

**Measurement of Stigma and Relationships between Stigma, Depression, and  
Attachment Style among People with HIV and People with Hepatitis C**

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## Abstract

This dissertation is composed of three studies that examined illness-related stigma, depressive symptoms and attachment style among patients living with HIV and Hepatitis C (HCV). The first study examined the psychometric properties of a brief HIV Stigma Scale (B-HSS) in a sample of adult patients living with HIV (PHA) ( $n=94$ ). The second study developed and explored the psychometric properties of the HCV Stigma Scale in a sample of adult patients living with HCV (PHC) ( $n=92$ ). Psychometric properties were evaluated with classical test theory and item response theory methodology. The third study explored whether illness-related stigma mediated the relationship between insecure attachment styles (anxious attachment or avoidant attachment) and depressive symptoms among PHA ( $n=72$ ) and PHC ( $n=83$ ). From June to December 2008, patients were recruited to participate in a questionnaire study at the outpatient clinics in The Ottawa Hospital. Findings indicated that the 9-item B-HSS is a reliable and valid measure of HIV stigma with items that are highly discriminatory, which indicates that items are highly effective at discriminating patients with different levels of stigma. The 9-item HCV Stigma Scale was also found to be reliable and valid with highly discriminatory items that effectively differentiate PHC. Construct validity for both scales was supported by relationships with theoretically related constructs: depression and quality of life. Among PHA, when HIV stigma was controlled the relationship between anxious attachment style and depression was not significant. However, the relationship between avoidant attachment style and depressive symptoms decreased but remained significant. Among PHC when HCV stigma was controlled the relationship between insecure attachment styles and depressive symptoms was not significant. Dissertation results emphasize the importance of identifying patients experiencing illness-related stigma and the relevance of addressing stigma and attachment style when treating

depressive symptoms among PHA and PHC.

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## Measurement of Stigma and Relationships between Stigma, Depression, and Attachment Style among Patients with HIV and Patients with Hepatitis C

### HIV

The World Health Organization (WHO) estimates that 34 million people are currently living with HIV/AIDS worldwide and approximately 2.7 million people were newly infected in 2010 (WHO, 2013). HIV/AIDS is a viral infection that disables the human immune system. As of 2011, there were approximately 71,300 people in Canada living with HIV (Public Health Agency of Canada, 2012).

HIV is a significant public health concern but its prognosis has changed. Formerly, HIV was considered a “death sentence” and life expectancy after diagnosis was often grim. The advent of highly active antiretroviral therapy (HAART) has dramatically changed the efficacy of HIV treatment. With the use of HAART, HIV mortality and morbidity rates have declined dramatically and HIV is now viewed as a chronic illness requiring long term therapy (Hawkins, 2006; Siegel & Schrimshaw, 2005). However, successful treatment with HAART requires strict adherence to a complicated lifelong medication regimen (i.e. daily pills, specific times when medication must be taken, etc.). Moreover, HIV medications often cause unpleasant side-effects (i.e. rashes, diarrhea, changes in fat distribution, etc.), which can interfere with adherence (Hawkins, 2006; Oette et al., 2002; Ware, Wyatt, & Tugenberg, 2006)

### Co-infection with HIV and Hepatitis C (HCV)

People living with HIV (PHA) are at high risk for being co-infected with the hepatitis C virus (HCV). The world wide HIV/HCV co-infection rate is predicted to be around 4-5

million people (Alter, 2006), and the Canadian co-infection rate is thought to be around 25% (Public Health Agency of Canada, 2007). In North America, HIV/HCV co-infection often stems from a shared route of transmission between the two blood-borne viruses, such as intravenous drug use (IDU) with contaminated equipment (Lahijani & Taylor, 2006). Cooper, Badley, & Angel (2001) reported co-infection rates ranging from 50% to 90% among HIV positive IDUs across several studies. However, recently, among men who have sex with men (MSM) high risk sexual behaviour has also been identified as a significant route of transmission (Danta et al., 2007; Van de Laar et al., 2007). Co-infection is increasingly relevant to PHA who are living longer with HAART. Longer life spans allow other medical problems to emerge and liver disease from chronic HCV infection has become a leading cause of death among PHA (Mohsen, Easterbrook, Taylor, Norris, 2002). Furthermore, HCV is the number one cause of end-stage liver failure and the greatest contributor to liver transplants in the developed world among HCV mono-infected and HIV/HCV co-infected patients (Foster, 1999; Golden, O'Dwyer, Conroy, 2005).

## HCV

Studies indicate that 170 million people worldwide are chronically infected with HCV (WHO, 2012) and that there are approximately 242, 500 people in Canada living with HCV (Public Health Agency of Canada, 2012). HCV is a blood-borne pathogen therefore transmission of the virus is possible through any blood to blood contact. The virus infects the liver cells of the body but paths of disease progression are highly variable. A small minority of individuals will clear the virus from their systems (though remain at risk for HCV re-infection) while a larger majority become chronically infected with the HCV virus (Public Health Agency of Canada, 2008). There is antiviral treatment available for HCV, however,

this treatment can challenge patient adherence due to significant side-effects (i.e. pain and fatigue). Furthermore, even if adherence is 100%, the treatment may not be effective, as some HCV genotypes do not respond well to HCV treatment (Lahijani & Taylor, 2006). For those who are chronically infected with HCV, the time frame for disease progression to liver cirrhosis/liver cancer is around 20 to 30 years. During this time, people living with HCV may appear asymptomatic and even be unaware of being infected which can result in unknowingly spreading the virus to others (Foster, 1999; Hopwood & Southgate, 2003).

Living with HIV and/or HCV has emotional and social implications that go beyond the physical effects of these diseases. People living with HIV/HCV experience significant life changes. These can include a new uncertainty about health status and fear of transmission to others, re-defining of self concept, and financial concerns. Notably, both groups report changes in or loss of personal relationships and experiences of stigma (Buseh, Kelber, Stevens, Park, 2008; Dunne & Quayle, 2002; Gore-Felton, Koopman, Spiegel, Vosvick, Brondino, Winningham, 2006; Hepworth & Krug, 1999; Kowal et al., 2008; Lally, Montstream-Quas, Tanaka, Tedeschi, Morrow, 2008; Minuk, Gutkin, Wong, Kaita, 2005). Given that experiences of stigma can be a significant component of living with HIV/HCV this dissertation aims to increase our understanding of stigma and contribute to this growing area of research.

#### A Biopsychosocial Perspective: Attachment Theory

Stigma can result from a social interaction between an individual with a stigmatizing feature and others (Goffman, 1963). Therefore, it is relevant to investigate stigma from the model of attachment theory, which helps explain individual differences in interpersonal behavior and emotional regulation (Feeney & Noller, 1996). Attachment theory suggests that

attachment behavior is activated in young children under alarming conditions including: a threatening environment, conditions regarding the caregiver (e.g., caregiver turns away), or conditions regarding the child, such as fatigue or sickness (Bowlby, 1980). Caregiver responses to a child's attachment seeking behaviours leads to the development of patterns of attachment, both secure and insecure, which will guide an individual's perceptions, emotions, thoughts and expectations in adult relationships (Bretherton & Munholland, 1999). Feeney (2000) suggests that ill health can serve as an activator of our personal attachment patterns and as such there may be heightened variations in reaction to physical symptoms, interpersonal perceptions, and psychological attributes among adults with different attachment styles. In adults with HIV, insecure styles of attachment have been related to reports of greater self-perceived stigma compared to those who were securely attached (Riggs, Vosvick, & Stallings, 2007).

This dissertation is composed of three studies that will examine the personal and social burden of self-reported stigma in PHA and PHC. This will be done by examining and improving the measurement of HIV and HCV stigma and by increasing our understanding of psychosocial variables associated with stigma. The aim of the first study is: (1) psychometric testing and validation of the Brief HIV Stigma Scale among adults living with HIV. The second study aims (2) to develop, psychometrically validate, and establish the properties of the HCV Stigma Scale among adults living with HCV. The third study aims (3) to increase our understanding of the relationship between attachment style, stigma, and depressive symptoms by examining a novel mediation model incorporating these variables.

The following will define stigma and characteristics of HIV and HCV that are associated with stigma. Next research relating to the measurement of stigma within these

populations will be reviewed. Followed by background research on attachment theory (i.e. history of attachment theory, key concepts of attachment, and application of attachment theory to adulthood), and a review of research on HIV and HCV stigma using an attachment framework.

## Illness-related Stigma

### *Stigma Defined*

The concept of stigma was delineated in Goffman's seminal work, 'Stigma: Notes on the Management of Spoiled Identity' (Goffman, 1963). Goffman (1963) defined stigma as "an attribute that is deeply discrediting" that devalues the individual "from a whole and usual person to a tainted, discounted one." He listed examples of stigmatization stemming from deformity, physical and mental illness, disability, race, and addiction.

Over the years, Goffman's work on stigma has been expanded to include a more global conceptualization of stigma. Current research can be delineated into two streams, namely, stigma imposed by others and self-reported stigma (Deacon, 2006). The former area of research often involves philosophical and ethical discussions of the ramifications of stigma and explorations of anti-stigma campaigns (Deacon, 2006; Link & Phelan, 2001). The latter aspect of stigma research examines the negative effects of self-reported stigma as experienced by those who are stigmatized. Research on self-reported stigma has emphasized the idea of compounded stigma, which is a stigma layered upon another stigma (Deacon, 2006; Gilmore & Somerville, 1994; Goffman, 1963; Parker & Aggleton, 2003). Gilmore & Somerville (1994) use the example of a person who is HIV positive to illustrate compounded

stigma, describing this individual as a “double scapegoat”; someone who is stigmatized for being HIV positive and for their sexual preferences.

### *The stigma of HIV and HCV*

There are a number of characteristics that contribute to HIV-related stigma. One of these is means of transmission; transmission behaviours are often considered socially illicit and may include unprotected anal sex, IDU, and penile-vaginal sex with multiple partners. Moreover, these behaviours can be considered voluntary therefore acquiring HIV is often perceived as being preventable and controllable (Alonzo & Reynolds, 1995; Deacon, 2006; Lee, Kochman, Sikkema, 2002; Swendeman, Rotheram-Borus, Comulada, Weiss, Ramos, 2006). Furthermore, many people still believe HIV is fatal and highly contagious and these beliefs are exaggerated by fear and lack of knowledge among the general public. In addition, HIV may be more stigmatized when the disease is visible to others, such as during the later stages of illness (e.g. muscle wasting) or when side-effects from long term medication use become apparent (Lee et al., 2002; Madru, 2003; Swendeman et al., 2006). Lastly, vulnerable populations are often easily further stigmatized. HIV stigma can be layered upon stigmas linked to homosexuality, drug use, sexual promiscuity, and prostitution (Lee et al., 2002; Reidpath et al., 2005; Sandelowski, Lambe, & Barroso, 2004). In this dissertation, the focus is on self-reported stigma and unless noted otherwise, when stigma is mentioned it refers to solely to self-reported stigma.

Little research has been conducted examining stigma in relation to HCV. The characteristics of HCV that trigger stigma have yet to be clearly identified. However, they likely bear a strong resemblance to the characteristics associated with HIV stigma. HCV is contagious, and infectious diseases are known to have been stigmatized historically (Fraser

& Treloar, 2006; Gilmore & Somerville, 1994). Furthermore, as with HIV, HCV is often acquired through behaviors which are considered to be illicit and voluntary (i.e. IDU) (Fraser & Treloar, 2006). Furthermore, though HCV does share similarities with HIV, it is often confused with HIV by the lay public and by the infected person themselves. For instance, it is presumed that HCV is always progressive, that it has no cure, and that it is easily transmitted through sexual contact (Butt, Paterson, McGuinness, 2008; Fontana & Kronfol, 2004; Fraser & Treloar, 2006; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). Moreover, HCV is particularly prevalent among already stigmatized and marginalized population groups including, intravenous drug users, the homeless, homosexual men, and those who have been incarcerated (Butt et al., 2008; Fontana & Kronfol, 2004).

## Implications of Stigma Research

### *Effects of HIV Stigma*

The United Nations Program on HIV/AIDS (2010) has documented many cases of people being stigmatized or discriminated due to being HIV positive. Yet, HIV stigma remains understudied and has often been treated by researchers as a backdrop to the HIV crisis as opposed to a phenomenon to be studied in its own right (Emlet, 2005). Studies have found that greater levels of HIV stigma are related to psychological distress, namely anxiety and depression; HIV stigma has also been associated with higher levels of self-blame, hopelessness, and difficulties with condom negotiation (Derlega, Winstead, Greene, Serovich, Elwood, 2002; Dowshen, Binns, Garofalo, 2009; Lichtenstein, Laska, Clair, 2002; Venable, Carey, Blair, Littlewood, 2006). Furthermore, an experience of HIV stigma leading to self-blame may prime the person to anticipate rejection from others in future interactions (Lee et al., 2002; Wong & Wong, 2006). HIV stigma has also been identified as a significant

barrier to accessing and adhering to HIV-related treatments (Relf, Mallinson, Pawlowski, Dolan, & Dekker, 2005; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Venable et al., 2006).

### *Effects of HCV Stigma*

To date, PHC have reported encountering most instances of HCV stigma within the health care environment which may result from their identification and visibility within this setting (Butt et al., 2008; Crofts, Louie, & Loff, 1997; Day, Ross, & Dolan, 2003; Hepworth & Krug, 1999; Hopwood & Southgate, 2003; Treloar & Hopwood, 2004). Similar to the HIV literature, stigma has been identified as a barrier to health-seeking behaviours (i.e. attending medical appointments) and has been associated with reluctance to disclose HCV status to others (Butt, McGuinness, Peltonen, & Mitchell, 2012; Moore, Hawley, & Bradley, 2007). Both men and women living with HCV who reported stigma were also more likely to report anxiety, depression, feelings of shame, blame, embarrassment and helplessness (Butt et al., 2008; Conrad, Garrett, Cooksley, Dunne, Macdonald, 2006; Zickmund et al., 2003). Impairments in memory/concentration, greater reports of HCV symptomatology, and decreased acceptance of illness have also been associated with reports of greater HCV stigma (Golden, Conroy, O'Dwyer, Golden, Hardouin, 2006). Furthermore, women have also reported the negative impact of HCV stigma on their roles as mothers and expressed concerns about transmitting HCV to their children through routine activities (Grundy & Beeching, 2004).

## Measurement of Stigma: A Foundation for Future Research

One of the major limitations of the existing literature on HIV and HCV stigma is that most studies have not utilized psychometrically validated measures of stigma. It is common in the HIV stigma field to do qualitative research (i.e. Ware et al. (2006) or Wong & Wong (2006)) or to adapt chosen items from a single scale or a number of existing scales into a new scale which is psychometrically not validated (i.e. Vanable et al. (2006), Rintamaki et al. (2006) or Relf et al., (2005)). There is a paucity of research on psychometrically valid brief HIVstigma scales and the use of unvalidated measures limits the validity of findings.

As of yet, a psychometrically validated HCV specific stigma measure has not been developed (Paterson, Backmund, Hirsch, & Yim, 2007). Clinically, there is a need for the brief and systematic measurement of HIV/HCV stigma since stigma has been associated with delayed help-seeking and poor treatment adherence (Weiss, Ramakrishna, & Somma, 2006). Failure to identify people who are affected by stigma could endanger their health. Moreover, if HIV/HCV stigma serves as a barrier to disclosure of medical status there is also danger for those who come into intimate contact with a person living with HIV/HCV. Yet, it is important to highlight, that stigma is not necessarily a universal experience for everyone living with HIV and/or HCV (Butt et al., 2008). Therefore, assessment of stigma with validated and brief measures will allow for tailored treatment of vulnerable patients living with HIV/HCV.

Also, there is little stigma research that feeds into the development of anti-stigma intervention, prevention, and advocacy efforts. Past stigma interventions in the fields of HIV and mental health have focused on creating interventions that target those who perpetuate stigma. The aim of these interventions has been to increase societal acceptance for the

stigmatized group by educational interventions about the effects of stigma or by “person-to-person interaction” interventions between those who perpetuate stigma and the stigmatized group (Parker & Aggleton, 2003; Paterson et al., 2007). These interventions have met with limited success in the field of HIV, with findings of moderate or small positive effects as well as negative effects (Brown, Macintyre, & Trujillo, 2003). In response to this research on anti-stigma interventions, a new foci of research has emerged, targeting the concept of “stigma resilience” (SR). The focus of SR is to look for those emotional factors that a person can bring to bear against the negative effects of stigma. Helping an individual to build up their resilience to the negative effects of stigma may improve their emotional health, reducing depression and anxiety, as well as improving their physical health by minimizing stigma as a barrier to treatment uptake (Sibitz, Unger, Woppmann, Zidek, & Amering, 2009). Researchers such as Ritsher & Phelan (2004) advocate for both community focused campaigns against stigma as well as the fostering of SR within individuals. The development of psychometrically validated HIV and HCV stigma scales, which correctly measure and gauge the relative success or failure of SR interventions, can significantly contribute to this new avenue of research.

### *Measures of HIV stigma*

A number of instruments have been used to measure HIV stigma in the literature. However, The HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001) is considered a benchmark measure of HIV stigma that is reliable and valid (Berger et al., 2001; Rao, Pryor, Gaddist, & Mayer, 2008). The 40-item HIV Stigma Scale was created specifically to examine HIV stigma and assesses multiple facets of stigma including perceived stigma, experienced stigma (discrimination), internalized stigma, and disclosure-related stigma

(Berger et al., 2001; Nyblade, 2006; Wright, Naar-King, Lam, Templin, & Frey, 2007). Furthermore, the HIV Stigma Scale has been used with a variety of PHA groups, including minority groups, and women, (Buseh et al., 2008; Rao et al., 2008; Relf, Mallinson, Pawlowski, Dolan, Dekker, 2005; Verma et al., 2004) and has been adapted for use with other disease populations, including lung cancer patients (Berger et al., 2001; Cataldo, Slaughter, Jahan, Ponquuan, & Hwang, 2011; Rongkavilit et al., 2010). Most recently the HIV Stigma Scale has been abbreviated for use in clinical settings. The abbreviated scale retains items from all facets of HIV stigma measured by the longer scale (Wright et al., 2007). This 10 item abbreviated HIV stigma scale has been validated in a very limited fashion with a sample of 48 African American youth (Wright et al., 2007). Preliminary support for construct validity of this short HIV stigma scale was established by positive correlations with measures of depression and alcohol use (Wright et al., 2007). Increased usability of the short HIV Stigma Scale will be possible with further psychometric validation. Therefore, the first study of this dissertation will thoroughly test the psychometric properties of the Brief HIV Stigma Scale (B-HSS) in a sample of adults living with HIV.

### *Measures of HCV stigma*

Paterson et al. (2007) report that there is little literature examining HCV stigma from a qualitative or quantitative perspective. The studies that have approached the subject from a quantitative perspective provide few details about the validity and reliability or derivation of the stigma scales employed (Paterson et al., 2007). Quantitative questionnaires that have been employed have been adapted from qualitative material or questionnaires that were not stigma specific (Banwell, Bammer, Gifford, & O'Brien, 2005; Gifford, O'Brien, Smith, et al., 2005; Gifford, O'Brien, Bammer, Banwell, & Stoope, 2003; Hopwood, Treloar, & Bryant,

2006). No further information was provided from the few quantitative HCV stigma studies about item selection or the psychometric properties of these scales. Due to a lack of validated psychometrically sound tools some researchers have chosen to use a scale which examines experiences related to illnesses in general (Experience of Illness Scale; Fife, 1995) which has not been specifically psychometrically validated to examine stigma in an HCV population (Golden et al., 2006; Zacks et al., 2006). Therefore, the second study of this dissertation aims to develop a brief and psychometrically sound HCV Stigma Scale.

#### A framework for HIV/HCV Stigma: Attachment Theory

A greater understanding of the psychological consequences of illness-related stigma could enhance stigma resilience and mitigate the effects of stigma in people living with HIV/HCV. Unfortunately, depressive symptoms are some of the most common sequelae associated with stigma among PHA and PHC (Golden et al., 2006; Hopwood & Treloar, 2003; Logie, James, Tharao, Loufty, 2013; Riggs et al., 2007). Attachment theory may serve as a useful framework to understand and conceptualize the relationship between illness-related stigma and depressive symptoms because attachment styles are thought to be triggered by physical illness and guide our perception of self and others (Feeney & Noller, 1996; Feeney, 2000). Maunder & Hunter (2001) suggest that insecure attachment styles worsen physical illness by three mechanisms: altering stress physiology, altering the use of external regulators of affect (e.g. substance abuse), and altering the use of protective factors (e.g. rejection of social support, lack of treatment adherence). Insecure attachment styles have been linked to experiencing poor sleep and physical symptoms, distorted perceptions of physical symptoms, differential treatment by physicians, and failure to adhere to medical treatment among people living with chronic illnesses (Ciechanowski, Sullivan, Jensen,

Romano, Summers, 2003; Ciechanowski et al., 2004; Maunder et al., 2006; Maunder, Hunter, Lancee, 2011). These studies suggest that attachment style, activated by illness, relates to perceptions of self and others and may have detrimental implications to maintaining health. Therefore, attachment theory is an ideal framework by which to examine stigma and depressive symptoms in response to the threat of HIV/HCV.

The following will introduce the framework of attachment theory, beginning with a review of attachment theory in children, followed by how attachment theory has been applied to adults. Thereafter, recent research that has been conducted regarding stigma and attachment theory will be examined.

#### *Attachment Theory and Children*

Attachment theory was initially conceptualized by Bowlby, emerging from his clinical work with hospitalized children, and drawing from evolutionary theory, ethnology, psychoanalysis and biology (Bowlby, 1980; Cassidy & Shaver, 1999; Feeney & Noller, 1996; Mikulincer & Shaver, 2007). Bowlby (1969) proposed that as infants, human beings are predisposed to seek out an attachment figure with whom they can bond and who can offer them protection and security. Accordingly, this attachment figure would serve as a secure base from which the infant could explore the world when there is no apparent threat of danger; danger would activate the attachment behavioural system and cause the infant to seek out the attachment figure (Bowlby, 1969; Bowlby, 1980; Feeney & Noller, 1996). Bowlby (1969) recognized three major types of threat, including threats from the environment, threats from within the attachment relationship (e.g. the attachment figure leaves), or conditions of the child, such as illness. Attachment theory can be conceptualized

as a theory of affect regulation whereby attachment styles guide responses to threatening situations (Feeney & Noller, 1996).

Ainsworth, Blehar, Waters, & Wall (1978) proposed three organized styles of attachment: insecure-avoidant attachment, insecure-anxious attachment, and secure attachment (Feeney & Noller, 1996). Researchers have explored and replicated Ainsworth et al.'s (1978) attachment research, in adolescent and adult samples, and adjustments have been made to her original typology with the addition of a "disorganized-disoriented attachment" type. This type is characterized by infants that display contradictory behavior when reunited with the attachment figure, such as confusion or depressed affect (Main & Solomon, 1986). Recently, Ainsworth et al.'s (1978) attachment styles have been conceptualized as continuous dimensions of avoidance and anxiety (Mikulincer, Shaver, Pereg, 2003; Mikulincer & Shaver, 2007). When Bartholomew and colleagues (1990) characterized insecure attachment by continuous dimensions of attachment anxiety and avoidance four typologies emerged. Preoccupied individuals are characterized by high attachment anxiety and low levels of attachment avoidance, while dismissing attachment style is typecast by low levels of attachment anxiety and high levels of attachment avoidance. People with fearful attachment style are thought to have both high attachment anxiety and high attachment avoidance; they are thought to characterize the recently added disorganized-disoriented type (Brennan, Shaver, & Tobey, 1991). Secure attachment is characterized as low attachment anxiety and avoidance.

### *Attachment Theory and Adult Relationships*

Research indicates that specific attachment styles that emerge from childhood are related to distinctive clusters of cognitions, feelings and behaviours in adults, known as

“internal working models” (IWMs) (Bretherton & Munholland, 1999). The following will describe the IWMs related to particular styles of attachment.

*Working Models.* Bowlby (1980) theorized that childhood experiences of attachment (especially with principal attachment figures) form IWMs of attachment in adults. These IWMs of self and of the attachment partner are used by the individual to regulate, interpret, and predict the behavior, thoughts, and feelings of themselves and of their attachment partner (Bretherton & Munholland, 1999; Feeney & Noller, 1996; Mikulincer & Shaver, 2007). IWMs are complimentary, for instance, an IWM of the self as devalued and incompetent is combined with a model of the attachment figure as rejecting or ignoring (Bretherton & Munholland, 1999). Furthermore, IWMs are thought to be generally stable and challenging to change (Feeney & Noller, 1996; Mikulincer & Shaver, 2007). IWMs operate mostly out of conscious awareness and are more easily accessed if they are based on numerous experiences and used frequently with success (Collins & Read, 1994). The overall purpose of attachment figures for adults remains the same as for infants; they are a target of proximity-seeking behaviour and they provide a safe haven and a secure base for exploration. However, the threshold for activating attachment systems is usually higher in adults because they have learned a variety of coping strategies and the ability to self-soothe. The mental representations of attachment interactions held by adults allow them to predict future interactions with partners and proceed through these interactions with automaticity (Mikulincer et al., 2003; Mikulincer & Shaver, 2007). This line of research suggests that IWMs, which encompass emotional regulation and interpersonal behaviours, are key aspects of social interaction and therefore likely play a role in the stigma experiences of people living with HIV and/or HCV.

*Attachment Styles.* Secure attachment in adults is characterized by generally positive IWMs of themselves and others. Securely attached adults generally desire intimate relationships and are comfortable with closeness. Also, they will generally see themselves as well-liked and others as well-intentioned and dependable (Bretherton & Munholland, 1999; Feeney & Noller, 1996). Therefore, they are comfortable seeking the support of others in times of stress (Bartholomew & Horowitz, 1991; Mikulincer et al., 2003). Anxiously attached adults are more likely to see themselves as having little control over their own lives and see others as difficult to understand. They are often interested in intimate relationships though they may find themselves preoccupied with creating extreme intimacy in the relationship and fearing rejection (Bretherton & Munholland, 1999; Feeney & Noller, 1996). This group can be characterized as having a negative IWM of themselves as unworthy of care and therefore susceptible to abandonment (Bartholomew & Horowitz, 1991; Mikulincer et al., 2003). Individuals with avoidant attachment styles will generally be interested in keeping others at a distance and limiting intimacy. Correspondingly, they will often see others as untrustworthy or undependable (Bretherton & Munholland, 1999; Feeney & Noller, 1996). They can appear compulsively self-reliant (Bartholomew & Horowitz, 1991; Mikulincer et al., 2003). Both anxious and avoidant attachment often result in the use of secondary attachment strategies. An anxious attachment style is often distinguished by hyper-activating strategies which are exaggerated strategies to get the attention of an attachment figure that is thought of as inadequately responsive. This can include clinging/controlling behavior and an exaggerated portrayal of themselves as vulnerable and dependent to get attention and concern from an attachment figure. People with an avoidant attachment style are often distinguished by deactivating strategies which are meant to create psychological distance between themselves and others. This can include avoiding interactions that involve intimacy or self-disclosure

and suppressing thoughts and feelings related to vulnerability and dependence (Mikulincer & Shaver, 2007).

### *The Measurement of Adult Attachment*

The measurement of adult attachment can best be conceptualized along a continuum bookended by measurement of attachment in the family domain and measurement of romantic attachment (Bartholomew & Shaver, 1998). Therein, measures can fall into the domain of interview or self-report measure and can vary in terms of measuring categories or dimensions of attachment (Bartholomew & Shaver, 1998). The preeminent interview measure in the family domain is the Adult Attachment interview (AAI) (Feeney & Noller, 1996). It is designed to explore participants' adult states of mind in relation to childhood relationships with parents, evaluations of these early experiences, and effects on adult personality to determine attachment patterns (Feeney & Noller, 1996; George, Kaplan, & Main, 1985). When measuring romantic attachment, Shaver & Fraley (2004) advocate for the measurement of the anxiety and avoidance dimensions that underlie attachment types. They argue that there is no clear evidence for attachment categories and that typological categorizations can result in loss of precision when measuring attachment (Fraley & Waller, 1998). Ravitz, Maunder, Hunter, Sthankiya, & Lancee (2010) recommend the measurement of attachment dimensions in research to facilitate the detection of subtle differences between individuals. Shaver & Fraley (2004) support the use of the Experiences in Close Relationships scale (ECR) (Brennan & Shaver, 1998) to examine anxiety and avoidance dimensions. Items for this instrument were derived from a factor analysis of most of the existing self-report measures of romantic attachment (Brennan & Shaver, 1998). Recently, the ECR has been revised to form the Experiences in Close Relationships-Revised Scale

(ECR-R), which has been found to be valid and reliable (Fraley, Waller, & Brennan, 2000), and abbreviated for clinical use, to form the Experiences in Close Relationships-Short (ECR-S), which has also been found to be reliable and valid (Wei, Russell, Mallinckrodt, & Vogel, 2007).

### *Attachment Theory, Depressive Symptoms and Stigma*

The relationship between insecure attachment styles (anxious or avoidant attachment styles) and greater depressive symptoms has been established among non-clinical samples, and people living with chronic illnesses, including HIV and HCV (Halpern, Maunder, Schwartz, Gurevich, 2011; Hinnen et al., 2012; Liu, Nagata, Shono, Kitamura, 2009; Permy, Marino, Fernandez-Rey, 2009; Meredith, Strong, & Feeney, 2007; Sockalingham et al., 2012; Turner-Cobb et al., 2002). However, there are few studies establishing a relationship between attachment style and HIV stigma. Hudson (2007) examined the relation of attachment style to disclosure of HIV positive status among African American women through unstructured interviews. She hypothesized that HIV stigma may serve as a barrier to disclosure. She found that attachment style strongly predicted disclosure of HIV status to intimate sexual partners. Women with a predominantly secure style of attachment were more likely to disclose their status and that women reported moderate levels of HIV stigma. However, the relationship between attachment style and stigma was not examined (Hudson, 2007). In contrast, Riggs et al. (2007) examined the direct relation between HIV stigma and attachment style. Uncommon in studies with HIV positive individuals, the sample studied by Riggs et al. (2007) was composed of predominantly heterosexual individuals and a large proportion of the sample were women (48%). Results suggested a relationship between attachment style and self-reported stigma among PHA. Secure attachment style was

associated with significantly lower levels of stigma as compared to participants with preoccupied and fearful attachment styles. Also, secure attachment was related to significantly lower levels of stress and depression as compared to all insecure types. Participants with a preoccupied attachment style reported significantly greater overall stigma than those with a dismissing attachment style and significantly greater concerns about disclosure of HIV status as compared to those who were securely attached. Additionally, anxious attachment style and HIV stigma, along with female gender and greater progression of HIV disease (i.e., disease-related infections, higher viral load, lowered immune function) significantly contributed to the prediction of depression. However, the measure of HIV disease progression (i.e. CD4 count decline and increased viral load) proved to be the best single predictor of depression. This investigation has promising results that merit further investigation among patients living with chronic illnesses'. To my knowledge, there are no studies examining the relationship between attachment style and HCV stigma to date. The relationship between attachment style, illness-related stigma, and depression is unclear. It's possible that attachment styles, which involve IWMs of self and other and impact affect regulation, sensitize individuals to illness-related stigma that in turn leads to greater depressive symptoms. Accordingly, the third study of this dissertation will explore whether the well established relationship between attachment style and depressive symptoms is mediated by illness-related stigma in Canadian samples of patients living with HIV/HCV.

### The Present Dissertation

The present dissertation is composed of three studies. Study 1 psychometrically validates a brief HIV Stigma Scale (B-HSS). Specifically, study 1 examines a) internal consistency b)

temporal stability c) construct validity and d) difficulty and discrimination parameters of the B-HSS scale items. Study 2 adapts the B-HSS into the HCV Stigma Scale and examines the psychometric properties of this newly created scale, specifically a) internal consistency, b) temporal stability c) construct validity and d) difficulty and discrimination parameters of each item. Both studies utilize classical test theory (CTT) and item response theory (IRT) methods. Study 3 examines HIV/HCV stigma and depressive symptoms within the framework of attachment theory. Specifically, this study explores whether illness-related stigma mediates the relationship between anxious/avoidant attachment styles and depressive symptoms among PHA and PHC.

#### *Classical Test Theory and Item Response Theory*

CTT is the most common methodology used to examine the psychometric properties of scales. In CTT a test score is considered to consist of the trait level that is being measured and random measurement error (Kline, 2005). The distribution of random error is assumed to be the same for everyone in the sample being tested; this is known as the standard error of measurement. The less random error in a measure the closer it will be to measuring a true score (Kline, 2005). Based upon these assumptions, CTT provides test information predominantly at the level of total test scores (i.e. reliability of the test calculated by Cronbach's alpha) (Kaplan & Saccuzo, 2009; Kline, 2005).

IRT, on the other hand, looks at each individual scale item and considers the level of the measured trait, measurement error, and characteristics of the item, namely item discrimination and item difficulty (Furr & Bacharach, 2008). Item discrimination ( $\alpha_1$ ) is an index of how well the item distinguishes participants who score high versus low on a trait. High item discrimination indicates that an item is very sensitive in detecting changes across trait levels. Items with low discrimination values are not strongly related to the underlying

trait and can be eliminated to increase the accuracy of total scores (Baker, 2001; Furr & Bacharach, 2008). Item difficulty (*b*) is an index that represents the trait level necessary to respond above a certain threshold with a .50 probability (Baker, 2001; Furr & Bacharach, 2008). IRT methods are an important complement to traditional CTT methodology and are increasingly being used to develop new measures in health outcomes research (Reeve, 2003).

Psychometric assessment of a brief measure of internalized HIV stigma (B-HSS) among  
adults living with HIV

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## Abstract

Patients living with HIV (PHA) report anxiety and depression related to stigma, and HIV stigma has been identified as a barrier to treatment and to disclosure of HIV status to intimate partners. Accurate measurement of HIV stigma is the first step in developing stigma interventions and engendering stigma resilience in PHA. A brief and psychometrically sound measure of HIV stigma is critical to ensure accurate measurement. This study aims to evaluate the psychometric properties of the Brief HIV Stigma Scale (B-HSS; Wright et al., 2007). From June to December 2008, PHA were recruited to participate in a questionnaire study at an HIV clinic in The Ottawa Hospital. A sample of 94 PHA participated in the study. Results indicated that the B-HSS is internally consistent ( $\alpha = .88$ ; marginal reliability of 0.91; mean inter-item correlation = 0.41). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from  $r = .53$  to  $.70$ . The only exception was Item 1 ('I am very careful who I tell I have HIV') which correlated at  $r = .27$  with the total scale. Item response theory (IRT) results yielded discrimination values ( $\alpha_i$ ) ranging from .66 to 3.03. Item 1 ( $\alpha_i = .66$ ) was the only item that was poorly discriminatory and was removed from the final scale. Also, results suggested that the scale measured most accurately for those with moderate levels of stigma. Construct validity of the 9-item B-HSS was supported by relationships with related constructs: depression and quality of life. Overall, the 9-item B-HSS is a sound measure that is reliable and valid. The 9-item B-HSS scale is a quick and easy-to-use tool to measure self-perceived stigma that is ideal for use in a clinical setting.

### **Psychometric assessment of a brief measure of internalized HIV stigma (B-HSS) among adults living with HIV**

The HIV/AIDS epidemic is more than thirty years old however HIV remains one of the most stigmatized medical conditions in the world (Mak et al, 2006). Recently, people living with HIV/AIDS (PHA) reported higher levels of stigma than people living with leprosy (Stevenson, Van Brakel, & Augustine, 2011). Contagion and transmission by voluntary socially deviant behaviours (e.g. IV drug use) are central to HIV related stigma (Deacon, 2006; Lee, Kochman, & Sikkema, 2006). Furthermore, there remain misconceptions regarding how HIV is contracted: for instance, the common myth that casual contact with an HIV positive individual leads to transmission of the virus (Herek, Capitanio, & Widaman, 2002).

PHAs report self-blame, anger, decreased self-esteem, hopelessness, loneliness and that they anticipate rejection from others as a result of HIV stigma (Derlega, Winstead, Greene, Serovich, Elwood, 2002; Grove, Golub, Parsons, Brennan, Karpiak, 2010; Lee et al., 2002; Sandelowski, Lamble, & Barroso, 2002; Wong & Wong, 2006). Moreover, studies indicate significant relationships between HIV stigma and psychological distress, namely anxiety and depression (Dowshen, Binns, & Garofalo, 2009; Grove et al., 2010; Hatzenbuehler, O'Cleireigh, Mayer, Mimiaga, Safren, 2011; Lee et al., 2002; Vanable, Carey, Blair, & Littlewood, 2006). The psychosocial effects of stigma are linked to negative physical health outcomes in PHAs including lower immune system functioning and higher HIV viral loads (Logie & Gadalla, 2009; Vanable et al., 2006). Also, HIV stigma has been identified as a barrier to accessing and adhering to HIV treatments (Reif, Golin, & Smith, 2005; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Ware, Wyatt, Tugenberg, 2006). Moreover, concern about social rejection stemming from HIV stigma can be an

obstacle to HIV status disclosure, pose difficulties in negotiating condom use, and is associated with transmission risk behaviours (e.g. unprotected anal intercourse) (Courtenay-Quirk, Wolitski, Parsons, Gomez, 2006; Derlega et al., 2002; Frost, Parsons, Nanin, 2007; Hatzenbuehler et al., 2010). In order to develop approaches that will build stigma resilience in individuals and effective anti-stigma strategies for groups it is necessary to first assess this stigma and its impact over time (Holzemer et al., 2007). The Brief HIV Stigma Scale is a concise and effective psychometric tool that can allow the caregivers of PHA to assess and address stigma.

### *Measures of HIV Stigma*

A limitation of the existing research literature on HIV stigma is that many studies have not utilized psychometrically validated measures of stigma. HIV stigma has commonly been studied qualitatively (e.g. Ware et al., 2006; Wong & Wong, 2006) or by using instruments without psychometric validation created from combining related scales or adapting items from a single scale (e.g. Vanable et al. 2006; Rintamaki et al. 2006; Reif et al., 2005). The HIV Stigma Scale (Berger, Ferrans, Lashley, 2001) is considered a benchmark quantitative measure of HIV stigma that is both reliable and valid (Berger et al., 2001; Rao, Pryor, Gaddist, Mayor, 2008). The 40 item HIV Stigma Scale was developed by Berger and colleagues (2001) based on the stigma literature and psychosocial aspects of having HIV. They utilized seven experts in stigma to evaluate the clarity, comprehensiveness, and relevance of items to the concept of perceived stigma. Thereafter, items were subjected to an exploratory factor analysis (EFA). The EFA yielded 4 factors: personalized stigma, experienced stigma (discrimination), disclosure concerns, and concern with public attitudes towards PHA (Berger et al., 2001). The HIV Stigma Scale yields an

overall total score and subscale scores. The HIV Stigma Scale has been used with a variety of PHA, including minority groups, and women, and the scale has been adapted for use with other disease populations (Berger et al., 2001; Buseh et al., 2008; Jeyaseelan et al., 2013; Relf, Mallinson, Pawlowski, Dolan, Dekker, 2005; Verma et al., 2004). Recently, the HIV Stigma Scale was shortened to facilitate its clinical use with American and Thai youth, respectively (Rongkavilit et al., 2010; Wright et al., 2007). The abbreviated scale for North American youth, which is the focus of this study, was created by choosing a minimum of 2 of the highest loading items in each subscale from Berger et al.'s original factor analysis (Wright et al., 2007). This 10 item abbreviated HIV stigma scale was validated in a very limited fashion with a sample of 48 African American youth. Reliability was examined by calculating coefficient alpha for all subscales. Wright et al. (2007) do not provide further information regarding item selection and did not conduct a factor analysis of the full scale. Preliminary support for predictive validity of the Brief HIV Stigma Scale (B-HSS) was established by positive correlations with self-report measures of general illness severity, depression, and alcohol use (Wright et al., 2007). Despite the limited nature of the validation study, the brief stigma scale has been used and adapted in a number of studies (e.g. Cluver & Orkin, 2009; Palmer et al., 2011; Zhao et al., 2010) indicating a need for a brief, thoroughly validated, and easy-to-administer measure of HIV-related stigma.

In the current study, both classical test theory (CTT) and item response theory (IRT) methodology are used to examine the psychometric properties of the B-HSS in a sample of adults living with HIV. Specifically, internal consistency, temporal stability, and construct validity were evaluated with CTT methodology; overall test reliability, item discrimination and difficulty were evaluated with IRT.

## Method

### *Participants*

Participants were drawn from two separate samples of PHA seen in the HIV clinic of The Ottawa Hospital. The first group of participants (Sample 1) consisted of PHA who were recruited from the HIV clinic to participate in a questionnaire study regarding the psychosocial experience of living with HIV. The second group of participants (Sample 2) were recruited as part of a smoking cessation study evaluating smoking behaviours, mood, and psychological health among PHA. All eligible PHA were recruited, including both anti-retroviral treatment naïve and experienced patients. Sample 1 was used for CTT and IRT analyses and sample 2 was used to examine temporal stability.

### *Procedures*

Participants in sample 1 ( $n = 94$ ) were recruited during their regularly scheduled outpatient HIV clinic visits at The Ottawa Hospital by trained research assistants. Potential participants were invited to take part in a psychological questionnaire study. If the patient was interested in participating, consent documentation was provided and reviewed. The study participants then completed the 30-minute questionnaire package. Participants were compensated \$15.

Similarly, participants in sample 2 ( $n = 32$ ) were recruited as part of separate pilot study. They completed a screening questionnaire on their smoking habits and if the patient met inclusion criteria they were asked if they would like to participate in a study on smoking cessation. All participants enrolled in the study were provided with nicotine patches, four in-person counseling sessions, and telephone-based support. Participants completed a self-report questionnaire package at baseline, quit date, and 4, 12 and 24 weeks post quit dates. At

their first follow-up session participants provided informed consent. Participants were compensated \$10 for each session.

Inclusion criteria for all participants included the following (i) ability to read, write, and speak English (ii) being HIV positive (antibody seropositivity). All study respondents provided oral and written consent prior to participating in the study. The Research Ethics Board of The Ottawa Hospital approved all study procedures and materials.

### ***Measures***

#### *Sociodemographic Information*

The 8-item self-report Patient Information Questionnaire includes questions related to demographic information, relationship status, and sexual orientation.

#### *Health Behaviours*

The Health Behaviours Questionnaire is a 16-item self-report questionnaire that assesses common health behaviors, such as smoking and exercise, which can be risk factors for chronic illness. This measure has been used previously to assess persons living with HIV (Balfour et al., 2007).

#### *Health-related Quality of Life*

The Short-Form Health Survey-12 (SF-12; version 2) is a widely used 12-item measure of health-related quality of life among patients with HIV. The SF-12 generates two composite scores of mental (MCS) and physical health (PCS) (Gandek et al., 1998; Ware, Kosinski, Kellar, 1996). Ware and colleagues (1996) found the SF-12 (v.2) composite scores to have good internal consistency ( $\alpha=.82$  to  $\alpha=.87$  for the PCS;  $\alpha=.70$  to  $\alpha=.84$  for the MCS) in a sample of people living with chronic illnesses (e.g. diabetes, congestive heart failure). In a sample of PHA the SF-12 (v. 2) has demonstrated discriminant validity, successfully

differentiating groups of persons with HIV by disease severity (Delate & Coons, 2000). In this study the MCS had a coefficient alpha of 0.84 and the PCS had a coefficient alpha of 0.88.

### *Depression*

Depressive symptoms were assessed with The Center for Epidemiological Studies-Depression Scale (CES-D). The CES-D is a 20 item measure that asks participants to rate the frequency with which they have experienced symptoms of depression over the past week (Radloff, 1977). The CES-D is a widely used, psychometrically well-validated, self-report screening measure of depression, which has been extensively used in HIV populations (Balfour et al., 2007; Grove et al., 2010; Hoover, Saah, Bacellar, 1993; Linn, Monnig, Cain, Usoh, 1993; Relf et al., 2005). In this study, the CES-D yields a high degree of internal consistency with a coefficient alpha of 0.94.

### *HIV-related Stigma*

The abbreviated 10-item HIV Stigma Scale (Appendix A) is a self-report measure of stigma with preliminary validation of its psychometric properties in a sample of 48 African American youth (Wright et al., 2007). Due to the small sample size and lack of factor analysis/item evaluation the 10-item HIV Stigma Scale is not adequately validated. Further psychometric validation of this scale is the focus of this study.

### *Objective Health Indicators - CD4 count and viral load*

The HIV positive status of the participants was confirmed by medical chart review. Also, the time since HIV diagnosis and values for CD4 count and HIV viral load were obtained by medical chart review.

### ***Data Analysis***

All statistics were conducted with the statistical package SPSS (PASW version 17), unless otherwise specified. Statistical significance was set at  $p < .05$ . The missing values analysis module (expectation maximization) from SPSS was used to calculate missing values that were imputed into the data set (Tabachnick & Fidell, 2004).

### *Classical Test Theory*

*Internal Consistency.* Internal consistency describes the extent to which items on a scale measure the same construct. The internal consistency of the overall B-HSS was examined with a calculation of coefficient alpha and the mean interitem correlation coefficient (Clark & Watson, 1995; Cronbach, 1951). A minimal acceptable level for the reliability coefficient was set at 0.80 (Nunnally & Bernstein, 1994). Mean interitem correlations ranging between 0.15 and 0.50 are considered acceptable (Clark & Watson, 1995). Correlations were also computed between each individual item and the total scale score corrected for that particular item. Item elimination was considered for items with a correlation less than 0.40 (Stevens, 2002).

*Temporal Stability.* Temporal stability is the extent to which scores measured by a scale are stable over time. Pearson correlation was used to examine the stability of the HIV stigma construct by correlating the total B-HSS score at baseline with the 30 day follow-up (deviations of +/- 5 days were considered acceptable) (Peers, 1996). A Pearson correlation coefficient of 0.80 or higher was considered satisfactory for test-retest reliability.

*Construct Validity.* Construct validity is established by demonstrating the ability of the scale to actually measure the construct being investigated. This was first assessed by conducting a principal components analysis (PCA), which evaluates the number of constructs or components assessed by this measure. Any item with at least a loading of 0.30 was

considered to load on that component (Stevens, 2002) and provides evidence that one construct is being measured. Second, Pearson correlations between the B-HSS and years since HIV diagnosis, depression (CES-D), and health-related quality of life (SF-12), which were anticipated to have a relationship with the stigma construct, were calculated to examine concurrent validity (Peers, 1996).

### *Item Response Theory*

Prior to conducting IRT analyses two assumptions must be made: 1) the underlying latent trait must be unidimensional, 2) the response of any one item must not depend on the response of any other item (local independence) (DeMars, 2010). The preliminary assumption of unidimensionality was examined by looking at the principal components analysis (PCA). The residual correlation matrix of the PCA was examined for local independence; residual correlations greater than 0.2 were noted and considered to violate local independence (Reeve et al., 2007). IRT analyses were conducted using the MULTILOG 7.03 program (Thiessen, 1991). Maximum likelihood methods are used to estimate item discrimination ( $\alpha_1$ ) and item difficulty ( $b$ ) parameters. Difficulty values typically range from -3 to +3 and discrimination parameters 1.35 and above can be classified as highly or very highly discriminatory (Baker, 2001). Due to the multiple ordinal response categories of the scale a polytomous graded response model (GRM) was considered appropriate for IRT analysis (Embretson & Reise, 2000; Samejima, 1969).

## Results

### *Sample Characteristics*

*Sample 1.* A total of 102 patients with HIV met eligibility criteria and agreed to participate. Of these eligible participants, 94 completed the questionnaires (92% response rate). Detailed sociodemographic characteristics are presented in Table 1.

*Sample 2.* A total of 50 participants met eligibility criteria for the pilot sample and agreed to participate. Of the 50 eligible participants, 32 adult participants living with HIV completed the survey at baseline and the 30-day follow up (+/- 5 days) (64% response rate).

Sociodemographic characteristics of Sample 2 are presented in Table 1.

### ***Psychometric Properties of the brief HIV Stigma Scale***

Prior to analyses, statistical assumptions were met and missing values were imputed (0.1% imputed in the Sample 1 data set; 0% imputed in the Sample 2 data set).

#### *Internal Consistency*

The 10-item B-HSS demonstrated a high level of internal consistency, with a coefficient alpha of 0.88 (95% CI = 0.54, 0.89) and a mean inter-item correlation of 0.41 ( $n = 94$ ). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from 0.53 to 0.70. The only exception would be item 1 which correlated with the total scale with a correlation of 0.27.

#### *Item Response Theory*

*Preliminary Analyses of IRT.* All IRT analyses were conducted with Sample 1.

*Unidimensionality.* The PCA indicated only one component (or construct) that accounted for 48.2% of the variance ( $n = 94$ ). Component loadings ranged from 0.39 to 0.77. These results suggest the measurement of a single construct by the 10-item B-HSS.

*Local Independence.* The local independence of the items of the B-HSS was determined by examining the residual correlation matrix of the PCA. There were no residual correlations greater than 0.2 suggesting local independence of items (Reeve et al., 2007).

#### *IRT Analyses*

A polytomous GRM was used for IRT analysis. All 10 items of the B-HSS were analyzed. The graphic of the TIC is presented in Figure 1. The TIC of the B-HSS is a unimodal curve with its highest point in the middle of the trait range indicating that the most reliable test scores (and lowest error) are gathered from those who demonstrate an average level of self-perceived stigma. The scale items are less reliable at measuring stigma in those who perceive themselves to be highly stigmatized or not at all stigmatized. Discrimination values for all 10 items are presented in Table 3. The discrimination parameters ranged from  $\alpha_1 = 0.66$  to  $\alpha_1 = 3.03$ . Item 1 was poorly discriminatory while all other items were highly or very highly discriminatory. Difficulty values for the items are presented in Table 4. A majority of the  $b_1$  to  $b_3$  parameters fell within the -3 to +3 range, with the exception of the  $b_1$  parameter of item 1 ( $b_1 = 3.71$ ), which was slightly out of range. Gradually increasing levels of the trait were related to endorsing higher level response categories for all items. Overall, difficulty values were concentrated around and below the midpoint (0) of the trait range indicating that the scale will be a strong measure of average and just below average levels of the HIV stigma trait.

Figure 2 displays the IRCCCs' and the item information curves for two items, item 1 which demonstrated poor discrimination, and item 3 which was strongly discriminatory. Item 3 has distinct and steeply sloping normal curves for each response option of the item. Meanwhile, the response options of Item 1 slope gradually and overlap each other. The item

information curves of the items also illustrated the differing contributions of the items to the scale. Item 3 had a steep unimodal normal curve at the average level of the trait indicating that it is most reliable at this level. Item 1 had a flat curve with no significant distinction at any level of the trait indicating its poor reliability. IRCCC and item information curves for all other items are presented in Appendix B. The B-HSS demonstrated a high level of internal consistency with an MRI of 0.91.

### *9-item B-HSS*

Previous analyses found item 1 to have poor internal consistency and discrimination. As a result, item 1 was removed from the scale and all further analyses were conducted on the 9-item version of the B-HSS. The 9-item B-HSS demonstrated a high level of internal consistency, with a coefficient alpha of 0.89 (95% CI = 0.85, 0.92) and a mean inter-item correlation of 0.47 ( $n = 94$ ). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from 0.55 to 0.70.

An examination of the Scree plot of the PCA, using Stevens (2002) method, indicated all items loaded on a single component, which accounted for 52.63% of the variance. The 9 items had component loadings ranging from 0.63 to 0.79. Results indicated a one-factor solution.

One month test-retest reliability of the 9-item B-HSS based on Sample 2 ( $n = 32$ ) yielded a correlation coefficient of  $r = 0.88$  ( $p < 0.01$ ). Also, there was no significant difference between the mean scores at baseline ( $M = 21.97$ ,  $SD = 5.51$ ) and timepoint 2 ( $M = 21.62$ ,  $SD = 5.86$ ;  $t(31) = 0.70$ ,  $p = .49$  (two-tailed). The magnitude of the differences in the means (mean difference = .34, 95% CI: -.66 to 1.35) was a small effect ( $d = .06$ ).

There was a significant positive correlation between HIV stigma scores on the 9-item B-HSS and depressive symptoms as reported on the CES-D ( $r = 0.67$ ,  $p < 0.01$ ). There was a

significant negative correlation between B-HSS stigma scores and the mental health composite score on the SF-12 ( $r = -0.52, p < 0.01$ ). The 9-item B-HSS was not significantly correlated to the physical health composite scores (PCS) of the SF-12. Also, there was a significant negative correlation between years since HIV diagnosis and self-reported stigma among participants ( $r = -0.25, p < 0.05$ ) with those living longer with HIV reporting less stigma.

## Discussion

This study validated a concise and easy-to-use self-report measure of HIV stigma. In a sample of PHA, results from CTT and IRT analyses suggested that the 9-item B-HSS is a valid and reliable instrument. CTT results suggested a singular construct with internal consistency, stability over time, and concurrent validity. IRT results suggested that the scale was most reliable at an average level of the stigma trait, and that all 9 items were highly or very highly discriminatory. Difficulty values suggested that the 4-point Likert response scale was functioning optimally. Gradually increasing levels of the stigma trait corresponded to responding at higher levels on the Likert scale between all response categories (1 to 4).

## Implications

Overall, these results suggest that removing item 1 ('I am very careful who I tell that I have HIV') from the 10-item B-HSS further strengthened the reliability and validity of the measure. This item represented the disclosure construct from the original Berger et al (2001) scale; this construct is still represented in the 9-item B-HSS. It is possible that item 1 is too broad and does not specifically address a negative or discrediting component resulting from revealing HIV status. For instance, being careful about disclosure does not necessarily result

from feelings of stigma therefore it would fail to discriminate levels of stigma among respondents.

The concise and psychometrically valid 9-item B-HSS has clinical and research applications. Clinically, the results of this study underscore the value of identifying those who perceive themselves to be stigmatized due to HIV. Given the relationships between depression and stigma and health-related QOL it may be particularly significant to address stigma when treating depression among PHA. Moreover, recent research has suggested that HIV stigma may play a pivotal role in hindering posttraumatic growth, which can be defined as an improvement in functioning after a trauma above baseline pre-trauma levels (Murphy & Hevey, 2013). Therefore, if clinicians hope to promote growth and resilience among their patients living with HIV, stigma should be identified and addressed (Murphy & Hevey, 2013). Also, the difficulties with treatment adherence and impact on physical health markers (e.g. immune function) associated with HIV stigma signify that addressing stigma may also lead to improved biological health (Logie & Gadalla, 2009; Rintamaki et al., 2006). In research, a brief scale with good test-retest reliability, such as the 9-item B-HSS, reduces instrument burden and is ideal for repeated measures studies. Longitudinal studies with repeated measures may be particularly important when examining stigma given that living longer with a diagnosis of HIV was related to lower HIV stigma in this study. Positive coping skills and a social network are factors that take time to develop but have been found to provide a degree of psychological acclimatization to the HIV diagnosis and may help to combat HIV stigma (Chenard, 2007; Gonzalez, Solomon, Zvolensky, Miller, 2009).

#### Strengths and Limitations

This study used CTT and IRT to complete a comprehensive psychometric evaluation of a brief HIV stigma scale that has hitherto been a significant gap in the literature. CTT

analyses were conducted with validated instruments in a sample of adults living with HIV, extending initial validation by Wright et al (2007). IRT methodology can often be challenging to employ due to lack of user-friendly software and firm guidelines on models, testing assumptions, and sample size (Fayers, 2007). However, as the results above support, IRT can be a powerful tool to supplement traditional CTT-based psychometrics. In this study, the sample size was relatively small and this may have had an impact on the results from the IRT analyses. Sample size requirements for IRT analyses remain unclear (Fayers, 2007). However, it is generally agreed that larger sample sizes produce more reliable parameters (discrimination and difficulty) therefore the results in this study must be interpreted with this caveat in mind (Embretson & Reise, 2000; Fayers, 2007; Lautenschlager, Meade, Kim, 2006). Moreover, it is unclear if study results generalize to a more diverse, HIV patient population. The study sample consisted of predominantly Caucasian, homosexual males living with HIV therefore study results may not generalize to females, individuals living with HIV in developing countries, and those who are living with other illnesses concurrent to HIV (e.g. diabetes, cardiac conditions, etc.). Moreover, Sample 2 consisted of patients who were HIV+ smokers so there is the possibility that the test-retest reliability results may not generalize to HIV+ non-smokers.

#### Future Directions

Investigators may wish to further validate this brief HIV stigma scale with a larger more diverse HIV+ sample. This would extend the validity of the IRT results in particular. Another avenue of future research would be to establish a cutoff score for a stigma level that is clinically significant by linking scores on the B-HSS to measures of treatment adherence. This could serve as a basis for determining whether an individual is in need of additional

support by the healthcare team (e.g. access to psychology, social work) so as to optimize treatment adherence.

In conclusion, the present study evaluated an easy to use, brief, and psychometrically valid scale to assess self-reported HIV stigma. Given the relationship between HIV stigma, depression, and health-related quality of life this measure fulfills the need for an accessible tool to accurately assess HIV stigma in clinical settings.

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Table 1.

*Descriptive characteristics of HIV patients-Sample 1 and Sample 2*

| Characteristic                                 | n (%) <i>(n=94)</i>     | n (%) <i>(n=32)</i>    |
|--|-------------------------|------------------------|
| Age (mean years $\pm$ SD)                      | 45.13 $\pm$ 9.99        | 45.53 $\pm$ 9.67       |
| Gender   |                         |                        |
| Male   | 73 (77.7%)              | 29 (90.6%)             |
| Female   | 21 (22.3%)              | 3 (9.4%)               |
| Sexual Orientation                             |                         |                        |
| Heterosexual                                   | 32 (36%) <sup>1</sup>   | 11 (34.4%)             |
| Homosexual                                     | 49 (55.1%)              | 20 (62.5%)             |
| Bisexual                                       | 8 (8.9%)                | 1 (3.1%)               |
| CD4 cell count (mean cells/ $\mu$ l $\pm$ SD)  | 500.67 $\pm$ 345.28     | 526.63 $\pm$ 265.29    |
| HIV plasma viral load(mean copies/ml $\pm$ SD) | 3953.87 $\pm$ 18518.36  | 2972.52 $\pm$ 14326.61 |
| Time since HIV diagnosis(mean years $\pm$ SD)  | 10.79 $\pm$ 7.42        | 12.43 $\pm$ 6.44       |
| Ethnicity                                      |                         |                        |
| Caucasian                                      | 62 (69.7%) <sup>1</sup> | 32 (100%)              |
| African  | 11 (12.4%)              |                        |
| Aboriginal                                     | 5 (5.6%)                |                        |
| Other  | 10 (12.4%)              |                        |
| Relationship Status                            |                         |                        |
| Single   | 50 (54.9%) <sup>2</sup> | 22 (68.8%)             |
| Married/Partner                                | 37 (40.7%)              | 10 (9.4%)              |
| Widowed  | 4 (4.4%)                |                        |
| Employment Status                              |                         |                        |
| Working  | 32 (34.5%) <sup>3</sup> | 12 (37.6%)             |
| Disability                                     | 46 (46.3%)              | 16 (50%)               |
| Unemployment                                   | 7 (7.5%)                | 3 (9.4%)               |
| Student  | 3 (3.2%)                |                        |
| Retired  | 8 (8.6%)                | 1 (3.1%)               |
| Education Level                                |                         |                        |
| Elementary                                     | 11 (11.8%) <sup>3</sup> | 1 (3.1%)               |
| High School                                    | 27 (29%)                | 9 (28.1%)              |
| College  | 33 (35.5%)              | 13 (40.6%)             |
| University                                     | 32 (23.7%)              | 9 (28.1%)              |
| Smoking  |                         |                        |
| Currently Smoking                              | 43 (45.7%)              | 32 (100%)              |

<sup>1</sup> Data missing for 5 participants<sup>2</sup> Data missing for 3 participants<sup>3</sup> Data missing for 1 participant

Table 2.

*Means and standard deviations for B-HSS, CESD, and SF-12*

| Measure   | Mean $\pm$ SD<br>(n=94) |
|---|-------------------------|
| Brief-HIV Stigma Scale (9 item)                         | 24.94 $\pm$ 7.19        |
| Center for Epidemiological Studies Scale<br>–Depression | 20.30 $\pm$ 13.97       |
| SF-12 – Mental Composite Scale                          | 44.00 $\pm$ 12.66       |
| SF-12- Physical Composite Scale                         | 42.46 $\pm$ 12.25       |

Table 3.

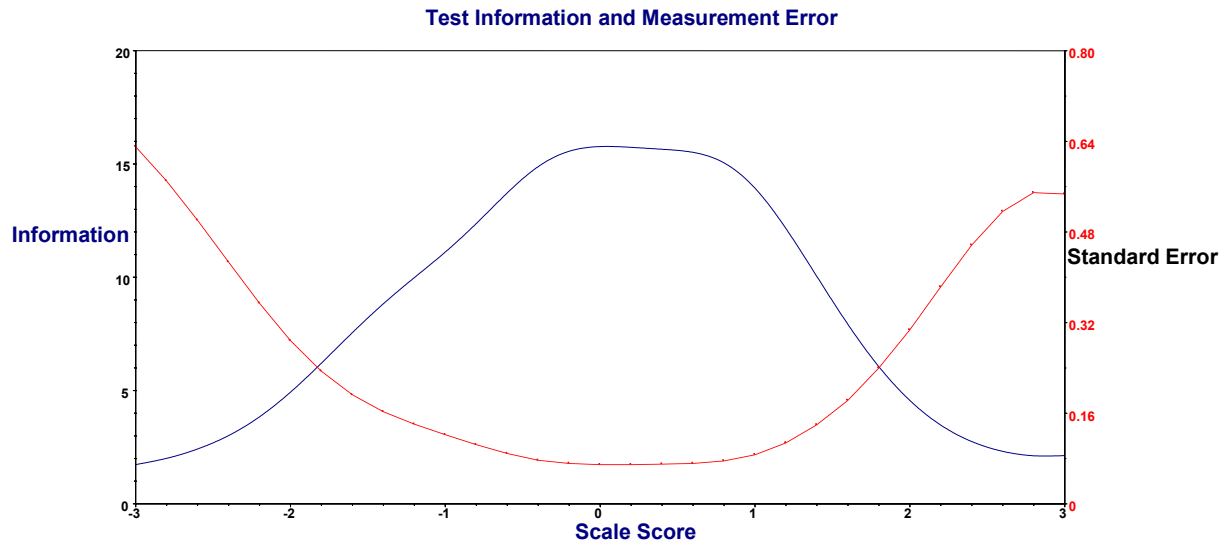
*Discrimination parameters for B-HSS items*

| Item<br>( <i>n</i> =94) | Discrimination<br>( $\alpha_1$ ) | Standard Error<br>(SE) |
|-------------------------|----------------------------------|------------------------|
| 1                       | 0.66                             | 0.30                   |
| 2                       | 2.46                             | 0.49                   |
| 3                       | 3.03                             | 0.55                   |
| 4                       | 2.83                             | 0.66                   |
| 5                       | 2.71                             | 0.51                   |
| 6                       | 2.74                             | 0.68                   |
| 7                       | 1.48                             | 0.37                   |
| 8                       | 2.06                             | 0.51                   |
| 9                       | 1.59                             | 0.44                   |
| 10                      | 2.27                             | 0.76                   |

Table 4.

*Difficulty parameters for B-HSS*

| Item<br>( $n=94$ ) | $b_1$        | $b_2$        | $b_3$        |
|--------------------|--------------|--------------|--------------|
| 1                  | -3.71 (1.81) | -2.25 (0.98) | -0.21 (0.48) |
| 2                  | -0.24 (0.16) | 0.40 (0.17)  | 0.91 (0.24)  |
| 3                  | -0.42 (0.13) | 0.23 (0.17)  | 0.88 (0.21)  |
| 4                  | 0.02 (0.13)  | 0.80 (0.18)  | 1.41 (0.32)  |
| 5                  | -1.12 (0.20) | -0.16 (0.14) | 0.54 (0.19)  |
| 6                  | -1.55 (0.27) | -0.37 (0.13) | 0.98 (0.23)  |
| 7                  | -1.47 (0.39) | -0.48 (0.22) | 0.83 (0.30)  |
| 8                  | -1.00 (0.24) | -0.22 (0.17) | 0.69 (0.23)  |
| 9                  | -0.88 (0.23) | 0.13 (0.22)  | 1.27 (0.40)  |
| 10                 | -1.08 (0.24) | -0.42 (0.17) | 0.53 (0.20)  |



*Figure 1. Test Information Curve for the B-HSS (N=94)*

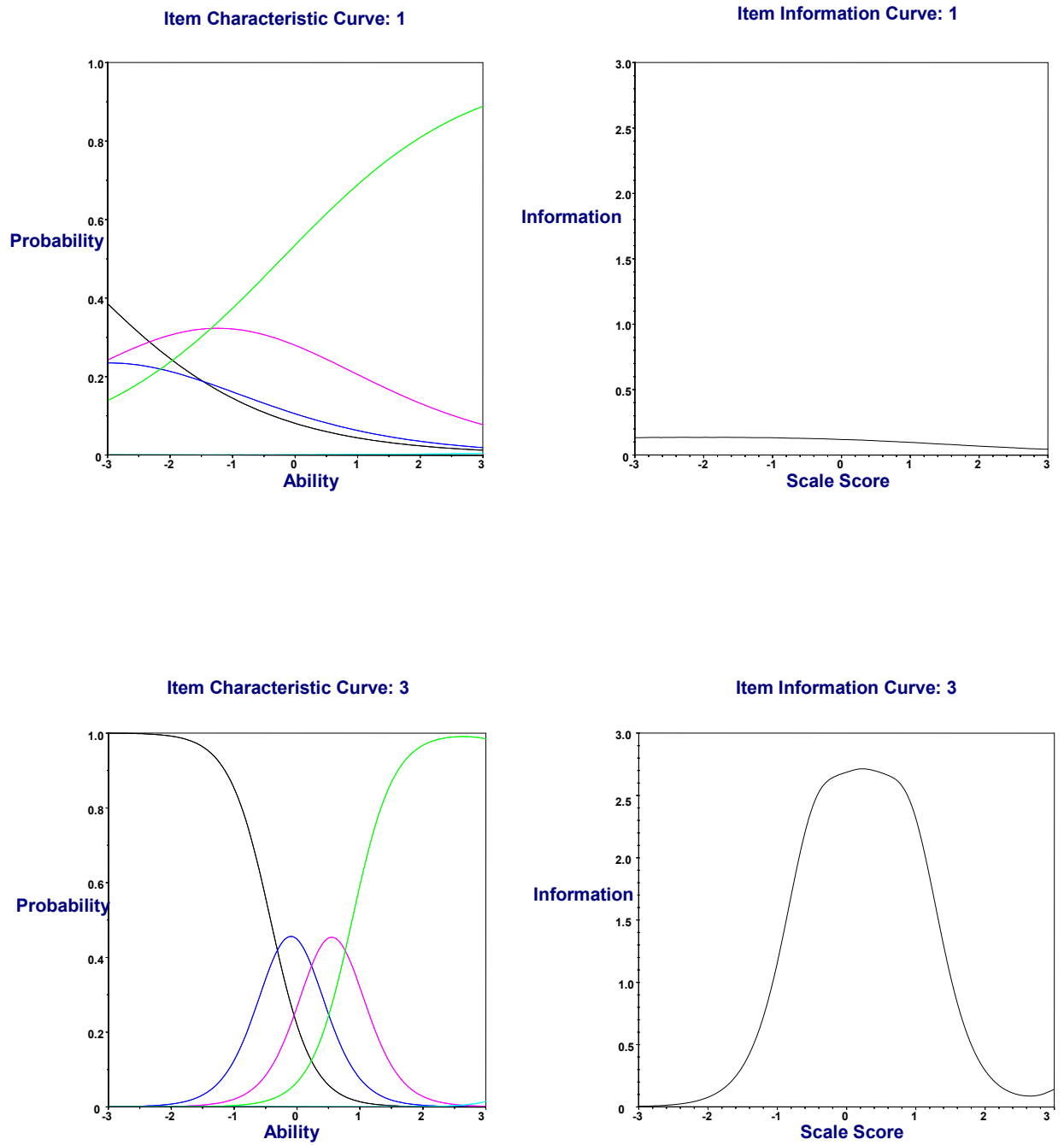


Figure 2. IRCC and item information curves for item 1 and item 3 ( $n=94$ )

## Appendix A

### Brief-HIV Stigma Scale

This scale asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the numbers that go with your answer. There is no right or wrong answer.

This first set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question. For each item, circle your answer:

|  | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|--|----------------------|----------|-------|-------------------|
| 1. I feel that I am not as good a person as others because I have HIV. | 1                    | 2        | 3     | 4                 |
| 2. Having HIV makes me feel unclean.                                   | 1                    | 2        | 3     | 4                 |
| 3. Having HIV makes me feel that I'm a bad person.                     | 1                    | 2        | 3     | 4                 |
| 4. Most people think that a person with HIV is disgusting.             | 1                    | 2        | 3     | 4                 |
| 5. Most people with HIV are rejected when others find out.             | 1                    | 2        | 3     | 4                 |

Many of the items in this next section assume that you have told other people that you have HIV, or that others know. **This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation.** Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

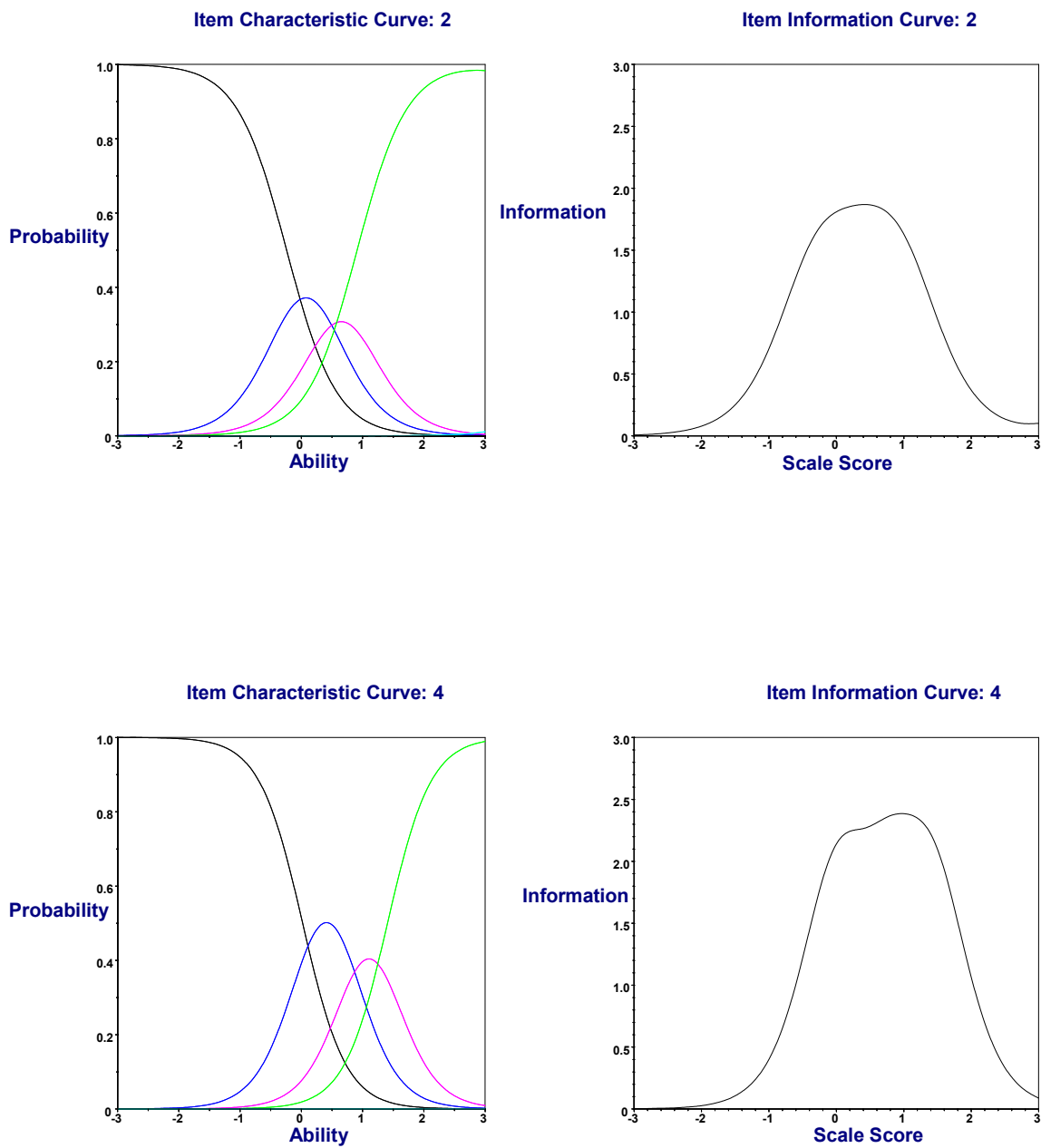
|   | Strongly<br>Disagree | Disagree | Agree | Strongly<br>Agree |
|---|----------------------|----------|-------|-------------------|
| 6. I have been hurt by how people reacted to learning I have HIV.                           | 1                    | 2        | 3     | 4                 |
| 7. I have stopped socializing with some people because of their reactions to my having HIV. | 1                    | 2        | 3     | 4                 |
| 8. I have lost friends by telling them I have HIV.  | 1                    | 2        | 3     | 4                 |
| 9. I worry that people who know I have HIV will tell others.                                | 1                    | 2        | 3     | 4                 |

#### Scoring

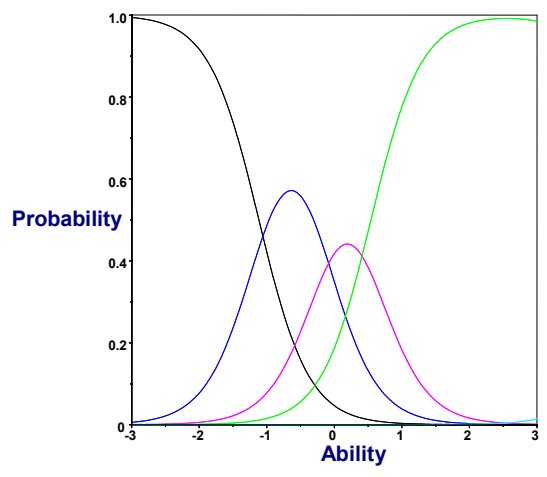
- Add up the values from each question. Higher scores correspond to higher levels of self-perceived stigma

## Appendix B

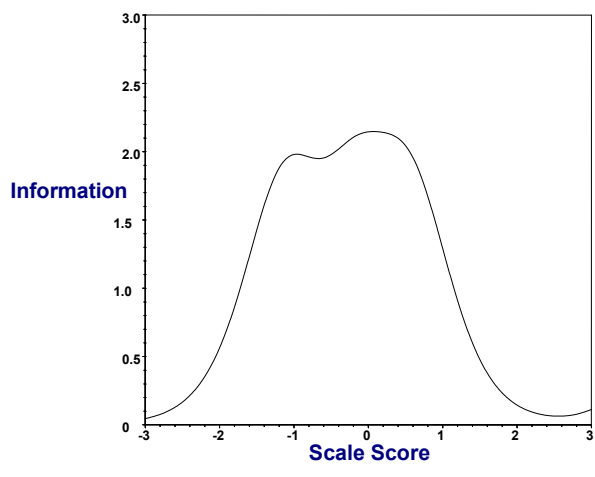
## IRCCC and Item Information Curves for remaining items



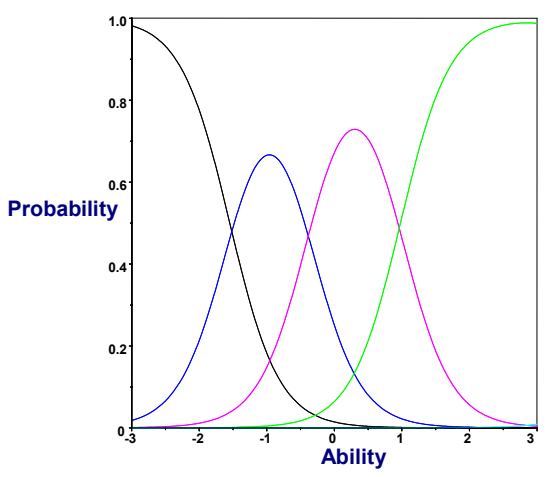
Item Characteristic Curve: 5



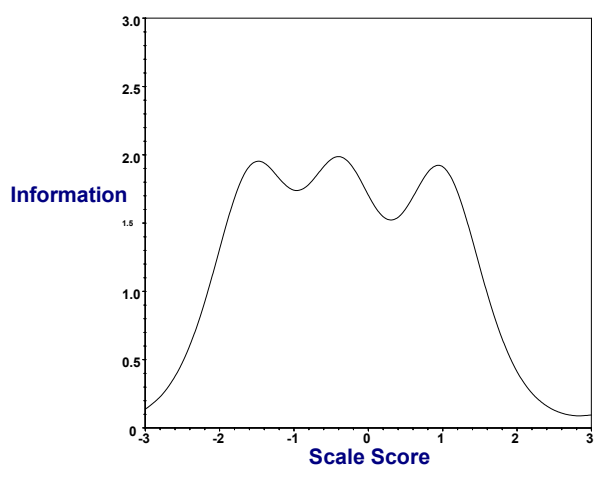
Item Information Curve: 5



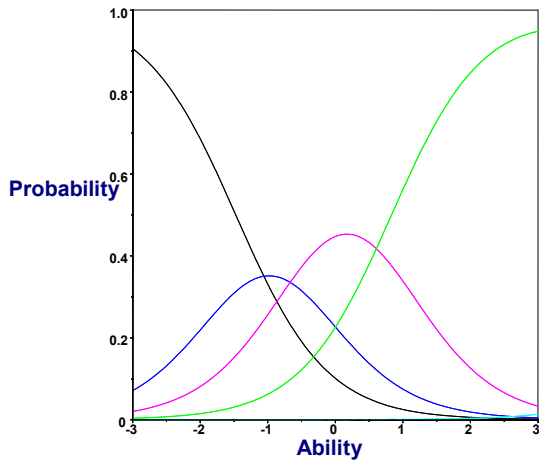
Item Characteristic Curve: 6



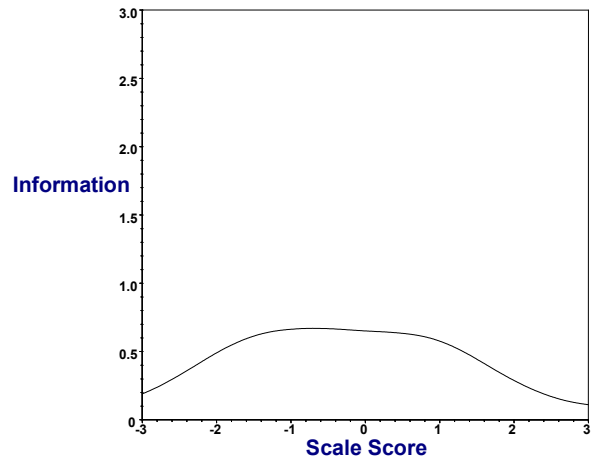
Item Information Curve: 6



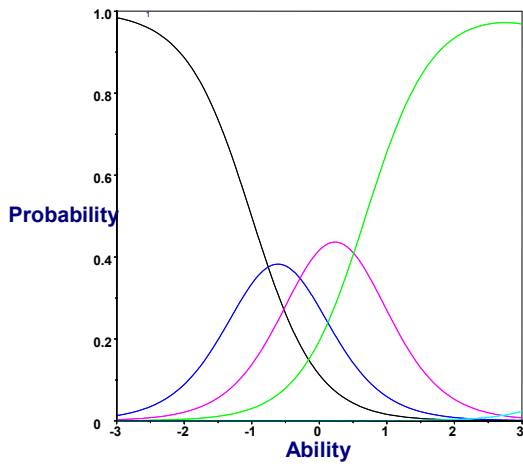
Item Characteristic Curve: 7



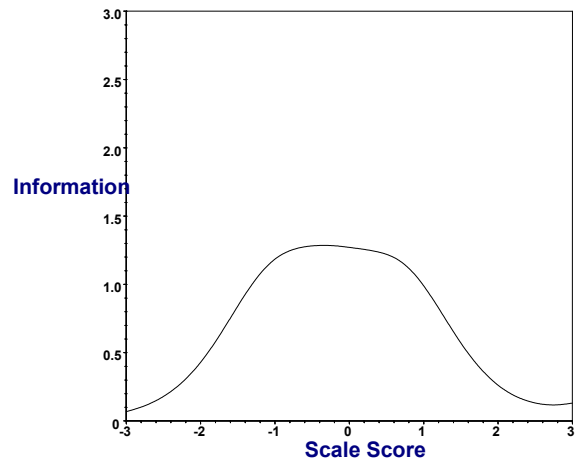
Item Information Curve: 7



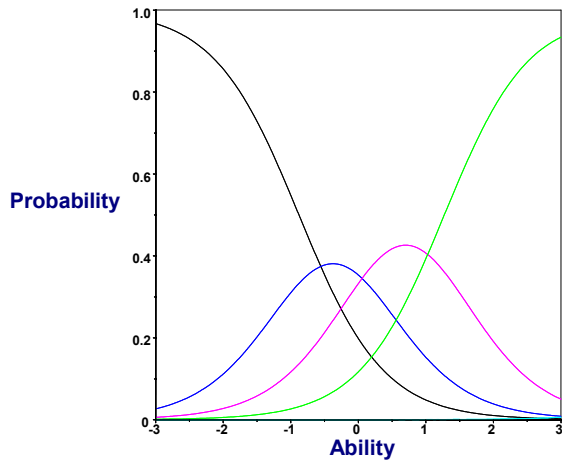
Item Characteristic Curve: 8



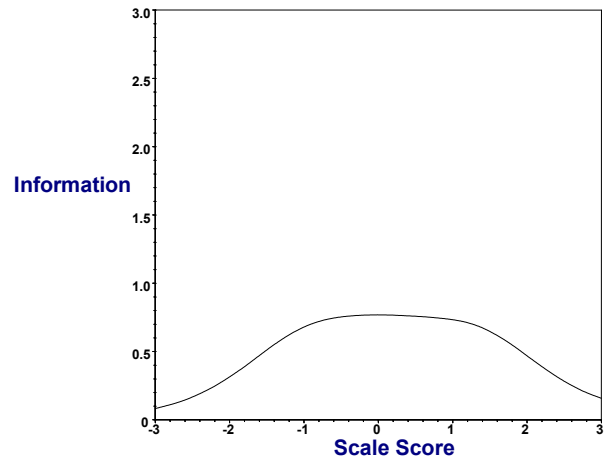
Item Information Curve: 8



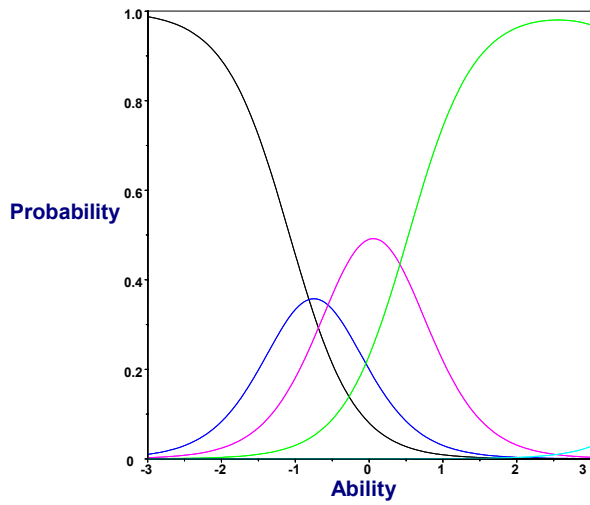
Item Characteristic Curve: 9



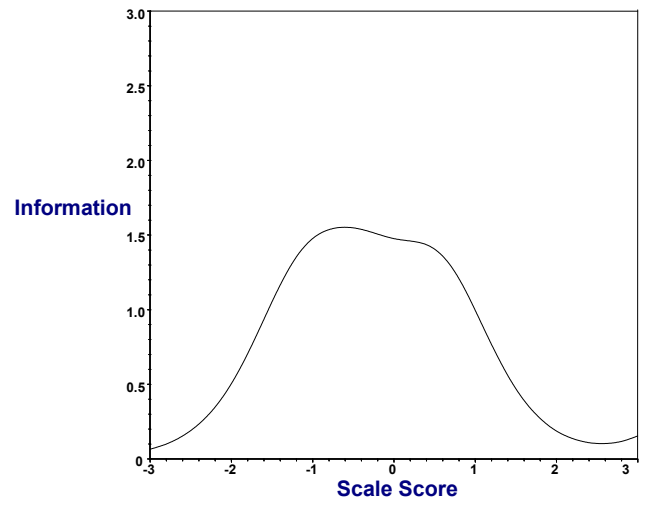
Item Information Curve: 9



Item Characteristic Curve: 10



Item Information Curve: 10



HCV Stigma Scale: Psychometric testing using classical test theory and item response theory

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### Abstract

Hepatitis C (HCV) can be a significant source of stigma due to its communicability and association with intravenous drug-use. HCV stigma can contribute to decreased quality of life, low mood, and be a barrier to accessing health care services. Currently, no psychometrically sound instrument exists for the measurement of HCV stigma. This study evaluated the psychometric properties of a 10-item measure developed to assess self-perceived HCV stigma in a sample of 92 HCV RNA positive patients attending their scheduled appointment at The Ottawa Hospital. The HCV Stigma Scale was internally reliable ( $\alpha = .88$ ; marginal reliability 0.93). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from  $r = .56$  to  $.77$ . The only exception was Item 1 which correlated at  $r = .28$  with the total scale. Construct validity was supported by relationships with related constructs: depression and quality of life. IRT results yielded discrimination values ( $\alpha_i$ ) ranging from  $.49$  to  $9.95$ . Item 1 ( $\alpha_i = .49$ ) was the only item with a poor discrimination level, hence this item was removed from the final version of the scale. The scale measured most accurately for those with moderate levels of stigma. Results suggest that the final 9-item HCV Stigma Scale is both reliable and valid. This measure can be used to accurately identify patients who feel stigmatized. Identifying and being sensitive to patients' HCV stigma may help health care providers increase HCV treatment uptake/ adherence.

*Keywords:* HCV stigma, depression, quality of life

## **HCV Stigma Scale:**

### **Psychometric Testing Using Classical Test Theory and Item Response Theory**

Chronic hepatitis C (HCV) affects an estimated 170 million people worldwide (World Health Organization, 2012). HCV is an RNA virus that infects the cells of the liver and is transmitted primarily by blood to blood contact (National Institute of Health, 2002). In North America transmission occurs predominantly through intravenous drug use (IDU) and shared drug equipment. HCV disease progression can lead to liver cirrhosis, liver cancer, and premature death (National Institute of Health, 2002; Public Health Agency of Canada, 2009). There is effective antiviral therapy (pegylated interferon and ribavarin) for HCV however there are many barriers to treatment uptake and adherence, including substance use, psychological disorders, and stigma (Edlin et al., 2005; Moore, Hawley, & Bradley, 2008; Mulhall & Younossi, 2005; Scheft & Fontenette, 2005).

HCV shares many traits with historically stigmatized diseases, including predominant transmission by socially marginalized behaviour (e.g., IDU), significant fear of contagion from uninfected others, and chronicity (Harris, 2009). HCV patients have identified stigma as a significant barrier to accessing healthcare services, and people at risk of infection have identified stigma as a barrier to being tested for HCV (Butt et al., 2008; Butt, McGuinness, Peltonen, Mitchell, 2012; Evon, Simpson, Esserman, Verma, Fried, 2010; Khaw, Stobbart, & Murtagh, 2007; Moore et al., 2008). Moreover, experiences of HCV stigma have been associated with poor quality of life, depression, anxiety, shame, and difficulties establishing social and intimate relationships (Coughlan, Sheehan, Hickey, & Crowe, 2002; Golden et al., 2005; Lenton, Fraser, Moore, & Treloar, 2011; Strauss & Teixeira, 2006; Zickmund et al., 2003). Researchers have called for a greater understanding of the complex social construction and origin of HCV stigma in order to facilitate treatment uptake/adherence, and

develop strategies that will address HCV stigma at individual and systemic levels (e.g. anti-stigma campaigns, stigma resilience) (Butt, 2008; Butt et al., 2008; Keusch, Wilentz, & Kleinman, 2006). One of the first steps to understanding HCV stigma is the accurate measurement of the phenomena. Currently, there is no psychometrically validated tool to assess HCV stigma (Paterson, Backmund, Hirsch, & Yim, 2007). This study aims to address this limitation in the research by psychometrically validating a new measure of HCV stigma.

Validation of the psychometric properties of a measure can be accomplished through two approaches: classical test theory (CTT) and item response theory (IRT) (Furr & Bacharach, 2008). In the current study, CTT and IRT methods were used to examine the psychometric properties of a newly developed HCV Stigma Scale in a sample of adults living with HCV. The HCV Stigma Scale items were adapted from a shortened HIV stigma measure (Berger, Ferrans, Lashley, 2001, Wright et al., 2007) for use with HCV populations due to the common stigmatizing features of HIV and HCV. Berger et al.'s (2001) scale encompasses factors of personalized stigma, disclosure concerns, negative self-image and concern with public attitudes. It has been adapted to other medical populations and cultural groups who experience stigma, including lung cancer patients, SARS patients, and Thai youth (Cataldo, Slaughter, Jahan, Ponquuan, & Hwang, 2011; Rongkavilit, Wright, Chen, Naar-King, Chuenyam, & Phanuphak, 2010; Verma, Mythily, Chan, Deslypere, Teo, Chong, 2004). Internal consistency, temporal stability, and construct validity were evaluated with CTT methods; overall test reliability, item discrimination and difficulty were evaluated with IRT (Thiessen, 1991).

## Method

### *Participants*

Participants ( $N = 160$ ) were drawn from two samples of HCV-RNA positive outpatients seen at a teaching hospital. The first group of participants (Sample 1,  $n=92$ ) consisted of HCV patients who were recruited from the clinic between June and December 2008 to participate in a questionnaire study regarding the psychosocial experience of living with HCV. The second group of participants (Sample 2,  $n=69$ ) were recruited as part of a longitudinal study evaluating HCV medication readiness in HCV positive participants between September 2010 and June 2011. All eligible HCV patients were recruited including both HCV antiviral treatment naïve and experienced patients. Participant inclusion criteria included (i) ability to read, write, and speak English (ii) HCV RNA + (confirmed by medical chart review). All study respondents provided oral and written consent prior to participation.

### ***Procedures***

Participants for Sample 1 were recruited during their regularly scheduled outpatient HCV clinic visits by trained research assistants (RAs). They were invited to participate in a health-related psychological questionnaire study. Interested participants then completed the 30 minute questionnaire package and were compensated \$15 thereafter.

Participants for Sample 2 were also recruited during their regularly scheduled outpatient HCV clinic visit to participate in a longitudinal questionnaire study. Participants were recruited at any time point during their HCV treatment process (i.e., pre or post HCV antiviral treatment) and received follow-up questionnaire packages for the duration of their HCV treatment (up to one year after the first questionnaire was administered). Participants were compensated \$15 for each completed questionnaire. The Ottawa Hospital's research ethics board approved study procedures and materials.

### ***Measures***

### Sociodemographic Information

The 8-item self-report Patient Information Questionnaire includes questions related to demographic information, relationship status, and sexual orientation.

### Health Behaviours

The Health Behaviours Questionnaire is a 16-item self-report questionnaire that assesses common health behaviors, such as alcohol or recreational drug use, which can be risk factors for chronic illness. It has previously been used to assess HCV patients (Balfour et al., 2004).

### Short-Form Health Survey-12 (SF-12; version 2)

The SF-12 is a well validated quality of life measure with excellent psychometric properties, used with many medical populations including HCV patients (Gifford, O'Brien, Bammer, Banwell, & Stoove, 2003; Mrus, Sherman, Leonard, Sherman, Mandell, & Tsevat, 2006; Ware, Kosinski, Kellar, 1996). In the current study (sample 1) coefficient alpha was .74 for the mental component scale (MCS), and .86 for the physical component scale (PCS), demonstrating a good level of internal consistency.

### The Center for Epidemiological Studies-Depression Scale (CES-D)

*The Center for Epidemiological Studies-Depression Scale (CES-D)* is a 20 item measure that assesses the frequency of depressive symptoms experienced over the past week. Higher scores indicate a greater degree of depressive symptoms with a clinical cut-off score of 16 (scores  $\geq 16$  denote clinical levels of depressive symptoms) (Radloff, 1977). The CES-D is a widely used, psychometrically well-validated, self-report measure of depression, which has been extensively used in HCV populations (Balfour et al., 2004; Clark, Mahoney, Clark, & Eriksen, 2002; Phillips, Prebis, Grumbeck, Hale, Cubillas, & Brown, 2010). In the current study (sample 1) coefficient alpha for the CESD was .90, indicating good internal consistency.

### Hepatitis C Stigma Scale (HCV Stigma Scale)

The newly developed HCV Stigma Scale is adapted from a 10-item HIV Stigma Scale developed by Wright et al. (2007). Wright et al. (2007) chose a minimum of two items that loaded highest on each of the subscales (personalized stigma, discrimination, disclosure concerns, and concern with public attitudes) of the original 40 item HIV Stigma Scale developed by Berger et al. (2001). Adaptation of items for the HCV Stigma Scale was minimal, for instance, the item “Having HIV makes me feel unclean” was adapted to read “Having HCV makes me feel unclean”.

### *Data Analysis*

All data was analyzed using SPSS (v.20), unless otherwise specified. Statistical significance was set at  $p < .05$ , and a two-tailed distribution was employed. The missing values analysis module (expectation maximization) from SPSS was used to calculate missing values that were imputed into the data set (Tabachnick & Fidell, 2004). Sample 1 was used for CTT/IRT analyses, and sample 2 data was used to examine temporal stability.

### *Classical Test Theory*

*Internal Consistency.* The internal consistency of the overall HCV Stigma Scale was examined with a calculation of coefficient alpha and the mean interitem correlation coefficient (Clark & Watson, 1995). A minimal acceptable level for the reliability coefficient was set at 0.80 (Stevens, 2002). Mean interitem correlations ranging between 0.15 and 0.50 were considered acceptable (Clark & Watson, 1995). Correlations were also computed between each individual item and the total scale score corrected for that particular item. Item elimination was considered for items with a correlation less than 0.40 (Stevens, 2002).

*Temporal Stability.* Pearson correlation was used to examine the stability of the stigma construct by correlating the total stigma score at baseline with the 30 day follow-up (deviations of +/- 5 days were considered acceptable) (Kaplan & Saccuzo, 2009). A Pearson correlation coefficient of 0.80 or higher was considered satisfactory for test-retest reliability.

*Construct Validity.* This was assessed by conducting a principal components analysis (PCA) to establish unidimensionality. Any item with a loading of 0.30 or greater was considered to load on the single latent stigma component (Stevens, 2002). Pearson correlations between the HCV Stigma Scale and years since HCV diagnosis, depression (CES-D), and health-related quality of life (SF-12), were calculated to examine concurrent validity (Kaplan & Saccuzo, 2009).

#### Item Response Theory

Prior to conducting IRT analyses two assumptions must be made: 1) the underlying latent trait must be unidimensional, and 2) the response of any one item must not depend on the response of any other item (local independence) (Reeve et al., 2007). The assumption of unidimensionality was examined by looking at the PCA. The residual correlation matrix of the PCA was examined for local independence; residual correlations greater than 0.2 were noted and considered to violate local independence (Reeve et al., 2007). IRT analyses were conducted using the MULTILOG 7.03 program (Thiessen, 1991). Due to the multiple ordinal response categories of the scale a polytomous graded response model (GRM) was considered appropriate for IRT analysis (Embretson & Reise, 2000). Maximum likelihood methods are used to estimate item difficulty ( $b$ ) and item discrimination ( $\alpha_1$ ) parameters. Difficulty values typically range from -3 to +3 and discrimination parameters 1.35 and above can be classified as highly or very highly discriminatory (Baker, 2001).

## Results

### ***Sample Characteristics***

*Sample 1.* A total of 105 HCV patients met eligibility criteria; of these eligible participants 92 completed the questionnaires (88% response rate). Participants were primarily Caucasian (86%) and on disability or sick-leave (59%). Moreover, 41% of participants were on HCV treatment and 20% were treatment experienced. Detailed demographics are presented in Table 1.

*Sample 2.* A total of 144 patients with HCV met eligibility criteria for the study. However, of these eligible participants, 69 completed questionnaires for both time points (55% response rate). Further demographic information is presented in Table 1.

### ***Psychometric Properties of the HCV Stigma Scale***

Prior to analyses, statistical assumptions were met and missing values were imputed (0.02% imputed in the Sample 1 data set; 0.01% imputed in the Sample 2 data set).

#### *Internal Consistency*

The 10 item HCV Stigma Scale demonstrated a high degree of internal consistency demonstrated by  $\alpha=.88$ , 95% CI = 0.84, 0.91, and a mean interitem correlation of 0.43 ( $N=92$ ). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from 0.56 to 0.77. The only exception was item 1 ('I am very careful who I tell I have HCV'), for which the correlation with the total scale was small ( $r = 0.28$ ).

#### *Item Response Theory*

#### *Preliminary Analyses of IRT.*

*Unidimensionality.* Results from the PCA indicated a unidimensional structure for the HCV Stigma Scale. The first component accounted for 49.7% of the variance in the scores, larger than the recommended criterion of 20% (Reckase, 1979). No other component emerged.

*Local Independence.* The residual correlation matrix of the PCA was examined and there were no values greater than 0.2 suggesting local independence of scale items (Reeve et al., 2007).

### *IRT Analyses*

All 10 items of the HCV Stigma Scale were analyzed. The graphic of the test information curve (TIC) is presented in Figure 1. The TIC for the scale was trimodal with two peaks surrounding the middle of the trait range and one peak on the higher end of the trait range. Consequently, the most reliable test scores are gathered from those with average and above average (by approximately one standard deviation (SD)) levels of self-perceived HCV stigma. The scale items are less reliable at measuring stigma in those who perceive themselves to be very highly stigmatized (i.e., 2 SDs above the mean trait level) or not very stigmatized (i.e., 1 SD below the mean trait level). Also, the HCV Stigma Scale demonstrated a high level of internal consistency with an MRI of 0.93.

Discrimination values for all 10 items are presented in Table 2. The discrimination parameters ranged from  $\alpha_1 = 0.49$  to  $\alpha_1 = 9.95$ . Item 1 was poorly discriminatory. All other items were highly or very highly discriminatory and Item 8 is of note with a discrimination parameter ( $\alpha_1 = 9.95$ ) that was substantially greater than those of other items. Table 3 contains the difficulty values for the 10 items. The majority of values within the  $b_1$  to  $b_3$

parameters fell within the acceptable range of -3 to +3 with the exception of the  $b_1$  parameter for item 1 ( $b_1 = -3.67$ ). Higher level responses were endorsed with gradually increasing levels of the trait amongst the  $b_1$  to  $b_3$  parameters. The majority of values between the parameters were concentrated around average and slightly above average trait levels indicating that the scale will best measure the trait at these levels.

Figure 2 displays the item response category characteristic curves (IRCCC) and the item information curve for two items, Item 2, which demonstrated moderate discrimination, and Item 8 which was very strongly discriminatory. This distinction can be seen when comparing the IRCCC of both items. Item 2 has distinctive and steep sloping normal curves for each response option of the item, which corresponds with its more moderate discrimination parameter ( $\alpha_1 = 1.60$ ). The response options of Item 8 have very steep slopes in comparison, the almost vertical slope for all of the response options correspond with its strongly discriminatory parameter. Item information curves for the items were also distinct. Item 2 has a mostly flat unimodal curve around the average level of the trait indicating that it is most reliable at this level. Item 8 has a distinctive trimodal curve with significant distinctions around the average level of the trait and above the average level of the trait (approximately between 1 and 2 *SDs* above the trait mean) indicating greater reliability at these points. The IRCCC and item information curves of all items (excluding items 2 and 8) are presented in Appendix A.

### *9 item HCV Stigma Scale*

Above analyses found item 1 to have poor discrimination and difficulty. Also, it was inconsistent with other items in the scale reducing the overall internal consistency of the scale. Consequently, item 1 was removed from the scale and all further analyses were

conducted on the 9-item version of the HCV Stigma Scale. The 9 item HCV Stigma Scale demonstrated a high level of internal consistency ( $\alpha = .89$ , 95% CI = 0.86, 0.92) and a mean interitem correlation of 0.48 ( $n=92$ ). Correlations among individual items and the total scale also indicated a high degree of internal consistency with values ranging from 0.55 to 0.80. An examination of the Scree plot of the PCA, using Stevens (2002) method, indicated all items loaded on a single component, which accounted for 54.23% of the variance. The 9 items had component loadings ranging from 0.64 to 0.87. Results indicated a one-factor solution.

One month test-retest reliability of the 9-item HCV Stigma Scale, based on Sample 2 ( $N = 69$ ), yielded a correlation coefficient of  $r = 0.80$  ( $p < 0.001$ ). Also, there was no significant difference between the mean scores at baseline ( $M = 17.93$ ,  $SD = 6.32$ ) and time-point 2 ( $M = 17.52$ ,  $SD = 5.88$ );  $t(68) = 0.87$ ,  $p = .40$  (two-tailed). The magnitude of the differences in the means (mean difference = .41, 95% CI: -.53 to 1.34) was a negligible effect ( $d = .08$ ).

There was a significant positive correlation between stigma scores on the 9-item HCV Stigma Scale and depressive symptoms reported on the CES-D ( $r = 0.43$ ,  $p = 0.01$ ). There was a significant negative correlation between the 9-item HCV stigma scores and the MCS scale on the SF-12 ( $r = -0.38$ ,  $p = 0.01$ ) (means and standard deviations presented in Table 4). The 9-item HCV Stigma Scale was not significantly correlated to years since HCV diagnosis ( $r = -0.008$ ,  $p = 0.94$ ) or the PCS scale of the SF-12 ( $r = -.14$ ,  $p = 0.18$ ). The final 9-item scale is presented in Appendix B.

## Discussion

The research findings of this study support the validity and reliability of the brief 9-item HCV Stigma Scale. Item 1 was not sensitive to the varying levels of stigma and was found to be inconsistent with the underlying HCV stigma construct. This item represented the disclosure factor from the original Berger et al. (2001) scale; this factor is still represented by an item in the 9-item HCV Stigma Scale. Inclusion of a poor item reduces the validity and reliability of a scale; therefore, item 1 was removed from the scale and analyses were performed on the 9-item HCV Stigma Scale. The final (9-item) HCV Stigma Scale represents all aspects of the stigma construct that composed Berger et al.'s original scale. Moreover, it was found to be internally consistent, stable over time, and demonstrated theoretically supported relationships to depression and mental health-related QOL. IRT analyses indicated that the scale was most reliable at average and above average levels of the stigma trait, and that all items were highly or very highly discriminatory. Difficulty values suggested that the 4-point Likert response scale was functioning optimally. Gradually increasing levels of the stigma trait corresponded to responding at higher levels on the Likert scale between all response categories (1 to 4).

## *Implications*

A brief psychometrically sound HCV Stigma Scale could be utilized in healthcare settings to identify those who are impacted by HCV-related stigma. The importance of identifying those who are stigmatized is underscored by the relationship found in this study and established in previous research between HCV stigma, increased depression, and reduced QOL (Coughlan et al., 2002; Golden et al., 2005; Strauss & Teixeira, 2006). If this is the case, then assessment of HCV stigma perceptions among all HCV patients, regardless of

illness severity, would be beneficial. For the purposes of widespread use and ease of administration, a brief measure is ideal for use by healthcare professionals in clinical settings. Furthermore, study results emphasize the continued importance of awareness and sensitivity by HCV healthcare providers of HCV stigma as a barrier to treatment uptake. Identifying and addressing stigma early in a patient's contact with a health care team could maximize the number of HCV patients who choose to be treated (Butt et al., 2012; Zickmund et al., 2003). Stigma may exacerbate depressive symptoms, which is a side-effect of interferon-based HCV antiviral treatment. Therefore, addressing stigma prior to treatment may have implications for treatment readiness and adherence.

In this study no relationship was found between time since HCV diagnosis and HCV stigma. However, Butt et al. (2008) suggests that the experience of HCV stigma may change over time and a brief valid measure of stigma would be ideal to examine these changing experiences with minimal instrument burden. Given the good temporal stability of the 9-item HCV Stigma Scale any scale score changes observed over time could be reliably attributed to true change in self-perceived stigma.

### *Strengths and Limitations*

A significant strength of this study is its comprehensive validation of the HCV Stigma Scale through CTT and IRT methodologies. Results from both analyses provided complimentary information that assisted in the identification of an item with poor discrimination that was not highly related to the stigma construct resulting in a more reliable and valid measure of HCV stigma. Moreover, until this study, the development of an HCV specific stigma measure was a significant gap within the literature. Further strengths of this study include the use of validated measures to examine concurrent validity and an independent sample to examine test stability over time. A limitation of this study is the

sample size used in the IRT analyses. Research suggests that larger sample sizes produce more reliable parameters (discrimination and difficulty). Therefore, the results in this study may be unstable and must be interpreted with some caution (Embretson & Reise, 2000; Fayers, 2007). It is possible that stigma measured in this study may be contaminated by stigma related to other conditions experienced by the patient sample (e.g. stigma from co-morbidities, including HIV). Furthermore, results from this study may not generalize to a diverse non-hospital population including people in prison or those who are more marginalized (e.g. homeless, active IDU).

#### *Future Directions*

Studies that expand on the current research may wish to replicate the findings with a larger and more diverse sample of participants. This replication would be particularly salient for the IRT portion of the analyses and could further investigate the reliability of the discrimination and difficulty parameters. Also, future investigators may want to consider the development of a clinically significant cut-off score on the stigma scale by relating stigma scores to measures of adherence or to attendance of treatment appointments. The 9-item HCV Stigma Scale serves as a useful, psychometrically valid scale that would be ideal to assess and identify patients experiencing HCV-related stigma in a clinical setting and could ultimately contribute to improved health care utilization and quality of life for patients living with HCV.

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Table 1

*Descriptive Characteristics of HCV Patients in Sample 1 and Sample 2*

| Characteristic                                    | Sample 1 (n=92)<br>n(%) | Sample 2 (n=69)<br>n(%) |
|---|-------------------------|-------------------------|
| Age (mean years $\pm$ SD)                         | 47.35 $\pm$ 9.24        | 48.17 $\pm$ 10          |
| Gender  |                         |                         |
| Male  | 64 (69.6%)              | 43 (62.3%)              |
| Female  | 28 (30.4%)              | 26 (37.7%)              |
| Sexual Orientation                                |                         |                         |
| Heterosexual                                      | 72 (87.8%) <sup>a</sup> | 61 (93.8%) <sup>b</sup> |
| Homosexual  | 6 (7.3%)                | 1 (1.5%)                |
| Bisexual  | 4 (4.9%)                | 3 (4.6%)                |
| Baseline ALT (mean cells/ $\mu$ l $\pm$ SD)       | 73.04 $\pm$ 73.55       | ---                     |
| Time since HCV diagnosis<br>(mean years $\pm$ SD) | 3.76 $\pm$ 3.48         | 12.33 $\pm$ 10.49       |
| Ethnicity   |                         |                         |
| Caucasian   | 78 (85.7%) <sup>c</sup> | 59 (85.5%)              |
| African   | 5 (5.5%)                | 2 (2.9%)                |
| Aboriginal  | 6 (6.6%)                | 3 (4.3%)                |
| Other   | 2 (2.2%)                | 5 (7.2%)                |
| Relationship Status                               |                         |                         |
| Single  | 49 (53.8%) <sup>c</sup> | 21 (30.9%) <sup>f</sup> |
| Married/Partner                                   | 37 (40.7%)              | 35 (51.5%)              |
| Separated/Widowed                                 | 5 (5.5%)                | 12 (17.6%)              |
| Employment Status                                 |                         |                         |
| Working   | 19 (21.2%) <sup>d</sup> | 25 (36.7%) <sup>f</sup> |
| Disability  | 53 (58.8%)              | 28 (41.2%)              |
| Unemployment                                      | 11 (12.2%)              | 3 (4.4%)                |
| Retired   | 6 (6.7%)                | 7 (10.3%)               |
| Other   | 1 (1.1%)                | 5 (7.4%)                |
| Education Level                                   |                         |                         |
| Elementary  | 12 (13.3%) <sup>d</sup> | 9 (13.2%) <sup>f</sup>  |
| High School                                       | 41 (45.6%)              | 35 (51.5%)              |
| College   | 30 (33.3%)              | 16 (23.5%)              |
| University  | 7 (7.8%)                | 8 (11.8%)               |
| Injection Drug Use                                |                         |                         |
| Used Previously                                   | 65 (70.7%)              | 38 (58.5%)              |
| Never Used  | 27 (29.3%)              | 27 (41.5%)              |

<sup>a</sup>Data were missing for 10 participants<sup>b</sup>Data were missing for 4 participants

<sup>c</sup>Data were missing for 1 participants<sup>d</sup>Data were missing for 2 participants

Table 2

*Item Response Theory Discrimination Parameters for HCV Stigma Scale Items*

| Item<br>( <i>n</i> =92) | Discrimination ( $\alpha$ ) | Standard Error (SE) |
|-------------------------|-----------------------------|---------------------|
| 1                       | 0.49                        | 0.34                |
| 2                       | 1.60                        | 0.41                |
| 3                       | 1.63                        | 0.50                |
| 4                       | 1.97                        | 0.54                |
| 5                       | 1.52                        | 0.55                |
| 6                       | 1.59                        | 0.45                |
| 7                       | 3.24                        | 0.77                |
| 8                       | 9.95                        | 2.05                |
| 9                       | 4.72                        | 0.76                |
| 10                      | 2.21                        | 0.44                |

Table 3

*Item Response Theory Difficulty Parameters for HCV Stigma Scale*

| Item<br>( <i>n</i> =92) | $b_1$        | $b_2$        | $b_3$       |
|-------------------------|--------------|--------------|-------------|
| 1                       | -3.67 (1.73) | -1.95 (2.18) | 1.50 (1.39) |
| 2                       | -0.56 (0.25) | 0.48 (0.24)  | 2.00 (0.69) |
| 3                       | -0.68 (0.26) | 0.38 (0.25)  | 1.90 (0.65) |
| 4                       | -0.37 (0.21) | 0.90 (0.26)  | 1.77 (0.53) |
| 5                       | -1.23 (0.36) | -0.01 (0.22) | 1.96 (0.44) |
| 6                       | -1.75 (0.41) | -0.05 (0.20) | 2.33 (0.73) |
| 7                       | -0.87 (0.19) | 0.16 (0.13)  | 1.42 (0.30) |
| 8                       | -0.55 (0.07) | 0.23 (0.08)  | 1.44 (0.19) |
| 9                       | -0.62 (0.13) | 0.48 (0.13)  | 1.29 (0.30) |
| 10                      | -0.81 (0.25) | -0.14 (0.17) | 1.19 (0.35) |

Table 4

*Means and Standard Deviations for HCV Stigma Scale (9-item), CESD, and SF-12*

| Measure<br>(n=92)  | Mean $\pm$ SD     |
|--|-------------------|
| HCV Stigma Scale (9 item)                                | 22.05 $\pm$ 6.35  |
| Center for Epidemiological Studies Scale –<br>Depression | 25.00 $\pm$ 11.65 |
| SF-12 – Mental Composite Scale                           | 39.10 $\pm$ 9.35  |
| SF-12- Physical Composite Scale                          | 37.30 $\pm$ 11.13 |

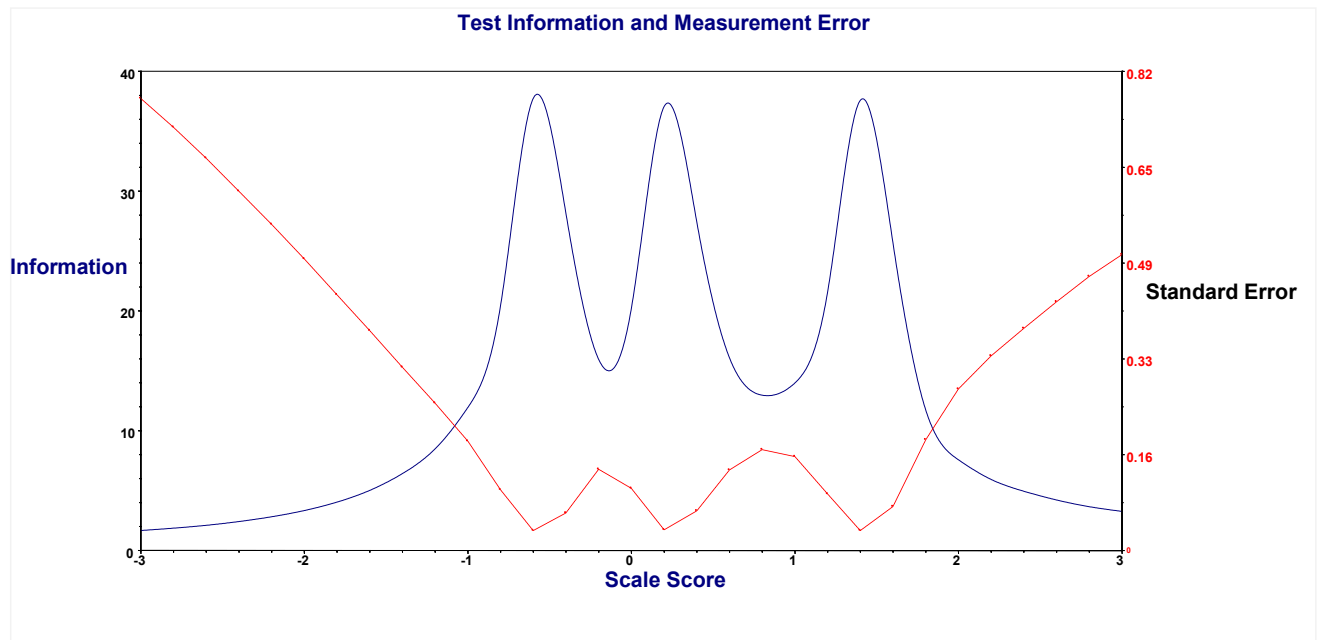


Figure 1. Test information curve for HCV Stigma Scale

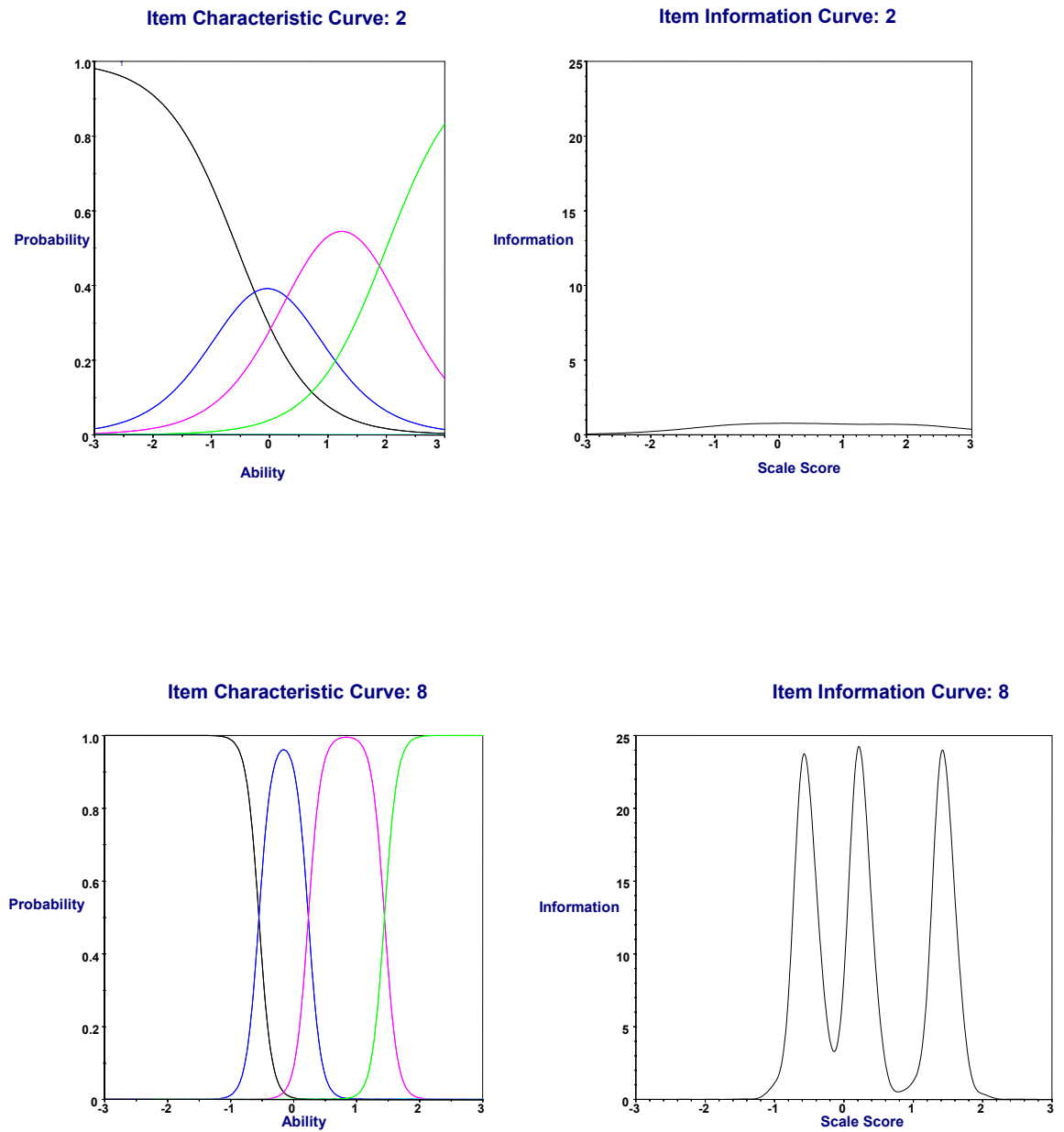
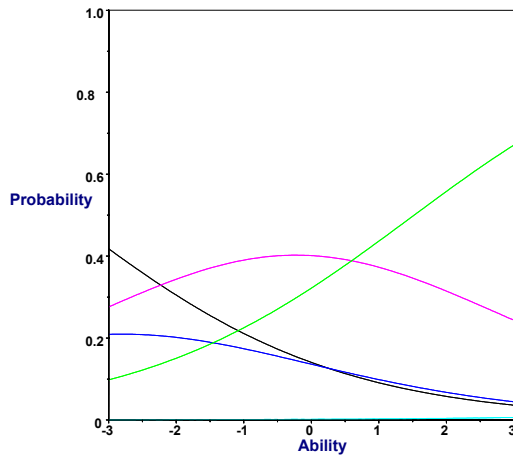


Figure 2. IRCC and item information curves for item 2 and item 8

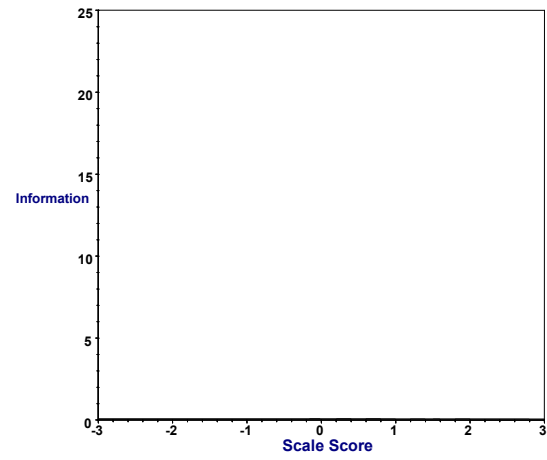
## Appendix A

IRCCC and item information curves for remaining items (excluding items 2 and 8 featured in Figure 2)

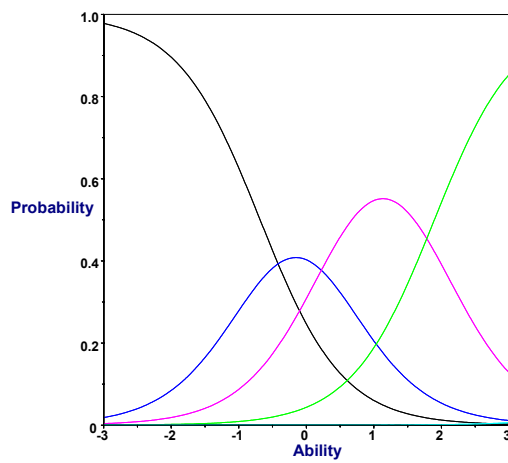
Item Characteristic Curve: 1



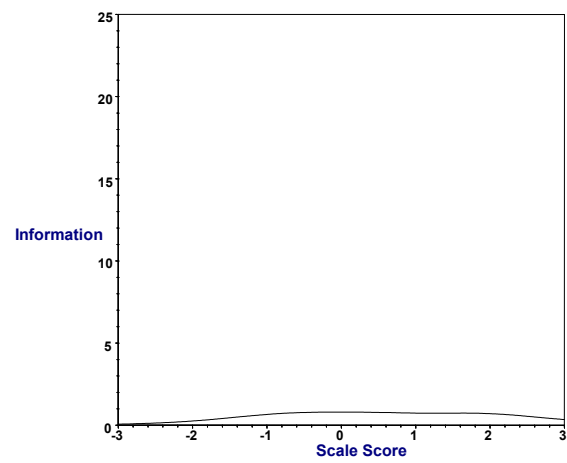
Item Information Curve: 1



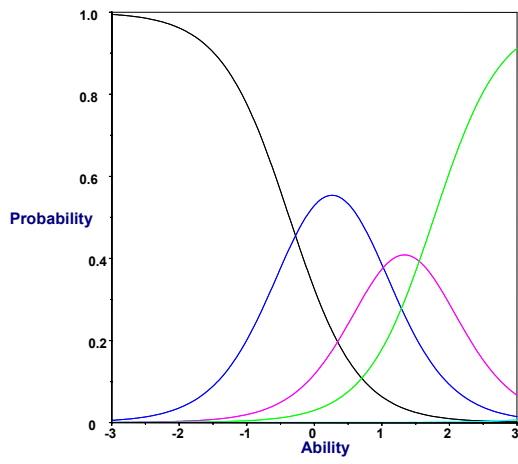
Item Characteristic Curve: 3



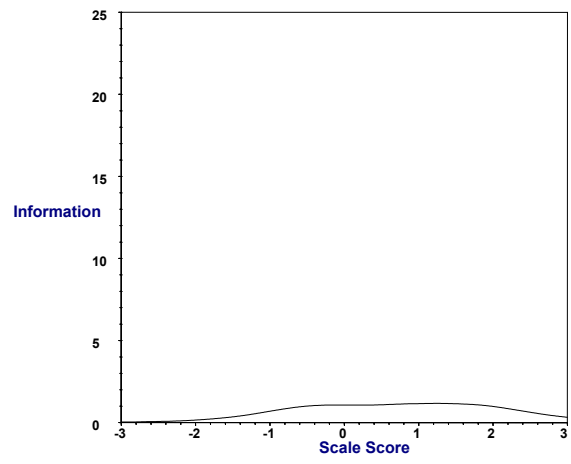
Item Information Curve: 3



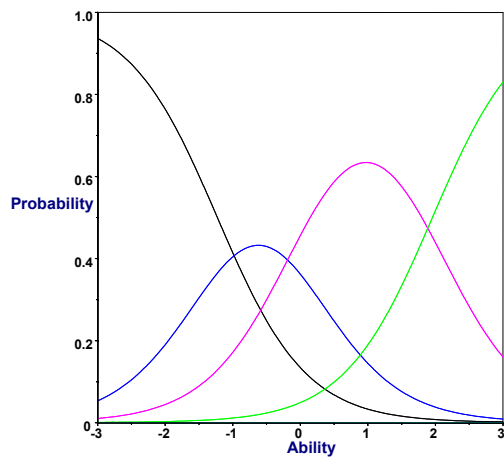
Item Characteristic Curve: 4



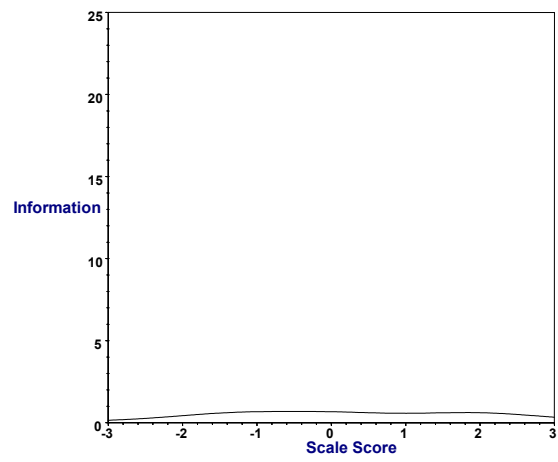
Item Information Curve: 4



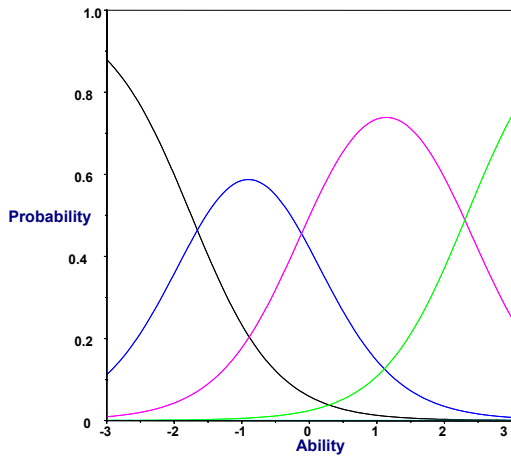
Item Characteristic Curve: 5



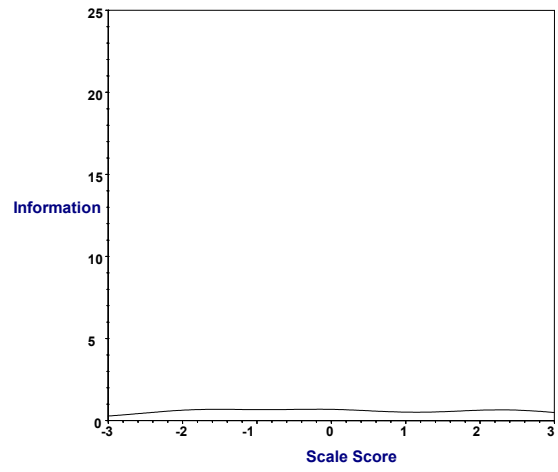
Item Information Curve: 5



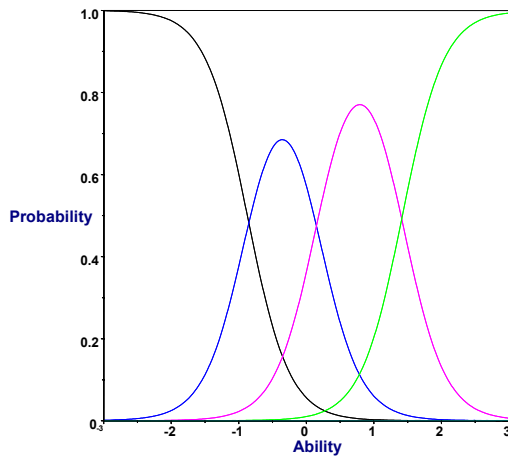
Item Characteristic Curve: 6



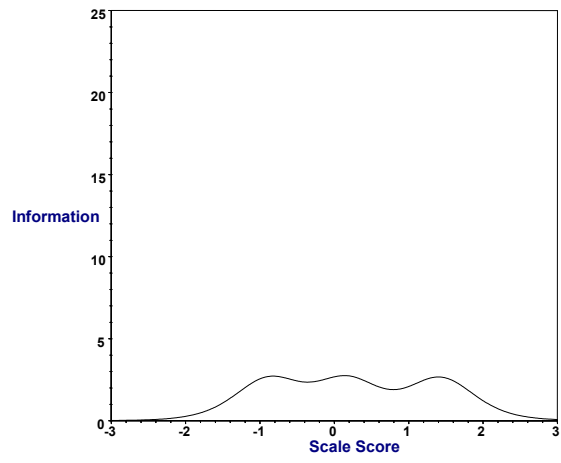
Item Information Curve: 6



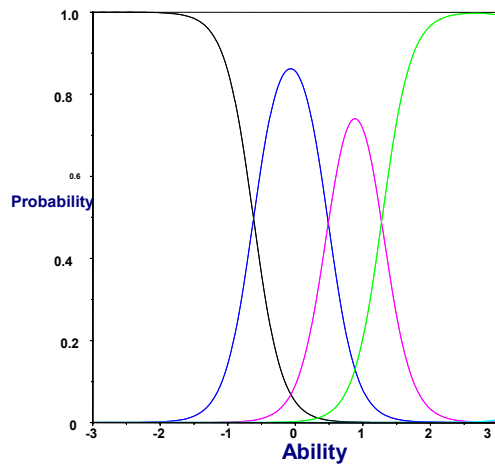
Item Characteristic Curve: 7



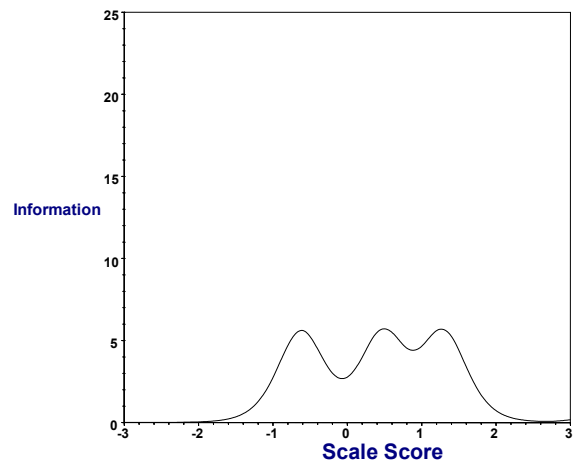
Item Information Curve: 7



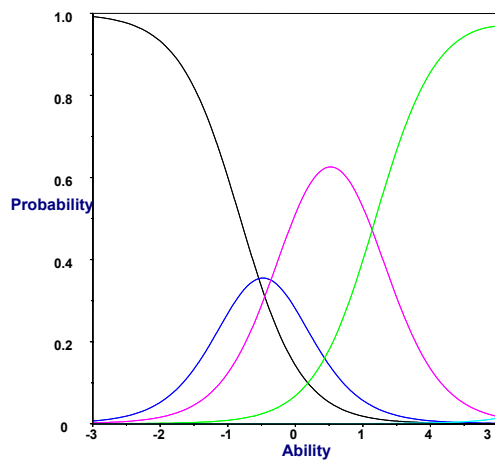
Item Characteristic Curve: 9



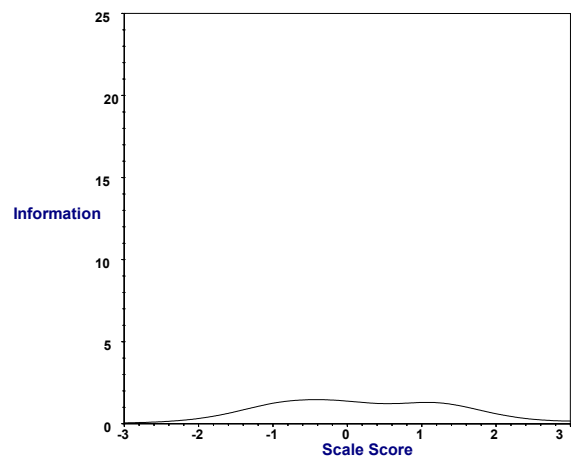
Item Information Curve: 9



Item Characteristic Curve: 10



Item Information Curve: 10



## Appendix B

### Hepatitis C Stigma Scale

This study asks about some of the social and emotional aspects of having Hepatitis C. For most of the questions, just circle the numbers that go with your answer. There are no right or wrong answers.

**Feel free to write in comments as you go through the questions.** This first set of questions asks about some of your experiences, feelings, and opinions as to how people with Hepatitis C feel and how they are treated. Please do your best to answer each question. For each item, circle your answer: **Strongly disagree (1), disagree (2), agree (3), or strongly agree (4).**

|  | Strongly Disagree | Disagree | Agree | Strongly Agree |
|--|-------------------|----------|-------|----------------|
| 1. I feel that I am not as good a person as others because I have Hepatitis C. | 1                 | 2        | 3     | 4              |
| 2. Having Hepatitis C makes me feel unclean.                                   | 1                 | 2        | 3     | 4              |
| 3. Having Hepatitis C makes me feel that I'm a bad person.                     | 1                 | 2        | 3     | 4              |
| 4. Most people think that a person with Hepatitis C is disgusting.             | 1                 | 2        | 3     | 4              |
| 5. Most people with Hepatitis C are rejected when others find out.             | 1                 | 2        | 3     | 4              |

Many of the items in this next section assume that you have told other people that you have Hepatitis C, or that others know. **This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation.** Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

|   | Strongly Disagree | Disagree | Agree | Strongly Agree |
|---|-------------------|----------|-------|----------------|
| 6. I have been hurt by how people reacted to learning I have Hepatitis C.                           | 1                 | 2        | 3     | 4              |
| 7. I have stopped socializing with some people because of their reactions to my having Hepatitis C. | 1                 | 2        | 3     | 4              |
| 8. I have lost friends by telling them I have Hepatitis C.  | 1                 | 2        | 3     | 4              |
| 9. I worry that people who know I have Hepatitis C will tell others.                                | 1                 | 2        | 3     | 4              |

Illness-based Stigma Mediates the Relationship between Insecure Attachment and  
Depressive Symptoms among Patients with HIV and Hepatitis C

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## Abstract

**Objective:** Insecure attachment may contribute to disease risk by increasing susceptibility to stress, increasing use of unhealthy coping strategies, and reducing attendance to medical appointments. Among people living with HIV/AIDS (PHA), insecure attachment (anxious and avoidant styles) has been linked to symptoms of depression and disease-related stigma. People living with hepatitis C (HCV) (PHC) report high levels of depression corresponding with a greater degree of stigma. This study investigated whether stigma explains the relationship between insecure attachment and depression among PHA and PHC.

**Method:** Between June to December 2008, PHA (antibody seropositivity) ( $n=72$ ) and PHC (HCV RNA +) ( $n=83$ ) were recruited to participate in a questionnaire study at an outpatient clinic in The Ottawa Hospital.

**Results:** Bootstrapping methods to test indirect effects indicated that stigma was a significant mediator of the relationship between attachment insecurity and depression among PHA and PHC.

**Conclusions:** The effective management of depression involves the treatment of illness-based stigma and the recognition of attachment styles among patients living with HIV and HCV.

Also, study results provide support for the model whereby attachment insecurity corresponds with poor coping in the context of illness.

*Keywords:* HIV stigma, HCV stigma, attachment style, depression

## **Illness-based stigma mediates the Relationship between Insecure Attachment and Depressive Symptoms among Patients with HIV/Patients with HCV**

Due to advancements in highly active anti retroviral therapies (HAART), HIV can now be characterized as a lifelong chronic illness in developed countries. However, HIV continues to be associated with many significant challenges, such as a daily medical regimen, inadequate social supports, and encounters with HIV stigma (Grove, Golub, Parsons, Brennan, & Karpiak, 2010; Konkle-Parker, Erlen, & Dubbert, 2008; Simbayi et al., 2007). For a proportion of patients, living with HIV is linked to feelings of self-blame, loneliness, anxiety, and depression (Derlega, Winstead, Greene, Serovich, Elwood, 2002; Dowshen, Binns, & Garofalo, 2009; Grove, Golub, Parsons, Brennan, Karpiak, 2010; Lee, Kochman, & Sikkema, 2002; Sandelowski, Lamble, & Barroso, 2002; Vanable, Carey, Blair, & Littlewood, 2006). Hepatitis C (HCV) is an RNA virus that infects the cells of the liver and is transmitted primarily by blood to blood contact (National Institute of Health, 2002). It shares many of the distinguishing psychosocial characteristics of living with HIV, and associated challenges, including experiences of isolation, social stigma, and feelings of depression (Golden, Conroy, O'Dwyer, Golden, & Hardouin, 2006; Janke, McGraw, Garcia-Tsao, & Fraenkel, 2008). HIV and HCV are both infectious illnesses associated with significant fears of transmission among the general public (Gilmore, 1994; Harris, 2009). Moreover, the social stigma of both illnesses is compounded by strong associations with highly stigmatized behaviours, such as sexual behaviour in the case of HIV, and intravenous drug use (IDU) in the case of HCV and HIV (Gilmore, 1994).

To optimize the quality of life and healthcare outcomes of people living with HIV (PHA) and people living with HCV (PHC), healthcare providers can work to gain insight

into factors that lead to successful adaptation to these chronic conditions. A component of this adaptation involves reducing depressive symptoms and maximizing the use of effective coping responses (e.g. social support) (Katon & Ciechanowski, 2002; Turner-Cobb et al., 2002). Patients who positively adjust to their chronic illnesses may have more effective interactions with healthcare staff as well as greater adherence to medical treatment, thus improving overall health (Thompson & Ciechanowski, 2003; Turan, Osar, Turan, Ilkova, & Damci, 2003; Turner-Cobb et al., 2002). Depressive symptoms may result from worsening disease symptomatology or side-effects in the course of antiviral treatment (Mulhall & Younossi, 2005; Riggs, Vosvick, & Stalling, 2007). However, it is also likely that perceptions of illness-related stigma and attachment style play a significant role (Golden et al., 2006; Lee et al., 2002; Riggs et al., 2007).

Attachment theory explores the impact of early attachment experiences on subsequent interpersonal behaviours and perceptions. Studies have shown that adults who experienced consistent responsive care giving during childhood often exhibit a secure style of attachment. Adults with childhoods with inconsistent/unresponsive caretaking often exhibit insecure styles of attachment. Attachment can be conceptualized as two continuous dimensions of attachment anxiety and attachment avoidance (Brennan, Clark, & Shaver, 1998; Fraley & Waller, 1998; Shaver & Mikulincer, 2002). Bowlby (1969) theorized that the internalizations of early childhood relationships with caretakers result in internal working models (IWM) of self and others that influence adult relationships. IWMs are often active during times of threat or stress. An anxious attachment style is based upon an IWM in which the person is preoccupied with relationships and significantly fears losing their close relationships. These worries correspond to an intensification of affect and a characterization of themselves as unloveable. In contrast, an avoidant attachment style is based upon an IWM in which the

person views others as unreliable/untrustworthy and potentially hurtful. Therefore the attachment avoidant person becomes self-reliant and distant in relationships. This corresponds with a down regulation of affect. Secure attachment style is based on an IWM in which the person views others as reliable and the self as worthy. Secure attachment is characterized by low levels of attachment anxiety and avoidance, and adaptive affect regulation (Brennan et al., 2008; Shaver & Mikulincer, 2002).

Health psychology researchers are paying greater attention to the relationship between attachment theory and illness adaptation (Feeney, 2000; Maunder & Hunter, 2001; Maunder et al., 2006; Mikail, Henderson, & Tasca, 1994; Riggs et al., 2007; Stuart & Noyes, 1999). Specifically, attachment theory suggests that illness can be experienced as a threat to survival and therefore activates the IWMs underlying attachment styles (Feeney, 2000). Activated IWMs impact health through 3 pathways: 1) enhanced perceptions of threat leading to greater stress; 2) altered use of external regulators of affect (e.g. substance use); and 3) altered use of protective factors (e.g. reduced help-seeking) (Maunder & Hunter, 2001). An anxious attachment style is associated with increased reporting of physical symptoms, and self blame as a means of coping with health concerns (Bayley, Slade, & Lashen, 2009; Feeney, 2000). An avoidant attachment style is associated with decreased health care utilization, poor adherence to treatment, and poor self-care behaviours in the context of chronic illness (Ciechanowski et al., 2004; Ciechanowski, Walker, Katon, & Russo, 2002; Feeney, 2000). Moreover, physicians may perceive those with insecure attachment styles as difficult, which can impede diagnosis and problem-solving around patient health concerns (Maunder et al., 2006).

Researchers found that PHA with insecure attachment styles have greater depressive symptoms and report a greater degree of HIV stigma (Riggs et al., 2007). Conversely,

researchers link a secure attachment style to better adjustment to HIV/AIDS and greater satisfaction with social support (Riggs et al., 2007; Turner-Cobb et al., 2002). A number of studies link greater stigma with increased depressive symptoms among PHA (Grove et al., 2010; Logie, James, Tharao, Loufty, 2013; Simbayi et al., 2007). Among PHC, Sockalingam et al. (2012) found significantly greater depressive symptoms among people with an insecure “fearful” attachment style compared to securely attached PHC. Also, PHC with anxious attachment styles report significantly more medically unexplained symptoms (Ciechanowski et al., 2002). Feelings of depression and experiences of stigma are well documented and recognized as a pressing concern that impedes the quality of life among patients living with HCV (Butt, Paterson, McGuinness, 2008; Dunne & Quayle, 2002; Hopwood & Treloar, 2003). Moreover, Golden et al. (2006) found higher levels of stigma were correlated with higher levels of depression among PHC.

The exact relationship between attachment style, illness-related stigma, and depression remains unexplored in both PHA and PHC. We argue that attachment styles sensitize individuals to illness-related stigma that in turn leads to greater depressive symptoms. The loss of social inclusion and sense of unworthiness that defines stigma make it a likely trigger for longstanding IWMs that are present in people with insecure attachment. This study will evaluate the role of stigma in sensitizing the IWMs that lead to greater depressive symptoms among patients living with HIV or HCV who have higher levels of anxious or avoidant attachment. Specifically, we hypothesize that greater insecure attachment (anxious attachment and avoidant attachment) will be associated with greater depression scores, and this relationship will be mediated by self-reported HIV or HCV stigma among PHA and PHC.

## **Method**

### *Participants*

Participants ( $N= 155$ ) were recruited at HIV and viral hepatitis clinics of The Ottawa Hospital. Patients with HIV (antibody seropositivity) ( $n = 72$ ) and patients with HCV (HCV RNA +) ( $n = 83$ ) were recruited from the clinics between June and December 2008 to participate in a questionnaire study regarding the psychosocial experience of living with HIV or HCV. Participant inclusion criteria included: (i) ability to read, write, and speak English, and (ii) being HCV RNA+ or HIV+ (antibody seropositivity). HCV antibody tests can be inaccurate; correspondingly HCV RNA testing ensured that participants had a current HCV infection (Centers for Disease Control and Prevention, 2013). All study respondents provided oral and written consent prior to participating in the study. The research ethics board of The Ottawa Hospital approved all study procedures and materials.

### *Procedures*

Eligible participants were recruited during their regularly scheduled outpatient visits. They were invited to participate in a questionnaire study and offered a brief explanation of the study. If interested, participants provided informed consent. The study participants then completed a 30 minute questionnaire package and were compensated \$15.

### *Measures*

*Sociodemographic Information.* The 8-item self-report Patient Information Questionnaire includes questions related to demographic information, relationship status, and sexual orientation.

*The Center for Epidemiological Studies-Depression Scale (CES-D).* Depressive symptoms were assessed with the 20-item CES-D (Radloff, 1977). It is a widely used, psychometrically

well-validated, self-report measure of depression, which has been extensively used in HCV and HIV populations (Balfour et al., 2004; Berger, Ferrans, & Lashley, 2001; Linn, Monnig, Cain, & Usch, 1993; Phillips et al., 2010). In the current study, coefficient alpha ranged from .90 (HCV patients) to .83 (HIV patients) for the CES-D, demonstrating a good level of internal consistency.

*Experiences in Close Relationships-Short Form (ECR-S).* Attachment style was assessed by the 12-item ECR-S which is composed of items selected from the original 40-item Experiences in Close Relationships (ECR) scale (Brennan, Clark, & Shaver, 1998). The ECR-S evaluates the dimensions of attachment anxiety and attachment avoidance (Wei, Russell, Mallinckrodt, & Vogel, 2007). In student and community populations the ECR-S has good internal consistency for both subscales (between  $\alpha=.71$  and  $\alpha=.88$ ), and excellent validity as demonstrated by theoretically appropriate relationships to measures of loneliness, depression, and life satisfaction (Hardy, 2010; Keleher, Wei, & Yu-Hsin Liao, 2010; Wei et al., 2007). The ECR-S has not been used in a sample of patients with chronic illness.

However, the ECR and Experience in Close Relationships-Revised (ECR-R) were utilized with chronically ill patients, including patients with HIV, and demonstrated adequate validity and reliability (Martin, Vosvick, & Riggs, 2012; Maunder, Lancee, Hunter, Greenberg, & Steinhart, 2006; Riggs et al., 2007). In the current study internal consistency reliabilities for the two ECR-S subscales ranged from  $\alpha=.61$  to  $\alpha=.74$  and mean inter-item correlations ranged from .20 to .32 indicating an acceptable level of internal consistency (Clark & Watson, 1995).

*Brief-HIV Stigma Scale.* HIV-related stigma was assessed by the 9-item Brief-HIV Stigma Scale (B-HSS). The B-HSS, developed from Berger and colleagues (2001) HIV Stigma Scale, encompasses four aspects of stigma, including: personalized stigma, disclosure,

negative public attitudes, and negative self image. The B-HSS received some limited validation of its psychometric properties within HIV positive youth in which it demonstrated adequate reliability and validity (Wright, Naar-King, Lam, Templin, Frey, 2007). Recently, a comprehensive evaluation in a sample of HIV positive adults, utilizing classical test theory and item response theory, indicated that item 1 should be removed from the B-HSS and that the 9-item B-HSS is a psychometrically sound instrument (Cabrera et al., N.d.). In the current study, coefficient alpha for the 9-item B-HSS was .89 indicating a high level of internal consistency.

*HCV Stigma Scale.* This 9-item self-report measure of HCV stigma was adapted from the brief HIV Stigma Scale created by Wright and colleagues (2007). Adaptation of items was very minimal, for instance, the item “Having HIV makes me feel unclean” was adapted to read “Having HCV makes me feel unclean”. The properties of this measure were the focus of comprehensive psychometric evaluation and item 1 was found to lack discrimination. The 9-item HCV Stigma Scale demonstrated good reliability and validity (Cabrera et al., Nd). In this study the 9-item HCV stigma scale demonstrated adequate internal consistency ( $\alpha=.88$ ).

#### *Data Analysis*

All statistics were conducted with the statistical package SPSS (v.20). Missing values were imputed with values calculated via expectation maximization (Tabachnick & Fidell, 2004). Pearson correlations were calculated to examine the relationships between HIV/HCV stigma, depression, and attachment anxiety/avoidance. To determine if the relationships between attachment styles and depression were mediated by stigma, indirect effects were assessed using bootstrapping to evaluate the mediation model as per methodology described by Preacher and Hayes (2004). This statistical method has a number of advantages:(a) it does

not require a normal sampling distribution, (b) the number of tests is minimized thus reducing Type 1 error, and (c) it lends greater confidence to results from small and moderately sized samples (Preacher & Hayes, 2004; Shrout & Bolger, 2002). The Preacher and Hayes (2004) SPSS macro (<http://www.afhayes.com/spss-sas-and-mplus-macros-and-code.html>) estimates the indirect effect and bias-corrected 95% confidence interval in simple mediation models. It was used for each mediation model depicted in Figure 1 based on 1000 bootstrap samples. In these analyses, mediation is significant if the 95% bias corrected confidence intervals for the indirect effect do not include 0 (Preacher & Hayes, 2004).

## Results

### *Sample Characteristics*

A total of 102 patients with HIV met eligibility criteria for the study and 94 agreed to participate (92% response rate). A final total of 72 participants completed the measures relevant to this study. Detailed characteristics of participants with HIV are presented in Table 1

A total of 105 patients with HCV met eligibility criteria for this study and 92 agreed to participate (88% response rate). Of these participants, 83 completed the survey measures relevant to this study and were included in the final sample. In the final sample of HCV participants, 18 participants were found to be co-infected with HIV (22%). Detailed characteristics for patients with HCV are presented in Table 1.

### *Preliminary Analyses*

Prior to analyses, statistical assumptions were met and missing values were imputed (1% imputed in the HIV data set; 4% imputed in the HCV data set). We examined correlations between the variables (see Table 2 for means and standard deviations of

variables) subsequent to mediation analyses. Both attachment anxiety and attachment avoidance, the independent variables, were significantly correlated with the mediator, HIV stigma. Both attachment anxiety and avoidance were significantly correlated to the dependent variable, depression. Also, HIV stigma was significantly correlated with depression (see Table 2 for correlations).

Among patients living with HCV there were significant correlations between the independent variables of attachment anxiety and attachment avoidance and the mediator of HCV stigma. Attachment anxiety and avoidance were also significantly related to the dependent variable of depression. Moreover, HCV stigma was significantly related to depression (see Table 2 for correlations).

#### *Mediation Analyses*

*Patients with HIV.* Bootstrapping results indicated that in the sample of PHA, the total effect between attachment anxiety and depression was significant. The indirect effect through the HIV stigma mediator was also significant. The direct effect of attachment anxiety on the dependent variable was no longer significant (Table 3). The results indicated that HIV stigma mediated the relationship between attachment anxiety and depression.

Bootstrap results indicated that the total effect of attachment avoidance on depression was significant. The indirect effect through the HIV stigma mediator was also significant, although the direct effect of attachment avoidance on depression remained significant (Table 3). The results indicated that HIV stigma mediated the relationship between attachment avoidance and depression.

*Patients with HCV.* The total effect of attachment anxiety on depression was significant. The indirect effect was significant, and the direct effect was not significant.

These results indicate that HCV stigma mediates the relationship between attachment anxiety and depression.

The total effect of attachment avoidance on depression was significant. The indirect effect was significant while the direct effect was not significant. The results indicate that HCV stigma mediates the relationship between attachment avoidance and depression. Table 3 summarizes results for mediation analyses.

## Discussion

Past research has consistently identified relationships between insecure attachment styles and psychological distress, difficulties with adjustment to illness, and depressive symptoms (Mikulincer, Florian, & Weller, 1993; Riggs et al., 2007; Turner-Cobb et al., 2002; Wei et al., 2003). This is the first study to investigate whether HIV and HCV stigma explain the relationship between attachment insecurity and depression. Results from this study indicated support for the proposed model whereby IWMs of insecure attachment, characterized by views of an inadequate self and/or unresponsive others, and primed by illness, leave a patient sensitive to illness-related stigma and therefore vulnerable to developing feelings of depression. Specifically, the relationship between insecure attachment styles and depressive symptoms among PHA and PHC decreased in strength when stigma was controlled. That is, self-reported stigma appears to mediate or explain the relationship between attachment insecurity and depressive symptoms in these patients.

Study results suggest that PHA and PHC higher in attachment insecurity are susceptible to greater depressive symptoms and this is consistent with findings in previous research (Riggs et al., 2007; Sockalingam et al., 2012). Moreover, study findings provide support for the proposed model of attachment insecurity, activated by illness, being

associated with poor coping (Feeney, 2000; Maunder & Hunter, 2001). However, the results were not identical within the two patient samples. Among PHC, the relationship between attachment insecurity (anxious or avoidant) and depression became non-significant when stigma was controlled. In other words stigma completely mediated or explained this relationship. This was also true of the relationship between anxious attachment and depression among PHA. On the other hand, among PHA the relationship between avoidant attachment and depression decreased in strength but remained significant when stigma was controlled. That is, stigma partially mediated or explained this relationship. These results suggest that stigma may play a distinctive role in different chronic illnesses and amongst different styles of insecure attachment. It may be that the interest in self-reliance and distrust of others that characterizes avoidant attachment has led to reduced contact with others. This may reduce experiences of stigma and discrimination among PHA, which would reduce self-reported stigma.

Research examining attachment theory in the context of chronic illness can form a basis for useful, evidence-based clinical interventions. Results suggest that stigma is a potential mechanism by which someone with an insecure attachment style, primed by illness, experiences greater depressive symptoms. Consequently, it appears that a psycho-social developmental model of treatment, that considers attachment styles and self-reported stigma, could facilitate conceptualization of patients' illness experiences and contribute to effective and efficient treatment of depression among PHA and PHC. Also, insecure attachment styles have been associated with interpersonal difficulties that can impair engagement with healthcare providers and be a barrier to treatment adherence (Ciechanowski et al., 2004; Maunder et al., 2006; Mikail et al., 1994). Therefore, it is possible that an insecure attachment style, in combination with stigma, may impede PHA and PHC from receiving

optimal treatment for depression, as well as adhering to treatment for their chronic illness. Correspondingly, it is important that healthcare providers be vigilant for this potential barrier.

There are a number of limitations present in this study. First, although the study utilizes bootstrapping to assess indirect effect for mediation analyses, the study design was correlational and cross sectional. Hence, it is possible that alternate theoretical models may also adequately fit the data or that there may be a third variable present that acts upon both the mediator and outcome variable. Further research of these causal relationships within a longitudinal or experimental design would cross validate these findings. Wei, Russell, & Zakalik (2005) suggest that self-disclosure and social self-efficacy may also play a role in mediating the relationship between attachment style and subsequent depression. Future studies could examine a multiple mediator model between attachment insecurity and depression, with mediators of stigma, social self-efficacy, and self-disclosure. This would determine the contribution and effect of each mediator to the overall theoretical model. Second, the participants in the present study were predominantly single, Caucasian males receiving care at a tertiary hospital outpatient clinic, and it is possible that the findings from this study may not generalize to other populations (e.g. women, ethnic minorities, prison population). Moreover, the HCV sample in this study had a proportion of patients co-infected with HIV (22%), which is reflective of real-world co-infection rates (Centers for Disease Control and Prevention, 2013), but which may have affected these patient's levels of depression and stigma. Further research is needed to generalize the present results to individuals with other illnesses (both chronic and acute) and sociodemographic characteristics. Third, this study utilized self-report measures and as a result it is possible that response bias, such as social desirability, and present mood of the respondents may have

affected the results. For example, to avoid self-report bias, future studies could assess mood with a clinical interview. Also, attachment style could be assessed with the Adult Attachment Interview (AAI) (George, Kaplan, & Main, 1985), which would allow measurement of attachment states which are not consciously available to the participant.

This study is the first to explore a theoretical model that proposes self-reported stigma as a mediator that activates the IWMs of insecure attachment styles leading to depressive symptoms among chronically ill patients. The findings have important clinical implications for the treatment of depression and address how insecure attachment styles, stigma, and depressive symptoms interact and impact illness experiences of PHA and PHC.

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Table 1.

*HIV and HCV participant characteristics*

| Characteristic   | HIV (n=72)<br>n(%)      | HCV (n=83)<br>n (%)     |
|--|-------------------------|-------------------------|
| Age (mean years $\pm$ SD)                              | 45.26 $\pm$ 10.61       | 47.10 $\pm$ 9.09        |
| Gender   |                         |                         |
| Male   | 59 (81.9%)              | 69 (79.3%)              |
| Female   | 13 (18.1%)              | 18 (20.7%)              |
| Sexual Orientation                                     |                         |                         |
| Heterosexual   | 19 (27.5%) <sup>1</sup> | 67 (88.2%) <sup>2</sup> |
| Homosexual   | 42 (60.9%)              | 6 (7.9%)                |
| Bisexual   | 8 (11.5%)               | 3 (3.9%)                |
| CD4 cell count(mean cells $\pm$ SD)                    | 509.79 $\pm$ 369.57     | -----                   |
| Baseline ALT (U/L $\pm$ SD)                            | -----                   | 77.12 $\pm$ 76.31       |
| HIV plasma viral load<br>(mean copies/ml $\pm$ SD)     | 2625.82 $\pm$ 8420.38   | -----                   |
| Time since HIV/HCV diagnosis<br>(mean months $\pm$ SD) | 10.59 $\pm$ 7.73        | 3.76 $\pm$ 3.96         |
| Ethnicity  |                         |                         |
| Caucasian  | 46 (67.6%) <sup>3</sup> | 73 (88%)                |
| African  | 9 (13.2%)               | 3 (3.6%)                |
| Aboriginal   | 2 (2.9%)                | 5 (6%)                  |
| Other  | 11 (16.2%)              | 2 (2.4%)                |
| Relationship Status                                    |                         |                         |
| Single   | 32 (46.4%) <sup>1</sup> | 41 (49.4%)              |
| Married/Partner  | 34 (49.3%)              | 37 (44.6%)              |
| Separated/Widowed                                      | 3 (4.3%)                | 5 (6%)                  |
| Employment Status                                      |                         |                         |
| Working  | 29 (40.8%) <sup>4</sup> | 18 (22%) <sup>4</sup>   |
| Disability   | 25 (35.2%)              | 47 (57.3%)              |
| Unemployment   | 6 (8.5%)                | 11 (13.4%)              |
| Retired  | 7 (9.9%)                | 5 (6.1%)                |
| Other  | 4 (5.6%)                | 1 (1.2%)                |
| Education Level  |                         |                         |
| Elementary   | 7 (9.9%) <sup>5</sup>   | 10 (12%)                |
| High School  | 16 (22.5%)              | 38 (45.8%)              |
| College  | 28 (39.4%)              | 29 (34.9%)              |
| University   | 20 (28.2%)              | 6 (7.2%)                |

<sup>1</sup> Data were missing for 3 participants <sup>2</sup> Data were missing for 7 participants <sup>3</sup>Data were missing for 4 participants<sup>4</sup>Data was missing for 1 participant

Table 2.

*Correlations between attachment, depression and stigma in HIV and HCV patients*

| HIV (N=72)                    | 1               | 2               | 3                | 4               |
|-------------------------------|-----------------|-----------------|------------------|-----------------|
| 1. ECR – Attachment Anxiety   | --              | --              | .50**            | .54**           |
| 2. ECR – Attachment Avoidance | --              | --              | .59**            | .55**           |
| 3. CESD Depression            | --              | --              | ---              | .66**           |
| 4. HIV Stigma                 | --              | --              | ---              | ----            |
| Mean ± SD                     | 21.83 ±<br>7.76 | 18.18 ±<br>7.03 | 18.96 ±<br>13.88 | 21.42 ±<br>7.09 |
| HCV (N=83)                    | 1               | 2               | 3                | 4               |
| 1. ECR – Attachment Anxiety   | --              | --              | .27*             | .24*            |
| 2. ECR – Attachment Avoidance | --              | --              | .34*             | .44**           |
| 3. CESD Depression            | --              | --              | ---              | .41**           |
| 4. HCV Stigma                 | --              | --              | ---              | ----            |
| Mean ± SD                     | 22.81 ±<br>6.69 | 20.58 ±<br>7.22 | 25.57 ±<br>11.51 | 19.33 ±<br>5.84 |

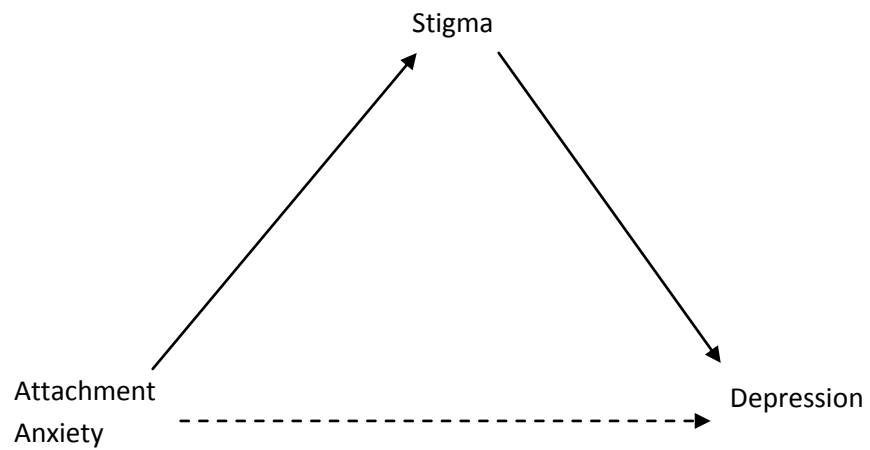
\* $p < .05$  \*\* $p < .01$

Table 3.

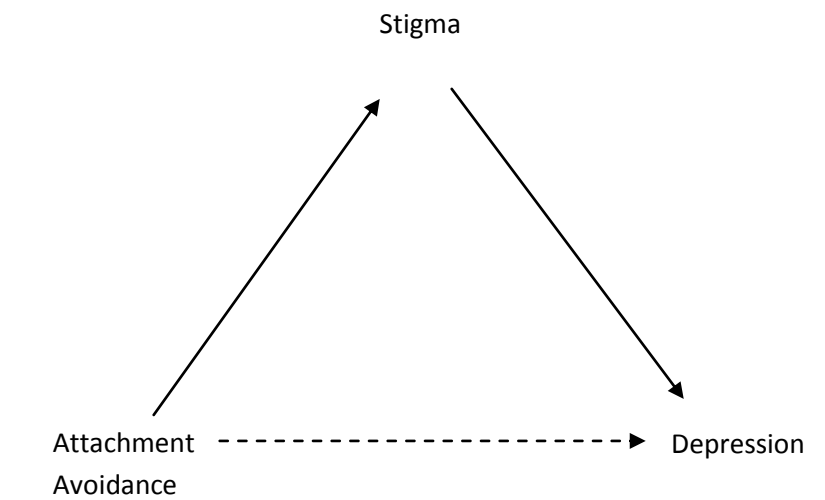
*Mediation models*

| Models                             | Coefficient | Standard Error | <i>P</i> | Bootstrap 95%<br>CI |
|------------------------------------|-------------|----------------|----------|---------------------|
| <b>HIV</b>                         |             |                |          |                     |
| Anx-Hstig-Dep                      |             |                |          |                     |
| <i>Total effect<br/>(C path)</i>   | .83         | .19            | <.001    | ----                |
| <i>Direct effect<br/>(C' path)</i> | .28         | .19            | .15      | ----                |
| <i>Indirect effect</i>             | .55         | .14            | <.001    | .31 ; .90           |
| Avd-Hstig-Dep                      |             |                |          |                     |
| <i>Total effect<br/>(C path)</i>   | 1.17        | .19            | <.001    | ----                |
| <i>Direct effect<br/>(C' path)</i> | .66         | .20            | <.001    | ----                |
| <i>Indirect effect</i>             | .52         | .14            | <.001    | .26 ; .85           |
| <b>HCV</b>                         |             |                |          |                     |
| Anx-HCstig-<br>Dep                 |             |                |          |                     |
| <i>Total effect<br/>(C path)</i>   | .47         | .18            | .01      | ----                |
| <i>Direct effect<br/>(C' path)</i> | .30         | .18            | .09      | ----                |
| <i>Indirect effect</i>             | .17         | .08            | .04      | .05 ; .37           |
| Avd-HCstig-<br>Dep                 |             |                |          |                     |
| <i>Total effect<br/>(C path)</i>   | .53         | .17            | <.001    | ----                |
| <i>Direct effect<br/>(C' path)</i> | .10         | .18            | .10      | ----                |
| <i>Indirect effect</i>             | .24         | .09            | .01      | .05 ; .49           |

Avd=Avoidance, Anx=Anxiety, Dep=Depression, Hstig=HIV stigma, HCstig=HCV stigma



Attachment Anxiety —————> Depression



Attachment Avoidance —————> Depression

*Figure 1. Mediation models in HIV and HCV participant samples*

### **General Discussion**

The negative impact of stigma on PHAs and PHCs is well established (Butt, 2008; Mak et al., 2006). Experiences of illness-related stigma have been associated with increased depressive symptoms and anxiety, decreased self-esteem, and difficulties establishing social/intimate connections (Coughlan et al., 2002; Dowshen et al., 2009; Grove et al., 2010; Zickmund et al., 2003). As a result, researchers and clinicians have demonstrated an interest in creating and evaluating anti-stigma campaigns, engendering stigma resilience (SR) in those who are vulnerable to stigmatization, and exploring the relationships between stigma and psychosocial variables (Brown, Macintyre, & Trujillo, 2003; Riggs et al., 2007; Ritsher & Phelan, 2004). The development of successful anti-stigma campaigns and SR interventions will be furthered by the development of psychometrically validated HIV and HCV stigma scales, which will correctly measure and gauge the relative success or failure of such interventions. Furthermore, individualized treatment for those who have an increased vulnerability to stigma can be enhanced by understanding psychosocial factors that have been linked to illness-based stigma, such as insecure attachment styles (Riggs et al, 2007). Consequently, the goals of the present dissertation were threefold 1) to psychometrically validate a brief measure of HIV stigma 2) to develop and psychometrically validate a brief measure of HCV stigma 3) to examine the relationship between insecure attachment styles, HIV/HCV stigma, and depressive symptoms within a novel mediation model. Specifically, a brief measure of HIV stigma was validated using classical test theory (CTT) and item response theory (IRT). The final 9-item Brief HIV Stigma Scale (B-HSS) was found to be a reliable and valid measure of a singular HIV stigma construct. The items were discriminatory and demonstrated theoretically appropriate relationships with relevant constructs (depressive symptoms and quality of life). This brief measure was adapted for use with PHC and its

psychometric properties were evaluated with CTT and IRT. The 9-item HCV Stigma Scale was found to be reliable and valid, demonstrated appropriate correlations with theoretically relevant constructs (depressive symptoms and quality of life), and all its items were found to be sufficiently discriminatory. The third article in this dissertation examined a mediation model which investigated the role of illness-based stigma in the relationship between insecure attachment styles (anxious or avoidant attachment) and depressive symptoms. Specifically, the relationship between anxious attachment and depressive symptoms among PHA was not significant when stigma was controlled; however, the relationship between avoidant attachment decreased in strength but remained significant. Among PHC when stigma was controlled the relationship between attachment insecurity and depression was not significant. These results indicate support for the role of stigma as a mediator between insecure attachment styles and depressive symptoms among PHA and PHC.

### Implications

In agreement with existing literature, greater illness-related stigma was associated with diminishing health-related QOL and greater depressive symptoms (Berger et al., 2001; Golden et al., 2006). These results underscore the importance of identifying illness-related stigma among PHA/PHC and suggest clinicians may increase the efficacy of depression treatment by addressing the illness-related stigma experienced by their patients. Moreover, Murphy & Hevey (2013) recently suggested that HIV stigma plays a role in limiting posttraumatic growth (PTG) after a diagnosis of HIV. Therefore, clinicians attempting to promote growth and resilience and the associated improved health outcomes (e.g. improved immune function) among PHA must identify and address illness-related stigma. Furthermore, given that stigma and depression have both been identified as barriers to antiviral treatment,

effectively identifying and addressing these factors, may also contribute to increased antiviral treatment uptake/adherence (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Leserman, 2008; Moore et al., 2008; Scheft & Fontenette, 2005). The valid and reliable measures of stigma developed in this thesis accurately identify vulnerable patients and are suitable for clinical use. Moreover, brief psychometrically valid stigma measures, which have shown good temporal stability, are ideal for use in repeated measures studies investigating anti-stigma campaigns or studies that wish to promote SR/PTG, because they will accurately capture changes in self-reported stigma over time.

Dissertation results also emphasize the importance of considering attachment style when addressing illness-related stigma and depression among individuals living with HIV/HCV. Among both patient groups, the relationship between insecure attachment styles, stigma and depressive symptoms emphasizes the importance of conceptualizing the patient in terms of a developmental model that considers their longstanding attachment style. Among insecurely attached individuals living with HIV/HCV, consideration of their views of self and others and the potential for stigma to trigger internal working models (IWMs), may significantly contribute to effective treatment of depressive symptoms. Moreover, the third study, which linked greater attachment insecurity with greater stigma and depressive symptoms, further supports theories which suggest that under threat of illness insecure attachment styles contribute to less effective coping (Feeney, 2000; Maunder & Hunter, 2001).

### Limitations

Several limitations were acknowledged regarding the studies contained in this dissertation. The participants in these studies were predominantly single Caucasian male

hospital patients and it is possible that the findings from this study may not generalize to other populations (e.g. ethnic minorities, prison populations). Also, the measures utilized in this dissertation were self-report and may be susceptible to bias (e.g. social desirability). A limitation of the first two studies is the sample size used in the IRT analyses. Research suggests that larger sample sizes produce more reliable parameters therefore the results in these studies are best interpreted with caution (Embretson & Reise, 2000; Fayers, 2007). The third study used a correlational and cross sectional design to examine the proposed mediation model. This study design limits the strength with which study investigators can assert a causal relationship because it allows for the possibility that alternative theoretical models may fit the data or that there may be a third variable present.

#### Future Directions

Future research might involve continued validation of the B-HSS and the HCV Stigma Scale among a larger, ethnically-diverse population to further assess the validity of the dissertation findings. It would be of particular value to replicate the IRT analyses for these scales in a larger sample to confirm the reliability of the discrimination and difficulty parameters. Future studies could also focus on the development of a cut-off value for the stigma scales which would be of significant clinical utility. Moreover, future research utilizing multiple mediator models could extend upon the simple mediation model supported by dissertation findings by examining other variables that have been found to contribute to the interaction between attachment style and depressive symptoms (Wei et al., 2005).

## Conclusions

This doctoral dissertation psychometrically validated a brief measure of HIV stigma, developed and validated a brief measure of HCV stigma, and explored the relationships between attachment insecurity, stigma, and depressive symptoms among PHAs and PHCs. Both brief measures of stigma were found to be valid and reliable and there was support for the proposed mediation model; illness-related stigma was found to mediate the relationship between insecure attachment styles and depressive symptoms. This dissertation contributes to the growing body of literature in HIV by providing psychometric support for a brief measure of HIV stigma, suitable for clinical use and derived from Berger et al.'s benchmark quantitative measure of HIV stigma. Moreover, the development of a specific measure of HCV stigma has filled a significant gap in the HCV literature (Paterson et al., 2007). These tools are accessible and effective measures to quantify the effectiveness of future stigma research, such as a recent model proposed by Earnshaw, Bogart, Dovidio, Williams (2013) which suggests a combination of anti-stigma campaigns and SR may be the ideal tool by which to combat stigma among multi-stigmatized ethnic minorities. Dissertation findings further support the relationships between greater stigma, increased depressive symptoms and impoverished QOL among people living with HIV/HCV established in previous literature (Golden et al., 2006). Also, findings offer support for the theory that illness serves as a threat that sensitizes IWMs of insecure attachment styles associated with poor coping (Maunder & Hunter, 2001). Assessing and attending to illness-related stigma and attachment style may lead to more effective and innovative interventions for the treatment of depressive symptoms among people living with HIV and HCV.

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Dear Dr. Balfour

Thank you for your interest in the Berger HIV Stigma Scale. For your convenience, I am attaching electronic copies of the HIV Stigma Scale and scoring instructions. You will notice that there are tiny numbers on the far right of each item in the scale -- these indicate which subscale(s) that item contributes to when calculating the subscale scores, but I do recommend removing them from any version given to research participants since some people may find them confusing or puzzling.

You have my permission to use the HIV Stigma Scale for research purposes and to modify it as you see fit for research on other stigma-related conditions. Please use the citation for the article that you mentioned when referencing the instrument:  
Berger, B, Ferrans, CE, & Lashley, FR. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Research in Nursing and Health, 24, 518-529.

Thanks again for your interest, and best wishes on your research --  
Barb Berger

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