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The impact of social context on self-management in women living with HIV

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ABSTRACT

HIV self-management is central to the health of people living with HIV and is comprised of the daily tasks individuals employ to manage their illness. Women living with HIV are confronted with social context vulnerabilities that impede their ability to conduct HIV self-management behaviors, including demanding social roles, poverty, homelessness, decreased social capital, and limited access to health care. We examined the relationship between these vulnerabilities and HIV self-management in a cross-sectional secondary analysis of 260 women living with HIV from two U.S. sites. All social context variables were assessed using validated self-report scales. HIV Self-Management was assessed using the HIV Self-Management Scale that measures daily health practices, HIV social support, and the chronic nature of HIV. Data were analyzed using appropriate descriptive statistics and multivariable regression. Mean age was 46 years and 65% of participants were African–American. Results indicated that social context variables, particularly social capital, significantly predicted all domains of HIV self-management including daily health practices ($F = 5.40$, adjusted $R^2 = 0.27$, $p < 0.01$), HIV social support ($F = 4.50$, adjusted $R^2 = 0.22$, $p < 0.01$), and accepting the chronic nature of HIV ($F = 5.57$, adjusted $R^2 = 0.27$, $p < 0.01$). We found evidence to support the influence of the traditional social roles of mother and employee on the daily health practices and the chronic nature of HIV domains of HIV self-management. Our data support the idea that women's social context influences their HIV self-management behavior. While social context has been previously identified as important, our data provide new evidence on which aspects of social context might be important targets of self-management interventions for women living with HIV. Working to improve social capital and to incorporate social roles into the daily health practices of women living with HIV may improve the health of this population.

Introduction

Women represent over 25% of those living with HIV in the United States and over 50% of HIV infections worldwide (Aziz & Smith, 2011; Centers for Disease Control and Prevention, 2010; UNAIDS, 2009). For this growing population, many self-management behaviors are required for improving and maintaining health. At the same time, however, many of these women are confronted by multiple social context vulnerabilities that may impede their ability to perform these necessary behaviors.

Self-management is comprised of modifiable daily tasks that individuals do to manage their chronic illnesses (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003; Richard & Shea, 2011). The development and widespread availability of HIV antiretroviral therapy has transformed HIV into one such chronic illness, requiring continual self-management work, generally outside of the health care system (Ford, Calmy, & Mills, 2011; Hammer et al., 2008). For HIV, self-management is a set of behaviors that directly and indirectly decrease susceptibility to worsening HIV. These behaviors also decrease susceptibility to other burdensome non-AIDS defining conditions including cardiovascular disease, cancer, and hepatic disease (Hasse et al., 2011; Richard & Shea, 2011). The beneficial behaviors of disease self-

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management include common health promoting activities such as eating a healthy diet or engaging in physical activity; health maintenance activities including medication adherence and accessing appropriate medical services; improving psychological and emotional functioning through self-efficacy and empowerment exercises and reducing negative emotional states; and improving social relationships by developing collaborative relationships with health care providers, developing and using a positive social support network, and coping with HIV stigma (Swendeman, Ingram, & Rotheram-Borus, 2009). Most self-management interventions have focused on HIV medication adherence or safe sex (Lyles et al., 2007; Rueda et al., 2006; Sandelowski, Voils, Chang, & Lee, 2009), however there is great opportunity within the field to adopt a more holistic approach and target the upstream behaviors to promote the overall health of the person living with HIV (High et al., 2012). For people living with HIV, self-management is a lifelong endeavor, and one that may be substantially affected by the social contexts in which they live.

The concept of social context refers to "patterns that reflect larger structural forces that shape the texture of people's day-to-day realities" (Sorensen et al., 2003). For women living with HIV, vulnerabilities within their social context may include demanding social roles (wife, mother, employee), poverty, homelessness, and inadequate access to health care, as well as pervasive structural issues such as powerlessness, racism, sexism, and classism (Bozzette et al., 1998; Hackl, Somlai, Kelly, & Kalichman, 1997; Hodder et al., 2010; Hunter, 2009; Merenstein et al., 2009; Schuster et al., 2000; Webel & Higgins, 2012). These women may also experience low levels of social capital, a construct that in its positive form implies factors such as social support and social integration could potentially facilitate self-management behaviors. The intersection of various social context vulnerabilities may inhibit self-management behaviors of a woman living with HIV, resulting in poor health outcomes (Adimora & Auerbach, 2010; Arrivillaga, Ross, Useche, Alzate, & Correa, 2009). However, the extent to which they affect HIV self-management is currently unknown. Identifying and determining the effect of these vulnerabilities on a women's self-management, and ultimately her health, may help us move toward more comprehensive interventions to improve the overall health and well-being of this population. Our purpose was to examine the relationship between social context vulnerabilities and HIV self-management, using a feminist sociological perspective. The specific research questions were: 1) Which social context variables were associated with *increased* HIV self-management? 2) Which social context variables were associated with *decreased* HIV self-management? and 3) What is the impact of gender-specific roles on HIV self-management?

This study utilized feminist sociological theory to guide assumptions and analysis. Feminist sociological theory provides a lens for understanding the complex social context and power structures within which women must manage their HIV infection. At its heart, feminist sociological theory examines the meaning of societal structure on women's agency, and acknowledges the microsociological and macrosociological issues that impact women's daily lives (Doyle, 2001). Women have been uniquely impacted by HIV, from shouldering the burden of caretaking, to threats to their reproductive decision-making, to being biologically and socially more vulnerable to infection than most men (Doyle, Naidoo, & Wilton, 1994). Feminist theory considers how the everyday lives of women are patterned by structural inequality (Doyle, 2001), capturing the competing demands that we hypothesized would affect women's ability to manage their HIV infection. Women may have less power within their social worlds and social structures, impacting health decision-making and health outcomes (Doyle, 2001; Doyle et al., 1994). A large body of research has been devoted to the unequal HIV risk faced by women (Higgins, Hoffman, & Dworkin, 2010; Kako, Stevens, Karani, Mkandawire-Valhmu, & Banda, 2012; Pettifor, Macphail, Anderson, & Maman, 2012; Zierler & Krieger, 1997), and many HIV prevention interventions are informed by feminist frameworks (Pinkham, Stoicescu, & Myers, 2012; Pitpitan, Kalichman, Eaton, Strathdee, & Patterson, 2013; Strathdee, Wechsberg, Kerrigan, & Patterson, 2013). Little work, however, has been done to examine the impact that gender, conflicting societal demands and lack of social power have on the self-management of HIV in women.

The studies that have looked at gender and health determinants in women living with HIV have primarily focused only on adherence to HIV antiretroviral therapy. Arrivillaga et al. (2009) found that women living with HIV in Colombia who reported being in a low social position had a significantly higher probability of low HIV antiretroviral therapy adherence (OR = 5.65, $p < 0.01$) than people of higher social standings (Arrivillaga et al., 2009). Women have been shown to be less likely to get access to HIV care and antiretrovial therapy due to low social standing (Gebo et al., 2005). While adherence to antiretroviral therapy is fundamental to maintaining and improving one's health, in order to live well with HIV, women have to do more than just adhere to their medications. This is particularly relevant today as people living with HIV are living longer and, as they age, must deal with multiple chronic comorbidities, each of which comes with its own set of necessary self-management behaviors (Hasse et al., 2011; Swendeman et al., 2009). In recognition of the shift in the HIV epidemic to an aging population, a more comprehensive examination of self-management under these current conditions is necessary.

One challenge that may affect a woman's HIV self-management is the social role of caregiver, specifically as a mother (Doyle et al., 1994). Consistent findings suggest that the increased work of motherhood and the responsibilities women living with HIV have in the context of family, may force women to prioritize the care of their families over their own needs. In order for any HIV self-management intervention to be effective and sustainable, it must address the need for mothers to better balance their role as a mother and a woman living with a chronic, manageable health condition.

Additionally, women living with HIV may have lower levels of social capital due to cultural and structural challenges (Doyle et al., 1994; Zierler & Krieger, 1997). Social capital has been described as the "aggregate or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (Bourdieu, 1986). These resources provide members with credit(s) to be used in the larger social world to achieve their interests (Bourdieu, 2001; Coleman, 1988; Helliwell & Putnam, 2004; Hsieh, 2008; Kawachi, Kennedy, & Glass, 1999; Pitkin Derose & Varda, 2009; Portes, 1998). Over the last half-century, investigators have examined the relationship between social capital, socioeconomic status and health with mixed results (Kouvonen et al., 2008; Lochner, Kawachi, Brennan, & Buka, 2003). However, it can be useful in quantifying the individuals' perception of the resources that being part of a social network can provide and is central to understanding how social context vulnerabilities affect self-management. This is especially true in women, where increased social capital has been shown to be influential on improved health outcomes (Eriksson, Ng, Weinehall, & Emmelin, 2011).

Women living with HIV are a highly vulnerable population, often underserved and understudied (Heidari, 2011). Their vulnerability may decrease their HIV self-management behaviors, resulting in a detrimental effect on their health. Given the increasing prevalence of HIV in women throughout the world (UNAIDS, 2009), there is a need to understand and address the