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The relationship between social roles and self-management behavior in women living with HIV/AIDS

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Introduction

Many people perform multiple social roles in their daily life, and in modern society, women are encouraged not to identify too closely with any single role but rather, to move between roles. In this paper, social role is inclusively defined as an individual's position in a social situation, which has clearly definable limits, internally consistent responses, and characteristics known to the general public (Cottrell, 1942; Henry, 1949). Much of the work on women's health and social roles has focused on issues associated with employment, family, or caregiving for an ill family member (Maclean, Glynn, & Ansara, 2004; Pavalko & Woodbury, 2000; Pinquart & Sorensen, 2006). Much less is known, however, about the social roles of women who live with a chronic disease such as HIV/AIDS. Similar to other populations such as diabetics, these women juggle the social roles mentioned above along with their role as an HIV/AIDS patient, a role that frequently is accompanied by stigmatization and always requires many daily tasks to maintain health and slow HIV disease progression. This care includes adherence to medication for HIV and comorbid conditions, symptom monitoring, diet changes, hygiene, physical activity, and preventing transmission to others (Beaglehole, et al., 2008; Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003; Swendeman, Ingram, & Rotheram-Borus, 2009). For women with HIV/AIDS, each of their social roles can both facilitate and inhibit the ability to manage their disease (Hackl, Somlai, Kelly, & Kalichman, 1997). The purpose of this paper is to identify and examine the main social roles of 48 HIV infected women, and to explore how these roles relate to their self-management of HIV/AIDS. All data are from focus groups designed to elicit information about how the women manage their disease.

Background and significance

In the United States an increasing number of women are infected with HIV. In 2007, 26% of all new HIV diagnoses in the United States occurred in women and, disproportionately, in African-American/Black women (~66%) (Centers, et al., 2010). The growing incidence in women has been explained, in part, by ecological challenges. Women are more impoverished than their male counterparts, which leads to less control over their lives and seemingly fewer choices (Rodrigo & Rajapakse, 2010). In the United States, poverty is perhaps the biggest risk factor for contracting HIV (Adimora & Schoenbach, 2005). One explanation for this is that chronic poverty contributes to women trading sex for housing and food (Adimora & Schoenbach, 2005; Amott & Matthaei, 1991). Additionally, minority communities tend to have fewer men than women due to increased incarceration rates, which can lead to marital instability and more female-headed households (Amott & Matthaei, 1991). Recently, a community-based surveillance study in Washington, DC, found that increased risk for HIV infection in the African-American/Black female community is related to social networks, rather than to individual risk factors (Magnus, et al., 2009), a conclusion that is supported by other research (Campsmith, Rhodes, Hall, & Green, 2009; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009; Kimbrough, et al., 2009; Stratford, Mizuno, Williams, Courtenay-Quirk, & O'Leary, 2008).

Traditional Social Roles for Women

In the face of these challenges, the social roles for women living with HIV/AIDS might be different than traditional social roles. However, the literature provides no data on this topic. A review of the literature yielded information on two traditional roles of American women: the employee and family roles.

Employee Role

Throughout history few women participated in the ideology of domesticity, where women worked in the home as “nurturers of children and civilizers of men, where wives stayed in the home to enjoy leisure, aided by servants” (Amott & Matthaei, 1991), p 298). Today, women comprise almost 47% of the U.S. labor force, a figure expected to grow in the next five years, and women have never had wage parity with male workers. In 2008, women employed full time earned 80% of their male counterparts' salary. Additionally, in 2008, women had an unemployment rate of 5.4%, compared with 6.1% for men, the highest unemployment was among black women (8.9%). For women living with HIV/AIDS, gainful employment can be a source of pleasure and a way to give back to society as well as providing money, insurance, stability and independence from a reliance on their partners. However, work can also add stress, especially when deciding whether or not to disclose their HIV status to co-workers-- a highly stressful and potentially stigmatizing event (Swendeman, et al., 2009). Work schedules can make it difficult to monitor symptom changes, enhance health promotion activities (diet, sleep and physical activity), and adhere to medication and other medical treatment plans. Barriers to these self-management tasks negatively impact one's health; however, there are many positive benefits of working that can be attained through balance of one's personal and professional goals with the commercial needs of the employer (Braveman, Levin, Kielhofner, & Finlayson, 2006; Vetter & Donnelly, 2006).

Family Roles

Breadwinner: Households in the United States are increasingly run by single women. Eighty-five percent of all single-parent households are run by women. Of those, 34% of these families are living below the poverty line and 66% of all female-headed households

have a family income less than \$40,000/year (compared to 15% and 45% of male-headed households, respectively)(Bureau, 2010). Accordingly, women have increasingly assumed the role of the family “breadwinner”. Breadwinner has been defined as the “extent to which (one) provides support for his (or her) family” and success was defined as “(one) whose partner does not have to enter the labor force” (Bernard, 1993; Gerson, 1987; Zuo & Tang, 2000).

Caregiver: Historically, the domestic role of caregiver is one in which women “perform unpaid tasks to satisfy the needs of family members or to maintain the home and the family's possessions” (Aguiar & Hurst, 2007; Evans & Thomas, 2009; Lachance-Grzela & Bouchard, 2010). These tasks often include cleaning and cooking, but also intermittent tasks such as car maintenance and yard work as well as emotional work in caring for family members. If the family has children, childrearing is a prominent part of the caregiving tasks. While women living with HIV/AIDS may not be considered average American women, this literature contextualizes the competing demands these women have on their health.

Today, in American society, the traditional roles of breadwinner and caregiver extend to non-traditional families. As seen in our sample, women assume these roles when caring for parents, nieces, nephews, siblings, partners, and friends. These evolving roles have both a positive and negative impact on self-management in women living with HIV/AIDS.

Materials and Methods

All participants were recruited through flyers left at Infectious Diseases clinics and AIDS service organizations in Northeast Ohio. Interested volunteers were instructed to call the research telephone line for screening. A research assistant assessed each caller for the following inclusion criteria: adult, biologically female, English-speaking, and having a documented HIV diagnosis. For callers who met the inclusion criteria, the research assistant explained the study's purpose and procedures and, if they agreed to participate, were scheduled for a focus group and sent an informed consent document to review. At the focus group, informed consent was explained and assessed prior to starting the session. All participants also completed a short demographic survey and gave consent for medical chart abstraction.

The data for this paper come from a larger, ongoing investigation to understand how women living with HIV/AIDS best manage this and other chronic conditions (Webel, 2009). Based on our literature review, we developed a semistructured interview guide to elicit answers about self-management of HIV. Each focus group contained 2-10 women and was digitally recorded. The qualitative data were transcribed verbatim and content analysis was used to analyze the data (Milne & Oberle, 2005; Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005) In this study, the research team read the transcripts and identified patterns, themes, and important features, while looking for commonalities and differences. Codes were inductively derived from, and systematically applied to, the data. The interview guide was refined according to these changes. Once data collection was complete, we finalized codes and two readers independently reread the transcripts, applied new codes, and met to compare coding. There were a few differences in coding, which were resolved by discussion. Transcripts were coded and entered into Atlas.ti (Scientific Software Development, Berlin, version 6. 2010) to assist with analysis (Atlasti, 2010).

All study procedures were approved by the Institutional Review Committee for the Protection of Human Subjects at University Hospitals, Case Medical Center in Cleveland, Ohio.

Results

Between January and May 2010, 48 HIV-infected women participated in 1 of 12 focus groups. One woman (2%) refused participation due to confidentiality concerns. We had predominantly middle-aged (mean=42 years), African-American (n=33; 69%), and single (n=28; 58%) women in our sample. Almost all of the women had children (n=43; 90%) and about 20% of the sample was currently employed. Additional demographic and medical characteristics of the participants can be found in Table 1.

Analysis of the qualitative comments revealed six predominant social roles that these women experience and which impact their self-management: Mother/Grandmother, Believer, Advocate, Stigmatized Patient, Pet Owner, and Employee (Table 2). These roles both positively and negatively impact a woman's self-management of her HIV disease and vary by age and experience living with HIV. Representative quotes from the focus group participants are included to illustrate the impact of these social roles on self-management.

Mother/Grandmother

The most frequently cited social role was that of mother/grandmother (n=18; 38%). For most women citing this role, their children and grandchildren were a source of inspiration and purpose to manage their HIV disease and prevent further illness.

“the grandchildren--that inspired me to take my meds.... He can also see me alive... I could be able to interact with him, and he wears me out. He's a 1-year-old and he wears me out, and so I get him every weekend ... so I can spend time with him” *51 years old, Caucasian, Diagnosed in 1989*

“I have a 6-year-old and I have seven grandbabies, and what I do today is I chill out with them. I'll go play something. My 6-year-old, me and him go down to the Tower City, grab a movie, eat lunch. My grandkids, I get them over on the weekend. I'll take them. I've got a bunch of nieces and nephews. Surround myself around kids today. That's what I do you know to keep me motivated. They said, my family said, I'm the mom and I'm the grandma and I'm the auntie that likes to kick it with the young crowd, but they, I tell them all the time they will keep me living. They will keep me living today. I think if I wouldn't be able to spend and enjoy time with them, I would sorrow, I would moan and stay in this pity party and be gone, you know, don't care about nothing, give up.” *41 years old, African American, Diagnosed in 2001*

However, sometimes an HIV diagnosis added negative stress to the responsibilities of juggling the mother role with disease management. This was especially prominent in the female-headed households.

“I can't afford to be sick because I'm a mom that has to take my kids to college and pick them up and take them to work and pick them up.” *51 years old, Latina, Diagnosed in 2001*

The role of mother and grandmother was generally reported to be a positive role. The participants looked forward to interacting with their children and grandchildren and completing the responsibilities of this social role. This social role was helpful in motivating some participants to perform self-management behaviors. But occasionally, the disease confounded the participant's ability to fulfill this role and added additional stress to their lives.

Faith Believer

A range of personal faith beliefs, both spiritual and practical, were a source of hope and were perceived as directly improving participants' health and self-management ($n=13$; 27%). Women spoke of their faith and of following rituals (prayer, church attendance) to help them cope:

"I think being a Christian kind of helps you know, and having faith in God or whoever you pray to, I think that helps a lot." *43 years old, African American, Diagnosed in 1997*

"When I got sick, I lost a lot of weight. I usually weigh about 130. I lost (weight) down to 98 pounds and I was scared. My husband would come in and catch me crying because when you're a heavier person and then you look in that mirror, I could just see. You know I just seen myself wasting away and it was like there was nothing I could do to stop it. So I had gotten saved while I was incarcerated years and years ago, and I went back to church and I just turned all my anxiety over to the Lord and let him deal with it, and I started picking up weight again. I'm up to almost 120 pounds, and I'm okay." *51 years old, Caucasian, Diagnosed in 1989*

Women also spoke of having faith in their physician, someone who provided advice in which they had confidence. A provider who supplied expertise and guidance in managing her disease but who also listened, recognizing that the woman was an active, not a passive follower.

"My doctor has been my doctor for 16 years. When I was in active drug addiction, she was there for them four years when I used ... off and on, and she was there throughout the whole process. I trust my doctor so much that whatever she says do, I do. Listen to your doctors. Take the darn pill." *46 years old, African American, Diagnosed in 1993*

"I love my doctor He's a real funny doctor, but I'm cool with him. He said, your exercise ain't working.' He gon' say 'Lay off the fried chicken and the french fries.'" *38 years old, African American, Diagnosed in 2003*

In these social situations the women were following advice given to them and because they had faith in the providers, the women performed the prescribed self-management practices. Prayer, church attendance, medication adherence, and exercise were the outcomes of meeting the responsibilities of this social role. These behaviors are attributed to their role as a faith believer and directly and indirectly affected the HIV self-management practices of the participants.

Advocate

The participants were experienced at living with HIV/AIDS, and many of them expressed gratitude for their emotional and spiritual growth after their HIV diagnosis. In recognition of that gratitude, several participants expressed a desire to help prevent other women from engaging in behaviors that would lead to HIV infection ($n=12$; 25%).

"My goal is, I'm trying to go to school and become a Chemical Dependency Counselor, because my mind frame is to try to reach the younger group, because they're out there. The teenagers, they just don't know and to try to get them information to have them stand a chance by the time they get to that age of being adults" *48 years old, African American, Diagnosed in 1998*

"I even give out condoms to my girlfriends. So for me, disclosure is a part of carrying the message and letting people know, „Hey, it don't have to happen. Use

protection.' But disclosure is wonderful because I want them to see the beautiful person that I am today." *46 years old, African American, Diagnosed in 1998*

"I've just been blessed truly as far as living with this disease. I truly have. I've been places where I've never thought I would've been, to conferences all over the United States, speaking. I've truly been blessed. Not that I wanted to do these things, but God came into my life and said This is what I want you to do." *49 years old, African American, Diagnosed in 1991*

The social role of advocate asks women to disclose their illness and the risks of transmission. This disclosure required an acceptance of the HIV condition by the participants. Self-acceptance has been linked to increased self-management practices and has been found to mediate positive health outcomes in other chronic disease populations (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007; Lillis, Hayes, Bunting, & Masuda, 2009). This role also made the participants more aware of their behavior, almost as a role model.

Stigmatized Patient

For nine (19%) of our focus group participants, HIV stigma was described as a role that had a harmful impact on their disease self-management. It prohibited women from disclosing their HIV status, seeking out social support, and acknowledging self-management tasks (Chenard, 2007; Swendeman, et al., 2009).

"I took a chance by telling her, and it's kind of like when I told her, she kind of like caretake me and I don't want that. You know don't take my sickness as if I'm in a coma or something. You know it's okay to come check on me every now and then, but don't try to pamper me and stuff like that. Just continue to be my friend, you know. That's all I want you to do." *32 years old, African American, Diagnosed in 2006*

"I still wouldn't say anything or let anybody know about us because I was afraid that they would judge her (HIV-infected daughter) for my mistake. So I never told anybody while she was young... I used to always try to protect her.... I would take her to school, none of her teachers knew. Nobody would know about our situation. If she was missing for a week because I was in the hospital, nobody would know. My sister would take her or there would be some kind of work around so that nobody would find out, because I didn't want my daughter hurt, and God forbid somebody threw a comment at her that was inappropriate, I think I would've lost it.... I didn't say anything. I kept it to myself. It was killing me, because it's hard. You won't have anybody to support you because you're afraid that they're going to reject your child, so you've got to deal with her pain and your pain, and the toughest thing in the world because you love her so much." *38 years old, Caucasian, Diagnosed in 1998*

Women reported that interactions with their community were shaded by the stigma that HIV was a dirty, deadly disease. Some participants in this study tried to avoid this stigma, for themselves and their family, by not disclosing their HIV status.

Pet Owner

Ten percent (n=5) of the sample identified their role as a pet owner as being helpful in managing their HIV disease. Pets were a primary source of support and pleasure.

"... I got my cat, Sunshine, and that's my baby. She's gong to be right there when I'm hurting, and that's unconditional love. She asks for nothing. She's right there for me, and I feed her and she'll get up on the couch with me, and she knows when I'm

feeling bad, because ... she'll rub up all against me and she'll look at me and she'll touch her nose to my nose and I know she knows that I'm feeling bad on the inside, and then I'll sing this little song that I sing You Are My Sunshine and ... that tail just gets to going, and that makes me feel good. That makes me feel at peace, and then I'm satisfied." *47 years old, Caucasian, Diagnosed in 2009*

"She's a German Shepherd mixed with Lab... and dogs know when you're in a bad mood ... she just lays up under me. She knows that I'm sick and everywhere I go, she goes. She wants to protect me." *45 years old, African American, Diagnosed in 2001*

In this social role, our participants reported social interactions with their pets, not other human beings. But the impact of fulfilling this social role, caring for the daily needs of the pet, providing love and support to them, and the perceived reciprocation by the pet, led women to report increased stress reduction related to their HIV disease-- an important self-management outcome.

Employee

Almost 20% of our sample was employed, but the employee role was not discussed as a major role by our participants. They indicated that HIV diagnosis and self-management of the disease affected their choice of work in that they chose jobs where their HIV status could be kept secret, as they did not want to risk disclosure. As more women live longer with this disease and have an increased quality of life, they may join or rejoin the workforce, but they will do so cautiously, as fear of discrimination is a barrier. One participant spoke from personal experience of how disclosure of her HIV status negatively affected past employment:

"Now as far as my job, I don't tell my coworkers or my employers because I did have a job (where they) found out and legally, they can't fire you, but they can make your time there miserable. So now... if it's not any of your business, I'm not going to tell you." *36 years old, Caucasian, Diagnosed in 2001*

Discussion and Conclusions

In this study we sought to describe the various social roles HIV+ women experience and the effect these roles have on self-management tasks. We found six common social roles that affect HIV self-management, some positive and some negative.

The literature is replete with studies documenting the employee and caregiving roles of women. While our study provides new information on how these roles impact the self-management behavior of women living with HIV/AIDS, we also found less-defined social roles that had a positive impact on self-management.

Almost 33% of our sample described being a faith believer as a positive influence on their HIV self-management. The role of faith and spirituality has recently been explored, with investigators reporting relationships between spirituality and important HIV outcomes, including psychological well-being, health, self-care, and long-term survival (Dalmida, 2009; Ironson & Kremer, 2009; Kremer, Ironson, & Porr, 2009). However, few studies have connected faith and spirituality to significant self-management behaviors in HIV+ women. In our study we also found faith and spirituality to be sources of optimism and motivation, and the participants directly attributed physical improvements to their faith practices. This study also reinforced the importance of the patient's perspective in self-management of a chronic disease and the need for faith in their physician.

Unexpectedly, we found that the social role of advocate was prominent in this population and may lead to improved self-management behaviors. While peer advocates are commonly used to increase medication adherence, an advocacy by HIV-infected women is not described in the literature (Almeleh, 2006; Hemsworth & Pizer, 2006; Iwelunmor, Zungu, & Airhihenbuwa). Our data support two general types of advocacy: formal employment as a counselor, or informally through sharing her story and encouraging other women to practice “safe” behaviors. This disclosure of HIV status was related to a self-acceptance of the chronic nature of the disease, itself an important self-management task (Swendeman, et al., 2009). Self-acceptance has recently been linked to increased self-management practices and improved health outcomes (Gregg, et al., 2007; Lillis, et al., 2009), making it a possible target for future interventions. Furthermore, this feeling of altruism can be used by healthcare professionals to improve health outcomes, such as reduced STD transmission, while also helping women currently living with HIV to gain a sense of control over their disease.

Another surprise was the central role that pet ownership had in the support of the women as they dealt with life. Although pets can increase one's risk for additional infections, the positive mental health benefits of pet ownership were clearly described in our sample and have been supported in other research (Davis, 2008; Gosselink & Myllykangas, 2007; Vetter & Donnelly, 2006). Pet ownership can be encouraged by healthcare providers, but they must also ensure that women living with HIV/AIDS understand the importance of pet hygiene, along with their own symptom assessment and medication adherence.

Our study identified one major social role that had a negative effect on self-management in HIV infected women--the stigmatized patient. HIV/AIDS has long been recognized as a stigmatizing disease, and the effect of the stigma on one's health is widely debated (Holzemer, et al., 2007; Mahajan, et al., 2008). Women in our focus groups said that disclosing their HIV status to friends or colleagues caused them to be viewed as someone different. Stigma also prevented women from seeking medical care, a critical self-management task that by avoiding it endangered their own health (Swendeman, et al., 2009). These results are similar to other literature on HIV stigma, finding increased stigma was related to decreased psychological and physical functioning (Clark, Linder, Armistead, & Austin, 2003; Vanable, Carey, Blair, & Littlewood, 2006), and suggesting any model or intervention to target self-management should include a way to address HIV stigma.

The study limitations included a convenience sampling method and a study sample that has been living with HIV for a mean of 11.5 years. These may limit the generalizability of the study findings to only similar women who have been living with HIV for a comparable amount of time. Additionally the demographic data was self-reported and is limited by the participant's memory. Lastly, the women in this study were recruited from organizations in Northeast Ohio. Cultural practices and norms specific to this geographic area, may have influenced the participant's responses. Future research should consider these issues.

Living with HIV/AIDS is difficult, and managing the many daily tasks required to live well with this disease is challenging for most women. But this is accomplished every day by millions of women around the world. The social context in which this happens is important, and the social roles that women perform can help or hinder women in the maintenance of their health. Healthcare and social service providers should learn about these roles in their individual patients and, in particular, how they can be developed to increase women's disease self-management.

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Table 1

Demographic and Medical Characteristics of Participants

Demographics (N=48)	Mean (+/- SD)	Number (%)
Age	42 (8)	
Race		
African American		33 (69)
White		10 (21)
Hispanic/Latina		5 (10)
Marital Status		
Single		28 (58)
Divorced		7 (15)
Married		5 (10)
Separated		4 (8)
Other		4 (8)
Have Children (Yes)		43 (90)
Pregnant (Yes)		2 (4)
Children living with them	1.5 (1.3)	
Educational Attainment		
11th grade or less		19 (40)
High School or GED		17 (35)
2 yrs college/AA		10 (21)
4 yrs college/BS/BA		2 (4)
Work for Pay (Yes)		8 (17)
Annual Income	\$7442 (4,969)	
Has Permanent Housing (Yes)		43 (90)
Has Health Insurance (Yes)		44 (92)
Type of Health Insurance		
Medicaid		27 (61)
Medicare		7 (16)
Private, not by work		4 (9)
AIDS Drug Assistance Program		3 (7)
Private, provided by work		2 (5)
Veteran's Benefits		1 (2)
Medical Information (N=33)		
Antiretroviral Therapy	28 (85)	
Has AIDS Diagnosis		26 (79)
Years living with HIV	11.5 years (6.3 years; range 1-25)	
Undetectable Viral Load		24 (73)
Viral Load for those with detectable values (n=9)	27,595 (48,137)	
CD4+T Cells	577 (345)	

Demographics (N=48)	Mean (+/- SD)	Number (%)
Comorbidities		
Depression		15 (45)
Hypertension		13 (39)
Obesity		9 (27)
Asthma		8 (17)
Hyperlipidemia		7 (21)
Herpes Simplex Virus		5 (15)
Admitted to Emergency Department in Past Year		16 (48)
Admitted to Hospital in Past 12 months		10 (30)
Percent Missed HIV Primary Care Appointments in Past Year	21 (28)	

Table 2

Social Roles Influencing Self Management

Social Role	N (%)
Mother/Grandmother	18 (38)
Believer	13 (27)
Advocate	12 (25)
Stigmatized Patient	9 (19)
Pet Owner/Parent	5 (10)
Employee (Formal Work Sector)	5 (10)