


Not Immune: A Research Plan for Better Understanding the Lived Experiences of HIV-Positive Women Age 50 and Older

By

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Abstract

Background:

This paper describes a literature review of peer-reviewed articles researching specific stressors, coping strategies and self perceived quality of life among HIV positive women age 50 and older. Following the literature review, a research plan for a qualitative study aiming to investigate these issues is explained, including preliminary data.

Methods of Research Project:

Qualitative in-depth interviews are being conducted among HIV-positive women age 50 and older who are current patients in the UNC Infectious Diseases Clinic. Interviews are tape-recorded, transcribed and coded by the primary investigator. Analysis for emergent themes is conducted following a grounded theory research approach.

Results:

Analyses on the first five interviews highlight important considerations for the remainder of the study. Issues regarding HIV status disclosure, the perceived lack of public acknowledgement regarding risks among older women, and the importance of individual faith as a coping strategy are common themes in the interviews.

Conclusion:

Completion of the study will continue to explain and characterize the preliminary results, and may point to previously unestablished means by which to approach and provide for this particular population.

Introduction

As the “baby-boomer” population in the United States continues to age, requiring a focused response on behalf of medical and service providers, specific knowledge regarding the needs of HIV-positive women age 50 and older is an important consideration. Historically, this population has not been involved in research or targeted prevention/education endeavors and, as such, little is known regarding the specific social stressors and coping strategies encountered by these women. Without this knowledge, it is impossible to evaluate how current models of assistance (community case workers, financial assistance organizations, support groups, etc.) appropriately respond to and serve their needs.

I preformed a literature review of relevant studies addressing these issues as well as programs aimed at developing more appropriate models for prevention, education and care. In collaboration with an Infectious Diseases attending physician, Kristine Patterson, MD and an epidemiologist, Sonia Napravnik, PhD, I then developed and initiated a qualitative research among women age 50 and older enrolled in the University of North Carolina Hospitals Infectious Diseases Clinic designed to further characterize the women’s lived experiences. We aim to utilize this data for hypotheses generation in future studies; in addition to creating

focused prevention messages and care/support frameworks appropriate for this specific population. This paper reflects the work-to-date, including background research, a review of the literature, the research project plan and preliminary results from the first five interviews.

Women and HIV

In 2004, women accounted for 30% of the reported HIV incidence and 27% of newly diagnosed AIDS cases in the United States, an increase of approximately 20% since 1985^{1,2}. Unlike trends observed early in the epidemic, in which most HIV cases in women occurred among users of injection drugs in the urban Northeast³, a large percentage of transmission to women now occurs via heterosexual exposure. Data from the 2004 CDC surveillance study reported that at least 45% of women contracting the virus that year acknowledged a heterosexual exposure to an individual at risk for HIV¹. However, this number is likely underestimated, as it may not have included women exposed through heterosexual contact with an individual of unknown, or presumed non-existent, risk. In North Carolina, specifically, 28% of new HIV/AIDS cases in 2004 were among women. Furthermore, the associated infection rate was 14 times higher among African-American women compared to Caucasian women, a disparity that merits specific attention^{4,5}.

Following initial acknowledgement and concern regarding the increasing prevalence of HIV among women, and the altered transmission risks, prevention strategies and research of effective therapeutics have traditionally targeted

younger populations of women. Substantiated by data reflecting that between 26% and 50% of all heterosexually acquired cases of HIV are among teenagers and young adults (< 24 years of age), such targeting is valid and necessary ⁶. Additionally, as early advances in the prevention of mother-to-child transmission and the subsequent dramatic effects associated with targeting women in pre-natal clinics became evident, further attention has been granted to women of child-bearing potential. While these focused interests are appropriate, they unfortunately neglect the specific needs of, and potential areas of prevention for, the sub-population of women age fifty and older.

HIV among older adults in the United States

Epidemiology

Each year, adults 50 years of age and older comprise approximately 11% of all reported AIDS cases in the United States ¹, and as of 2000, has become the fastest growing population of individuals affected by HIV/AIDS ⁷. This number is secondary to the increasing survival of individuals with HIV in addition to incident cases occurring in the older populations. With regard to the later cause, specifically since 1993, this age group has experienced a 13.8% increase in incidence of HIV⁷. Women in this population comprise about 40 percent of the HIV positive population over 50⁸, and ten percent of the AIDS cases diagnosed in adult women in the United States, 32% of whom are diagnosed after age 59 ⁹. These women follow similar trends to those seen in other groups of HIV positive individuals. Specifically, the incidence of HIV and AIDS is higher among

African-American women, accounting for 50% and 65% of cases in older women, respectively ⁷, and the majority of cases resulted from sexual transmission⁹.

Overlooked Risk Factors

Despite these statistics, research has been slow to acknowledge the effects of HIV on this population or to include older women in targeted study populations, primarily under the belief that such women do not engage in sexual activity outside exclusively monogamous relationships and do not engage in the use of injection drugs¹⁰. However, even as early as 1992, one study among non-infected women from 40 to 75 years of age, found that 8% of participants had at least one risk factor for HIV¹¹. According to 2000 census data, this would translate to approximately 4.3 million American women who are at risk for contracting HIV⁹. The high number of older women at risk is most likely secondary to two factors: 1. sexually active older women consider themselves to be at little risk for acquiring HIV, and may participate in high risk activities without concern for potential repercussions ⁷; and 2. prevention/educational efforts are not specifically targeted to this population.

Condom Use among Women over 50

People over 50 tend to use condoms less frequently than younger adults with similar sexual behaviors (one sixth as likely)^{12, 13}, and are one fifth as likely to have been tested for HIV¹³. A study conducted by the CDC in 1996 found that, compared to younger women, women age 50 or older with HIV were more likely

to have never used a condom before HIV diagnosis (63% vs 37%)¹⁴. Postmenopausal women may be physiologically more susceptible to infection due to atrophic changes in the vaginal mucosa, posing further risks when coupled with lack of regular condom use. Yet, a woman's motivation to use barrier contraception may be diminished by the absence of concern for potential pregnancies¹⁴. Even if women wish to use condoms, their partners may disagree with their arguments or perspectives. In many retirement communities and social centers frequented by older adults, women generally outnumber men. Women in such settings, where the increasing gender gap limits their selectivity with regard to sexual partnerships, may fear offending a potential male companion and forego any discussion of condom use^{15, 16}.

Risk Perceptions: Where are We Going Wrong?

The Knowledge Deficit

Compounding women's self-perception of risk is the lack of prevention and education methods specifically designed to target older women, leading to a substantial deficit in HIV knowledge within this population. Numerous studies have demonstrated that older adults generally possess less knowledge with regard to HIV transmission and prevention compared to younger counterparts^{9, 17-19}, with older African-American and Latino women scoring the lowest on knowledge assessments²⁰. This deficit undoubtedly contributes to a lack of awareness regarding personal risks for HIV, protection strategies and delayed access to appropriate medical care²¹.

Hesitancy in Diagnosis

Delay of induction into appropriate HIV-related care among older individuals has also been linked to the hesitancy of health care providers to elicit sexual histories and/or recommend serologic testing for HIV, attributing early symptoms of HIV to “normal” changes in the geriatric population¹⁵. Even after appropriate diagnosis and care referral, older women are at increased risk for non-compliance with appointments and medications, primarily due to the unique roles women serve in society, as well as the association between activities evoking a “high-risk” status and lived situations involving poverty, violence and/or inadequate social support structures²². Whether such experiences and perceptions directly contribute to decreased quality of care and access to antiretroviral medications is an important aspect of consideration.

Initial Steps

Targeted education, screening and intervention strategies can be more appropriately developed if we acquire a better understanding of how women age 50 and older respond to and experience living with HIV.

Review of Current Literature

I initiated a review of the literature to better understand the lived experiences- including stressors, coping strategies, and influences on self-perceived quality of life among HIV-positive women age 50 and older.

Subsequent to the paucity of studies specifically dealing with older women and HIV, the literature review was extended to examine these factors among all HIV-positive women.

Literature Search

I searched MEDLINE/PubMed, Expanded Academic ASAP, and ISI Citation Databases (Web of Science) to identify relevant articles, including the terms: HIV, older women, postmenopausal, quality-of-life, psychosocial stressors, coping, support networks, social stigma, and status disclosure. Initially limiting our search to articles published in English after 1990, the search generated over fifty unduplicated articles. Reviewing the initial abstracts, we excluded articles that focused on pathophysiological aspects of HIV-positive women. While this is an important aspect of living with HIV, I was primarily concerned with the experiences of women within their social environments, outside the physicians' offices and separate from the physiological responses to HIV and its related treatments. Additionally, I excluded those studies involving both women and men as participants to allow for exploration of social experiences specific to women. Also excluded were review articles, editorials, and studies based on theoretically based causal models. As our research question is conducive to triangulated inquiry, I included studies using a variety of qualitative methods as well as descriptive and quantitative analyses. My criteria resulted in eight studies, detailed in Table 1^{8, 23-29}. Among the included studies, two are of cross-sectional design, three are case-series and three used qualitative methodologies.

Internal Validity of Reviewed Literature

I assigned quality ratings for each of the eight articles, based on scores (poor, fair, good, excellent) for categories appropriate to the research design. Specific criteria for the ranking process, based on research methodology, are included in the following sections and final categorical scores are included in Table 1.

Quantitative Ratings

The quantitative studies were reviewed for appropriateness of sampling strategy, measurement methodologies, statistical analysis and clinical relevance of results. Evaluation of the sampling strategy was based on the inclusion of a clear description of an appropriate source population, and the selection of a study population that was adequately representative of that source population. Methods of data measurement were based on reliability and validity of specific tools used and statistical analysis was evaluated for awareness and control for potential confounding and appropriate use of analysis strategies. A checklist for ranking categories is included in Appendix A. The final grade for each quantitative study was based on the frequency of sub-group rankings.

Qualitative Ratings

The appropriateness of quality checklists and standardized methods of evaluating qualitative research is contested by many scholars and highly debated

in the current literature. these criteria are generally regarded as valid descriptors of methodological rigor³⁰⁻³⁵. However, I wished to attempt a relative comparison between the studies with hopes that such an analysis would assist in the development of our own research methodology. Avoiding quality rankings, I opted instead for a descriptive analysis of each study based on criteria generally regarded as valid descriptors of methodological rigor³⁰⁻³⁵.

The three qualitative studies were assessed on the basis of a short question set (Appendix B) adopted from the work of Barbour³⁰, Greenhalgh and Taylor³², and Mays and Pope³³ for: appropriateness of methodology and study population, data collection and analysis methodologies, and clinical relevance of results (Table 1). The researchers' decision to use a qualitative design was evaluated for appropriateness based on the prescribed aim to, "study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them"³⁴. The study population was evaluated for the level of definition and justification for sampling methods. Quality of data collection and analysis was based on the degree of explanation for the protocol's evolution, the reliability and verifiability of data collection tools, and the appropriateness of analysis techniques and quality control measures. In particular the use of grounded theory, reflexivity, multiple coding, triangulated results, methodological congruence and respondent validations are a few of the particular methods for validating qualitative research. I further describe these techniques, their uses and limitations, in the following section.

Explanations of Techniques to Improve Rigor in Qualitative Research

1. Grounded Theory

Grounded theory is a qualitative technique in which all results, explanations and theoretical development are derived from the data itself^{30, 34, 36, 37}. It is an “iterative process by which the analyst becomes more and more ‘grounded’ in the data and develops increasingly richer concepts and models of how the phenomenon being studied really works”³⁷. Opposed to traditional quantitative research, in which the study is engaged to analyze a hypothesis generated a priori, the grounded theory approach is used in attempt to reduce the impact of researcher bias and influence. However, even with use of the technique, many have argued that the methodology does not prevent this from occurring^{30, 36}. Critics of grounded theory argue for the need of a constructivist approach, in which the data is recognized as organized by the researcher and the conferred meaning is framed by the influence of both researcher and subject^{33, 36}. Determination of credibility calls for a step by step explanation of how the data coding, analysis and final conclusive insights were formed.

2. Reflexivity

To follow a constructivist approach to grounded theory, reflexivity, or “the process of reflecting critically on the self as researcher,” is required³⁸. This insures that throughout the research process, the

researcher is aware of a certain degree of observer bias present in qualitative research, and responds with a reflexive presentation of their own experience, influences and a priori assumptions in reaction to the research agenda, data collection and analysis^{32-34, 38}.

3. Multiple Coding

Coding of the texts by more than one individual allows for a better understanding of themes as identified by independent readers, therefore limiting the influence of bias that a single coder may create^{30, 37}.

Alternatively, this can be accomplished to a less rigorous degree of reliability with a single reader, analyzing the texts at two different points in time³⁰.

4. Triangulation of Results

Triangulation refers to the comparison of results from studies addressing the same research question through varied methods of data collection^{30, 33}. The method is often used to validate results by demonstrating congruence and rigor of findings through a corroborative interpretation of data^{30, 33}. While a common means of reinforcing the strength of findings, it is important to keep in mind that the studies may not, by nature of the various techniques used, address the exact same research question. In many forms, then, triangulation ensures not validity, but comprehensiveness of inquiry³⁹.

5. Methodological Congruence

Congruence of qualitative research is described as involving four components: rigor in documentation, rigor in procedures, rigor in ethical approach, and confirmability³¹. Broadly speaking, this involves an analysis of how well researchers documented integral steps in the study process. The first step is an accurate identification of the research question and support for the research design's ability to adequately address the problem and significantly contribute to the existing body of knowledge³¹. Following the study's initiation, methodological congruence necessitates appropriate and ethical methods of informed consent, data collection and results analysis, including an accurate description of all procedures³¹.

6. Respondent Validation

With the growing impact of participatory action research, respondent validation of research results is becoming a more popular means though which qualitative data is validated. While it is a useful tool to refine meanings and correct epistemological errors in terms of those who initially presented the data upon which the meanings are conferred, it must also be approached as a source of potentially new data in itself and appropriately addressed as such³⁰.

Studies and Data: Results of the Literature Review

Each included study is presented in the following sections, divided into subgroups based on the aim of the study's research question(s).

Subgroup One: Sources of Perceived Stress among HIV-Seropositive Women

Gray, in 1999, examined responses to the question, "What [aspect] about living with HIV infection has been most difficult for you?" among a convenience sample (n= 80), as part of a larger triangulated study analyzing aspects of stress experienced by HIV positive women²³. The appropriately designed qualitative study recruited participants from ten states via nurses who were employed by the study through a professional journal and conference networking. Based on reported statistics from the Centers for Disease Control, the convenience sample adequately represented the diverse demographics of HIV positive women in the US²³. Responses to the question were obtained via written samples to control for differences among volunteer data collectors and settings and were theme coded by the author using the constant comparative method, a formulation of the grounded theory technique^{30, 40}. No information was given regarding the particularities of approach to coding or analysis, however, it is stated that repeat coding and analysis was conducted by the author several months following the initial assessment. While the author offered no explanation of her own role or potential influence in the research project, she did describe the importance of placing nurses well established in AIDS care, and therefore privy to issues of confidentiality, as data collectors. The published study was part of a larger,

triangulated research project; however, results from other studies were not available. Participant validation, as well, was not employed.

Gray determined four primary sources of stress for the interviewed women: fear, limitations, symptoms and emotions. In particular, her finding that the women's expressed fears were not only of their unknown future and potential mortality but also of disclosure and perceived stigma was particularly interesting. While the study was limited by the above issues in methodology as well as the use of a written tool to aid in verbal data collection, the results point to important areas of consideration for future research as well as provision of support services.

Stigma was also found to be a common theme of perceived stress in the study by Ingram and Hutchinson with 18 volunteering HIV-positive mothers in Georgia²⁴. The small qualitative study was used to initially explore the experiences of being a HIV-positive mother. Findings were presented as a description of Goffman's theory of stigma in which the negative consequences of stigmatization involves a loss of perceived normalcy²⁴. This "emergent fit" analysis was used to assist the researcher in "expand[ing] personal work by exploring in depth... a small part of a larger phenomenon," and was validated among both participants and colleagues²⁴. However, little detail is presented regarding the steps through which researchers developed the association between their data and the associated theory.

Women expressed a similar fear to those in the study by Gray. In particular, participants feared disclosure and the associated stigma it would entail; living "double lives" that involved a myriad of lies, cover-ups and feelings of

“abnormality²⁴.” Furthermore, the authors conclude the paper with suggestions to HIV providers on means to decrease stigma, such as closed clinic doors and discrete labeling; as well as to improve sensitivity to the diverse needs expressed by HIV positive women.

Among the quantitative studies, the case series published by Kirkham and Lobb found that significant stressors among the 110 participating women were: financial difficulties (60.9% of respondents), lack of intimacy (53.6%), fear of rejection or discrimination (51.8%) and own health/medical problems (40.9%)²⁵. The study was conducted via a mailed survey developed in consultation with medical experts, an epidemiologist, a statistician, community AIDS educators, and HIV-positive women; and was pre-tested among a small group of HIV-positive women with subsequent integrated feedback. While the survey distribution was initially large, information on the source population demographics or precise percentage of respondents is not presented due to limitations in identifying HIV-positive women through anonymous testing. Based on a statistical back-calculation, the authors estimate that 15-25% of the HIV-positive women in the province completed the survey.

Researchers presented bivariate results on variables such as the association between IV drug use and sexual assault (those who identified as an IV drug user were twice as likely to have experienced sexual assault as an adult, $p=0.001$) and the likelihood of having a doctor refuse care based on year of diagnosis (refusal was more common if the diagnosis was made prior to 1991, 32% vs. 5.5%, $p<0.001$); yet no similar data is presented for associations with various reported

psychosocial stressors. While such data may have been helpful if significant, the identification of specific concerns among these women is instrumental in providing direction for future research.

Subgroup Two: The Utilization of Various Coping Methods

The case series conducted by Simoni and Cooperman explored sources of stresses and strengths among a non-probability group of HIV-positive women living in New York City²⁷. The included women were predominately African-American (44%) or Hispanic (42%), and of low economic status (85% reported an income of < \$1,000/month). While not as important for their research methodology, the source population was poorly described as were the recruitment strategies used to establish the convenience sample, leading to the common concern for selection bias in case series analyses. The participant group (n=373), however, was sufficiently large with demographics generally representative of the HIV positive population of women in the United States. Through face-to-face interviews, the researchers accessed perceived stressors, strengths, and psychological as well as physical wellbeing, using pre-validated scales.

In addition to reporting descriptive findings (significantly that a high percentage of the women had experienced sexual abuse [59%]), the authors conducted multiple bivariate analyses. Their results indicated that spirituality and mastery were significantly associated with less depressive symptomatology ($p < 0.001$). After conducting an analysis of partial correlations, however, they found that mastery and spirituality were highly correlated ($p < 0.001$) and that

controlling for mastery drastically attenuated the association between spirituality and depression, suggesting the role of mastery as a mediator for the effects of spirituality. Additionally, Simoni and Cooperman determined a correlation between higher levels of reported satisfaction with social support and better psychological and physical adaptation ($p < 0.001$ and $p < 0.01$, respectively)²⁷.

While the potential for social desirability bias secondary to the face-to-face interviews exists in their study, Simoni and Cooperman succeeded in highlighting two potential areas for interventions for HIV positive women: the reliance upon spirituality for bolstering self-strength, and the need for adequate support systems to maintain psychological and physical wellbeing.

Following this initial study, Simoni (with Martone and Kerwin) conducted a cross-sectional analysis on the role of spirituality as a coping mechanism among a similar group of women in 2002²⁸. After controlling for demographics, social support indices and drug use in a multivariate model, the researchers found that spirituality and spiritually based coping significantly correlated with less drug use, increased social support, and improved psychological adaptation (p -values all < 0.05). Data for the analysis was collected using modified pre-validated scales administered through highly structured face-to-face interviews conducted by women previously trained as part of a larger investigation. The interviewers included health care consumers from the seropositive women's community. While selection bias (lack of information on establishment of study population), measurement bias (self-reported data), social desirability bias (due to community members serving as interviewers), potential influences of unknown confounders

and the lack of causal directionality in cross-sectional studies all limit the study's findings, the authors point to an important area of potential assistance to similar HIV-positive women.

In a qualitative manuscript, Malone, a social worker, reported the voiced concerns, opinions and beliefs of the five regular members of her support group for women over the age of 50. While the group served an important role in the lives of the author and the participants, and was based on the establishment of a long-term relationship between those involved, it is difficult to qualify the study as a classic participant observation project as it was structured with Malone in the role of director/moderator⁴¹. Neither was the study a focus-group as it lacked the necessary procedural structure⁴². However, following the post-structural movement of researchers in the social sciences away from the difficult nuances of participant observation, it could be argued that Malone succeeds in writing a brief ethnography in which she posits herself in the midst of the support group's interactions, subjectively presenting the women's voices within its specific context⁴¹.

While lacking reflexivity, Malone's observations highlight the need to focus research agendas on women above the age of 50. Malone found the women in her group coped with their diagnosis through a sense of individual control (sustained through knowledge/information obtainment), a sustaining purpose in life, faith and spirituality, and through overcoming negative emotions. Such themes require more extensive research in this population as they may lead to improved prevention strategies and care for older women.

Subgroup Three: Self-perceived Quality of Life

The case series report by Kirksey et al. of a group of HIV-positive women attending a university-based AIDS clinic in Houston, Texas (n=61) found that perceived quality of life and social support were related to overall perception of health with borderline significance ($p=0.019$, $p=0.031$, respectively)²⁶. The study included a convenience sample of women, reported as adequately representing the overall clinic population. Surveys were comprised of pre-validated questionnaires that were self-administered. Their analyses involved multiple regression model controlling for the potential confounders of ethnicity and self-efficacy. As with similar studies, the potential influence of unanticipated and unidentified confounders, the role of selection bias within a convenience sample and the measurement bias associated with self-reported data all limit the validity of the study's findings.

In a similar study, Sowell et al. addressed the relative importance of social and psychological factors as predictors of self-perceived quality of life among a group of HIV-positive women receiving care at one of eight public clinics in Georgia. The researchers found that disclosure to a greater number of individuals, presence of intrusive thoughts and increased age were significant positive predictors of HIV symptoms in the final multiple regression model (p -values all <0.01)²⁹. Larger amounts of material resources, full-time job status and African-American race were negative predictors of HIV symptoms (p -values all <0.01).

Women who were married or living with a partner reported greater levels of general anxiety and HIV symptoms.

Data for the analysis was collected using predominately pre-validated scales through highly structured face-to-face interviews with trained, female research assistants as well as clinic chart reviews. Scales were modified based on findings from an initial focus-group session during the formative phase of the study. While the study is limited by selection bias (lack of information on establishment of study population), measurement bias (use of self-reported data), potential influence of unknown confounders and the lack of causal directionality in cross-sectional studies, the presented findings point to potential factors influencing the quality of life among HIV-positive women.

External Validity of Results from Literature Review

Quality ratings for external validity were not assigned to particular studies. In general, however, all but one study⁸ enrolled women of all ages and were predominately comprised of women with a mean age of 35-40.

Other issues, as well, limit the applicability of study findings to diverse populations of women. In particular, the studies by Gray and Kirksey relied upon the use of a written tool for data collection^{23, 26}. While an appropriate step to regulate data collection techniques, it limits the transferability of results to populations of illiterate or non-English speaking women as well as those for whom varied levels of education and cultural differences may have limited their ability to adequately communicate in writing. The study by Kirkham and Lobb,

conducted in British Columbia among predominately Canadian (76.4%) and Caucasian (80.9%) women is also limited in its applicability to diverse populations, notably those within the United States where women may have access to different levels of community and financial support than do their Canadian counterparts²⁵ .

All of the studies included in the literature review include women who are established with service providers either through provider clinics or social service organizations. Subsequently, an unknown number of women who have not presented for care or services are not represented in these populations. It may be that these women, including those age 50 and older in particular, have different experiences living as an HIV positive individual. They may encounter different stressors and coping strategies than women who are in care, and may require different methods of intervention and support as a population.

Furthermore, as illustrated in the above review, only one study specifically included only HIV-positive women age 50 and older⁸ . With data primarily from populations of younger women, it is incorrect to assume that the conclusions found within this literature review involving aspects of social stressors, coping mechanisms and perceptions of quality of life appropriately represent women above the age of 49.

Important Considerations from Excluded Studies

In summary, research specific to the lived experiences of HIV-positive women 50 years of age and older is lacking. Although, data from studies

including both women and men above the age of 50 was excluded from the formal literature review, two studies within this category offered important considerations for our research.

A qualitative study conducted in New York City among HIV positive individuals age 50- 68 revealed a variety of potentially relevant themes of both advantages and disadvantages of older age when dealing with HIV. Advantages included: developed wisdom, enhanced problem-solving skills, greater cautiousness and sense of emotional moderation, patience, sense of illness and physical decline as expected aspects of advancing age, and pre-illness achievement of life goals. Disadvantages included: communication issues with providers, sense of self-deprivation with regard to care, stigma, and having more “vulnerable bodies”⁴³.

The second study highlighted difficulties in the measurement of quality of life among older populations of HIV-positive individuals⁴⁴. Avis and Smith concluded that secondary to common co-morbidities as well as differences in perceptions of what constitutes quality of life, current methods of evaluating this variable among an older population may not adequately assess the true perceptions or needs.

In summary, the literature review finds that research specifically targeted to HIV-positive women age 50 and older is needed to better understand and respond to the social, emotional and physical needs of this growing population.

Study Plan: Characterizing the social contexts of women 50 years of age or older who are living with HIV

Methods

The following sections include our research project's methodology at this point in the study process. As the nature of qualitative research provides for continuous reflection on results and data obtainment/analysis, minor modifications of the methods throughout the project are expected.

Approach to methodology

The project involves qualitative methods and analytical modeling to explore particular social experiences of women age 50 and older currently living with a diagnosis of HIV. The use of in-depth qualitative analysis is a well-founded approach to “exploring unknown or understudied phenomenon and to promote the development of conceptual and theoretical frameworks”⁴⁵. Such frameworks can then be utilized to generate hypotheses for further qualitative and quantitative research. Investigating our research question initially through a qualitative model provides an opportunity to uncover previously unrecognized variables within the women's lives as well as the ways in which those variables are influenced by particular situations. In other words, the qualitative design allows us as researchers to explore the “*hows* of people's lives (the constructive work involved in producing order in everyday life) as well as the traditional *whats* (the activities of everyday life)”(emphasis in original)⁴⁶. One approach to data collection in qualitative research, the semi-structured interview, provides opportunities for informal interactions between the principle investigator/author

and the interviewee (the research participant) in a space that allows for candid expression through narrative experience, and appropriate reflexivity in data obtainment and analysis. Defined as “a performance that positions the author in relationship to the field, the act of research, writing and the production of knowledge more generally”⁴⁷, the interview itself requires a continual appreciation of the idiosyncratic experiences and attitudes brought into context by both interviewer and interviewee.

Recruitment

I am currently identifying eligible women consecutively in the UNC Infectious Diseases Clinic (UNC ID Clinic) and approaching them for enrollment in the clinic either while they are waiting to be seen by their provider or after completion of their clinic visit. Inclusion in this convenience sample is limited to HIV positive women who are age 50 or above, are current patients of the UNC ID Clinic, and who have demonstrated willingness to be approached for research study participation (as documented by previous written informed consent to participate in the UNC Center for AIDS Research Database). The only exclusion criteria are an inability to provide written informed consent and/or inability to speak English. The initial encounter script is included as Appendix C. If a woman agrees to participate in the study, consent is obtained (Appendix D) and interviews are scheduled to be held in a private and confidential location at a time convenient to the participant. To date, all completed interviews have been conducted before and/or immediately following the conclusion of the participant’s

physician visit in a private clinic room. Permission to audio tape the interviews is requested; however, individual women are able to refuse audio taping and still participate in the research study. No participants have refused audio taping at this time. At the completion of the first five interviews, six women declined to participate in the study. For the six women, the stated reason for refusal involved difficulty with the time commitment. Four women could not rearrange their transportation and two women had pressing engagements or responsibilities.

Interviews

I conduct each semi-structured interview with women who give written informed consent to participate in the study. The interviews follow a framework based on a grounded theory research approach in which the interviewer begins with a broad open-ended question and then follows-up with more focused questions or probes³⁶. This approach allows for an awareness of “*emic* points of view, or insider meanings, that are attached to social phenomena” (emphasis in original)⁴⁸. The interview guide (Appendix E) is designed to elicit information from the women on psychosocial aspects of their lives, as well as perceived similarities or differences between their experiences and those of younger women with HIV. Additionally, these interviews provide participating women with an opportunity to elucidate examples of the various situations, knowledge obtainment and emotions experienced since they learned of their HIV infection. The primary focus of the interviews is to identify the social stressors, aspects of home life, perceptions of faith, personal and social responsibilities and degree of

social support. A UNC Infectious Diseases Attending Physician (Kristine Patterson, MD) is available by pager if any issues arise during the interview process. Each interview lasts approximately one hour and women are reimbursed \$15 for their participation. During the course of each interview, I refer back to trends and concepts demonstrated in previous interviews in order to inform the questions and associated probes in progress, thus incorporating a continuous comparative analysis between interviews.

Analyses

Following an understanding of interviews as “a form of discourse between two or more speakers or as a linguistic event in which the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondent”⁴⁹, the research team will not attempt to “lift the results of [the] interviews out of the context in which they were gathered and claim them as objective data with no strings attached”⁴⁶. Instead, we will approach the texts as negotiated presentations of individuals’ lived experiences through conversations held with a researcher who embodies dissimilar demographic characteristics.

Transcription

I transcribe each interview within 48 hours of completion. As the transcription process itself is a “pivotal aspect of qualitative inquiry,” “powerfully affect[ing] the way participants are understood, the information they share, and the conclusions drawn”⁴⁸, I will approach the recorded interviews with an

awareness of who the women are in context of the interview process. Through this reflective interaction, I will allow for an intermediate step to contemplate the manner through which our transcription process is reflecting and representing the words and ideas of each research participant. The development of and justifications for this intermediate step as described in a study by Oliver et al.⁴⁸ are included in the following section.

An Intermediate Step in Transcription: The Oliver et al. Study

The intermediate step in transcription reflects the methodology employed by Oliver et al. in their qualitative research project among HIV positive men in Ohio⁴⁸. During the study, investigators realized that their research question warranted neither a completely naturalized approach to transcription (in which every utterance, pause and speech overlap is noted to fully analyze the conversation) nor a completely denaturalized approach (in which idiosyncratic elements of language are excluded in an effort to focus on embedded meanings and perceptions). They felt it was difficult to accurately portray the interviewees' words verbatim in a way that adequately demonstrated their broader significance to a wider audience.

Despite their use of grounded theory techniques, which normally rely upon a denaturalized transcription style, the researchers felt that this method neglected important aspects of *how* particular meanings and perceptions were conveyed. In contrast they felt that a naturalized approach, while perceived to

objectively allow the interviewees to speak for themselves, ignored the social and ideological influences of the transcriptionist as he/she proceeds to translate that communication and creates a hegemonic ideal of “standard speech”⁴⁸. To allow for the spoken words of their participants while preventing the attachment of prejudiced assumptions to their analysis, Oliver et al. adopted an intermediate step in the transcription process to reflect upon how particularly conveyed pronunciations, use of slang, geo-ethnic accents, diction, involuntary vocalizations, and nonverbal vocalizations were a) necessary to completely convey meanings and interpretations and b) affected the interviewee’s presentation with risk of stereotypical influence. This step allowed the researchers to work with the interviewees’ words, approaching them as data sources while simultaneously appreciating how their portrayal of those words affected the subsequent analysis.

Transcription: Implications for Current Research Project

The reflective, intermediate, step in the transcription process had led us to adopt a more naturalized approach to the transcription process. Idiosyncratic language is regularly transcribed as we believe that it represents the influence of the interviewee’s own connotation or conversation style in context of discussing personal issues with the principle investigator. As this study’s aim is to address the real-life beliefs and perceptions of the participating women, we believe that the ability to present as much information as possible in the precise vocabulary used is important in conveying the particular contexts in which there perceptions

were shared. Granting ownership of their words to the individual women is an important aspect of our research agenda.

Coding

Following transcription, the interviews are each then entered into a qualitative research software program, Atlas t.i, vol. 5.1. As there exist current debates regarding the validity of computer based qualitative analysis, I will utilize the program for organizational ease, but will also review hard copies of the transcribed interviews for a analysis “by hand⁵⁰.” Using this dual method, I will iteratively review interviews to identify themes, and assign codes. To insure credibility and authenticity, the interview field notes and transcripts will then be independently reviewed by two study co-investigators. These will then be compared and themes will be characterized and modified based on consensus. Throughout the study process, an audit trail of written documentation illustrating the process of developing themes will be maintained. This will allow for precise demonstration of the framework in which the interviews were approached, analyzed and understood. In part this information will be used to inform additional interviews, and in part to determine when theme saturation has occurred as well as to enhance validity. Once theme saturation has occurred we will close enrollment. Based on prior work among HIV-infected women using similar techniques, we anticipate requiring at most 20 interviews⁵¹.

Results to Date

At the time of this report, five interviews have been completed, transcribed and coded. All women interviewed were African-American and between the ages of 50 and 79. Four of the five women were between 50 and 54 years of age. Two of the women were divorced, two were widowed and one was married. All believed they contracted HIV from a heterosexual contact; four felt that they contracted the virus from their concurrent husband. Previous alcohol and/or drug dependence was common, with two of the women reporting a positive history and one who discussed currently struggling with her addiction. At the time of the interview, she reported a week of sobriety. Trends apparent from these interviews include: the importance of faith in God, a need for selective disclosure of HIV status, and dissatisfaction with available education and prevention efforts.

Strength from Faith

Each of the five women interviewed specifically addressed the importance of God and their personal faith as a vital source of strength. While they each stated that faith and spirituality had always played a role in their lives, most of the women felt that the strength they derived through their faith increased following their diagnosis and helped them handle the implications of living with HIV. In the words of three women:

I talk to Jesus a lot. It makes you grow closer to
God, I think.

Oh, yes, I prays every night and every morning. Yes
I do. I sure do. Yes, and asks God to be with me
through the night and watch me through the days.

If it wasn't for me believing that God was helping me and taking care of me, I don't know whether I would be here or not.

Two participants did not feel that her faith had changed since being diagnosed, but believed that their previously established relationships with God assisted them in facing the new challenge of an HIV diagnosis. One woman stated:

I've always been [faithful]. My mom took me to church when I was little, so... I've always been in the church. I guess it has just never changed. I know that you have challenges that you have to go through and you have to face them. And, like I said- it could be worse than it is, so it's not. So, I am grateful for that too.

Another woman felt that her faith was always important, but increased when God assisted with her decision to become clean from drugs and alcohol. In her words:

No, it's always been real important, because God didn't leave me. I left him when I was using. The minute I decided that I didn't want to do that anymore, he was a big part of my life. Cause I know that he spoke to me. That's just for me; I can't say for anybody else. But, I know that's how things happened. He said, "Stop, or you are going to die." So, I decided to live, with him.

Following the description of HIV as an acceptable challenge to be faced, two of the women expressed beliefs that their diagnosis was specifically implemented by God in order to facilitate a growth in spiritual strength. One woman's words illustrated this belief:

Sometimes God likes things to happen for us to get stronger with him... So, you just have to say, God,

give me this mountain and give me the strength to
climb. When you give it to me Lord, give me the
strength to climb.

One woman, currently battling an ongoing addiction to crack cocaine, described how she believed God orchestrated her life: “I can’t control the HIV anyway, only God can. You know, he has already written my life.” For another woman, God served as a confidant, providing an outlet for self-reflection. She stated:

It [faith] is very important. I am not sure that I would have made it through the initial shock and acclimation to it all without my faith. There have been many times when I didn’t have anyone to talk to, and I had to talk to God.

For all of the women interviewed so far, their faith provided an important tool with which they were able to accept their diagnosis, and face the day-to-day challenges of living with HIV. Of the five, four brought up an aspect of their faith or spirituality before I specifically probed on the topic.

Interestingly, only two of the women interviewed discussed the importance of attending church, or having a church community. Both women elaborated on the difficulties faced when deciding to whom they would tell their status, and stated that church members were not appropriate for this sort of disclosure. Such acknowledgement leads into the next commonly encountered theme: that of living in two worlds- one in which their HIV status is known by others and one in which it is hidden.

A Lived Duality

For most of the women interviewed, the decision to disclose their positive status to others was one that involved serious considerations of implications. These included: an awareness of the potential effects such knowledge would have on those individuals being told; the potential for negative reactions and stigma; and, the likelihood that these individuals would tell others, making their status publicly known in a community. One woman did not tell her children initially as her diagnosis followed closely behind her divorce from their father. She felt that, “it would be too much for them at the time.” Years later, she had still not told them, stating that:

Now that so much time has passed, I don't really know how. Sometimes I wonder how they will react when they do find out.

For her, the concern regarding disclosure to her immediate family was based more on how the knowledge might disturb their lives than on the impact it would have on her own experiences.

Others believed that through self-disclosure they could increase awareness among others and potentially contribute towards increased education and prevention strategies. The level of openness to achieve this, however, required a great deal of courage not easily employed by the women. In the words of one woman:

And I want to tell them so bad, what difference does it make? You know, you can't get it like that, just by talking to them or being around them. You just can't get it like that. But, or course, I don't tell them. I just keep it to myself. I just go like this, by myself... And I would like to tell them people, but I

don't know how. I'm kind-of like, I don't really want them to know that I have HIV. I don't know what to do. Sometimes I think about it, that I just need to get up there and tell it. And then I think about it and think, 'no, no, I better not do that.' So, I don't know. Tell my story... I feel scared. So, I don't know. I think it would help other people. I haven't even told my own daughter. I should tell her, but I haven't. I don't know why. It's just tough."

Another woman was contemplating whether or not she wanted to participate in a panel educating teenagers in other town. She realized the potential contribution she could make, and felt more comfortable with the panel not being in her hometown:

I don't think that it would be harmful for me to do it in [town x]. I wouldn't want to do it in [my hometown]. Nah. It's just something I wouldn't want to do there.

For these women, disclosure involved a self-negotiation in which they balanced potential benefits to others with potential harms to themselves. For others, disclosure to any one individual could result in many others knowing about their diagnosis. To prevent public awareness of their diagnosis, they used careful discretion in choosing those individuals to whom they would disclose.

One woman stated:

You know, it's just- that is a fine line right there. If I decide to have somebody else [know], are they going to conceal? I mean, tell my private things or whatever. So, I don't do that.

The common fear associated with disclosure related to a perceived risk of subsequent stigma and discrimination. Three women discuss this issue:

I don't tell everybody, but there are certain peoples that I do talk to like my case worker. Sometimes it's not good to tell your church members... My cousin does [know about my status]. I don't tell nobody else. I tell only the one that I know won't talk because people treat you bad... The only think I had to do was to keep my mouth shut and not to talk my business to everybody. The people are not good to you if they find out. They are scared of you. They think that if they drink some water behind you then they will get it. But, that's not the way that you get it.

I feel like I just can't be honest with people anymore now that I have HIV. Just as far as people are concerned, I just try to stay my distance... I don't want someone saying that I gave it to them, or I caused them to get it. I know that I couldn't, you know, just by cooking or whatever, but people don't always know these things. I kind-of just stay in the back you know. I can't control what everybody thinks or believes and I don't want them making me feel worse about everything, you know.

People tend to treat you a little different, kind-of standoffish. I attend church, but no friends there. No, no. I don't trust nobody but my family with this stuff.

Much of the fear expressed by these women related to the lack of accurate knowledge regarding HIV in their community. Because of misconceptions and myths, they were concerned about potential blame for any subsequent diagnoses among others. Appropriate education was deemed vitally important by all of the women interviewed.

Needed Improvements in Education and Prevention

It was evident while talking with the women that they generally appreciated a need for more specific education and prevention messages for older

individuals as well as for providers treating such populations. One woman in particular held resentment for her previous primary care physician who never tested her for HIV even after she became quite ill. She described how her diagnosis was finally made when she attempted to apply for life insurance:

I had been sick for a while. Feeling horrible, losing weight, extreme fatigue, my lymph nodes were swollen up like golf balls- I was convinced that I was going to die. I went to my regular doctor numerous times, and he performed every test in the book. I was tested for everything, except HIV. They assume that because I am successful, because I am not a crack addict, because I am educated-that I couldn't possibly have HIV. So, I went along, completely convinced that I was dying from some unknown illness, a malignancy that they could not find. I was worried about my children. This was almost three years ago and at that time I still had two kids in college. So, I decided to try to get life insurance, to cover my children. I was completely convinced that I was going to die. I applied and they denied me on the basis of a "severe blood abnormality." That, of course, was HIV. To think that I went along for so long, not knowing what I had, not taking medication that I needed...

Other women, as well, discussed the need for providers to talk with older women about potential risks and strategies for prevention. As two women stated:

But, if a doctor would just talk to people about it more, I think that we would get a better understanding too.

Doctors need to tell those women to think, think about what you don't have and if you don't want it, then be smart about it. Just think.

These women believed that many providers did not see older women as being at risk for HIV, leading to a lack of education on the importance of safe sex

and screening. Explaining a potential cause of increased risk among older women, one woman stated:

But I think for many women who find themselves in mid-life and single, either divorced or widowed, that dating is a very difficult thing. It is probably difficult to think about condom negotiation when you are afraid of 'scaring off' the one man you managed to find what was not married or interested in other men. Now, that's a prevention message that needs to be put out there. That needs to be talked about.

After her diagnosis, this same woman felt that available educational materials for HIV-positive individuals were not applicable to her life experiences.

In her words:

As for being an older woman with HIV, you quickly realize that absolutely none of the educational materials mean anything to you. You sit out here in the waiting room and all of the pamphlets are about alcohol and drug abuse, about 'how to tell a partner that you are HIV positive,' 'how to start dating again.' These issues are not of concern to me. I am not a drug or alcohol abuser, I am not planning to date. The reading material is just not for me.

Several women offered suggestions for targeting populations of both infected and non-infected older women. Common vehicles for education discussed were advertisements and human interest stories in magazines commonly read by older women, as well as a reinvigorated focus on popular television talk shows. As discussed by three of the women:

Women my age read a lot of magazines. I mean a lot! There needs to be articles in those magazines, real-life articles. But, the editors assume that all of their readers are married with two kids. They don't think that real women out in the world deal with these issues, or at least need to think about them.

And, well, they do. Educators are missing a very powerful venue to make a difference. Actually, now that I think about it, talk shows don't talk about it either... if only we could get Oprah to bring it up on her show. Awareness is out there for gay men and even for young women, but among my age, there is nothing. Magazines are the way to go; magazines with real life stories about real life women who have experienced HIV in some way. That, and lets get Oprah focused on some topics that really matter to us at home.

And then, through magazines. A lot of women order those magazines. That's a good way too.

I think that the TV would be more. People watch stuff, they watch documentaries and stuff like that on TV. I think that there would be a whole lot of interest for stuff like that on TV. And talk-show hosts, if they would do more on it. Well, like Oprah, of course.

Only one of the women interviewed felt that the education and prevention messages currently used were adequate if "you are paying attention". She did debate whether or not she felt they were targeted to women her age:

I think that they are targeted to younger people, kind-of. At that age... What age do you have to be? Anybody can get it. It doesn't matter, right? So, I don't know. I'll have to think about that a little more, to see if it is targeted for women like me or if it really matters as long as the message is out there. I don't know.

Discussion

While the results presented above are preliminary and based on only five completed interviews, they highlight important considerations for the remainder of the study as well as potential implications of our results. All of the women interviewed discussed difficulties associated with HIV status disclosure. While

they may have experienced varied levels of openness with their diagnosis, each woman expressed a need for boundaries. Within certain circles of individuals, they felt comfortable acknowledging their HIV status. Beyond these circles, however, fear of public knowledge and negative reactions prevented full disclosure.

It seems possible that a perceived lack of public acknowledgment regarding the risk of HIV among older women, and the prevalence of inaccurate knowledge of transmission could contribute to the fear of disclosure reported by the interviewed women. They view themselves as members of a population believed to be at no risk for HIV due to stereotypes that women above the age or 50 are either in stable and monogamous relationships or are abstinent. Disclosure, then, could marginalize them not only as HIV-positive individuals, but also as HIV-positive individuals who should not be infected. If this association remains valid, many of the ideas for increased dissemination of educational messages may be important targets for public health efforts.

The importance of faith highlights a potential vehicle for agendas aimed to benefit older HIV-positive women. Support groups, held at churches and involving spiritually-based counseling programs, could be useful in assisting these women with HIV associated challenges as well as providing a protected environment for self-expression and growth. However, the difficulty some of the women expressed concerning disclosure to church members must also be appreciated. It may be important for these groups to be held at locations other

than the participant's home congregation. Further interviews may help to elucidate the feasibility and desirability of such initiatives.

Methodological Limitations

The findings from the completed study will be unavoidably subject to limitations in methodology. The sampling method is non-random, resulting in a potentially inadequate representation of the clinic population and a subsequent difficulty in generalizing findings to the source population. The five initial interviews included mostly women between the ages of 50 and 53, likely overlooking important differences in the lived experiences of older sub-groups.

Further limiting the study is self-reported data in a face-to-face setting that risks the influences of social desirability, reporting and interpretation biases. Finally, the lack of an HIV-negative comparison group, and the cross-sectional methodology preclude any assumptions regarding the directionality of associations proposed by the research findings.

Impact of My Role in Study Processes

Important to note, as well, is my own role in the research project as the principle investigator, interviewer, transcriptionist and primary coder/analyst. As a Caucasian, 28-year old, medical/public health student I enter the interview setting with unavoidable pre-conceived ideas regarding the women's lived experiences. I do not live in poverty; I have not experienced drug abuse or physical violence; I am obtaining an advanced degree of education; I am not a

mother or a grandmother; I am not African-American; I do not know what it is like to live with HIV. I can not fully comprehend the lives of women who have any number of the above lived experiences different from our own. Yet, such differences are inevitably brought into the interview setting. It is immediately obvious to the participating interviewees that I am not like them, if for no other apparent reason than the fact that I am younger than 50. Furthermore, because of the setting in which the study occurs, the UNC Infectious Diseases Clinic, there is an aspect of provider/patient dichotomy at play during the interaction. I am entering into a territory in which they are defined by their seropositive status, offering participation in a study primarily for that reason.

These potential differences are not discussed, but we are both aware of them to some degree. Without awareness, they have the potential to subconsciously impact the probes I employ and the tone of voice or body language with which I react to particular answers; as well as the truths the participant decides to share and the manner through which those truths are communicated. It is vital, as I continue the interviews, transcriptions, coding and analysis, that I remain conscious of these potential effects and approach the data through a continually reflexive process.

Previous studies have demonstrated that the level of information revealed by a respondent is positively correlated with the degree of privacy employed during the interview⁵². This has both potentially negative and positive implications for the research study. First, I am not a regular provider for the participants. We interact for the first time on the day of initial study recruitment.

While the unfamiliarity may limit the degree of comfort the women feel when expressing opinions and emotions, it may also provides an opportunity to talk and share perspectives within a confidential setting with someone who is not directly linked to their regular care and without the time constraint of a regular clinic appointment.

Implications for Future Research

Despite these limitations, the role of our research project will be formative to the future of research targeting HIV-positive women age 50 and older. Results obtained from this study can be used to generate hypotheses for more systematic, quantitative research as well as larger, more in-depth qualitative studies. The use of an initial qualitative study design may point to previously unestablished means by which to approach and provide for this particular population of HIV-positive individuals, potentially aiding in the development of more appropriately targeted prevention strategies and improved guidelines for screening, education and service provision.

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Table 1. Studies Included in Literature Review

Subgroup One: Sources of Perceived Stress among HIV- Seropositive Women						
Authors, Year	Study Design	Source Population	Study Population	Measurements	Significant Results	Quality Considerations
Gray, 1999	Qualitative, questionnaire	HIV positive women living in 10 states in the US (predominately urban)	<p>Convenience sample of 80 women (response rate not described) who could read/write recruited from support groups and via nurses in AIDS care recruited as data collectors through a professional journal and conferences</p> <p>Race/Ethnicity: 41 (51.4%) Minority, of which 33 were African-American Age: Average 35.8(SD 9.2, range 20-65) Educ: 21 High school, 28 Some college, 10 College degrees Income: 38 <\$9,999/yr, 6 > \$50,000/yr</p>	<p>Women responded to the question, "What [aspect] about living with HIV infection has been most difficult for you?" on a written survey.</p> <p>Question was part of a larger study examining both quantitative and qualitative aspects of stress among HIV positive women</p>	<p>Four primary sources of stress identified:</p> <ol style="list-style-type: none"> 1. Fears- Fear of disclosure/need for secrecy due to perceived associated stigma; fear of dying/the unknown future of potential new treatments/cures 2. Disease-related limitations- physical, sexual, emotional, and financial 3. Symptoms-physical, feeling helpless 4. Emotions-anger, depression, loneliness, concern for the emotional issues of caregivers, etc. 	<p>Qualitative study design appropriate for research question.</p> <p>Well defined sampling strategy.</p> <p>Little information regarding approach to coding or analysis; temporal triangulation used.</p> <p>Study part of a larger methodologically triangulated study-no details presented.</p> <p>Little use of reflexivity, no participant validation.</p> <p>Overall deficits in methodological congruence.</p> <p>Results clinically relevant.</p>

<p>Ingram, Hutchinson, 1998</p>	<p>Qualitative, In-depth interviews based on grounded theory and "emergent fit"</p>	<p>HIV positive women attending eight public health HIV/AIDS clinics in urban and rural Georgia</p>	<p>18 women who agreed to participate in the interview study.</p> <p>Race/ethnicity: 9 Caucasian, 8 African-American, 1 Latina Age: Range 18-44 Partner status: 50% married or cohabitating</p>	<p>Audio-taped focusing on experience of being an HIV positive mother lasting approximately one hour. Follow-up interviews completed to confirm and expand the initial interviews completed via telephone with six participants.</p> <p>Goffman's theory of stigma was discovered to fit much of the data and used in analysis. Validity of fit was determined by members checks with participants and peer review with colleagues.</p>	<p>Themes:</p> <ul style="list-style-type: none"> -Pain of isolation and fear expressed by others, stigma as creation of feelings of being "abnormal". -Spread of stigma to close associates: spouses, children. -Leading of double lives: caring for their illness and interacting with "normal" people, feeling forced to lie to others through cover-ups, etc. -Importance of gaining support from other HIV positive women, but limitations of identification with members of HIV support groups. -Concerns regarding reproduction, assumptions by providers that they should cease child bearing. 	<p>Qualitative study design appropriate for research question.</p> <p>Poorly defined sampling strategy.</p> <p>Little information regarding approach to coding or analysis; temporal triangulation used.</p> <p>No use of reflexivity, no participant validation.</p> <p>Overall deficits in methodological congruence.</p> <p>Results clinically relevant.</p>
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<p>Kirkham and Lobb, 1998</p>	<p>Case Series</p>	<p>HIV positive mothers involved with community organizations providing AIDS care in Florida</p>	<p>Women who returned survey (n=110) Race/Ethnicity: 80.9% white Citizenship: 76.4% Canadian Age: 10% <25, 70% 25-39, 18.2% >39 Current sex partner: 57.3% Mean educ: NR Income: 50.9% <20,000/yr</p>	<p>Mailed/hand-delivered, anonymous questionnaire consisting of 75 multiple-choice and short-answer questions accessing:</p> <ul style="list-style-type: none"> • Socio-demographics • HIV risk factors • HIV testing • Health status/med tx • Use of health care services • Degree of satisfaction with health care services • Psychosocial stressors 	<p>53.1% reported a history of sexual abuse as an adult, 43.2% as a child, and 27.2% as both a child and an adult</p> <p>Psychosocial problems experienced "quite often" or "most of the time"</p> <ul style="list-style-type: none"> • Not having enough money 60.9% • Lack of intimacy/satisfying sexual relationship 53.6% • Fear of rejection or discrimination 51.8% • Own health/medical problems 40.9% • Lack of affordable housing 38.2% 	<p>Source Population Adequately Described?- <i>Good</i></p> <p>Study Population Representative of Source Population?- <i>Fair</i></p> <p>Measurement Tools Reliable and Valid?- <i>Good</i></p> <p>Analysis Appropriate- <i>Fair</i></p> <p>Results Reported Appropriately?- <i>Fair</i></p> <p>Results Clinically Relevant?- <i>Fair</i></p> <p>Grade- <i>Fair</i></p>
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Subgroup Two: The Utilization of Various Coping Methods

Authors, Year	Study Design	Source Population	Study Population	Measurements	Significant Results	Quality Considerations
<p>Simoni and Cooperman, 2000</p>	<p>Case Series</p>	<p>HIV positive women living in New York City</p>	<p>373 women in convenience sample</p> <p>Race/Ethnicity: 42% Hispanic 44% African-American 14% other or mixed backgrounds</p> <p>Mean age: 39.61 (SD 7.22) Current sex partner: 53% Mean educ. (in years): 11.24 Income: 85% <\$ 1,000/mo</p>	<p>Standardized, Likert-like scales used to assess: history and frequencies of physical and sexual abuse, substance abuse.</p> <p>Used previously validated 13-item scale of spirituality, 7-item measure of mastery, and 24-item scale of social support and the CES-D depression scale.</p> <p>Also accessed 4 self-reported HIV-related med. variables</p>	<p>59% reported a history of sexual abuse, 69% reported a history of physical abuse</p> <p>Substance use in past 30 days: EtOH 27%, Marijuana 18%, Crack cocaine 17%, Cocaine 12%, Heroin 12%, Sedatives 6%.</p> <p>61% scored above cut-off for depression Participants rated themselves highly on spirituality, mastery and social support (Alphas: 0.94, 0.74, 0.88)</p> <p>Self- appreciation of strengths associated with less depression and better physical well-being. Positive effects of spirituality mediated through mastery.</p>	<p>Source Population Adequately Described- <i>Good</i></p> <p>Study Population Representative of Source Population- <i>Fair</i></p> <p>Measurement Tools Reliable and Valid- <i>Fair</i></p> <p>Analysis Appropriate- <i>Good</i></p> <p>Results Reported Appropriately- <i>Good</i></p> <p>Results Clinically Relevant- <i>Good</i></p> <p>Grade- <i>Good</i></p>

<p>Simoni, Martone, Kerwin, 2002</p>	<p>Descriptive, cross-sectional</p>	<p>HIV positive women, low-income women in New York City</p>	<p>230 women recruited by word of mouth and posted notices at several HIV/AIDS outpatient clinics and community-based AIDS organizations serving low-income women by 12 trained - interviewers (including health-care consumers from the seropositive women's community) who were part of a larger investigation (STAR: Stress, Strength, and Resilience Among Seropositive Women).</p> <p>Race/Ethnicity: 82% African-American Age: Median 39.5 (Range 24.6- 61) Currently living with partner: 14%; Single/never married 56% Educ: Mean 11 year (SD 2.6), High school degree or GED 44% Income: 91% <\$1,000/mo</p>	<p>Highly structured face to face interviews involving scaled question items based on Likert-type format and yes/no formatted questions devised to address basic demographics, drug use, social -support, coping, spirituality, and psychological adaptation. When available, specific pre-validated scales were used.</p>	<p>Respondents ranked themselves highly spiritual (M=3.28 out of possible 4.00, SD 0.50), majority Catholic (38%) and Baptist (26%). 35% were members of a church or other place of worship. Church membership/attendance was more strongly associated with spiritually based coping - than with spirituality in general.</p> <p>African-American women were less likely than others to report church membership.</p> <p>Spirituality and spiritually based coping significantly correlated with less drug use, increased social support, and psychological adaptation in multivariate analysis (after controlling for social support indices).</p> <p>Use of coping strategies (community involvement, constructive cognitions, realistic acceptance, and avoidance) associated with younger age, less education, less drug use and more social support. 65% scored 16 or above on the CES-D depression scale (indicating possible clinical depression)</p>	<p>Source Population Adequately Described- <i>Good</i></p> <p>Study Population Representative of Source Population- <i>Fair</i></p> <p>Measurement Tools Reliable and Valid- <i>Good</i></p> <p>Analysis Appropriate- <i>Good</i></p> <p>Results Reported Appropriately- <i>Good</i></p> <p>Results Clinically Relevant- <i>Excellent</i></p> <p>Grade- <i>Good</i></p>
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<p>Malone, 1998</p>	<p>Qualitative, participant observation</p>	<p>HIV positive women over the age of 50, living in Houston and attending a bi-weekly support group</p>	<p>5 women who are regular in-person members of support group (group also includes a telephone network)</p>	<p>Informal, non-structured conversations with participating women</p>	<p>Themes: Importance of sense of control over illness, supported by targeted education about HIV/AIDS.</p> <p>Need for sustaining purpose in life: grandchildren, volunteer work, etc.</p> <p>Importance of faith/spirituality as support.</p> <p>Surviving and accepting the associated emotional roller coaster, association between isolation and fear</p>	<p>Formal qualitative study design not well justified for research question.</p> <p>Well defined sampling strategy.</p> <p>Little information regarding approach to coding or analysis.</p> <p>No use of reflexivity. Some participant validation.</p> <p>Overall deficits in methodological congruence.</p> <p>Results fairly clinically relevant, important considerations for further research.</p>
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Subgroup Three: Self-perceived Quality of Life

Authors, Year	Study Design	Source Population	Study Population	Measurements	Significant Results	Quality Considerations
<p>Kirksey, Hamilton, Holt-Ashley, 2003</p>	<p>Case Series</p>	<p>HIV positive women attending a university-based AIDS clinic in Houston, TX.</p>	<p>61 women who were at least 18 years of age, proficient in English, with no severe visual impairment and absence of stupor, unconsciousness, or confused state.</p> <p>Race/Ethnicity: 77% African-American, 9.8% Latina, 9.8% White</p> <p>Age: Mean 40.48 (range 22-71)</p> <p>Partners: 83.6% never married/currently separated or divorced, 90.2% heterosexual</p> <p>Educ: 47.5% completed some high school or college</p> <p>Income: 98.4% < \$15,000/yr.</p>	<p>Used patient completed questionnaire packet (author-developed sociodemographic survey, Sickness Impact Profile, Norbeck Social Support Questionnaire, and Strategies Used by Patients to Promote Health Questionnaire) to address relationships among self-efficacy, social support, quality of life and overall health perception.</p> <p>Questionnaire packets were primarily self-administered, with a few ("n" unknown) required the questionnaires to be read aloud by research associated individual</p>	<p>88.6% perceived health status as "about average."</p> <p>African-Americans perceived themselves to be healthier than other ethnic groups.</p> <p>Significant positive correlation between social support and quality of life with overall health perception.</p>	<p>Source Population Adequately Described- <i>Good</i></p> <p>Study Population Representative of Source Population- <i>Fair</i></p> <p>Measurement Tools Reliable and Valid- <i>Good</i></p> <p>Analysis Appropriate- <i>Fair</i></p> <p>Results Reported Appropriately- <i>Good</i></p> <p>Results Clinically Relevant- <i>Fair</i></p> <p>Grade- <i>Fair to Good</i></p>

<p>Sowell, Seals, Moneyham, Demi, Cohen, & Brake, 1997</p>	<p>Descriptive, Cross-sectional (part of longitudinal study) Interview Study</p>	<p>HIV positive women living in Georgia and receiving care from one of eight public HIV/AIDS clinics (urban and rural)</p>	<p>264 HIV positive women who were English speaking with no evidence of dementia participated. According to the study, their demographic characteristics reflected that of the clinic populations:</p> <p>Race/Ethnicity: 47% Hispanic (84% Puerto Rican), 46% non-Hispanic African-American, 7% women of color or mixed ethnic backgrounds Age: Mean 34, Range 15-64 Currently living with partner: 66% Educ: 59% completed HS Income: 70% < 10,000/yr</p>	<p>Socio-demographic characteristics provided by participant responses and chart reviews.</p> <p>Quality of life assessed through the 36-item Short Form Health Survey and the General Anxiety Subscale of the Brief Symptom Inventory.</p> <p>Social support, material resources, disclosure and family functioning measured with a summated 33-item inventory taken from previously validated scales and researcher-created questions</p> <p>Stigma, emotional distress, intrusive thoughts and fatalism with a summated 43-item inventory taken from previously validated scales and researcher-created questions.</p>	<p>Fatalism, stigma, emotional distress, and intrusion were positively associated with limited daily function, self-reported HIV symptoms, and general anxiety.</p> <p>Material resources and cohesive family functioning was negatively associated with self-reported HIV symptoms, disclosure was positively associated.</p> <p>In the final multiple regression model: disclosure, intrusion and age were significant positive predictors of HIV symptoms.</p> <p>Women who were married/lived with partner reported greater levels of general anxiety and HIV symptoms</p>	<p>Source Population Adequately Described- <i>Good</i></p> <p>Study Population Representative of Source Population- <i>Good</i></p> <p>Measurement Tools Reliable and Valid- <i>Good</i></p> <p>Analysis Appropriate- <i>Good</i></p> <p>Results Reported Appropriately- <i>Good</i></p> <p>Results Clinically Relevant- <i>Good</i></p> <p>Grade- <i>Good</i></p>
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Appendix A: Critical Appraisal Checklist for Quantitative Studies

1. Source Population Adequately Described?

Poor- No description of source population included.

Fair- Description included, but vague and difficult to interpret.

Good- Description included with basic demographics, inclusion and exclusion criteria, and geographic location(s).

Excellent- Description included with basic demographics, inclusion and exclusion criteria, geographic location(s) and justification for decisions.

2. Study Population Representative of Source Population?

Poor- No description of study population included.

Fair- Description included, but vague and difficult to interpret with high risk for selection bias.

Good- Description included with initial comparability to source population, number of refusals to participant, loss to follow up (if appropriate), drop outs (if appropriate). There may be some issues with selection bias, but negative impact is limited.

Excellent- Description included with initial comparability to source population, number of refusals to participant, loss to follow up (if appropriate), drop outs (if appropriate) with detailed outline of steps taken from source population to study population including description of recruitment and detail of potential differences among individuals declining participation. There is little or no risk for selection bias.

3. Measurement Tools Reliable and Valid?

Poor- No description of measurement tools/methods included.

Fair- Description of measurement tools/methods included, but vague with regard to justification of reliability and validity. High risk for measurement bias.

Good- Detailed description of measurement tools/methods and data collectors included. Reliability and validity justified with description of validation process. Some risk for measurement bias.

Excellent- Detailed description of measurement tools/methods and data collectors included, with outline of development processes for questionnaires, etc. Reliability and validity justified with description of validation process including a sophisticated discussion on potential limitations of study's measurement tools (ie: self-reported data) and steps taken to curtail negative impact of such limitations. Little or no risk for measurement bias.

3. Analysis Appropriate?

Poor- No description of analysis included.

Fair- Some description included, but vague. Difficult to understand steps taken in analytical process. High risk for confounding.

Good- Use of appropriate analytical tools. Study may be limited by potential confounding due to nature of study design (ie: cross-sectional, case-series).

Excellent- Use of sophisticated methods of analysis including regression models and awareness of potential covariates. Risk of confounding small.

4. Results Reported Appropriately?

Poor- No reporting of results.

Fair- Some description of results, but vague. Important findings may be missing or not adequately described.

Good- Results described in detail, with tables or charts for ease of interpretation. P-values and confidence intervals used when appropriate.

Excellent- Results described in detail, with tables or charts for ease of interpretation. P-values and confidence intervals used when appropriate. Associations and potential limitations fully addressed.

5. Results Clinically Relevant?

Poor- No reporting of potential relevancy.

Fair- Some description of relevancy, but vague. Potential for external validity low or unknown.

Good- Relevancy described in detail, with justification of external validity.

Excellent- Relevancy described in detail, with justification of external validity and sophisticated discussion of populations to which the study's findings could be related.

Appendix B: Critical Appraisal Checklist for Qualitative Research

1. Did the paper describe an important clinical problem addressed via a clearly formulated question?
2. Was a qualitative approach appropriate?
3. Was the sampling strategy clearly defined and justified?
4. What methods did the researcher use for collecting data? Was the process and its evolution clearly explained?
5. Were data sources used appropriate?
6. Were data collection methods reliable and independently verifiable?
7. Was more than one method of collection used?
8. What methods did the researcher use to analyze the data, and what quality control measures were implemented?
9. Were systematic methods used to reduce the researchers' biases?
10. Did the researchers critically examine their own role, potential bias and influence?
11. What were the main findings? Are they coherent, do they address the research question? Are they credible? Is there data available for independent assessment?
12. Was there inclusion of respondent validation?
13. What are the conclusions? Are they consistent with the data and results (valid)?
14. Are the results transferable to other settings?
15. Should the results be used to influence practice and policy, or to plan more definitive, quantitative research, or neither?

Appendix C: Initial Contact with Potential Participant

As of 2000, adults who are 50 and older are the fastest growing population of individuals affected by HIV in the United States. Women in this age group may experience differences in social stressors, support systems, home life and responsibilities, compared to younger women, that could affect their ability to access medical care, attend regular clinic appointments and comply with medications.

In order to learn more about the particular experiences of women who are 50 years of age and older and who have HIV, I am currently conducting an interview study with women such as yourself. I hope to be able to identify commonalities and difficulties experienced, and use this information to assist physicians, social workers and other care-providers in targeting areas of needed assistance and continuing to improve the care of older women with HIV. The study would involve a one hour commitment on your part that can be scheduled for a time convenient to you.

Would you be interested in talking more about this interview?

If potential participant answers "yes": Thank you for your willingness to participate. Your assistance in the project is very helpful. I will now read through the informed consent and we can discuss arranging a time during which we can complete the interview.

If potential participant answers "no": I appreciate your consideration and respect your decision. Do you have any further questions?

Appendix D: Consent for Research Participation

**University of North Carolina-Chapel Hill
Consent to Participate in a Research Study
Adult Participants
Social Behavioral Form**

IRB Study # _05-2871_____ **Consent Form Version Date:** _January
28, 2006

Title of Study: Characterizing the social contexts of women 50 years of age or
older who are living with HIV

Principal Investigator: Melinda Abernethy, BA

UNC-Chapel Hill Department: UNC SOM/SPH

UNC-Chapel Hill Phone number: 919-260-9328

Email Address: melabern@med.unc.edu

Co-Investigators: Kristine Patterson, MD, Sonia Napravnik, PhD

Faculty Advisor: Merry-K Moos Telephone: (919) 966-1601

Funding Source: None

Study Contact telephone number: (919) 260-9328

Study Contact email: melabern@med.unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is
voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for
any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information
may help people in the future. You may not receive any direct benefit from
being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand
this information so that you can make an informed choice about being in this
research study.

You will be given a copy of this consent form. You should ask the researchers
named above, or staff members who may assist them, any questions you have
about this study at any time.

What is the purpose of this study?

As of 2000, adults who are 50 and older are the fastest growing population of
individuals affected by HIV in the United States. Women in this age group may
experience differences in social stressors, support systems, home life and

responsibilities, compared to younger women, that could affect their ability to access medical care, attend regular clinic appointments and comply with medications.

The purpose of this research study is therefore to learn more about the particular experiences of women who are 50 years of age and older and who have HIV. We hope to identify commonalities among this group of women and better understand difficulties they may experience in caring for themselves and maintaining a healthy life. This information will assist physicians, social workers and other care-providers in targeting areas of needed assistance and continuing to improve the care of older women with HIV.

You are being asked to be in the study because as a member of this population, your personal experiences and opinions are valuable in helping to better understand the social situations of women like yourself.

How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 15-20 people in this research study.

How long will your part in this study last?

Your participation in the study will last approximately one hour, the length of time necessary to conduct the interview.

What will happen if you take part in the study?

If you agree to take part in the study, a time and location for the interview will be scheduled with you at your convenience. A researcher will meet you at the confidential location at the decided time. At the beginning of the interview, the researcher will request permission to use an audio tape to record the interview. If you agree its use, the interview will continue with the use of the audio tape recorder. If, at any point, you become uncomfortable with the audio-tape, it will be turned off and any recorded tape will be destroyed. If you do not agree to the use of an audio tape, the interview will continue without any recording.

The interview itself will involve questions related to your experiences living with HIV. The interview is meant to be a conversation, and therefore, you will be encouraged to share openly. However, if at any point you are uncomfortable with a particular question, you are not required to answer.

After the interview, only the study researchers will have access to your recorded tape. We will transcribe the audio-tape, leaving out any identifying information about you, and destroy the original tape.

Are there any reasons you should not be in this study?

You should not be in this study if you do not wish to discuss aspects of your life and experiences regarding living with HIV.

What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study. However, through the interview you may think about aspects of your life that, if changed, would make it easier for you to care for yourself. If you wished, you would then be able to share this information with your provider(s).

What are the possible risks or discomforts involved from being in this study?

There are no physical risks or discomforts to you for participating in this study. There is always the risk of breach of confidentiality. However, this will be minimized by keeping all study records anonymous and in a locked cabinet. Information regarding your medical condition(s) will be shared only between the three researchers.

How will your privacy be protected?

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

The transcribed interviews and audio-tapes will not become a part of your medical record. Any information that you wish to be shared with your HIV provider or the HIV Social Worker will be honored. Otherwise, all information will remain confidential and tracked through patient identification numbers that are different from your hospital medical record.

The audio-tapes will be stored in a locked cabinet until they are transcribed, no longer than one month. Immediately after transcription, the tapes will be destroyed.

Will you receive anything for being in this study?

You will be receiving \$15 for the completion of the interview.

Will it cost you anything to be in this study?

There will be no costs to you for participating in the study

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

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Title of Study: Characterizing the social contexts of women 50 years of age or older who are living with HIV
Principal Investigator: Melinda Abernethy, BA

Participant's Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

Signature of Research Participant

Date

Printed Name of Research Participant

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

Appendix E: Interview Guide

Introductions:

Thank you for agreeing to participate in this interview. The discussion that we have today will help the researchers on my team better understand how real women such as you experience real day-to-day issues, and how HIV has affected those issues. This information will help your providers continue to make the care they give you as sensitive as possible to the needs of women over 40. While we are here, I want you to feel comfortable in sharing with me any attitudes or opinions my questions may raise. Some of the topics we cover today will be personal. If at any time you do not feel comfortable answering a particular question, or would like for our discussion to take a different path, please let me know and I will adjust the interview accordingly. You can also stop the interview completely at any time.

Before I begin the interview, I will start recording our conversation with this audio tape-recorder. The purpose of recording our interview is to assist me in recovering details of our conversation and putting your experiences, feelings and thoughts into your own words. Following our interview, I will transcribe the interview, leaving out any identifying names, phrases, etc, and destroy the audio cassette. If you feel uncomfortable with the audio recording at any time during the interview, let me know. I will stop recording and continue the interview without the use of the audio tape-recorder. In addition to the tape recorder, I will also be taking notes during our discussion, so that I do not forget to ask questions that arise during our discussion.

Do you have any questions for me about the interview itself or the information I discussed?

Question #1

What are some challenging aspects of your day-to-day life?

Probes:

- a) How have the challenges in your life changed over the past 10 years?
- b) Tell me about your home and the people who live there. Are you responsible for the well-being of any of these individuals?
- c) Is HIV difficult to deal with in your day-to-day life? What about other illnesses or conditions (high blood pressure, diabetes, arthritis, etc)? How does the stress of dealing with other conditions compare to that of dealing with HIV?
- d) How do you get to the UNC clinic? Is this method of transportation ever a problem to obtain?
- e) How many people know about your HIV status?
- f) Do you have a support system to help you out if you need it?
- g) Are there any individuals or organizations that help you handle the challenges in your life? Close friends, close relatives, social workers? Are you involved in a church?

- h) Does your individual faith play a role in helping you to manage challenges in life?
Has this changed over time?

Question #2

Has your life changed since you were diagnosed with HIV?

Probes:

- a) How has being HIV positive affected you? Your daily life? Your perspective on life itself?
- b) How do you feel about being HIV positive? Towards yourself? Towards other people?
- c) Has being HIV positive affected any relationships in your life- with friends, family, sexual partner(s)?
- d) How have your sexual practices changed since you found out you were HIV positive? Are you currently sexually active? (If so- How many sexual partners have you had in the past year? Is this more or less compared to when you were younger? Before you were diagnosed with HIV?)
- e) Tell me about being diagnosed with HIV. How long ago were you first told that you were HIV positive?
- f) When do you think you were infected with HIV?
- g) What led to your decision to be tested for HIV?
- h) What led you to seek care for HIV? How long after being diagnosed did you first see a doctor about being HIV positive?

Question #3

Are you different from women younger than 40 with HIV?

Probes:

- a) Do you think that you have an easier or harder time living with HIV compared to HIV positive younger women in general (or, if diagnosed before the age of 40, when you were younger?)
- b) Are the numbers of clinic visits and hospital stays you have each year more or less compared to younger women living with HIV?
- c) How do you feel about having to go to the doctor for your HIV? Are your clinic visits important to you? Do you have an easier or harder time keeping these appointments compared to younger women with HIV? How do you feel when you are sitting in the waiting room to be seen by your HIV provider?
- d) Do you have an easier or more difficult time taking your medications compared to younger women with HIV? How often do you miss taking a dose of your medications? (If medication doses are missed- What are the most common reasons

- you miss your medications? Are there less common reasons? Do you miss because you can't pay for the medications? Because you did not have time to take the medications? Because you were afraid that someone would figure out that you have HIV? Because the medications are hard to take? Are your reasons for missing doses similar to or different from those of younger women with HIV?) Do you think the reasons younger women in general might miss their medications would be the same as those of a women in your age group? Are there ways they might be different?
- e) Compared to younger women (or if diagnosed before the age of 40, when you were younger), are you more or less likely to participate in a research study here at UNC?
 - f) Do concerns about potential pregnancies and raising children affect how women live with HIV? Is this similar or different between older and younger women? Do you have children? (If so- How many? Were any born after you were diagnosed with HIV?) How long ago did you begin menopause?
 - g) Are older women with HIV more or less likely to use condoms during sex compared to younger women with HIV? (If not similar-Why do you think differences in condom use exist?) Do you always use condoms during sex? Why or why not?
 - h) What about alcohol and drug use? Do you think the amount of use is similar or different between older and younger women with HIV? Have you ever had a drinking problem, or used drugs on a regular basis? Do you now? (If positive history, but no current use- When did you quit? What led to you deciding to become clean?)
 - i) How do you think that we can best reach out to older women your age to educate them about HIV, including women who are already HIV positive as well as women who are HIV negative? Through churches? Forums? In doctors' offices?

Closure:

That concludes the interview. Thank you so much for taking this time to help us learn more about how HIV has affected your everyday life. I also thank you for your openness about difficult and private matters. I was wondering if you have any suggestions for me about how this interview went, because I will be talking to other women and I want to be as respectful as I can to everyone. Do you mind telling me how you felt about this interview? How did it feel to talk about these issues? Were you uncomfortable at any point during the interview? Are there any questions that you think I should have asked? Do you have any questions for me?

Again, thank you!