SOCIAL NETWORKS, SOCIAL CAPITAL, AND LONELINESS OF RURAL AND SUBURBAN OLDER ADULTS LIVING WITH HIV

By

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To those individuals who believed in my abilities, my strength and my fortitude.
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LIST OF ABBREVIATIONS

AIDS  Acquired Immunodeficiency Virus, most serious stage of HIV in which an individual's immune system is compromised and further susceptible to increasing number of severe illnesses or opportunistic infections. (https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids)

Area 313  A 15 county region located in North Central Florida that receives allocated Ryan White Federal funding to be distributed by county health departments to persons living with HIV based upon personal socioeconomic need; see Figure 2-1.

HIV  Human Immunodeficiency Virus, virus spread through certain body fluids (blood, semen, vaginal fluid, etc.,) that attacks the body’s immune system, in specific CD4 or T Cells. (https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids)

OPLWH  Older persons living with HIV (OPLWH), persons who are 50 and above living with the HIV infection.

Ryan White  Ryan White was a teenager who contracted HIV from a blood transfusion that later developed into AIDS. He was a nationally known public figure in protecting his right to attend public school. The Ryan White CARE Act was passed after his death.

Ryan White Program  A federally funded program designed to provide persons who are HIV positive with primary medical care and essential services otherwise not provided but other programs. (https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/about-ryan-white-hiv-aids-program)
This exploratory, Mixed Methods pilot study serves as the foundation to describe how social network structure and social ties, including components of social capital in the context of rurality, affect loneliness of older persons living with HIV (OPLWH). With advancements in antiretroviral therapy, prevalence rates of adults aging with HIV is expanding globally, posing multiple socioeconomic, health and quality of life concerns. Social networks have been identified as buffers to and perpetuators of HIV disease related stigma. Stigma has been described as impacting lack of HIV disclosure, fragmented social networks, social reclusion and loneliness. Further, predominant studies focused on OPLWH have been performed in urban or metropolitan areas with a prevailing gap focused on persons living in rural communities. Therefore, there is a critical need to further describe the network structure and social function of the relationships of OPLWH living in rural communities.

In completing this interdisciplinary research, a convergent mixed method design was used throughout data collection and analyses to integrate social network quantitative and qualitative data, and spatial data. Instruments included were: 1)
Sociodemographic GIS survey, 2) Personal Network Questionnaire, 3) De Jong Loneliness Scale, and 4) semi-structured qualitative interviews. The sample included 30 persons, aged 50 or above, living with HIV in the designated study region, Area 313, of North Central Florida. Quantitative, geo-spatial analyses were presented descriptively and participants’ spatial data were mapped within the target region. A simultaneous regression analysis was used to explore the influence of ego-based and social network data on loneliness. A semi-structured interview guide was used to better understand contextual narratives of participants’ experience with living with HIV and to elicit participants’ thoughts of their networks. Two reviewers initially performed qualitative analyses independently, followed by inter-coder agreement and generation of overarching themes. Primary integration methods were used to compare datasets and to assess for congruency or contradictory study findings. Further, integration of data aimed to at providing a more holistic purview of how OPLWH’s social environment may impact loneliness within the context of their physical (geographic), rural environment.
CHAPTER 1
INTRODUCTION

Outline of Non-Traditional Dissertation

This chapter is reprinted with permission from the Journal of the Association of Nurses in AIDS Care. This is a non-traditional dissertation, which will describe three separate articles currently in publication or to be published. The overall goal of all three articles is to bring awareness to an understudied population and to demonstrate mixed-method research (MMR) to investigating the role and implications of social ties among older persons living with HIV (OPLWH) who reside in rural communities. Uniquely, this dissertation uses an interdisciplinary approach to better understand how the complex social interactions of networks of OPLWH may influence loneliness. Moreover, this dissertation presents an innovative way to integrate MMR to gain a more comprehensive understanding of participants’ social and physical (geographic) world.

The purpose of this non-traditional dissertation, as it is outlined in each article, is to: 1) explore and highlight the significant lack of literature of rural-dwelling OPLWH; 2) demonstrate the integration of mixed methods including, SNA quantitative and qualitative methods, expanding our understanding of social relations; and 3) evaluate the impact of OPWLH social networks on loneliness within the context of their physical, rural environment.

As part of this three-publication dissertation, Chapters 1 and 2 will present article one which was an integrative review of rural and urban literature. After an initial

preliminary review of the literature revealing a significant lack of network studies focused on older persons living with HIV in rural communities, the published review was expanded to include urban-based literature. Although urban literature included several network studies of OPLWH, there was a significant gap identified in the use of network analysis methods to assess network composition, structure and role of relationships in these studies. Methods used to explore networks of OPLWH to date include qualitative interviews and focus groups, survey-based quantitative studies and combination thereof.

Chapter 3 will present the unique mixed-methods approach, integrating quantitative and qualitative SNA methods, to investigate the networks of OPLWH within the designated study region comprised of rural and sub-urban communities, known as Area 313. Area 313 will be discussed throughout this dissertation and was mapped in Chapter 4 for the purpose of the study’s analyses. Mixed-method approaches that have been used to investigate the social networks and implications of OPLWH include quantitative and qualitative methods. To our knowledge, there is no study conducted in the United States that has used social network analysis methods in this sub-population solely or in combination with qualitative methods to portray networks of persons aging with HIV. Therefore, Chapter 3 will present the methodology used and discuss the outcomes of primary integration of quantitative and qualitative SNA methods using some cases of OPLWH.

Chapter 4 will include article 3, which will summarize results of the relationship between OPLWHs social environment with loneliness in the context of one’s physical (geographic) environment. Various methods were used to analyze one’s social network
in relation to loneliness including creation of network visualizations, descriptive statistics and regression analysis. Geographic environment was analyzed using spatial data and mapped to portray and compare distributions of macro-components (i.e., population density, poverty and racial/ethnic groups) between participants’ within their residential locations. Lastly, Chapter 5 will present the final discussion of this dissertation and present limitations, directions for future research and application to nursing science.

Older Persons Living with HIV

Worldwide, aging populations represent an emerging phenomenon. Global estimates project that by 2050, the older population will almost triple and is expected to surpass two billion (United Nations, Department of Economic and Social Affairs, Population Division, 2013). Problems associated with the aging population include: increased co-morbidities, decreased personal network size, and increased depression rates (Luppa et al., 2012; Smith et al., 2014; Vanderhorst & McLaren, 2005), particularly for older rural residents who experience social loneliness and scarce assisted living and health care resources (Averill, 2012; Drennan et al., 2008; Winterton, Clune, Warburton, & Martin, 2014). The aforementioned evidence is important as strong network ties are linked to resilience, improved subjective well-being and self-efficacy, and also result in reduced risk of mortality in the elderly (Holt-Lunstad, Smith, & Layton, 2010; Wells, 2009; Yuasa, Ukawa, Ikeno, & Kawabata, 2013).

Aging with HIV, defined as those ages 50 and older, is also a rapidly emerging phenomenon with advances in antiretroviral therapies (Centers for Disease Control and Prevention, 2010). By 2015, more than half of those living with HIV will likely be older than 50; yet this population is infrequently evaluated compared to their younger counterparts (Kirk & Goetz, 2009). Globally, 4.2 million adults ages 50 and older were
living with HIV in 2013 and this number is expected to increase (Joint United Nations Programme on HIV/AIDS, 2013). Although not the fastest growing newly infection population, this demographic will continue to grow and will pose special long-term pharmacologic, prevention, and health maintenance considerations and challenges.

Despite being into the fourth decade of the HIV epidemic, stigma, whether perceived or experienced, continues to be a prevailing issue within the United States and throughout the world (Vandable, Carey, Blair & Littlewood, 2006). Research has shown that HIV-infected older adults experience disease-related and age-related social discrimination that may consequentially decrease utilization of available HIV resources and contribute to higher rates of poor mental health (Emlet, 2007; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Vandable et al., 2006). An additional layer of stigma, known as "ageism" and defined as the belief that older people are no longer attractive, productive, or valued members of society, is detrimental to the well-being, mental state, and self-conceptualization of older adults managing HIV (Vance, Moneyham, Fordham, & Struzick, 2008). The stigma we are addressing is not unidimensional or universal. It encompasses any form of discrediting, discrimination, or prejudice toward an older person living with HIV (OPLWH), whether directly experienced and/or anticipatorily perceived (Emlet, 2006a). Because of the complexity of the construct, all identified forms of stigma were included in this review.

Aging with HIV can further disrupt social networks due to associated stigma and fear of disclosure and rejection (Emlet, 2006b; Grov et al., 2010; Heckman et al., 2000). In addition, the dynamic social interactions of aging with HIV in rural and urban communities may present added challenges to formation and utilization of social
networks. For instance, despite the availability of formal AIDS Service Organizations, HIV-infected older adults may not know of, feel comfortable with or use these services. Geographic location, social network size, and type of social interaction may contribute to disease management, mental well-being, and quality of life (QOL) for aging infected and uninfected older adults.
CHAPTER 2
LITERATURE REVIEW

A Rural-Urban Comparison of Social Networks of Older Adults Living with HIV

This chapter is reprinted with permission from the Journal of the Association of Nurses in AIDS Care. An integrative review of the literature was performed, which provided the ability to systematically, conceptually, and theoretically evaluate and summarize pre-existing literature (Whittemore & Knafl, 2005). The purpose of an integrative review is to incorporate various study methods to comprehensively describe study concepts, themes, and outcomes of a relatively new or understudied topic to provide an initial conceptualization of the topic (Torroco, 2005). Integrative reviews may combine experimental versus non-experimental studies and combine data from empirical versus theoretical literature in order to more fully understand a phenomenon (Whittmore & Knafl, 2005). Through this approach, articles with diverse methods were retrieved to capture multiple elements of HIV-infected older adults’ social networks and the emerging concepts of the benefits and barriers of those networks. This conceptual, integrative review of OPLWH in rural and urban communities also intended to highlight the significant lack of literature of rural-dwelling OPLWH. We reviewed qualitative, quantitative and mixed-method studies; systematic reviews; and meta-analytic reviews.

Methods of Review of the Literature

Articles were collected from target databases (PubMed, CINAHL, Age and Cancer Research Abstracts, Google Scholar, PsychInfo, and AgeLine) in 2015. Prior to data collection, a preliminary search of the literature was performed to refine and

organize the proposed search terms and to ascertain the volume of literature for social networks of rural-dwelling HIV-infected older adults. Due to the significant lack of studies investigating OPLWH in rural communities, the review also incorporated and compared articles related to social network components of urban-dwelling, HIV-infected older adults.

Final key terms used in the review included: “networks, social networks, informal and formal networks, social support, aging, older adult(s), elderly, HIV, AIDS, HIV/AIDS, aging with HIV, rural, rural communities, and rurality.” A snowball approach of listed references also facilitated identification of potential articles. The abstracts of articles with identified key-terms were reviewed if inclusion criteria were met. These included human subjects, written in English, and published within the past 10 years. Aging with HIV encompassed adults 50 years of age and older, as this demographic has been widely recognized within the HIV literature and by formal HIV organizations. Rigorous study methods were ensured through a thorough search for relevant studies via multiple databases, explicit inclusion and exclusion criteria, and critical appraisal of data using NVivo software.

For the purpose of this review, the conceptual application of rural and/or rurality encompassed the subject’s experienced and perceived life world as well as the surrounding geographic space in which they lived (Philo, Parr, & Burns, 2003). Overall, the review focused on concepts such as the social network structure for older adults aging with HIV in rural and urban areas and social utility and function in their communities.

**Analysis of Literature Findings**

Articles were organized, coded and analyzed using NVivo 10 software. Critical
analysis was initially performed using a broad framework, which included location of the investigation, research method(s) used, location of study, main concepts, significant and non-significant outcomes, gaps, and future direction for research (Torraco, 2005). Because HIV is a global health concern, location of retrieved studies were evaluated to assess magnitude of published national and international articles. Data were extracted from the articles through an iterative process of simultaneous article selection, analysis, and coding. Themes, represented as nodes, were generated through a rigorous, qualitative analytical process of open coding, axial coding and theoretical coding, followed by thematic comparisons between the two different bodies of literature (Creswell, 2008). Overall, the goal of this analysis was to evaluate and compare studies for a greater understanding of OPLWH in rural and urban communities, their social network components, and their emerging concepts. For example, assessment of access and/or use of health care resources, support groups, familial support and peer support.

Results of Literature Review

A total of 29 eligible articles were reviewed; Figure 2-1 lists 15 urban-based articles focused on OPLWH and 5 non-U.S.-based articles focused on rural older adults aging with HIV. All of the rural-based OPLWH studies were performed outside of the U.S. reflecting a significant gap in current literature of social networks of OPLWH living in rural, U.S. communities.

Of the various methods used, only one article used social network analysis methods to investigate this population (Moore, 2013). Although limited, a majority of the U.S.-based studies investigating social networks of adults aging with HIV were conducted in urban areas using various qualitative and quantitative methods (Emlet, 2006a; 2006b, 2006c; Emlet, 2007; Emlet, Tozay, & Raveis, 2011; Shippy & Karpiak,
2005). While these methods added to a body of knowledge, they did not directly measure desired network components, including network composition, size, density, and strength of social ties.

A general thematic analysis, including all articles, revealed four themes related to social networks of OPLWH in rural and urban communities: (a) limited and/or fragile networks, (b) social inclusion versus social isolation, (c) social capital, and (d) health outcomes. Figure 2-2 highlights the prominent, congruous, and unique themes from each review.Aligned with the first study aim, Figure 2-2 compares emerging themes of rural-dwelling older adults with urban-dwelling adults aging with HIV.

**Thematic findings**

**Limited and/or fragile networks.** Social network size and trust relationships are crucial links to social resources, which in turn bear beneficial effects for health, well-being, and accomplishment of life tasks in older adults (Wrzus, Hänel, Wagner, & Neyer, 2013). Overall, there were a lack of studies investigating social networks of OPLWH in rural communities, and available urban study results were inconclusive. While some rural studies depicted seropositive older adults as estranged from their families, others described relatives and neighbors being significant support networks (Groft & Vollman, 2007; Zhang et al., 2012; Zhang, Fuller-Thomson, Mitchell, & Zhang, 2013).

Prevailing social network studies of HIV-infected older adults were performed within highly populated metropolitan areas, with contradictory findings (Emlet, 2006a; Emlet, 2006b; Poindexter & Shippy, 2008; Shippy & Karpiak, 2005). In some studies urban-dwelling HIV-infected older adults described their networks as sparse and delicate, while others posited their networks were multifaceted and key to provision of
informal support (Nobre, Kylma, Kirsi, & Pereira 2015). As a result of HIV stigma and ageism, urban-dwelling OPLWH often lived alone, were isolated from informal networks, and had disproportionate, smaller social networks in comparison to younger HIV-infected counterparts (Emlet, 2006b; Shippy & Karpiak, 2005).

Evidence of existing urban networks of OPLWH were found to be threatened due to discomfort of disclosing HIV status to personal networks, for fear of rejection and withdrawal (Emlet, 2006b; Emlet, 2006c; Poindexter & Shippy, 2008; Schrimshaw & Siegal, 2003). Further, in urban communities, OPLWH not linked to formal health service networks could experience heightened isolation and potential exclusion (Roger, Mignone, & Kirkland, 2013). In comparison to their younger counterparts, OPLWH often lived alone, were isolated from their informal networks, and had disproportionate, smaller social networks as a result of disease-related stigma and ageism (Emlet, 2006b; Shippy & Karpiak, 2005). Stigma has also been perpetuated in health care settings due to provider discomfort in discussion of sexual health practices or lack of perceived risk of infection for older adults, along with widespread beliefs of elder asexuality (Linley et al., 2012; Shippy & Karpiak, 2005).

Socioeconomic disadvantages may exist between younger and older adults living with HIV, which may further impact social networks. Several studies showed that OPLWH used HIV and non-HIV clinical and non-clinical services much less than young PLWH and were more likely to be unemployed; as a result, OPLWH could experience heightened isolation and potential exclusion (Fritch, 2005; Pitts, Grierson, & Misson, 2007; Roger et al., 2013).

Identified barriers to social networks of OPLWH included poor community
infrastructure, infrequent contact with informal networks, geographic isolation, declining health, low socioeconomic status, being widowed or separated, lack of transportation, and inadequate access to health care services and assisted living facilities (Drennan et al., 2008; Groft & Vollman, 2007; Pitts et al., 2005).

**Social inclusion versus social isolation.** In general, social inclusion was defined by OPLWH as feeling engaged with and/or accepted by family, peers, and community. This feeling is often threatened by perceived or experienced stigma in urban and rural-dwelling OPLWH (Oreal, 2014; Poindexter & Shippy, 2008; Shippy & Karpiak, 2005; Vanable et al., 2006). HIV stigma can severely impact an infected individual’s ability to actively engage in social interactions and has been associated with social isolation, non-medication adherence, and non-disclosure by OPLWH (Vanable et al., 2006; Vance, Brennan, Enah, Smith, & Kaur, 2011). Urban research has demonstrated that, while personal networks may be central to mediating disease-related stigma, fear of multi-layered discrimination based on disease status, age, sexual orientation, gender, and so forth may prevent infected individuals from engaging with support groups (Oreal, 2014). Thus, the context of stigma, whether felt or anticipated, can either mediate or exacerbate social interactions. Social engagement can be further diminished in this population by perceptions of being morally unfit and inherently dirty, resulting in a protective silence and social reclusion (Vance et al., 2011).

The benefits of social network engagement for urban, OPLWH have been shown to be enhanced ability to cope with the disease, management of negative emotions and disclosure, reliance on faith and spirituality, and taking charge of one’s health (Slomka, Lim, Gripshover, & Daly, 2013). Because these results were derived from primarily
urban-based studies with better availability of social and tangible resources, further studies are essential to understand how social networks may mediate or exacerbate stigma in rural communities.

**Social capital/social support.** Social capital theory has been primarily discussed and used as a theoretical foundation to capture network components across retrieved network studies. Despite many definitions, social capital is broadly defined as the social relationship between groups of people and is often measured through trust, reciprocity, and networks that facilitate support (Gray, 2009; Heenan, 2014). In fact, social support, a facet of social capital theory, is broadly discussed in both rural and urban studies, as it relates to the well-being of HIV-infected participants.

Positive coping strategies of long-term survivors with HIV have been linked to both formal and informal networks (e.g., family, friends, health professionals, community or support groups, and pets; Slomka et al., 2013). These networks can provide emotional and informational support, encourage social exchange, and in some cases, provide participants with a purpose for living (Emlet et al., 2011; Slomka et al., 2013). In particular, formal HIV-related networks, also known as AIDS service organizations, may maximize social capital by providing tangible resources, peer-to-peer relationships, and, oftentimes, families of choice (Emlet, 2006c Groft & Vollman, 2007; Poindexter & Shippy, 2008). Yet the majority of these organizations are located in metropolitan areas, with a lack of available health resources for rural community members (Emlet, 2006c; Emlet et al., 2011; Poindexter & Shippy, 2008). Although unclear, the benefits of social capital for OPLWH include more social support, available resources, and trusting relationships.
Findings in the rural aging literature have posited that social capital and social support are threatened due to disease-related stigma, further perpetuating social reclusion, fear of disclosure of one’s HIV status, and lack of tangible and emotional support (Vance et al. 2011). Rural-dwelling individuals have been shown as less likely to be personally acquainted with someone with HIV, to talk about HIV, or to know about the infection (Veinot & Harris, 2011). Comparative studies of HIV-infected younger versus older adults has revealed that older adults primarily receive support from their children, are more likely to live alone, and have fewer close friends (Emlet, 2006b; Zhang et al., 2013).

Urban and rural-based studies found that opportunities for support were limited for OPLWH as a result of disease severity, such as disease progression, lack of HIV status disclosure, geographic distance, and economic disadvantages (Zhang et al., 2012; Zhang et al., 2013). Personal demographics have also been linked to discrimination, further limiting informal social support; these include being male, a person of color, and having heterosexual transmission of HIV (Emlet, 2006b). Thus, socio-demographic characteristics, lack of understanding of HIV, and fewer support exchange opportunities may influence poorer mental well-being and heightened experiences of stigma for those living in rural and urban communities.

Social support may further be limited due to stigma and fear of disclosure. Although the impact of non-disclosure is known, the likelihood of disclosing one’s HIV status to a particular network or group is contradictory. While some studies reported that OPLWH were more likely to disclose to their kin rather than non-kin (Moore, 2013), other studies have found that disclosure was more likely with non-kin (Shippy & Karpiak,
Disclosure of HIV status varied due to contextual circumstances and to the nature of relations within networks such that interpersonal trust-based relationships may be a positive factor in disease status disclosure.

**Health outcomes.** Social networks have been found to impact physical and mental health outcomes. Studies have posited the quality of relationships for OPLWH may be a buffer to or predictor of depression and anxiety. Depression and suicidal ideation in this population has been associated with synergistic effects of stigma, emotional and social loneliness, decreased support, declining health, and financial distress (Grov et al., 2010; Shippy & Karpiak, 2005; Vance et al., 2008). Outcomes of persistent mental distress in OPLWH include poor QOL, decreased cognitive function, reduced levels of energy, and rapid disease progression (Grov et al., 2010; Vance et al., 2008). Although rates of depression are high for OPLWH, several studies suggested no differences in mental health of older versus younger PLWH (Pitts et al., 2005). Thus, with limited support systems, high physical health stressors, and omnipresent stigma, those aging with HIV have increased threats to mental health stability, disease-related resiliency, and overall well-being (Vance et al., 2008).

In contrast, rural OPLWH may benefit from social engagement with formal and informal networks (i.e., volunteering, membership in resource groups, and leisure activities) as evidenced by lower depression scores, feelings of emotional closeness, positive coping strategies, and greater positive (Mavandadi, Zanjani, Ten Have, & Oslin, 2009; Slomka et al. 2013). Indeed, both formal and informal networks provide emotional and informational support, encourage social exchange, and in some cases, provide OPLWH a purpose for living (Emlet et al., 2011; Slomka et al., 2013).
**Summary of literature.** Themes discovered in rural and urban-based literature of OPLWH revealed a perceived lack of social networks and social support (Emlet, 2006a; Groft & Vollman, 2007). OPLWH may experience heightened stigma, have more fragmented social support networks, and increased social reclusion (Groft & Vollman, 2007; Emlet, 2007; Shippy & Karpiak, 2005). Previously reviewed findings related that rural-dwelling individuals could face more socioeconomic disadvantages in comparison to their urban counterparts. However, results of our literature review were contradictory, as findings supported the fact that those with and without HIV desired supportive networks, but, at the same time, their personal lives and communities may also be a source of anxiety-inducing fear, discrimination, and isolation (Groft & Vollman, 2007). Ultimately, pervasive stigma may lead to negative health outcomes and may further inhibit the receipt of HIV care for OPLWH.

**Discussion of Literature Findings**

Overall, the emerging themes from the literature were similar for those aging with HIV in rural and urban areas, with a heightened experience of lack of available networks and increased social isolation for OPLWH. Findings from retrieved studies may be limited in generalizability with concerns such as having a small sample size and lack of generalizable study methods. Despite potential threats to generalizability, this review illustrates the significant lack of literature focused on OPLWH and their social networks. Due to the paucity of rural and urban-based literature of social networks of OPLWH, additional qualitative, quantitative and mixed-method studies are needed to broaden our current knowledge of this population. With an aging HIV population, this topic is of importance to current and future health care concern and policy.

Rural communities may present added challenges to successful aging with HIV.
due to cumbersome socioeconomic challenges, including geographic isolation, lack of transportation and transportation services, limited access to skilled living facilities, and lack of health care services and HIV resources (Drennan et al., 2008; Groft & Vollman, 2007; Zhang et al., 2013). Further research is needed to investigate existing disparities between rural and urban OPLWH and how challenges may preclude these individuals from maximizing physical and mental health and overall QOL.

The first theme, limited and/or fragile networks, identified in this review, demonstrated a universal lack of social networks. In general, the size, composition, and dynamics of aging networks changed in accordance with life events (Wrzus et al., 2013). This seemed to be especially true for OPLWH in rural communities. But, with very limited evidence, it was uncertain how rural communities impacted the social networks of OPLWH. Networks of OPLWH were further jeopardized due to the stigmatizing nature of the disease and fear of rejection and social reclusion (Emlet, 2006b; Shippy & Karpiak, 2005). Moreover, rurality may present a unique domain associated with social hierarchy, established order, and socially constructed norms. These aspects were congruent with a lack of knowledge about HIV, issues of stigma, fear of disclosure, and violation of confidentiality in HIV-based literature (Groft & Vollman, 2007; Philo, Parr & Burns 2003; Schatz & Gilbert, 2012; Veinot & Harris, 2011). Thus, further investigation of network components of OPLWH in rural communities is needed to understand the dynamism of aging, networking, managing a chronic disease, and the effects of rurality.

The second theme identified in the literature, social inclusion versus social isolation, was closely associated with familial, peer, and neighboring community
networks (Slomka et al., 2013). Social networks were perceived as protectors to and/or perpetuators of stigma depending on the context of the relationship and the environment. Studies in urban-based HIV literature suggest that the added fear of disclosure, prejudice, and judgment often became an inhibiting factor to social engagement and perpetuated isolation (Poindexter & Shippy, 2008; Vance et al., 2011). In contrast, social inclusion may prevent feelings of social isolation, support overall quality of life and enhance one’s ability to cope with the disease (Slomka et al., 2013). Rural-based research is needed to fill the current gap in the literature on networks of and support for rural-dwelling OPLWH.

The third theme identified in our review, social capital, revealed inconsistent findings for urban and rural-dwelling OPLWH. Reciprocity and trust relationships for OPLWH were limited due to the effects of stigma and fear of rejection. Although HIV-infected older adults desire trust relationships with individuals of “like-status,” the social taboo of HIV in rural communities does not permit discussion of the disease, foster network linkages, or support education programs (Veinot & Harris, 2011). Urban and rural-based literature demonstrated advantages of social capital through improved mental well-being, tangible and emotional support, and improved QOL. Because social capital theory is not fully understood as it relates to this population, further exploration of networks and the impact of interpersonal relationships is crucial.

The fourth theme, health outcomes, has been defined as positive and negative, impacting physical and mental health outcomes. In general, social networks may be either protective or harmful to health outcomes, depending on perceived stigma, availability, and utilization of social support and geographic isolation (Grov et al., 2010;
Roger et al., 2013; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011; Vandervoort & Skorikov, 2002; Wrzus et al., 2013). Improved mental health and well-being in OPLWH was demonstrated by having a trusted confidant (Emlet, 2006b). Yet loneliness, poor psychological well-being, and rapid disease progression was also associated with OPLWH social networks and perceived stigma (Bhavan, Kampalath, & Overton, 2008). Although multiple studies in the aging literature address loneliness, there is a need to understand how rurality and stigma can further influence mental well-being, physical health, and limited social networks in this population.

Stigma was an omnipresent theme in the urban and rural-based HIV literature and was closely tied with older adults’ fragmented social networks, lack of social support, and compromised engagement in social activities (Poindexter & Shippy, 2008; Vance et al., 2011). There is a symbiotic interaction between the multiple layers of stigma, such as ageism, social discrimination, stereotyping, homophobia, and violations of confidentiality, that negatively affect successful aging in those who have HIV (Bhavan et al., 2008; Emlet, 2006c). Perceived threats of discrimination and rejection are barriers to adequate sustainable social networks, social interactions, and mental well-being across populations of infected individuals (Goodkin et al. 2003; Grov et al., 2010; Heckman et al., 2000; Lyons, Pitts, Grierson, Thorpe, & Power, 2010). Additional studies investigating the interplay of social networks, stigma, and rurality are needed to further understand the impact on mental health and well-being on OPWLH.

Future Directions

Overall, few studies have investigated the components of and impact of social networks on rural-dwelling, HIV-infected, older adults. Because of existing evidence of limited, fragile networks, future investigation of the components of these networks and
how they may provide social capital or perpetuate stigma is essential. More advanced methods are needed to capture the interplay of social network components for older adults aging with and without HIV and the stigma in their environments, in order to clarify and enrich the knowledge base. For example, social network analysis affords researchers the ability to create, analyze, and visually represent personal, egocentric network components for their density, structure, key ties, centrality, and so forth (McCarty, Molina, Aguilar, & Rota, 2007). Thus, future analysis should use a variety of sophisticated methods to explore OPLWH networks to assess individuals' perceived networks and the roles of interpersonal relationships on the interplay between social networks, rurality, HIV, aging, disease management, and stigma.
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Figure 2-1. Rural versus urban literature.
Figure 2-2. Comparison of rural-urban themes.
CHAPTER 3
INTEGRATION OF MIXED METHODS

Integration of Social Network Analysis and Qualitative Methods

Introduction to Mixed Methods Research

Over the past few decades mixed methods research (MMR) has been widely discussed and employed across various disciplines, including social, behavioral, educational, humanities and nursing sciences. Many MMR designs incorporating qualitative and quantitative methods have been used to examine, validate and better understand different phenomena. Indeed, there is significant value to combining various data sources such as, use of multiple worldviews during investigation and enhancement of the breadth and depth of research findings and of knowledge acquisition (Creswell, Shope, Clark, & Green, 2006; Dobbie, Reith, & McConville, 2018; Mason, 2006; Viswanath, Brown, & Bala, 2013). Due to gaining acceptance, there has been a heightened impetus to define, conceptualize, and to provide structure to conducting MMR (Creswell & Clark, 2018; Greene, 2006).

The intent of this study is to demonstrate the use and integration of social network analysis methods, quantitative and qualitative, and network visualizations to investigate social connections and exchanges among them. The methodological approach to be presented in this paper is a convergent design combining quantitative SNA methods to analyze network structure and the use of network visualizations as means for qualitative data inquiry and analysis of social functions (Creswell, 2013; Johnson, Onwueguzie, & Turner, 2007).
The Gap in Mixed Methods Research in OPLWH

A significant body of research exists combining quantitative and qualitative social network analysis (SNA) methods in various ways, whether using a stepwise approach or simultaneous approach to collect and analyze data in different populations (Dobbie, Reith, McConville, 2018; Moore, 2013; Skyes, Venkatesh, & Gosain, 2009). Current U.S. based literature focused on OPLWH has used various mixed method approaches to discuss network structure, network effects and respondents’ perceptions of their social networks (Eddens, Fagan & Collins, 2017; Emlet, 2006b, 2007; Groft & Vollman, 2007; Poindexter & Shippy, 2008). Few studies have applied a MMR parallel design, as proposed in this study, implementing simultaneous collection of quantitative and qualitative network data using the visualization as a qualitative tool to elicit responses (Bernardi, Keim, & von der Lippe, 2007). To our knowledge, there are no studies simultaneously integrating both methods in evaluation of social networks of older persons living with HIV. In addition, this study is unique as social network analysis or combination of SNA methods are not widely used in nursing research.

In China, a network study was performed to evaluate persons living with HIV in rural versus urban areas with quantitative network data obtained to describe support networks including size, composition and strength of ties (Zhang et al., 2012). Likewise, a study completed in Africa described networks of OPLWH by composition and disclosure patterns, finding that immediate kin and extended kin predominately comprised their networks with higher disclosure of HIV status to immediate family members (Moore, 2013). Though network analysis methods were utilized in both aforementioned studies, network visualizations were not generated or utilized. To our
knowledge, network visualizations of OPLWH have not been displayed in any current HIV literature to date.

With a rapidly expanding population of persons living with HIV 50 and above, there is an increased need to explore innovative methods to understanding the role of network relations and their impact on OPLWH outcomes, including disclosure of HIV status, social connectedness and perceived loneliness (Centers for Disease Control and Prevention, 2018). In addition, the integration of this methodological approach could serve as an exemplar for studying the role of social ties and contextual relations; essential to understand how networks may influence knowledge dissemination, provide support, and facilitate social engagement and quality of life related to chronic health issues.

**Network Theory and Social Capital Theory**

Network theory is a way of thinking about the social systems and the relationships between the entities that make up the network (Borgatti, Everett, & Johnson, 2013). Network theory suggests that one’s position in a network including the opportunities and constraints are important to understanding their outcomes such as behavior, beliefs, performance status, and access (Borgatti et al., 2013; Kadushin, 2012). In humanities science, network analysis investigates the relationships between persons, known as nodes, who make up the network. Closely related to network theory is social capital theory, broadly defined as the advantages and/or disadvantages that are made available through social relations or networks (Kadushin, 2012). Network relations or resources may contribute to informational flow, opportunity linkages, and financial and emotional support. For example, the lack of knowledge of HIV has been associated with rural-dwelling, older age, lower levels of education, not being personally
acquainted with a person living with HIV and lack of positive beliefs of the disease (Veinot & Harris, 2011). Moreover, current research holds that social capital may be maximized for OPLWH through formal HIV-related networks, known as AIDS service organizations (ASOs), which may provide increased access to tangible resources, peer-to-peer relationships and oftentimes, creation of families of choice (Emlet, 2006c; Groft & Vollman, 2007; Poindexter & Shippy, 2008).

Network Representations

Initially developed by Moreno in 1930s, hand drawn network representations called sociograms portrayed people in two-dimensional space with directional lines drawn between pairs of individuals to represent relationship ties (Wasserman & Faust, 1994; Freeman, 2000). Over time, network representations have included freestyle drawings by participants and hierarchal mapping technique in which the respondent places persons in one of the three concentric circles based upon perceived closeness (Antonucci, 1986; Coates, 1985). In addition, genograms have been used as a therapeutic framework in psychology and social work to better understand one’s social environment (DeMaria, Weeks & Hof, 1999). Indeed, the use of interactive personal network drawings has served as a tool to bring an individual’s social world to life and giving meaning to his or her relationships (Dominguez & Hollstein, 2014).

Personal network visualizations are a means of network representation of the ego (participant) that portrays network composition (summary of network personal characteristics) and structure (density, size, and centrality) (McCarty, 2002; McCarty, Molina, Aguilar, & Rota, 2007). Using computer-based software programming, such as EgoNet, EgoWeb, UCINET and NetDraw, researchers have been able to illustrate participant’s personal networks (Borgatti, Everett, & Freeman, 2002; McCarty &
Broadly, personal network analysis has been used to explore components of social support across the human illness-wellness continuum (Wellman & Wortley, 1990; Kapadia et al., 2014). Relative to HIV research, network analysis methods have been used to examine social support in the relationship between drug use, HIV transmission and disclosure of one's HIV status (Curtis et al., 1995; Latkin et al., 1995; Moore, 2013; Neaigus, et al., 1994).

**Social Network Analysis and Mixed-Methods**

Social network analysis has been described as neither qualitative nor quantitative rather structural, highlighting the context and relevance of social relationships (Bellotti, 2010; Kolleck, 2013). Social network analysis allows for exploration of patterns in relationships by means of operationalizing these relationships (Wasserman & Faust, 1994). Personal or (egocentric) networks allow for analysis of a single individual (ego) together with the persons (alters) they are connected to and the links between their alters (Everett & Borgatti, 2005).

Social network analysis research can be qualitatively and/or quantitatively focused, depending upon the design of the study. Quantitative network design focuses on testing relations, interactions and structures of networks by using objective measurement(s) to collect data and numerical data analysis. Quantitative analysis may include mathematical descriptions, with frequencies and prevalence, and/or relational causal analyses of interactions, together with density, centrality, and strength of ties. In addition, more sophisticated statistical applications have been described and used in SNA research including regression, cluster and block model analyses (Antonucci, 1998; Wasserman & Faust, 1994).
Alternatively, qualitative network design may include methods of data collection via use of semi-structured interviews and co-creation of network visualizations and/or validation methods. In fact, studies have employed an interactive process during data collection where respondents co-create network representations (Eddens et al., 2017) and during initial analysis to include respondent subjective understanding of their interview narratives (Mccarty & Govindaramanujam, 2005). Analysis strategies are dependent upon the design of the study and of the study inquiry. The qualitative data are represented as written text of the network which provides richness to relations portrayed in the visualization and may be used to further conceptualize the utility of network relations (Dominguez & Hollstein, 2014).

Quantitative SNA methods have been used to analyze network structures among participants using standardized measures while qualitative SNA methods explore the meanings and relevancies of social phenomena of networking (Dominguez & Hollstein, 2014). In fact, this is a symbiotic process to which both data sources contribute to the overall study inquiry. Utilizing quantitative and qualitative methods in network research can provide a comprehensive understanding of the complexity of social exchange, validate network formation, and describe underlying social context (Bilecan, 2016; Kolleck, 2013). The proposed convergent MMR design, integrating quantitative and qualitative SNA methods, can contribute to the development of innovative research and unveiling of data that would be otherwise unknown.

**Networks of Older Persons Living with HIV**

To date, qualitative and quantitative studies have described social networks of OPLWH as a buffer to and perpetuator of HIV stigma (Poindexter & Shippy, 2008; Vance et al., 2011; Slomka et al., 2013). The role of stigma has been broadly discussed
in the HIV literature as multi-dimensional negatively impacting one’s HIV disclosure, engagement in network relations, loneliness and isolation (Earnshaw & Chaudoir, 2009; Emlet et al., 2013; Grov et al., 2010). Few studies have investigated social network structure and contextual relationships among older persons living with HIV (Moore, 2013; Nobre et al., 2013; Poindexter & Shippy, 2008; Vance et al., 2011; Zhang et al., 2012). Urban and rural studies have described networks of older persons living with HIV (OPLWH) as fragmented, limited and threatened (Emlet, 2006b, 2007; Groft & Vollman, 2007; Poindexter & Shippy, 2008). Similarly, both rural and urban literature have discussed the importance to OPLWH of their families and friends and of the desire for increased community education, tangible support and emotional support (Emlet, 2006b; Groft & Vollman, 2007; Shippy & Karpiak, 2005; Poindexter & Shippy, 2008; Zhang et al., 2012; Zhang et al., 2013; Veinot & Harris, 2011). Differing from their urban counterparts, rural OPLWH have been shown to have a lack of health and formal HIV support services, limited ability to foster social network linkages, and lack of geographic mobility due to transportation issues (Groft & Vollman, 2007; Veinot & Harris, 2011; Zhang et al., 2012; Zhang et al., 2013).

The use of mixed methods research, integrating qualitative and quantitative SNA, can further contribute to the understanding of complex interactions of social network components that can influence social relationships and capital exchange. Quantitative personal network analysis provides the opportunity to create, analyze, and visually represent an individual’s network in terms of structure, density, and centrality (McCarty, Molina, Aguilar, & Rota, 2007). In addition, qualitative investigation may broaden the conceptual richness to the roles of the interpersonal relationships and the interplay
between phenomena (Creswell, 2006; Creswell & Clark, 2013). Using MMR, integrating both quantitative and qualitative approaches may enhance the understanding of “who” network persons are, “what” their social function is, under what dynamic conditions these relations occur, and their contributions to certain network outcomes (Dominguez & Hollstein, 2014; Heaney & Israel, 2008).

Thus, the purpose of this article is to illustrate the integration of quantitative SNA data and qualitative semi-structured interviews using network visualizations as a tool; contributing to a comprehensive understanding of the social phenomena. This integration will be demonstrated by presenting data from a larger MMR study, illustrating four cases of OPLWH living in rural areas of North Central Florida, to better understand the social networks structures - the “who” and the “what” - and the complexity of “the how” social networks’ function.

**Mixed Methods Research Design**

This is a methodological article, part of a larger MMR performed to evaluate structural and compositional network properties and the meaning of social exchanges - what their functions are - of OPLWH living in rural and sub-urban areas of North Central Florida. Four case studies will be presented to illustrate MMR convergent design, using the integration of quantitative network data and visualizations as tool for collecting qualitative data. For this MMR study, four major steps were followed: 1) concurrent data collection using both SNA data and qualitative data of OPLWH; 2) independent analysis of data sets using separate analytic procedures; 3) direct comparison of data sets in order to further combine results; and 4) discussion of the extent and ways results relate to each other, converge or diverge, and/or further contribute to create a better
understanding to the overall study purpose (Creswell & Clark, 2018; Dominguez & Hollstein, 2014).

Network analysis will be discussed as the method for analyzing social structure and composition (e.g., density, centrality and homophily), highlighting the types of personal network structures of OPLWH. Network visualizations of OPLWH will be illustrated to demonstrate how structural and compositional measures of a personal network may visually represent one’s social relations. Using the visualizations as a tool, participants’ are able to see their social world, further validate or disprove the representation, and provide context to the social function of the members within their networks. This is as a form of member checking in which validation of the visual network and represented social ties are reinforced through an interactive process between the interviewer and respondents (Creswell, 2013). In fact, individuals’ may perceive more than they ever responded when answering structured questions about their social connections.

**Description of the Sample**

The target population included older persons living with HIV aged 50 and above, from Area 313, a 15 county area in Northern Central Florida encompassing sub-urban and rural communities (Figure 1). The rural and sub-urban population of OPLWH was selected because aging with HIV is a new area of research and is widely understudied. Area 313 is a designated 15 county district in which the federally funded Ryan White Program allocates monies to state health departments to provide variable HIV-related services based upon community needs. Within Area 313, older adults ages 50 and older accounted for 49.1% of HIV-infected individuals living with HIV or AIDS in Citrus, Lake, Marion, and Sumter counties (Florida Department of Health, 2015).
Recruitment and Data Collection

This study was approved by UF IRB 01 #201601205. Initially, community health workers (CHW) linked to the University community health center located in North Central Florida pre-screened agreeable community members and obtained initial consent to store private health information. When the study became available, eligible persons were contacted by the CHW to discuss study content and if desired, were placed on a call list to be contacted by the investigator. In addition, the primary investigator (PI) engaged in the community by attending local HIV support groups and LGBTQ+ events to talk about the research and to recruit potential participants.

Data were collected via face-to-face meetings; participants met the PI at a community health center, where reliable Internet was available and a private room was provided. Data were collected via computer-based network software EgoWeb 2.0. Field notes were recorded by hand throughout the interview and immediately thereafter. Computerized network data were stored in a share drive accessible by only those approved by IRB01. Accordingly, paper formatted material were transported via a locked brief case and stored in a locked cabinet provided by the affiliated University.

Description of the Instruments

Personal network questionnaire. Designed by the PI, this questionnaire focused on participant’s personal (or egocentric) network and identified personal associations (alters) that a participant (ego) knows (Borgatti et al., 2013). The network questionnaire consists of three modules. (1) Name generator – a single question that asks the individual to list 20 names or nicknames of persons’ in their network. "Please list the names of 20 people that you know and who know you, with whom you have had some form contact in the past two years (face-to-face, by phone, text, email or by the
Internet." This question aims to identify the participant’s personal contacts’ such as their family, friends and acquaintances and to obtain a representative sample of the respondent’s current network (McCarty, 2002). (2) Name interpreter – This is a set of questions that collect information about each alter and the relationship to ego (e.g., spouse, family, coworker, or friend) and alter attributes (e.g., age, sex, gender, and HIV status). This part of the questionnaire also assess facets of social capital including (emotional support, instrumental support (i.e., financial and health related) and interpersonal trust-based relations. An ordinal 5-point Likert scale was used to assess ego’s perception of support they received from each alter and of their perceived trust and disease disclosure. (3) Name interrelater – A single question that asks the ego to evaluate whether each of the personal contacts knows each other: "Do these two people know each other? ‘Knowing each other’ means that if they met on the street they would talk to each other even if you are not there.”

**Using social network visualizations during interviews.** After completion of the personal network questionnaire, EgoWeb generates individual network visualization. Basic principles of the visualization were explained to the participants (e.g., meaning of grey scale color hues representing degree of HIV disclosure, shape of node representing relationship type, and size of the node portraying degree of betweenness centrality of alter(s)). Follow up semi-structured questions were then asked. Questions included: 1) the accuracy of representation of network visualization; 2) thoughts about participants’ network structure and the interview process; 3) inquiry of whether anything emerged; and 4) a dialogue of how their network would look based upon time of diagnosis. Overt field notes were taken throughout the interview including a detailed
observation of the physical environment, participant attire, verbal and non-verbal cues, and narrative discourse with interviewees (Creswell, 2013). The PI employed member checking, respondent validation of interviewer’s impression of their narrative throughout data collection to reinforce the credibility of results. For instance, the PI used repeat back technique to validate hearing appropriate terminology and to clarify participant’s intended meanings.

**Mixed Method Data Analyses**

**Network Analysis**

Social network analysis is used to evaluate patterns in one’s social environment, referred to as structure (Wasserman & Faust, 1994). Network data were exported from EgoWeb into UCINET and NetDraw to evaluate structural and compositional components of OPLWH networks’ including density, centrality, and homophily. Density is a measure of the network structural shape which is broadly described as the proportion of alters’ who are connected to each other (Borgatti et al., 2013). Further, loosely defined, centrality is the contribution of the node to the structure of the network; sociologically viewed as the gatekeepers, leaders, and having great autonomy or influence (Borgatti et al., 2013). For example, a central node may accrue advantages by virtue of position in the network and may be able to control informational flow through a network. Lastly, the concept of homophily is used to assess similarities of alter attributes with participants (egos) including demographics, behavior(s), attitudes (McCarty & Govindaramanujam, 2005). Patterns in each network presented were analyzed to create a specific typology.

Social capital components including perceived trust, emotional support, financial support and health care support were analyzed in the network visualization by
portraying “who” provided listed types of support. For example, the PI assigned colors to each measure of support and numerically counted the number of persons in that network work provided that support. Numerically (1-5) alters’ was deemed low, (6-10) alters was characterized as moderate and (11-20) alters’ was labeled as high level of support under analysis.

**Semi-Structured Qualitative Analysis**

Qualitative data were initially recorded by hand, transcribed, managed and analyzed using NVivo 11 software. Prior to conducting this study a reflexive statement of the investigator’s experiences, presumptions and ideations was performed. Free coding was initially performed followed by semi-structured coding using a social capital framework for thematic analyses (Creswell, 2013). This conceptual framework entails viewing capital as a function that facilitates action(s) through means of persons and relations embedded within a social structure (Coleman, 1988). This framework was used as a structure to identify various forms of social capital among participants’ transcripts, including forms of support (e.g., emotional, spiritual, and instrumental) and trustworthiness. For example, if the individual referenced an individual in their network that they call when they were sad or low, this was coded as “emotional support.”

Two separate reviewers analyzed qualitative data independently then formally met for consensus coding to discuss generated themes and to ascertain congruency of the qualitative findings, also known as intercoder agreement (Creswell, 2013). Overarching themes or constructs that emerged were agreed upon and sub-concepts/themes were then intertwined as they related. Several themes were coded in vivo, meaning use of participants’ words verbatim, to emphasize the perspective of participants’ within their sociocultural context.
Integration and Interpretation Analyses

Quantitative values, network visualizations, and qualitative themes were then compared and reviewed simultaneously to assess for areas of convergent and divergent results by the co-investigator and secondary reviewer. This process of interpretive analysis is a way to review results that may relate to, compliment or differ from one another in order to produce a more complete understanding of networks of OPLWH (Creswell & Clark, 2018). Data were then integrated to provide a more comprehensive understanding of the dynamic relationship of network structure, social ties and social capital related to HIV disease disclosure and stigma.

Results of Integration of Methods

In order to illustrate the MMR design, four cases were chosen from a larger MMR study in order to demonstrate the richness of integrating quantitative and qualitative network data using the personal networks visualizations as a tool for data collection and analysis. Table 3-1 shows the demographic characteristics of the four cases.

Network Analysis and Social Capital Results

Network Typologies. Network typologies of the four cases included: 1) family/friend-centered network, 2) faith-based network, 3) heterogeneous network, and 4) fragmented network. The structure of OPLWH was either dense Cases 1, 3 and 4 (Figures 3-2, 3-4, 3-5) with many connections between alters of persons in the ego’s network or fragmented, loosely connected with separate cliques which are sub-group(s) of alters that are directly tied to one another (Case 2, Figure 3-3). The family/friend-centered network was moderately dense, homogeneous and primarily composed of family (kin) relations and friends (Case 4, Figure 3-5). The faith-based network was also dense, homogenous with majority of network persons being church members few kin
relations were noted (Case 1, Figure 3-2). The heterogeneous network was moderately dense, composed of their family, friends, work related affiliates and faith-based member (Case 3, Figure 3-4). Lastly, the fragmented network was composed primarily of family and friends had the lowest density score and contained several isolates (Case 2, Figure 3-3).

**Social Capital.** From the visualizations we gleaned that density of networks did not necessarily correspond with increased emotional, health-related or financial support. Network members that mainly provided support to the participants were persons who were trusted “very much.” However, in regard to disclosure of one’s HIV status participants’ trust of network members did not directly relate and varied case-by-case. For example, Case 1 (Figure 3-2) did not disclose his HIV status to any members of the network, despite high levels of trust. In contrast, Case 2 (Figure 3-3) did disclose his HIV to persons most trusted. Similarly, the type of relationship (i.e., family, friend, neighbor, partner) or alters’ HIV status did not directly correspond to whom participants’ frequently discussed their HIV with.

**Density.** Calculated in UCINET, this measure accounts for the total number of possible ties between alters in a network. Results are computed on a scale of zero-to-one whereas the higher the numerical value the denser the network. In the cases shown, only “strong ties” are portrayed which are links between network members who were identified as “very likely” to know each other. This process eliminates ties shown between persons who were identified as “maybe” to know each other. Overall, Case 3 (Figure 3-4) represents a “dense network” with a density score of (0.513) followed by
“moderately dense networks” Case 1 (0.437) and Case 4 (0.429) presented in (Figure 3-2 and 3-5)

A very dense network may positively or negatively impact an ego depending on their social context. For example, within a moderately dense network, the participant of Case 1 (Figure 3-2) revealed a perceived threat of rapid dissemination of his HIV or sexuality if someone discovered his HIV status due to interrelations within his network. Contextually, Case 1 identified as a Black/African American male in his 60s who has lived with HIV over 20 years. His network was primarily comprised of his faith-based community with no known persons in his network who were also HIV positive. Overall, he had low level of financial support though he had high levels of emotional support and trust within his network. Thus, in this scenario density may be seen as a “potential threat to disclosure” to the participant with a highly embedded network.

In contrast, Case 2 (Figure 3-3) represents a fragmented network with very “low density” (0.213). The network is very fragmented with three isolates, which are persons linked solely to the ego and may be seen as persons with little brokerage (Borgatti, Everett & Johnson, 2013). The participant of Case 2 identified as a Black/African American homosexual male in his 60s who has been living with HIV for nearly 30 years. Majority of his network members were male, ages 56-75, predominately family (kin) and friends to whom he communicated with primarily by phone or text monthly. Most persons were trusted little, excluding the a few family members. Overall, he had little emotional, financial and health support. Uncovered by the qualitative interview, this participant recently relocated to North Central Florida and did not openly identify as
homosexual within his network, which may have contributed to fragmentation within his network and little support received.

**Network Composition.** Compositionally, the networks were predominantly made up of family, friends or one’s faith based organization. Homophily between the egos’ and alters’ was identified by racial/ethnic background in all four cases. Case 2 (Figure 3-3) demonstrated increased homophily within his network with majority of members’ being male, ethnocentric (also Black/African American) and predominately above the age of 50. Comparatively, homophily was not demonstrated in terms of age, gender, or concurrent HIV status in Cases (1, 3 and 4). The participant who relocated, Case 2 (Figure 3-3) had an increased heterogeneous network composition, which in this case, may be due to geographic residential relocation.

**Centrality.** Betweenness centrality is a SNA measure of the extent to which an alter lies on the shortest paths (geodesics) between alters. A result of 0 implies that there is no more of a bridge than any other alter. This measure is important as it measures potential information control through a network (McCarty, 2002). For example, alter number 3 in Case 4 (Figure 3-5) had the highest betweenness centrality with the network. This is important because these members are considered potential brokers within the network, whether negative or positive. Alter number 3 was identified as an immediate family member to whom she reported high levels of trust, emotional, financial and health support. Thus, in this case, alter 3 may be seen as a positive broker for the ego in this network.

Alternatively, alters’ 4 and 3 had highest levels of betweenness centrality in Case 1 (Figure 3-2). These alters’ were identified as a faith-based community member and
neighbor to which the participant reported high levels of perceived trust and emotional support though he disclosed his HIV to no one in his network. Divergently, qualitative data provided explanatory power to participants’ lack of disclosure to his personal network due to his identified sexuality and HIV status. In this case, the brokers of his network may negatively influence the social relations within his network if his HIV was disclosed to these individuals.

**Qualitative Themes and Integration**

Overall, research participants described the interview as therapeutic and were appreciative for the ability to talk about their HIV openly in a safe environment. Qualitative data enhanced the quantitative SNA data by providing context to network relationships beyond typical categorization of “who” alters’ are and “what” their social functions entail. In all cases, qualitative data further highlighted participant’s life circumstances, perceptions of themselves and of their HIV, and the extent of their relationship with their network members. Overarching themes generated from the qualitative analysis were: stigma and self-actualization. Stigma was further sub-divided by type of stigma and self-actualization was categorized as those who were ‘moving beyond’ or ‘taking on’ one’s HIV diagnosis.

**Stigma.** Stigma was a predominant theme and was primarily identified in the forms of anticipatory or internalized stigma. Disease related stigma was intertwined with participants’ fear of disclosure and fear of rejection in the cases presented. Further, stigma was also seen within participant’s sexuality or perception of promiscuity. Each participant alluded to stigma of HIV as being “marked” as someone who used intravenous drugs or participated in socially unacceptable sexual acts. Cases 1 and 2, were individuals’ who openly identified as homosexual for study purposes, but admitted
to lack of disclosure to their community members due to anticipated fear of network rejection. Therefore, we identified layers of stigma within the experience of living with HIV and based upon sexuality.

**Anticipatory stigma.** Described as a sense of fear of judgment, including how one’s HIV was contracted or of their underlying sexuality. Those who described anticipatory stigma also related a sense of fear of disclosure of their HIV due to potential discrimination. Hence, societal perception of an individual’s lifestyle choices may be related to HIV disease related stigma. Sexual identity was notably intertwined with stigma; of those participants who identified somewhere on the LGBTQ+ spectrum one’s identity was represented as another layer of shame in some cases.

Participant disclosed: “I wish I could tell my network of my condition but I would feel ostracized; no one in my church community knows about my HIV or sexual orientation.” Congruently, his network visualization demonstrated that he does not disclose his HIV to anyone in his social community (Case 1, Figure 3-2). With the qualitative narrative, we were able to understand ‘why’ in his case he chooses to keep his HIV status and his sexuality a secret from his network. Circumstantially, he alluded to protecting himself from the threat of complete loss of his network and discrimination as a result of potential disclosure.

**Internalized stigma.** Described as a self-perception of being dirty, unclean and shameful of one’s past behaviors that may have exposed them to HIV. This sense of self-imposed shame was equated with a sense of deserving public stigma. In other words, internalized stigma entailed carrying one’s shame with them as one participant explained it: “this is my cancer, I’m living with this every day.”
**Self-Actualization.** Abraham Maslow (1943/1954) initially defined self-actualization as the growth of an individual toward the highest level of self-fulfillment and the meaning of life (Mcleod, 2018). In this study, each participant portrayed their lived experience as either finding meaning in their diagnosis or as fulfilling a life’s purpose beyond their HIV status. We categorized this as ‘taking on’ or ‘moving beyond’ the diagnosis. In both categories, participants’ discussed a sense of growth and movement toward becoming self-actualized. Intertwined with this theme included one’s faith or belief in a higher spiritual being. For example, one participant stated: “No matter how much we think we suffer, God doesn’t give us more than we can handle and we will never suffer as much as Jesus; when I accepted Christ into my life, my entire life and perspective began to change and I changed my life” (Case 3, Figure 3-4).

In order to self-actualize, the participants described acceptance of self and of one’s situation as pivotal. In regard to acceptance of one’s self, this encompassed “accepting one’s sexuality,” and “how HIV was contracted.” For instance, Case 3 (Figure 3-4) is Black/African American female in her 60s who has lived with HIV for over 30 years. Her network was primarily composed of her family members, including persons of various ages, to whom she communicates with on a weekly-to-monthly basis predominately in person. She had high levels of emotional support, moderate health support and low financial support. She disclosed her HIV to all persons in her network. During her interview she revealed a history of sexual violence followed by a history of unhealthy life choices, including drug use. Instead of carrying shame with her, she admittedly decided to accept her past and “give back to the HIV community”.

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Moving beyond. This theme was identified as acknowledgment that their HIV diagnosis was a part of their life journey but not their life's journey. This was described as not letting the diagnosis define them and focusing on other important matters. Participants' who described moving on from their HIV primarily focused on routine, physical health such as diet and exercise, and on other life matters. A participant mentioned: “Yes, I am living with it big deal; so many other things are killing people, diabetes, obesity…”

Taking on. This theme encompasses embracing one's diagnosis in a way that participant’s freely disclosed their HIV status and used their diagnosis as a compelling force to educate others at the interpersonal, community and societal level. Taking on one’s HIV is synonymous with giving back to the HIV community as a HIV positive peer advocate, a community leader or educator or as a beacon for knowledge dissemination. The participant Case 3 (Figure 3-4) described her diagnosis as a wakeup call, as something that gave her life purpose and continuing to be forthright with her positive diagnosis in order to combat underlying social stigma. This participant related: “I changed my narrative from ‘why me’ to ‘why not me’ and got involved, learned about HIV and became an HIV educator and advocate.”

Congruent with her visualization, the qualitative data supported her disclosure patterns to all persons in her network despite level of perceived trust or support provided by alters’ Case 3 (Figure 3-4). For this participant, qualitative data enhanced the network findings by providing context to understanding her self-acceptance and self-perceived role as an HIV advocate whereby, disclosure was not directly linked to the perceptions of her network members.
Overall, qualitative data enhanced our understanding of individuals’ networks by providing context and richness to participants’ networks and life circumstances. The qualitative visualization was a beneficial tool to elicit ego-alter social functions beyond typical quantitative SNA data including categorization of network composition and ties. These findings are unique as participants’ described visualizing their networks as beneficial and verbalized appreciation for the opportunity to dialogue about it. One participant stated: “I learned that when you are faced and asked questions about things you don’t really pay attention to, you start to really think about your surroundings.”

The qualitative narratives also highlighted individuals’ perceptions of their HIV and of their relationships with their network members beyond social capital components that were asked in the personal network survey. For example, Case 4 (Figure 3-4) described her significant other as her main source of social and emotional support. Divergent from her visualization, revealing a structurally dense network with several persons to whom she discloses her HIV status to and overall high levels of trust, the participant verbalized a sense of loneliness and desire to discuss her HIV with more individuals during her follow up interview. Unexpectedly, the respondent disclosed that her current partner who was HIV negative is supportive of her diagnosis, yet prevents her from disclosing her HIV to others. Participant mentioned: “My partner is supportive but does not want me to disclose my HIV status; I wish I could talk to more people about it, you [I] feel like you are [I am] lying but like you are [I am] saving yourself [myself]. My days can sometimes be very lonely and dark.

**Discussion of SNA and Qualitative Methods Integration**

The primary aim of this article was to illustrate how the process of integrating SNA quantitative data and qualitative semi-structured interviews with use of network
visualizations as a tool contributes to a more comprehensive understanding of social relations’ and phenomena. Formally, use of simultaneous data collection of quantitative and qualitative data facilitated interviewee engagement and provided further explanatory power of interpersonal relations. The use of network visualizations during data collection provided a visual representation of participants’ social world and allowed them to observe and gain new insights about themselves (Molina, Maya-Jariego, McCarty, 2014). During the analysis phase, network visualizations served to explore visual typologies and generate inferences by visually comparing variables (Molina et al., 2014).

The use of the visualization enabled a therapeutic unfolding for participants and contributed to our understanding of OPLWH interpersonal social relationships in which they function. We discovered underpinning themes such as stigma and self-actualization in relation to their HIV status, interpersonal relationships and receipt of social capital. Utilization of the semi-structured interviews enabled exploration of topics such as disclosure of one’s HIV status, stigma, and of personal sociocultural influences that were not addressed in the personal network questionnaire. As an interface between quantitative and qualitative data, visualizations are a uniquely powerful tool for the purposes of interviewee-interviewer collaboration, classification of structural and compositional components and development of theoretical models (Crossley, 2010; Turbaro, Ryan & D’Angelo, 2016; Weishaar, Amos & Collin, 2015).

During the analysis phase, interactive software programs that assist in creation of network visualizations (i.e., UCINET, NetDraw) allowed us to explore visual typologies and generate inferences by visually comparing compositional and quantitative structural
variables (Molina et al., 2014). Comparison of various social capital components (i.e., emotional support, instrumental support, and health support) as well as HIV disclosure and perceived trust were assessed by assigning size, color, and shape of the node. The ability to manipulate visual components of the participant’s network was beneficial during primary integration analyses whereby both quantitative measures and qualitative themes were evaluated simultaneously. This process of integrating analyses of quantitative and qualitative network data enabled creation of meta-inferences (Bacchus et al., 2018).

Using a quantitative network design various measures such as density, centrality and alter-based characteristics (e.g., percent alters who were female or male) provided numerical value to network structure and composition (Wasserman & Faust, 1994). Quantitative network insights allow for comparable network information within egocentric networks and between egos (Bernardi, Keim & Klarner, 2014). The visualization served as a qualitative tool, to engage participants’ in analysis of their social worlds, validation of the representation, and as an interface for integration analyses. The qualitative interviews facilitated identification of underlying social context to which OPLWH function and overarching themes that ultimately influenced all of participants’ personal ideations of their HIV and of their social interactions.

The second aim of this study was to demonstrate case exemplars of MMR integrating SNA methods and visualizations to better understand the complexity of social networks and their outcomes of OPLWH living in North Central Florida. The cases exemplars demonstrated how the integration of both quantitative and qualitative data contributes to in-depth understanding of the structure, composition and social
relations therein as a dynamic process (Williams & Shepherd, 2017). The integration of MMR proved complementary in visualizing the social structure ego’s networks followed by qualitative data providing explanatory power of ‘who’ alters are and ‘what’ the social exchange was in the network.

Use of SNA methods provided the ability to quantitatively measure compositional and structural network components and contribute to a typology of networks of OPLWH. Quantitative network insights allow for comparable network information within egocentric networks and between egos (Bernardi, Keim & Klarner, 2014). To date, quantitative and qualitative studies describe networks of OPLWH as small, fragmented and limited (Emlet, 2006b, 2007; Groft & Vollman, 2007; Poindexter & Shippy, 2008; Zhang et al., 2013). Compositionally, networks primarily included informal support persons, such as partners, family and friends (Emlet, 2006b; Moore, 2013; Nobre et al., 2016; Shippy & Karpiak, 2005; Zhang et al., 2013). Of the four cases presented, structurally networks were primarily dense, not fragmented. Notably, the fragmented case represented a more heterogeneous composition of network persons due to geographic relocation, which is also found within the literature (Dominguez & Hollstein, 2014).

This study is unique as it is the only social network study based in the United States that has integrated SNA MMR to investigate social relationships of OPLWH living in rural and sub-urban communities. Cases presented revealed that density did not directly relate to disclosure of one’s HIV. While disclosure of HIV corresponded with persons in the network most trusted (Foster & Gaskins, 2009), networks displayed in this study did not show a direct correspondence. Similarly, a study with OPLWH in
Africa were less likely to disclose their HIV status to those they felt close to and more likely to disclose to persons who could loan them a sum of money (Moore, 2013). Uniquely, disclosure of one’s HIV status been described as dependent upon one’s social capital needs (Foster & Gaskins, 2009; Moore, 2013) and selectively, to those who pose the least risk of harm (Emlet, 2008; Serovich, 2001). Through integration, qualitative data provided narrative insights which were crucial to understanding the social and relational environment to which OPLWH were embedded. Narrative text unveiled that HIV disclosure intersects with an individual’s ideation of stigma and under what social conditions they are willing and not willing to disclose.

Stigma, both internalized and anticipatory was captured by the qualitative part of this study, as a direct question of the experience of stigma was not asked in the personal network questionnaire. In fact, the presence and negative impact of stigma is largely discussed in the HIV literature (Emlet. 2006c; Emlet et al., 2013; Grov et al., 2010), along with experiences of discrimination based upon one’s sexual-identity (Lyons, Pitts, Grierson, Thorpe & Power, 2010) and of ‘how HIV was contracted’ (Earnshaw & Choudoir, 2009). Compositional network data revealed “who” egos’ disclosed their HIV to but did not explain the “why”. Qualitative data of case exemplars indicated that lack of HIV disclosure to network members was a protective mechanism to prevent potential rejection (Vance et al., 2011; Foster & Gaskins, 2009).

With the combination of qualitative and quantitative methods we were able to structurally analyze networks of OPLWH and qualitatively reveal the influence of underlying stigma. The existence and influence of stigma is pivotal to understanding the context to which social relations occur among persons living with HIV. However, the role
of stigma would not have been unveiled if the quantitative network portion of the study was performed alone. All cases described stigma as a prevalent phenomenon; how each individual reacted to stigma and functioned within their interpersonal social networking world. Using MMR we have demonstrated the significance to evaluating complex social relations and the continued pervasive impact of stigma.

Nursing research, as well as other disciplines, can benefit from employing MMR network approaches in light of the complexities of social interactions and their impact on human behavior and well-being. Qualitative research methods are broadly used in nursing research, but social network analysis methods are still in infancy. In order to enhance human relations’ science, it is imperative to continue to employ interdisciplinary and innovative research methods as proposed in this study. Knowing that social connections influence health, the use of social network analysis is a preeminent method of investigation. Even though integrating methods can be challenging, results of MMR are meaningful in testing and creating theories and research questions. With the appropriate framework, integration is merely a process of innovative science in order to better grasp the underlying phenomena.
Figure 3-1. Area 313 of north central Florida.
Table 3.1. Description of demographic characteristics for case exemplars

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Case 1</th>
<th>Case 2</th>
<th>Case 3</th>
<th>Case 4</th>
</tr>
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<tbody>
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<td>52</td>
</tr>
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<td>Gender</td>
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<td>Female</td>
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</tr>
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<td>Black/AA</td>
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<td>30</td>
<td>11</td>
</tr>
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</tr>
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</tr>
<tr>
<td>HIV support group</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Note: AA = African American. EA = European American. CR = Committed Relationship
Figure 3-2. Case 1 portraying a homogenous, dense network with lack of HIV disclosure. Note: Figure shape (circle – friend, diamond – church member, circle in a box – neighbor); grey scale coloring (white – never discloses HIV and black – always discloses HIV); size of shape represents degree of betweenness centrality (larger the size of the node, higher betweenness centrality).
Figure 3-3. Case 2 is a fragmented, homogenous network with isolates and moderate HIV disclosure. Note: Figure shape (circle – friend, upward triangle – immediate family); grey scale coloring (white – never discloses HIV and black – always discloses HIV); size of shape represents degree of betweenness centrality (larger the size of the node, higher betweenness centrality).
Figure 3-4. Case 3 is a dense, homogenous network with complete HIV disclosure. Note: Figure shape (circle – friend, upward triangle – immediate family, downward triangle – extended family; diamond – church member, square – work related); grey scale coloring (white – never discloses HIV and black – always discloses HIV); size of shape represents degree of betweenness centrality (larger the size of the node, higher betweenness centrality).
Figure 3-5. Case 4 is a moderately dense network and moderate HIV disclosure. Note: Figure shape (circle – friend, upward triangle – immediate family, downward triangle – extended family, hourglass – partner/significant other); grey scale coloring (white – never discloses HIV and black – always discloses HIV); size of shape represents degree of betweenness centrality (larger the size of the node, higher betweenness centrality).
CHAPTER 4
SOCIAL NETWORKS ON LONELINESS FOR OLDER PERSONS LIVING WITH HIV IN RURAL COMMUNITIES

Social Gerontology

The rate of older adults living with HIV continues to rise and successful aging with HIV is an emerging topic (United Nations on AIDS, 2013) that requires more attention from health professional and scientists. According to the Center for Disease Control and Prevention (CDC), adults aged 50 and over accounted for 45% diagnosed Americans living with HIV in 2014 (2018). Now seen as a chronic manageable disease, long term management and aging with HIV poses significant socioeconomic, physical, and mental health concerns. The extensive body of literature with this population focuses on older persons living with HIV (OPLWH) in large metropolitan communities (Emlet, 2006b, 2007; Shippy & Karpiak, 2005; Poindexter & Shippy, 2008). Few studies have focused on older persons living with HIV (OPLWH) in rural communities and the unique impact social networks and rurality may pose to mental health (e.g., loneliness) and HIV disclosure (Gannon & Stacciarini, 2016).

Social networks of older adults are multidimensional and depend upon many factors, including proximity, physical and cognitive status of the aging adult, and necessity of and/or provision of support resources (i.e., emotional or instrumental support) (Fiori, Smith, Antonucci, 2007; Wegner, 1997). Typologies of networks of aging adults have generally been described as: 1) diverse, 2) family-focused, 3) friend-focused, 4) restricted (socially isolated), and 5) neighbors (Fiori, Antonucci, & Cortin, 2006; Fiori, Smith & Antonucci, 2007; Litwin, 2001). Additionally, support networks have been analyzed relative to location of the respondent (i.e., predominately composed of persons within 1 mile, less than or more than 50 miles, etc..) to determine how regional
distribution of network members may influence the health of older adults (Wegner, 1997). Overall, results reveal that aging adults’ utilize networks differently depending upon their physical and cognitive health status, sociocultural and economic opportunities and geographic proximity of their support (Ajrouch et al., 2001; Fiori et al., 2007; Litwin, 2001; Wegner, 1997).

Interpersonal relationships have been described as beneficial to successful aging (Berkman, Glass, Brissette, & Seeman, 2000) however, the mere existence of relationships alone does not indicate that older adults are aging well (Adams & Blieszner, 1995). Facets of social connectedness or disconnectedness within networks have been analyzed in relation to physical and mental health among older adults. In fact, social disconnectedness and perceived isolation of aging adults have been associated with feelings of loneliness, perceived lack of support and worse physical and mental health outcomes (Cacioppo et al., 2006; Cornwell & Waite, 2009; Schnittker, 2007).

One’s social world is not static; for the aging population natural changes to one’s network may occur due to normative life events, including retirement, death of a spouse/life partner, decline in physical and/or cognitive health, and migration from one’s own home into congregate communities (i.e., assisted living) (Li & Ferraro, 2006; Schafer, 2015; Weiss, 2005; Wrzus et al., 2013). Uniquely, HIV survivors or individuals who have lived with HIV for many years may experience diminished social networks due to multiple AIDS-related deaths of peers, contributing to loneliness (Owen & Catalan, 2012). In fact, several studies have attributed loneliness of OPLWH to living alone, lack of social support and social engagement (Bhavan, Kampalath, & Overton, 2008;
Poindexter & Shippy, 2008; Zhang et al., 2012). OPLWH who have higher subjective loneliness scores were more likely to be a current smoker, have depressive symptoms and have lower social support systems in place (Greene et al., 2018). Overall, little is known of the role of networks of adults aging with HIV living in rural areas; and the role of these networks on their mental health, specifically perceived loneliness.

**Definitions of Rurality**

To date there is no consensus to define “rural” and “rurality” as a uni-dimensional measure or experience of physical environment; there have been attempts to define rurality as a subjective state of mind versus as an objective quantitative measure. Mainstream definitions define rural environment at the community level in terms of physical space and of land use, including census and county data (United States Department of Agriculture (US DOA), 2016). For example, the land cover definition includes percent coverage by forest, agricultural or natural areas and may also include the human built environment (US DOA, 2016). The built environment entails how persons are distributed across physical space and measures of 1) density (variable of interest per unit of area – e.g., population or dwelling units), 2) diversity (number of and type of different land uses), and 3) design (street characteristics within an area) (Euwing and Cervero, 2010). At the individual level, rurality has also been measured in terms of accessibility (i.e., measurement of travel distance(s), density of roads, and time between destinations) (Wang & Cheng, 2001).

The US Census Bureau uses demography to define urbanized areas as 50,000 persons or more, urban clusters as a population of at least 2,500 but less than 50,000 persons, and rural areas as all persons, housing, and territory otherwise not included in the urban definition (n.d.). Similarly, the Office of Management and Budget (OMB)
(2010) delineates Federal statistical areas by Metropolitan area, Metropolitan divisions and Micropolitan areas. By definition, Micropolitan statistical areas are defined as having one urban cluster of at least 10,000 but less than 50,000 persons along with an adjacent territory that has a high degree of social and economic integration with cores (OMB, 2010).

Current definitions of ‘rural’ as a measure of geographic/physical environment include agriculture landscapes, limited accessibility to services, low population density, homogenous ethnicity and lower road connectivity, may be too limiting (Mao, Yang & Deng, 2018). To incorporate a more holistic perspective, macro-components of rurality have been identified and composited to evaluate rurality as a dynamic phenomenon; typology includes measures of demography, socio-economy, and accessibility (Campbell, Merwin, & Yan, 2009; Caschili et al., 2015; Higgs & White, 2009; Li, Long, & Liu, 2015). The combination of the aforementioned measures have been used to create individuals’ rurality index; used to assess the influence of rurality on mental well-being and social isolation of rural Latino immigrants’ and rurality on late stage cancer diagnoses (Mao, Stacciarini, Smith & Wiens, 2015; Mao et al., 2018).

In addition, socioeconomic macro-components, distributions of poverty and racial/ethnic groups have been used as socioeconomic component to explain rurality (US Department of Agriculture, 2018). Geographically, poverty tends to be clustered in certain regions, counties, and neighborhoods with disproportionate rates of poverty in non-metropolitan counties mainly distributed in the South (US DOA, 2018). Moreover, non-metropolitan Blacks/African Americans had the highest incidence of poverty at 33%
in 2016, followed by American Indians and Alaskan Natives 31.8%, and Hispanics/Latinos at 25.9% (US DOA, 2018).

Conceptually, there are synergistic pathways between physical space and social relations (Doreian & Conti, 2012; Gluckler, Lazega, & Hammer, 2017). Inextricably, geography and social networks are interrelated; networks occur within a physical space and within that space certain characteristics may facilitate or preclude social exchange (Adams, Faust, & Losavi, 2012). For example, geography has been described as a condition to network formation (Gluckler et al., 2017). In other words, physical environment may set the stage to our social connections in terms of access to, diversity within, and opportunities for exchange therein.

Social scientists are typically interested in the nature of how relationships and social networks occur between a set of actors (i.e., humans), under what conditions, and the outcomes of the social connectivity (Wasserman & Fraust, 1994). From a sociocultural perspective, rural definitions aim to depict the interaction between social and spatial attributes (Halfacree, 1993). An individual's rural, physical environment can impact how they experience their social world (Bossen, Hipp, Butts, Nagel & Smith, 2017). Rural environment influences what individuals may or may not have access to, including social settings and social exchange (Bossen et al., 2017). For example, population density can be key for network structure as population density represents the “potential opportunity” of human exchange (Butts, Acton, Hipp & Nagle, 2012).

**Conceptual Framework**

A Social Ecological multi-level approach was used to conceptualize the potential interplay among one’s individual and interpersonal environment within their geographic (neighborhood) environment. The CDC (2015) revised social ecologic framework
typifies levels of interaction by individual, interpersonal, organizational, community and policy. In fact, this framework has been used to explain how interrelations between personal and environmental factors influence health promotion, illness and human behavior (CDC, 2015; Stokols, 1996; Fluery & Lee, 2006). Applicable to HIV literature, the social ecological framework has been used to investigate how factors at various levels may influence risk of HIV transmission and HIV prevention (Baral, Logi, Grosso, Wirtz & Beyer, 2013; Kaufman, Cornish, Zimmerman & Johnson, 2014). The interplay of among these environments was evaluated in this study at the individual level (participants' socioeconomic status), interpersonal level (network density and alters' HIV status) and at the community level (neighborhood racial/ethnic diversity and poverty status).

This novel study employs interdisciplinary, mixed methods research (MMR) to investigate the relationship between social connections and perceived loneliness of OPLWHs in rural environments. Social network methods and geographic information system (GIS) were used to describe participant’s social and physical (geographic) worlds. The purpose of this exploratory study is to evaluate the impact of OPWLH social networks on loneliness within the context of their physical, rural environment. The specific aims were to: 1) to evaluate the relation of OPLWH’s social environment on loneliness within the context of their geographic (neighborhood) environment; and 2) to describe the rural physical space by (neighborhood) or tract level data of OPLWHs. In this study, rurality was conceptualized as the reciprocal relationship between one’s social and physical environment, intending to explore OPLWH’s physical space from a
geographic perspective by descriptively portraying socioeconomic and demographic data.

**Methods to Investigating Social and Geographic Rurality**

This pilot study used a convergent mixed methods design, integrating both quantitative and qualitative methods to evaluate the impact of OPLWH social environment on loneliness within the context of their geographic environment. Social network methods were used to elicit information of network composition, characteristics of network members and potential ties between network members. In addition, qualitative semi-structured interviews were conducted to further explore and validate participants’ perceptions of their social network representations. Lastly, geo-spatial data were used to describe participants’ physical environment for components of rurality, including poverty and racial/ethnic distribution. Geographic environment will be descriptively presented by the population density, distribution of poverty and racial/ethnic groups due to disproportionate rates of poverty impacting persons living in non-metropolitan areas in the South and of racial/ethnic minority groups (US Department of Agriculture, 2018).

**Data Collection**

Ethical committee approval was obtained by UF IRB 01 #201601205 prior starting the study. Data was collected from June 2017 through May 2018 via a face-to-face meeting with the PI; one-time interview for approximately 2-hours. Participants were interviewed at the University community health center (CHC) or an alternative safe, community space with a private room and Internet access. An adapted version of Folstein’s (1975) Mini-Mental State Exam (MMSE) was implemented to ensure
participants’ were able to consent. After consent was obtained, the PI implemented data collection.

Sample and Recruitment

Persons 50 years old and above, self-identified as living with HIV, fluent in English, and living within North Central Florida, also known as Area 313, were recruited. Area 313 is a rural and sub-urban 15 county district in which federal funds provided by the Ryan White Program are allocated to state health departments for medical, social and housing services for persons living with HIV based upon socioeconomic needs. This population was selected due to the significant gap in the literature focusing on OPLWH in rural communities.

To optimize enrollment of a vulnerable, stigmatized population participants were recruited using different methods, including: 1) Referral from the "Health Street" - a community engagement program at the university that aims to improve the health of the community, providing services and engaging community members in research. Community health workers (CHW), from Health Street, perform a general health survey in surrounding communities and consent voluntary persons for consideration of future health-related research projects. Health Street members then link the researcher to pre-consented eligible participants who are willing to be contacted for study participation. 2) Participants were also recruited through the university affiliated hospital program “Consent2Share” whereby a list of potential participants who were pre-consented and willing to participate in a research study could be contacted by the investigator. 3) The investigator also established relations with the community by attending local HIV and LGBTQ support groups.
Instruments. The following instruments were used to collect data: 1) Sociodemographic GIS Survey, 2) De Jong Loneliness Scale, 3) Personal Network Questionnaire, and 4) Semi-structured interview. Overt field notes were recorded throughout the interview.

**Sociodemographic GIS Survey.** Developed by the investigator, this survey inquired of socio-demographic characteristics (e.g., age, self-identified gender, race/ethnicity, employment status, annual income), location of participants’ current residence, and location of where they receive care for their HIV. To preserve anonymity, participants were able to provide nearest crossroads or zip codes. Latitude and longitude coordinates were retrieved by the interviewer using Google Maps with verification of location by participants’.

**De Jong Loneliness Scale.** This is an 11-item, 5-point Likert scale that measures both emotional and social components of loneliness to composite a total score (De Jong & Van Tilburg, 1999). Scoring ranges include 0-2 (not lonely), 3-8 (moderately lonely), and 9-to-11 (extremely lonely). This scale was designed for and studied in older adults with evidence of sufficient validity and reliability with α = .84 in the general population (Cornwell & Waite, 2009; De Jong & Van Tilburg, 1999; De Jong & Van Tilburg, 2006).

**Personal Network Questionnaire.** Designed by the researcher, there are three sections to eliciting a personal or egocentric network, including: 1) Name Generator, 2) Name Interpreter and 3) Name Interrelater. Using EgoWeb, an open name generator was used to elicit names of 20 persons, also known as alters, in respondents’ network. The name interpreter section was used to inquire of alter-based characteristics (i.e.,
age, race/ethnicity, HIV status) and social capital components (i.e., emotional, instrumental and health support). Lastly, the name interrelater section aims to identify independent interrelations between the respondent’s alters’. A network visualization is immediately generated by EgoWeb, displaying a visual representation of respondents’ networks, highlighting 1) who they discuss their HIV with, 2) relationship type, and 3) who they talk to when they are sad/depressed.

**Qualitative Interviews.** Semi-structured qualitative interviews were implemented immediately after completion of the personal network questionnaire, using the visualization as a tool to elicit conversation. Components of their network structure were explained, then participants’ were asked about: 1) accuracy of representation of network visualization; 2) thoughts about participants’ network structure and the interview process; 3) inquiry of whether anything emerged; and 4) how their network would look based upon time of diagnosis.

**Analyses of Pilot Data**

This is a convergent, MMR pilot using both quantitative and qualitative data; which were independently analyzed and then simultaneously reviewed for analysis of congruency and/or differences at the interpretive level. Various programs were used for data analyses including UCINET, NetDraw, ArcGIS ArcMap, NVivo and SPSS.

**Quantitative Analysis using Simultaneous Multiple Regression**

Structural and compositional network components were exported from UCINET and analyzed in SPSS descriptively, by examining the mean scores of: 1) homophily, 2) network density, 3) degree centralization, 4) connectedness, and 5) fragmentation. Homophily is the tendency to have ties or relationships with persons who are socially similar (Borgatti, Everett & Johnson, 2013). Network density describes the proportion of
actual network connections by the total number of possible ties measuring strong ties or definitive alter-alter relations (McCarty, 2005). Degree centralization measures the extent to which the network structure is dominated by a single alter in terms of degree (McCarty et al., 2007). Connectedness is defined as the proportion of pairs of alters’ that can reach each other by any length and fragmentation is a measure of the number of pairs of alters that cannot reach each other by any means (Borgatti, 2006).

Prior to performing the regression analysis, univariate and bivariate analyses were performed in SPSS of SNA and loneliness data, including: 1) ego characteristics (i.e., gender, age, income, educational status and sexual orientation), 2) alter attributes (gender, ethnic/racial background, relationship to participant, and HIV status), 3) structural properties (densities, connectedness, fragmentation and degree centralization), and 4) total De Jong Loneliness scores.

Predictor variables included in the regression model were: 1) ego’s income, 2) HIV status of alters’, and 3) network density. Of the few significant bivariate results, ego’s educational level was not used along with participants’ income to prevent multicollinearity. Although not significant, interpersonal variables (network density and alters’ HIV status) were included in the regression model in order to compare to current literature supposing networks of OPLWH as fragmented and composed of persons who are also HIV positive (Shippy & Karpiak, 2005). Moreover, at the individual level, lower socioeconomic status has been studied as a predictor to poorer mental health outcomes and well-being (Steptoe & Feldman, 2001).

A simultaneous multiple regression model was used to explore the variance of OPLWH loneliness explained by participants’ income, network density, and alters’ HIV
status. Predictor variables were selected based upon structural, compositional and ego-based characteristics to evaluate how measures at the individual (ego’s income) and interpersonal (alters HIV status and network density) level relate to loneliness.

**Geographic Analysis**

The Environmental Science and Research Institute’s (ESRI) ArcGIS ArcMap Version 10.5 was used to develop maps, and to describe participant’s socioeconomic and demographic data (2018). The following steps were applied: 1) retrieval of block group data from Florida Geographic Data Library, 2) participant’s geo-location (i.e., residences) were plotted, 3) block level data were aggregated to tract and county levels, and 4) spatial data layers were added to map county and tract boundaries to portray population density, poverty rates and racial/ethnic distribution.

The US Census Bureau 2015 Block Group Data from the 2012 - 2016 American Community Survey (2016) was retrieved from the Florida Geographic Data Library (FGDL), which is Florida’s State Repository for geographic data (2018). Block groups are the smallest geographical unit used by the US Census Bureau generally containing 600-3,000 people within clusters of blocks (localized area) (2012). This dataset was used to extract respondent values based upon their current home location. Initially, participant points (including nearest latitude and longitude of their current home residences) were geo-coded using Google Maps. Latitude and longitude coordinates were plotted in ArcMap and projected to a common coordinate system, Florida Modified Albers (FGDL, 2018).

Block group data were then aggregated to the census tract and county levels. Census tracts are larger areas representing several block groups, which will be referred to as neighborhoods interchangeably. Tract level data is displayed in order to protect
the anonymity of participants’ specific geo-locations. Rural county level data were used to map the boundaries of the recruitment Area 313, located in North Central Florida (Figure 4-1). County data were mapped and visually compared with tract data but was not used to for comparative descriptive analyses due to the uneven regional disbursement of poverty and racial/ethnic groups (US DOA, 2018).

This study used several spatial data layers, including Area 313 county boundaries, census tracts, and participants’ tracts. These layers were used to visualize selected macro-components of rurality, demography and socioeconomic characteristics (i.e., poverty levels and ethnicity) (Higgs & White, 2000; Campbell, 2009). According to the 2018 Poverty Guidelines for the 48 Contiguous States and the District of Columbia, poverty was established at ($12,140) for a one-person household (Department of Health and Human services, 2018). Accordingly, as the sociodemographic GIS survey aligned with DHHS definition of poverty with a designated income level less than 15,000 considered poverty.

Further, respondents’ individual level socioeconomic characteristics were compared to tract spatial data for similarities and differences. In social network analysis, homophily can be related to availability of persons in one’s environment versus preferential inclusion (Borgatti et al., 2013). For example, residing in an area (i.e., rural community) with low population density influences the availability of persons who may comprise a personal network. Therefore, we compared levels of sociodemographic characteristics (i.e., participants’ level and tract level) to better understand the individuals’ physical environment.
Qualitative Data Analysis

Qualitative data were transcribed and analyzed using NVivo 11 software. Two reviewers free-coded initial themes then met to discuss and agree upon overarching themes. A consecutive review of thematic findings was performed. In this study, themes reflective of 1) mental health, 2) loneliness, or 3) rural environment were incorporated. Other broad themes and their impact to network connections are discussed in another article, to be published.

Results of Social, Geographic, and Loneliness Data

Descriptive Statistics and Regression Analysis

Of all participants (N=30), the largest proportion of the sample was between the ages of 50-60 years old, with 43.3% of persons living with HIV greater than 20 years. They were mostly males (70%); about half of total sample identified as homosexual 46.7% and heterosexual 46.7% and the majority (63.3%) completed high school. While 100% of participants were linked to care, 40% of them attended a formal HIV support group. Participants (N=30) had moderate loneliness, ascertained with the mean of 4.2 for the total loneliness score. Participants’ descriptive statistics are summarized in Table 4-1.

Structural network measures of each participant (N =29) network were calculated with averages taken of each measure (i.e., density, fragmentation, connectedness and degree centralization). One participant was not included in the social network analysis due to inability to complete the network questionnaire during initial interview and consecutive loss to follow up. Numerically, each structural measure was analyzed on a scale of 0-to-1 with a value closer to one reflecting and increased value of the variable. The mean score of 29 networks for each measure included density (.231),
fragmentation (.918), connectedness (.325), and degree centralization (.508). For each participant network, the average of the 20 alters’ were calculated in order to assess for homophily, these included: alters’ gender, race/ethnicity, and HIV status (Table 4-2). The results showed that homophily was ascertained between ego’s and their alters’ in regard to racial/ethnic background, though not due to gender, age or HIV status. The majority of study participants were unemployed and receiving federal funds for disability, thus we have a restricted view of persons who are employed.

A simultaneous regression model was performed to detect whether personal income, network density and alters’ HIV status could significantly predict loneliness. The results of the regression indicated that the model explained 19% of the variance and was a significant predictor of participant’s loneliness, F(3, 25) = 3.22, p = .040. Individually, participant’s income was the only significant coefficient that contributed to the model (β = -.575, p < .05). The coefficients with weighted values and significance are shown in Table 4-3.

**Rurality Mapping**

Area 313 was mapped with participants’ tracts highlighted (Figure 4-1). Block group data derived from the American Community Survey (ACS) were aggregated to portray county boundaries, demographic and socioeconomic data of participant tracts (US Census Bureau, 2016); see maps Figure 4-2 and Figure 4-3. Some tracts contain more than one participant within the outlined region. The population density per acre of the tracts, with majority of study participants concentrated in the denser areas of Alachua County (Figure 4-2). In part, this is due to study recruitment challenges with limited access to participants’ beyond Alachua County.
Demographic and socioeconomic descriptors of rurality for tract data within each county are showed in Figure 4-2. Of note, Alachua County had the highest density by persons per acre within Area 313 with majority of persons’ above poverty. Disproportionately, within the outlined tract areas in Alachua County there is a higher distribution of persons below poverty and of persons who identified as Black/African American (Figure 4-3). Immediately surrounding the highlighted Alachua County participant tract areas (neighborhoods), proportion of those living below poverty is less. From a socioeconomic perspective, this regional pocket of high level of poverty within Alachua County aligns with the Department of Agriculture’s data portraying pockets of rural poverty (2018). In this study sample, (53.3%) of participants’ income were less than 15,000 annually, this is not mapped in order to protect anonymity. Aligned with our sample racial/ethnic distribution Area 313 had the highest population of White/European Americans and Black/African Americans (Figure 4-3).

Overall, descriptive geographic data of participants’ surrounding physical environment provided context. A pattern was discerned between participants’ socioeconomic status with their neighborhood. Participants’ individual level of income corresponded to their (neighborhood) or tract data such that participants with an income less than 15,000 annually generally resided in an area where a majority of persons were also below poverty. Thus, if alters’ of respondent’s personal networks (including neighbors or family members) also reside in their neighborhood, regional geographic disadvantage may limit social capital exchange. Because direct inquiry of alters’ location was not asked in this pilot, we cannot validate this assumption.
Qualitative Results

Overall, results of qualitative interviews provided insight to participants’ social relations and loneliness. With a focus on 1) mental health, 2) loneliness, and 3) rurality, the following themes arose: 1) “lack of disclosure to the network,” 2) “fear of rejection,” 3) “living a double life” 4) “geographic relocation,” and 5) “lack of support” within their network. Aforementioned themes are presented as they relate to loneliness and stigma. Loneliness was described as the feeling of isolation; the desire to discuss their HIV with others non-biased persons’ yet due to potential perceived threat of rejection, majority of participants’ described their HIV as a “need to know matter.” More directly, some participants’ disclosed feeling “alone in their diagnosis,” which is reflective of perceived isolation due to their diagnosis.

Most participants identified a “lack of disclosure” to their network members due to anticipatory stigma and “fear of rejection.” Moreover, “living a double life,” emerged in several cases such that participants’ did not disclose their sexuality and/or HIV status to their network members. These participants verbalized feeling misunderstood, shame, fear of rejection and fear of social stigma surrounding their HIV and their sexual identity. A participant disclosed: “I am he and I am she, they don’t know that; I feel like they can’t handle that and will reject me.” Another participant disclosed: “My family knows I’m gay but it is seen as an abomination in our religion and some of them don’t even talk to me.”

Moreover, the desire for more support was evident in most narratives, whether for increased financial, emotional or health related support. Participants’ often viewed their network with the PI and when shown who provided support in their networks, they were in congruence with the network visualization findings. Some participants’ saw their network and stated they wish they had more people to talk to, call on when they needed
basic assistance such as a ride some place and to discuss their health concerns with. A participant stated: “When [alter name] and [alter name] are busy and I need help, I feel stuck and I don’t know who to call for assistance.”

**Integration of SNA, Qualitative and Loneliness Data**

The visualization of the egos’ network, dense versus fragmented, did not necessarily correspond with their perceived loneliness scores and qualitative description of their loneliness. For example, despite higher levels of density some participants’ described feeling lonely, the desire to discuss their HIV with more network members, and for more persons to provide instrumental and emotional support. In contrast, some participants’ with more fragmented networks described having enough persons they felt close to and could rely on with equivalent low total loneliness scores. Thus, network shape does not directly reflect OPLWH experience of loneliness.

Figure 4-4 is a case exemplar of a participant whereby their network visualization does not correspond with his objective or subjective loneliness. Contextually, this ego is a male in his 50s who has lived with HIV for 30+ years, identified as divorced and lived alone. His network visualization reveals one denser component of interconnected peers in addition to several alters’ not tied to the main network. The connected pair of alters’ (component) were identified as his health care providers to whom he always disclosed his HIV status to.

During the interview, the participant disclosed a significant history of mental health issues throughout his life. He was able to identify persons in his network to whom he relied on for emotional and mental health support. Regardless of peer support, he disclosed that he often felt very lonely, in part, due to significant loss of his former peer group due to HIV. Congruently, his overall loneliness score was (10), reflecting a high
level of loneliness. In this case, the participant contributed his loneliness to loss of his peers who were also HIV positive and a longstanding history of mental health issues. This information was elicited from the interview dialogue that would have otherwise not been known.

**Discussion of Social and Geographic Environments and Loneliness**

The first aim of this study was to evaluate the impact of OPLWH’s social environment on loneliness within the context of their geographic (neighborhood) environment. Measures of social environment, including income, density and alters’ HIV status were used in a regression analysis to determine their effect on OPLWH perceived loneliness. While 19% of the variance was explained by regression model with a significant value for personal income, network density and proportion of network persons (alters) living with HIV were not significant. Due to the nature of pilot studies, the sample size of this study was too small to infer or generalize these results to the larger population of OPLWH with a small sample and effect size (Polit, 2010).

Rather than generalizing, the intent of the first aim was to explore an uncharted area of research evaluating how the relationship of one’s social environment at the individual and interpersonal levels may impact loneliness for OPLWH living in rural areas. Studies focusing on social networks, social capital exchange and loneliness in older adults living with chronic disease (i.e., stroke, diabetes, peripheral vascular disease) have shown that limited instrumental support was associated with increased loneliness (Cacioppo et al., 2006; Pennix et al., 1999). In addition, a strong relation between respondents’ network density with loneliness have been demonstrated in college students (Berg & McQuinn, 1989; Stokes 1985). Thus, a replicative study
including a larger sample is recommended to capture whether network density relates to loneliness of OPLWH in rural communities.

Uniquely, results of the qualitative narratives provided contextual richness and explanatory power to participants’ experience of loneliness. While the overarching theme was stigma, intertwined themes included “lack of disclosure to network,” “fear of rejection,” “geographic relocation,” and “lack of instrumental support.” Participants often described having very few persons to discuss their HIV with and even fewer to whom they could rely on for instrumental support. Indeed, the sense of “lack of support” was related to a sense of loneliness. Additionally, the visualization and semi-structured interviews complimented each other well and permitted expansion of qualitative discourse.

Social gerontologists have presented that as adults’ age, network options evolve based upon life situations, such as health status (healthy versus frailty) and wealth status (low versus high income) (Adams & Blieszner, 1995). Thus, contextual factors and attributes of networks are important to investigate when establishing how networks provide various types of support. Descriptively, OPLWH networks were primarily composed of informal networks, including family, friends and church/religious affiliates, as evidenced in the literature (Fiori, Smith & Antonucci, 2007; Litwin, 2001).

The second aim of this study was to descriptively evaluate physical space by (neighborhood) or tract level data of OPLWH. This was performed by plotting participants’ geo-location, aggregating block level data derived from the US Census Berueu (2016) to the tract level to protect anonymity of participants, and by mapping regional statistics of participants’ neighborhoods. Geographic results revealed
participants’ personal socioeconomic status (SES) descriptively mirrored that of their immediate tract level (neighborhood) data. Although patterns were discerned between participant’s SES and neighborhood level conditions, we cannot surmise that geographic infrastructure and spatial proximity necessarily affects the formation of network composition or structure (Adams et al., 2012; Doriean & Conti, 2012).

From a social capital purview, we could infer that alters’ are a potential resource for social exchange made available through OPLWHs geographic space. Geographic findings supported that majority of participants’ were unemployed, receiving Federal disability funds, made less than 15,000 annually and living in neighborhood pockets with higher rates of proportion of persons living below poverty. Building upon this data, future studies with a focus on the symbiotic interaction between spatial data and social network data may be used to assess their impact on loneliness among OPLWH (Adams et al., 2012).

To date, studies have investigated health outcomes in relation to their physical environment (Mclafferty, 2003; Mao & Deng, 2018). Steptoe and Feldman (2001) found that those who resided in neighborhoods of lower, socioeconomic status had increased chronic stress and lower physical health ratings. Moreover, persons living with HIV face an additional layer of stress while living in rural areas due to stigma that may prevent them from utilizing their social ties for various forms of support, accessing local health services, or disclosing their HIV status (Groft & Vollman, 2007; Zhang et al., 2012).

There are limitations when interpreting results of this pilot study: 1) The sample size limited interpretation of statistical analyses of our regression model, 2) limited geographic distribution of study participants’, and 3) temporality of residential home
locations. Despite limited ability to generalize, the intent of this pilot study was to bring awareness to an understudied area of research. Uniquely, these findings portrayed that there is no universal way to analyze data and through combining methods, a broader view of the study question may be elicited.

In terms of geo-spatial analyses, geographic classifications of rurality by regional sociodemographic characteristics cannot fully conceptualize this phenomenon alone (Adams, Faust, Lovasi, 2012). Future research aims to explore how individuals’ experience rurality as they travel within and beyond their community, also known as activity-based modeling (Mao, Wang, & Deng 2018) which can be used to assess travel patterns of participants. Lastly, while assessing an individual’s geo-spatial rurality, temporality of participants’ residence should be considered. Because spatial data is a snapshot in time and does not account for participant’s geographic mobility or changing socioeconomic circumstances results should not be generalized longitudinally.

Although these limitations should be considered, they do not override the benefits that were gained from integrating methods. The results of quantitative and qualitative SNA data and of the visual representations of participants’ network and of their geographic space (neighborhood) were powerful. Not presented in the literature to date, the figures provide a formal illustration of and exclusive insight into the social and geographic environments in which OPLWH function. Acknowledging the role social and geographic environments have on overall health specifically, this pilot intended to bring a heightened awareness to this population and to the dynamic interactions of environment on loneliness among persons aging with HIV.
Further, the qualitative aspect of this study provided us an interpretive lens to better understand structural networks and physical environments of OPLWH living in Area 313. Ultimately, stigma, whether anticipated or internalized, was an overarching theme that contributed to lack of disclosure of participant’s HIV, fear of rejection, and self-shame. Networks were seen as both positive and potentially negative in this study. They were positive as they may provide various forms of support, including instrumental, emotional and health-related. The qualitative dialogue gave us a better understanding of the potential “harm” networks may have “if” one’s sexual identity or HIV status was discovered within their network, especially for those who were living “double lives” or with dense networks.

Uniquely, this study presented “who” makes up the network, “what” networks looks like, “how” persons perceive their social world and “how” they function within them, under “what” social conditions they function and “where” geographically these relationships occur and under “what” geographic conditions. The “why” of this study is demonstrated through rich qualitative themes and descriptions. For instance, OPLWH expressed “lack of disclosure” to their network persons due to “fear of rejection” and maintaining a “protective silence,” ultimately due to an overarching, yet implicit theme stigma. Future studies will aim to and further analysis of temporal content differences.

There are several areas that may be considered for future studies, including 1) use of a qualitative approach to investigate individual’s experience of rurality and 2) use of various statistical methods to integrate geographic data (i.e., tract statistics) with social network data (structural or compositional components) to further assess impact on loneliness of OPLWH. Several studies have attempted to incorporate spatial data as
covariates in statistical models for social network, quantitative analyses (Verdery, Entwistle, Faust, & Rindfuss, 2012), which may be considered. Investigating the interplay between environments is not simple, but through an interdisciplinary approach we were able to further portray the lived environments and the social functions of OPLWH networks.
Figure 4-1. Florida Area 313 counties and respondents' census tracts.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent of (n = 30) participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>50 – 60</td>
<td>60.6</td>
</tr>
<tr>
<td>61 – 70</td>
<td>26.6</td>
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<td>71 – 75</td>
<td>3.3</td>
</tr>
<tr>
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<td>3.3</td>
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<td><strong>Self-identified gender</strong></td>
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<tr>
<td>Female</td>
<td>30.0</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>50.0</td>
</tr>
<tr>
<td>Black/African American</td>
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</tr>
<tr>
<td>Pacific Islander</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Sexual Identification</strong></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>46.7</td>
</tr>
<tr>
<td>Homosexual</td>
<td>46.7</td>
</tr>
<tr>
<td>Pansexual</td>
<td>3.3</td>
</tr>
<tr>
<td>Other</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>30.0</td>
</tr>
<tr>
<td>Married/Committed relationship</td>
<td>43.3</td>
</tr>
<tr>
<td>Divorced</td>
<td>13.3</td>
</tr>
<tr>
<td>Widowed</td>
<td>10.0</td>
</tr>
<tr>
<td>Separated</td>
<td>3.3</td>
</tr>
<tr>
<td><strong>Years lived with HIV</strong></td>
<td></td>
</tr>
<tr>
<td>0 – 5</td>
<td>13.3</td>
</tr>
<tr>
<td>6 – 10</td>
<td>13.3</td>
</tr>
<tr>
<td>11 – 15</td>
<td>20.0</td>
</tr>
<tr>
<td>16 – 20</td>
<td>10.0</td>
</tr>
<tr>
<td>21 – 25</td>
<td>23.3</td>
</tr>
<tr>
<td>26 +</td>
<td>20.0</td>
</tr>
<tr>
<td><strong>Years Education completed</strong></td>
<td></td>
</tr>
<tr>
<td>High School (9th – 12th)</td>
<td>63.3</td>
</tr>
<tr>
<td>Associates degree (2 years college)</td>
<td>20.0</td>
</tr>
<tr>
<td>Bachelor’s degree (4 years college)</td>
<td>10.0</td>
</tr>
<tr>
<td>Graduate degree (6 years college)</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Estimated annual income</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 15,000</td>
<td>53.3</td>
</tr>
<tr>
<td>16,000 – 35,000</td>
<td>23.3</td>
</tr>
<tr>
<td>36,000 – 55,000</td>
<td>16.7</td>
</tr>
<tr>
<td>Greater than 56,000</td>
<td>6.6</td>
</tr>
<tr>
<td><strong>Attend HIV support group</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>40.0</td>
</tr>
<tr>
<td>No</td>
<td>60.0</td>
</tr>
</tbody>
</table>
Table 4-2. Average alter attributes derived from n=29 personal networks.

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Average Percent alters for 29 networks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>55.5%</td>
</tr>
<tr>
<td>Female</td>
<td>43.5%</td>
</tr>
<tr>
<td>Black/African American</td>
<td>45.7%</td>
</tr>
<tr>
<td>White/European American</td>
<td>47.9%</td>
</tr>
<tr>
<td>HIV Positive</td>
<td>8.8%</td>
</tr>
</tbody>
</table>

Note: Each personal network named 20 alters. The percent of each attribute was calculated for 20 alters’ in each network.
Table 4-3. Predictors of total loneliness of older persons living with HIV.

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>9.119</td>
<td>2.039</td>
<td>4.473</td>
<td>0.000</td>
<td></td>
</tr>
<tr>
<td>Ego Income</td>
<td>-1.545</td>
<td>0.499</td>
<td>-0.575</td>
<td>-3.094</td>
<td>0.005</td>
</tr>
<tr>
<td>Alter HIV</td>
<td>-2.461</td>
<td>4.817</td>
<td>-0.091</td>
<td>-0.511</td>
<td>0.614</td>
</tr>
<tr>
<td>Network Density</td>
<td>-7.888</td>
<td>5.322</td>
<td>-0.289</td>
<td>-1.482</td>
<td>0.151</td>
</tr>
</tbody>
</table>

Note: N = 29. Dependent Variable = Total loneliness
Figure 4-2. Maps of population density and percent population below poverty.
Figure 4-3. Maps of percent population by racial/ethnic distribution.
Figure 4-4. OPLWH network displaying disclosure, relationship type and persons discuss with when sad/depressed. Note: Shape type (circle – health care, square – neighbor, triangle – friend); color of shape (black – complete disclosure to white – nondisclosure); size of shape (degree of who ego discusses with when sad/depressed according to 5-point Likert scale – never, rarely, sometimes, most of the time, always).
CHAPTER 5
CONCLUSION

Discussion of the Non-Traditional Dissertation

The intent of this non-traditional dissertation was to: 1) explore and highlight the significant lack of literature of rural-dwelling OPLWH; 2) demonstrate the integration of mixed methods including, SNA quantitative and qualitative methods to investigate social relations and strengthen overall results; and 3) evaluate the impact of OPWLH social networks on loneliness within the context of their physical, rural environment. In this dissertation research methods were integrated at multiple levels of data collection, analysis, and interpretation by using convergent, mixed-methods design.

Article 1, Chapter 2. An integrative review of the literature was performed to evaluate for current studies focused on social networks of OPLWH living in rural and urban communities and the impact of their social relations (Gannon & Stacciarini, 2015). Initially, the purpose of the review was to highlight rural-based literature solely, but due to a significant lack thereof the investigation was expanded to incorporate urban areas. Overall, findings of current studies suggested that OPLWH were more likely to have fragmented networks, have lack of perceived social support, and experience layers of stigma and increased social reclusion. To our knowledge, no studies performed in the U.S. used network analysis methods to explore social structure and connections within networks. Further, few studies were rural focused. Of the rural based literature, rurality was discussed by means of socioeconomic challenges, including geographic isolation, lack of transportation and transportation services, and lack of health care services and HIV resources.
**Article 2, Chapter 3.** This chapter was a methodological presentation of convergent MMR design, integrating quantitative and qualitative approaches of social network analysis. It demonstrated that network visualizations are a structural representation of participants’ social world and may be used as a tool for semi-structured interviews and for validation of interpersonal relationships. According to the process of convergent design, integration of methods was implemented during data collection, analysis and interpretation of results. Through primary integration, analyses of quantitative and qualitative data were initially performed independently, followed by concurrent comparison for consistent versus contradictory findings and pursuit of explanatory influence.

Use of the network visualization as a qualitative tool enabled a therapeutic unfolding for participants and provided a greater understanding of interpersonal relationships and of social context. By integrating these methods we were afforded a more comprehensive perspective of OPLWH social relations and under what conditions they function. Though integration of mixed methods were labor-intensive, they were remarkably powerful as they added an interpretive richness to the data. Using a mixed methods approach, multidimensionality of social exchanges within interpersonal relationships and under what conditions was explored (Dominguez & Hollstein, 2014).

Case studies from a larger MMR study that employed this convergent MMR design were used to demonstrate the integration of selected methods. Findings of case exemplars revealed that networks of OPLWH living in area 313 were primarily composed of informal network members; network typologies included: 1) family/friend-centered network, 2) faith-based network, 3)
heterogeneous network, and 4) fragmented network. Homophily was represented in this study based upon ethnic/racial affiliation to the participants’. Comparatively, cases presented did not ascertain homophily relative to age of alters’ or by HIV status (Poindexter & Shippy, 2008; Emlet, 2006c).

Further, a 5-point Likert scale to measure social capital (i.e., types of support including emotional, instrumental, and health care related) was used in the personal network questionnaire to assess who provided the support and to what degree (i.e., always, most of the time, sometimes, rarely, never). Despite network type, receipt of emotional and instrumental support did not directly relate to trust or to disclosure of one’s HIV status. The qualitative component of this convergent design enabled exploration as to ‘why’ respondents’ chose to disclose to certain members in their network and not to others. Using the visualization, qualitative data was elicited from participants and themes such as anticipatory versus internalized stigma, and ‘taking on’ versus ‘moving beyond’ HIV were identified.

Uniquely, analyses of respective data types occurred independently, followed by concurrently. Consequentially, each dataset contributed a unique perspective and understanding to the networks of OPLWH, under ‘what’ conditions they function, and ‘how’ certain phenomena (i.e., stigma) contribute to their interactions within their networks. Meta-inferences were then created through integrating data based on network typologies and over encompassing themes that arose from mixing methods.

**Article 3, Chapter 4.** This chapter was a presentation of a pilot MMR aimed to: 1) evaluate the influence of participants’ socioeconomic and social
network variables on loneliness in OPLWH, and 2) describe the context of OPLWH physical environment (neighborhood) through comparison of U.S. Census based data with participant data. Using a multi-level social ecological framework for investigation, several recognized research methods rooted in sociology and geography were used to explore the participant’s social and geographic environment. Personal networks were created in EgoWeb then exported to UCINET and Netdraw to analyze and visualize structural and compositional components. Florida based, geographic county data was retrieved from the FGDL library and analyzed in ArcGIS ArcMap in order to map and compare with participants’ geo-location. Geo-spatial data was used to descriptively portray OPLWH’s physical environment based upon socio-economic status and racial/ethnic distribution. In addition, the De Jong Loneliness scale was used to evaluate loneliness from a social and emotional perspective, and was the dependent variable. A regression analysis was performed of network data to explore if network density and alters’ HIV status influenced loneliness.

Social network analyses revealed network typologies of OPLWH were comparable to current literature of aging adults, composed of family (kin), friends, neighbors, and faith-based community members (Fiori et al., 2006; Fiori et al., 2007; Litwin, 2001). Interestingly, health care personnel and social/case workers were rarely identified in the network though in several cases of those newly diagnosed they were. An open name generator was used to depict an unbiased representation of participants’ day-to-day network, also known as “core” network persons. Of this network, further questions of social capital receipt were asked. Findings revealed that most participants’ had low levels of instrumental support,
health support and emotional support. Those select members who were “trusted most,” often provided support. Discussion of one’s HIV status with network members did not directly correspond with high levels of trust of network persons in all cases.

Descriptive geo-spatial data were mapped to display physical (neighborhood) environments to which OPLWH live day-to-day. Components of rurality were described by participants’ income and racial/ethnic background. Tract level (neighborhood) data reinforced the existence of “pockets of poverty” and the racial/ethnic disparities within these neighborhoods. For example, Alachua County is predominately comprised of persons above poverty yet, tract areas of multiple participants’ highlighted a disproportionate rate of poverty and of persons who were Black/African American in these areas. This is important as it reinforces regional disparities within communities and counties, to which economic and health resources are to be distributed.

The results of the regression model explained 19% of the variance of OPLWH loneliness by the selected variables (income, alters’ HIV status and density). Importantly, the social network variables (alters’ HIV status and density) were not significant in bivariate analysis likely due the sample size of this pilot. Conditionally, results of this study do not explain a step-wise approach to how geographic and social environments may influence one another. Rather, this study descriptively portrayed participant’s neighborhoods as contextual factors. Evaluation of the relationship between or role of rurality with loneliness among persons aging with HIV may be explored in future research.
Qualitative data provided additional insight into social context beyond categorization of ego and alter-based attribute data (i.e., gender, age, educational status, years living with HIV, marital status and economic status). Qualitative results contributed to the “how” and under “what” conditions OPLWH function in their social environments. Such that, stigma was a prevailing yet discrete theme that heavily influenced how participants’ disclosed their HIV and portrayed themselves within their networks. Those who held “dual lives,” had higher loneliness scores and expressed increased loneliness despite being embedded in a denser network. Further exploration of stigma and loneliness of OPLWH in rural communities may be considered as part of a program of research.

**Contribution of Three Articles.** Overall, the three articles discussed within this non-traditional dissertation brought an increased awareness to a widely understudied population. This exploratory study employed innovative approaches to combining MMR in order to investigate the dynamic interaction between our social and physical environments. Through a social lens, networks were investigated structurally and expounded upon qualitatively. Through a geographic lens, rurality was descriptively analyzed by statistical discussion of demography, persons below poverty and racial/ethnic variation. This geographic lens intended to portray the disparities among geographic regions.

Results of this study demonstrated the symbiotic process of integrating methods enhanced the breadth of knowledge obtained from this research. Overall, this dissertation provides the foundation to understanding “who” comprise networks of OPLWH, structurally “what” networks look like, “how” egos’
perceive their networks and “how” they function within them, and in what physical space OPLWH live. Further, this study contributes to how individual and interpersonal factors contribute to loneliness of OPLWH.

**Dissertation of Limitations**

There are several limitations to note within this dissertation, including: 1) recruitment challenges, 2) small sample size, 3) limited alter size, and 4) temporality of residences.

**Recruitment challenges.** Due to limited access to the HIV community, sampling of participants was performed primarily by convenience and snowball methods. Although these sampling methods may introduce bias and limit generalizability of pilot results contextually, they were appropriate for targeting a protected, stigmatized population (Polit, 2010; Portney & Watkins, 2008). Moreover, all of the enrolled participants’ were linked to care, receiving medical and social supportive resources, which presents another sampling issue. Consequentially, those participants’ not linked to care or unaware of their status were not captured. As a result of limited access, recruitment of participants was conducted for approximately 12 months.

**Small sample size.** Although generalizability of quantitative results is limited with a small sample size, this pilot study serves as the foundation to better understand the structure and composition of networks of OPWLH and the impact of social relations with loneliness. Rather than aiming to generalize findings, this dissertation study serves to increase awareness to an understudied and vulnerable population of individuals who are rural-dwelling.
**Limited alter size.** Moreover, in order to prevent participant survey fatigue and cognitive burden the name generator was standardized to include 20 alters’. Prior to beginning the Personal Network Questionnaire, participants’ completed the Sociodemographic and GIS Survey and the De Jong Loneliness Scale. If a larger alter sample size was designated, this would have likely increased respondent burden. For example, using the name generator to elicit 45 alters, followed by name interpreter for 10 alter-based questions that are equivalent to 450 questions prior to completion of the name interrelater section (McCarty, Killworth & Rennel, 2007).

Study findings on the precise number of alters’ necessary to have a representative sample of the target subpopulation are contradictory (McCarty et al., 1997; Killworth, 1990). Importantly, due the nature of contextual differences across populations (i.e., sociocultural, economic, geographic, age, gender, disease, and profession) there may not be one universal numerical number of necessary alters (Killworth, 1990). Due to this variation among populations, contextual differences also merits exploration and are relevant to “why” networks are being studied. Because little is known of the actual structure and composition of networks of OPLWH living in rural or sub-urban communities, this exploratory pilot achieved the intended goal to obtain baseline data for a largely ignored research population.

**Temporality of residences.** Interpretation of geo-spatial descriptive statistics can be skewed by temporality of participants due to mobility and relocation of residences. For example, several participants’ were homeless or living in temporary housing situations. Thus, the temporality of participants’ geo-
location and analyses of spatial data must be considered when interpreting results of participants’ geographic location. Moreover, how participants’ travelled (i.e., mode of transportation), where participants travelled to and frequency of travel, were not yet analyzed in this study, rather macro-constructs (poverty and racial/ethnic distribution) were used to describe rurality of participants.

Aforementioned limitations warrant a more sophisticated design but they do not override the significance of the present study. This research is one of the first attempts to describe personal networks of persons aging with HIV using a social network analysis MMR. Combining methods opens new opportunities for understanding how social networks may facilitate social support and social capital. Further, combination of data collection and analysis approaches permitted exploration of participants’ social and geographic environment, contributing to a more holistic understanding.

**Directions for Future Research**

There are several areas for future studies that may contribute to a program of research. Formally, investigating the impact of one’s social and rural environment on OPLWH, incorporating: a larger sample size, transformation of data for secondary integration analyses, and expansion of qualitative interviews, may facilitate this area of research (Creswell & Clark, 2018). Widely understudied, OPLWH have unique structural network patterns that are influenced by the natural aging course in conjunction with living with a chronic, manageable but stigmatized illness (Emlet, 2006a; Fiori et al., 2006; Fiori et al., 2007; Groft & Vollman, 2007; Shippy & Karpiak, 2005). Further investigation of how one’s physical environment may further contribute to network composition
and structure of their networks and overall impact to mental well-being and loneliness is crucial.

In describing networks of OPLWH, this exploratory study generated typologies to assess for patterns in structural and compositional measures. Contributing to a program of research, additional analyses may be expanded to explore racial/ethnic differences among OPLWH typologies and of health outcomes (i.e., loneliness). In comparing racial/ethnic differences of older adults, (Ajrouch, Antonucci, & Janevic, 2001) found that Black/African Americans had smaller networks, with increased proportion of family members and increased communication with network members than their White/European American counterparts. Incorporating an ethnographic approach to compare differences and similarities among ethnic and cultural groups could be crucial to expanding our knowledge of the relation between intrapersonal, interpersonal and geographic characteristics among older persons living with HIV.

In addition, support networks of vulnerable populations have been described as expectedly different based upon the population of interest and the nature of vulnerability, which should be accounted for when making care based decisions (Grant & Wenger, 1993). Adults aging with HIV are a unique, vulnerable population as stigma is pervasive and repercussions of stigma have been found to impact mental health outcomes (Rueda et al., 2016), linkage to and continued care (Bauman et al., 2013; Dombrowski, Simoni, & Katz, 2015), and detrimental effects to social engagement (Poindexter & Shippy, 2008; Vance et al., 2011). In this study, stigma, whether internalized or anticipatory, was described as a barrier to HIV disclosure, self-shame, and fear of rejection. The
role of environmental influence, including rurality, may be explored in future studies as it relates to disease related stigma.

In evaluating loneliness, this study utilized the De Jong Loneliness scale served as a measure of quantification. Although reliability and validity has been established for this instrument, investigation of loneliness using qualitative methods can add to our understanding of the experience and impact of loneliness for OPLWH residing in rural communities. For instance, consecutive research may consider interviewing participants’ after completion of network studies and inquire whom they may call when they are lonely, if their physical environment or other factors contribute to their feelings of loneliness.

Lastly, descriptive analysis methods were used to describe geo-spatial data of OPLWH physical environment and to portray tract level statistics. Future research may include assessment of respondents’ travel patterns and roadway distribution in attempt to further define rurality (Mao et al., 2015). For example, if our sample was larger with a broader distribution of participants across area 313 calculation of a rurality index would have been feasible. Moreover, with a larger sample statistical analyses may be performed to determine further correlational value between network size and strength of ties in relation to loneliness.

Implications Nursing Research

The use of mixed methods is becoming increasingly widespread across disciplines, including nursing. Although nursing science has employed combination of quantitative and qualitative methods, partnering with interdisciplinary team members to explore additional methods for investigation is imperative for developing as a novice researcher. Because there is no single way
to explore phenomena, especially in human based science, integration of methods is necessary to achieve accurate and robust results.

The initial intent of this study was to evaluate how OPLWH social network’s and geo-spatial data were inter-related and may relate to loneliness. Results of primary integration of qualitative and quantitative methods were very rich and future endeavors may include pursuit of secondary integration methods. In general, secondary integration includes transforming the results from one of the datasets into the other type of data, analysis of transformed data and advance interpretations of how this new dataset contributes to the study inquiry (Creswell & Clark, 2018). By transforming further, social phenomena such as social capital and rurality may be used in analyses to contribute to a body of literature of OPLWH.

Overall, the process of integration is important in exploring new constructs, identifying potential relationships and contradictory findings, and in validating current studies. Because systematic integration of data takes significant time and effort, forming a research team with similar goals from various disciplines can further enrich study approaches and provide alternative perspectives.

Implications for Clinical Practice

Understanding that multiple factors may be related to health outcomes of OPLWH is imperative to clinical practice. OPLWH are the fastest growing population of current persons living with HIV; as this cohort continues to grow successful aging with HIV is the goal. Beyond physical health, successful aging entails mental well-being and quality of life (CDC, 2009). Screening for,
diagnosing, and managing HIV is not the only task when working with patients who are aging with HIV. Beyond medical management of the virus, clinicians must acknowledge the dynamic interactions of social and geographic factors that may influence OPLWH's care and their mental well-being. Thus, this study aimed to portray how one's social environment may influence loneliness and how geographic environment may influence the experience of aging with HIV in area 313.

Results of geo-spatial data for Alachua county revealed that despite higher levels of density, there were concentrated “pockets of poverty” or areas of socioeconomic disparities. Notably, these areas also had higher concentrations of Black/African Americans and higher proportion of persons living below poverty. Understanding participant’s socioeconomic and environmental circumstances allows clinicians to additionally screen for external stressors (i.e., personal safety and financial circumstances) and extend available, supportive services (i.e., provision of free medication and housing assistance). Moreover, evaluating data by more intimate geographic units (i.e., tract level) statistics we are able to critically evaluate neighborhood-level, community needs and better allocate services to these regional areas of higher need.

Understanding the role stigma may play in an individual’s life and resultant lack of disclosure is essential for clinicians to promote well-being. Participants’ of this study described a sense of appreciation in the ability to discuss their HIV openly with the researcher. For persons who do not self-disclose to family and friends, the clinician may take on the role of “listener” or as a “mediator” if the patient desires assistance with disclosure. As an active listener, the health care
clinician may extend himself or herself to assist patients in an emotional unfolding. Through this process, providers may also identify mental health concerns as they relate to one’s HIV or otherwise. As a mediator, the clinician can assist in the disclosure process and provide face-to-face education with the desired network persons. Nonetheless, engaging patients in topics surrounding their HIV outside of their treatment and immune function status can serve as a therapeutic outlet for some persons.

**Summary**

In summary, this dissertation attempts to show the integral need to explore how contextual social and physical environments of OPLWH are related health outcomes. Nurses, community health workers, and social services are the frontline in working with patients and adults aging with HIV in the community. With knowledge of the potential relationship one’s social and physical environment can have on health outcomes, scientists should acknowledge and utilize various approaches in consideration of this relationship. Overall, it is essential that current research reflect the need of OPLWH and of their environment, in order to facilitate knowledge growth and policy change.
Seeking Participants for Interview Research Study

Do you have a story about living with HIV age (50) and above?

Researchers at the University of Florida are trying to understand social networks and networking of individuals aging with HIV, age (50) and above. From this research, we hope to better understand positive and negative contributors of networks of those living with HIV. This research will involve a 2-hour interview with a nurse researcher. We are specifically seeking:

- Persons aging with HIV age 50 and above living with HIV who are willing to discuss their social networks: family, friends, community and so forth.

All information discussed in the interviews is confidential. There are no direct personal benefits to participation.

**Study Title:** Social Networks, Social Capital and Loneliness of Older Persons Living With HIV

For more information, please contact Brittany Gannon, at 954-609-4352.
APPENDIX B
SOCIODEMOGRAPHIC AND GEOGRAPHIC INFORMATION SYSTEM SURVEY

Date: ____________________ Time: _______________________

Interviewer: _______________________

The survey is only for members who are living with HIV over the age of 50. Your participation is completely voluntary. You can refuse to answer any question that you don't want to answer. Your identity will remain confidential. The questionnaire is completely anonymous. Your participation, as well as answers to specific questions, will not in any way affect your services. Please answer the following questions as best as you can.

Section 2: Personal information

1a. What is your self-identified gender?
   □ Male
   □ Female
   □ Trans-male
   □ Trans-female
   □ Other, please specify

1b. What age are you?

1c. What is your sexual orientation?
   □ Heterosexual
   □ Homosexual
   □ Bisexual
   □ Pansexual
   □ Other, please specify

1d. Where is your current residence located?
   Place ID | Latitude | Longitude
   1
   2

1e. How many people live in your home?

1f. Who do you live with?
   □ Spouse/significant other
   □ Friend(s)
   □ Parent(s)
   □ Extended family
   □ Other, please specify
Section 2: Family structure
2a. What is your current marital status?
☐ Single
☐ Married or living together (in a committed relationship)
☐ Divorced
☐ Widowed
☐ Separated

2b. Do you have children?
☐ No
☐ Yes, their ages are: Boys _____________
☐ Girls _____________

2c. Do you have friends or relatives that live close by?
☐ Yes
☐ No

2d. If answered yes, who are they (e.g. sibling, friend, etc.)?__________________________

2f. Do you visit them?
☐ Yes
☐ No

2h. If you answered yes, please fill in the following information for each friend or relative listed

<table>
<thead>
<tr>
<th>Place ID</th>
<th>Latitude</th>
<th>Longitude</th>
<th>How do you get there?</th>
<th>How long does it take you to get there (minutes, hours)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td>(a) Own Car</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td>(b) Walking</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(c) Ride</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(d) Other (specify)</td>
<td></td>
</tr>
</tbody>
</table>

2i. How often do you visit friends or relatives?
☐ Every day
☐ Every week
☐ Once a month
☐ Every other month
☐ Here and there
☐ Once a year
☐ Never visit anyone

Section 3: HIV/AIDS Focused Questions
3a. How long have you been living with HIV?
☐ 0 – 5 years
☐ 6 – 10 years
☐ 11 – 15 years
☐ 16 – 20 years
☐ 21 – 25 years ☐ 26 + years
3b. Are you currently accessing health care services for your HIV (i.e., medications)?
□ Yes
□ No

3c. If you answered yes, please fill in the following information for each health care facility you receive HIV specific care from:

<table>
<thead>
<tr>
<th>Place ID</th>
<th>Latitude</th>
<th>Longitude</th>
<th>How do you get there?</th>
<th>How long does it take you to get there (minutes, hours)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3d. If you answered yes to 3c, please specify why you receive HIV care from this facility:
□ It is convenient/close by
□ I like the medical staff at the facility
□ I do not feel judged/discriminated against at the facility
□ No particular reason
□ I do not want to go to my local facility; if yes, please specify why

3e. If you answered no to 3c, please specify why you do not receive HIV care services at this time:
□ I do not know where to seek HIV care
□ I do not like the medical staff
□ I feel or anticipate feeling judged/discriminated against
□ I do not have transportation to and from a health care facility for HIV care
□ I do not want my family or friends discovering my HIV status

3d. Do you go to or attend any HIV support group service?
□ Yes
□ No

3e. If you answered yes to 3d, please fill in the following information for each HIV support group you attend:

<table>
<thead>
<tr>
<th>Place ID</th>
<th>Latitude</th>
<th>Longitude</th>
<th>How do you get there?</th>
<th>How long does it take you to get there (minutes, hours)?</th>
</tr>
</thead>
<tbody>
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</table>
3f. If you answered no to 3d, please select or explain why you do not attend an HIV support group:
□ I do not know of any local HIV support groups
□ The group is too far to travel to
□ My family are my support
□ My friends are my support
□ I do not need a support group
□ I am afraid to discuss my HIV
□ Other, please explain: ________________________________

Section 4: Education History
4a. How many years of formal education have you received (How many years did you attend school)?
□ Kindergarten – 5th grade
□ Middle school (6th – 8th)
□ High school (9th – 12th)
□ Associates degree (2 years college)
□ Bachelor’s degree (4 years college)
□ Graduate degree (4 years college)

Section 5: Employment & Financial status
5a. What is your total estimated annual income?
□ Less than 15,000
□ 16,000 – 35,000
□ 36,000 – 55,000
□ 56,000 – 75,000
□ 76,000 – 100,000
□ Greater than 100,000

5b. Are you currently employed?
□ Yes
□ No

FOR RESPONDENTS WHO ARE WORKING (YES TO QUESTION 5B):
5c. In what capacity are you employed?
□ Employed full-time at one job (30 hours/week or more)
□ Employed part-time at one job (less than 30 hours/week)
□ Employed part-time at more than one job (30 hours/week or more)
□ Employed part-time at more than one job (less than 30 hours/week)
□ Self-employed
□ Other: ________________

5d. What are you currently doing? ______________________

5e. How long have you been at your current place of employment?
□ Less than one month
□ Less than one year
□ 1-2 years
□ 2-5 years
□ More than 5 years
5f. If you answered yes to 5b, please fill in the following information for your place of employment. Note: location zip codes (ex. 32608), and/or nearest road intersection OK.

Where is the facility located? (Please identify the location on the Google Earth and ask a student to help you fill out) | How do you get there? | How long does it take you to get there (minutes, hours)?
---|---|---
| Place ID | Latitude | Longitude | (a) Own Car | (b) Walking | (c) Ride | (d) Other (specify) |
| 1 |  |  |  |  |  |
| 2 |  |  |  |  |  |

**FOR RESPONDENTS WHO ARE NOT WORKING (NO TO QUESTION 5B):**

5f. Which of the following best describes your situation:
- Unemployed, currently looking for job
- Unemployed, not currently looking for job
- Full-time student, so I’m unable to work
- Unable to work for another reason: ____________________________
- Full-time home

5g. How long has it been since you were last employed?
- Less than one year
- 1-2 years
- 2-5 years
- More than 5 years
- Never worked
- Retired
Section 7: Places and Transportation

7a. Please list the places (except for home and workplace) where you have been in the past month. For each place you have been, please fill in the following information:

<table>
<thead>
<tr>
<th>Place ID</th>
<th>Latitude</th>
<th>Longitude</th>
<th>Name of place</th>
<th>How do you get there?</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>(a) Own Car</td>
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<td>(b) Walking</td>
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<td>(c) Ride</td>
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<td>(d) Public transit</td>
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<td>(e) Other</td>
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<td>How long does it take you to get there? (minutes)</td>
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<td></td>
<td>How often do you go there?</td>
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<td></td>
<td>(a) Every day</td>
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<td></td>
<td>(b) Every week</td>
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<td></td>
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<td></td>
<td>(c) Once a month</td>
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<td></td>
<td>(d) Every other month</td>
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<td></td>
<td>(e) Here and there</td>
<td></td>
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<td></td>
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<td></td>
<td>(f) Once a year</td>
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<td></td>
<td>Who do you go with?</td>
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APPENDIX C
PERSONAL NETWORK ANALYSIS QUESTIONNAIRE

Name Generator – Alter Naming
1. Please list the first initial and last name of 20 people that you know and who know you, with whom you have had some contact in the past two years (face-to-face, by phone, or by the Internet), and whom you could still contact if you needed to. NOTE: You may use an alternative name to preserve confidentiality of identified person(s).

Name Interpreter - Questions About the Participants’ Network
The following are questions asked about each person that the participant listed

1. What is the gender of this person?
   A. Male
   B. Female
   C. Trans-male
   D. Trans-female
   E. Other, please specify

2. Approximately how old is this person?

3. Does this person also have HIV?
   A. Yes
   B. No
   C. Don’t know

4. What type of relationship do you have with this person?
   A. Immediate family
   B. Extended family
   C. Significant other/partner
   D. Work related
   E. Religious related
   F. Neighbor
   G. Health care related
   H. Other, please specify

5. Where or how did you meet this person for the first time?

6. What is the ethnicity of this person?
   A. White/Caucasion
   B. Black/African American
   C. Hispanic/Latino
   D. Asian
   E. Other, please specify

7. How do you mostly contact this person?
   A. In person
   B. By phone or texting
   C. Online (email, facebook)
   D. Other, please specify
8. How often do you usually communicate with this person?
   A. Once a year or less
   B. Few times a year
   C. Monthly
   D. Weekly
   E. Daily

9. How much do you trust this person?
   A. Not at all
   B. A little
   C. Moderately
   D. Quite a bit
   E. Very much

10. Do you contact this person when you have a health-related problem?
    A. Never
    B. Rarely
    C. Sometimes
    D. Most of the times
    E. Always

11. Do you contact this person when you have a financial problem?
    A. Never
    B. Rarely
    C. Sometimes
    D. Most of the times
    E. Always

12. Do you contact this person when you need medical advice?
    A. Never
    B. Rarely
    C. Sometimes
    D. Most of the times
    E. Always

13. How does this person help you?
    A. Financial support
    B. Emotional support
    C. Spiritual support
    D. Spends time with you
    E. Practical support (gives rides, pet sits, fixes things, etc.)
    F. Other

14. Do you ever talk to this person about your HIV positive status?
    A. Never
    B. Rarely
    C. Sometimes
    D. Most of the time
    E. Always
15. Do you talk to this person if you are feeling sad or depressed?
   F. Never
   G. Rarely
   H. Sometimes
   I. Most of the time
   J. Always

Name Interrelater - Questions about pairs of contacts in network
This question is asked about every possible (non directional) pair of contacts.
1. What is the likelihood that X and Y talk to each other independently of you? If they
   would only talk in your presence then your response should be “Not at all likely”. If
   you know that they talk when you are not around them, then your response should
   be “Very likely”. If it is possible but you are not sure then your answer should be
   “Maybe”.
   A. Not at all likely
   B. Maybe
   C. Very likely
# APPENDIX D
## DE JONG LONELINESS SCALE

Date: __________ Time: __________ Participant: ____________________________

Please indicate for each of the statements, the extent to which they apply to your situation, the way you feel now. Please circle the appropriate answer. Answer categories ("yes!" "yes," "more or less," "no," and "no!" or "yes," "more or less," and "no")

1. There is always someone I can talk to about my day to day problems.

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<tbody>
<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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2. I miss having a really close friend.

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<tbody>
<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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3. I experience a general sense of emptiness.

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<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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4. There are plenty of people I can rely on when I have problems.

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<tbody>
<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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5. I miss the pleasure of company of others.

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<tbody>
<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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6. I find my circle of friends and acquaintances too limited.

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<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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7. There are many people I can trust completely.

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<tr>
<td><strong>Yes!</strong></td>
<td><strong>Yes</strong></td>
<td><strong>More or less</strong></td>
<td><strong>No</strong></td>
<td><strong>No!</strong></td>
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8. There are enough people I feel close to.

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<th></th>
<th>Yes!</th>
<th>Yes</th>
<th>More or less</th>
<th>No</th>
<th>No!</th>
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</table>

9. I miss having people around.

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<th>Yes!</th>
<th>Yes</th>
<th>More or less</th>
<th>No</th>
<th>No!</th>
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10. I often feel rejected.

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<th>Yes!</th>
<th>Yes</th>
<th>More or less</th>
<th>No</th>
<th>No!</th>
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11. I call on my friends whenever I need them.

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<th></th>
<th>Yes!</th>
<th>Yes</th>
<th>More or less</th>
<th>No</th>
<th>No!</th>
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APPENDIX E
REFLEXIVE STATEMENT

Formally, acknowledging that one’s presumptions and beliefs may impact study investigation methods, content analysis, and overarching research results is important to acknowledge both in conducting qualitative and quantitative research.

Contextually, I was propelled to do Human Immunodeficiency Virus (HIV) research after an experience I had caring for a geriatric patient with AIDS related dementia. At the time I was a fairly new Registered Nurse (RN) with little exposure to persons living with HIV that had progressed to Autoimmunity Deficiency Syndrome (AIDS). While under my care, I witnessed her family and friends surround her at the bedside as she was in a completely non-responsive state. The room was vibrant; filled with family, friends and faith-based community persons with audible gospel music playing in the background and pictures placed throughout the room.

After several days off, I was advised during nursing shift report that the patient was now alone in her room. My fellow nurse disclosed that a medical doctor in training inappropriately disclosed that the patient had AIDS dementia to her family without the patient’s consent. Her family was unaware of her HIV status; unknown is whether she knew of her HIV status. After the disclosure, her prior visitors, the music, and the pictures were gone, leaving the medical supplies only. There was no gospel music and no persons in the room with the patient.

This was my first time witnessing stigma. This was also my first experience witnessing abandonment by her social network due to an inappropriate disclosure of her HIV/AIDS. I was shocked. Empathetically, I was hurt and sad. I didn’t understand how
her personal network could abandon her and I was curious what their knowledge of HIV/AIDS was.

During this shift my fellow nurse technicians, persons who assist in provision of bathing, feeding and bathroom assistance, demonstrated stigma. While preparing to enter the patient’s room, I noticed the nurse technicians applying a protective gown, gloves, face mask and eye wear. When I asked why they were applying full protective layering for vital signs, the response was “because she has HIV.” To which I responded, “yes but this virus is transmitted through blood or sexual contact and with normal body contact they could not be infected.”

This experience struck me. I realized layers of issues. I witnessed stigma, lack of education regarding HIV and lack of permission to disclose one’s HIV status. I set out on my mission to research HIV, current advancements, issues, and up to date literature on the topic. Through this, I identified a gap including evaluation of persons living with HIV who were 50 and above living in rural areas. I chose to select rural communities based upon my experience working as a Research Assistant (RA) with my mentor with a focus on rural Latino mental health and well-being.

Lastly, I chose to pursue the conceptual framework of “social network research” after witnessing my patient’s network dissipate after discovering her HIV status. I desired to explore how one’s “perceived closest” network persons and support persons could abandon their family member. I acknowledge my personal experience frames the way I perceive stigma, disclosure and abandonment.


EgoWeb (Version 2.0) [Computer software]. http://github.com/qualintitative/egoweb


ESRI. ArcGIS ArcMap (Version 10.5) [computer software]. Redlands, CA.


NVivo qualitative data analysis (Version 10). [Computer software]. QSR International Pty Ltd.


BIOGRAPHICAL SKETCH

Brittany Gannon obtained her Doctor of Philosophy in Nursing Sciences in August 2018 from the University of Florida. During her studies, Brittany obtained her Master of Science in Nursing in 2015 and became a board certified Primary Care Adult-Geriatric Nurse Practitioner. After graduation, she worked as a nurse practitioner with the Department of Hepatology and was responsible for caring for patients with various liver diseases. Prior to 2015, she worked as a Registered Nurse (RN) with her Bachelor of Science in Nursing (BSN) at UF Health on a Medical-Surgical Unit. She obtained her bachelor’s degree from the University of Florida, College of Nursing Program in 2012 and graduated with honors.

She developed a passion for infectious disease, stigmatized populations, and rural and community health during her time in her graduate studies and while working with disenfranchised populations. She gained experience working with underrepresented populations and rural-based mental health outcomes during her employment as a Research Assistant (RA) with her mentor. Throughout her studies, she also retained active membership in several nursing organizations, including Southern Nursing Research Society (SNRS) and Sigma Theta Tau International Honors Nursing Society. She was passionate about disease related stigma and was engaged in the HIV community as a volunteer, advocate and researcher by attending local HIV support group meetings regularly. She presented several posters of her dissertation work at multiple conferences, including the SNRS annual conference, STTI International Research Congress and at University of Florida’s Graduate Student Research Day.