, and age. The two provinces with the highest prevalence of HIV in Zambia are Copperbelt (18.2%) and Lusaka (16.3%) (Central Statistical Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], & ICF International, 2014). HIV prevalence is highest for women aged 35-39 at 24.2% and is highest for men aged 40-44 years at 21% (Central Statistical Office (CSO) [Zambia] et al., 2014).

Since the introduction of free ART in Zambia in 2005 (World Health Organization, 2005), there has been a statistically significant reduction in HIV prevalence among adults (aged 15-49) between 2001-02 and 2013-14 (Central Statistical Office (CSO) [Zambia] et al., 2014). Although there are no prevalence statistics available specific to men and women aged 50 years and older, the Zambian Demographic and Health Survey found that HIV prevalence increased with age, peaking at 23% between the ages of 40-44 (Central Statistical Office (CSO) [Zambia] et al., 2014). With continued availability and use of ART in Zambia and a stabilization of mortality rates, this peak could possibly shift into the older age categories. As such, those aging with HIV may periodically experience disability and the long-term impacts of HIV, its treatment, and other co-morbidities (Hanass-Hancock & Nixon, 2009).

Currently, there is no published research literature on the experiences of older adults living with HIV in Zambia. Of the studies done on HIV infected individuals in Zambia during the era of free ART, many are demographic health surveys and therefore tell us little about the significance and meaning that older HIV infected individuals attribute to their experiences. To address this gap in knowledge, Chapter 3 will explore the phenomenon of disability related experiences of older adults living with HIV in Zambia.

Chapter 1 Summary: Overarching Purpose of Thesis

This chapter provided an overview of background information needed to understand the rationale and purpose of this manuscript thesis. In Chapter 2, I scope out literature pertaining to quality of life of HIV-infected older adults in sub-Saharan Africa and in Chapter 3, I explore disability related experiences of older HIV-infected adults living in Zambia. Research attention to older adults in a HIV hyper-endemic context is imperative to stimulate discussions in research, practice, and policy in order to place appropriate supports for the kinds of disabilities they experience in this context. With this backdrop of disease burden, this thesis offers a timely contribution to advance dialogue on HIV, aging, and disability with a geographically global perspective.

References

- Avelino-Silva, V. I., Ho, Y.-L., Avelino-Silva, T. J., & De Sousa Santos, S. (2011). Aging and HIV infection. *Ageing Research Reviews, 10*(1), 163–72. <http://doi.org/10.1016/j.arr.2010.10.004>
- Barofsky, I. (2012). Can quality or quality-of-life be defined? *Qualitative Life Research, 21*, 625–631. <http://doi.org/10.1007/s11136-011-9961-0>
- Baylies, C. (2002). HIV/AIDS and older women in Zambia : concern for self , worry over daughters, towers of strength. *Third World Quarterly, 23*(2), 351–375.
- Boon, H., Ruiter, R. A. C., James, S., van den Borne, B., Williams, E. W., & Reddy, P. (2010). Correlates of grief among older adults caring for children and grandchildren as a consequence of HIV and AIDS in South Africa. *Journal of Aging and Health, 22*(1), 48–67. <http://doi.org/10.1177/0898264309349165>
- Central Statistical Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], & ICF International. (2014). *Zambia Demographic and Health Survey 2013-2014*. Rockville, Maryland, USA.
- Chambers, L., Wilson, M. G., Rueda, S., Gogolishvili, D., Shi, Q., Rourke, S. B., & The Positive Aging Review Team. (2012). *Evidence Informing the Intersection of HIV , Aging and Health - A scoping review Evidence*. Toronto. Retrieved from <http://www.ohtn.on.ca/Documents/Research/OHTN-Positive-Aging-Final-Report-2012-12.pdf>

- Emlet. (1997). HIV/AIDS in the Elderly: A Hidden Population. *Home Care Provider*, 2(2), 69–75.
- Emlet. (2006). “You’re Awfully Old to Have This Disease”: Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS. *The Gerontologist*, 46(6), 781–790. <http://doi.org/10.1093/geront/46.6.781>
- Emlet. (2007). Experiences of stigma in older adults living with HIV/AIDS: a mixed-methods analysis. *AIDS Patient Care and STDs*, 21(10), 740–52. <http://doi.org/10.1089/apc.2007.0010>
- Emlet. (2008). Truth and consequences: a qualitative exploration of HIV disclosure in older adults. *AIDS Care*, 20(6), 710–7. <http://doi.org/10.1080/09540120701694014>
- Ezeh, A., Chepngeno, G., Kasiira, A. Z., & Woubalem, Z. (2006). The Situation of Older People in Poor Urban Settings: The Case of Nairobi, Kenya. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for Furthering Research* (pp. 189–213). Washington, D.C.: The National Academic Press. Retrieved from <http://www.nap.edu/catalog/11708.html>
- Fauci, A. S. (2003). HIV and AIDS: 20 years of science. *Nature Medicine*, 9(7), 839–843. <http://doi.org/10.1038/nm0703-839>
- Ferrans, C. E. (2005). *Outcomes assessment in cancer*. (J. Lipscomb, C. C. Gotay, & C. Synder, Eds.). New York: Cambridge University Press.
- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans’ management of HIV/AIDS stigma. *AIDS Care*, 21(10), 1306–12. <http://doi.org/10.1080/09540120902803141>
- Gebo, K. A. (2008). Epidemiology of HIV and response to antiretroviral therapy in the middle aged and elderly. *Aging Health*, 4(6), 615–627. <http://doi.org/10.2217/1745509X.4.6.615>.Epidemiology
- Gosselink, C. A., & Myllykangas, S. A. (2007). The leisure experiences of older US women living with HIV/AIDS. *Health Care for Women International*, 28(1), 3–20. <http://doi.org/10.1080/07399330601001402>
- Han, N., Wright, S., O’Connor, C., Hoy, J., Ponnampalavanar, S., Grotowski, M., ... Kamarulzaman, a. (2015). HIV and aging: insights from the Asia Pacific HIV Observational Database (APHOD). *HIV Medicine*, 16(3), 152–160. <http://doi.org/10.1111/hiv.12188>
- Hanass-Hancock, J. (2009). Disability and HIV/AIDS - a systematic review of literature on Africa. *Journal of the International AIDS Society*, 12(1), 34. <http://doi.org/10.1186/1758-2652-12-34>

- Hanass-Hancock, J., & Nixon, S. A. (2009). The fields of HIV and disability: past, present and future. *Journal of the International AIDS Society*, 12(1), 28.
<http://doi.org/10.1186/1758-2652-12-28>
- Knodel, J., Watkins, S., & Vanlandingham, M. (2003). AIDS and Older Persons: An International Perspective. *Journal of Acquired Immune Deficiency Syndrome*, 33(Suppl. 2), S153– S165.
- Lazarus, J. V., & Nielsen, K. (2010). HIV and people over 50 years old in Europe. *HIV Medicine*, 11(7), 479–481. <http://doi.org/10.1111/j.1468-1293.2009.00810.x>
- Lorenz, K. A., Shapiro, M. F., Asch, S. M., Bozzette, S. A., & Hays, R. D. (2001). Associations of symptoms and health-related quality of life: Findings from a national study of persons with HIV infection. *Annals of Internal Medicine*, 134(9 (Part 2)), 854–860.
- Maharaj, P. (2013). *International Perspectives on Aging and Disasters*. (J. L. Powell & S. Chen, Eds.) *Generations* (Vol. 4). New York: Springer. <http://doi.org/10.1007/978-1-4419-8357-2>
- Martin, C. P., Fain, M. J., & Klotz, S. A. (2008). The Older HIV-Positive Adult: A Critical Review of the Medical Literature. *American Journal of Medicine*, 121(12), 1032–1037. <http://doi.org/10.1016/j.amjmed.2008.08.009>
- Mast, T. C., Kigozi, G., Wabwire-Mangen, F., Black, R., Sewankambo, N., Serwadda, D., ... Wu, a W. (2004). Measuring quality of life among HIV-infected women using a culturally adapted questionnaire in Rakai district, Uganda. *AIDS Care*, 16(1), 81–94. <http://doi.org/10.1080/09540120310001633994>
- Mocroft, A., Ledergerber, B., Katlama, C., Kirk, O., Reiss, P., d'Arminio Monforte, A., ... Lundgren, J. D. (2003). Decline in the AIDS and death rates in the EuroSIDA study: an observational study. *The Lancet*, 362(9377), 22–29.
- Munthre, C., & Maharaj, P. (2010). Growing old in the era of a high prevalence of HIV/AIDS: The impact of AIDS on older men and women in KwaZulu-Natal, South Africa. *Research on Aging*, 32(2), 155–174. <http://doi.org/10.1177/0164027510361829>
- Mutevedzi, P. C., & Newell, M.-L. (2011). A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future Virology*, 6, 755–767. <http://doi.org/10.2217/fvl.11.43>
- O'Brien, K. K., Bayoumi, A. M., Strike, C., Young, N. L., & Davis, A. M. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health and Quality of Life Outcomes*, 6(76). <http://doi.org/10.1186/1477-7525-6-76>
- O'Brien, K. K., Davis, A. M., Strike, C., Young, N. L., & Bayoumi, A. M. (2009). Putting episodic disability into context: a qualitative study exploring factors that influence

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society*, 12(1), 5. <http://doi.org/10.1186/1758-2652-12-30>

- Onen, N., Overon, E., Seyfried, W., Stumm, E., Snell, M., Mondy, K., & Tebas, P. (2010). Aging and HIV infection: a comparison between older HIV-infected persons and the general population. *HIV Clinical Trials*, 11(2), 100–109. <http://doi.org/doi:10.1310/hct1102-100>
- Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., ... HIV Outpatient Study Investigators. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New England Journal of Medicine*, 338(13), 853–860. Retrieved from <http://www.nejm.org/doi/pdf/10.1056/NEJM199803263381301>
- Phiri, A. N. (2004). *A phenomenological study of ageing amongst the older persons in Zambia*.
- Plattner, L. E., & Meiring, N. (2006). Living with HIV: the psychological relevance of
- Rutakumwa, R., Zalwango, F., Richards, E., & Seeley, J. (2015). Exploring the Care Relationship between Grandparents / Older Carers and Children Infected with HIV in South-Western Uganda : Implications for Care for Both the Children and Their Older Carers, 2120–2134. <http://doi.org/10.3390/ijerph120202120>
- Samman, E., & Rodriguez-Takeuchi, L. K. (2013). *Old age, disability and mental health: data issues for a post-2015 framework - ODI Background Notes - Discussion papers*. London. Retrieved from www.odi.org.uk
- Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). What do we know about older adults and HIV? a review of social and behavioral literature. *AIDS Care*, 23(10), 1187–1207. <http://doi.org/10.1080/09540121.2011.564115>
- Savasta, A. M. (2004). HIV: associated transmission risks in older adults--an integrative review of the literature. *The Journal of the Association of Nurses in AIDS Care : JANAC*, 15(1), 50–9. <http://doi.org/10.1177/1055329003252051>
- Schatz, E., & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health*, (May), 1–16. <http://doi.org/10.1080/17441692.2015.1035664>
- Siegel, K., Dean, L., & Schrimshaw, E. W. (1999). Symptom Ambiguity among Late-Middle-Aged and Older Adults with HIV. *Research on Aging*, 21(4), 595–618. <http://doi.org/10.1177/0164027599214004>
- Siegel, K., Raveis, V., & Karus, D. (1998). Perceived Advantages and Disadvantages of Age among Older HIV-Infected Adults. *Research on Aging*, 20(6), 686–711. <http://doi.org/10.1177/0164027598206004>

- MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
- Simpson, A., & Bond, V. (2014). Narratives of Nationhood and HIV/AIDS: Reflections on Multidisciplinary Research on the HIV/AIDS Epidemic in Zambia over the Last 30 Years. *Journal of Southern African Studies*, 40(5), 1065–1089. <http://doi.org/10.1080/03057070.2014.946222>
- UNAIDS. (2013). *Global Report: UNAIDS report on the global AIDS epidemic 2013*. Retrieved from <http://www.unaids.org/en/media/unaids/contentasset>
- UNAIDS. (2014). *The Gap Report*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf
- United Nations. (2015). *The Millennium Development Goals Report 2015*. New York. Retrieved from [http://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG2015_rev\(July1\).pdf](http://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG2015_rev(July1).pdf)
- Warren, N., & Manderson, L. (2013). *Reframing disability and quality of life: A global perspective. Reframing disability and quality of life: A global perspective*. <http://doi.org/http://dx.doi.org/10.1007/978-94-007-3018-2>
- World Health Organization. (1997). *WHOQOL Measuring Quality of Life*. Retrieved from http://www.who.int/mental_health/media/68.pdf
- World Health Organization. (2001). *International Classification of Functioning , Disability and Health, Final Draft, Full Version*. Geneva. Retrieved from <http://www.sustainable-design.ie/arch/ICIDH-2Final.pdf>
- World Health Organization. (2005). Developing Countries & Free Access Fact Sheet- Countries offering free access to HIV treatment. Geneva. [http://doi.org/10.1016/S0002-8223\(97\)00353-2](http://doi.org/10.1016/S0002-8223(97)00353-2)

Chapter 2: Scoping Review

Background

With 24.7 million people infected with HIV, sub-Saharan Africa is the hardest hit region in the world (UNAIDS, 2014) and accounts for just under a third of the world's HIV infected population. With the availability of antiretroviral therapy (ART), people who are HIV infected and can tolerate treatment are now leading longer lives (Palella et al., 1998). Evidence on reduced adult mortality suggests that people are now living with HIV as a chronic condition rather than an acute one (Floyd et al., 2012). Morbidity, mortality, and the incidence of opportunistic infections have decreased over time regardless of sex, race, age, and other HIV transmission factors (Palella et al., 1998). Researchers suggest there may be an increase in incidence among older adults, further contributing to an increasing pool of long-term HIV survivors (Emlet, 2006).

Little is known about older adults living with HIV in SSA despite the likelihood that people aged 50 years and older will require specialized care (UNAIDS, 2014). Indeed, the Joint United Nations Program on HIV and AIDS (UNAIDS) published the *Gap Report* in 2014 to highlight groups of people who have been largely ignored in HIV treatment and prevention programs. People aged 50 years and older were one of the 12 groups identified as being left behind in these efforts (UNAIDS, 2014). The *Gap Report* estimated that of the 4.2 million people aged 50 years and older living with HIV globally, 2.5 million live in sub-Saharan Africa (UNAIDS, 2014). In the era of available ART, health systems in sub-Saharan Africa may not be prepared to address the unique needs and specialized care that may be required for managing HIV and other chronic conditions (Mutevedzi & Newell, 2011, p. 760).

While some attention has been given to older adults living with HIV, most studies were conducted outside of sub-Saharan Africa (Avelino-Silva et al., 2011; Centre for Disease Control and Prevention, 2015; Chambers et al., 2012; Emler, 2006, 2007, 2008; Foster & Gaskins, 2009b; Gebo, 2008; Gosselink & Myllykangas, 2007b; Han et al., 2015; Knodel & Vanlandingham, 2002; Lazarus & Nielsen, 2010; Samman & Rodriguez-Takeuchi, 2013). In the global North, aging with HIV has led to complexities such as premature aging (Wallach & Brotman, 2012), increased co-morbidities (Martin, Fain, & Klotz, 2008b; Mutevedzi & Newell, 2011; Namisango et al., 2012; Shippy & Karpiak, 2005), and an unexpected increase in disablement that impacts quality of life (Nixon, Forman, et al., 2011; O'Brien et al., 2008; Rusch et al., 2004). The effects of age have been demonstrated to cross over between resource rich and resource limited settings (Han et al., 2015). As such, aging with HIV in sub-Saharan Africa is anticipated to have similar age effects on the body as seen in the global North but with varied contextual and environmental factors that shape quality of life.

In sub-Saharan Africa, studies on older adults in the context of HIV have focused on those who are HIV-affected. Many studies investigated the impact HIV has on an older adult populations as they care for their children ailing or dying from AIDS or serve as caregivers to their AIDS-orphaned grandchildren (Baylies, 2002; Ezeh et al., 2006; Munthree & Maharaj, 2010; Phiri, 2004; Rutakumwa et al., 2015; Schatz & Seeley, 2015; Simpson & Bond, 2014). In a scoping review conducted on HIV, aging and health, the Ontario HIV Treatment Network (OHTN) found that in 2012, only 3.9% (n= 8) of the 204 published studies globally came from the WHO region of Africa and most of those studies had a quantitative focus that calculated frequency, prevalence, length of survival, and adherence to ART (Chambers et al., 2012). Yet, information on prevalence does not help us understand the impact of aging with HIV on overall quality of life. Quality of life offers a useful way to either quantify or

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. conceptualize facets of a broad understanding of health and disability. Quantitative and qualitative techniques can be used to capture the impact HIV, associated comorbidities, and contextual factors may have on well-being.

To advance understandings of HIV among older adults, it would be useful to know the current state of published research literature as it pertains to the quality of life of older adults infected by HIV in the sub-Saharan Africa region. While some general research on HIV and aging in sub-Saharan Africa exists, the extent of published research literature on the quality of life adults aged 50 years and older living with HIV in this region is unknown. To inform future research directions, it is appropriate to use a scoping review methodology to systematically search, map, extract, collate, and synthesize peer-reviewed literature.

Research Question

What is the current state of knowledge in the existing published, peer-reviewed literature about the quality of life of an aging population of people aged 50 years and older living with HIV in sub-Saharan Africa?

Methods

To answer the research question, Arksey & O'Malley's 2005 scoping review framework was used to answer the research question (Arksey & O'Malley, 2005). The purpose of a scoping review is to "map the key concepts underpinning a research area and the main sources and types of evidence available" (Mays, Roberts, & Popay, 2001, p. 194). The first step of the 5-staged framework was to identify a research question. Once the research question for this study was articulated, the component key terms of the question were studied to gain conceptual clarity, inform key search terms, and establish a comprehensive inclusion and exclusion criteria for the second and third step of the framework, which was to identify

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. and select relevant studies. The key terms extracted from the research question were:

HIV/AIDS, older adults, sub-Saharan Africa, and quality of life. The fourth stage of the framework was charting the data. For each of the included studies, the following descriptive components were extracted: characteristics of the authors, year of study publication, years of data collection, study site, title, methodological design, purpose and aims of the study, participant demographics (i.e. sex, age, HIV infected or affected), component of quality of life addressed, and the key findings of the study. Stage 5 involved collating, summarizing, and reporting quantitative and qualitative results from the included studies. The framework offered consultation as an optional sixth step to enhance the results and to attempt to improve the usefulness of the scoping review as an end product. However, it was deemed that a consultation was unnecessary to answer the present research question as the aim is to provide a description of the present published, peer-reviewed literature and not to elicit opinions of stakeholders on their thoughts on how much and of what nature literature was published on older adults living with HIV in sub-Saharan Africa.

Databases Searched

Six research databases were identified in consultation with a librarian based on the likelihood of finding studies that cover the defined concept domains outlined above. These were: 1. Ageline 2. CINAHL 3. EMBASE 4. Global Health 5. Medline 6. PsychInfo. Ageline was chosen because of the focus on social gerontology for adults exclusively over the age of 50. CINAHL was selected because of its focus on journals that publish research relevant to nurses and other allied health professionals. Embase (Excerpta Medica database) was chosen because it contains a wide variety of publications on biomedical and pharmacological studies. Global Health was relevant as the intention of the study was to inform work of policy makers, practitioners and researchers working in the field of global health. To capture HIV

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. specific articles, Medline was selected because it contains biomedical research articles from around the world. Finally, PsychInfo was chosen to address behavioral sciences and mental health and to ensure psychological components of quality of life such as psychological adaptation, self-perceptions and self-evaluation were captured. Overall, these journals covered a breadth of literature and disciplinary topics identified as appropriate to capture the predetermined broad concept domains outlined in our research question. The database searches were performed in March 2015. Once the database searches were complete, titles, authors, years of publication, and abstracts were downloaded and extracted into excel spreadsheets to further sort through the articles to include or exclude from the review. Using the inclusion and exclusion criteria, all titles and abstracts were screened.

Initial searches were conducted in each of the databases as an initial preview and scope of the literature. After a preliminary scan of the articles that were retrieved from the searches, the search strategy was refined based on appropriate terms used in the databases. Ageline only allowed for a key term search. The five other databases (CINAHL, EMBASE, Global Health, MEDLINE, and PsychINFO) allowed for a broader search with both keyword and subject heading searches for some terms. Both keyword and subject heading searches were conducted when available. See Appendix A for a full detailed report on the search terms used, the number of hits per search line and whether the terms were searched as key words or key concepts.

Concept Clarity, Selected Search Terms, and Inclusion and Exclusion Criteria

Below, the four concept domains of HIV/AIDS, older adults, sub-Saharan Africa, and quality of life are outlined along with their accompanying search terms. With the meaning of concept domains in mind, inclusion and exclusion criteria were established (Table 1). In an effort to select papers for the scoping review that would be relevant to answering the research

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. question, I provide an explanation on how each of these criteria aligned with the respective concept domains.

Once there was clarity in meaning of each of the concept domains (HIV/AIDS, older adult, sub-Saharan Africa, and quality of life), synonyms were generated. Each chosen synonym of a concept domain was searched on an independent line either as a keyword or a subject-heading search. Once the synonyms for the key concept were entered into the database, I used medical subject headings (MeSH) terms and Boolean connectors “OR”, “AND” and “NOT” to isolate potentially relevant articles. The Boolean connector “OR” was used between all related concepts in order to capture the articles under each of these sub-headings. This was repeated for all concept domains with the exception of the concept “older adult” in which minor differences pertaining to what was captured in the general concept domain are elaborated upon in more detail below. The final step was to merge all of the concept domains together with the Boolean operation “AND” to find articles that overlapped with all concept domains. I searched each of the six aforementioned databases line by line with this same pattern and process of combining the general concept domains.

HIV/AIDS

HIV/AIDS as a concept domain is understood as the human-immunodeficiency virus or a disease that can exist simultaneously with other co-morbidities. To be included in the review, studies must have participants who are infected with HIV. Positive HIV status could be verified through self-report or serological testing. I included studies that conducted research on both HIV infected and affected participants as long as HIV infected participants were present in the sample. The search terms used for HIV/AIDS were: HIV, AIDS, human immunodeficiency virus, acquired immunodeficiency syndrome.

Older Adults

In the context of HIV in sub-Saharan Africa, I defined people aged fifty years and older to be “older adults”. I justify this categorization in two ways. First the average life expectancy between people living in the region of sub-Saharan Africa is far younger than that of developed countries. The average estimated life expectancy at birth in sub-Saharan Africa is 57 years of age while in a country such as Canada, it is 84 (The World Bank, 2015b). In addition, due to the precarious nature of HIV, the life expectancy of those infected has historically been lower than the general population. This definition is also in alignment with definitions used by policy makers and international government organizations in the context of HIV (Aghaizu et al., 2013; Centre for Disease Control and Prevention, 2015; Chambers et al., 2012; Public Health Agency of Canada, 2010). Subsequently, it is appropriate to describe a person who is 50 years and older and living with HIV in sub-Saharan Africa as an “older adult”. Although some studies identified in the initial search may have had individuals aged 50 years and older included as part of their participant pool, I included only those that had participants who were exclusively older than 50. This decision was strategic in that the results that are reported would pertain only to this age cohort.

The search terms used to capture the concept of older adults were: older adult, aging, elderly care, accelerated aging, geriatrics, old age, senescence, middle aged, and adult. Middle aged was included because in many databases people aged 45 -64 are considered middle aged, which overlaps with the age range of this study. In order to do a comprehensive search of this concept, the search terms needed to encompass all papers that would include an older adult population, which may unintentionally capture additional papers that may not necessarily fit the exclusive 50 years and older criteria. As such, the inclusion and exclusion criteria became a crucial screening tool to ensure only articles that have participants who are

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. exclusively over the age of 50 were included. To reduce the number of extraneous articles arising from the search, I removed younger age groups by searching concepts such as “children” or “adolescents” and from there, used the Boolean term “NOT” in combination with the general domain concept search of “older adults” and “aging”.

Sub-Saharan Africa

Sub-Saharan Africa was defined as the geographic region below the Sahara desert with countries listed as part of the region by the World Bank (The World Bank, 2015a). A broad search for sub-Saharan Africa and Africa South of the Sahara was completed along with a line-by-line search for each of the 47 sub-Saharan countries listed (List 1).

Quality of Life

There is no universally agreed upon definition of quality of life despite being used widely in colloquial language. Quality of life holds a number of meanings but is often used without much thought or clear explanation. As such, it is challenging to operationalize the term for a systematic search of the literature especially when databases vary by disciplines. However, in this study an understanding of quality of life as defined by the World Health Organization (WHO) is merged with Lorenz and colleagues definition of health-related quality of life (Lorenz et al., 2001). Both definitions provide some conceptual overlap, but also include complementary components that allow for a broad understanding of quality of life. The WHO defines quality of life as an "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (World Health Organization, 1997, p.1). Lorenz et al (2001) described health-related quality of life as an

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individuals' ability to perform daily activities and their level of satisfaction with various components of their lives (Lorenz et al., 2001).

Given this understanding, and with recognition that quality of life has yet to have an agreed upon definition, this paper adopts components of quality of life to create a broad understanding of the term. Daily functioning was found to be the most significant factor of life satisfaction, otherwise known as quality of life, so a search term of activities of daily living/ daily activities was used to supplement and capture content that would fall within that defined realm (Phaladze et al., 2005).

To operationalize the meaning of quality of life in this study the five search terms used were quality of life, psychological adaptation, activities of daily living, self-concept and self-efficacy as these were identified as key components to the definitions above. Any study that addressed an aspect of participant's quality of life, well-being, function, and daily lives was included. It is important to recognize that my choice in terminology could have been broader or narrower, resulting in more or fewer studies. I recognize there are other terms that could have been used synonymously, but concluded that the five chosen terms, one of them being quality of life itself, is sufficiently broad enough to capture the scope of our defined conceptual understanding of quality of life without including extraneous articles that would likely be excluded from the study in subsequent screening steps.

Different databases defined quality of life in different ways through suggested related terms or as indicated in the scope note of flagged key terms. For example, in the Global Health database, some related terms included: basic needs, cultural environment, leisure, lifestyle, living standards, social systems and working conditions. For MEDLINE, quality of life was described in the scope note as: "A generic concept reflecting concern with the modification and enhancement of attributes. E.g. Physical, political, moral and social

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. environment; the overall condition of human life.” The terms that were associated with quality of life were: lifestyle, sickness, impact profile, and value of life. In the EMBASE database, quality of life encapsulated articles pertaining to quality of life or health related quality of life, although a definition was not explicitly provided in the scope note. In CINAHL, the scope note of quality of life was: “The general well-being of an individual”.

General Search Strategy

Once the final searches for each of the databases were complete, titles and abstracts were sorted into a “keep”, “unclear”, and “discard” pile. Four databases allowed for extraction of titles and abstracts into an excel spreadsheet (EMBASE, Global Health, MEDLINE, and PsychINFO). The other two databases (Ageline and CINAHL) allowed for extraction of titles and abstracts in a RIS format that allowed for sorting in the reference manager, Mendeley. For all of the eliminated papers, the reasons for elimination or being placed in the “discard” pile were documented in an excel spreadsheet. The full text was retrieved for those studies in which a title and abstract did not provide enough information to apply the inclusion and exclusion criteria (those were originally sorted into the “unclear” pile). The full article text was then downloaded and analyzed according to the same inclusion and exclusion screening techniques. From there, these “unclear” articles were re-categorized into the “keep” or “discard” pile. Once all included articles from the database search were finalized, a hand-search of the citation list for each of the included articles was conducted until no new studies met the inclusion criteria.

Results

The six databases searched yielded a total of 1021 titles and abstracts. Many articles were eliminated based on the strict age inclusion/exclusion criteria. The majority of titles and abstracts were eliminated on the basis of age as many studies failed to meet the inclusion

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. criteria of having participants exclusively aged 50 years and older included in their sample.

Some studies only indicated that participants were aged 18 years and older but did not provide a separate analysis based on chronological age. Of the studies that met inclusion criteria for age, more articles and titles were eliminated because participants were affected but not infected by HIV (served as caregivers of their HIV-orphaned grandchildren). Further still, other titles and abstracts were simply excluded because HIV was only briefly discussed in context of the introduction of articles but was not the main focus of the paper, or articles did not include participants (i.e. modeling and projections for cost-effectiveness analyses), or studies were conducted in locations outside of sub-Saharan Africa (i.e. study was conducted in England on HIV positive migrants). Figure 1 in Appendix A provides a flowchart of included articles, removed duplicates, and outcomes of hand-search of citations leading to the total of eight included articles for the study. Table 2 provides an overview of characteristics of the included studies and a detailed breakdown of the databases searched, the number of title hits and articles included along with the authors of the final included can be found in the tables and images provided in Appendix A.

Authors

A total of 24 different authors contributed to at least one of the eight included studies. Of these, 10 authors in total contributed to more than one study. Four of these authors, (in alphabetical order by last name: Boerma, Mutevedzi, Newell, and Kinyanda) contributed to 2 studies, while Chatterji and Zalwayngo contributed to 3 studies. Kowal contributed to four studies, and the lead authors for one of the eight included papers, Mugisha, Scholten and Seeley, contributed to 5, 6, and 7 studies respectively. I did this analysis in part to identify prominent scholars working in the field of aging and HIV in sub-Saharan Africa and draw connections to understand the disciplinary and locale of where these studies are taking place.

Author's Location

Through identification of their affiliated institution, there were 30 authors in total representing 5 countries. Many had more than one academic affiliation. The specifics of these affiliations can be found in Table 3.

Authors and Journals that Articles are Published In As An Indication of Discipline

Based on the institutions and departments that authors were associated with, authors' academic backgrounds included medicine, public health, health sciences, international development, health statistics and information systems, population studies, social and human sciences, epidemiology and biostatistics, and tropical medicine. Most of the authors were affiliated with departments of public health, medicine, and social sciences.

Journals in which the articles were published were examined to understand which general fields of study were engaged in quality of life work with this particular demographic. One paper was a proceeding from a conference (Seeley et al. 2010), therefore journal-related information was not extracted. Two studies were published in the African Journal of AIDS Research and two articles were published in BMC Public Health. Articles were published in journals that catered to an audience interested in HIV/AIDS, public health, social sciences and gerontology although many of these journals accepted articles from a wide range of disciplines.

Year of Publication, Year of Data Collection, and Study Site

All of the articles included in this study were published after 2010 with the majority (6) being published in 2012 and 2013. Data collection occurred after 2009 with most of the data being collected in 2010. Of the included studies from the search, data were collected in only two countries in sub-Saharan Africa: Uganda and South Africa. With the exception of the two articles published by Nyirenda as the lead author, all the studies collected data from

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. Uganda. One of Nyirenda and colleagues' studies had data collected from South Africa only (2012) while the other study provided a comparison between data collected in South Africa and Uganda (2013).

Methodological Design

Four studies utilized quantitative approaches, while the other four used qualitative approaches to study different facets of quality of life among older adults living with HIV. Only one study collected original data (Kuteesa, Seeley, Cumming, & Negin, 2012), while the rest conducted a secondary analysis on data from one of two data repositories. For the studies that did a secondary analysis in Uganda, all the data came from the Medical Research Council/Uganda Virus Research Institute (MRC/UVRI). For the two studies that used data collected from South Africa, Nyirenda and colleagues accessed data from the Africa Centre surveillance area in rural South Africa using adapted instruments from the World Health Organization's Study on Global Ageing and Adult Health (SAGE). Various component samples were chosen based on the research question of each of the studies, but all of the quantitative-based studies were from these original dataset repositories.

Exclusively HIV Infected or HIV Infected and Affected

Kuteesa et al. (2012) and Seeley et al. (2010) authored the only two studies that examined quality of life among exclusively HIV infected participants. The other studies included some participants who were infected with HIV and some who were affected by HIV. In these studies, the authors sometimes separated out components of their analyses, while other times aggregated the results to draw broader conclusions about the quality of life of older adults in sub-Saharan Africa.

Quality of Life Concept Addressed

Depending on the study design, included studies engaged with various component concepts of quality of life. Only one paper (Nyirenda et al., 2012) provided an explicit definition of quality of life. Using different methods, the studies offered descriptions, comparisons and analyses on various components of the quality of life. Some provided quantitative evidence and used standardized tools such as the World Health Organization Quality of Life WHOQOL assessment tool (Mugisha et al., 2013; Nyirenda et al., 2012, 2013), the World Health Organization Disability Assessment Schedule- II WHODAS II (Nyirenda et al., 2012; Scholten et al., 2011) to study quality of life in populations, while others used qualitative methods to understand the underlying mechanisms. When analyzed together, qualitative studies provided a richer explanation for the reasons and context behind quality of life scores quantitatively provided.

Synthesis of Key Findings

Given the small number of articles identified in the scoping review, a synthesis of findings from each study will be reported thematically. However, it is important to be aware that the included studies were not assessed for quality, so the following synthesis will be predominantly descriptive. The synthesis of key findings will be presented in three broad topics that combine findings from both quantitative and qualitative components of included studies: 1. Aging with HIV and the impact on health, activities, and relationships; 2. Gravity of systemic factors and 3. Comparative findings on quality of life, functional status, and overall health.

Aging with HIV and the Impact on Health, Activities, and Relationships

Some of the included studies identified the impact aging with HIV had on the health, activities, and relationships of the populations included in their respective studies. Physical-

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. health and self-reported health were found to decrease with increasing age (Scholten et al., 2011). Older adults tended to have a decreased sex drive (Richards, Zalwango, Seeley, Scholten, & Theobald, 2013). Despite having HIV, many older adults continued to take on caregiving responsibilities (Mugisha et al., 2013). Kuteesa et al. (2012) noted that older adults with HIV experienced the double burden of stigma of both HIV and old age. Sero-discordant couples in denial of their HIV status tended to have a delay in access to treatment and care (Kuteesa et al., 2012). Generally, participants who sought and received care in the study by Kuteesa and colleagues (2012) felt they were well respected by healthcare workers and many wished to give back to their communities through service, education and emotional support. Seeley et al. 2010 noted that older adults who were HIV infected and were not on ART treatment had less social interaction than those who were on treatment and likely suffered an impaired social network (Seeley et al., 2010).

Gravity of Systemic Factors

Several studies emphasized the importance of systemic level factors such as gender and income that have an impact on participant's quality of life. Gender has a quantifiable effect on quality of life scores where HIV-infected women had better health and functional status than HIV-infected men in the study (Nyirenda et al., 2012). Using an expanded definition in which safety and violence were included as part of quality of life, Richards et al. (2013) found that women reported facing gender violence.

Income and poverty largely shaped participants' quality of life. Income was shown to have more of an impact on shaping participants' quality of life than HIV and aging (Wright, Zalwango, Seeley, Mugisha, & Scholten, 2012). Some participants complained consistently about aging and HIV related health matters, however these were not the main factors that negatively affected their wellbeing and caused despondency (Wright et al., 2012). Rather,

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. they found that problems related to “finances, work, diet, other resource constraints, lack of assistance and support, loneliness, isolation and separation from important relatives” (Wright et al., 2012, p. 329) were more important factors that influenced their quality of life. These findings are consistent with those found by Nyirenda et al. (2012) where income was also found as the greatest factor that affected quality of life. Participants who had a source of income and belonged in the upper two economic quintiles tended to have better overall health regardless of HIV status (Nyirenda et al., 2012). Richards et al. (2013) offers a qualitative understanding of income by indicating that few older adults had access to pensions and that many older adults were without financial support. Seeley et al. (2010) further supports this income challenge by using a framework of poverty. Poverty, closely tied with food insecurity, jeopardized adherence to ART (Kuteesa et al., 2012). Seeley et al. (2010) noted that several people in her study mentioned stomach pains when they took their medicines on an empty stomach because they did not have enough food in the house.

Comparative Findings on Quality of Life, Functional Status, and Overall Health

Several studies compared quality of life, functional status, and overall health between subgroups within each study. HIV positive older adults generally had similar health status than those uninfected (Nyirenda et al., 2012, 2013; Scholten et al., 2011; Seeley et al., 2010). The only significant difference between these two groups was reported by Scholten et al. (2011) where BMI was significantly lower for those who were HIV positive. HIV positive individuals had better access to health care (Seeley et al., 2010). Older adults who had access to health care in the study by Scholten et al. (2011) were less susceptible to depression because of their ability to access care and support. Another study identified that those who were HIV infected had more financial support than those that were not infected (Mugisha et al., 2013). Table 4 provides a summary of comparisons made by study author and year.

On a wider scale of comparison between two populations of older adults, a paradoxical discrepancy between physical wellbeing and subjective quality of life measures for participants from South Africa and Uganda was found (Nyirenda et al., 2013). Despite having poorer physical well-being indicators as measured by obesity (BMI >30) in the study, South African participants were twice as likely to report being in good health than Ugandan participants (Nyirenda et al., 2013).

The synthesis of key findings reveal that of the studies that reported poorer health as participants aged, activities such as caregiving responsibilities were maintained despite HIV status. Additionally relationships were affected as a result of the stigma surrounding a positive HIV status. Of the reported comparisons, it appears that HIV positive individuals scored better on many health and functional status measures than their HIV negative peers. Studies reported a paradox between physical and subjective well-being which may challenge assumptions about the similarities and differences in quality of life among HIV infected and HIV uninfected older adults.

Discussion

This is the first scoping study that examines the current state of the published research literature on quality of life for an older adult population who are infected with HIV/AIDS in sub-Saharan Africa. Despite an expected growing proportion of older adults living with HIV in sub-Saharan Africa, this scoping review search revealed only one article, by Kuteesa et al. (2012), that exclusively attended to the quality of life of adults aged 50 years and older living with HIV. To generate a more complete picture of aging and HIV needs, understanding this population's quality of life through surveys, questionnaires, and daily experiences will be crucial.

The disciplinary backgrounds of research team members provided a sense of encouragement, as the response to complex global health issues typically requires an integrated and collaborative solution that can arise when a number of perspectives are taken into consideration. From the studies identified, the number and location of studies were primarily centered on data collected from a single site in Uganda using the MRC/UVRI data that were available. As a result of repetitious use of data from these repositories, information on the year of publication and data collection timeline report within the same time range and does not provide enough information about a pattern or trend. Those involved in this initiative demonstrated great use of data collected, international collaborative research teams, and a carefully planned out forward-thinking research design. Yet, there are limitations to the data provided as only two of 47 countries in sub-Saharan Africa were represented and the region is not homogenous. Further research is needed on older adults from different sociocultural, economic, and political contexts in different sub-Saharan African countries to gain a more wholesome picture of quality of life among older adults in the region.

Incongruent findings on quality of life from quantitative studies and qualitative studies posed an interpretation challenge between population level data and the experiences offered by individual narratives. Quantitative studies showed that there was no difference in quality of life or functional status between HIV positive older adults and those who were uninfected. In some counter-intuitive cases, HIV positive individuals were found to be better off on health and functional measures than their HIV negative peers (Nyirenda et al., 2012, 2013). This could be a result of participants reframing the meaning of living with HIV from a negative and fatalistic state to one that was more accepting (Plattner & Meiring, 2006). This was similar to what was seen in the disability and quality of life paradox where those with

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. disabilities reconceptualised their experiences and ended up reporting a high quality of life (Albrecht & Devlieger, 1999).

In contrast the qualitative studies provided a negative outlook on the quality of life of older adults living with HIV. The issues addressed painted a bleak picture of the challenges of living with HIV as an older adult in sub-Saharan Africa. Topics and themes that arose from qualitative studies focused on the double burden of stigma (Kuteesa et al., 2012), gender violence and vulnerabilities (Richards et al., 2013), decreased sex drive (Richards et al., 2013), decreased social networks(Seeley et al., 2010), lack of assistance and support (Wright et al., 2012), hunger pains from food insecurity (Seeley et al., 2010), and other financial resource constraints (Wright et al., 2012).

With half the studies included in this scoping review utilizing quantitative methods to understand quality of life and the other half of studies using qualitative methods, there were synergistic benefits of having both methodological designs included in the review. Quantitative findings provided breadth of understanding quality of life on a population level, while qualitative findings provided depth in understanding how some people personally defined their quality of life. However, different measures of quality of life with methodological epistemologies and ontologies resulted in a paradoxical understanding of overall health and well-being. Further quantitative research is needed to understand and monitor the extent of self-rated quality of life on a population, but there is also a need for further expansion of qualitative research to understand the experiences of older people living with HIV in sub-Saharan Africa as the standardized questionnaires in WHOQOL had limits in providing an understanding of the subjective experiences.

Limitations

There are some limitations that should be considered when interpreting the findings of this study. The first is with regards to the search strategy and noting that only 6 databases were identified to be relevant to the search. Although possible, it is unlikely that searches in additional databases will reveal additional articles that could meet the inclusion criteria as we intentionally chose databases that were broad in scope and other databases that were specific to our study population. A second limitation pertains to selecting and operationalizing search terms for quality of life. Although effort was made to be inclusive of a broad conceptualization of quality of life, studies that may be relevant but did not utilize the selected quality of life terminology defined in the search may not have been included in this review.

The third limitation to this study that could affect the interpretation of the synthesized findings is the small number of articles identified in the initial search. Of the 8 studies included, only studies conducted in Uganda and South Africa were captured. This certainly does not provide complete picture of older adults living with HIV in all of sub-Saharan Africa, especially with the heterogeneity of contexts in the region. Further, data came mostly from two repositories meaning that information came from the same database and location. Consequently, there is still much to learn and discover within those two countries and in other countries in sub-Saharan Africa.

Future Directions

Future studies could examine an expanded definition of quality of life and update the literature search as more studies on HIV infected older adults in sub-Saharan Africa are anticipated to be published with increased patient survival. Understanding the experiences of an older adult population in sub-Saharan Africa will remain an important endeavor for

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. researchers to inform policy makers and practitioners on the factors that could improve the quality of life of older adults with HIV. Additionally, rather than applying a chronic illness perspective to a quality of life model for people living with HIV, a disability framework could be better positioned to orient the micro to macro contexts within which older HIV-positive adults live.

Conclusion

In this scoping review, it was affirmed that there is a gap in current research knowledge published on the quality of life of HIV/AIDS among an older adult population in sub-Saharan Africa. A systematic search of six databases revealed only 8 studies that met inclusion criteria after screening. Of the studies identified, quantitative studies pointed to minute differences in health and functional status between HIV positive and HIV negative older adults in sub-Saharan Africa while qualitative studies focused on contextual factors such as poverty that illuminated a greater burden to the quality of life of HIV positive older adults. In the context of a growing need to understand and prepare health systems for an aging demographic shift, further research needs to be done.

References

- Aghaizu, A., Brown, A., Nardone, A., Gill, O., Delpech, V., & contributors. (2013). *HIV in the United Kingdom: 2013 Report: data to end 2012*. London. Retrieved from http://www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317140300680
- Albrecht, G. L., & Devlieger, P. J. (1999). The disability paradox: high quality of life against all odds. *Social Science and Medicine*, 48, 977–988.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework, (783016864). <http://doi.org/10.1080/1364557032000119616>
- Avelino-Silva, V. I., Ho, Y.-L., Avelino-Silva, T. J., & De Sousa Santos, S. (2011). Aging and HIV infection. *Ageing Research Reviews*, 10(1), 163–72. <http://doi.org/10.1016/j.arr.2010.10.004>
- Baylies, C. (2002). HIV/AIDS and older women in Zambia : concern for self , worry over daughters, towers of strength. *Third World Quarterly*, 23(2), 351–375.

- MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
Centre for Disease Control and Prevention. (2015). *HIV Among People Aged 50 and Older*.
Retrieved from
http://www.cdc.gov/hiv/pdf/group/age/olderamericans/hiv_among_people_aged_50_and_over.pdf
- Chambers, L., Wilson, M. G., Rueda, S., Gogolishvili, D., Shi, Q., Rourke, S. B., & The Positive Aging Review Team. (2012). *Evidence Informing the Intersection of HIV, Aging and Health - A scoping review Evidence*. Toronto. Retrieved from
<http://www.ohtn.on.ca/Documents/Research/OHTN-Positive-Aging-Final-Report-2012-12.pdf>
- Emlet. (2006). “You’re Awfully Old to Have This Disease”: Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS. *The Gerontologist*, 46(6), 781–790. <http://doi.org/10.1093/geront/46.6.781>
- Emlet. (2007). Experiences of stigma in older adults living with HIV/AIDS: a mixed-methods analysis. *AIDS Patient Care and STDs*, 21(10), 740–52. <http://doi.org/10.1089/apc.2007.0010>
- Emlet. (2008). Truth and consequences: a qualitative exploration of HIV disclosure in older adults. *AIDS Care*, 20(6), 710–7. <http://doi.org/10.1080/09540120701694014>
- Ezeh, A., Chepngeno, G., Kasiira, A. Z., & Woubalem, Z. (2006). The Situation of Older People in Poor Urban Settings: The Case of Nairobi, Kenya. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for Furthering Research* (pp. 189–213). Washington, D.C.: The National Academic Press. Retrieved from <http://www.nap.edu/catalog/11708.html>
- Floyd, S., Marston, M., Baisley, K., Wringe, A., Herbst, K., Chihana, M., ... Zaba, B. (2012). The effect of antiretroviral therapy provision on all-cause, AIDS and non-AIDS mortality at the population level - a comparative analysis of data from four settings in Southern and East Africa. *Tropical Medicine and International Health*, 17(8). <http://doi.org/10.1111/j.1365-3156.2012.03032.x>
- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans’ management of HIV/AIDS stigma. *AIDS Care*, 21(10), 1306–12. <http://doi.org/10.1080/09540120902803141>
- Gebo, K. A. (2008). Epidemiology of HIV and response to antiretroviral therapy in the middle aged and elderly. *Aging Health*, 4(6), 615–627. <http://doi.org/10.2217/1745509X.4.6.615>.Epidemiology
- Gosselink, C. A., & Myllykangas, S. A (2007). The leisure experiences of older US women living with HIV/AIDS. *Health Care for Women International*, 28(1), 3–20. <http://doi.org/10.1080/07399330601001402>
- Han, N., Wright, S., O’Connor, C., Hoy, J., Ponnampalavanar, S., Grotowski, M., ... Kamarulzaman, a. (2015). HIV and aging: insights from the Asia Pacific HIV

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
Observational Database (APHOD). *HIV Medicine*, 16(3), 152–160.
<http://doi.org/10.1111/hiv.12188>

- Knodel, J., & Vanlandingham, M. (2002). The impact of the AIDS epidemic on older persons. *AIDS*, 16((Suppl 4)), 77–84.
- Kuteesa, M. O., Seeley, J., Cumming, R. G., & Negin, J. (2012). Older people living with HIV in Uganda: understanding their experience and needs. *African Journal of AIDS Research*, 11(4), 295–305. <http://doi.org/10.2989/16085906.2012.754829>
- Lazarus, J. V., & Nielsen, K. (2010). HIV and people over 50 years old in Europe. *HIV Medicine*, 11(7), 479–481. <http://doi.org/10.1111/j.1468-1293.2009.00810.x>
- Lorenz, K. A., Shapiro, M. F., Asch, S. M., Bozzette, S. A., & Hays, R. D. (2001). Associations of symptoms and health-related quality of life: Findings from a national study of persons with HIV infection. *Annals of Internal Medicine*, 134(9 (Part 2)), 854–860.
- Martin, C. P., Fain, M. J., & Klotz, S. A. (2008). The Older HIV-Positive Adult: A Critical Review of the Medical Literature. *American Journal of Medicine*, 121(12), 1032–1037. <http://doi.org/10.1016/j.amjmed.2008.08.009>
- Mays, Roberts, & Popay. (2001). Synthesising research evidence. In Fulop, Allen, Clarke, & Balck (Eds.), *Studying the organisation and delivery of health services: Research methods*. London: Routledge.
- Mugisha, J., Scholten, F., Owilla, S., Naidoo, N., Seeley, J., Chatterji, S., ... Boerma, T. (2013). Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda. *AIDS Care*, 25(11), 1341–8. <http://doi.org/10.1080/09540121.2013.765936>
- Munthree, C., & Maharaj, P. (2010). Growing old in the era of a high prevalence of HIV/AIDS: The impact of AIDS on older men and women in KwaZulu-Natal, South Africa. *Research on Aging*, 32(2), 155–174. <http://doi.org/10.1177/0164027510361829>
- Mutevedzi, P. C., & Newell, M.-L. (2011). A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future Virology*, 6, 755–767. <http://doi.org/10.2217/fvl.11.43>
- Namisango, E., Harding, R., Atuhaire, L., Ddungu, H., Katabira, E., Muwanika, F. R., & Powell, R. A. (2012). Pain Among Ambulatory HIV/AIDS Patients: Multicenter Study of Prevalence, Intensity, Associated Factors, and Effect. *Journal of Pain*, 13(7), 704–713. Retrieved from <http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2011604225&site=ehost-live&scope=site>

- MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
- Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: A crucial component in the future of HIV care and support. *The Southern African Journal of HIV Medicine*, 12–17.
- Nyirenda, Chatterji, Falkingham, Mutevedzi, Hosehood, Evandrou, ... Newell. (2012). An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC Public Health*, 12(259).
<http://doi.org/10.1186/1471-2458-12-259>
- Nyirenda, M., Newell, M., Mugisha, J., Mutevedzi, P. C., Seeley, J., Scholten, F., & Kowal, P. (2013). Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa. *Global Health Action*, 6(19201), 1–11.
<http://doi.org/http://dx.doi.org/10.3402/gha.v6i0.19201>
- O'Brien, K. K., Bayoumi, A. M., Strike, C., Young, N. L., & Davis, A. M. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health and Quality of Life Outcomes*, 6(76).
<http://doi.org/10.1186/1477-7525-6-76>
- Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., ... HIV Outpatient Study Investigators. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New England Journal of Medicine*, 338(13), 853–860. Retrieved from
<http://www.nejm.org/doi/pdf/10.1056/NEJM199803263381301>
- Phaladze, N. A., Human, S., Dlamini, S. B., Hulela, E. B., Mahlubi Hadebe, I., Sukati, N. A., ... Holzemer, W. L. (2005). Quality of life and the concept of “living well” with HIV/AIDS in sub-Saharan Africa. *Journal of Nursing Scholarship*, 37(2), 120–126. Retrieved from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2005109309&site=ehost-live&scope=site>
- Phiri, A. N. (2004). *A phenomenological study of ageing amongst the older persons in Zambia*.
- Plattner, L. E., & Meiring, N. (2006). Living with HIV: the psychological relevance of meaning making. *AIDS Care*, 18(3), 241–245. Retrieved from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2009267983&site=ehost-live&scope=site>
- Public Health Agency of Canada. (2010). HIV/AIDS Among Older Canadians. Retrieved July 10, 2015, from <http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/6-eng.php>
- Richards, E., Zalwango, F., Seeley, J., Scholten, F., & Theobald, S. (2013). Neglected older women and men: Exploring age and gender as structural drivers of HIV among people aged over 60 in Uganda. *African Journal of AIDS Research*, 12(2), 71–78.
<http://doi.org/10.2989/16085906.2013.831361>

- Rusch, M., Nixon, S., Schilder, A., Braitstein, P., Chan, K., & Hogg, R. S. (2004). Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality of Life Outcomes*, 2(46). <http://doi.org/10.1186/1477-7525-2-46>
- Rutakumwa, R., Zalwango, F., Richards, E., & Seeley, J. (2015). Exploring the Care Relationship between Grandparents / Older Carers and Children Infected with HIV in South-Western Uganda : Implications for Care for Both the Children and Their Older Carers, 2120–2134. <http://doi.org/10.3390/ijerph120202120>
- Samman, E., & Rodriguez-Takeuchi, L. K. (2013). *Old age, disability and mental health: data issues for a post-2015 framework - ODI Background Notes - Discussion papers*. London. Retrieved from www.odi.org.uk
- Schatz, E., & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health*, (May), 1–16. <http://doi.org/10.1080/17441692.2015.1035664>
- Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubukwa, S., Kowal, P., ... Grosskurth, H. (2011). Health and functional status among older people with HIV/AIDS in Uganda. *BMC Public Health*, 11(1), 886. <http://doi.org/10.1186/1471-2458-11-886>
- Seeley, J., Zalwango, F., Mugisha, J., Kinyanda, E., Wake, C., & Scholten, F. (2010). Poverty, ageing and HIV in Wakiso district Uganda. In *Chronic Poverty Research Centre 2010 Conference* (pp. 1–19).
- Shippy, R. a, & Karpiak, S. E. (2005). The aging HIV/AIDS population: fragile social networks. *Ageing & Mental Health*, 9(3), 246–54. <http://doi.org/10.1080/13607860412331336850>
- Simpson, A., & Bond, V. (2014). Narratives of Nationhood and HIV/AIDS: Reflections on Multidisciplinary Research on the HIV/AIDS Epidemic in Zambia over the Last 30 Years. *Journal of Southern African Studies*, 40(5), 1065–1089. <http://doi.org/10.1080/03057070.2014.946222>
- The World Bank. (2015a). Country and Lending Groups. Retrieved January 28, 2015, from <http://data.worldbank.org/about/country-and-lending-groups>
- The World Bank. (2015b). Life expectancy at birth, total (Years). Retrieved May 24, 2015, from <http://data.worldbank.org/indicator/SP.DYN.LE00.IN>
- UNAIDS. (2014). *The Gap Report*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf
- Wallach, I., & Brotman, S. (2012). Ageing with HIV/AIDS: a scoping study among people aged 50 and over living in Quebec. *Ageing and Society*, 33, 1212–1242. <http://doi.org/10.1017/S0144686X12000529>

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
World Health Organization. (1997). *WHOQOL Measuring Quality of Life*. Retrieved from
http://www.who.int/mental_health/media/68.pdf

Wright, S., Zalwango, F., Seeley, J., Mugisha, J., & Scholten, F. (2012). Despondency among HIV-Positive older men and women in Uganda. *Journal of Cross-Cultural Gerontology*, 27(4), 319–333. <http://doi.org/10.1007/s10823-012-9178-x>

Chapter 3: Secondary Qualitative Analysis

Introduction

HIV and the Advent of Antiretroviral Therapy (ART): Attention to Older Adults

The introduction of antiretroviral therapy (ART) has allowed for a decline in mortality (Palella et al., 1998) but an increased chronicity and disability for people living with HIV (Nixon, Hanass-Hancock, Whiteside, & Barnett, 2011). Effective treatment has transformed HIV from an acute infection to a chronic condition for many people. People with HIV who have access to and can tolerate treatment can have approximately the same life expectancy as those who are uninfected (Manfredi, 2004). Success of available treatment has prompted researchers to inquire about the impact HIV has on an older adult population (Boon et al., 2010; Emler, 2008; Emler, 1997; Martin, Fain, & Klotz, 2008; Mutevedzi & Newell, 2011; Savasta, 2004; Siegel, Dean, & Schrimshaw, 1999).

More than 2.5 million HIV positive people who are aged 50 years and older live in sub-Saharan Africa, accounting for more than half the older adults living with HIV around the globe (UNAIDS, 2014). However, due to earlier access to ART in high-income countries, much of what is known about HIV among older adults originates from data outside of sub-Saharan Africa. The Ontario HIV Treatment Network conducted a scoping review on HIV, aging, and health from countries around the world and found that the majority of the 451 studies included (95.6%) were conducted in high-income countries with 160 studies (35.5%) conducted in the United States alone. (Chambers et al., 2012).

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Conceptual Frameworks: The International Classification of Functioning, Disease, and Health and The Episodic Disability Framework

As mortality rates stabilize, more people may expect to develop long-term adverse effects, herein described as disability, associated with living chronically with HIV (Yoshida, Hanass-Hancock, Nixon, & Bond, 2014). In this study, disability is conceptualized in terms of the WHO's International Classification of Functioning, Disability and Health (ICF) where impairments to the body structure and function, activity limitations, or participation restrictions are all components of disability (World Health Organization, 2001). The ICF attempts to integrate both the medical model of disability and the social model of disability (Hanass-Hancock & Nixon, 2009).

The Episodic Disability Framework (EDF) was developed to understand periodic disability specifically in the context of HIV. The "episodic" nature of HIV is characterized by periods of good health that are unexpectedly interrupted by periods of illness (O'Brien et al., 2009). Uncertainty of the timing of episodes may further exacerbate disability (O'Brien et al., 2009). Environmental factors are a component of the framework that allow for it to be applied in different cultural or environmental contexts. While the EDF has been used to understand the experience disability among people living with HIV in Canada, (Solomon, O'Brien, Wilkins, & Gervais, 2014; Solomon, O'Brien, Wilkins, & Gervais, 2014) this framework has not been applied in a hyper-endemic or low-income country such as Zambia.

Zambian Context

Resource-limited settings are experiencing the fastest growth of an aging population around the world; this shift comes with substantial social implications for HIV infected individuals and their wider global communities (Samman & Rodriguez-Takeuchi, 2013). Zambia is one of the sub-Saharan African countries most severely affected by HIV. It is a

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hyper-endemic country with an estimated 1,100,000 people living with HIV in 2013

(UNAIDS, 2013). In 2005, Zambia's Ministry of Health announced the elimination of ART user fees after securing sufficient funding to provide treatment for up to 100,000 people in the country (World Health Organization, 2005). Before 2004, ART in Zambia were available only to those paying for private health care, participating in research, or working as senior government officials (Simpson & Bond, 2014).

Since the introduction of free ART in Zambia, there has been a statistically significant reduction in HIV prevalence among adults (aged 15-49) between 2001-02 and 2013-14 (Central Statistical Office (CSO) [Zambia] et al., 2014). Prevalence estimates have varied widely by province, rural or urban settings, gender, and age. Although there are no prevalence statistics that are specific to women and men aged 50 years and older in Zambia, the 2014 Zambian Demographics Health Survey found that HIV prevalence tended to increase with age, peaking at 23% for Zambians aged 40-44 (Central Statistical Office (CSO) [Zambia] et al., 2014). As prevalence of HIV increases with age in Zambia and with HIV transitioning to a chronic condition, it is important to consider HIV-related disability for people on ART (Nixon, Hanass-Hancock, et al., 2011). This study focuses on the HIV-related disability experiences of older adults living with HIV in Zambia.

Purpose and Rationale

Qualitative health studies can supplement demographic health surveys (Simpson & Bond, 2014) and provide a deeper understanding into the social contexts that shape disability related lived experiences of people living with HIV. To date, no studies have focused exclusively on the experiences of adults aged 50 years and older who are living with HIV in Zambia. Given the successes of ART in reducing mortality, research in Zambia is needed to understand and prepare for an aging cohort of HIV-positive individuals and the anticipated

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HIV-related disability they may experience. The purpose of this qualitative,
phenomenological inquiry is to explore experiences of disability among men and women
aged 50 years and older living with HIV in Zambia.

Methodology

Phenomenology

A phenomenological approach was used to understand the experience of living with HIV while on ART as an older adult in Zambia. The purpose of phenomenological research is to understand the qualities of a given experience whereby the inquirer seeks to understand the essence of a particular experience from participants by constructing a rich, detailed description of the phenomenon of interest (Creswell, 2013). The goal of phenomenology is to depict the experience of a phenomenon under study, and not to generalize to a theory or model (Krefting, 1991). Starks & Trinidad (2007) provide a comparison among three qualitative research methodologies that can be used in health research: phenomenology, discourse analysis, and grounded theory. Phenomenology was the chosen method for this study as the purpose of the inquiry was to understand disability experienced by older adults living with HIV in Zambia as the phenomenon of interest. Analysis of qualitative research more broadly requires de-contextualization and re-contextualization through the process of coding, sorting, identifying themes and relationships, and drawing conclusions (Starks & Trinidad, 2007). The identified themes are presented as part of the final product that describes the “essence” of lived experience (Starks & Trinidad, 2007).

Study Design

This inquiry is part of a larger longitudinal qualitative project called the Sepo II Study that explored the functioning, disability, and health of men and women living with HIV in urban and peri-urban parts Zambia from 2012 to the present. The Sepo II Study included 35

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. participants, interviewed at three points in time approximately six months apart. This manuscript presents a cross-sectional analysis drawing on the first wave of data collection, with a focus on the ten participants who were 50 years or older. With the large volume of data generated from the longitudinal study as well as a short time frame for analysis, a cross sectional analysis was chosen to address the research question. Additionally, a cross-sectional analysis is appropriate because the goal of this study is to understand lived experiences and not to understand how lived experiences change over time. As this was a secondary qualitative study, interview guide sought responses focused on disability experiences but did not have any specific questions pertaining to aging. Interviews were conducted in either a public or a private clinic. The Sepo II research team used the ICF and the EDF as a guide to organize semi-structured interview questions that were conducted in one of three languages (English, Nyanja, or Bemba) that were later transcribed and translated to English simultaneously as needed.

Analytical Framework

The goal of phenomenology is to depict the experience of the phenomenon of interest and not to generalize to a theory or a model (Krefting, 1991). The steps for analyzing interview data in phenomenology are similar to analytic techniques used in other qualitative research methods (Starks & Trinidad, 2007). The analytic steps and guidelines for data analysis of qualitative data as outlined by Burnard (1991) were followed for each of the interviews. Transcripts were read repetitively and analytic memos consisting of general comments and impressions of each interview were made to allow for familiarization and immersion into the data.

The qualitative data management software, NVIVO 10 (QSR International, 2015), was used to facilitate the organizational coding the data. Each transcript was read line by line

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. and assigned a unit of meaning called a “code”. Codes were organized and sorted into broader meaning units called “categories”. Once the first round of coding was complete, a codebook was generated and refined with a senior researcher on the Sepo II team. The codebook contained all codes sorted into broader categories that emerged from the data along with a brief description and a sample quote. The senior researcher then independently coded an interview and met with the student researcher to discuss preliminary themes and reconcile any differences in coding. After all interviews were coded and organized into categories, relationships and patterns among various categories were explored and reported as “themes”. Patterns between categories were established while taking into consideration the individual attributes of participants. Data were analyzed with particular attention to individual attributes such as gender, length of time on ART, and estimated income based on whether participants attended a public or private clinic.

Ethics Approval

Ethics review communities at the University of Toronto, McMaster University, University of Zambia and the University of KwaZulu-Natal approved the research procedures for the larger Sepo II study. Ethics approval was also received from the Government of Zambia Ministry of Health for this study. All members of the Sepo II Study Research Team signed a confidentiality agreement (Appendix A) prior to receiving access to data.

Results

Individual interviews were conducted from January 2013 to January 2014 and lasted between 23 and 59 minutes in length. Five men and five women were included in this analysis. The average age of participants was 51 years old and ranged from 50 to 56. Men were either married (n=4) or divorced (n=1), while women were either married (n=2) or

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. widowed (n=3). Participants had an average of 3.4 children living with them in their household (ranged between 0 and 6 children) with 2 women also living with 3 grandchildren each. Two male participants were interviewed at Lusaka Trust Hospital, a privately funded clinic, and the rest of the participants were interviewed at Chawama Clinic, which is a publically funded clinic. It is expected that participants who attend Chawama Clinic are quite poor while participants who attend Lusaka Trust Hospital are wealthier. The average length of time on treatment for participants was 8.9 years and ranged from 1 to 13 years. Further details on participant characteristics can be found in Table 6.

Six themes were identified related to the disability experiences of these older adults living with HIV: 1) Multiple Symptoms and Impairments: Variation in Onset and Duration; 2) Daily Activities and Participation: Shaped by Gender Roles; 3) HIV status disclosure: Hindered by stigma, driven by a purpose; 4) Poverty and Food Insecurity: Precarious Employment; 5) Managing an Altered Uncertainty: Changes Resulting From A Prolonged Life (see Figure 2).

1. Multiple Symptoms and Impairments: Variation in Onset and Duration

Participants listed a myriad of symptoms and impairments that varied in presentation and duration. Participants reported that their symptoms persisted, fluctuated, or terminated over the course of their HIV infection and ART initiation. Symptoms such as fever, coughing blood, and abdominal pain occurred prior to initiating treatment for some participants. These symptoms were often exacerbated by co-morbidities such as opportunistic infections (e.g. malaria, ringworms and tuberculosis) or chronic diseases (i.e. cancer, high or low blood pressure, and diabetes). Participants reported that once they had initiated treatment, some symptoms (i.e. loss of appetite, diarrhea, weakness and memory lapses) terminated while others (i.e. bad dreams, vomiting, shivering, weakness, diarrhea, dizziness, headaches,

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. fatigue, shortness of breath and swelling of the joints) began immediately lasting anywhere between a week to months on end. At the time of the interview, some participants described symptoms such as fatigue, pain, and numbness.

Generally, explicit references to age were rare among participants unless they attempted to attribute a cause to one of their symptoms such as fatigue: “What is making me feel this way [fatigued]? Maybe it is old age or the medicine I don’t know” (Participant 8, woman). Others contemplated work as being another potential factor for some of the persisting or progressing symptoms such as fatigue: “When I get home I feel... very much drained as opposed to how I used to feel like before, but I think maybe it is part of work, maybe it’s age am growing old I don’t know” (Participant 9, man). The findings presented in this theme suggest that there was no predictable presentation of “disability” in terms of the diverse and multi-faceted symptoms and impairments experienced among participants.

2. Daily Activities and Participation: Shaped by Gender-Based Roles

Participants reported an impact on their day-to-day activities. Often, the activities that participants described appeared to be linked to gender-roles. For example, women primarily described challenges with their housework and caregiving activities while men mainly described compromised employment. Although data on the age of their children were not collected, some participants indicated in their interviews that their children had married, graduated, were working, or have children of their own, suggesting that they had adult children. Other participants described having children for whom they couldn’t afford to send clothing to or were currently unable to assist with paying school fees for, suggesting that their children were younger or school-aged.

Most women were engaged in caregiving activities of their children or grandchildren and also completed chores such as sweeping, cooking, and washing dishes. Some women

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. reported challenges with completing household chores. For example, one woman expressed how chest pain and fatigue limited the ease with which she could collect and carry water to her home. She hypothetically differentiated men and women's experiences of feeling fatigued: "If... a man [is tired] he would probably stop carrying heavy things but because we are women we can't stop carrying water on [our] head[s] otherwise there would be no water in the home" (Participant 3, Woman). However, most women did not report limitations to engaging with household chores, particularly after initiating ART. One woman indicated that she was even able to wash clothes for her children and grandchildren once she regained strength from taking ART. Aging with HIV, particularly after initiating treatment, did not change the social role of women as caregivers to their children and grandchildren. Rather, once health was restored, women in this study would dutifully fill these social roles.

The male participants mainly described how HIV affected their employment. Although most men remained in employment, some had their working hours cut short or had to engage in piecework. One male participant attributed losing his job to symptoms of HIV before knowing his status: "I got frustrated [when my employers] wanted me to continue working while I was not in a good state of working...I remember at one time I even collapsed at work but they never cared for me...I even told my wife maybe let me just stop working, I might end up dying...I lost my job because of HIV, had it not been HIV I am sure even now I was going to be in employment" (Participant 1, Man). When this participant was asked how his household managed financially with him out of employment, he first attributed it to the grace of God, but then later indicated that his first-born son was financially supporting his family. For one older man in the study, having grown and working children decreased financial concerns and placed fewer demands on participation in daily employment.

3. HIV Status Disclosure: Hindered by Stigma, Driven by a Purpose

All participants in the study disclosed their HIV status to at least one person, typically a close family member or friend as a precautionary measure. Some participants intentionally disclosed their status to a select few, while a few would openly disclose their status through widespread public announcements. One participant elaborated on why she believed it was important to disclose her status: “Because you need support from the family, even from the community [and] friends there they need to know about the way you are because sometimes [when] you are sick you need people to come to the clinic and get medicine for you” (Participant 6, Woman). Some participants found out about their HIV status when their children were quite young and did not discuss their status with their children until they were older. Participants who disclosed their HIV status to their children often received the added benefit of getting reminders from them to take their ART.

Fear of gossip and stigma prompted some participants to conceal their HIV status from the wider community as a protective measure. The fear of stigma isolated some participants from the wider community and reduced social ties. Negative comments that suggested to participants that they were “finished” (dead) or hurtful jokes and statements implying that participants should live alone were among some of the stigmatizing comments that prompted a hesitation to disclose their status. One participant provided a poignant comparison that explained why she personally preferred not to disclose her HIV status to the community: “[Telling people I have HIV] is just the same [as] your husband defecat[ing] on the bed and you start telling people that he defecates the bed they’ll say you don’t have respect (laughs)” (Participant 3, Woman). Depending on the community, participants indicated that people in their church were more judgmental than their wider community

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while others found their church to be a safe place to privately disclose their status in a registry.

For participants willing to disclose widely, their HIV positive status fuelled a sense of duty and purpose to help others in their wider community who were also affected by HIV. These participants shared their stories to encourage others to seek care when needed. One participant reflected on the personal and community benefits of widely disclosing his status: “After going open about my HIV status, what I have come to realize is that a lot of people they have appreciated [it] because they realized that [HIV] actually affects each and every person in the community. So me being... open about my HIV status... has really helped me and it has helped a lot of people in the community.” (Participant 1, Man). Even with the risk of being stigmatized, some participants chose to publicly disclose their status. One participant was the first to stand up in front of his church to disclose his status, another participant asked his employer if he could be a “champion” to share his story in public talks, and another participant shared his story on a radio show. Participants who lived longer lives than originally anticipated often viewed themselves as positive examples and success stories to other HIV positive individuals. They would describe the success of treatment for them as a form of encouragement for others. There were no patterns indicating that those who were older or who were on treatment longer tended to disclose their status more widely than those who were younger or on treatment for a shorter period of time. Disclosure of HIV status was influenced more by personal preference and perceptions of HIV.

4. Poverty and Food Insecurity: Precarious Employment

Participants described systemic issues, often linked with money and finances, to be at the forefront of their concerns. Lack of money was disabling to some participants as it forced them to dedicate their time and energy towards obtaining food for basic survival rather than

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. taking time to plan for and manage aging with HIV. Concern for HIV as an infection itself was left as a relatively minor issue under the enveloping shadow of poverty. Money was necessary to pay for supplies in the home, to purchase items to sell at the market, to spend on transportation to clinic appointments and to obtain food. When participants found themselves without enough money, some resorted to borrowing: “I find it very difficult either to get the resources that we are supposed to use at home because of HIV and you cannot live on borrowed life, you go here and there where you say I will borrow some money somewhere and yet you do not know how you will pay back” (Participant 1, Man). Women mainly expressed lacking financial resources to secure food: “Our friends who are well off they don’t face any bad challenges they’re okay because if they want to eat they eat very well they manage. Anything they want they manage. The problem is with us who can’t afford [food], who are not working” (Participant 3, Woman).

Not all participants had financial concerns but many recognized and appreciated their financial privilege. It could be a possibility that poorer participants would attend the public clinic and wealthier participants would attend the private clinic, but this pattern did not directly match the participants in this study. For example, Participant 7, who attended the public clinic and is assumed to be poor, reflected on how even a small amount of money changed her circumstance and helped her overcome initial concerns about the future: “What helps me is that the time I was sick I had no money I was suffering, but now I sell [bananas and oranges]. I find money I feel there is no problem that I find” (Participant 7, Woman). Participants who had enough money were able to use food as prevention or treatment for some of the symptoms that they were experiencing (i.e. carrots for vision, cucumbers for appetite or vegetables for iron). One of the male participants who attended the private clinic described how lucky he was to have his private health care services paid for by his employer.

5. Managing an Altered Uncertainty: Changes Resulting From A Prolonged Life

For most participants, regardless of length of time on treatment, uncertainty for the future shifted from worries and concerns when initially diagnosed with HIV to a state of acceptance post initiation of ART. One participant who was on treatment for the shortest length of time among the 10 participants (1 year) was not concerned about becoming sick again as he diligently takes his medicine and finds that it has makes him feel better. The initial uncertainty that participants experienced was composed of unpredictable occurrences of illness that could have been fatal rather than disabling. At initial diagnosis, many participants expressed concern about who would care for them if they became ill again. However, those moments of uncertainty diminished with the advent of ART. Many participants were also more accepting of death as they aged and found relief in knowing that if they died, their young adult or adult children would be capable of taking care of themselves. One female participant was widowed when her children were still quite young and she reminisced about her concern at the time of her husband's death and recalled wondering who would take care of her children if she died then as well. Having aged by the time of the interview, she expressed how she was grateful for the availability and effectiveness of ART and later mentioned that her children were now old enough to take care of themselves: "I am just thankful for the medicine because I would have died long ago... and my children would have forgotten me long ago, you see a lot of people died long ago because there was no medicine .We don't know, maybe even my husband would have been around so [I] am thankful for this medicine that has come because my life has been prolonged that is why I put in a lot of effort when it comes to taking medicine so that my children should be seeing me and I should be seeing their problems" (Participant 5, Woman).

Rather than uncertainties surrounding the occurrence of death and how this could affect children, participants faced new uncertainties with longevity in view. These new uncertainties were not related to the episodic nature of the illness, but rather to the long-term sustainability of programs and services that assisted with living with HIV. Concerns about changing services were expressed by a participant who reminisced about a food service that was offered by a former volunteer organization: “Long ago when I started coming here [to the clinic] as a volunteer, white people used to donate... and give everyone at the ART section [food]... They would give us maize we make mealie meal, soap, cooking oil, everything... They used to send for us. We were eating well, soya, everything I don’t know why they stopped, they used to help us” (Participant 3, Woman).

Another participant whose employer paid for his private health care costs was concerned about the long-term sustainability of maintaining his current treatment life style: “If I were to stop working and am so used to getting such medical [services], how is it going to be[?]. The government offers [ART for] free but if it was somebody who was not able to access ART at a particular time ... I have heard of people ... living with HIV they say they will go to the clinic and find the medicine is not there, so what happens...it will actually linger in my mind. (Participant 9, Man).

Participant 1 expressed concerns about the sustainability of the Zambian government relying on external funding: “I think the government is paying a lot of money through donor funding [for ART]...the government should stop depending on donor funding [for] drugs. I remember we [were] advocating to have [an] ART levy where people could be paying just a small token to contribute towards the buying of drugs for HIV... At one time the donors will pull out completely, remember what happened to the global fund, we had failed to account for the money, they withheld their funding, we got affected. It means that all of us we are

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. going to die. So if the government could put these measures to say even if we do not have donor funding we will be able to sustain ourselves as a government that will be for me, will be good.”

Discussion

Most studies on older adults in the context of HIV in sub-Saharan Africa are about older adults caring for their HIV positive ailing children or their HIV-orphaned grandchildren (Ainsworth & Dayton, 2003; Boon, James, et al., 2010; Dayton & Ainsworth, 2004; Ice, Zidron, & Juma, 2008; Juma, Okeyo, & Kidenda, 2004; Kanya & Poindexter, 2009; Moore & Henry, 2005; Mugisha et al., 2013; Munthree & Maharaj, 2010; Nyanzi, 2009; Seeley, Wolff, Kabunga, Tumwekwase, & Grosskurth, 2009; Ssengonzi, 2007; Williams & Tumwekwase, 2001). In this study, while older adults particularly older women, continued to fulfill caregiving roles, their children were typically not dying with HIV, nor did HIV orphan their grandchildren. Instead, participants were caregiving to fulfill their duty as a family member. Female participants provided care to their children and grandchildren mainly in the form of chores. Male participants would provide financially for their children if they were able. It is assumed that most of the participant's children were older given that they were able to remind participants to take medicine, were married and had children, or had finished school and were providing financially for the family. Adult children were an important proxy that indicated an important relational role in understanding the disability experiences of older adults in Zambia. This study illuminated the experiences of older adults who are HIV-infected rather than HIV-affected. As such, this is the first study to provide a glimpse into the disability-related experiences of HIV-positive older adults aged 50 years and older in Zambia.

Since the advent of ART and the associated increase in life expectancy, an increasing number of people may be living with HIV-related disability as a result of HIV, its treatments, or co-morbidities (Hanass-Hancock, Regondi, & Nixon, 2013). Over time, HIV positive individuals will likely experience further disability as they age due to natural aging processes. Subsequently, understanding disability experiences, especially as it pertains to a low-income country that is HIV hyper-endemic such as Zambia, is an important first step to plan for alleviation of further disability.

This study builds on previous work on HIV and aging using a disability lens (Solomon et al., 2014a, 2014b) by conceptually applying the episodic disability framework (EDF) to a new geographic region. In Canada, uncertainty was found to be a key component of disability experiences in older adults living with HIV with fluctuations in periods of good health with periods of illness (Solomon et al., 2014a, 2014b). It was found that uncertainty related to aging with HIV in Canada encompassed sources of health challenges, financial uncertainty, transition to retirement, appropriate long-term housing, consideration of future caregivers, in addition to the episodic nature of illness (Solomon et al., 2014a). Participants in this study also faced uncertainty, but uncertainty arose from different sources. These were related to concerns about what life would be like in the event of death and the consequences death could have on their children. Over time and as participants and their children aged, this uncertainty surrounding death diminished as ART became available and were seen as effective. Uncertainty took on the form of long-term concern of the sustainability of programs and services that provided ART to facilitate aging with HIV in a hyper-endemic setting. Availability of resources in a setting of poverty does not allow for uncertainty surrounding retirement pensions or long-term housing plans to arise, but rather, older adults

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. in Zambia still looked to long-term concerns such as sustainability of program and service funding from external donors and the Zambian government on ART supply.

Anticipating Future Aging Factors

Although the demographic focus for this study was adults aged 50 years and older, participants did not frequently mention age or aging as contributing factors to their disability experiences. Rather, participants described aging related challenges when contemplating the cause of some of their current symptoms. Of note, the participants in this study were fairly young (with a mean age of 51) so it may be possible that age-related contributors to their disability experiences will appear in the coming decades. As this cohort of men and women aged 50 years and older continue to experience both the successes and burdens of living with HIV in the era of ART, continued monitoring of any age-related changes and experiences may provide even further insight into the trajectory and experiences of living with HIV as a chronic condition.

Poverty and Food Insecurity

Systemic issues such as poverty and food insecurity were more prominent concerns than HIV itself. Poverty was found to have threatened the health and well-being of older adults living with HIV in Uganda (Seeley et al., 2010). Three women in this study were widows and only two women sold fruit at the market, making them particularly vulnerable to living in poverty and needing to rely on extended family members for support. HIV also affected employment security for men, and in some cases, participants had to resort to borrowing money to pay for additional medications (i.e. to alleviate back pain).

Food insecurity has implications on ART adherence. HIV positive individuals from a general Zambian population who were also food insecure were found to be less likely to access treatment and services (Ntalasha, 2015). Many participants in this study were aware of

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. the importance of taking food with their medication. Food security was found to be integral to ART adherence and continual active recovery among people with disabilities in Zambia (Nixon et al., 2014).

Interplay Between Intrinsic and Extrinsic Contextual Factors for Status Disclosure

According to the EDF, stigma is an extrinsic disability factor while living strategies are intrinsic factors (O'Brien et al., 2009). These contextual factors may aggravate or alleviate experiences of disability (O'Brien et al., 2009). In this study, intrinsic and extrinsic contextual factors were closely inter-related when it comes to status disclosure. Depending on personal circumstances, participants either concealed their HIV status out of fear or revealed it to the wider community as way to encourage others going through the same process. The experiences surrounding stigma by participants in this study are also accurately reflected in a description provided by Simpson & Bond: "Initial silence and denial around HIV fuelled stigma, but they have been replaced since the advent of ART with a greater degree of openness and cautious disclosure" (2014, p. 1086). Further, the relative ubiquity of HIV in a hyper-endemic setting such as Zambia allowed participants to share their status more willingly with status disclosure with the intention to reduce HIV-related stigma.

Impact of Uncertainty and the Influence of Environmental Factors

Initial worries and concerns surrounding death and the future were turned into a trusting faith and acknowledgement that HIV was just another ailment that can be managed. Similarly, participants in another study who began ART reoriented their thinking from a short-term ailment to a long-term chronic condition (Brashers et al., 1999). The availability of effective treatment drastically changed initial concerns for the future and worries about death to a dedicated desire to adhere to treatment regardless of experiencing newly developed

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. symptoms. Long-term survival allowed participants to express a sense of gratitude for ART, which further motivated their dedication to adhere to treatment.

With an appreciation for the effectiveness of available treatment, participants expressed new concerns related to the sustainability of some of the ART programs and related services. Simpson and Bond also describe implications of donor funding freezes on ART treatment access and provided an example of what happened in 2009: “Allegations of corruption with the Ministry of Health led to freezing of donor funds for HIV in 2009, adversely affected HIV drug supply in 2010” (Simpson & Bond, 2014, p. 1070). The interaction between broad governing structures and the international community can have life-altering consequences for people reliant on consistent free supplies of ART. Therefore, it is important to consider the long-term sustainability of the drug supply chain in policies, and to consider effectiveness of programs for supporting HIV positive people as they continue taking ART.

Relating Back to a Disability Lens

The ICF provides a useful conceptualization of disability that links symptoms and impairments with activity limitations and participation restrictions (World Health Organization, 2001). O’Brien et al. (2009) noted the importance of personal factors in shaping experiences of disability. While environmental contextual factors of the ICF have been described extensively, personal contextual factors were critiqued by O’Brien et al. (2009) to be limited in its classification due to a “large social and cultural variance associated with them” (World Health Organization, 2001, p. 6). The EDF was developed to describe the episodic nature of HIV over time, its association with uncertainty, and introduces the concept of “living strategies” that HIV positive individuals use to manage HIV-associated uncertainty. Noting that the EDF was developed within a context of in a high resource

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. setting, this study applied the EDF to a low-resource setting and demonstrated how contextual factors could exacerbate or alleviate experiences of disability. The following discussion relates the findings from this study to these two disability frameworks.

Contributions of a Disability Perspective

Both the ICF and the EDF offer a framework to study both positive and negative experiences of older adults living with HIV in Zambia. The focus on body function and structure, activities and participation allow for participants to outline aspects of their lives that are going well. At the same time, the two disability frameworks also allow participants to describe the challenges of living with HIV. The distinct environmental factors of living with HIV in a low-resource country in tandem with challenges associated with poverty likely intensified disability related experiences. Macro, systemic and complex aggravation of disability experiences may also be attributed to an altered sense of uncertainty. This study investigated various levels of disability experiences, but also highlighted moments of gratitude in the era of ART as an older adult in Zambia. With more HIV-positive individuals aging into their fifties and beyond, the two disability frameworks offer a way to conceptualize the micro to macro impacts of aging with HIV has on disability.

Limitations

This study contains some limitations. First, use of chronological age to define older adults living with HIV may not translate into a defining feature of the meaning of being an older adult (Sankar et al, 2011). Second, participants included in this study were relatively young despite being described as older adults (mean age= 51 years old). Third, this study is limited in its ability to comment on the long-term disability and aging experiences of older adults because the study analyzes cross-sectional data for a process that occurs over time.

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. Finally, as I did not conduct the interviews, the analysis could not incorporate contextual and cultural nuances nor was I able to probe or ask clarifying questions.

Future Directions

This study offers value to understanding the disability related experiences of older adults aged 50 years and older living with HIV in Zambia. Others researchers interested in the field are encouraged to expand research in this area with recognition that more research is needed to understand the experiences of growing older with HIV in Zambia over time. In future studies, it would be helpful to continue to monitor older adults on ART as they age with HIV. Longitudinal analysis of the second and third cross sections of Sepo II data can illuminate changes in disability and aging experiences over time. With continued prolonged engagement, a longitudinal design will continue facilitating building rapport with participants.

Conclusion

This was the first study to explore disability experiences of older HIV-positive adults who are on ART in Zambia. By using an episodic disability framework this study found major themes in older adults living with HIV in Zambia. Themes included a variety of symptoms being experienced, symptoms impacting different components of men and women's day-to-day activities, and potentially affecting their financial and food security. Disclosure of their HIV status was intended to encourage others in their community to be tested while concealment of status were driven by fear of gossip and stigma. The apparent transformation in perspectives resulting from the effectiveness of ART, shifted the mindsets of participants from one of uncertainty of the life trajectory of living with HIV to a mindset

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of acceptance where new uncertainties such as concerns surrounding the sustainability of
current HIV services and programs were more considered.

References

- Boon, H., Ruiter, R. A. C., James, S., van den Borne, B., Williams, E. W., & Reddy, P. (2010). Correlates of grief among older adults caring for children and grandchildren as a consequence of HIV and AIDS in South Africa. *Journal of Aging and Health, 22*(1), 48–67. <http://doi.org/10.1177/0898264309349165>
- Central Statistical Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], & ICF International. (2014). *Zambia Demographic and Health Survey 2013-2014*. Rockville, Maryland, USA.
- Chambers, L., Wilson, M. G., Rueda, S., Gogolishvili, D., Shi, Q., Rourke, S. B., & The Positive Aging Review Team. (2012). *Evidence Informing the Intersection of HIV , Aging and Health - A scoping review Evidence*. Toronto. Retrieved from <http://www.ohtn.on.ca/Documents/Research/OHTN-Positive-Aging-Final-Report-2012-12.pdf>
- Creswell, J. W. (2013). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Sage Publications; 4 edition.
- Emler, (1997). HIV/AIDS in the Elderly: A Hidden Population. *Home Care Provider, 2*(2), 69–75.
- Emler. (2008). Truth and consequences: a qualitative exploration of HIV disclosure in older adults. *AIDS Care, 20*(6), 710–7. <http://doi.org/10.1080/09540120701694014>
- Hanass-Hancock, J., & Nixon, S. A. (2009). The fields of HIV and disability: past, present and future. *Journal of the International AIDS Society, 12*(1), 28. <http://doi.org/10.1186/1758-2652-12-28>
- Hanass-Hancock, Regondi, I., & Nixon, S. (2013). HIV-related disability in HIV hyper-endemic countries: a scoping review. *World Journal of AIDS, 3*(September), 257–279.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 45*(3), 214–222.
- Manfredi, R. (2004). HIV infection and advanced age emerging epidemiological, clinical, and management issues. *Ageing Research Reviews, 3*(1), 31–54. <http://doi.org/10.1016/j.arr.2003.07.001>
- Martin, C. P., Fain, M. J., & Klotz, S. A. (2008). The Older HIV-Positive Adult: A Critical Review of the Medical Literature. *American Journal of Medicine, 121*(12), 1032–1037. <http://doi.org/10.1016/j.amjmed.2008.08.009>

- Mutevedzi, P. C., & Newell, M.-L. (2011). A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future Virology*, 6, 755–767. <http://doi.org/10.2217/fvl.11.43>
- Nixon, Hanass-Hancock, J., Whiteside, A., & Barnett, T. (2011). The increasing chronicity of HIV in sub-Saharan Africa: Re-thinking “HIV as a long-wave event” in the era of widespread access to ART. *Globalization and Health*, 7(1), 41. <http://doi.org/10.1186/1744-8603-7-41>
- O’Brien, K. K., Davis, A. M., Strike, C., Young, N. L., & Bayoumi, A. M. (2009). Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society*, 12(1), 5. <http://doi.org/10.1186/1758-2652-12-30>
- Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., ... HIV Outpatient Study Investigators. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New England Journal of Medicine*, 338(13), 853–860. Retrieved from <http://www.nejm.org/doi/pdf/10.1056/NEJM199803263381301>
- Samman, E., & Rodriguez-Takeuchi, L. K. (2013). *Old age, disability and mental health: data issues for a post-2015 framework - ODI Background Notes - Discussion papers*. London. Retrieved from www.odi.org.uk
- Sankar, A., Nevedal, A., Neufeld, S., Berry, R., & Luborsky, M. (2011). What do we know about older adults and HIV? a review of social and behavioral literature. *AIDS Care*, 23(10), 1187–1207. <http://doi.org/10.1080/09540121.2011.564115>
- Savasta, A. M. (2004). HIV: associated transmission risks in older adults--an integrative review of the literature. *The Journal of the Association of Nurses in AIDS Care : JANAC*, 15(1), 50–9. <http://doi.org/10.1177/1055329003252051>
- Siegel, K., Dean, L., & Schrimshaw, E. W. (1999). Symptom Ambiguity among Late-Middle-Aged and Older Adults with HIV. *Research on Aging*, 21(4), 595–618. <http://doi.org/10.1177/0164027599214004>
- Simpson, A., & Bond, V. (2014). Narratives of Nationhood and HIV/AIDS: Reflections on Multidisciplinary Research on the HIV/AIDS Epidemic in Zambia over the Last 30 Years. *Journal of Southern African Studies*, 40(5), 1065–1089. <http://doi.org/10.1080/03057070.2014.946222>
- Solomon, O’Brien, K., Wilkins, S., & Gervais, N. (2014a). Aging with HIV and disability: The role of uncertainty. *AIDS Care*, 26(2), 240–5. <http://doi.org/10.1080/09540121.2013.811209>
- Solomon, O’Brien, K., Wilkins, S., & Gervais, N. (2014b). Aging with HIV: A Model of Disability. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, 13, 519–525. <http://doi.org/10.1177/2325957414547431>

- MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
- Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372–1380. <http://doi.org/10.1177/1049732307307031>
- UNAIDS. (2013). *Global Report: UNAIDS report on the global AIDS epidemic 2013*. Retrieved from <http://www.unaids.org/en/media/unaids/contentasset>
- UNAIDS. (2014). *The Gap Report*. Retrieved from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf
- United Nations. (2015). *The Millennium Development Goals Report 2015*. New York. Retrieved from [http://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG2015_rev\(July1\).pdf](http://www.un.org/millenniumgoals/2015_MDG_Report/pdf/MDG2015_rev(July1).pdf)
- World Health Organization. (2001). *International Classification of Functioning, Disability and Health, Final Draft, Full Version*. Geneva. Retrieved from <http://www.sustainable-design.ie/arch/ICIDH-2Final.pdf>
- World Health Organization. (2005). Developing Countries & Free Access Fact Sheet- Countries offering free access to HIV treatment. Geneva. [http://doi.org/10.1016/S0002-8223\(97\)00353-2](http://doi.org/10.1016/S0002-8223(97)00353-2)
- Yoshida, K., Hanass-Hancock, J., Nixon, S., & Bond, V. (2014). Using intersectionality to explore experiences of disability and HIV among women and men in Zambia. *Disability and Rehabilitation*, 36(25), 2161–8. <http://doi.org/10.3109/09638288.2014.894144>

Chapter 4: Conclusion

Chapter Overview

The purpose of this chapter is to synthesize the major findings and implications from the preceding two data chapters. By connecting the two papers as a synergistic scholastic endeavor, I demonstrate some of the advantages and disadvantages of conducting a manuscript thesis. In Chapter 2, I established the extent of knowledge in the literature on quality of life and wellbeing of older adults living HIV in sub-Saharan Africa. Then in Chapter 3, I attended to the disability experiences of HIV positive older adults in Zambia.

This chapter will begin with an overview of the purpose and relevant contributions of each study followed by a discussion and contemplation on how these two chapters complement one another to create an entity that is greater than the sum of its parts. Key findings from both data chapters will be discussed simultaneously to generate a more wholesome picture of HIV among older adults in sub-Saharan Africa, and in particular, in Zambia. The discussion will focus on the following points: ART and transformation of expected experiences, continuity of social roles (i.e. caregiving), pervasiveness of stigma, giving back to the community, and challenges of poverty. The chapter will end with a discussion of the significance of the findings, the limitations, and future research directions.

Summary of Key Points from Chapter 2 and Chapter 3

Chapter 2 aimed to identify what was known in the current published literature regarding the quality of life of older adults living with HIV in sub-Saharan Africa. The scoping review in Chapter 2 affirmed that a gap in knowledge on older adults living with HIV in sub-Saharan Africa exists (UNAIDS, 2014). The review found that the gap in knowledge on older HIV positive individuals is larger than anticipated with only one out of the eight identified studies that focused exclusively on adults older than 50 years of age living with HIV. Further, out of 47 countries in sub-Saharan Africa, only 2 countries (Uganda and South Africa) currently have published quantitative or qualitative data pertaining to the quality of life among older adults living with HIV. Data came primarily from 2 repositories and were written by a small group of authors. Therefore the findings presented in the scoping review may be redundant further reinforcing the need for further research among different older adult populations in sub-Saharan Africa. In recognition that HIV among older adults is a relatively new phenomenon in sub-Saharan Africa, researchers,

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. policy makers and practitioners are encouraged to be vigilant in understanding the unique experiences of this population.

The purpose of Chapter 3 was to explore the disability experiences of older adults living with HIV in Zambia using the ICF and the EDF as disability frameworks. Findings from the qualitative study illuminate the disability-related experiences of 10 older men and women living in Zambia. This study began to address the dearth in the literature identified by the scoping review by offering a qualitative understanding of disability experiences of older adults living with HIV in Zambia. Using the WHO's International Classification of Functioning, Disability, and Health (ICF) and the Episodic Disability Framework (EDF) offered insights on individual factors that influenced disability and described the limitations on activities and participation restrictions that were influenced by low-resourced and HIV hyper-endemic contextual factors. Although previous studies recognized the importance of contextual factors on participants' experiences, the EDF offered a means to connect these factors with their influence on disability (O'Brien et al., 2009).

Affirmation and Extension of the HIV and Aging Literature

One of the greatest benefits of pairing a scoping review and a qualitative study together in a thesis is that it allows for direct comparisons of what is known in the literature to be, at least partially, addressed by the findings in the study. The scoping study confirmed the dearth of literature on older adults living with HIV while the qualitative study revealed facets of aging with HIV that could be explored further. One of the most dramatic changes contributing to the initial availability of data and research interest on HIV among older adults in sub-Saharan Africa has to do with the introduction of ART to the region and the anticipated increase in longevity of HIV infected individuals. The advent of ART changed perceptions surrounding the fear and fatality that once permeated HIV affected communities

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. even in the global North. In a study on older HIV positive African Americans, participants viewed HIV “not as a terminal illness, but rather as a chronic, manageable illness similar to hypertension, diabetes, or heart disease” (Foster & Gaskins, 2009b, p. 1310). Physical restoration as determined by CD4 counts were met with new uncertainties in studies done on HIV positive adults in the United States (Brashers et al., 1999). Simpson & Bond described ART as a transformative factor in sub-Saharan Africa that could shift moods in the community from “fatalistic pessimism” to one of “buoyant hope” (Simpson & Bond, 2014, p. 1070). Availability of ART was crucial for reducing disease burden and allowing for re-engagement in activities. In the scoping review, older HIV positive adults who were not on ART treatment were found to have less social interaction than those who were on treatment and likely suffered an impaired social network (Seeley et al., 2010).

The qualitative study in Chapter 3 revealed that available and effective ART generated a deep sense of gratitude among participants and motivated adherence to treatment despite experiencing noticeable side effects. ART altered circumstances of older adults in the qualitative study as they expressed new concerns about the long-term sustainability of ART funding by the Zambian government and external donors. Whether it be reassurance and instilling hope, increased interaction with the health care sector or new contemplations of long-term sustainability of programs, ART played an important role in shaping the emotions, interaction, and thinking of older adults with HIV in sub-Saharan Africa.

The increase in life expectancy due to ART in the global North has led to complexities such as premature aging (Wallach & Brotman, 2012), increased co-morbidities (Martin et al., 2008b; Mutevedzi & Newell, 2011; Namisango et al., 2012; Shippy & Karpiak, 2005), and an unexpected increase in disablement (Nixon, Forman, et al., 2011; O’Brien et al., 2008; Rusch et al., 2004). The effects of age have been demonstrated to cross

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. over between resource rich and resource limited settings (Han et al., 2015). It was anticipated that older adults living with HIV in sub-Saharan Africa would follow a similar symptom trajectory. The scoping review revealed that physical-health and self-reported good health decreased with increasing age (Scholten et al., 2011) and one study found that older adults also tended to have a decreased sex drive (Richards et al., 2013). The qualitative findings revealed a myriad of symptoms and impairments experienced by participants that varied in presentation, onset, and duration. These symptoms persisted, fluctuated, or terminated over the course of HIV infection and ART initiation. The causes of symptoms or impairments could be a result of a combination of HIV itself, medications, age, or co-morbidities as was found in another study conducted in the US (Siegel et al., 1999). Together, the two manuscripts in this thesis build on the existing literature and offered examples on how aging and symptoms associated with HIV, its comorbidities and treatments could impact on disability experiences and quality of life of older adults in sub-Saharan Africa.

Much of the literature in sub-Saharan Africa focused on older adults who cared for their children who were ailing or dying from AIDS or served as caregivers to their AIDS-orphaned grandchildren (Baylies, 2002; Ezeh et al., 2006; Munthree & Maharaj, 2010; Phiri, 2004; Schatz & Seeley, 2015; Simpson & Bond, 2014). As part of the inclusion and exclusion criteria for the scoping review, studies were sorted according to whether these included solely HIV infected participants or if these also included HIV affected participants. The scoping review attempted to separate those who were HIV infected from those who were HIV-affected (i.e. the caregivers to those who have HIV). However, literature was sparse with only 1 out of 8 articles that exclusively included older adults living with HIV (Kuteesa et al., 2012). To address the gap in knowledge, the qualitative study included participants who were HIV-infected and over the age of 50. Despite being HIV positive, many of the

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. caregiving roles that have traditionally been delegated to parents and grandparents continued.

After taking ART and regaining strength, one participant from the qualitative study even described washing clothes for her children and her grandchildren. Similarly, many older adults in one of the studies included in the scoping review continued to take on caregiving responsibilities despite having HIV (Mugisha et al., 2013). Combined, the scoping review and the qualitative study revealed that caregiving roles for older adults are still a component of their daily activities and are possible with effective ART. Rather than limiting caregiving roles to those who have been affected by having a child die from HIV or grandchildren orphaned by HIV, this study reveals that gender-based social roles, such as providing care for grandchildren, were still met regardless of HIV status.

Stigma was a pervasive element described in the literature that was also found in both the scoping review and the qualitative study. Many studies have been conducted to explore stigma experiences of HIV-positive individuals around the globe (Emlet, 2006, 2007; Foster & Gaskins, 2009b; Greeff et al., 2010; Kalichman et al., 2006; Ogunmefun, Gilbert, & Schatz, 2011; Tsai, Bangsberg, et al., 2013; Tsai, Weiser, et al., 2013; Tucker et al., 2014; Uys et al., 2009). Stigma is often a barrier for those to actively seek HIV testing, treatment and prevention services. However, for those who have tested for HIV and are on ART, stigma still remains a hurdle. In the scoping study, there was the double stigma of being HIV positive and an older adult. Ageism can serve as an additional layer of burden where participants tend to delay seeking care (Emlet, 2006). The experience of stigma was largely dependent on the participants' reaction to their communities. Participants wanting to help and contribute to their community were more willing to disclose their status in comparison to those who feared stigma and gossip from church communities, workplaces, and compounds. Stigma is still a prominent concern for older adults living with HIV. One possibility is that

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stigma could become more burdensome as participants age and experience ageism.

Alternatively if older adults are more accepting to their circumstances and want to serve others in a purpose to provide hope and encouragement it could become less prominent.

Further exploration on what compels certain individuals to widely disclose their HIV status amidst the risk of being stigmatized might illuminate an additional option to encourage the uptake of HIV programs and services among older adults.

External factors such as stigma and the social determinants of health can affect disability experiences and quality of life. Poverty is one of the social determinants that is intricately linked with other determinants of health and is an important contextual factor that shapes the contextual and environmental disability experiences of older adults in different settings around the world. For example, the concept of uncertainty although present in the experiences of older adults in Zambia, presented itself differently than the uncertainty experienced by older adults living with HIV in Canada (Solomon et al., 2014). Much of the uncertainty in sub-Saharan Africa were tied to resource limitations. Many studies included in the scoping study suggested that poverty and financial wellbeing were found to be quantitatively and qualitatively prominent factors that influenced a person's quality of life rather than their age or HIV status (Kuteesa et al., 2012; Nyirenda et al., 2012; Richards et al., 2013; Seeley et al., 2010; Wright et al., 2012). In the qualitative study, poverty intertwined with gender, employment and food insecurity. Women tended to engage in household chores while men participated in paid employment. Participants described being disabled by resource constraints whether it be paying for items in the home, for food, or even for back pain medication. The lack of steady and reliable income left participants with few available choices to stay healthy. Although not commonly considered in the disability realm, the social determinants of health and in particular, the effects of poverty, play an important

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. and significant role in shaping disability experiences and quality of life of individuals, especially as older adults age with HIV in resource-limited and HIV hyper-endemic settings.

Limitations

This thesis had limitations within each of the two manuscripts contained and some overarching limitations. One limitation was assigning a numerical cut-off for defining older adults. Chronological age is not directly indicative of life stages that may be culturally determined. In addition, aging is a process that occurs over time, but the studies included in the scoping review and the cross-sectional analysis of data only allows for aging to be studied at a single point in time. Finally, the secondary nature of the qualitative study poses a contextual limitation to interpretation of the findings and withholds the opportunity for age-related clarifying questions to be asked.

Future Directions

Future studies can bridge gaps in the literature found with scoping studies by conducting studies that serve to address part of this known gap in knowledge. Future research on aging and HIV should analyze longitudinal data and watch specifically for changes in illness experiences of older adults over time.

Given the dearth of knowledge about aging with HIV in sub-Saharan Africa, it is important to understand how this thesis informs an international context especially with the understanding that HIV-related disability can be episodic in nature. Although context matters when it comes to understanding experiences and the steps taken to make decisions on how or why one perceives their health status to be good or poor, lessons of the human condition and what enables or inhibits a good quality of life or influences disability can be drawn globally that may be transferable and related to different local contexts.

Gender was found to be a prominent component of themes surrounding ability to participate in daily activities and is an important future area of study. While some authors have focused particularly on older adult women as caregivers of their grandchildren in Uganda (Kamya et al. 2009), a similar focus on the specific challenges HIV-infected older women, particular widows, may face as they age with HIV will be an important area of focus for future practice and research considerations.

Countries can look to one another and learn and grow, utilizing those essential global health connections through knowledge sharing and global partnerships. Further partnerships within and between countries on HIV, aging and disability can strengthen global health research capacity and align with locally identified research priorities. Solutions developed in tandem with interdisciplinary teams will become increasingly important to address the complexities inherent with “wicked” global health problems. Knowledge of varied experiences of older adults in Zambia is crucial to understanding the unique challenges they face and the role rehabilitation can play in supporting them to improve their quality of life.

Concluding Remarks: Planning Ahead so that Fewer People are Left Behind

As successes in HIV treatment continue, there needs to be preparation for the generations of individuals who will be living with the chronic effects of HIV. Sub-Saharan Africa is likely ill prepared for health system reforms required to engage with an aging cohort of people, and it is essential that policy makers and health officials begin to plan ahead so that the longevity of life on ART is one that is rich in quality.

This manuscript thesis provides a scoping review to identify the gaps in knowledge on HIV, aging and quality of life in sub-Saharan Africa and a qualitative study to illuminate the disability related experiences of ten older adults living with HIV. This thesis presents findings that are relevant to changing times. As effects of globalization continue to shift and

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health. shape demographics and disease burden around the globe, researchers, policy-makers and practitioners need to work collaboratively to adapt to changing population health needs. This thesis provides information to academics doing collaborative work, but can also serve to inform social policies surrounding the care and support needs of older adults in a resource-limited setting. It is hoped that the initial glimpse into the lives of older people in sub-Saharan Africa will foreshadow the challenges they may face along with the living strategies that may engage in to plan for future health systems reform for an aging population.

In summary, this manuscript thesis will inform researchers, practitioners, and policy makers of the gaps in knowledge as well as the experiences of older people living with HIV in sub-Saharan Africa. The background, methods, findings, and discussion contained within this thesis is more than a scholastic endeavor; it serves as an affirmation and contribution to the fundamental belief that health is an important resource for all. Regardless of income, age, gender, or ability, people have a right to health. Consequently, it remains imperative to actively contribute to addressing gaps in knowledge and to be inclusive in those efforts so that no one is overlooked. In conclusion, this research is important because it highlights lessons learned from past and present experiences of older adults to anticipate and look forward in time so that fewer people are left behind.

References

- Baylies, C. (2002). HIV/AIDS and older women in Zambia : concern for self , worry over daughters, towers of strength. *Third World Quarterly*, 23(2), 351–375.
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. a, & Haas, S. M. (1999). “In an important way, I did die”: uncertainty and revival in persons living with HIV or AIDS. *AIDS Care*, 11(2), 201–219. <http://doi.org/10.1080/09540129948090>
- Emler. (2006). “You’re Awfully Old to Have This Disease”: Experiences of Stigma and Ageism in Adults 50 Years and Older Living With HIV/AIDS. *The Gerontologist*, 46(6), 781–790. <http://doi.org/10.1093/geront/46.6.781>

- Emlet. (2007). Experiences of stigma in older adults living with HIV/AIDS: a mixed-methods analysis. *AIDS Patient Care and STDs*, 21(10), 740–52. <http://doi.org/10.1089/apc.2007.0010>
- Emlet. (2008). Truth and consequences: a qualitative exploration of HIV disclosure in older adults. *AIDS Care*, 20(6), 710–7. <http://doi.org/10.1080/09540120701694014>
- Ezeh, A., Chepngeno, G., Kasiira, A. Z., & Woubalem, Z. (2006). The Situation of Older People in Poor Urban Settings: The Case of Nairobi, Kenya. In B. Cohen & J. Menken (Eds.), *Aging in Sub-Saharan Africa: Recommendations for Furthering Research* (pp. 189–213). Washington, D.C.: The National Academic Press. Retrieved from <http://www.nap.edu/catalog/11708.html>
- Foster, P. P., & Gaskins, S. W. (2009). Older African Americans' management of HIV/AIDS stigma. *AIDS Care*, 21(10), 1306–12. <http://doi.org/10.1080/09540120902803141>
- Greeff, M., Uys, L. R., Wantland, D., Makoae, L., Chirwa, M., Dlamini, P., ... Holzemer, W. L. (2010). Perceived HIV stigma and life satisfaction among persons living with HIV infection in five African countries: a longitudinal study. *International Journal of Nursing Studies*, 47(4), 475–486. Retrieved from <http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2010620204&site=ehost-live&scope=site>
- Han, N., Wright, S., O'Connor, C., Hoy, J., Ponnampalavanar, S., Grotowski, M., ... Kamarulzaman, a. (2015). HIV and aging: insights from the Asia Pacific HIV Observational Database (APHOD). *HIV Medicine*, 16(3), 152–160. <http://doi.org/10.1111/hiv.12188>
- Kalichman, S. C., Simbayi, L. C., Cain, D., Jooste, S., Skinner, D., & Cherry, C. (2006). Generalizing a model of health behaviour change and AIDS stigma for use with sexually transmitted infection clinic patients in Cape Town, South Africa. *AIDS Care*, 18(3), 178–182. Retrieved from <http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2009267959&site=ehost-live&scope=site>
- Kanya, H. Poindexter, C.C. (2009). Mama Jaja: The stresses and strengths of HIV-affected Ugandan grandmothers. *Social Work in Public Health*. 24 (1-2): 4-21.
- Kuteesa, M. O., Seeley, J., Cumming, R. G., & Negin, J. (2012). Older people living with HIV in Uganda: understanding their experience and needs. *African Journal of AIDS Research*, 11(4), 295–305. <http://doi.org/10.2989/16085906.2012.754829>
- Lazarus, J. V., & Nielsen, K. (2010). HIV and people over 50 years old in Europe. *HIV*
- Martin, C. P., Fain, M. J., & Klotz, S. A. (2008). The Older HIV-Positive Adult: A Critical Review of the Medical Literature. *American Journal of Medicine*, 121(12), 1032–1037. <http://doi.org/10.1016/j.amjmed.2008.08.009>

- Mugisha, J., Scholten, F., Owilla, S., Naidoo, N., Seeley, J., Chatterji, S., ... Boerma, T. (2013). Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda. *AIDS Care*, 25(11), 1341–8. <http://doi.org/10.1080/09540121.2013.765936>
- Munthree, C., & Maharaj, P. (2010). Growing old in the era of a high prevalence of HIV/AIDS: The impact of AIDS on older men and women in KwaZulu-Natal, South Africa. *Research on Aging*, 32(2), 155–174. <http://doi.org/10.1177/0164027510361829>
- Mutevedzi, P. C., & Newell, M.-L. (2011). A missing piece in the puzzle: HIV in mature adults in sub-Saharan Africa. *Future Virology*, 6, 755–767. <http://doi.org/10.2217/fvl.11.43>
- Namisango, E., Harding, R., Atuhaire, L., Ddungu, H., Katabira, E., Muwanika, F. R., & Powell, R. A. (2012). Pain Among Ambulatory HIV/AIDS Patients: Multicenter Study of Prevalence, Intensity, Associated Factors, and Effect. *Journal of Pain*, 13(7), 704–713. Retrieved from <http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2011604225&site=ehost-live&scope=site>
- Nixon, S., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H., & Retis, C. (2011). Rehabilitation: A crucial component in the future of HIV care and support. *The Southern African Journal of HIV Medicine*, 12–17.
- Nyirenda, Chatterji, Falkingham, Mutevedzi, Hosehood, Evandrou, ... Newell. (2012). An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC Public Health*, 12(259). <http://doi.org/10.1186/1471-2458-12-259>
- O'Brien, K. K., Bayoumi, A. M., Strike, C., Young, N. L., & Davis, A. M. (2008). Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health and Quality of Life Outcomes*, 6(76). <http://doi.org/10.1186/1477-7525-6-76>
- O'Brien, K. K., Davis, A. M., Strike, C., Young, N. L., & Bayoumi, A. M. (2009). Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society*, 12(1), 5. <http://doi.org/10.1186/1758-2652-12-30>
- Ogunmefun, C., Gilbert, L., & Schatz, E. (2011). Older Female Caregivers and HIV/AIDS-Related Secondary Stigma in Rural South Africa. *Journal of Cross-Cultural Gerontology*, 26(1), 85–102. <http://doi.org/10.1007/s10823-010-9129-3>
- Phiri, A. N. (2004). *A phenomenological study of ageing amongst the older persons in Zambia*.
- Richards, E., Zalwango, F., Seeley, J., Scholten, F., & Theobald, S. (2013). Neglected older women and men: Exploring age and gender as structural drivers of HIV among people

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
aged over 60 in Uganda. *African Journal of AIDS Research*, 12(2), 71–78.
<http://doi.org/10.2989/16085906.2013.831361>

- Rusch, M., Nixon, S., Schilder, A., Braitstein, P., Chan, K., & Hogg, R. S. (2004). Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality of Life Outcomes*, 2(46). <http://doi.org/10.1186/1477-7525-2-46>
- Samman, E., & Rodriguez-Takeuchi, L. K. (2013). *Old age, disability and mental health: data issues for a post-2015 framework - ODI Background Notes - Discussion papers*. London. Retrieved from www.odi.org.uk
- Schatz, E., & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global Public Health*, (May), 1–16.
<http://doi.org/10.1080/17441692.2015.1035664>
- Scholten, F., Mugisha, J., Seeley, J., Kinyanda, E., Nakubukwa, S., Kowal, P., ... Grosskurth, H. (2011). Health and functional status among older people with HIV/AIDS in Uganda. *BMC Public Health*, 11(1), 886. <http://doi.org/10.1186/1471-2458-11-886>
- Seeley, J., Zalwango, F., Mugisha, J., Kinyanda, E., Wake, C., & Scholten, F. (2010). Poverty, ageing and HIV in Wakiso district Uganda. In *Chronic Poverty Research Centre 2010 Conference* (pp. 1–19).
- Shippy, R. a, & Karpiak, S. E. (2005). The aging HIV/AIDS population: fragile social networks. *Aging & Mental Health*, 9(3), 246–54.
<http://doi.org/10.1080/13607860412331336850>
- Simpson, A., & Bond, V. (2014). Narratives of Nationhood and HIV/AIDS: Reflections on Multidisciplinary Research on the HIV/AIDS Epidemic in Zambia over the Last 30 Years. *Journal of Southern African Studies*, 40(5), 1065–1089.
<http://doi.org/10.1080/03057070.2014.946222>
- Solomon, O'Brien, K., Wilkins, S., & Gervais, N. (2014a). Aging with HIV and disability: The role of uncertainty. *AIDS Care*, 26(2), 240–5.
<http://doi.org/10.1080/09540121.2013.811209>
- Solomon, O'Brien, K., Wilkins, S., & Gervais, N. (2014b). Aging with HIV: A Model of Disability. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, 13, 519–525. <http://doi.org/10.1177/2325957414547431>
- Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17(10), 1372–1380. <http://doi.org/10.1177/1049732307307031>
- The World Bank. (2015a). Country and Lending Groups. Retrieved January 28, 2015, from <http://data.worldbank.org/about/country-and-lending-groups>

- MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.
The World Bank. (2015b). Life expectancy at birth, total (Years). Retrieved May 24, 2015,
from <http://data.worldbank.org/indicator/SP.DYN.LE00.IN>
- Tsai, A., Bangsberg, D., Bwana, M., Haberer, J., Frongillo, E., Muzoora, C., ... Weiser, S.
(2013). How Does Antiretroviral Treatment Attenuate the Stigma of HIV? Evidence
from a Cohort Study in Rural Uganda. *AIDS & Behavior*, 17(8), 2725–2731. Retrieved
from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2012314186&site=ehost-live&scope=site>
- Tsai, A., Weiser, S., Steward, W., Mukiibi, N., Kawuma, A., Kembabazi, A., ... Bangsberg,
D. (2013). Evidence for the Reliability and Validity of the Internalized AIDS-Related
Stigma Scale in Rural Uganda. *AIDS & Behavior*, 17(1), 427–433. Retrieved from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2011891283&site=ehost-live&scope=site>
- Tucker, A., Liht, J., de Swardt, G., Jobson, G., Rebe, K., McIntyre, J., & Struthers, H.
(2014). Homophobic stigma, depression, self-efficacy and unprotected anal intercourse
for peri-urban township men who have sex with men in Cape Town, South Africa: a
cross-sectional association model. *AIDS Care*, 26(7), 882–889. Retrieved from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2012562293&site=ehost-live&scope=site>
- UNAIDS. (2014). *The Gap Report*. Retrieved from
http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/UNAIDS_Gap_report_en.pdf
- Uys, L., Chirwa, M., Kohi, T., Greeff, M., Naidoo, J., Makoae, L., ... Holzemer, W. L.
(2009). Evaluation of a health setting-based stigma intervention in five African
countries. *AIDS Patient Care & STDs*, 23(12), 1059–1066. Retrieved from
<http://libaccess.mcmaster.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=2010521085&site=ehost-live&scope=site>
- Wallach, I., & Brotman, S. (2012). Ageing with HIV/AIDS: a scoping study among people
aged 50 and over living in Quebec. *Ageing and Society*, 33, 1212–1242.
<http://doi.org/10.1017/S0144686X12000529>
- Wright, S., Zalwango, F., Seeley, J., Mugisha, J., & Scholten, F. (2012). Despondency
among HIV-Positive older men and women in Uganda. *Journal of Cross-Cultural
Gerontology*, 27(4), 319–333. <http://doi.org/10.1007/s10823-012-9178-x>

Appendix

Appendix A - Chapter 2 Scoping Review: Lists, Tables, and Figures

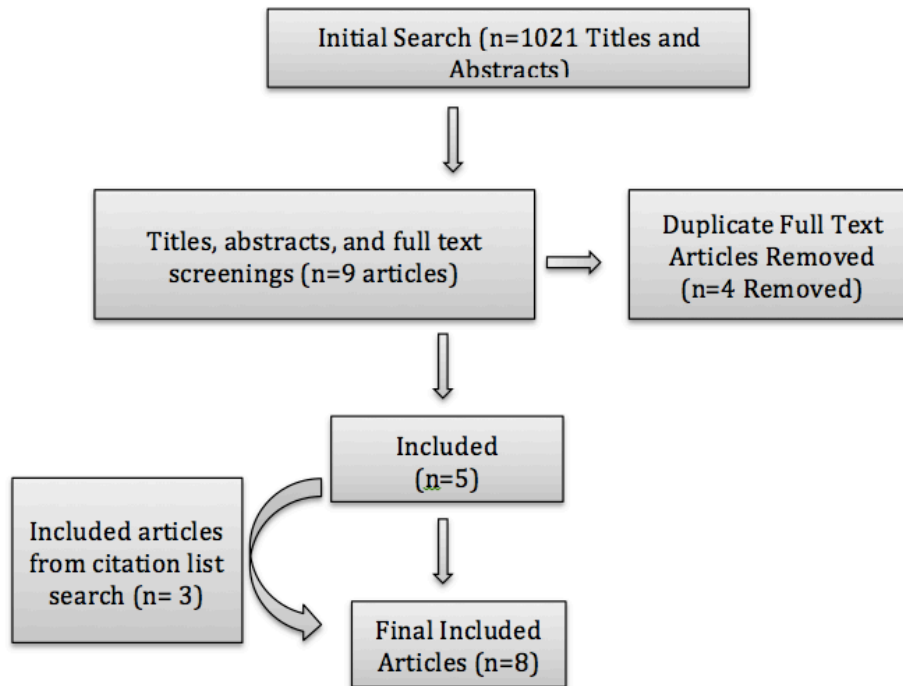


Figure 1- Flowchart of included articles

List 1- Countries in Sub-Saharan World Bank (The World Bank, 2015a)

1. Angola
2. Benin
3. Botswana
4. Burkina Faso
5. Burundi
6. Cameroon
7. Cabo Verde
8. Central African Republic
9. Chad
10. Comoros
11. Congo, Democratic Republic of the
12. Congo
13. Côte d'Ivoire
14. Eritrea
15. Ethiopia
16. Gabon
17. Gambia, The
18. Ghana
19. Guinea
20. Guinea-Bissau
21. Kenya
22. Lesotho
23. Liberia
24. Madagascar
25. Malawi
26. Mali
27. Mauritania
28. Mauritius
29. Mozambique
30. Namibia
31. Niger
32. Nigeria
33. Rwanda
34. Sao Tome and Principe
35. Senegal
36. Seychelles
37. Sierra Leone
38. Somalia
39. South Africa
40. South Sudan
41. Sudan
42. Swaziland
43. Tanzania/ United Republic of Tanzania
44. Togo
45. Uganda
- 46.
47. Zimbabwe

Table 1- Inclusion and Exclusion Criteria

Topic Idea	Descriptor	Include	Exclude
Participants	Study must include participants	Has participants	Does not have participants (i.e. theoretical papers or cost-effectiveness papers)
Location where data were collected is stated	Study must have indicated where the data were collected (can be regional or country)	Studies that indicate where data were collected	Studies that do not explicitly indicate where data were collected from
HIV/AIDS	At least some participants are infected with HIV/AIDS	Some participants are reported to be HIV infected or HIV positive	Studies that include HIV affected participants only or focus on diseases other than HIV
Older adult	Exclusively include people 50 years and older	All participants are aged 50 years and older	Studies where any of the participants in the sample is 49 years or younger
Sub-Saharan Africa	Data must be exclusively collected in sub-Saharan Africa	Studies where data were collected in sub-Saharan Africa or in any of the countries listed by the World bank as geographically belonging in sub-Saharan Africa	Studies where data were collected in part (i.e. comparative studies) or fully in a region outside of sub-Saharan Africa or where participants don't currently reside in sub-Saharan Africa (i.e. migrants from sub-Saharan Africa to France)
Quality of Life	Study must address concepts of quality of life as defined by either the WHO 1995 Quality of Life Group definition or Lorenz et al 2001 definition of Health Related Quality of life	Any study that addresses perceptions, psychological state of mind, bodily functioning, attitudes, position of life of a participant, description of daily activities, and various aspects of well-being	Studies with a primary purpose of developing a validating tool for a quality of life instrument
Language	The study must have been published in the English language	Any study where the abstract and full text are written in English	Any study where either the abstract or the full text are written in another language

Table 2- Characteristics of Included Studies

Authors	Year Published	Title	Methodological Design	Purpose of Study (Aim)	HIV Infected and/or affected	Component of Quality of Life Addressed
Kuteesa, Seeley, Cumming, and Negin	2012	Older people living with HIV in Uganda: Understanding their experience and needs	Qualitative: Original individual in-depth interviews and focus groups	To examine older HIV-infected people's perspective of what their healthcare needs are, how such needs impact their wellbeing, and what implications all this may have on health-promotion strategies	HIV infected	Participant's perceptions of their healthcare needs and how these impact their well-being
Mugisha, Scholten, Owilla, Naidoo, Seeley, Chatterji, Kowal, and Boerma	2013	Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda	Quantitative: Secondary analysis of longitudinal cohort data	To assess factors affecting the association of caregiving responsibilities and perceived caregiving burden with the health status and well-being of older people, with special attention to HIV status	HIV infected and HIV affected (caregivers)	Perceptions of caregiving burden using an adapted version of the WHOQOL tool deriving from participant's perceptions of life

Nyrienda, Chatterji, Falkingham, Mutevedzi, Hosegood, Evandrou, Kowal, and Newell	2012	An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa	Quantitative: Secondary analysis of longitudinal health and household survey data	To examine the correlates of health and well-being of HIV-infected older people aged 50 years and above, relative to their HIV-affected peers in rural South Africa	HIV infected and HIV affected (adult child infected or by adult child death)	Cites the WHO definition of quality of life and uses the WHOQOL Tool and the WHODAS II
Nyrienda, Newell, Mugisha, Mutevedzi, Seeley, Scholten, and Kowal	2013	Health, wellbeing, and disability among older people infected or affected by HIV in Uganda and South Africa	Quantitative: Secondary analysis of cross-sectional cohort survey data	To describe and compare self-rated health, subjective well-being and functioning of older people in Uganda and South Africa who are HIV infected or affected by HIV in their families	HIV infected and HIV affected	General wellbeing is measured using the WHOQOL tool and physical wellbeing is measured using BMI. Also sought information on self-perceived financial status.
Richards, Zalwango, Seeley, Scholten, and Theobald,	2013	Neglected older women and men: Exploring age and gender as structural drivers of HIV among people aged over 60 in Uganda	Qualitative: Original interviews and focus groups	To explore how women's and men's gendered experiences from childhood to old age have shaped their vulnerability in relation to HIV both in terms of their individual risk of HIV and their access to and experiences of HIV services	HIV infected (2/5 of participants) and HIV affected	Perceptions, experiences, perceived risk, changing positions and livelihood activity; changes in psychological and emotional agency for women, and changing positions and attitudes in society for both men and women

Seeley, Zalwayngo, Mugisa, Kinyanda, Wake, and Scholten	2010	Poverty, ageing and HIV in Wakiso district Uganda	Qualitative: Case studies and themes from structured questionnaire purposively selected group of participants from a larger longitudinal quantitative survey	To describe the health and well-being of older people living in poverty and living with HIV in a resource-constrained setting in Uganda	HIV infected	Health and well-being embedded within the context of poverty
Scholten, Mugisha, Seeley, Kinyanda, Nakubukwa, Kowal, Naidoo, Boerma, Chatterj, and Grosskurth	2011	Health and functional status among older people with HIV/AIDS in Uganda	Quantitative: Cross-sectional survey	To describe the health and functional status of older people in a peri-urban and rural Ugandan population, who are themselves HIV infected or indirectly affected by HIV/AIDS in the family, with special attention to the effects of the introduction of anti-retroviral therapy	HIV infected and HIV affected	WHO-DAS Physical functioning, self-reported measures of health
Wright, Zalwango, Seeley, Mugisha, and Scholten	2012	Despondency among HIV-positive older men and women in Uganda	Qualitative: Semi-structured extended conversation of a purposively selected group of participants from a larger longitudinal quantitative survey	To understand the direct and indirect effects of HIV/AIDS and anti-retroviral treatment (ART) on the health and well-being of older people, particularly despondency and psychological well-being	HIV infected (26/ 40 older participants) and HIV affected	Psychological well-being

Table 3- All Authors and Lead Authors' Location of Institutional Affiliation by Exclusive Affiliation with a Single Institution or Inclusive Affiliation with More Than One Institution

Country	All authors (exclusive)	All authors (inclusive)	Lead authors (exclusive)	Lead authors (inclusive)
Australia	2	5	0	2
South Africa	3	4	1	1
Switzerland	2	3	0	0
Uganda	6	9	1	4
United Kingdom	6	9	2	3
Total	19	30	4	10

Table 4- Comparisons Made By Different Studies and Their Respective Findings

Author	Comparison Groups	Findings
Mugisha <i>et al.</i> 2013	HIV + (with ART or not) versus HIV -	Same level of caregiving responsibilities
Mugisha <i>et la.</i> 2013	Caregiving versus no caregiving	Those caregiving had better health indicators (self-reported health, BMI, and grip strength)
Mugisha <i>et al.</i> 2013	HIV + (with ART or not) versus HIV -	HIV infected have more financial support
Nyirenda <i>et al.</i> 2012	HIV + vs. HIV - (affected)	HIV + better quality of life
Nyirenda <i>et al.</i> 2013	HIV+ (infected or affected) vs. HIV -	HIV+ (infected or affected) were better off than affected *Note: Findings repeated from the Nyirenda 2012 findings
Nyirenda <i>et al.</i> 2013	South Africa vs. Uganda on physical well-being	Uganda was better off than South Africa in terms of physical well-being as measured
Nyirenda <i>et al.</i> 2013	South Africa vs. Uganda on overall subjective quality of life	South Africa was better off than Uganda in terms of quality of life measures
Scholten <i>et al.</i> 2011	HIV+ vs. HIV-	HIV+ less susceptible to depression than HIV -
Seeley <i>et al.</i> 2010	HIV+ vs. HIV-	HIV+ better access to services (because of frequency of visits to the clinics for meds)

Table 5- Search Term Combination For Each Database

EMBASE	March	556	1. HIV.mp. or exp Human immunodeficiency virus/ 2. aids.mp. or exp acquired immune deficiency syndrome/
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31, 2015	Hits	<p>3. older adult.mp. 4. exp aging/ or aging.mp. 5. elderly care.mp. or exp elderly care/ 6. accelerated aging.mp. 7. geriatrics.mp. or exp geriatrics/ 8. old age.mp. 9. exp senescence/ or senescence.mp. 10. middle aged.mp. or exp middle aged/ 11. adult/ 12. adolescence.mp. or exp adolescence/ 13. young adult.mp. or exp young adult/ 14. infant/ 15. child/ 16. subsaharan africa.mp. 17. africa south of the sahara.mp. or exp "Africa south of the Sahara"/ 18. angola.mp. or exp Angola/ 19. benin.mp. or exp Benin/ 20. botswana.mp. or exp Botswana/ 21. burkina faso.mp. or exp Burkina Faso/ 22. burundi.mp. or exp Burundi/ 23. cameroon.mp. or exp Cameroon/ 24. cabo verde.mp. 25. central african republic.mp. or exp Central African Republic/ 26. chad.mp. or exp Chad/ 27. comoros.mp. or exp Comoros/ 28. democratic republic of the congo.mp. or exp Democratic Republic Congo/ 29. congo.mp. or exp Congo/ 30. cote d'ivore.mp. or exp Cote d'Ivoire/ 31. eritrea.mp. or exp Eritrea/ 32. ethiopia.mp. or exp Ethiopia/ 33. gabon.mp. or exp Gabon/ 34. gambia.mp. or exp Gambia/ 35. ghana.mp. or exp Ghana/ 36. exp Guinea/ or guinea.mp. 37. guinea-bissau.mp. or exp Guinea-Bissau/ 38. kenya.mp. or exp Kenya/ 39. lesotho.mp. or exp Lesotho/ 40. liberia.mp. or exp Liberia/ 41. madagascar.mp. or exp Madagascar/ 42. malawi.mp. or exp Malawi/ 43. exp Mali/ or mali.mp. 44. mauritania.mp. or exp Mauritania/ 45. mauritius.mp. or exp Mauritius/ 46. mozambique.mp. or exp Mozambique/ 47. namibia.mp. or exp Namibia/ 48. exp Niger/ or niger.mp. 49. nigeria.mp. or exp Nigeria/ 50. rwanda.mp. or exp Rwanda/ 51. "sao tome and principe".mp. or exp "Sao Tome and Principe"/ 52. exp Senegal/ or senegal.mp. 53. seychelles.mp. or exp Seychelles/ 54. sierra leone.mp. or exp Sierra Leone/ 55. somalia.mp. or exp Somalia/ 56. south africa.mp. or exp South Africa/ 57. south sudan.mp. 58. exp Sudan/ or sudan.mp. 59. swaziland.mp. or exp Swaziland/ 60. tanzania.mp. or exp Tanzania/ 61. togo.mp. or exp Togo/ 62. uganda.mp. or exp Uganda/ 63. zambia.mp. or exp Zambia/ 64. zimbabwe.mp. or exp Zimbabwe/ 65. quality of life.mp. or exp "quality of life"/ 66. psychological adaptation.mp. 67. activities of daily living.mp. 68. 1 or 2 69. 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 70. 12 or 13 or 14 or 15 71. 69 not 70 72. 16 or 17 73. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 74. 72 or 73</p>
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			<p>75. self-concept.mp. or exp self concept/ 76. self-efficacy.mp. 77. 65 or 66 or 67 or 75 or 76 78. 68 and 71 and 74 and 77</p>
Global Health	March 31, 2015	58 Hits	<p>1. HIV.mp. or exp Human immunodeficiency virus/ 2. aids.mp. or exp acquired immune deficiency syndrome/ 3. older adult.mp. 4. aged.mp. or exp Aged/ 5. elderly.mp. 6. aging.mp. or exp aging/ 7. accelerated aging.mp. 8. geriatrics.mp. or exp geriatrics/ 9. old age.mp. 10. exp "Aged, 80 and over"/ or "aged, 80 and older".mp. 11. middle aged.mp. or exp Middle Aged/ 12. adult.mp. or exp Adult/ 13. adolescent.mp. or exp Adolescent/ 14. young adult.mp. or exp young adult/ 15. infant.mp. or exp infant/ 16. child.mp. or exp child/ 17. subsaharan africa.mp. 18. africa south of the sahara.mp. or exp "Africa south of the Sahara"/ 19. angola.mp. or exp Angola/ 20. benin.mp. or exp Benin/ 21. botswana.mp. or exp Botswana/ 22. burkina faso.mp. or exp Burkina Faso/ 23. burundi.mp. or exp Burundi/ 24. cameroon.mp. or exp Cameroon/ 25. cabo verde.mp. 26. central african republic.mp. or exp Central African Republic/ 27. chad.mp. or exp Chad/ 28. comoros.mp. or exp Comoros/ 29. democratic republic of the congo.mp. or exp Democratic Republic Congo/ 30. congo.mp. or exp Congo/ 31. cote d'ivoire.mp. or exp Cote d'Ivoire/ 32. eritrea.mp. or exp Eritrea/ 33. ethiopia.mp. or exp Ethiopia/ 34. gabon.mp. or exp Gabon/ 35. gambia.mp. or exp Gambia/ 36. ghana.mp. or exp Ghana/ 37. exp Guinea/ or guinea.mp. 38. guinea-bissau.mp. or exp Guinea-Bissau/ 39. kenya.mp. or exp Kenya/ 40. lesotho.mp. or exp Lesotho/ 41. liberia.mp. or exp Liberia/ 42. madagascar.mp. or exp Madagascar/ 43. malawi.mp. or exp Malawi/ 44. exp Mali/ or mali.mp. 45. mauritania.mp. or exp Mauritania/ 46. mauritius.mp. or exp Mauritius/ 47. mozambique.mp. or exp Mozambique/ 48. namibia.mp. or exp Namibia/ 49. exp Niger/ or niger.mp. 50. nigeria.mp. or exp Nigeria/ 51. rwanda.mp. or exp Rwanda/ 52. "sao tome and principe".mp. or exp "Sao Tome and Principe"/ 53. exp Senegal/ or senegal.mp. 54. seychelles.mp. or exp Seychelles/ 55. sierra leone.mp. or exp Sierra Leone/ 56. somalia.mp. or exp Somalia/ 57. south africa.mp. or exp South Africa/ 58. south sudan.mp. 59. exp Sudan/ or sudan.mp. 60. swaziland.mp. or exp Swaziland/ 61. tanzania.mp. or exp Tanzania/ 62. togo.mp. or exp Togo/ 63. uganda.mp. or exp Uganda/ 64. zambia.mp. or exp Zambia/ 65. zimbabwe.mp. or exp Zimbabwe/ 66. quality of life.mp. or exp "quality of life"/ 67. psychological adaptation.mp. 68. activities of daily living.mp. 69. self-concept.mp. or exp self concept/</p>

			<p>70. self-efficacy.mp. 71. 1 or 2 72. 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 73. 13 or 14 or 15 or 16 74. 72 not 73 75. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 76. 66 or 67 or 68 or 69 or 70 77. 71 and 74 and 75 and 76</p>
Medline	March 31, 2015	235 Hits	<p>1. exp HIV/ or HIV.mp. 2. AIDS.mp. or exp Acquired Immunodeficiency Syndrome/ 3. older adult.mp. 4. aged.mp. or exp Aged/ 5. elderly.mp. 6. aging.mp. or exp Aging/ 7. accelerated aging.mp. 8. geriatrics.mp. or exp Geriatrics/ 9. old age.mp. 10. exp "Aged, 80 and over"/ or "aged, 80 and older".mp. 11. middle aged.mp. or exp Middle Aged/ 12. adult.mp. or exp Adult/ 13. adolescent.mp. or exp Adolescent/ 14. young adult.mp. or exp Young Adult/ 15. infant.mp. or exp Infant/ 16. child.mp. or exp Child/ 17. exp "Africa South of the Sahara"/ 18. subsaharan africa.mp. 19. sub-saharan africa.mp. 20. angola.mp. or exp Angola/ 21. Benin.mp. or exp Benin/ 22. botswana.mp. or exp Botswana/ 23. burkina faso.mp. or exp Burkina Faso/ 24. burundi.mp. or exp Burundi/ 25. cameroon.mp. or exp Cameroon/ 26. cabo verde.mp. 27. central african republic.mp. or exp Central African Republic/ 28. chad.mp. or exp Chad/ 29. comoros.mp. or exp Comoros/ 30. democratic republic of the congo.mp. or exp "Democratic Republic of the Congo"/ 31. exp Congo/ or republic of congo.mp. 32. Cote d'ivoire.mp. or exp Cote d'Ivoire/ 33. eritrea.mp. or exp Eritrea/ 34. ethiopia.mp. or exp Ethiopia/ 35. gabon.mp. or exp Gabon/ 36. gambia.mp. or exp Gambia/ 37. ghana.mp. or exp Ghana/ 38. guinea.mp. or exp Guinea/ 39. guinea-bissau.mp. or exp Guinea-Bissau/ 40. kenya.mp. or exp Kenya/ 41. lesotho.mp. or exp Lesotho/ 42. liberia.mp. or exp Liberia/ 43. madagascar.mp. or exp Madagascar/ 44. malawi.mp. or exp Malawi/ 45. mali.mp. or exp Mali/ 46. mauritania.mp. or exp Mauritania/ 47. mauritius.mp. or exp Mauritius/ 48. mozambique.mp. or exp Mozambique/ 49. namibia.mp. or exp Namibia/ 50. exp Niger/ or niger.mp. 51. nigeria.mp. or exp Nigeria/ 52. rwanda.mp. or exp Rwanda/ 53. (sao tome and principe).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 54. senegal.mp. or exp Senegal/ 55. seychelles.mp. or exp Seychelles/ 56. sierra leone.mp. or exp Sierra Leone/ 57. somalia.mp. or exp Somalia/ 58. south africa.mp. or exp South Africa/ 59. south sudan.mp. 60. sudan.mp. or exp Sudan/ 61. swaziland.mp. or exp Swaziland/</p>

			<p>62. tanzania.mp. or exp Tanzania/ 63. togo.mp. or exp Togo/ 64. uganda.mp. or exp Uganda/ 65. zambia.mp. or exp Zambia/ 66. zimbabwe.mp. or exp Zimbabwe/ 67. quality of life.mp. or exp "Quality of Life"/ 68. psychological adaptation.mp. or exp Adaptation, Psychological/ 69. activities of daily living.mp. or exp "Activities of Daily Living"/ 70. 1 or 2 71. 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 72. 13 or 14 or 15 or 16 73. 71 not 72 74. 17 or 18 or 19 75. 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 76. self-concept.mp. or exp Self Concept/ 77. self-efficacy.mp. or exp Self Efficacy/ 78. 74 or 75 79. 67 or 68 or 69 or 76 or 77 80. 70 and 73 and 78 and 79 81. 70 and 73 and 78 and 79</p>
Psych Info	March 31, 2015	21 Hits	<p>1. HIV.mp. or exp Human immunodeficiency virus/ 2. aids.mp. or exp acquired immune deficiency syndrome/ 3. older adult.mp. 4. exp aging/ or aging.mp. 5. elderly care.mp. or exp elderly care/ 6. accelerated aging.mp. 7. geriatrics.mp. or exp geriatrics/ 8. old age.mp. 9. exp senescence/ or senescence.mp. 10. middle aged.mp. or exp middle aged/ 11. adult.mp. or exp Adult/ 12. adolescence.mp. or exp adolescence/ 13. young adult.mp. or exp young adult/ 14. infant.mp. or exp infant/ 15. child.mp. or exp child/ 16. subsaharan africa.mp. 17. africa south of the sahara.mp. or exp "Africa south of the Sahara"/ 18. angola.mp. or exp Angola/ 19. benin.mp. or exp Benin/ 20. botswana.mp. or exp Botswana/ 21. burkina faso.mp. or exp Burkina Faso/ 22. burundi.mp. or exp Burundi/ 23. cameroon.mp. or exp Cameroon/ 24. cabo verde.mp. 25. central african republic.mp. or exp Central African Republic/ 26. chad.mp. or exp Chad/ 27. comoros.mp. or exp Comoros/ 28. democratic republic of the congo.mp. or exp Democratic Republic Congo/ 29. congo.mp. or exp Congo/ 30. cote d'ivoire.mp. or exp Cote d'Ivoire/ 31. eritrea.mp. or exp Eritrea/ 32. ethiopia.mp. or exp Ethiopia/ 33. gabon.mp. or exp Gabon/ 34. gambia.mp. or exp Gambia/ 35. ghana.mp. or exp Ghana/ 36. exp Guinea/ or guinea.mp. 37. guinea-bissau.mp. or exp Guinea-Bissau/ 38. kenya.mp. or exp Kenya/ 39. lesotho.mp. or exp Lesotho/ 40. liberia.mp. or exp Liberia/ 41. madagascar.mp. or exp Madagascar/ 42. malawi.mp. or exp Malawi/ 43. exp Mali/ or mali.mp. 44. mauritania.mp. or exp Mauritania/ 45. mauritius.mp. or exp Mauritius/ 46. mozambique.mp. or exp Mozambique/ 47. namibia.mp. or exp Namibia/ 48. exp Niger/ or niger.mp. 49. nigeria.mp. or exp Nigeria/ 50. rwanda.mp. or exp Rwanda/ 51. "sao tome and principe".mp. or exp "Sao Tome and Principe"/</p>

MSc. Thesis- Samantha Cheuk; McMaster University- Global Health.

			<p>52. exp Senegal/ or senegal.mp. 53. seychelles.mp. or exp Seychelles/ 54. sierra leone.mp. or exp Sierra Leone/ 55. somalia.mp. or exp Somalia/ 56. south africa.mp. or exp South Africa/ 57. south sudan.mp. 58. exp Sudan/ or sudan.mp. 59. swaziland.mp. or exp Swaziland/ 60. tanzania.mp. or exp Tanzania/ 61. togo.mp. or exp Togo/ 62. uganda.mp. or exp Uganda/ 63. zambia.mp. or exp Zambia/ 64. zimbabwe.mp. or exp Zimbabwe/ 65. quality of life.mp. or exp "quality of life"/ 66. psychological adaptation.mp. 67. activities of daily living.mp. 68. 1 or 2 69. 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 70. 12 or 13 or 14 or 15 71. 69 not 70 72. 16 or 17 73. 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 74. 72 or 73 75. self-concept.mp. or exp Self Concept/ 76. self-efficacy.mp. or exp Self Efficacy/ 77. 65 or 66 or 67 or 75 or 76 78. 68 and 71 and 74 and 77</p>
CINAHL	March 31, 2015	144 Hits	See PDF print out below for a full listing of the search terms used
Ageline	March 31, 2015	7 hits	See PDF print out below for a full listing of the search terms used

CINAHL

Print Search History: EBSCOhost

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Tuesday, March 31, 2015 12:04:59 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S82	S74 AND S77 AND S78 AND S81	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	144
S81	S71 OR S72 OR S73 OR S79 OR S80	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S80	(MM "Self-Efficacy") OR "self-efficacy"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S79	(MM "Self Concept+") OR "self-concept"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S78	S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display

	OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70			
S77	S75 not S76	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S76	S15 OR S16 OR S17 OR S18 OR S19	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S75	S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S74	S1 OR S2	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S73	(MM "Activities of Daily Living+") OR "activities of daily living"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S72	(MM "Adaptation, Psychological+") OR "psychological adaptation"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S71	(MM "Quality of Life+") OR "quality of life"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S70	(MM "Zimbabwe") OR "zimbabwe"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S69	(MH "Zambia")	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S68	(MM "Uganda") OR "uganda"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S67	(MM "Togo") OR "togo"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S66	(MM "Tanzania") OR "tanzania"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S65	(MM "Swaziland") OR "swaziland"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S64	(MM "Sudan") OR "sudan"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S63	"south sudan"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S62	(MM "South Africa") OR "south africa"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S61	(MM "Somalia") OR "somalia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S60	(MM "Sierra Leone")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S59	"seychelles"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S58	(MM "Senegal") OR "senegal"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S57	"sao tome and principe"	Search modes -	Interface - EBSCOhost	Display

		Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - CINAHL	
S56	(MM "Rwanda") OR "rwanda"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S55	(MM "Nigeria") OR "nigeria"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S54	(MM "Niger") OR "niger"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S53	(MM "Namibia") OR "namibia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S52	(MM "Mozambique") OR "mozambique"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S51	(MM "Indian Ocean Islands") OR "mauritius"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S50	(MM "Mauritania") OR "mauritania"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	Display

			Search Screen - Advanced Search Database - CINAHL	
S49	(MM "Mali") OR "mali"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S48	(MM "Malawi") OR "malawi"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S47	(MM "Madagascar") OR "madagascar"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S46	(MM "Liberia") OR "liberia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S45	(MM "Lesotho") OR "lesotho"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S44	(MM "Kenya") OR "kenya"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S43	(MM "Guinea-Bissau") OR "guinea-bissau"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	Display

			Search Database - CINAHL	
S42	(MM "Guinea") OR "guinea"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S41	(MM "Ghana") OR "ghana"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S40	(MM "Gambia") OR "gambia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S39	(MM "Gabon") OR "gabon"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S38	(MM "Ethiopia") OR "ethiopia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S37	(MM "Eritrea") OR "eritrea"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S36	(MM "Cote d'Ivoire") OR "cote d'ivoire"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S35	(MH "Congo") OR "congo"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S34	(MM "Democratic Republic of the Congo") OR "democratic republic of the congo"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S33	"comoros"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S32	(MM "Chad") OR "chad"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S31	(MM "Central African Republic") OR "central african republic"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S30	(MM "Cape Verde") OR "cape verde"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S29	"cabo verde"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S28	(MM "Cameroon") OR "cameroon"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S27	(MM "Burundi") OR "burundi"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S26	(MH "Burkina Faso") OR "burkina faso"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S25	(MM "Botswana") OR "botswana"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S24	(MM "Benin") OR "benin"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S23	(MM "Angola") OR "angola"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S22	"sub-saharan africa"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S21	"subsaharan africa"	Search modes -	Interface - EBSCOhost	Display

		Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - CINAHL	
S20	(MM "Africa South of the Sahara+") OR "africa south of the Sahara"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S19	(MM "Child+") OR "child"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S18	(MM "Infant+") OR "infant"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S17	(MM "Young Adult") OR "young adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S16	(MM "Young Adult") OR "young adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S15	(MM "Adolescence") OR "adolescents"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S14	(MM "Adult") OR "adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	Display

			Search Screen - Advanced Search Database - CINAHL	
S13	(MM "Middle Age") OR "middle aged"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S12	"aged: 65+ years"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S11	"aged, 50 and over"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S10	(MM "Aged, 80 and Over") OR "aged, 80 and over"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S9	"old age"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S8	(MM "Geriatrics") OR "geriatric"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S7	"accelerated aging"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	Display

S6	(MM "Aging+") OR "aging"	Search modes - Boolean/Phrase	Search Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S5	"elderly"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S4	(MM "Aged+") OR "aged"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S3	(MM "Frail Elderly") OR "older adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S2	(MM "Acquired Immunodeficiency Syndrome") OR "aids"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S1	(MM "HIV-Infected Patients+") OR "hiv"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display



Tuesday, March 31, 2015 12:08:03 PM

#	Query	Limiters/Expanders	Last Run Via	Results
S82	S74 AND S77 AND S78 AND S81	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - AgeLine	Display
S81	S71 OR S72 OR S73 OR S79 OR S80	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S80	(MM "Self-Efficacy") OR "self-efficacy"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S79	(MM "Self Concept+") OR "self-concept"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S78	S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display

	OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70			
S77	S75 not S76	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S76	S15 OR S16 OR S17 OR S18 OR S19	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S75	S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S74	S1 OR S2	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S73	(MM "Activities of Daily Living+") OR "activities of daily living"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S72	(MM "Adaptation, Psychological+") OR "psychological adaptation"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S71	(MM "Quality of Life+") OR "quality of life"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S70	(MM "Zimbabwe") OR "zimbabwe"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S69	(MH "Zambia")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S68	(MM "Uganda") OR "uganda"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S67	(MM "Togo") OR "togo"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S66	(MM "Tanzania") OR "tanzania"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S65	(MM "Swaziland") OR "swaziland"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display

S64	(MM "Sudan") OR "sudan"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S63	"south sudan"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S62	(MM "South Africa") OR "south africa"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S61	(MM "Somalia") OR "somalia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S60	(MM "Sierra Leone")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S59	"seychelles"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S58	(MM "Senegal") OR "senegal"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S57	"sao tome and principe"	Search modes -	Interface - EBSCOhost	Display

		Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - CINAHL	
S56	(MM "Rwanda") OR "rwanda"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S55	(MM "Nigeria") OR "nigeria"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S54	(MM "Niger") OR "niger"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S53	(MM "Namibia") OR "namibia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S52	(MM "Mozambique") OR "mozambique"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S51	(MM "Indian Ocean Islands") OR "mauritius"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S50	(MM "Mauritania") OR "mauritania"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	Display

			Search Screen - Advanced Search Database - CINAHL	
S49	(MM "Mali") OR "mali"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S48	(MM "Malawi") OR "malawi"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S47	(MM "Madagascar") OR "madagascar"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S46	(MM "Liberia") OR "liberia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S45	(MM "Lesotho") OR "lesotho"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S44	(MM "Kenya") OR "kenya"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S43	(MM "Guinea-Bissau") OR "guinea-bissau"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	Display

S42	(MM "Guinea") OR "guinea"	Search modes - Boolean/Phrase	Search Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S41	(MM "Ghana") OR "ghana"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S40	(MM "Gambia") OR "gambia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S39	(MM "Gabon") OR "gabon"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S38	(MM "Ethiopia") OR "ethiopia"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S37	(MM "Eritrea") OR "eritrea"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S36	(MM "Cote d'Ivoire") OR "cote d'ivoire"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S35	(MH "Congo") OR "congo"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S34	(MM "Democratic Republic of the Congo") OR "democratic republic of the congo"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S33	"comoros"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S32	(MM "Chad") OR "chad"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S31	(MM "Central African Republic") OR "central african republic"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S30	(MM "Cape Verde") OR "cape verde"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display
S29	"cabo verde"	Search modes - Boolean/Phrase	Database - CINAHL Interface - EBSCOhost Research Databases Search Screen - Advanced Search	Display

S28	(MM "Cameroon") OR "cameroon"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S27	(MM "Burundi") OR "burundi"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S26	(MH "Burkina Faso") OR "burkina faso"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S25	(MM "Botswana") OR "botswana"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S24	(MM "Benin") OR "benin"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S23	(MM "Angola") OR "angola"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S22	"sub-saharan africa"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S21	"subsaharan africa"	Search modes -	Interface - EBSCOhost	Display

		Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - CINAHL	
S20	(MM "Africa South of the Sahara+") OR "africa south of the Sahara"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S19	(MM "Child+") OR "child"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S18	(MM "Infant+") OR "infant"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S17	(MM "Young Adult") OR "young adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S16	(MM "Young Adult") OR "young adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S15	(MM "Adolescence") OR "adolescents"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S14	(MM "Adult") OR "adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	Display

			Search Screen - Advanced Search Database - CINAHL	
S13	(MM "Middle Age") OR "middle aged"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S12	"aged: 65+ years"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S11	"aged, 50 and over"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S10	(MM "Aged, 80 and Over") OR "aged, 80 and over"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S9	"old age"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S8	(MM "Geriatrics") OR "geriatric"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S7	"accelerated aging"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced	Display

			Search Database - CINAHL	
S6	(MM "Aging+") OR "aging"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S5	"elderly"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S4	(MM "Aged+") OR "aged"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S3	(MM "Frail Elderly") OR "older adult"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S2	(MM "Acquired Immunodeficiency Syndrome") OR "aids"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display
S1	(MM "HIV-Infected Patients+") OR "hiv"	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	Display

Appendix B - Chapter 3 Qualitative Study Appendix: Tables and Figures**Table 6- Participant Characteristics**

Participant Number	Age	Sex	Relationship Status	Number of Children Residing in the household	Clinic Attended to receive ART	Years on Treatment
1	51	Man	Married	2	Public	7
2	50	Man	Divorced	5	Public	1
3	53	Woman	Widowed	0	Public	8
4	56	Man	Married	3	Public	13
5	51	Woman	Married	5 (+3 Grandchildren)	Public	2
6	51	Woman	Widowed	1	Public	6
7	51	Woman	Married	4	Public	5
8	51	Woman	Widowed	6 (+3 Grandchildren)	Public	5
9	51	Man	Married	3	Private	12
10	54	Man	Married	5	Private	3
Summary	Average Age: 51	5 men and 5 women	6 Married, 1 Divorced, and 3 Widowed	Average number of children living in the same household as the participant: 3.4	8 attended a public clinic and 2 attended a private clinic	Average number of years on treatment 8.9

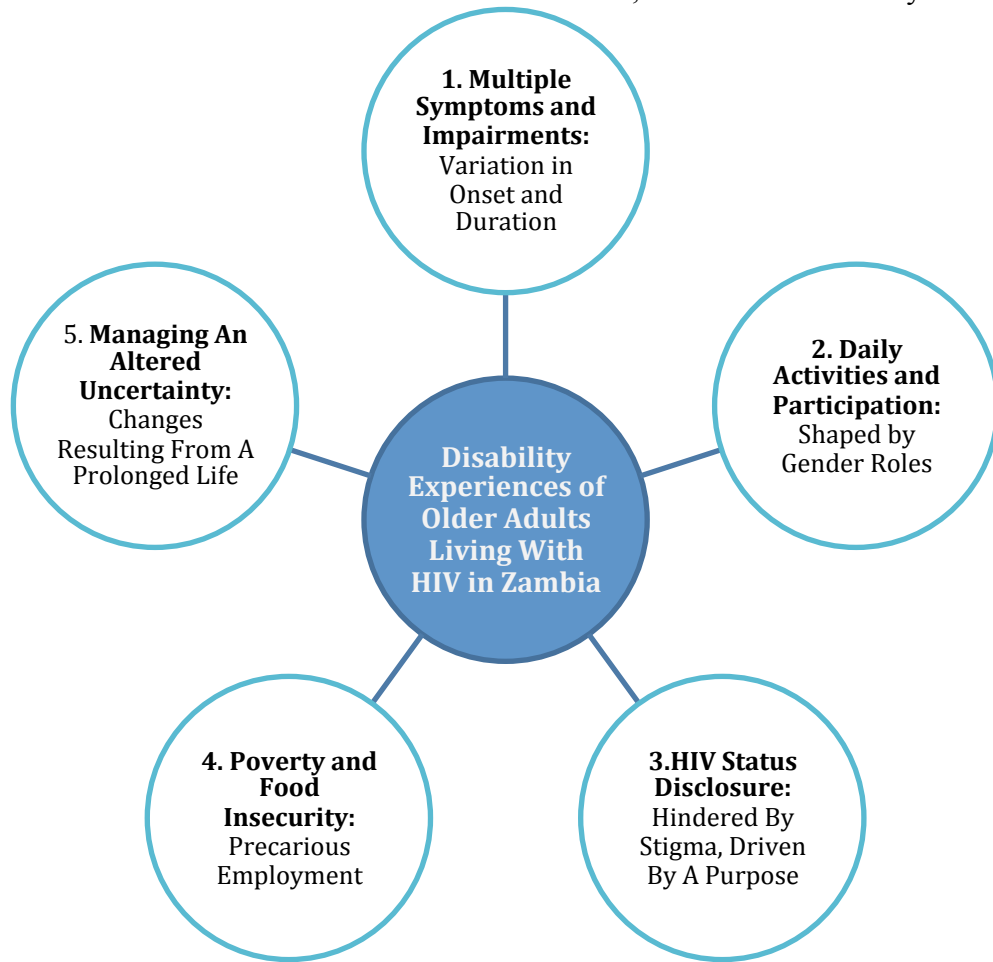


Figure 2- Themes Related to Disability Experiences of Older Adults Living With HIV In Zambia

Confidentiality Agreement for Research Team Members

Exploring the 'Functioning, Disability and Health' of Women and Men Living with HIV in Zambia: Shifting Perspectives for a Longer-Term Approach to HIV Care in Southern Africa

As a member of the Sepo II research team you will have access to personal information that needs to remain confidential and must be protected. Maintaining privacy and confidentiality involves protecting (keeping secret) the information that participants share with you. Information that you learn through your involvement in this project must not be discussed or shared with anyone other than members of the research team.

I understand the importance of maintaining the confidentiality of all the information that I have access to including, but not limited to, demographic information, audio recordings and transcripts. I agree to keep the information which individuals who participate in this project provide, confidential by:

- Not discussing or sharing the names, contact information, HIV-status, personal information or stories of people that participate in this project
- Keeping all study information in a safe and secure place (i.e. locked cabinet for hard copy files, password protected computers and USB keys for electronic files)
- Shredding hard copies and deleting electronic files when they are no longer required for analysis

Any questions or concerns about confidentiality during the research study should be immediately shared with the Principal Investigator, Dr. Stephanie Nixon stephanie.nixon@utoronto.ca or +1-416-946-3232.

My signature acknowledges that I understand and agree to this document.



Signature

Samantha Cheuk
Please Print Name

December 17, 2019
Date

Figure 3- Confidentiality Agreement for Sepo II Research Team Members