Development and psychometric evaluation of the Chronic Illness Anticipated Stigma Scale

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Abstract

The Chronic Illness Anticipated Stigma Scale (CIASS) was developed to measure anticipated stigma (i.e., expectations of prejudice, stereotyping, and discrimination) among people living with chronic illnesses. The CIASS is a 12-item scale with three subscales differentiating among sources of anticipated stigma, including friends and family members, work colleagues, and healthcare workers. Results support the reliability, validity, and generalizability of the CIASS in two samples of people living with chronic illnesses. The CIASS was correlated with other stigma-related constructs as well as indicators of mental health, physical health, and health behaviors. The CIASS can help researchers gauge the degree to which people living with chronic illnesses anticipate stigma, better understand the processes by which anticipated stigma contributes to the health and behavior of people living with chronic illnesses, and compare the extent to which people living with different types of chronic illnesses anticipate stigma.

Keywords

Anticipated stigma; Chronic illness; Scale; Measure; Discrimination

Introduction

> I feel so embarrassed by this–this thing… Who would want a wife like this? How can I go out and not feel unable to look people in the eyes and tell them the truth? Once I do, who would want to develop a friendship, I mean a close one? (Milo quoted by Kleinman, 1988; p. 163)

> I am concerned that some people will label me as a 'poor bet' for the future, particularly in the work-place. I may be less likely to gain promotion in my current place of work and less likely to be appointed to a new job. Who would choose to employ someone who has an increased risk of becoming ill and disabled? (Green, 2009; p. viii)

> Until every doctor knows exactly what they're dealing with and believes it and agrees with each other, you're always going to have the fibromyalgia patient doubting if—wondering who believes them, who doesn't, who thinks you need psychiatric help. (Patient quoted by Acker, 2008; p. 58)

In the quotes above, people living with chronic illnesses discuss their fears of anticipated stigma. Anticipated stigma is expecting to experience prejudice, discrimination, and stereotyping from others in the future (Earnshaw & Chaudoir, 2009; Quinn & Earnshaw, 2011). Milo (Kleinman, 1988) fears that others will not want to develop close friendships and intimate relationships with her once they learn of her ulcerative colitis, possibly resulting in social rejection. Green (2009) worries that employers and coworkers will view her as less competent because of her multiple sclerosis, potentially costing her important career opportunities. The patient quoted by Acker (2008) is concerned that doctors will not believe her when she describes her symptoms of fibromyalgia, possibly leading to poor treatment or management of her disease.

Given that approximately 50 % of adults are living with at least one chronic illness in the United States (Anderson, 2004; Wu & Green, 2000); Milo, Green, and the patient above are likely not alone in anticipating stigma associated with chronic illness. Importantly, social stigma associated with chronic illness may add to the burden of diminished physical and mental health already experienced by people living with chronic illnesses (Leventhal et al., 2004). Below, we characterize stigma associated with chronic illness, discuss the importance of better understanding anticipated stigma specifically, and argue for differentiating between sources of stigma when measuring anticipated stigma. We then describe the development and psychometric evaluation of a scale designed to measure anticipated stigma among people living with chronic illnesses from three different sources: friends and family, work colleagues, and healthcare workers.

Chronic illness stigma

Stigma is social devaluation or discrediting due to a mark or attribute (Goffman, 1963). In the case of chronic illness stigma, the mark or attribute is the diagnosis of chronic illness itself. With this diagnosis, a person transitions from 'normal' to 'discreditable' (Goffman, 1963), from the 'kingdom of the well' to the 'kingdom of the sick' (Sontag, 1991). Why are chronic illnesses stigmatized? Recent theorists (e.g., Kurzban & Leary, 2001; Phelan et al., 2008) argue that stigma exists to serve a function or solve a problem associated with human sociality. In the case of chronic illness, stigma may exist to enhance the avoidance of threats to dyadic cooperation. Kurzban and Leary (2001) theorize that people are motivated to avoid entering into relationships with others who are perceived to be poor social exchange partners —those who are perceived to pose a greater social cost than benefit, thereby hindering the potential success of their partners. Kurzban and Leary further theorize that the factors of

unpredictability and having poor prospects are associated with perceptions that others are poor social exchange partners.

People living with chronic illnesses may be perceived as both unpredictable and having poor prospects, therefore representing poor social exchange partners and threats to dyadic cooperation. Unpredictability impedes people's ability to predict the behaviors and worth of their partners (Kurzban & Leary, 2001). People living with chronic illnesses may be perceived as unpredictable because they may experience periods of health followed by periods of disability (Leventhal et al., 2004). Someone living with a chronic illness who is healthy and a good social exchange partner one month may be ill and a poor partner the next month if they experience a flare-up of illness symptoms. Poor prospects involves having little to offer to enhance partners' well-being. Kurzban and Leary (2001) specifically identify people who are ill as having poor prospects. They may be perceived to have fewer physical, social, emotional, and economic resources to offer to their exchange partners. Taken together, people living with chronic illnesses may be perceived to be poor social exchange partners because of beliefs that they cannot be consistently relied on and that they may have fewer resources to offer others.

This conceptualization suggests commonality in stigma associated with chronic illnesses. Although chronic illnesses can be quite different in symptoms and outcomes, the stigma experienced will be similar. By stressing commonality in stigma associated with chronic illnesses, this conceptualization builds on past work exploring both stigma (e.g., Beatty & Joffee, 2006; Joachim & Acorn, 2000) and experiences (Chan et al., 2005; Hampel et al., 2005; Katz & McHorney, 2002; Stanton et al., 2007; Thorne & Paterson, 1998) associated with chronic illnesses generally. However, it is important to note that there are important differences in chronic illnesses that may impact the degree to which people are perceived to be poor social exchange partners and therefore the extent to which they experience chronic illness stigma. For example, chronic illnesses perceived to be more unpredictable or depleting of resources may be associated with greater stigma. Multiple sclerosis, which is characterized by symptom flare-ups and physical depletion, may be associated with greater stigma than diabetes, which is characterized by greater symptom stability and less physical depletion. Despite these differences in the strength of stigma, people living with both multiple sclerosis and diabetes may experience stigma and therefore suffer its negative consequences.

There are several ways in which people living with chronic illnesses can experience stigma (Earnshaw & Chaudoir, 2009; Quinn & Earnshaw, 2011). In addition to anticipating stigma, people living with chronic illnesses may experience enacted stigma (i.e., experiences of prejudice, discrimination, and stereotyping directed at them from others) and/or internalized stigma (i.e., endorsing negative stereotypes about people living with chronic illnesses and applying them to the self). Past work has demonstrated that these manifestations of stigma are related: people living with stigmatized identities who anticipate greater stigma are more likely to have experienced enacted stigma and to have internalized greater stigma (Earnshaw & Quinn, 2012; Steward et al., 2008).

Anticipated stigma

Although stigma may be experienced in multiple ways, it may be particularly important for researchers to understand the extent to which people living with chronic illnesses anticipate stigma. These expectations have been shown to predict important outcomes in research involving people living with other stigmatized attributes, including psychiatric patients (Link, 1987), gay men (Meyer, 1995), and African-Americans (Mendoza-Denton et al., 2002). Anticipated stigma has been linked to negative health outcomes, including increased psychological distress (Meyer, 1995; Quinn & Chaudoir, 2009), diminished mental health (Link, 1987), decreased well-being (Mendoza-Denton et al., 2002), and increased physical illness symptoms (Quinn & Chaudoir, 2009). Anticipated stigma may have a substantial impact on the health of people living with stigmatized identities, in part, because it is a chronic strain. Unlike enacted stigma, which is a discrete event and therefore an acute strain, anticipated stigma has the potential to be perpetually present and constantly weighing on one's mind. Research suggests that chronic strains have a substantial impact on physical and mental health, and that this impact may be greater than that of acute strains (Thoits, 2010).

Further, anticipated stigma may play a unique role in determining the behaviors of people living with stigmatized identities, including chronic illnesses. People living with stigmatized identities who expect to be treated poorly may avoid others or approach interactions in such a way that results in negative intra- and interpersonal consequences (Henry et al., 2010; Link, 1987; Pinel, 2002). For example, people living with chronic illnesses who anticipate stigma from healthcare workers are less likely to access healthcare (Earnshaw & Quinn, 2012). They may be avoiding the healthcare workers from whom they anticipate stigma. Given its role as a chronic strain and importance in people's interactions with others, measuring anticipated stigma may be particularly helpful in understanding the health and behavior of people living with chronic illnesses.

Sources of stigma

Measures of anticipated stigma may be maximally informative if they take specific sources of stigma into account. However, most stigma scales ignore the source of stigma. Instead, the few scales that exist ask people about the extent to which they anticipate stigma from others *in general* rather than from *specific* others such as family members, employers, or healthcare workers (e.g., Berger et al., 2001; Fife & Wright, 2000). Given that interpersonal relationships vary greatly in function and importance, stigma may also vary greatly in its expression and impact depending on the relationship. That is, people living with stigma may anticipate different forms of stigmatizing treatment from different sources, and anticipated stigma may impact people differently depending on the source. Indeed, both Goffman (1963) and more recent stigma theorists (e.g., Link & Phelan, 2001; Parker & Aggleton, 2003) have encouraged greater attention to social context when studying stigma. For example, in defining stigma Goffman (1963) stressed that "a language of relations, not attributes, is really needed" (p. 3). That is, Goffman conceptualized stigma as a social phenomenon that is constructed within relationships between people. Recent empirical evidence supports the theoretical claims that social context matters when assessing stigma. Stutterheim et al. (2009) found that people living with HIV/AIDS report experiencing different forms and amounts of enacted stigma from different sources, and that enacted

stigma from different sources impacts people in different ways. Given the theoretical and empirical significance of social context in relation to stigma, measures of anticipated stigma should differentiate between sources of stigma.

It may be particularly important to differentiate between stigma experienced from friends and family members, work colleagues, and health care providers. Past work has explored stigma experienced by people living with illnesses from friends and family members (e.g., social distancing; Berger et al., 2001; Chapple et al., 2004; Conrad et al., 2006; Fife & Wright, 2000), work colleagues (e.g., workplace discrimination relating to hiring, promotions, wages, harassment, and discharge; Chan et al., 2005; West et al., 2006), and healthcare workers (e.g., receiving poor care, being denied care, being treated differently; Conrad et al., 2006, Rogge et al., 2004; Sayles et al., 2007). Additionally, people living with chronic illnesses may frequently interact with each of these groups of people by living with them, working with them, or seeing them for treatment; and may depend on them for social support and belongingness, financial stability and economic well-being, or medical treatment and physical health. Given the frequency of interactions with and importance of these groups of people, anticipating stigma from them may be particularly detrimental to people living with chronic illnesses.

Current work

Despite the potential importance of anticipated stigma in predicting the health and behavior of people living with chronic illnesses, there is currently no published, psychometrically validated scale to measure anticipated stigma associated with chronic illness from different sources. Scales have been developed to gauge anticipated stigma among people living with other stigmatized identities such as mental illness (e.g., Link, 1987) and HIV/AIDS (e.g., Berger et al., 2001). However, given that the stigma related to chronic illness may be different from that of other stigmatized identities (Kurzban & Leary, 2001), it is important to develop an anticipated stigma scale specific to people living with chronic illness to best study the construct within this population. For example, such a scale would allow researchers to gauge the degree to which people living with chronic illnesses anticipate stigma, study health and health behavior outcomes of anticipated stigma, and better understand the processes by which anticipated stigma contributes to the health and behavior of people living with chronic illnesses.

Additionally, a scale measuring anticipated stigma among people living with a variety of chronic illness, rather than specific chronic illnesses, has advantages. In his review of measures of health-related stigma, van Brakel (2006) noted that the outcomes of stigma are similar across health conditions and called for the development of more generic, or non-condition specific, measures of illness stigma. Three generic measures of illness stigma were included in his review; the rest were illness-specific but many included items measuring similar themes. Researchers are beginning to answer van Brakel's (2006) call by developing scales to measure stigma-related constructs across conditions (e.g., neurological conditions, Rao et al., 2009; tuberculosis and HIV/AIDS, van Rie et al., 2008). A generic scale measuring anticipated stigma would allow researchers to compare levels and outcomes of anticipated stigma among people living with different chronic illnesses and enable

researchers to test the validity and utility of inclusive theories of chronic illness stigma. Further, it would allow researchers to contribute to growing understanding of experiences of people living with chronic illnesses generally (e.g., Beatty and Joffee 2006; Chan et al., 2005; Hampel et al., 2005; Joachim & Acorn, 2000; Katz & McHorney, 2002; Stanton et al., 2007; Thorne & Paterson, 1998).

The Chronic Illness Anticipated Stigma Scale (CIASS) was developed to measure anticipated stigma among people living with a variety of chronic illnesses from three different sources: friends and family members, work colleagues, and health care providers. The current study evaluates the psychometric properties of the CIASS.

Method

Design

The study involved two separate samples of participants. Data collected from sample 1 were used to assess the reliability, validity, and generalizability of the CIASS. To assess reliability, we examined the scale's internal consistency and three-week test–retest stability. For structural validity, we examined the factor structure of the scale relative to the theorized construct structure of the three stigma sources using confirmatory factor analysis. For construct validity, we tested both convergent and discriminant validity by examining the extent to which anticipated stigma is correlated with theoretically related and unrelated constructs. We expected anticipated stigma to be moderately correlated with other stigma-related constructs (i.e., enacted stigma, internalized stigma, and stigma consciousness), indicators of negative mental and physical health (i.e., depression, anxiety, and illness symptoms), and poor health behaviors (i.e., lower care access). We expected anticipated stigma to be less correlated with interpersonal rejection sensitivity, which is a general tendency to readily perceive and overreact to rejection (Downey & Feldman, 1996). We expected that people who anticipate stigma due to their chronic illness are not simply especially sensitive to rejection, and therefore the correlation between these constructs would be low. For external validity, we tested the extent to which anticipated stigma predicts health and health behavior outcomes. We expected that anticipated stigma would predict decreased mental and physical health (i.e., depression, anxiety, and illness symptoms) and poor health behavior (i.e., lower care access) even after controlling for participant demographic and illness-related characteristics.

Data collected from sample 2 were used to assess the generalizability of the scale to a sample of community-recruited adults living with chronic illness. Internal consistency was re-examined within sample 2. An analysis of factorial invariance was conducted to test for measurement equivalence among samples 1 and 2. Participant scores on the CIASS among samples 1 and 2 are compared. Finally, the correlation between the CIASS and care access is examined and compared to the correlation found within sample 1. We chose to re-examine the correlation between the CIASS and care access using data from sample 2 because it is a behavior that is particularly influenced by anticipated stigma and is critical for maintaining the health of people living with chronic illnesses (Earnshaw & Quinn, 2012).

Both studies were approved by the University of Connecticut Institutional Review Board.

Participants and procedures

Sample 1—Participants included in sample 1 were undergraduate and graduate students living with chronic illness who were recruited from the University of Connecticut through the psychology department participant pool and the university-wide student listserv. Participants recruited through the participant pool received partial course credit for their participation. Students were eligible to participate in the study if they had a medical condition for which they had to see a doctor two or more times in the past year. Prior to completing the study, participants provided informed consent.

One hundred and eighty-four students living with a chronic illness responded to the survey. Participant demographic information for samples 1 and 2 is included in Table 1. Participants of sample 1 were primarily in their early twenties, female, and White or European-American. They reported living with between 1 and 7 chronic illnesses in total. Participants were asked to list the illness that impacts their lives the most, and think of this illness when responding to the remainder of the study. The three most common chronic illnesses in sample 1 included asthma, inflammatory bowel disease, and diabetes and accounted for 44 % of the sample. Other chronic illnesses included epilepsy, lupus, and heart disease. On average, participants reported living with their illness for 33 % of their life. Most indicated that their illness "somewhat" or "very much" affects their life in response to the question "How much does your health condition affect your life?" Most described their health in general as "good" or "very good" in response to the question "How would you describe your health in general?"

Sample 2—Participants in sample 2 were community-recruited adults living with chronic illness. Part of the sample was recruited in person from support groups and events for people living with chronic illnesses. Participants completed a paper version of the study in person, and were offered $10 that they could either receive in cash or donate to an organization of their choice (e.g., National Multiple Sclerosis Society, Epilepsy Foundation of America). The remainder of the sample was recruited from websites that serve people living with chronic illnesses. Participants completed an online version of the study. Although participants who completed the study online did not receive direct compensation, donations were made to the websites that hosted the survey. Community adults were eligible to participate in the study if they had been diagnosed with a chronic illness. All participants provided informed consent prior to participating in the study.

One hundred and seventy-two adults living with a chronic illness responded to the survey either in person or online. Fifty-three participants completed the study in person, and 119 completed the study online. On average, participants were in their early forties, female, and White or European-American. Participants who completed the study in person were slightly older than participants who completed the study online [in person: $M = 48.78$, SD = 13.00; online: $M = 41.19$, SD = 13.09; $F(1,155) = 11.83$, $p < .001$; $\eta_p^2 = .07$]. Female participants comprised a smaller percentage of participants who completed the study in person than participants who completed the study online [in person: 59.6 %; online: 85.7 %; $\chi^2(1) = 14.26$, $p < .001$]. There were no racial or ethnic differences between participants who completed the study in person versus online [$\chi^2(5) = 3.91$, $p = .56$].

Participants reported living with between 1 and 8 chronic illnesses. They were asked to list the illness that impacts their lives the most, and think of this illness when responding to the remainder of the study. The three most common chronic illnesses in sample 2 included inflammatory bowel disease, multiple sclerosis, and fibromyalgia and accounted for 63.4 % of the sample. Other chronic illnesses included epilepsy, lupus, and diabetes. On average, participants reported living with their illness for 22 % of their life. Most indicated that their illness "very much" affects their life, and described their health in general as "good" or "fair."

Measures

Chronic Illness Anticipated Stigma Scale—The CIASS initially included 53 items: 17 items representing anticipated stigma from friends and family members, 19 items representing anticipated stigma from work colleagues, and 17 items representing anticipated stigma from healthcare workers. Items were developed based on a literature review exploring stigma anticipated and experienced by people living with a variety of chronic illnesses (e.g., epilepsy, cancer, HIV/AIDS, fibromyalgia). Qualitative depictions of stigmatizing treatment and the context in which the treatment occurred were noted. Initial scale items were created from these descriptions. For example, the item "Your employer will not promote you" was created based on the quote from Green cited at the beginning of this paper. Items captured a wide range of experiences, including stereotyping, prejudice, and discrimination from each of the sources. Participants were asked to rate the likelihood that they would encounter these stigmatizing experiences in the future on a scale ranging from 1 (*very unlikely*) to 5 (*very likely*).

Items were individually evaluated for inclusion in the final version of the scale. As recommended by DeVellis (2003), this evaluation involved examining the item-scale correlations, item variances, and item means. Items were chosen that correlated well with the overall scale, had relatively high variance, and had means that were far from the extremes of the scale. The process resulted in the selection of 12 items, 4 per subscale, that were evaluated for reliability and validity.

Enacted stigma—The measure of enacted stigma assessed participants' experiences of stigma. The measure was modeled after the measure of enacted stigma employed by Kessler et al. (1999). Participants were asked to indicate whether they had ever experienced stigma from friends and family (17 items), work colleagues (19 items), and healthcare workers (17 items). Items included "A friend or family has not invited you to a social event," "Your employer has fired you," "A healthcare worker has thought that your illness is your fault." For each item, participants were asked to check a box if the event described had happened to them at any time in the past. Four measures of enacted stigma were computed for the current study: a total enacted stigma score representing the total number of boxes checked, a friends and family enacted stigma score representing the number of boxes checked in relation to friends and family only, a work colleagues enacted stigma score representing the number of boxes checked in relation to work colleagues only, and a healthcare workers enacted stigma score representing the number of boxes checked in relation to healthcare workers only.

Internalized stigma—The measure of internalized stigma evaluated the extent to which participants endorse prejudicial beliefs and stereotypes (Zimet et al., 1988) about people living with health conditions. The internalized stigma measure included five items adapted from the Negative Self-Image subscale of the HIV Stigma Scale (Berger et al., 2001; e.g., "I feel I'm not as good as others because I have a health condition") as well as six items developed for the current study to more fully capture feelings of internalized stigma. Items developed for the current study included "It is my fault that I have a health condition," "I can't do a lot of things because I have a health condition," "Because I have a health condition, I'm not a good employee," "I can't fulfill many of my responsibilities because I have a health condition," "I am as capable as people who do not have a health condition" (reverse coded), and "People who do not have health conditions are not better than me" (reverse coded). Participants were asked how strongly they agree with the eleven items, on a scale from 1 (*strongly disagree*) to 5 (*strongly agree*). An internalized stigma score was derived by averaging scale items ($\alpha = .75$).

Stigma consciousness—The Stigma Consciousness Scale (SCQ; Pinel, 1999) was employed to evaluate participants' stigma-consciousness, the extent to which they expect to be stereotyped by others. The SCQ has been adapted for specific stigmatized identities, including women as well as gay men and lesbians (Pinel, 1999). For the purposes of the current study, the scale was adapted for people living with chronic illness. The SCQ asks participants to rate the extent to which they agree with statements on a scale from 0 (*strongly disagree*) to 6 (*strongly agree*). Items include "Most people who do not have a health condition have a problem viewing people who do have a health condition as equals." Seven items of the original 10-item scale were retained in the current study. A stigma consciousness score was derived by averaging the 7 items ($\alpha = .78$).

Depression—The Center for Epidemiologic Studies Depression Scale (CES-D Scale; Radloff, 1977) was used as a measure of participants' depressive symptomatology. The CES-D Scale asks participants to indicate how frequently they have experienced symptoms of depression during the past week. Items include "I felt depressed" and "I thought my life had been a failure," and response options include: 0 *[rarely or none of the time (less than 1 day)]*; 1 *[some or a little of the time (1–2 days)]*; 2 *[occasionally or a moderate amount of time (3–4 days)]*; 3 *[most of all of the time (5–7 days)]*. 15 items from the original 20-item scale were retained. Items that referred to physical symptoms were eliminated from the scale because they may be a symptom of chronic illness rather than depression. A depression score was derived by summing scale items ($\alpha = .92$).

Anxiety—Anxiety was assessed with the trait version of Spielberger's Trait Anxiety Inventory (STAI-T; Spielberger et al., 1980). The trait version measures the extent to which individuals experience anxiety on a trait level, or across a variety of situations. Participants are asked to rate the extent to which they generally feel moods such as worried and inadequate on a scale from 1 (*almost never*) to 4 (*all of the time*). There are 20 items of the scale, including "I worry too much" and "I feel inadequate." An anxiety score was derived by averaging scale items ($\alpha = .94$).

Care access—The care access measure gauges the extent to which participants seek medical care and has been used in previous work (Earnshaw & Quinn, 2012). Participants were asked to indicate how strongly they agree with six items on a scale from 1 (*strongly disagree*) to 5 (*strongly agree*). Items included "I see my doctor regularly" and "I should see my doctor more frequently" (reverse coded). A care access score was derived by averaging scale items (sample 1: α = .79; sample 2: α = .76).

Illness symptoms—Participants' experience of physical illness symptoms was measured using the Pennebaker Inventory of Limbic Languidness (PILL; Pennebaker, 1982). The PILL asks participants to indicate how often they have experienced 54 different physical illness symptoms including "coughing," "upset stomach," and "headaches." Response options include: 1 (*have never or almost never experienced the symptom*), 2 (*less than 3 or 4 times per year*), 3 (*every month or so*), 4 (*every week or so*), 5 (*more than once every week*). An illness symptom score was derived by summing scale items (α = .94).

Interpersonal rejection sensitivity—The Rejection Sensitivity Questionnaire (RSQ; Downey & Feldman, 1996) was used as a measure of the extent to which participants expect to be rejected by others. The RSQ assesses participants' rejection sensitivity by asking participants about their expectations regarding a variety of situations, including "you ask a friend to do you a big favor" and "you ask someone in one of your classes to coffee." Participants are asked to rate their concern about these situations on a scale from 1 (*very unconcerned*) to 6 (*very concerned*) as well as the likelihood that the other person will respond in an accepting fashion on a scale from 1 (*very unlikely*) to 6 (*very likely*). Nine items from the original 18-item RSQ were included in the current study. The RSQ is scored by first multiplying the concern that participants had for each situation by the likelihood that they thought each situation would occur. These individual weighted scores were then averaged into a mean score (α = .78).

Results

Internal consistency and test–retest reliability

Indicators of reliability were calculated for both the entire 12-item scale and each 4-item subscale using the data from sample 1. To account for the ordinal nature of the items, we calculated ordinal alpha as an indicator of internal consistency (Zumbo et al., 2007). The entire CIASS was highly internally consistent with an ordinal alpha of .95. Additionally, the friends and family, work colleagues, and healthcare workers subscales were internally consistent, with ordinal alphas of .92, .95, and .95 respectively.

Test–retest reliability was calculated by correlating the time 1 and time 2 scores of the 38 participants from sample 1 who completed the CIASS twice. Participant scores on the entire scale were highly correlated at .82 ($p < .001$). Additionally, participant scores on the friends and family, work colleagues, and healthcare workers subscales were correlated at .67, .83, and .61 (all ps $< .001$) respectively. Taken together, the tests of internal consistency and test–retest reliability indicate that the CIASS is an internally reliable scale.

Structural validity

The structural validity of the CIASS was evaluated using a confirmatory factor analysis with the data from sample 1. The goal of the analysis was to evaluate whether a three-factor model, representing the three sources of anticipated stigma included in the scale, yielded a good fit for the data. The confirmatory factor analysis strategy was chosen to account for the ordinal nature of the data. The analysis was performed in LISREL using a polychoric correlation matrix and robust diagonally weighted least squares to estimate the model. All factor loadings were statistically significant (see Table 2). The Chi-square was small but statistically significant, $\chi^2 (51) = 88.59$, $p = .0008$. However, the root mean square residual (RMR) was .05 and the goodness-of-fit index (GFI) was .99, indicating that the model is a strong fit for the data. Given that the RMR and GFI are arguably better indices of fit than the Chi-square in the current analysis due to the sample size (Kline, 2005), the results suggest that the model is a good fit for the data. Therefore, the analysis indicates that the CIASS is structurally valid.

Construct validity

The construct validity of the CIASS was evaluated by correlating participant responses to the CIASS with responses to other measures using the data from sample 1 (see Table 3). As expected, and supporting convergent validity, the CIASS was positively correlated with enacted stigma, internalized stigma, stigma consciousness, depression, anxiety, and illness symptoms, and was negatively correlated with care access. This suggests that participants who anticipate greater stigma from others as measured by the CIASS also have experienced more stigma because of their illness from others, endorse prejudicial beliefs and stereotypes about people living with chronic illness to a greater extent, expect to be stereotyped by others more, are more depressed and anxious, and experience decreased physical health. Furthermore, they are less likely to access medical care. Notably, the subscales of the CIASS were most strongly correlated with the enacted stigma subscales of the same source. For example, the friends and family subscale of the CIASS was most strongly correlated with enacted stigma from friends and family.

In contrast, correlations between the CIASS and interpersonal rejection sensitivity were smaller, supporting discriminant validity. This suggests that the CIASS is only weakly related to interpersonal rejection sensitivity. Therefore, participants who anticipate stigma due to their chronic illness do not seem to expect stigmatizing treatment because they are overly rejection sensitive, readily perceiving and overreacting to rejection. Instead, they anticipate prejudice, stereotyping, and discrimination specifically because of their chronic illness.

External validity

The external validity of the CIASS was evaluated by examining its ability to predict health and health behavior outcomes of anticipated stigma. Using data from sample 1, four linear regressions were conducted. The first steps controlled for all demographics included in Table 1 [i.e., age, gender, race (dummy code representing White/European-American), total chronic illnesses, most common chronic illnesses (dummy codes representing asthma, inflammatory bowel disease, and diabetes), proportion of life with illness, illness affects life,

and general health]. The second steps included participants' total score on the CIASS, centered for this analysis. The third steps included the interaction terms between the total CIASS and the three chronic illnesses represented in these analyses. These interactions were included to examine whether the relationship between CIASS and the outcome variables differed depending on chronic illness type.

Results revealed that participants' score on the CIASS predicted increased depression [$B = 1.26$, SE $= .56$, $\beta = .19$, $t(154) = 2.26$, $p = .03$], increased anxiety [$B = .25$, SE $= .06$, $\beta = .34$, $t(154) = 4.35$, $p < .001$], increased illness symptoms [$B = 8.22$, SE $= 3.50$, $\beta = .20$, $t(144) = 2.35$, $p = .02$], and decreased care access [$B = -.41$, SE $= .10$, $\beta = -.36$, $t(152) = 4.26$, $p < .001$] in steps 2 of the analyses. The interaction terms included in the third steps were not statistically significant. Therefore, anticipated stigma was associated with decreased health and poor health behaviors even controlling for the effects of demographics, health, illness-related characteristics (e.g., proportion of life living with illness, extent to which illness affects life), and type of chronic illness. These relationships did not differ depending on illness type.

Generalizability

The generalizability of the CIASS was evaluated by comparing the scale across the two samples. Sample 1 is composed of young, relatively healthy university students. Sample 2 is an older, slightly less healthy community sample. First, we examined the internal consistency of the measure in sample 2 in comparison to sample 1. The entire scale was again highly consistent with an ordinal alpha of .93. The friends and family, work colleagues, and healthcare workers subscales were also highly consistent with ordinal alphas of .93, .93, and .95 respectively. Thus, the CIASS was internally consistent among the sample of community-recruited adults.

Next, we tested for measurement equivalence of the CIASS in the two samples by conducting an analysis of factorial invariance (Jöreskog, 2006). We evaluated two models: the first tested the null hypothesis that the factor loadings were identical across the two samples and the second tested the alternative hypothesis that the factor loadings were not identical. We then conducted a Chi-square difference test based on the results of these analyses. This test yielded a non-statistically significant Chi-square, $\chi^2 (12) = 13.58$, $p = .34$, indicating factorial invariance between the samples. Therefore, we found evidence of measurement equivalence of the CIASS across the student and adult samples.

We also examined the descriptive statistics of and correlations between the total CIASS and its subscales in samples 1 and 2. These statistics are included in Table 3 for sample 1 and Table 4 for sample 2. Participant scores on the CIASS were higher in sample 2 for the overall scale [$F(1,355) = 90.78$, $p < .001$, $\eta_p^2 = .20$], friends and family subscale [$F(1,355) = 29.91$, $p < .001$, $\eta_p^2 = .08$], work colleagues subscale [$F(1,343) = 123.10$, $p < .001$, $\eta_p^2 = .27$], and healthcare subscale [$F(1,354) = 56.92$, $p < .001$, $\eta_p^2 = .14$]. However, the pattern of correlations between the CIASS subscales was similar for samples 1 and 2, with the weakest correlation occurring between the work colleagues and healthcare workers subscales in both samples. Further, the correlations between the CIASS and its subscales were not statistically significantly different among the two samples (all ps > .20). Therefore, the community-

recruited adult sample anticipated greater stigma than the student sample but the relationship between the CIASS and its subscales did not differ between the two samples.

Finally, generalizability was evaluated by comparing the relationship between the CIASS and care access in samples 1 and 2. The correlations between the CIASS and care access for sample 2 are included in Table 4. These correlations were not statistically significantly different than those resulting from sample 1 (all ps > .40). Similar to sample 1, participant scores from sample 2 on the total CIASS and its subscales were correlated with care access. Again, the healthcare workers and friends and family subscales of the CIASS were more strongly correlated with decreased care access than the work colleagues subscale. Taken together, these analyses suggest that the CIASS is a reliable, valid, and generalizable scale that can be used in multiple settings and with adults at different life stages.

Discussion

The current work evaluated the psychometric properties of the CIASS, a new scale designed to measure anticipated stigma among people living with chronic illnesses from their friends and family members, work colleagues, and healthcare workers. Both students (sample 1) and community-recruited adults (sample 2) living with chronic illnesses completed the CIASS along with several other measures. Results support the reliability (i.e., internal consistency and test–retest reliability), validity (i.e., structural, construct, and external), and generalizability of the CIASS.

Several of the results are particularly convincing in their support of the utility of the CIASS in research involving people living with chronic illnesses. First, anticipated stigma may be especially important to study to the extent that it impacts the health and behaviors of people living with chronic illnesses. In the current work, the CIASS predicted decreased mental (i.e., increased depression and anxiety) and physical health (i.e., increased illness symptoms), and decreased engagement in an important health behavior (i.e., decreased care access) even after controlling for participants' demographic and illness-related characteristics. The CIASS can help researchers better understand the consequences of anticipated stigma on the health and behavior of people living with chronic illnesses. Second, researchers may be particularly interested in studying stigma among adults living with chronic illnesses. Analyses of generalizability suggest that the CIASS is reliable and valid in a sample of community-recruited adults, and that anticipated stigma may be higher among adults living with chronic illnesses.

Third, theory (Goffman, 1963; Link & Phelan, 2001; Parker & Aggleton, 2003) and empirical evidence (Stutterheim et al., 2009) suggest that it is important to differentiate between sources of stigma. Analyses of structural and construct validity demonstrate that the CIASS measures anticipated stigma from three distinct sources of stigma: friends and family, work colleagues, and healthcare workers. Differentiating between sources may be particularly important for researchers and/or clinicians who want to intervene in the negative relationship between anticipated stigma and health and behavior. For example, results suggest that anticipated stigma from friends and family, and healthcare workers is more highly correlated with care access than anticipated stigma from work colleagues.

Researchers and/or clinicians who want to increase care access among people living with chronic illnesses might therefore prioritize addressing anticipated stigma from friends, family, and healthcare workers above anticipated stigma from work colleagues.

There are several strengths of the CIASS that may increase its utility in behavioral research. The CIASS is short, including only 12 items that capture anticipated stigma from three different sources. Therefore, the participant demand for completing the scale is low. The CIASS can also be used to measure anticipated stigma among people living with a variety of chronic illnesses, answering a recent call for generic measures of illness-related stigma (van Brakel, 2006). Therefore, the CIASS can be used to compare anticipated stigma between people living with different chronic illnesses. It can also be used to study people living with specific chronic illnesses, and may be especially useful for researchers studying illnesses that have not received a great deal of empirical attention and therefore may not have other psychometrically validated measures of stigma (e.g., fibromyalgia or Lyme disease). The CIASS also provides a nuanced measurement of stigma. It takes into account sources of stigma, and does not conflate multiple stigma mechanisms (see Earnshaw & Chaudoir, 2009). The CIASS provides specific information on the extent to which participants are anticipating chronic illness stigma and from whom. This may allow researchers to better tailor stigma interventions to achieve maximum effectiveness.

There are several limitations of the CIASS that are important to consider. The psychometric properties of the CIASS were evaluated using samples of people living with chronic illnesses who reside in the United States. The extent to which it is generalizable to other geographic locations is unknown. Future work might evaluate the psychometric properties of the CIASS in other countries. This evaluation is especially important given that stigma is theorized to be a social construct (Goffman, 1963; Link & Phelan, 2001; Parker & Aggleton, 2003), and therefore may differ in strength and content in different places. Additionally, given the sampling methods (i.e., recruitment from university listservs, online communities, and support groups), certain people living with chronic illnesses may be underrepresented in this work. For example, men and racial/ethnic minorities may be underrepresented as well as adults who do not have as many concerns regarding their chronic illness and therefore do not use online communities or support groups for people living with chronic illnesses. Future work should continue to evaluate the psychometric properties of the CIASS among more diverse samples, including racial/ethnic minorities and people with chronic illnesses recruited from doctors' offices and community clinics. Further, certain people living with chronic illnesses may be overrepresented in this work. For example, there is a high frequency of people living with inflammatory bowel disease in both samples. Although recent work has shown that people living with inflammatory bowel disease perceive stigma from others and that their perceptions of stigma are related to negative health outcomes (Taft et al., 2009, 2011), future work should evaluate the CIASS among people living with a greater diversity of chronic illnesses.

Further, the CIASS was evaluated among people living with a variety of chronic illnesses. Although a scale that measures anticipated stigma among people living with a variety of chronic illnesses has several advantages and such generic measures have been called for by recent theorists (e.g., van Brakel, 2006), it may also overlook key experiences that are

unique to people living with specific chronic illnesses. For example, people living with lupus may be stereotyped as being overly tired and/or unable to engage in physical activities. Researchers studying specific illnesses may find it useful to supplement the CIASS with items tailored to those illnesses, and evaluate the psychometric properties of supplementary items along with the CIASS among people living with specific illnesses.

Despite these limitations, the CIASS is a reliable and valid scale that can be used to measure anticipated stigma among people living with chronic illnesses in the United States. Stronger, more nuanced understandings of anticipated stigma experienced by people living with chronic illnesses may contribute to interventions that improve the health of people living with chronic illnesses.

Acknowledgments

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Table 1

Sample 1 and sample 2 participant demographic characteristics

Variable	Sample 1				Sample 2			
	n	%	*M*	SD	*n*	%	*M*	SD
Sample size	184				172			
Age			21.74	5.94			43.68	13.29
Gender								
Female	134	72.8 %			133	77.8 %		
Male	50	27.2 %			38	22.2 %		
Race/ethnicity								
Asian/Asian-American	12	6.5 %			3	1.8 %		
Black/African-American	5	2.7 %			5	2.9 %		
Latino(a)/Hispanic-American	3	1.6 %			4	2.3 %		
Native American	1	0.5 %			3	1.8 %		
White/European-American	152	82.6 %			154	90.1 %		
Multi-racial	8	4.3 %			2	1.2 %		
Other	3	1.6 %			0	0 %		
Total chronic illnesses			1.39	0.87			1.88	1.36
Most common chronic illnesses: sample 1								
Asthma	53	28.8 %						
Inflammatory bowel disease	17	9.2 %						
Diabetes	11	6.0 %						
Most common chronic illnesses: sample 2								
Inflammatory bowel disease					55	32.0 %		
Multiple sclerosis					28	16.3 %		
Fibromyalgia					26	15.1 %		
Proportion of life with illness			0.33	0.29			0.22	0.22
Illness affects life			3.32	0.92			3.65	0.64
Not at all	1	0.5 %			1	0.7 %		
Barely	25	13.6 %			8	4.8 %		
Somewhat	86	46.7 %			45	26.9 %		

Variable	Sample 1				Sample 2			
	n	%	*M*	SD	*n*	%	*M*	SD
Very much	59	32.1 %			113	67.6 %		
Extremely	13	7.1 %			N/A	N/A		
General health			3.24	0.90			2.70	0.93
Poor	4	2.2 %			14	8.2 %		
Fair	32	17.4 %			58	33.9 %		
Good	77	41.8 %			72	42.1 %		
Very good	58	31.5 %			20	11.7 %		
Excellent	13	7.1 %			7	4.1 %		

Illness affects life was measured on a 5-point Likert scale ranging from *not at all* to *extremely* in sample 1 and a 4-point Likert scale ranging from *not at all* to *very much* in sample 2

Table 2

Structural validity of the CIASS: factor loadings from confirmatory factor analysis

Item	Factor loading (SE), *z*-value
Friends and family	
A friend or family member will think that your illness is your fault	.69 (.05), 14.51[**]
A friend or family member will not think as highly of you	.77 (.04), 19.81[**]
A friend or family member will blame you for not getting better	.81 (.04), 22.50[**]
A friend or family member will be angry with you	.78 (.04), 20.36[**]
Work colleagues	
Someone at work will think that you cannot fulfill your work responsibilities	.85 (.02), 36.13[**]
Your employer will assign a challenging project to someone else	.94 (.02), 62.81[**]
Someone at work will discriminate against you	.85 (.02), 35.34[**]
Your employer will not promote you	.83 (.03), 30.71[**]
Healthcare workers	
A healthcare worker will blame you for not getting better	.83 (.03), 29.11[**]
A healthcare worker will be frustrated with you	.92 (.02), 48.10[**]
A healthcare worker will give you poor care	.74 (.04), 18.59[**]
A healthcare worker will think that you are a bad patient	.84 (.03), 31.24[**]

[**] *p* .001

Table 3

Construct validity of the CIASS: means (SDs) and correlations between CIASS subscales and other variables

	Mean (SD)	CIASS: Total	CIASS: friends and family	CIASS: work colleagues	CIASS: healthcare workers
CIASS: total	1.65 (0.75)	—			
CIASS: friends and family	1.63 (0.89)	.84**	—		
CIASS: work colleagues	1.78 (0.99)	.81**	.51**	—	
CIASS: healthcare workers	1.55 (0.88)	.81**	.57**	.45**	—
Enacted stigma: total	4.49 (5.94)	.75**	.61**	.60**	.62**
Enacted stigma: friends and family	2.38 (3.07)	.69**	.67**	.53**	.50**
Enacted stigma: work colleagues	1.19 (2.33)	.44**	.29**	.55**	.22*
Enacted stigma: healthcare workers	.92 (2.14)	.59*	.41**	.31**	.77**
Internalized stigma	1.96 (0.63)	.55**	.50**	.47**	.39**
Stigma consciousness	2.92 (1.25)	.49**	.40**	.46**	.34**
Depression	16.62 (5.22)	.24*	.21*	.24*	.13†
Anxiety	2.22 (0.56)	.38**	.34**	.36**	.25*
Illness symptoms	119.60 (31.08)	.28**	.20*	.27**	.22*
Care access	3.29 (.86)	−.32**	−.30**	−.19†	−.31**
Interpersonal rejection sensitivity	9.92 (4.17)	.17†	.15‡	.17†	.10

‡ p .10;

† p .05;

* p .01;

** p .001

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Table 4

Generalizability of the CIASS: means (SDs) and correlations between CIASS subscales and care access

	Mean (SD)	CIASS: total	CIASS: friends and family	CIASS: work colleagues	CIASS: healthcare workers
CIASS: total	2.51 (.93)	–			
CIASS: friends and family	2.22 (1.12)	.84**	–		
CIASS: work colleagues	3.08 (1.19)	.76**	.46**	–	
CIASS: healthcare workers	2.35 (1.10)	.80**	.57**	.34**	–
Care access	3.27 (.86)	−.30**	−.22*	−.17†	−.26**

†
p .05;

*
p .01;

**
p .001