

Perspectives of Clinicians and Social Services Personnel on Needs of Older Adults with HIV Who Access Healthcare at a Major Metropolitan

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Abstract

We explored the perspectives of clinicians (nurses, nurse practitioners, and physicians) and social services personnel (i.e., case coordinators, social workers) on the needs of older adults living with HIV and who receive healthcare at a major metropolitan hospital. We utilized a small qualitative study (n=10) as a means of developing an understanding of the perspectives shared within the framework of inter-professional collaboration for purposes of quality care for older adult patients with HIV. Five themes emerged from our qualitative research study. The first theme involves the idea of access to healthcare while the second theme suggests that older adults with HIV experience psychological issues. Third, older adults with HIV demonstrate high levels of adherence to medication regimens. Next, HIV is no longer viewed as a 'death sentence'. Finally, education across disciplines and professions is necessary.

Keywords: HIV; Hospitalization; Inter-professional collaboration; Older adults; Perspectives of clinicians; Perspectives of social services personnel; Qualitative research

Introduction

HIV among older adults is not uncommon. On the contrary, older adults – defined in the literature as 50 years old or older [1] are known as an overlooked epidemic and silent risk group [2] as a result of the increase in the numbers of older adults diagnosed with this chronic health condition [3-5]. Because of highly active antiretroviral therapy (HAART), the numbers of older adults living longer with HIV has increased dramatically [6,7], though estimates suggest that approximately 20% of adults living with HIV and within the United States do not know that they are HIV-positive [8]. This occurrence also may be due to the misconception that older adults are not susceptible to contracting HIV [4,9].

Thus, the clinical course of HIV as well as the need for various clinical and social services differ for older adults as compared to other age groups, particularly given the lack of a 'gold standard' for adherence assessment and interventions pertaining to HIV [10] regardless of the age of the individual. Although any number of perspectives exist with regard to the types of resources that might be useful in establishing a 'gold standard' for adherence, its assessment, and pertinent interventions, clinicians and researchers acknowledge that adherence assessment and interventions consist of a complexity of issues involving cultural, economic, personal and social factors [10,11]. Rather than engaging in debates while searching for the 'elusive gold standard,' perhaps the efforts, focus and time of clinicians and researchers would be better spent in recognition of one or more models that may act to guide assessment and interventions as these pertain to the needs of older adults with HIV from the perspectives of clinicians as well as researchers [10].

Literature review

Research demonstrates that clinicians (e.g., nurses, nurse practitioners, physicians) fail to recognize the presence of HIV in older adults [4,5,12]; the same may be said for social services personnel, including social workers [12]. Subsequently, clinicians and social services personnel do not tend to suggest testing for HIV [5,9,13,14] possibly resulting in older adults being diagnosed with HIV later than their younger counterparts [4]. This is unfortunate, given research indicating

that older adults comprise the fastest-growing population of individuals with HIV infection [3,4,6,15] and that approximately 10% of individuals with AIDS in the United States are 50 years old and over [4,5].

Yet, what sorts of needs arise for older adults with HIV as this population of patients is treated and cared for within the hospital setting? The literature is sparse with regard to qualitative explorations of the needs of older adults with HIV. This is especially the case in relation to older adults with HIV who access healthcare through the hospital setting. Particularly as these needs apply to the behavioral, physical, socio-emotional, and spiritual health of older adults with HIV, clinicians and social services personnel are vital to the development of an awareness and understanding of these factors [5,10,12,16-18].

Clinical challenges and the experiences of older adults with HIV

Any numbers of clinical challenges exist as a result of issues pertinent to older adults with HIV. To being with, a number of older adults do not place trust in the testing that determines the presence of HIV and sero-positive status [16]. This results in the clinical challenge of attempting to encourage older adults to seek testing for HIV, even though this group of older adults may be resistant to the idea because of a lack of trust in the healthcare system [19]. Unsafe sexual practices and an unwillingness to discuss sex with (potential) partners are risk factors that may increase the occurrence of HIV in older adults, thereby resulting in clinical challenges associated with educating older adults on safer sexual practices as well as the importance of adherence to a regimen of antiretroviral medications for the treatment of HIV, if present (e.g., as a result of unsafe sexual practices) [17].

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Age-related physiological changes that may increase the number of entry points for HIV infection [3-5] are another potential source of clinical challenges, particularly given the potential for comorbidities and the need to treat these conditions along with HIV. Additionally, gender appears to act as a risk factor, as women over the age of 50 are diagnosed with HIV more often than men in the same age group [3,4]; this is believed to result from the physical changes (e.g., vaginal dryness, tearing of vaginal walls) that many post-menopausal women experience [3,4]. At the same time, men over the age of 50 who have sex with men constitute the group of individuals who most frequently receive a new diagnosis of HIV [20]. The potential for clinical challenges associated with gender differences may be alleviated somewhat by means of educating female and male patients about changes that may occur to their bodies because of (1) age and (2) HIV.

Additionally, symptoms of HIV and AIDS may be mistaken as signs of the normal aging process [2-4,20]; one such symptom presumed to be associated with the aging process is a decline in immune function and resulting infections such as pneumonias [20]. Misconceptions about aging with HIV and AIDS versus the normal aging process present clinical challenges in that assessment and evaluation skills must be strong so as to discern whether active disease is present and, if so, which course of treatment is preferred. Likewise, polypharmacy for treatment of comorbid health conditions [5,18,21,22] as well as the prevalence of the comorbid health conditions themselves are considered to be more common in older adults as compared to younger adults, thereby potentially masking the progression of HIV in older adult populations [2,4,18,20]. In particular, the presence of depression in older adults with HIV may be overlooked by clinicians, even though depression may be related to comorbidities experienced by older adults with HIV [18,23].

The need for interventions

Once identified, the needs of older adults with HIV may be addressed by means of interventions that address clinical challenges and solve clinically-related problems as they present themselves in hospitalized older adults with HIV [10,20]. Specifically, education is believed to be of utmost importance in helping to prevent HIV in older adults [4,6]. In particular, education for older adults is necessary with regard to the types of sexual acts that require consistent use of protection against sexually transmitted infections, including HIV [3]. Likewise, older adults should be encouraged to discuss HIV serostatus with sexual partners [3], despite the hesitancy of many in this population of older adults to discuss sexual relationships in an open and outspoken manner [4,12]. Not surprisingly, then, education is needed as to what HIV is, how it is transmitted, and how to prevent oneself from contracting HIV [12,21].

Primary objective and research question

Education is most effective when clinicians and social services personnel working in the hospital setting are aware of and understand the needs of older adults with HIV. In this way, clinicians and social services personnel are able to address behavioral, physical, socio-emotional, and spiritual health needs of older adults living with HIV. Given the lack of research on specific needs of older adults with HIV as defined by clinicians and social services personnel, we ask the question: According to clinicians and social services personnel who work with hospitalized older adults diagnosed with HIV, what are the needs of this patient population?

Background to research question

Originally, our research sought to explore patient perspectives

about their needs, as the presumption is made that patients themselves know what their needs are. Yet, based on our interactions and work with clinicians and social services personnel by means of inter-professional collaboration within the hospital setting for the care of older adult patients with HIV, we believe that clinicians and social services personnel also are aware of the needs of patients with HIV. We believe that clinicians and social services personnel can speak in a more objective manner on these needs.

Gaining the perspectives of patients is only one way in which to explore our research question; asking clinicians and social services personnel for their perspectives provides another effective manner in which to do this. Thus, our research explores the viewpoints of nurses, nurse practitioners, physicians, and social services personnel with regard to the needs of older adults with HIV. As a result, we then can begin to identify appropriate interventions to address these needs effectively in relation to hospitalized older adults with HIV.

Methodology

Type of study and rationale

A qualitative approach was employed in this exploratory research due to its appropriateness for use with newer areas of research, namely that pertaining to inter-professional collaboration and perspectives of clinicians and social services personnel on the needs of older adults with HIV. Exploratory research permits the asking of questions and, in turn, the acquisition of illuminating, rich data that provide insight while increasing awareness and understanding of said perspectives. By utilizing a narrative approach in order to listen to, record, and interpret the perspectives of nurses, nurse practitioners, physicians, and social workers as well as case coordinators who work with hospitalized older adults with HIV, we sought to develop greater awareness and understanding of the needs of this population of patients.

Setting and time frame

This study took place at a major metropolitan hospital of an inner city area located in the Eastern United States. The study took place over the course of three months. Specific interviews occurred in the private office of one of the researchers during the dayshift hours (7 am to 3 pm).

Participants

Our sample size consisted of ten participants. The ten participants in our research study were categorized as follows: registered nurses (n=2), nurse practitioners (n=2), infectious disease physicians (n=2), clinical social workers (n=2), and case coordinators (n=2). Our rationale for selecting these participants included the requirements that all were employed within this same major metropolitan hospital and also regularly had contact with older adult in-patients diagnosed with HIV (e.g., by working on an infectious disease unit) Because generalizability is not the goal of qualitative research, a large sample size was unnecessary for this study.

Data collection and rationale

Semi-structured interviews were used as a means of collecting data and information so as to learn about the perspectives of nurses, nurse practitioners, physicians, and social services personnel who work with hospitalized older adults diagnosed with HIV. Based on our clinical experiences/expertise as well as the literature (though limited in nature), we developed an interview guide that includes a series of structured questions as well as a number of open-ended questions (Appendix A).

Time frame for semi-structured interviews

Interviews took place over the course of 30 minutes to an hour, given the limited time that busy clinicians and social services personnel possess in which to be interviewed. Participants received a post-interview payment of \$50 for their time. With permission of the interview participants, all interviews were tape-recorded and transcribed within 24 hours. Otherwise, notes were taken as the interviewees answered the questions. Interview transcripts were reviewed by the researchers for the presence of themes surrounding the needs of hospitalized older adults diagnosed with HIV (for specific interview questions, see Appendix A).

Data analysis

By using a semi-structured interview approach, we planned to include additional participants only if saturation of the data (e.g., repeated themes) was not reached after we interviewed the sample of ten clinicians and social services personnel. By means of conventional content analysis, we focused on the characteristics of the language content found within the text of the transcribed interviews [24,25]. After data were collected via the semi-structured interviews, we used conventional content analysis in order to recognize and systematically categorize data [24,25].

We then used narrative summary analyses as a means of taking apart and then putting back together the data so as to discover the essences that emerged from the information provided to us by the ten participants in this study [24]. Each researcher independently reviewed the interview transcripts and determined the categories (themes) that emerged from the data. Then the researchers collaborated and compared their results, agreeing on a total of five themes. The entire process of comparison took approximately three months. The decision to use conventional content analysis was based on the rationale that existing research and theory are limited in relation to the perspectives of clinicians and social services personnel on the needs of older adults with HIV.

Ethical concerns

Approval of Institutional Review Board (IRB): Before beginning our qualitative research study, we obtained IRB approval at this large, inner-city hospital in which we proposed to conduct our research. After this step was completed successfully, we posted fliers on units throughout the hospital while also using word-of-mouth communications during inter-professional meetings so as to recruit a sufficient sample size of approximately ten individuals employed either as clinicians (e.g., nurses, nurse practitioners, physicians) or social services personnel (e.g., social workers and case coordinators) who work with older adults diagnosed with HIV. Recruitment took place over the course of one month, after which we acquired our targeted sample size of ten individuals.

Confidentiality, privacy and security of information: Confidentiality and privacy of the clinicians and social services personnel were maintained throughout the entire study. This is evidenced by our maintaining records of the interviews in accordance with applicable federal and state laws. Likewise, the hospital in which the research was conducted requires that records are maintained in a securely locked cabinet in the locked office shared by the researchers. Also, the hospital in which the research occurred has the requirement that a computer designated only for the purpose of this research is used. We followed these requirements so as to maintain the confidentiality and security of our interview transcripts as well as information pertaining to the ten interviewees.

Results

Our results revealed five themes that emerged from this qualitative research study. These themes are as follows: (1) accessibility to HIV medications; (2) coping and psychological issues; (3) older adults adhere to medication regimens; (4) HIV is not a 'death sentence'; and, (5) the necessity of education. Exemplars of each of the five main themes are included below.

Theme 1: accessibility to HIV medications

Overall, the patients with whom the clinicians interact have access to the medications for the treatment of HIV. In particular, the state in which this large metropolitan hospital is located has programs to assist with the costs of antiretroviral medications. Exemplar statements of this phenomenon are as follows:

- *I don't think that (accessibility to HIV medications) is a problem for the people that are poor, because their medications are free. They go to the clinic and they get their medications for free. – RN #1*
- *As far as accessibility of medications, it's not bad. Actually, they get their medications from social services provided in different clinics, depending upon the clinic.*

-- Infectious Disease Physician #1.

- *Accessibility... I think, in my experience with HIV, patients have very good accessibility to medications because the government is paying for it.*

– Infectious Disease Physician #2.

Theme 2: coping and psychological issues

Older adults with HIV appear to have a greater number of psychological issues as they age. Not only this, but individuals in this population of patients face seclusion and social isolation. Exemplar statements of this theme are as follows:

Usually, patients who are older than 50 with HIV... have... more psychological issues associated with the diagnosis... They can have a lot of depression... I think that the biggest negative coping strategy is that the patient has to deal with seclusion. When they are secluded and to themselves, I think it makes them quite worse.

– Infectious Disease Physician #2.

This physician goes on to state that the general reaction of older adults to the diagnosis of HIV is one of denial and surprise:

They are surprised. (Long pause.) Sometimes there is huge denial. It takes them a longer time to accept the diagnosis (of HIV)... it's very difficult... The majority of patients are afraid that they will be physically rejected from their peers, and I think that this is the biggest problem. They are not accepted... and experience peer rejection.

– Infectious Disease Physician #2

One statement suggests that the reaction of older adults diagnosed with HIV is that of shame:

They have a lot of shame, you know. A lot of shame. It's something that they weren't expecting. A lot of them have very little knowledge about HIV, and when they start talking about it, you know, they're really surprised. – Adult Nurse Practitioner #1

And we have families from here for whom this is a big tragedy... At

the beginning, they think that there has to be a mistake... They want to do the test again. You know a lot of denial. Denial and shame. – Case Coordinator #1.

Yet, older adults with HIV seem to be 'getting through' their experiences while living with HIV:

I think that the coping strategy is that they live day to day. Which I think seems to be kind of what all of these older people do. Not just one... they're getting through this admission or they're getting through this infection. And that's what they focus on is getting through that. – RN #2.

Theme 3: older adults with HIV adhere to medications

Overall, older adults diagnosed with HIV are highly adherent to antiretroviral medication regimens, as evidenced by the following exemplar statements:

I think that the older they are, the more likely they are to be compliant. I think that's the reason they are older. (Laughter.) They have made it. – RN #2.

Surprisingly, (older adults with HIV) are some of the most compliant patients... and I mean those older than 60. They tend to be very compliant with their medications. I think that, in my population, it's a cultural issue. Some of them have been infected unknowingly... and they're very concerned. They're worried about, you know, dying from this disease. -- Adult Nurse Practitioner #2.

Those patients who are on medications and who are compliant, if you show them their numbers... like you show them their CD4 count is good and you show them their viral load is undetectable... you have a positive impact... This just definitely has an impact on the patients, and they can be more compliant with the medications.

– Infectious Disease Physician #1.

Theme 4: HIV is not a 'Death Sentence'

Older adults with HIV are living long, relatively healthy lives as adequate care and support are provided. This is evident by the following exemplar statements:

They're living longer... (and) they're now over the age of 50 or 60... and the medications came out and, you know, we're having people live longer. – Case Coordinator #2.

I have (older) patients whose... viral load is undetectable, and they're doing great. And they're living a perfectly normal life. – Infectious Disease Physician #1.

This physician goes on to say that:

(N)owadays, if (older adults with HIV) adhere to the medications, if they are not doing active drug use, they can live normal lives... (HIV) can be treated. There's no cure, but you can treat it like you'd treat hypertension. Which reminds me that one of my attending (physicians) tells me that, if given the choice between diabetes and HIV, he would choose to live with HIV rather than diabetes. – Infectious Disease Physician #1.

Theme 5: education is necessary

Education is necessary for many reasons in hospitalized older adults with HIV. One such reason is to help older adults with HIV avoid unemployment:

(An unmet) need is that, since their education status is so low, they have trouble finding employment. Some of these patients have been incarcerated... and started with a very poor life, a terrible life syndrome.

So, it's very difficult for them – on the basis of their previous life history – not only to gain education but also regarding employment.

– Infectious Disease Physician #2

Another benefit of education is to facilitate adherence with antiretroviral medications for the treatment of HIV, especially if older adults with HIV use and/or abuse illicit drugs:

The most important thing is to provide education regarding IV drug abuse. If you can make them not use IV drugs, then they could stay compliant with medications. They can live a normal life. So, that's the most important thing... education about not doing IV drugs. – Infectious Disease Physician #1.

Education allows for the asking of questions by clinicians and social services personnel, in order to help older adults with HIV maintain their health status longer:

I feel that HIV should be (something) that every provider taking care of the older population should educate their patients and ask questions. A lot of times, we're afraid of asking questions... When we get to (the point of diagnosis of HIV), it's very hard to make them healthy again. Their immune system is already so low.

-- Social Worker #1

If we don't ask (older adults with HIV) any questions, (then) how are we going to know what the best answers are? – Social Worker #2

Synthesis of themes

While each of the five themes stands alone as a potential area of intervention with regard to the needs of older adults with HIV, together these themes represent a collective experience and perspective about the ways in which the inter-professional healthcare team can and should work to benefit older adults with HIV who access the hospital setting for treatment. Thus, in order for treatment to occur, access to healthcare (theme 1) is an absolute necessity for this group of individuals. In turn, access to healthcare and treatment as provided by an inter-professional team consisting of clinicians and social services personnel allows older adults with HIV the opportunity to view this condition as chronic rather than as a 'death sentence' (theme 4). Furthermore, the ability of the healthcare team to address the psychological issues faced by older adults with HIV (theme 2) rests upon this group's being able to access healthcare professionals (theme 1) who are able to educate patients about the realities of living with HIV (theme 5); this includes the idea supported by clinical research that HIV can be thought of as a chronic health condition (theme 4) that responds to management and treatment with medications (theme 3).

Discussion

The perspectives of clinicians and social services personnel valuable within the hospital setting, and these perspectives have potential for informing and shaping healthcare policy as it pertains to the five themes at an individual level as well as a collective, more synthesized level. Access to healthcare (theme 1) is an ongoing issue for older adults with HIV [26] that may be brought more vigorously to the forefront of healthcare policy by the actions of concerned clinicians and social services personnel who are knowledgeable about the difficulties faced by older adults with HIV in accessing quality healthcare across the continuum of hospitalization as well as community-based services. By accessing healthcare in a consistent and timely manner, older adults with HIV may have psychological issues addressed (theme 2) [23,27,28] received education about the need for adherence to antiretroviral

medications (theme 3) [21,29], and learn that HIV does not have to be viewed as a 'death sentence' (theme 4) but rather as a chronic health condition that requires ongoing management and treatment. Clinicians and social services personnel who are knowledgeable about older adults with HIV while also applying this knowledge towards healthcare policy (theme 5) may impact most favorably the duration, intensity, and meaning of the lives of older adults with HIV [26].

Limitations

While large sample sizes are unnecessary for qualitative research approaches, we acknowledge that the addition of participants to our original sample of ten likely would have contributed to our results being more advanced in focus and form. Arguably, our results are presented in their initial form that may benefit from additional analysis and synthesis as well as interpretation based upon the interviews of a greater number of participants. We begin to approach a richness of data through the analysis, synthesis and interpretation of the results of the ten interviews included in this research study. Yet, the development and inclusion of a greater number of open-ended questions on the interview guide - coupled with greater amounts of time on the part of busy clinicians and social services personnel - may contribute to a more complete and exhaustive set of themes emerging from the text of the interview transcripts. At this point in our research study, we believe that saturation was reached; however, we would like our future research involve a more in-depth interview guide as well as the allotment of greater amounts of time in which to interview clinicians and social services personnel.

Conclusions and Implications

Although the results of this qualitative research study are not generalizable to the larger population, the five themes that arose from our exploratory research study suggest a starting point for the basis of studies that are broader in scope and that examine the perspectives of an even greater number of healthcare professionals. Future research involves by means of additional qualitative research studies as well as quantitative studies in order to capture more fully an understanding of the needs of older adults with HIV as well as potential interventions to address these needs. Mixed methods studies may be used in order to capture these perspectives.

Based on the themes that emerged from this exploratory research study, five key points can be made. First, access to healthcare is present in a vibrant manner within the state in which this research study took place; specifically, this is the case with regard to the provision of the anti-retroviral medications to older adults for the treatment of HIV. Such is not the case for all states, however [26], and policies such as the Affordable Care Act (ACA) aim to change the lack of healthcare coverage within the United States.

Second, older adults with HIV tend to experience a greater number of psychological issues, according to the results of our research. Implementation of policies such as the ACA would help in 'paving the way' for the provision of psychological care that may not be present on a consistent basis throughout the course of treatment for older adults affected both physically and psychologically by HIV. Third, older adults living with HIV are highly adherent to their medication regimens. As a result, the potential exists for the healthcare system to be spared the high financial costs related to the hospitalization of older adults with HIV for the treatment of conditions such as pneumonia (e.g., *Pneumocystis jiroveci*) and other infectious conditions that may affect individuals whose immune systems are compromised. Because patients

with HIV require guidance throughout the course of antiretroviral treatment, the perspectives of clinicians and social services personnel are imperative to patients' health status being improved and maintained over the life course.

Next, HIV is not a 'death sentence.' At the same time, older adults with HIV must access the healthcare system in order to receive the medical and nursing treatment needed to augment and enhance the chances of survival. Policies that allow for individuals with pre-existing conditions such as HIV to take part in health insurance exchanges at the state level [26] significantly help to remove one of the most formidable barriers to treatment: the lack of access to healthcare [26]. Finally, education is necessary for older adults with HIV, their families, and inter-professional teams of clinicians and social services personnel with regard to the needs of older adults with HIV as well as appropriate interventions to address these needs. Surely, the clinicians and social services personnel in the hospital setting and who work most closely with older adults diagnosed with HIV would be able to provide an even higher quality of care if patients, their families, and working teams consisting of professionals across disciplines were to receive ongoing education pertaining to the needs of older adults with HIV.

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