

Health-Related Stigma in Adolescents with Functional Abdominal Pain: Instrument
Development and Model Testing

By

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To my parents,
whose unconditional love provided me with the inspiration to pursue
and the support to complete this work.

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CHAPTER 1

INTRODUCTION

Goffman (1963) defines stigma as an “undesired differentness” (p. 5) that results in an individual being “disqualified from full social acceptance” (p. 9). Several researchers have attempted to identify the features of a condition that lead to stigma. Jones (E. E. Jones, 1984) identifies six dimensions of stigma. *Concealability* indicates the extent to which it is possible to conceal the stigma from others. *Course* indicates whether the stigmatizing condition is reversible over time, with irreversible conditions eliciting greater stigma (Link, Yang, Phelan, & Collins, 2004). *Disruptiveness* indicates the extent to which the stigma obstructs or creates discomfort in social interactions. *Aesthetic* reflects the extent to which the stigma elicits disgust. *Origin* refers to how the stigma originated, with presumed individual responsibility for one’s condition being associated with greater stigma (Link et al., 2004). Finally, *peril* refers to feelings of danger or threat that the stigma induces in others.

While some researchers have suggested that disruptiveness is the main factor predicting stigmatization (Albrecht, Walker, & Levy, 1982), others propose that origin plays the greatest role (Crandall & Moriarty, 1995; Rush, 1998; Wiener, Battles, & Heilman, 1999). In one study, 113 undergraduate students rated 66 illnesses across several dimensions (e.g., contagious vs. non-contagious; rare vs. common; Crandall & Moriarty, 1995). Both greater illness severity and greater perceived responsibility/ controllability predicted increased stigma in that sample.

Stigma is a risk factor for poor mental health, physical health and functioning. This relation has been demonstrated in individuals with concealable stigmas including sexual minority

status (A. E. Goldberg & Smith, 2011), mental illness (Link, Cullen, Frank, & Wozniak, 1987; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2014; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Markowitz, 1998; Perlick et al., 2001), HIV (Greeff et al., 2010; Hatzenbuehler, O’Cleirigh, Mayer, Mimiaga, & Safren, 2011), epilepsy (Hermann, Whitman, Wyler, Anton, & Vanderzwagg, 1990; Westbrook, Bauman, & Shinnar, 1992), and chronic pain (Vaugh, Byrne, & Nicholas, 2014) as well as in individuals with non-concealable stigmas including racial/ ethnic minority status (Paradies, 2006; Williams, Neighbors, & Jackson, 2003) and obesity (Hatzenbuehler, Keyes, & Hasin, 2009).

Individuals with concealable stigmas are exposed to a unique set of stressors. First, they must decide whether or not to disclose their hidden status. Disclosure of stressful experiences and sharing important aspects of one’s identity appear important to building intimacy within personal relationships (Derlega, Metts, Petronio, & Margulis, 1993) and maintaining physical and mental health (Frattaroli, 2006; Pennebaker & Beall, 1986). However, disclosure of a concealable stigmatized identity also carries a risk of negative outcomes, including social devaluation, rejection and discrimination (Chaudoir & Fisher, 2010). Anticipation of such outcomes often leads individuals with concealable stigmas to avoid disclosing their stigmatized status (Corrigan et al., 2009; Greene et al., 2012; R. Smith, Rossetto, & Peterson, 2008; Toth & Dewa, 2014). The decision not to disclose, in turn, can lead to anxiety about the possibility of discovery, isolation from similarly stigmatized others, and “being detached from one’s true self” (Pachankis, 2007).

Results of several studies indicate that stigma concealment may undermine coping and compound the negative impact of the stigma on mental health. For example, in a prospective study of women with a history of abortion, those who anticipated stigmatization were more

likely to conceal their abortion history from others (Major & Gramzow, 1999). Concealment was associated with increased thought suppression and intrusive thoughts, which in turn predicted increased psychological stress over time (Major & Gramzow, 1999). Similarly, stigma concealment has been associated with increased depressive symptoms in HIV-seropositive parents (Wiener et al., 1999) and HIV-seropositive gay men (Ullrich, Lutgendorf, & Stapleton, 2003). Stigma concealment has also been associated with decreased social support (Letteney, 2006) and quality of life (QOL) in HIV-seropositive adults (Chaudoir & Quinn, 2010; Greeff et al., 2010). A daily diary study conducted with 102 sexual minority individuals found that concealment of sexual orientation was associated with decreased life satisfaction, positive affect, and self-esteem (Beals, Peplau, & Gable, 2009). These studies suggest that disclosure of one's concealable stigma may result in improved mental health and functioning.

In addition to the potentially deleterious effects of stigma concealment on mental health, concealment also appears to negatively impact physical health. Several studies have investigated whether decreased mental health may mediate the effect of stigma concealment on physical health. In a cross-sectional study of 73 HIV-seropositive gay men, sexual identity concealment was associated with decreased immunological functioning, and this effect could not be attributed to changes in depressive symptoms or social support (Ullrich et al., 2003). In a five-year longitudinal study of 222 HIV-seronegative gay men, sexual identity concealment was found to increase risk for infectious disease (pneumonia, bronchitis, sinusitis, and tuberculosis) and cancer, and this effect could not be fully explained by increased symptoms of anxiety, depression, or relevant behavioral patterns (Cole, Kemeny, Taylor, & Visscher, 1996). Similarly, in a nine-year longitudinal study of 80 HIV-seropositive gay men, HIV infection advanced more rapidly among those who concealed their sexual orientation, and this effect was not mediated by

symptoms of depression, anxiety, or social support (Cole, Kemeny, Taylor, Visscher, & Fahey, 1996). Finally, a study of 373 psychiatric outpatients from a large HIV clinic found that consistent disclosure of both sexual orientation and HIV status independently predicted improved immune functioning (Strachan, Bennett, Russo, & Roy-Byrne, 2007), and that this effect was independent of changes in mental health and relevant health behaviors. Together, these studies suggest that stigma concealment adversely affects physical health, and that this effect may be independent of effects on mental health.

Health-Related Stigma

Stigma is a feature of many chronic health conditions, and may serve as a “hidden burden of illness” that compounds the negative impact of a health condition on physical and mental well-being (Weiss, Ramakrishna, & Somma, 2006). Health-related stigma can have profound consequences, including the avoidance or termination of medical care. For highly stigmatizing disorders, the impact of stigma can be even greater than the physical symptoms themselves (Weiss et al., 2006).

Stigma is thought to be more prevalent in chronic as opposed to acute health conditions because chronic illness tends to redefine the identity of affected individuals (Weiss et al., 2006) and because individuals with chronic illness may be perceived as having less “social value” compared to healthy individuals (Reidpath, Chan, Gifford, & Allotey, 2005). Stigma may be especially prevalent in “functional” (i.e., medically unexplained) syndromes compared to conditions with a clear medical pathology because of skepticism regarding the validity of these disorders (Looper & Kirmayer, 2004). For example, physicians and family members may suspect that symptoms are a result of malingering or a mental cause that is at least partially under the

individual's control (Åsbring & Närvänen, 2002; Charmaz, 1983; Looper & Kirmayer, 2004). Indeed, qualitative research reveals that individuals with somatic syndromes such as fibromyalgia and chronic fatigue syndrome often report that their experiences are not validated and that others dismiss their symptoms as an emotional problem (Åsbring & Närvänen, 2002). Similarly, the stigmatization of chronic pain (pain persisting for three months or longer than medically expected; Poobalan et al., 2003) is widespread (De Ruddere & Craig, 2016; D. S. Goldberg, 2017).

Stigma in Chronic Pain

The stigmatization of chronic pain has been shown to interfere with care-seeking, decrease rehabilitation participation (Slade, Molloy, & Keating, 2009), and profoundly impact self-esteem (Holloway, Sofaer-Bennett, & Walker, 2007). Among a sample of 92 adults with chronic pain, internalized stigma was also significantly associated with greater catastrophizing, after controlling for the relationship between internalized stigma and depression (Waugh et al., 2014). Data from that same study indicated that internalized stigma was also significantly associated with lower sense of control over pain ("pain self-efficacy), after controlling for the relation between sense of control and functional disability. Thus, research suggests that stigma is associated with greater mental health symptoms (anxiety and depression), greater catastrophizing (including greater perceived pain threat and lower pain self-efficacy), greater severity of physical symptoms (abdominal pain, nausea, and other somatic symptoms), and greater functional impairment.

Stigma in Adolescence

Because the development of self-identity and peer relationships are especially salient during adolescence, stigma encountered at this life stage may have even greater influence on psychosocial adjustment and functioning than stigma encountered later in life (Austin, MacLeod, Dunn, Shen, & Perkins, 2004). Social, cognitive, and physical changes in adolescence may also increase adolescents' susceptibility to the internalization of stigmatizing messages and experiences (Reimer, 1996). Evidence that stigma may impact mental health in adolescents with chronic pain comes from a cross-sectional study of 36 children and adolescents ages 7-16 with juvenile rheumatic disease (Sandstrom & Schanberg, 2004). Moderation analyses from that study showed that peer rejection appeared to amplify the effect of pain on depressive symptoms (Sandstrom & Schanberg, 2004). Because there is currently no validated measure of stigma for use with adolescents with chronic pain, it is unknown whether these effects are due to general peer rejection or health-specific stigma. The extent to which stigma persists over time and is responsive to psychological intervention is also unknown. Although several psychological therapies have been shown to improve mental health, physical health, and functioning in adolescents with chronic pain (Humphreys & Gevirtz, 2000; Levy et al., 2013; Levy et al., 2010; Robins, Smith, Glutting, & Bishop, 2005; van der Veek, Derkx, Benninga, Boer, & de Haan, 2013; van Tilburg et al., 2009), it is unknown whether these interventions reduce stigma and whether reductions in stigma partially account for treatment effects. Investigation of stigma's impact, persistence, and responsiveness to psychological intervention requires the development of a validated measure to reliably assess stigma in this population.

One major problem in advancing stigma research is the lack of consensus among researchers as to the major components of stigma. For example, facets identified by researchers

include “enacted” (or “experienced”), “anticipated”, “perceived”, “felt”, and “internalized” (or “self-stigma”; Brohan, Slade, Clement, & Thornicroft, 2010; Luoma et al., 2007; Rensen, Bandyopadhyay, Gopal, & Van Brakel, 2011). These constructs can broadly be divided into two major categories: 1) psychological constructs, and 2) environmental or social constructs (see Figure 1 for a diagram of stigma constructs). Enacted or “experienced” stigma is perhaps the most common form of environmental stigma and can be defined as “directly experienced social discrimination such as difficulty obtaining employment, reduced access to housing, poor support for treatment, or interpersonal rejection” as a result of one’s stigmatized status (Luoma et al., 2007). Enacted stigma is most accurately assessed via laboratory experiments (Darley & Gross, 1983; Henderson-King & Nisbett, 1996; Linville & Jones, 1980), field experiments (Ahmed & Hammarstedt, 2008; Bertrand & Mullainathan, 2004), or audit/ paired-testing methodology (S. L. Ross & Yinger, 2002).

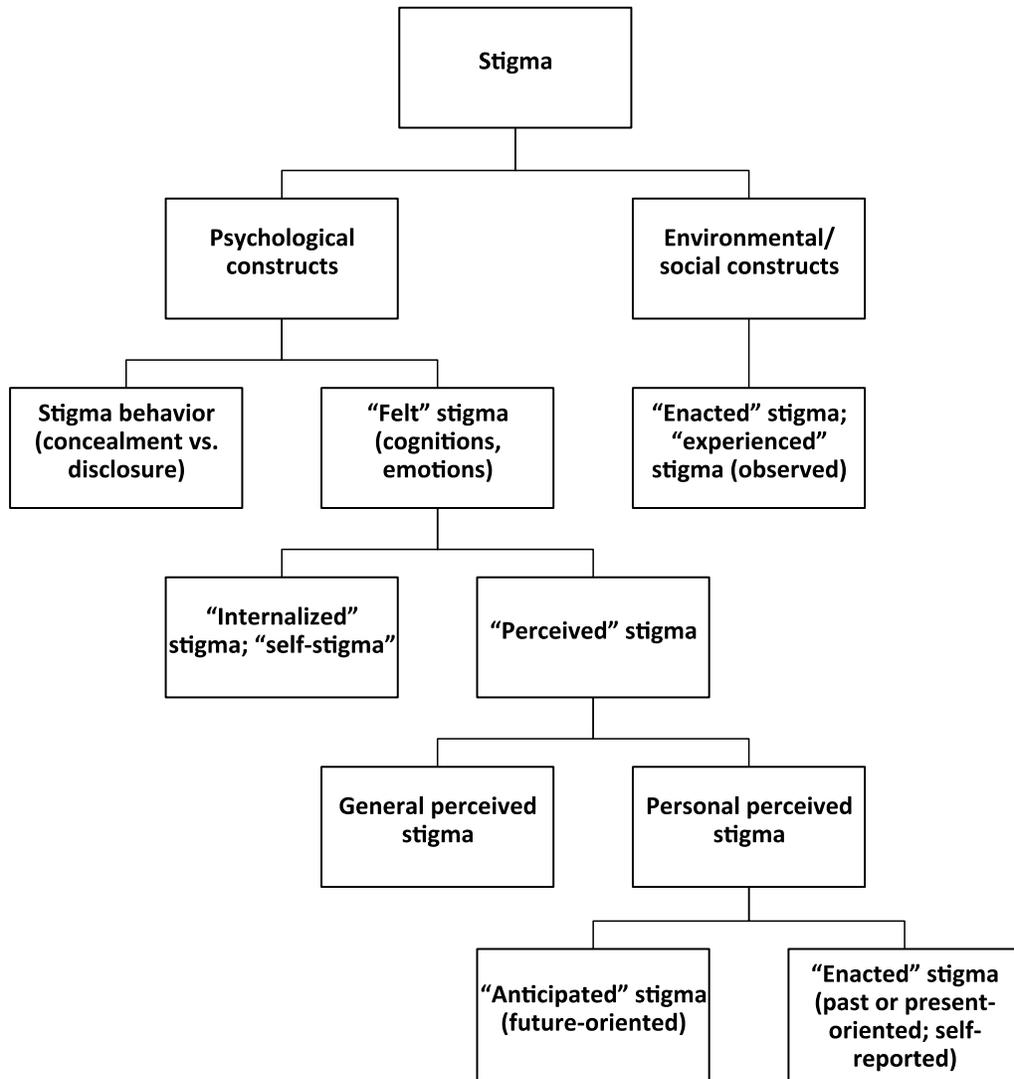


Figure 1. Flow diagram of stigma constructs.

The current study focuses on psychological stigma constructs – that is, thoughts, emotions, and behaviors related to stigma¹. As previously discussed, stigma behaviors consist of concealment and disclosure. Stigma-related thoughts and emotions include perceived stigma (generally conceptualized as a purely cognitive construct) and internalized stigma (comprised of

¹ Not only are these constructs more accurately assessed via self-report compared to enacted stigma, but they may also be more closely related to mental health outcomes. For example, in a cross-cultural study of gay men, anticipated social rejection was more strongly predictive of psychological distress than were actual experiences of enacted rejection (M. W. Ross, 1985).

both cognitions and emotions). Perceived stigma has been defined as “stigma and discrimination [that individuals with a stigma] fear or perceive to be present in the community” (Brohan et al., 2010). Perceived stigma includes both the individual’s beliefs about how society generally reacts to the stigmatized group (henceforth referred to as “general perceived stigma”) and how society reacts to him or her personally as a member of the stigmatized group (henceforth referred to as “personal perceived stigma”; Brohan et al., 2010). Anticipated stigma can be conceptualized as future-oriented form of personal perceived stigma. That is, anticipated stigma is “the degree to which individuals expect that others will stigmatize them if they know about the concealable stigmatized identity” (Chaudoir & Quinn, 2010). Finally, internalized stigma (also referred to as “self-stigma”) has been defined as the extent to which a stigmatized individual accepts society’s negative evaluation and incorporates it into his or her own personal value system and sense of self (Link et al., 2002; Livingston & Boyd, 2010; Corrigan & Watson, 2002). Internalized stigma is thought to have the most direct negative impact on the mental health and emotional well-being of the stigmatized individual because it is the mechanism by which cultural prejudice leads the individual to devalue him or herself (Link et al., 1989; Link & Phelan, 2001; Drapalski et al., 2014; Waugh, Byrne, & Nicholas, 2014). Indeed, the negative effects of internalized stigma on psychological well-being may endure even when symptoms of a disorder have remitted due to treatment (Link et al., 1997). Finally, the term “felt” stigma has been proposed to describe an element of stigma encompassing both perceived and internalized stigma (Brohan et al., 2010).

Several studies have investigated the efficacy of interventions designed to reduce psychological stigma in individuals with stigmatizing conditions. One RCT demonstrated the efficacy of an acceptance-based therapy designed to reduce internalized stigma and improve mental and physical health outcomes in overweight and obese women (Palmeira, Pinto-Gouveia,

& Cunha, 2017). Another RCT found that a “Self-stigma Reduction Program” (an integrative approach including psychoeducation, cognitive behavioral therapy (CBT), motivational interviewing, and social skills training) was effective for improving self-esteem and treatment engagement in adults with schizophrenia (Fung, Tsang, & Cheung, 2011), although these effects were not maintained at 6-month follow up. A third RCT demonstrated the efficacy of a narrative enhancement and cognitive therapy (NECT) treatment for reducing internalized stigma and improving self-esteem both at post-treatment and 6-month follow-up (Hansson, Lexén, & Holmén, 2017). Finally, at least one intervention has been designed specifically to promote stigma disclosure (Murphy, Armistead, Marelich, Payne, & Herbeck, 2011). In that study, 80 HIV-seropositive mothers with young children naïve to their mother’s serostatus were randomly assigned to receive either four individual disclosure training sessions or treatment as usual (TAU). Mothers in the disclosure training group showed increased disclosure efficacy, increased emotional functioning, and were six times more likely to disclose their HIV status than mothers in the TAU control group (children of mothers in the intervention group also showed improvements in anxiety and depression).

Research on the consequences of psychological stigma to physical and mental health is currently limited by the lack of quality instruments to clearly assess stigma’s various facets. In some cases, this is due to lack of specificity, as is the case when measures of “stigma” appear to assess a mixture of perceived, anticipated, and internalized stigma (e.g., Austin et al., 2004). However, even when the facet of stigma under investigation is clearly stated, the measure’s items often do not reflect the same degree of clarity (see Table 1). For example, one measure of “internalized” stigma includes an item about what others think (i.e., “I feel others think I am to blame for my illness”), which is more consistent with definitions of perceived than internalized

stigma (Fife & Wright, 2000). Similarly, the “Internalized Stigma of Mental Illness” scale contains a “Perceived Discrimination” subscale comprised of items that appear to capture enacted or perceived stigma (Ritsher, Otilingam, & Grajales, 2003). Other scales claiming to assess stigma (Austin et al., 2004; Wahl, 1999), perceived stigma (M. P. Jones et al., 2009), and self-stigma (Kanter, Rusch, & Brondino, 2008) include items reflecting concealment behavior (e.g., “I am very careful about who I tell about having depression”; Kanter et al., 2008).

Although concealment is a common reaction to stigma, cognitive-behavioral theory asserts that these two constructs are importantly distinct. While other facets of stigma represent internal processes (beliefs and emotions) related to stigma, concealment represents a behavioral response to those processes. Evidence supporting this differentiation comes from research demonstrating that concealment behaviors are not always consistent with self-reports of psychological stigma. For example, a study of 64 adolescents with epilepsy found that although 60-69% denied feeling stigmatized, 69% kept their epilepsy a secret, and 70% rarely or never talked about their epilepsy with others (Westbrook et al., 1992). This study highlights the need to assess stigma concealment independently of other stigma facets.

Table 1*Items That May Assess a Construct Other Than That Identified by the Scale's Authors.*

Item	Source	Author-defined Construct	Alternative Construct
People discriminate against me because I have a mental illness.	Ritsher et al., 2003	internalized	enacted; perceived
I feel others think I am to blame for my illness.	Fife & Wright, 2000	internalized	perceived
How often do you keep your seizure condition a secret from other kids?	Austin et al., 2004	undefined	concealment
I have avoided telling others outside my immediate family that I am a consumer.	Wahl, 1999	undefined	concealment
I keep my IBS symptoms hidden from these people because they will treat me differently.	Jones et al., 2009	perceived	concealment; anticipated
I am very careful about who I tell about having depression.	Kanter et al., 2008	self-stigma	concealment

Another shortcoming of the stigma literature is that assessments of enacted stigma frequently rely on self-report (Franklin, Tora, Deribe, Reda, & Davey, 2013; Fuster-Ruizdeapodaca, Molero, Holgado, & Mayordomo, 2014; King et al., 2007; Neilands, Steward, & Choi, 2008; Saewyc et al., 2013). This approach is problematic because it attempts to measure an objective construct through a subjective lens. Cognitive behavioral theory asserts that an individual's beliefs about the prevalence of unfavorable attitudes towards their stigmatized group (i.e., "general perceived stigma"), expectations of enacted stigma (i.e., "anticipated stigma"), and emotional responses to these beliefs ("internalized stigma") each influence his or her interpretation of ambiguous situations in which true discrimination due to stigma (i.e., "enacted stigma") may or may not be present. As others have argued, stigmatized individuals "may become rejection sensitive, attributing all signals of possible rejection to their stigmatized status" (Merin & Pachankis, 2011). Thus, while it is possible that self-report measures of enacted stigma indeed assess enacted stigma, these measures also likely reflect varying degrees of anticipated, perceived, and internalized stigma.

Adolescents with functional abdominal pain (FAP; defined here as episodic abdominal pain that recurs for at least two months and lacks organic etiology (e.g., ulcerative colitis or Crohn's disease) constitute an ideal population in which to investigate psychological stigma. FAP has several elements that are common to stigmatizing conditions, as it is 1) a chronic condition, 2) medically unexplained, and 3) often associated with a range of gastrointestinal symptoms which frequently elicit disgust (i.e., diarrhea, constipation, bloating, flatulence). In many cases, individuals with FAP meet criteria for a functional gastrointestinal disorder (FGID; e.g., irritable bowel syndrome; IBS; Baber, Anderson, Puzanovova, & Walker, 2008; Walker et al., 2004). Although no research to our knowledge has investigated the prevalence or degree of stigma in adolescents with FAP, research on adults with IBS indicates that anticipated stigma is prevalent (Taft, Keefer, Artz, Bratten, & Jones, 2011). For example, in a study of 148 adults with IBS, 45% reported that others believe their illness is self-inflicted and 63% reported limited disclosure of their illness (M. P. Jones et al., 2009). Furthermore, anticipated stigma in IBS has been associated with symptoms of anxiety, somatization, global symptom severity, self-esteem, and overall mental health (Taft et al., 2011). Similarly, parents of children with FAP frequently report that others view their child's condition as originating from a psychological cause, such that gastroenterologists treating children with FAP are often cautioned to avoid implying that the pain is "just in (the child's) head" (Bufler, Gross, & Uhlig, 2011). As previously discussed, disorders perceived as self-inflicted are associated with greater stigma, suggesting that stigma may be prevalent in adolescents with FAP. Abdominal pain occurs weekly in 13-17% of adolescents, potentially making FAP one of the most common stigmatizing conditions encountered by adolescents (Hyams, 1997).

An investigation of the prevalence, stability, and impact of stigma in FAP requires the development of a reliable measure that clearly differentiates the key facets of stigma. The current study therefore had two main aims. The first was to develop and validate a measure of psychological stigma constructs relevant to adolescents with FAP. Participants were adolescents enrolled in an RCT of CBT vs. education for FAP. We focused on three facets of psychological stigma: anticipated stigma (we chose to focus on this specific form of perceived stigma because we expected it to more strongly influence stigma behavior), internalized stigma, and stigma behavior (concealment vs. disclosure). Validation included investigating the measure's factor structure, internal consistency, and degree of relation to other variables predicted to be associated with stigma, as well as to explore predictive validity and stability of stigma constructs over time. The second aim was to explore the mechanisms by which stigma may affect outcomes by investigating whether cross-sectional data are consistent with a model in which stigma concealment mediates the effect of anticipated stigma on mental health, physical health, and functioning.

Proposed Model

Our proposed model is diagrammed in Figure 2. We hypothesized that among adolescents with FAP, 1) greater anticipated stigma is associated with increased mental health symptoms, physical symptoms, and functional impairment, and 2) increased stigma concealment and internalized stigma partially mediate this relationship. Within a cognitive-behavioral model parallel to the Fear-Avoidance Model of chronic pain (in which anticipation of pain leads to activity avoidance, ultimately increasing pain, distress and disability; Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen & Linton, 2000), it is reasonable to hypothesize that individuals who anticipate rejection as a result of their illness may attempt to conceal their illness from others

(Corrigan et al., 2009; Greene et al., 2012; R. Smith et al., 2008; Toth & Dewa, 2014), which may ultimately increase physical symptoms, emotional distress, and disability. Because internalized stigma can be defined as the devaluation of the self, we expected this construct to be especially highly correlated with mental health symptoms. Similarly, because stigma concealment presumably leads individuals to avoid situations in which their FAP may be revealed, we expected stigma concealment to be especially strongly related to functional impairment.

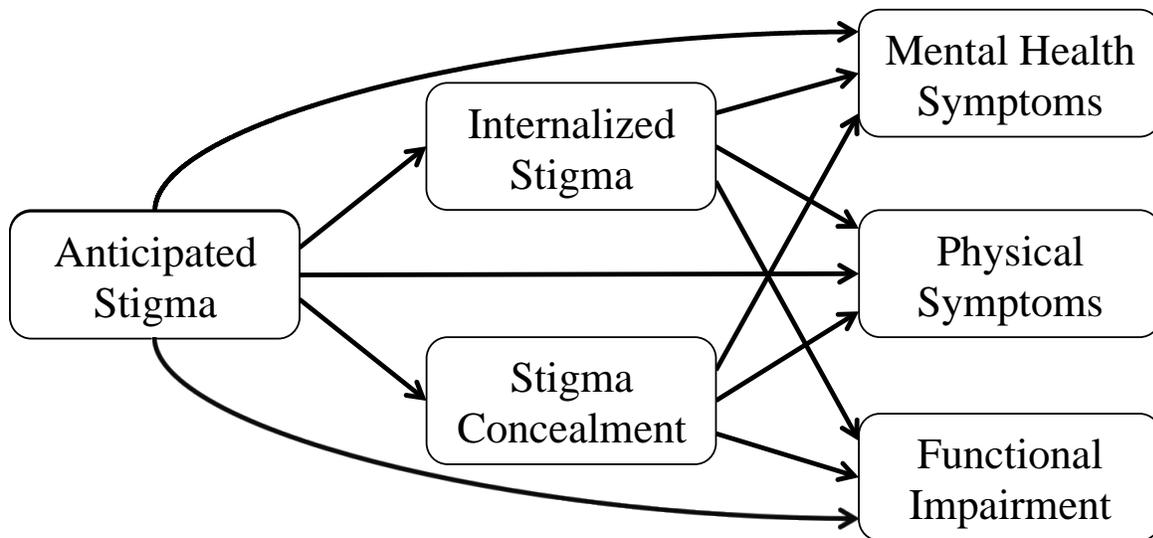


Figure 2. Initial hypothesized model. Internalized stigma and stigma concealment as pathways for the relation between anticipated stigma and poor outcomes in adolescents with FAP. All constructs were assessed at baseline.

Whether stigma and concealment would be related to healthcare utilization was an exploratory question. In highly stigmatized conditions, stigma concealment can interfere with treatment seeking, reduce treatment adherence, or lead to premature treatment termination (Weiss et al., 2006). However, those individuals perceiving high degrees of stigma are also likely find their symptoms more distressing, which could lead to *greater* healthcare seeking compared

to individuals perceiving less stigma. Because there were no strong a priori hypotheses about the direction of this relation, healthcare utilization was not included in the model.

Another exploratory question was whether stigma and stigma concealment would decrease pre- to post-treatment to a greater extent in adolescents assigned to the CBT vs. education control condition. Although the CBT protocol was not designed to target psychological stigma, it is reasonable to hypothesize that participating in a psychological intervention where FAP is normalized as a common and manageable health condition may reduce perceived or internalized stigma among participants. Participants' exposure to videos and case stories of other adolescents with FAP may also serve to reduce perceived or internalized stigma. Furthermore, one of the modules in the CBT condition ("School") includes tips for adolescents on how to talk to their teachers and friends about their FAP, which could reasonably be hypothesized to reduce stigma concealment.

Study Aims and Hypotheses

Aim 1: Develop and Validate a Measure of Psychological Stigma

Aim 1a: Investigate factor structure. Develop preliminary scales consistent with the constructs of anticipated stigma, internalized stigma, and stigma concealment and utilize exploratory factor analysis (EFA) to evaluate whether these scales assess discrete constructs in a sample of adolescents with FAP. In line with previous research (Brohan et al., 2010; Westbrook et al., 1992), concealment behaviors in particular were predicted to emerge as distinct from cognitive and emotional facets of stigma.

Aim 1b: Investigate internal consistency. Investigate the internal consistency of the scales identified during factor analysis.

Aim 1c: Describe relations between stigma constructs and other variables. First, explore the association of stigma constructs with demographic variables (age, sex, race). Second, test the association of stigma constructs with type of FAP. It was hypothesized that participants who met criteria for IBS would report greater degrees of perceived stigma, internalized stigma, and stigma concealment compared to those who did not. No such differences were predicted between participants who met criteria for functional dyspepsia vs. those who did not.

Aim 1d: Evaluate construct validity. Evaluate the construct validity of the identified stigma scales by examining their correlation with related self-reported constructs. We expected moderate correlations between these scales and mental health symptoms (anxiety and depression), pain cognitions (pain catastrophizing and pain threat appraisal), and physical symptoms (abdominal pain, nausea, and other somatic symptoms). It was hypothesized that lower gastrointestinal (GI) symptoms would be more strongly related to stigma and stigma concealment than upper GI (e.g., nausea) and non-GI somatic symptoms due to the increased potential of lower GI symptoms for eliciting disgust. Finally, we expected moderate correlations between stigma constructs and functional impairment (functional disability; pain interference). Whether stigma constructs would be related to increased healthcare utilization (medical visits and mental health visits) was an exploratory question.

Aim 2: Explore the Mechanisms by Which Stigma May Affect Outcomes

Aim 2a: Investigate the potential role of stigma concealment as a mediator. Test whether cross-sectional data are consistent with a model in which stigma concealment mediates the effect of anticipated stigma on three domains of health related outcomes.

Mental health. It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and anxiety (Hypothesis 1). It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and depression (Hypothesis 2).

Physical symptoms. It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and abdominal pain (Hypothesis 3). It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and GI-related somatic symptoms (Hypothesis 4).

Functional impairment. It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and functional disability (Hypothesis 5). It is hypothesized that stigma concealment will mediate the relation between anticipated stigma and pain interference (Hypothesis 6).

Aim 2b: Investigate the potential role of internalized stigma as a mediator. Test whether cross-sectional data are consistent with a model in which internalized stigma mediates the effect of anticipated stigma on three domains of health related outcomes.

Mental health. It is hypothesized that internalized stigma will mediate the relation between anticipated stigma and anxiety (Hypothesis 7). It is hypothesized that internalized stigma will mediate the relation between anticipated stigma and depression (Hypothesis 8).

Physical symptoms. It is hypothesized that internalized stigma will mediate the relation between anticipated stigma and abdominal pain (Hypothesis 9). It is hypothesized that internalized stigma will mediate the relation between anticipated stigma and GI-related somatic symptoms (Hypothesis 10).

Functional impairment. It is hypothesized that internalized stigma will mediate the relation between anticipated stigma and functional disability (Hypothesis 11). Internalized stigma will mediate the relation between anticipated stigma and pain interference (Hypothesis 12).

Exploratory Aims

In addition to the specific aims detailed above, the current study had three exploratory aims.

Exploratory Aim 1

Exploratory Aim 1 was to investigate the degree of psychological stigma in adolescents with FAP. The extent to which participants agreed with statements reflecting psychological stigma related to FAP was explored.

Exploratory Aim 2

Exploratory Aim 2 was to investigate the stability of stigma constructs over time. The stability of psychological stigma constructs pre-post participation in a 12-week online program for FAP (either CBT or education attention control) was investigated. Whether endorsement of stigma constructs decreases to a greater extent among adolescents assigned to CBT compared to the education attention control condition was an exploratory question.

Exploratory Aim 3

Exploratory Aim 3 was to investigate predictive validity of the HR-SCQ. Predictive validity was evaluated by testing the extent to which baseline stigma constructs predict changes in health-related outcomes (mental health, physical symptoms, and pain interference) following

an online pain management intervention. Hierarchical linear regressions were used for these analyses in order to control for covariates (i.e., baseline scores on health-related outcomes). CBT participants were expected to experience greater improvement in health-related outcomes from pre-post treatment; thus, group was entered as a covariate when it significantly predicted health outcomes at post-treatment. We expected that, controlling for baseline scores on the health-related outcome of interest (and group assignment, when significant), greater degrees of our psychological stigma constructs at baseline would predict greater degrees of the following constructs at follow-up: (1) anxiety, (2) depressive symptoms, (3) abdominal pain severity, (4) GI symptom severity, and (5) pain interference.²

² Because the FDI was not administered at follow-up, the predictive value of stigma and concealment on functional impairment was measured using pain interference only.

CHAPTER 2

METHOD

Part I: Development of the Health-Related Stigma and Concealment Questionnaire

(HR-SCQ)

Questionnaire Instructions

Questionnaire instructions were designed to decrease social desirability bias. Instructions stated: “There are no right or wrong answers. We just want to know what’s true for you”. In order to increase readability and decrease participant burden, physical symptoms associated with FAP (pain, bloating, gas, constipation, diarrhea) were presented only once (in list format) at the beginning of the questionnaire. Instructions indicated that the word “symptoms” in subsequent questions would refer to the symptoms in the list.

Item Generation

A review of the literature identified three published manuscripts reviewing measures of stigma (Brohan et al., 2010; Link et al., 2004; Stevelink, Wu, Voorend, & van Brakel, 2012). Each of the scales cited in these reviews was located. When scale authors cited another scale, an attempt was made to locate it. Items from all identified scales were then reviewed.

Anticipated stigma. Anticipated stigma was defined as “the degree to which an individual expects that others will stigmatize him/her if they know about the concealable stigmatized identity”. Items thought to reflect this construct were adapted from the Perceived

Stigma Scale (PSS-IBS; validated with adults with IBS; M. P. Jones et al., 2009), the Child Stigma Scale (validated with children with epilepsy; Austin et al., 2004), the Chronic Pain Stigma Scale (Reed, 2005), the Perceived Devaluation/ Discrimination scale (Link et al., 1997), the HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001), an untitled measure of “attributed” or anticipated stigma in individuals with HIV (Visser, Kershaw, Makin, & Forsyth, 2008), the Depression Self-Stigma Scale (Kanter et al., 2008), and the Substance Abuse Perceived Stigma Scale (Luoma et al., 2007). Qualitative data were also considered. For example, research suggests that accusations of malingering are salient aspects of anticipated stigma in chronic illness (e.g., (Austin et al., 2004; Tong, Jones, Craig, & Singh- Grewal, 2012). Thus, the item, “People would think I was faking it if I told them about my symptoms” was added. Additional items were constructed based on review of the literature, definition of anticipated stigma, and experience working with adolescents with FAP, resulting in an initial pool of 24 items.

Internalized stigma. Internalized stigma was defined as “the extent to which a stigmatized individual accepts society's negative evaluation and incorporates it into his or her own personal value system and sense of self”. Items thought to reflect this construct were adapted from the Child Stigma Scale (Austin et al., 2004), the Internalized Stigma of Mental Illness Scale (Ritsher et al., 2003), the Self-Stigma of Depression Scale (Barney, Griffiths, Christensen, & Jorm, 2010), the Child Attitude Toward Illness scale (Heimlich, Westbrook, Austin, Cramer, & Devinsky, 2000), the HIV Stigma Scale (Berger et al., 2001), a measure of internalized HIV stigma (Sayles et al., 2008), another measure of HIV-related stigma (Visser et al., 2008), the Weight Self-stigma Questionnaire (Lillis, Luoma, Levin, & Hayes, 2010), the Internalized Shame Scale of the Social Impact Scale (Fife & Wright, 2000), and the IBS-QOL

scale (Patrick, Drossman, & Frederick, 1998). Additional items were inspired by qualitative data (Drossman et al., 2009; Tong et al., 2012), resulting in an initial pool of 25 items.

Stigma concealment. Stigma concealment was defined as “behaviors of a stigmatized individual that are intended to keep his or her stigma secret”. Items representing this construct were adapted from a measure by Austin and colleagues (Austin et al., 2004), the PSS-IBS (M. P. Jones et al., 2009), (Kanter et al., 2008), the Withdrawal Scale (Link et al., 1997), the Secrecy Scale (Link et al., 1997), and the Internalized Shame Scale from the Social Impact Scale (Fife & Wright, 2000). One additional item thought to be relevant to adolescents (“I don’t want my parents to tell anyone about my symptoms”) was generated, resulting in an initial pool of 14 items.

Response Options

In order to increase participants’ familiarity with response options, we preferred to use the same options for all items. Thus, we aimed to select a set of response options that best reflected the range of experiences described in the pool of items. Included items described emotions (“I’m embarrassed about my symptoms”), behaviors (“I avoid telling others about my symptoms”) and cognitions (“most people would be supportive if I told them about my symptoms”). Three possible types of response options were identified: endorsement (i.e., the extent to which the respondent agrees with the statement), frequency (i.e., the frequency with which the respondent has had the indicated experience), and intensity (i.e., the intensity with which the respondent has had the indicated experience). It was thought that while the frequency response type would be appropriate for the emotion and behavior items, the intensity response type might be better suited for items reflecting cognitions. Thus, the endorsement option (“Please

tell us how much you agree or disagree with each of the following sentences”) was chosen because it was judged to be the option that could most sensibly be applied to all items.

Another consideration was whether to offer a neutral category for respondents who have no opinion on a particular item or to provide an additional level of gradation. Some researchers have argued that a neutral category should not be provided because participants may choose it instead of being more committal (Converse, 1976). In the current study, a neutral category was provided on the assumption that it often proves a valid response (Hays, Sherbourne, & Mazel, 1995).

The optimum number of response choices was also considered. While some researchers have argued that reliability is optimized by the use of seven categories, others have reported higher reliabilities for five-point scales, and still others propose that reliability is largely independent of the number of response categories provided (Preston & Colman, 2000). Thus, in order to increase participant’s familiarity with the response choices, it was decided that five response choices would be offered, as this was the number of options provided in other validated scales being completed by participants (and is the most common number of options provided in Likert scales; Krosnick & Presser, 2010; Likert, 1932).

Next, the order of response choices was considered. Empirical studies suggest that respondents are slightly more likely to endorse the first response item presented (Carp, 1974; Hays et al., 1994), and tend to agree with statements regardless of content (termed “agreement acquiescence”; Bentler & Eichberg, 1975). An attempt was made to offset the effects of these biases by pitting them against one another (i.e., listing “Strongly Disagree” as the first response choice).

Finally, research suggests that reliability increases (Krosnick & Berent, 1993) and respondents express greater satisfaction (Dickinson & Zellinger, 1980) when all scale points are verbally labeled. Response choices were therefore labeled with the following descriptors: “Strongly Disagree (1)”, “Disagree (2)”, “Neither Agree or Disagree (3)”, “Agree (4)”, and “Strongly Agree (5)”.

Expert Evaluation

Preliminary items thought to reflect anticipated stigma, internalized stigma, and concealment were merged and shuffled to create a list of 63 items for review by content experts. Reviewers were professionals from medical, psychology, and public health backgrounds with expertise in stigma or adolescents with FAP (Lynn S. Walker, PhD, a pediatric clinical psychologist and researcher; Craig Anne Heflinger, PhD, a adolescent mental health researcher with a focus in stigma; Laurie Keefer, PhD and Tiffany Taft, PhD, clinical psychologists with research experience related to stigma in adults with FGIDs; Julie Anderson, MD, a pediatric gastroenterologist). Reviewers were asked to 1) provide feedback on each item for its relevance to the construct of stigma as applied to adolescents with FAP, 2) evaluate the questionnaire instructions, response choices, and the readability of the items for adolescents aged 11 years and older, and 3) identify which construct (anticipated stigma, internalized stigma, or concealment) they believed each item to reflect. Reviewers were provided with the definitions of the constructs as defined above (see Item Generation). Items perceived as acceptable and sorted into the same construct category by all reviewers were selected for possible inclusion in the final questionnaire. Twenty-six items remained following expert evaluation and questionnaire revision.

Cognitive Interviewing

Cognitive interviewing was performed with four adolescents with FAP to evaluate remaining items for possible inclusion. Participants were two females and two males ages 13 to 18. A combination of the “Think-aloud” and “Verbal Probing” techniques, as detailed in the cognitive interviewing manual developed by Research Triangle Institute, was used (Willis, 2004). Participants were asked to respond to each item and to describe in as much detail as possible how they arrived at their answer. Participants also rated the degree of difficulty they experienced in responding to each item. Based on participant feedback, one item was added (“People would think I was exaggerating if I told them about my symptoms”) and one question was altered (“tease” was substituted for “make fun of”, resulting in the item “Some people would tease me if they knew about my symptoms”). Items perceived as redundant were eliminated after assessing participants’ phrasing preferences. Questions with low levels of endorsement (an average of ≤ 1.5 on a scale from 1-5) were also removed.

The readability of remaining items was assessed using the Flesch–Kincaid readability test (Kincaid, Fishburne, Rogers, & Chissom, 1975). The Flesch-Kincaid Grade Level was determined to be 5.1 (5th grade), which was judged as acceptable as it is below the 6th grade reading level required for participants to enter the study. Thus, no items were eliminated at this stage. The preliminary scales, constituting a total of 18 items, are presented in Table 2.

Table 2

Preliminary Stigma and Concealment Scales

Anticipated Stigma					
	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
People would think I was faking it if I told them about my symptoms.	1	2	3	4	5
Some people would tease me if they knew about my symptoms.	1	2	3	4	5
Most people would be supportive if I told them about my symptoms.	1	2	3	4	5
Most people would be uncomfortable around me if they knew about my symptoms.	1	2	3	4	5
People would avoid me if they knew about my symptoms.	1	2	3	4	5
People would think I was exaggerating if I told them about my symptoms.	1	2	3	4	5

Internalized Stigma					
	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
I feel different from other kids because of my symptoms.	1	2	3	4	5
I'm embarrassed about my symptoms.	1	2	3	4	5
I feel disgusting because of my symptoms.	1	2	3	4	5
I am a burden to others because of my symptoms.	1	2	3	4	5
My symptoms make me feel less attractive.	1	2	3	4	5
My symptoms have made me a stronger person.	1	2	3	4	5
I feel bad about myself because of my symptoms.	1	2	3	4	5

Concealment Behavior					
	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
I am careful who I tell about my symptoms.	1	2	3	4	5
I try not to let other people know when I'm having symptoms.	1	2	3	4	5
I avoid telling others about my symptoms.	1	2	3	4	5
I hide my symptoms from others.	1	2	3	4	5
I don't want my parents to tell anyone about my symptoms.	1	2	3	4	5

Note. The 18 items were scrambled and administered to all participants. Construct labels (anticipated stigma, internalized stigma, and concealment behavior) were not included. Questionnaire instructions were as follows: "For the following questions, 'symptoms' refers to abdominal (belly) symptoms including: abdominal pain, bloating or feeling gassy, constipation (not being able to go poop), diarrhea (when your poop is watery or when you have to hurry to the bathroom)."

Part II: Measure Validation and Model Testing

Participants

Data were collected as part of an RCT evaluating the efficacy of online CBT for adolescents with FAP. Recruitment took place through the Pediatric Gastroenterology Clinic at Monroe Carell Jr. Children's Hospital at Vanderbilt. Adolescent patients were eligible for participation if this was their first visit to the clinic, the primary reason for their appointment was abdominal pain, they were 11-17 years of age, reported abdominal pain of at least 2 months duration, had no history of chronic illness for which they had been hospitalized in the past six months, could read at the sixth grade reading level, had access to a computer with internet, and had no organic disease diagnosis from the referring physician that could account for the abdominal pain. Healthcare utilization was assessed via parent report.

Power analysis. A power analysis was conducted in G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) to determine the number of adolescent participants needed to have an 80% chance of detecting the weakest predicted relation between variables in the model. A review of the literature indicated that the strength of the correlations in the model (diagramed in Figure 2) range from $r = 0.27$ to $r = 0.63$, with a mean of $r = 0.45$. Power analyses revealed that an 80% chance of detecting the weakest relation in the model (between internalized stigma and physical symptoms) would require a sample of 81 adolescents. Allowing for 15% drop out over the course of online treatment, we aimed to recruit at least 93 adolescent participants.

Procedure

A member of the research staff approached adolescent patients and their parents who had agreed to hear more about the study in the clinic. Adolescents were informed that study surveys included questions about pain, mood, and activities, and that their parents and medical team

would not be able to see their answers. Informed consent from parents and informed assent from adolescents was obtained. Adolescents completed questionnaires on REDCap, a secure online survey site (Harris et al., 2009), during their clinic visit. The Vanderbilt Institutional Review Board approved all study procedures. After completion of baseline questionnaires, a computer-generated randomization protocol was used to randomize families to either the CBT or education control condition. Questionnaires were re-administered via REDCap following completion of the online pain management program an average of 12 weeks later.

Treatment conditions. Both pain management programs (CBT and education attention control) were comprised of 8 sessions. Participants were allowed up to 12 weeks to complete the protocol. All participants continued with the medical care recommended by their gastroenterologist during the treatment period. The average number of physician visits during the treatment period was two.

CBT condition. Following completion of baseline assessments, participants assigned to CBT were given access to the treatment content of the web program (Web-MAP; Web-based Management of Adolescent Pain). Web-MAP has been shown to be effective for reducing pain and activity limitations in adolescents with mixed chronic pain (Palermo et al., 2016; Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009). The program consists of two separate websites, one for adolescent access and one for parent access. Content was modified for the current study to be specific to abdominal pain. Adolescent modules were: (1) education about chronic pain, (2) recognizing stress and negative emotions, (3) deep breathing and relaxation, (4) school, (5) cognitive strategies, (6) lifestyle, (7) goal setting, activity pacing, and pleasant activity scheduling, and (8) relapse prevention. Parent modules included: (1) education about chronic pain, (2) recognizing stress and negative emotions, (3) operant strategies I, (4) operant

strategies II, (5) modeling, (6) lifestyle, (7) communication, and (8) relapse prevention. Children and parents interacted with the program by responding to queries (e.g., listing current stressors), which tailored subsequent assignments. The program included vignettes and videos of teens who had experienced chronic pain and their parents, as well as audio files with guided deep breathing, muscle relaxation, and guided imagery exercises. Homework was submitted weekly and reviewed by a Web-MAP online therapist. Online therapists were 4th, 5th, or 6th year clinical psychology doctoral student with experience delivering CBT. Therapists used a previously developed online coaches' manual to standardize their responses and were supervised by the developer of the intervention (a licensed clinical psychologist with experience in CBT for pediatric chronic pain management; Palermo et al., 2009).

Education condition. Following completion of baseline assessments, participants assigned to the education condition were given access to a version of the Web-MAP website that only contained publicly available education materials about FAP. Families in the education condition did not interact with an online therapist.

Measures. The following demographic variables were collected: age, sex, and race.

Health-related stigma. The preliminary 18-item Health-Related Stigma and Concealment Questionnaire (HR-SCQ) were administered to assess psychological constructs related to health-related stigma. Participants rated the extent to which they agreed with each statement on a scale from “Strongly Disagree” (1) to “Strongly Agree” (5). Reverse-scored items were reversed³ and items were averaged to create a total score. Higher scores reflect a greater degree of the

³ Following factor analysis, all reverse-scored items were deleted, such that this step is no longer necessary in the final version of the measure.

construct. EFA (described below) resulted in the elimination of four items. Alpha reliability was 0.93 for the nine-item felt stigma scale and 0.89 for the five-item stigma concealment scale.

Mental health. Symptoms of anxiety and depression were assessed via the Pediatric Promis Anxiety and Depression short forms (Pilkonis et al., 2011). These scales have been shown to have good psychometric properties (Varni et al., 2014). Each scale is comprised of eight items each and uses a seven-day recall period. The response scale ranges from “Never” (1) to “Almost Always” (5); responses are summed to create a total score. Alpha reliability in the current study was 0.95 for Promis Anxiety and 0.97 for Promis Depression. An additional, more comprehensive measure of depression (the Child Depression Inventory; CDI) was administered at baseline only. The CDI is comprised of 27 items indicating overt symptoms of depression. Support for the reliability and validity of the CDI has been demonstrated (Kovacs, 1992). Alpha reliability for the CDI in the current study was 0.92.

Pain cognitions: pain catastrophizing. Several types of cognitions related to pain were assessed. First, pain catastrophizing was assessed via two instruments – The Pain Catastrophizing Scale (PCS; Sullivan, Bishop, & Pivik, 1995), and the catastrophizing subscale of the Pain Response Inventory (PRI). The PCS asks respondents to reflect on past painful experiences and to indicate the degree to which they experience each of 13 thoughts or feelings when experiencing pain. Items represent three components of catastrophic thinking: rumination (e.g., “I keep thinking about how much it hurts”), magnification (e.g., “I wonder whether something serious may happen”), and helplessness (e.g., “There is nothing I can do to stop the pain”). Response options range from “Not at All” (0) to “All the Time” (4). The PCS has been shown to have good internal consistency (Sullivan et al., 1995). Alpha reliability for the PCS in the current study was 0.95. The catastrophizing subscale of the PRI is comprised of 5 items (L.

Walker, Smith, CA, Garber, J, Van Slyke, DA., 1997). The stem for each item is, “When you have a bad stomach ache, how often do you...” (e.g., “think to yourself that it’s going to get worse”). Response options range from “Never” (0) to “Always” (4). Items are averaged to create a total score. Alpha reliability for the catastrophizing subscale of the PRI in the current study was 0.90.

Pain cognitions: pain threat. Second, adolescents’ pain appraisals (Lazarus & Folkman, 1984; C. A. Smith & Lazarus, 1990) were assessed via the Pain Beliefs Questionnaire (PBQ; Walker et al., 2005). For each item, respondents indicate how true the statement is using a scale ranging from “Not at all true” (0) to “Very true” (4). The Primary Appraisal (“pain threat”) subscale (20 items) assesses the degree to which pain is perceived as threatening to one’s well-being (e.g., “My stomach aches mean I have a serious illness”). Items are averaged to create a total score. Reliability of the PBQ to treatment has been documented (Anderson, Acra, Bruehl, & Walker, 2008; Langer et al., 2007; Levy et al., 2010; Lipsitz, Gur, Albano, & Sherman, 2011; Walker, Baber, Garber, & Smith, 2008; Walker, Smith, Garber, & Claar, 2005). In the current study, alpha reliability of the pain threat subscale of the PBQ was 0.84.

Pain cognitions: pain coping self-efficacy. The PBQ was also used to assess pain coping self-efficacy. Six items assess problem-focused pain coping self-efficacy (henceforth referred to as “problem-focused self-efficacy”), which refers to the individual’s perceived ability to do something to reduce pain (e.g., “When I have a bad stomach ache, there are ways I can get it to stop”). In the current study, alpha reliability of the 6-item problem-focused self-efficacy subscale was 0.86. Another six items of the PBQ assess emotion-focused pain coping self-efficacy (henceforth referred to as “emotion-focused self-efficacy”), which refers to the individual’s perceived ability to accept and adjust pain (e.g., “I know I can handle it no matter how bad my

stomach hurts”). In the current study, alpha reliability of the emotion-focused self-efficacy subscale was 0.82.

Physical symptoms. Three domains of physical symptoms known to be prevalent in adolescents with FAP were assessed: abdominal pain, nausea, and other somatic symptoms. Abdominal pain was assessed via the Abdominal Pain Index (API), a four-item measure of abdominal pain intensity, frequency, and duration (Laird, Sherman, Smith, & Walker, 2015). The recall period for the API is two weeks. Good concurrent, discriminant, and construct validity, as well as good internal consistency, has been demonstrated for the API in children and adolescents with FAP (Laird et al., 2015). Alpha reliability for the API in the current study was 0.76. Nausea was assessed via a four-item measure adapted from the API (the Nausea Severity Scale; NSS), using the same recall period and response choices. Alpha reliability for the NSS in the current study was 0.88. The 24-item Children’s Somatization Inventory (CSI-24; Walker, Beck, Garber, & Lambert, 2009) was administered to assess the severity of 24 somatic symptoms (e.g., headaches, low energy, dizziness, chest pain). Participants rate how much they were bothered by each symptom during the past two weeks using a five-point scale ranging from “Not at All” (0) to “A Whole Lot” (4). Subscale scores are computed for GI symptoms (eight items; e.g., abdominal pain, nausea, constipation, diarrhea, bloating) and non-GI symptoms (16 items; e.g., dizziness, back pain, headaches, sore muscles) by averaging the relevant items for each subscale. Both the GI and non-GI subscales have been demonstrated to have good internal consistency (Walker, Sherman, Bruehl, Garber, & Smith, 2012). Alpha reliabilities for GI and non-GI somatic symptoms in the current study were 0.75 and 0.91, respectively. The Rome III (Drossman, 2006) was administered to determine whether adolescents met symptom diagnostic criteria for IBS and functional dyspepsia.

Functional Impairment. The Functional Disability Inventory (FDI; Walker & Greene, 1991) assesses difficulty in physical and psychosocial functioning due to physical health during the last two weeks. Each item describes one activity (e.g., “walking up stairs”, “doing something with a friend”, “being at school all day”). Participants in the current study completed the 10-item short form of the FDI, which was administered at baseline only. Participants respond to items on a scale from 0 (indicating “No trouble” with the given activity) to 4 (indicating the activity was “Impossible”). Items are averaged to create a total score. The FDI has high internal consistency and reliability in adolescents with FAP (Claar & Walker, 2006). Alpha reliability for the FDI in the current study was 0.87. The effect of pain on relevant aspects of participants’ lives was further assessed via the 13-item Pediatric Promis Pain Interference Scale (Amtmann et al., 2010). The scale measures the extent to which pain hinders engagement with social, cognitive, physical, and recreational activities, affects emotional wellbeing, impacts sleep, and reduces enjoyment of life. The response scale ranges from “Never” (1) to “Almost Always” (5) and uses a seven-day recall period. Responses are summed to create a total score. The scale has been shown to have good psychometric properties (Varni et al., 2014). Alpha reliability in the current study was 0.91.

Healthcare utilization. Parents reported on their child’s healthcare utilization over the past three months. Number of medical appointments (visits to a clinic to see a medical doctor, nurse practitioner, or physicians assistant) and mental health appointments (visits to a mental health provider such as a social worker, psychologist or psychiatrist) were reported separately. Possible responses for healthcare utilization were: “0”, “1”, “2”, “3”, “4”, “5”, or “6 or more”. Thus, these two variables were assessed on an ordinal and not a variable scale.

Data Analysis

All analyses were conducted using IBM SPSS version 24.0. Because the HR-SCQ was added to the survey protocol after the larger RCT was already underway, 28 of the 153 participants completed the HR-SCQ only once, after completion of the 8-session online program (CBT or education control). Data from the full sample of 153 participants were used for EFA and for assessment of internal consistency (125 of whom completed the HR-SCQ at baseline; 28 of whom completed the HR-SCQ post-treatment). All other analyses were conducted using only the sample of participants who completed the HR-SCQ at both time points (N=125). Effect size magnitude was interpreted by applying Cohen's (1977) guidelines; *ds* of 0.2-0.3, 0.5, and 0.8 were interpreted as small, medium, and large effects, respectively.

EFA was conducted to determine whether each of the three preliminary scales (anticipated stigma, internalized stigma, and concealment) assessed a discrete construct in our sample of adolescents with FAP. First, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity were used to determine whether there was sufficient sampling adequacy for factor analysis. The assumption of a linear relationship between all variables was investigated. Items whose deletion resulted in increased alpha reliability were removed.

Internal consistency. Internal consistency was evaluated for all study measures. Internal consistency was considered adequate if Cronbach's alpha coefficient ≥ 0.7 .

Construct validity. Construct validity for the scales was considered adequate if each predicted relation was $r \geq 0.25$. This criterion was based on a literature review indicating that the weakest predicted relation (between internalized stigma and physical symptoms) was $r = 0.27$.

Model testing. Power calculations were designed to allow sufficient power to test the association of stigma constructs with measures of mental health, physical symptoms, and pain interference. As such, the sample was unlikely to be sufficient for structural equation modeling (to formally test the mediational model). Exploratory path analyses were conducted using the PROCESS macro in SPSS (Hayes, 2013) with 5000 bootstrapped samples following Preacher and Hayes (Preacher & Hayes, 2008). Confidence intervals that did not contain zero were interpreted as indicative of a significant indirect effect (mediation). Continuous predictors were mean-centered prior to analysis.

CHAPTER 3

RESULTS

Demographic Characteristics

The sample comprised 153 adolescents with FAP between the ages of 11 and 17. Demographic characteristics of the sample are presented in Table 3. The average age of participants at baseline was 13.88 (SD=1.83). The majority of participants were White (84.31%) and female (64.71%). A minority of participants were African American (7.84%), Native American or Alaska Native (1.31%), multiracial/ other (4.58%), or did not report their race (1.96%). Seventy-four participants (48.37%) endorsed chronic pain in at least one of five common non-abdominal chronic pain sites (head, back, arm, leg, and joint), and 12 participants (7.84%) endorsed chronic widespread pain. Ninety adolescent participants (58.82%) met symptom-based criteria for IBS, twenty-two (14.38%) met criteria for functional dyspepsia, five (3.27%) met criteria for both IBS and functional dyspepsia, and thirty-six (23.53%) met criteria for neither IBS nor functional dyspepsia.

Table 3*Sample Characteristics*

	M(SD)/ N(%)
Age	13.88 (1.83%)
Gender	
Male	54 (35.29%)
Female	99 (64.71%)
Race	
White	129 (84.31%)
African American	12 (7.84%)
Native American or Alaskan Native	2 (1.31%)
Multiracial/ Other	7 (4.58%)
Declined to Report	3 (1.96%)
Other Chronic Pain	
Non-abdominal Chronic Pain	74 (48.37%)
Chronic Widespread Pain	12 (7.84%)
No Other Chronic Pain	67 (43.79%)
FGID Diagnosis	
IBS	90 (58.82%)
Functional Dyspepsia	22 (14.38%)
IBS and Functional Dyspepsia	5 (3.27%)
Neither IBS nor Functional Dyspepsia	36 (23.53%)

Note. Total sample N=153.

Healthcare Utilization

The most common number of medical appointments in the three-month period was two (29% of the sample; see Figure 3). Twenty-three percent endorsed fewer than two visits and 48% endorsed more than two visits over the past three months. The most common number of appointments to a mental healthcare provide was zero; eighty-three percent of the sample denied visiting a mental healthcare provider in the past three months (see Figure 4).

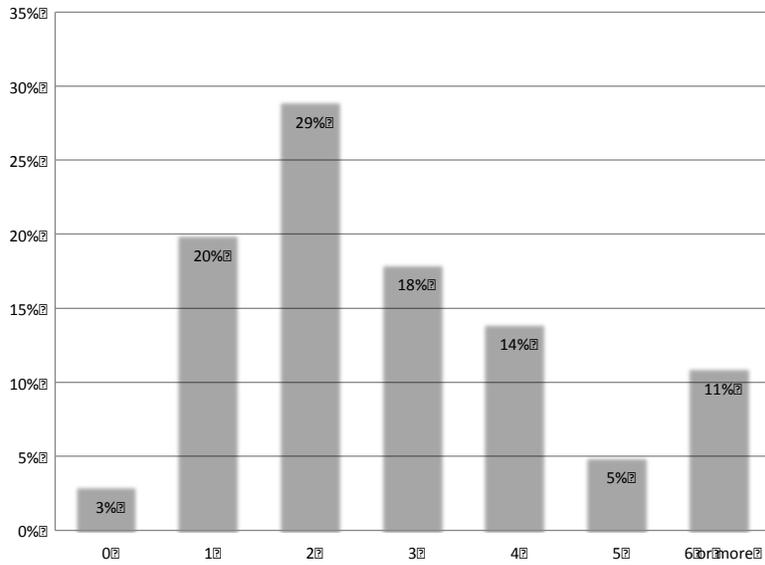


Figure 3. Number of medical appointments attended over three months.

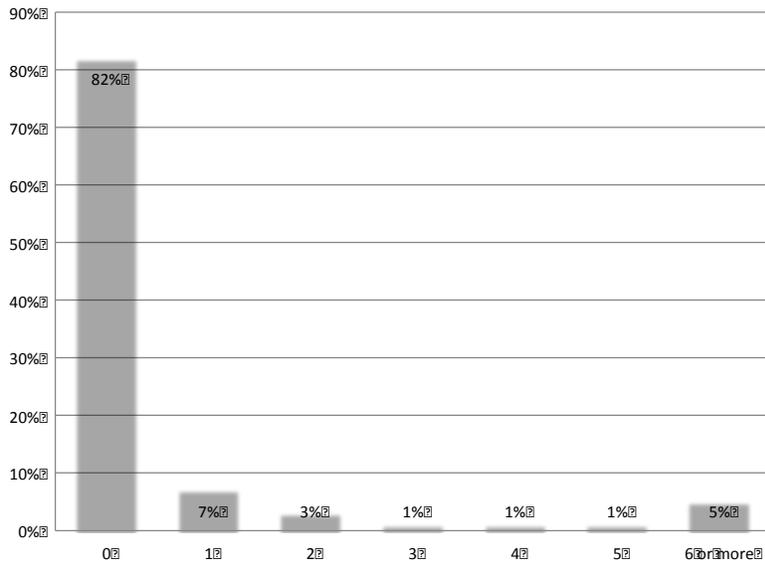


Figure 4. Number of mental health appointments attended over three months.

Aim 1: Measure Validation

Aim 1a: Investigate the Factor Structure of the HR-SCQ

EFA was conducted to determine whether each of the three preliminary scales (anticipated stigma, internalized stigma, and concealment), assesses a discrete construct in the sample of adolescents with FAP. In order for a dataset to be suitable for factor analysis, two assumptions must be met. First, the sample size must be sufficient. Tinsley and Tinsley (Tinsley & Tinsley, 1987) recommend a ratio of at least 5 participants per item (90 participants for a 18-item scale). By this criterion, the assumption of sampling adequacy was satisfied, as 153 participants completed the measure. Adequacy of the sample size was further investigated using the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy. The KMO tests for linear relationships between variables, with higher numbers indicating greater linearity. Values above 0.6 are suggested as the minimum requirement for sampling adequacy, and values above 0.8 are considered good (Kaiser, 1974). The overall KMO of the preliminary HR-SCQ was 0.92, interpreted as “marvelous” according to Kaiser’s (1974) classification of measure values. Additionally, Bartlett’s test of sphericity was used to determine whether there was sampling adequacy for each individual variable. This analysis tests the null hypothesis that there are no correlations between any variables. Results were statistically significant ($df=120$, $\chi^2 = 1766.60$, $p<0.001$), indicating rejection of the null hypothesis. No communalities lower than 0.50 were identified. Thus, multiple methods indicated adequate sample size.

The second, related, assumption that is required to be met in order for data to be suitable for factor analysis is that there is a linear relationship between all variables. This assumption was tested using a correlation matrix. A cut point of $r < 0.3$ was used to identify low correlations.

One item (“My symptoms have made me a stronger person”; reverse scored) was found to have low or negative correlations with all other variables. This indicated that, in contrast to expectations, individuals expressing stronger endorsement of this statement tended to endorse *greater* stigma and concealment as indicated by the remaining items. This item was therefore removed. Another item (“Most people would be supportive if I told them about my symptoms”) had low correlations with the majority of the remaining items ($r < 0.3$ for 13 of the remaining 16 items). Cronbach’s alpha was slightly higher (0.95 rather than 0.94) with the removal of this item; thus, this item was removed. No other items were negatively correlated with any other items and no other item’s deletion resulted in increased alpha reliability. Thus, the assumption of a linear relationship between all variables was met, with 16 of the original 18 items maintained.

A scree plot failed to identify a distinct elbow (Cattell, 1966; Figure 3). A principal component analysis revealed three factors with eigenvalues greater than one. An eigenvalue of less than one indicates that a factor explains less variance than an individual variable; thus, it is generally thought that only factors with eigenvalues greater than one should be maintained (Kaiser, 1960). The percentage of variance explained by each factor was also investigated. Each of the three factors with eigenvalues greater than one explained at least 5% of the total variance, and a three-factor solution explained 70.41% of the total variance.

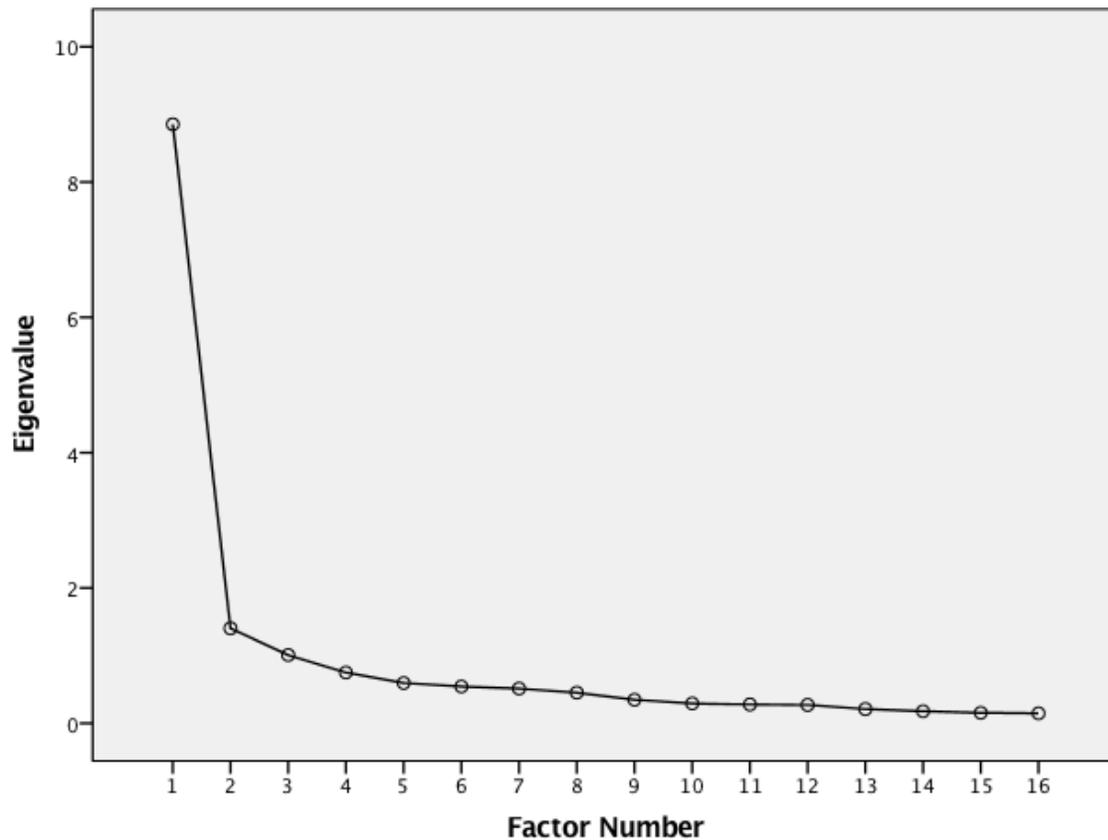


Figure 5. Scree plot.

The direct oblimin rotation method was used because a correlation between these three factors was expected. The factor correlation matrix confirmed that all three factors were correlated with one another at an $r < 0.4$, confirming a non-orthogonal relationship. Thus, a promax rotation method was used. The resulting pattern matrix (Table 4) identified a first factor including all items from the preliminary internalized stigma scale and the majority of the items from the preliminary anticipated stigma scale. A second factor comprised all of the concealment items, and a third factor comprised the two anticipated stigma items related to malingering. Thus, the pattern matrix did not support the hypothesis that anticipated stigma and internalized stigma would emerge as discrete constructs. The two malingering items were thus deleted and the EFA re-run.

Table 4

Initial Pattern Matrix Results From Exploratory Factor Analysis

	Factor 1	Factor 2	Factor 3
I feel disgusting because of my symptoms. (Internalized)	0.98		
I feel bad about myself because of my symptoms. (Internalized)	0.87		
My symptoms make me feel less attractive. (Internalized)	0.84		
Some people would tease me if they knew about my symptoms. (Anticipated)	0.75		
I am a burden to others because of my symptoms. (Internalized)	0.69		
Most people would be uncomfortable around me if they knew about my symptoms. (Anticipated)	0.68		
I feel different from other kids because of my symptoms. (Internalized)	0.58		
People would avoid me if they knew about my symptoms. (Anticipated)	0.57		
I'm embarrassed about my symptoms. (Internalized)	0.57		
I hide my symptoms from others. (Concealment)		0.90	
I avoid telling others about my symptoms. (Concealment)		0.88	
I try not to let other people know when I'm having symptoms. (Concealment)		0.75	
I am careful who I tell about my symptoms. (Concealment)		0.70	
I don't want my parents to tell anyone about my symptoms. (Concealment)		0.64	
People would think I was faking it if I told them about my symptoms. (Anticipated)			1.03
People would think I was exaggerating if I told them about my symptoms. (Anticipated)			0.66

Note. Extraction method was principal axis factoring and rotation method was promax with Kaiser normalization. A rotation converged in 5 iterations.

The resulting pattern matrix is depicted in Table 5. The results demonstrated a two-factor solution; factor one comprised the nine remaining (anticipated and internalized) stigma items and factor two comprised the five concealment items. The two-factor solution explained 67.12% of the total variance. Again, the EFA suggested that internalized stigma and anticipated stigma are so closely related that they do not present as discrete constructs in the current sample. This result

supports Brohan’s definition of “felt stigma”, and this term will henceforth be used to refer to the combined (internalized plus anticipated) stigma construct identified through EFA. The two identified factors, felt stigma and stigma concealment, were significantly correlated with one another ($r = 0.70$). Thus, the pattern matrix supported the hypothesis that concealment behavior is a discrete construct that is separate, but related to, stigma-related cognitions and emotions.

Table 5

Final Pattern Matrix

	Factor 1: Felt Stigma	Factor 2: Concealment
I feel disgusting because of my symptoms. (Internalized)	0.91	
I feel bad about myself because of my symptoms. (Internalized)	0.88	
My symptoms make me feel less attractive. (Internalized)	0.85	
Some people would tease me if they knew about my symptoms. (Anticipated)	0.74	
I am a burden to others because of my symptoms. (Internalized)	0.73	
People would avoid me if they knew about my symptoms. (Anticipated)	0.67	
Most people would be uncomfortable around me if they knew about my symptoms. (Anticipated)	0.67	
I feel different from other kids because of my symptoms. (Internalized)	0.65	
I'm embarrassed about my symptoms. (Internalized)	0.55	
I hide my symptoms from others. (Concealment)		0.90
I avoid telling others about my symptoms. (Concealment)		0.85
I try not to let other people know when I'm having symptoms. (Concealment)		0.74
I am careful who I tell about my symptoms. (Concealment)		0.73
I don't want my parents to tell anyone about my symptoms. (Concealment)		0.64

Note. Extraction method was principal axis factoring and rotation method was promax with Kaiser normalization. A rotation converged in 3 iterations.

Aim 1b: Investigate the Internal Consistency of the Revised HR-SCQ

The internal consistency of the revised two-factor HR-SCQ was evaluated using Cronbach's alpha. Cronbach's alpha for the nine-item felt stigma scale was 0.93. No item was identified that would result in higher alpha if removed. Cronbach's alpha for the five-item stigma concealment scale was 0.89. No item was identified that would result in higher alpha if removed.

Aim 1c: Describe Relations Between the Stigma Constructs and Other Variables

Demographic variables. Participant age was significantly correlated with felt stigma, such that older age was associated with greater felt stigma ($r = 0.18, p = 0.023$). Age was not significantly associated with stigma concealment ($r = 0.13, p = 0.099$). There were no significant sex differences in self-reports of felt stigma ($F[1,151] = 0.17, p = 0.07$) or stigma concealment ($F[1,151] = 1.51, p = 0.133$). There was insufficient racial diversity in the sample to test for possible racial differences in felt stigma or concealment. Baseline means and standard deviations on the HR-SCQ by age are presented in Table 6.

Table 6***Baseline Felt Stigma and Concealment Scores by Age***

Felt Stigma					
Age	Mean	SD	Range	10%	90%
11	2.36	1.11	1.11-4.44	0.93	3.78
12	2.00	0.99	1.00-4.78	0.73	3.27
13	1.96	0.85	1.00-4.11	0.88	3.05
14	2.56	1.07	1.00-5.00	1.19	3.93
15	2.52	1.31	1.00-4.67	0.84	4.20
16	2.54	1.22	1.00-5.00	0.98	4.10
17	2.51	0.86	1.00-3.67	1.41	3.62

Concealment					
Age	Mean	SD	Range	10%	90%
11	3.10	1.19	1.00-5.00	1.58	4.62
12	2.71	1.14	1.00-5.00	1.26	4.16
13	2.61	1.20	1.00-4.80	1.08	4.15
14	2.94	1.01	1.00-5.00	1.65	4.23
15	3.08	0.94	1.60-4.80	1.88	4.28
16	3.01	1.12	1.00-5.00	1.57	4.44
17	3.38	1.18	1.00-5.00	1.88	4.89

Type of FAP. Felt stigma was significantly higher among participants who met Rome III criteria for IBS ($M = 2.59$, $SD = 1.07$) than among those who did not ($M = 1.93$, $SD = 0.99$; $F[1,151]=0.50$, $p < 0.001$). Cohen's d , indicating the difference between these two means in standard deviation units, was 0.64 (a medium-sized effect, according to Cohen's guidelines; Cohen, 1977). Similarly, stigma concealment was significantly higher among participants with IBS ($M = 3.18$, $SD = 1.03$) than among those without ($M = 2.55$, $SD = 1.14$; $F[1,151] = 2.38$, $p < 0.001$). Cohen's d , indicating the difference between these two means in standard deviation units,

was 0.58 (a medium-sized effect). There were no significant differences in stigma or concealment between participants according to functional dyspepsia diagnosis.

Aim 1d: Evaluate Construct Validity

Construct validity of the HR-SCQ was evaluated by examining the correlation of the felt stigma and stigma concealment scales with related constructs. Observed Pearson correlations among all variables hypothesized to correlate with the HR-SCQ are reported in Table 7. In addition, two exploratory analyses investigating the possible relation between the HR-SCQ and healthcare utilization (medical visits and mental health visits) are included in the table. All predicted relations were statistically significant for felt stigma (small to medium effect sizes). Hypothesized relations were also statistically significant for concealment (small to medium effect sizes), with three exceptions; stigma concealment was not significantly related to self-efficacy, nausea or non-GI somatic symptoms. With regard to exploratory analyses, neither felt stigma nor stigma concealment was significantly associated with number of medical visits. Felt stigma was positively associated with mental health service utilization ($r = 0.23$, $p < 0.05$; small effect size).

Table 7

Descriptive Statistics, Reliability Coefficients and Observed Pearson Correlations Among All Variables

	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7	7	8	9	10	11	12	13	14	15	16	17
1. Felt Stigma	2.32	1.08	(0.93)																	
2. Stigma Concealment	2.92	1.11	0.69**	(0.89)																
3. Anxiety (Promis)	15.32	11.42	0.51**	0.23**	(0.95)															
4. Depression (Promis)	10.51	11.65	0.51**	0.22*	0.80**	(0.97)														
5. Depression (CDI)	1.03	0.75	0.49**	0.25**	0.76**	0.85**	(0.92)													
6. Pain Catastrophizing (PCS)	22.51	13.75	0.48**	0.27**	0.74**	0.60**	0.61**	(0.95)												
7. Pain Catastrophizing (PRI)	1.69	1.13	0.50**	0.26**	0.73**	0.61**	0.63**	0.89**	(0.90)											
8. Pain Threat (PBQ)	1.78	0.98	0.43**	0.35**	0.52**	0.46**	0.49**	0.73**	0.83**	(0.84)										
9. Problem-Focused SE	1.61	0.96	-0.20*	-0.15	-0.31**	-0.31**	-0.37**	-0.55**	-0.54**	-0.61**	(0.86)									
10. Emotion-Focused SE	2.40	0.95	-0.42**	-0.16	-0.58**	-0.57**	-0.58**	-0.77**	-0.72**	-0.64**	0.53**	(0.82)								
11. Abdominal Pain (API)	2.25	0.89	0.32**	0.22*	0.33**	0.27**	0.32**	0.48**	0.48**	0.65**	-0.45**	-0.36**	(0.76)							
12. Nausea (NSS)	1.60	1.16	0.19*	0.12	0.29**	0.24**	0.24**	0.37**	0.36**	0.42**	-0.30**	-0.18*	0.45**	(0.88)						
13. GI Symptoms (CSI)	1.48	0.73	0.33**	0.24**	0.35**	0.31**	0.32**	0.43**	0.50**	0.57**	-0.37**	-0.25**	0.49**	0.65**	(0.75)					
14. Non-GI Symptoms (CSI)	0.97	0.71	0.35**	0.17	0.53**	0.50**	0.54**	0.43**	0.47**	0.44**	-0.28**	-0.30**	0.43**	0.45**	0.58**	(0.91)				
15. Pain Interference	23.07	14.55	0.49**	0.29**	0.73**	0.62**	0.66**	0.70**	0.63**	0.67**	-0.40**	-0.57**	0.53**	0.43**	0.55**	0.65**	(0.91)			
16. Functional Disability	1.05	0.73	0.32**	0.24**	0.49**	0.41**	0.48**	0.52**	0.50**	0.56**	-0.29**	-0.46**	0.51**	0.46**	0.58**	0.58**	0.77**	(0.87)		
17. Medical Visits	2.00	n/a	-0.11	-0.10	0.04	-0.03	-0.04	0.04	0.00	0.09	-0.07	-0.03	0.15	0.23**	0.06	0.10	0.09	0.10	(n/a)	
18. Mental Health Visits	0.00	n/a	0.23*	0.08	0.22**	0.27**	0.22**	0.19*	0.22**	0.18*	-0.09	-0.17*	0.20*	0.10	0.13	0.13	0.22**	0.14	0.11	(n/a)

Note. SE = Self-efficacy. Reliability coefficients (Cronbach's alpha) are listed in the diagonal. ** Correlation is significant at the 0.01 level (two-tailed). * Correlation is significant at the 0.05 level (two-tailed). Healthcare utilization (number of medical visits and mental health visits over 3 months) were measured on an ordinal scale and therefore modes are presented in lieu of means.

Aim 2: Explore the Mechanisms by Which Stigma May Affect Outcomes

EFA results suggested that internalized stigma and perceived stigma are so closely related that they do not present as discrete constructs in the sample. With this in mind, the hypothesized model was revised such that anticipated and internalized stigma are now represented as one construct (“felt” stigma; Figure 4). The amended model posits that concealment mediates the relation between felt stigma and health-related measures (physical symptoms and functional impairment). Concealment was not expected to mediate the effect of felt stigma on mental health symptoms because of theory and research indicating an especially strong relation between internalized stigma and mental health (Link et al., 1989; Link & Phelan, 2001; Drapalski et al., 2014; Waugh, Byrne, & Nicholas, 2014; Link et al., 1997). Exploratory path analyses were conducted using the PROCESS macro.

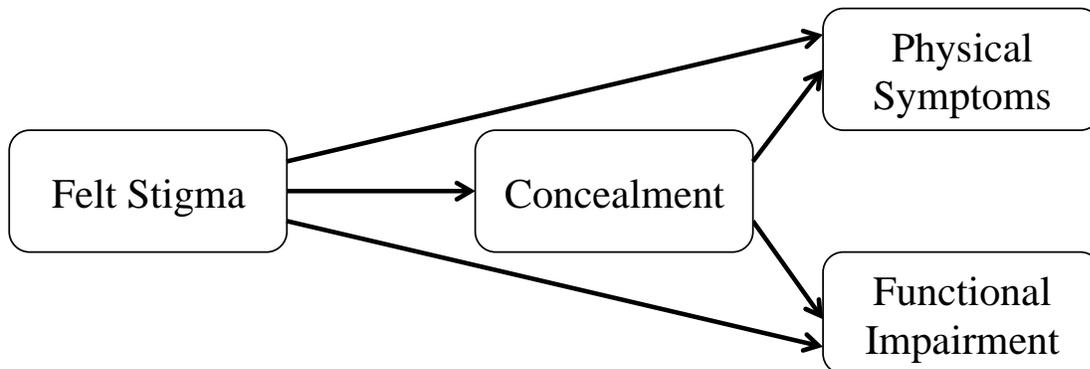


Figure 6. Revised model. Concealment as a pathway for the relation between felt stigma and poor outcomes in adolescents with FAP.

Physical Symptoms

We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on abdominal pain (revised hypothesis 3). The

direct effect of felt stigma on abdominal pain was $b = 0.27$ (SE = 0.10). This effect was significantly different from zero, $t(124) = 2.77$, $p = 0.007$. The indirect effect of felt stigma on abdominal pain via concealment was $b = 0.02$ (Boot SE = 0.06). This effect was not significantly different from zero (95% CI = -0.11 - 0.14). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on GI symptoms (revised hypothesis 4). The direct effect of felt stigma on GI symptoms was $b = 0.21$ (SE = 0.08). This effect was significantly different from zero, $t(124) = 2.66$, $p = 0.009$. The indirect effect of felt stigma on GI symptoms via concealment was $b = 0.03$ (Boot SE = 0.05). This effect was not significantly different from zero (95% CI = -0.07 - 0.13). Thus, baseline data did not support the proposed model in which concealment mediates the effect of felt stigma on physical symptoms.

Functional Impairment

We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on functional disability (revised hypothesis 5). The direct effect of felt stigma on functional disability was $b = 0.20$ (SE = 0.08). This effect was significantly different from zero, $t(124) = 2.54$, $p = 0.012$. The indirect effect of felt stigma on functional disability via concealment was $b = 0.03$ (Boot SE = 0.06). This effect was not significantly different from zero (95% CI = -0.07 - 0.15). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on pain interference (revised hypothesis 6). The direct effect of felt stigma on pain interference was $b = 7.11$ (SE = 1.45). This effect was significantly different from zero, $t(124) = 4.92$, $p < 0.001$. The indirect effect of felt stigma on pain interference via concealment was $b = -0.14$ (Boot SE = 1.08). This effect was not significantly different from zero (95% CI = -2.34 - 1.88). Thus,

baseline data did not support the proposed model in which concealment mediates the effect of felt stigma on functional impairment.

Sensitivity Analyses

One possible explanation for the lack of significant indirect effects is that the predictor variable (felt stigma) included items thought to represent internalized stigma, a construct hypothesized to be more strongly correlated with outcomes than the original hypothesized predictor variable (anticipated stigma). To rule out this possibility, analyses were re-run using only the three “anticipated stigma” items in the predictor variable (Cronbach's alpha = 0.82). Results were similar to those using felt stigma as the predictor, with the exception that direct effects were no longer statistically significant for either measure of physical symptoms (see Supplementary Appendix A). No statistically significant indirect effects emerged for any outcome. This suggests that the conflation of anticipated stigma with internalized stigma does not account for the lack of significant indirect effects.

Another possible explanation for the lack of significant indirect effects is that there were insufficient degrees of felt stigma and stigma concealment in the current population, which may have limited our ability to detect indirect effects. In order to explore this possibility, analyses were re-run including data only from participants who met criteria for IBS (among whom the degree of felt stigma and stigma concealment was slightly higher). No statistically significant indirect effects emerged for any outcome, indicating that data were not consistent with our mediational model either in adolescents with FAP in general or with IBS in particular. See Supplementary Appendix B for details of these analyses.

Exploratory Analyses Using Internalized vs. Anticipated Stigma Items

Although EFA failed to support the differentiation of internalized vs. anticipated stigma, we thought it important to explore whether these two constructs were differentially related to mental health, as we had expected mental health symptoms to be more strongly correlated to internalized vs. anticipated stigma. Pearson correlations and confidence intervals for Pearson correlations are provided in Table 8.

Table 8

*Observed Pearson Correlations and 95% Confidence Intervals
Between Measures of Mental Health and Anticipated vs. Internalized
Stigma*

	Anticipated Stigma	Internalized Stigma
Anxiety (Promis)	0.35 (0.18-0.49)	0.55 (0.41-0.66)
Depression (Promis)	0.39 (0.23-0.53)	0.52 (0.38-0.64)
Depression (CDI)	0.41 (0.25-0.54)	0.49 (0.35-0.61)

Note. All correlations were significant at the 0.01 level (two-tailed).

As predicted from the pre-hoc model as well as the lack of differentiation of these constructs in the EFA, anticipated stigma and internalized stigma were highly correlated ($r = 0.78$). Cronbach's alphas were acceptable for these constructs (0.88 for the 6-item internalized stigma scale and 0.82 for the 3-item anticipated stigma scale). Results from the correlation matrix broadly supported study hypotheses; that is, correlations were consistently higher between mental health symptoms and internalized stigma vs. anticipated stigma. However, 95% confidence intervals were overlapping, suggesting that the possibility that these two scales measure the same construct cannot be ruled out. Because Cronbach's alphas were acceptable and correlations supported original study hypotheses, it was determined that these pre-hoc

(internalized stigma and anticipated stigma) scales would be used to explore whether data support our original model in which internalized stigma mediates the effect of perceived stigma on health-related outcomes.

Exploratory Analysis 1: Internalized stigma as a mediator of the effect of anticipated stigma on mental health. We hypothesized that baseline data would be consistent with a model in which internalized stigma mediates the effect of anticipated stigma on anxiety (hypothesis 7). The direct effect of anticipated stigma on anxiety was -2.16 (SE = 1.34). This effect was not significantly different from zero, $t(124) = -1.62$, $p = 0.109$. The indirect effect of anticipated stigma on anxiety via internalized stigma was 6.07 (Boot SE = 1.03). This effect was significantly different from zero (95% CI = 4.16 - 8.21). We hypothesized that baseline data would be consistent with a model in which internalized stigma mediates the effect of anticipated stigma on depression (hypothesis 8). First, this hypothesis was tested using the Promis depression measure. The direct effect of stigma on Promis depressive symptoms was -0.31 (SE = 1.35). This effect was not significantly different from zero, $t(124) = -0.23$, $p = 0.819$. The indirect effect of anticipated stigma on depression via internalized stigma was 4.63 (Boot SE = 1.11). This effect was significantly different from zero (95% CI = 2.59 - 7.02). Second, this hypothesis was tested using the CDI. The direct effect of anticipated stigma on CDI score was 0.05 (SE = 0.09). This effect was not significantly different from zero, $t(124) = 0.54$, $p = 0.592$. The indirect effect of anticipated stigma on CDI score via internalized stigma was 0.23 (Boot SE = 0.07). This effect was significantly different from zero (95% CI = 0.12 - 0.38). Thus, baseline data were consistent with the hypothesized model in which internalized stigma significantly mediates the effect of anticipated stigma on mental health symptoms (anxiety and both measures of depression).

Exploratory Analysis 2: Internalized stigma as a mediator of the effect of anticipated stigma on physical symptoms. We hypothesized that baseline data would be consistent with a model in which internalized stigma mediates the effect of anticipated stigma on abdominal pain (hypothesis 9). The direct effect of anticipated stigma on abdominal pain was $b = -0.01$ (SE = 0.12). This effect was not significantly different from zero, $t(124) = -0.08$, $p = 0.934$. The indirect effect of anticipated stigma on abdominal pain via internalized stigma was $b = 0.24$ (Boot SE = 0.09). This effect was significantly different from zero (95% CI = 0.07 - 0.42). We hypothesized that baseline data would be consistent with a model in which internalized stigma mediates the effect of anticipated stigma on GI symptoms (hypothesis 10). The direct effect of anticipated stigma on GI symptoms was $b = 0.03$ (SE = 0.10). This effect was not significantly different from zero, $t(124) = 0.31$, $p = 0.756$. The indirect effect of anticipated stigma on GI symptoms via internalized stigma was $b = 0.17$ (Boot SE = 0.07). This effect was significantly different from zero (95% CI = 0.03 - 0.31). Thus, baseline data were consistent with the hypothesized model in which internalized stigma significantly mediates the effect of anticipated stigma on physical symptoms (abdominal pain and GI symptoms).

Exploratory Analysis 3: Internalized stigma as a mediator of the effect of anticipated stigma on functional impairment. We hypothesized that baseline data would be consistent with a model in which internalized stigma mediates the effect of anticipated stigma on functional disability (original hypothesis 11). The direct effect of anticipated stigma on functional disability was $b = 0.12$ (SE = 0.10). This effect was not significantly different from zero, $t(124) = 1.21$, $p = 0.230$. The indirect effect of anticipated stigma on functional disability via internalized stigma was $b = 0.10$ (Boot SE = 0.07). This effect was not significantly different from zero (95% CI = -0.03 - 0.26). We hypothesized that baseline data would be consistent with

a model in which internalized stigma mediates the effect of anticipated stigma on pain interference (original hypothesis 12). The direct effect of anticipated stigma on pain interference was $b = 0.21$ (SE = 1.79). This effect was not significantly different from zero, $t(124) = 0.12$, $p = 0.908$. The indirect effect of anticipated stigma on pain interference via internalized stigma was $b = 5.40$ (Boot SE = 1.34). This effect was significantly different from zero (95% CI = 2.89 – 8.22). Thus, baseline data partially supported the hypothesized model in which internalized stigma mediates the effect of anticipated stigma on functional impairment. Specifically, internalized stigma significantly mediated the effect of anticipated stigma on pain interference, but not on functional disability.

Exploratory Aims

Exploratory Aim 1: Explore the Degree of Psychological Stigma in Adolescents with FAP

We adopted the practice (Ritsher & Phelan, 2004; Waugh et al., 2014) of considering average total scores above the midpoint of the possible range as indicating endorsement of the stigma construct. This was an intuitive approach, as it identified individuals whose average response was in the range of “agree” or “strongly agree” with the scale items. By these criteria, 36 (24% of) participants endorsed felt stigma related to their FAP and 75 (49%) endorsed stigma concealment. Among 90 participants who met criteria for IBS, 26 (29%) endorsed felt stigma related to their FAP and 53 (59%) endorsed stigma concealment.

Exploratory Aim 2: Investigate the Stability of Stigma Constructs Over Time

Baseline felt stigma was significantly correlated with post-treatment felt stigma ($r = 0.50$, $p < 0.001$, $N = 72$). Baseline stigma concealment was also significantly correlated with post-treatment stigma concealment ($r = 0.34$, $p = 0.003$, $N = 72$). Analysis of variance (ANOVA)

revealed no main effect of time (baseline vs. post-treatment; $F[1,70] = 1.17, p = 0.284$) and no significant group (CBT vs. education) X time interaction on felt stigma scores ($F[1,70] = 2.36, p = 0.129$). Although mean felt stigma score decreased roughly a third of a standard deviation from baseline ($M = 2.25, SD=0.95$) to post-treatment ($M = 1.96, SD=0.86$) in the CBT group, this effect was not statistically significant ($t(31) = 1.65, p = 0.109$). Mean felt stigma scores in the education group were virtually identical at baseline ($M = 2.22, SD=0.90$) and post-treatment ($M = 2.27, SD = 1.07; t(39) = -0.36, p = 0.719$). Similarly, ANOVA revealed no main effect of time ($F[1,70] = 1.04, p = 0.310$) and no significant group X time interaction on stigma concealment scores ($F[1,70] = 0.18, p = 0.678$). As was the case with felt stigma, a non-significant decrease in stigma concealment was observed from baseline ($M = 2.91, SD = 0.90$) to post-treatment ($M = 2.72, SD = 0.96; t(31) = 0.91, p=0.370$) among participants assigned to CBT. Stigma concealment was unchanged from baseline ($M = 2.97, SD = 1.00$) to post-treatment ($M = 2.89, SD = 1.07; t(39) = 0.48, p = 0.636$) in the education control group. Thus, both felt stigma and stigma concealment were fairly stable from pre-post treatment, regardless of group assignment. According to Cohen's criteria, the magnitude of pre-post correlation was medium for felt stigma and small-to-medium for stigma concealment.

Exploratory Aim 3: Investigate Predictive Validity of the HR-SCQ

We expected small-to-moderate prospective relations between baseline stigma constructs and measures of mental health, physical health, and pain interference at post-treatment follow-up. Hierarchical linear regressions were conducted in order to control for covariates (baseline scores on these measures). Prior to analyses, data were evaluated for the appropriateness of hierarchical linear regressions. Linear relationships between independent and dependent variables were confirmed via visual inspection of scatterplots. Independence of observations was

tested using the Durbin-Watson statistic. The Durbin-Watson statistic ranged from 1.57 to 2.19, confirming independence of residuals. No major outliers were identified; all standardized residuals were below 3.05. There was homoscedasticity, as assessed by visual inspection of plots of standardized residuals versus standardized predicted values. Multicollinearity was investigated using the Tolerance Collinearity Statistic, where values less than 0.1 can indicate multicollinearity. No regression analysis produced a Tolerance value lower than 0.69, indicating that multicollinearity was not an issue. Residuals were normally distributed as assessed by visual inspection of normal probability plots. Regression analyses were initially run including group assignment as a covariate; however, group assignment did not significantly increase the predictive value of any model and was therefore omitted from the final model results described below.

Predictive validity of felt stigma on anxiety. We predicted that greater felt stigma at baseline would predict greater anxiety at follow-up, controlling for baseline anxiety. Hierarchical regressions revealed that baseline symptoms of anxiety significantly predicted follow-up anxiety ($F[1,69] = 50.72, p < 0.001, R^2_{\text{model1}} = 0.42$). The addition of baseline felt stigma to the model did not significantly increase the predictive power of the model ($F_{\text{change}}[1,68] = 3.50, p = 0.066; R^2_{\text{model2}} = 0.45$).

Predictive validity of felt stigma on depression. We predicted that greater felt stigma at baseline would predict greater depressive symptoms⁴ at follow-up, controlling for baseline depressive symptoms. Hierarchical regressions revealed that baseline depressive symptoms significantly predicted follow-up depressive symptoms ($F[1,69] = 66.05, p < 0.001, R^2_{\text{model1}} =$

⁴ As the CDI was administered at baseline only, analyses of the effect of stigma on depressive symptoms at follow-up were conducted using the Promis measure only.

0.49). The addition of baseline felt stigma to the model did not improve predictive power ($F_{\text{change}}[1,68] = 0.39, p = 0.536; R^2_{\text{model2}} = 0.49$).

Predictive validity of felt stigma on abdominal pain. We predicted that greater felt stigma at baseline would predict greater abdominal pain at follow-up, controlling for baseline abdominal pain. Hierarchical regressions revealed that baseline abdominal pain significantly predicted follow-up abdominal pain ($F[1,68] = 23.72, p < 0.001, R^2_{\text{model1}} = 0.26$). The addition of baseline felt stigma to the model did not improve predictive power ($F_{\text{change}}[1,67] = 1.47, p = 0.230; R^2_{\text{model2}} = 0.28$).

Predictive validity of felt stigma on GI symptoms. We predicted that greater felt stigma at baseline would predict greater GI symptoms at follow-up, controlling for baseline GI symptoms. Hierarchical regressions revealed that baseline GI symptoms significantly predicted follow-up GI symptoms ($F[1,70] = 26.77, p < 0.001, R^2_{\text{model1}} = 0.28$). The addition of baseline felt stigma to the model did not improve predictive power ($F_{\text{change}} [1,69] = 2.00, p = 0.162; R^2_{\text{model2}} = 0.30$).

Predictive validity of felt stigma on pain interference. We predicted that greater felt stigma at baseline would predict greater pain interference at follow-up, controlling for baseline pain interference. Hierarchical regressions revealed that baseline pain interference significantly predicted follow-up pain interference ($F[1,70] = 26.75, p < 0.001, R^2_{\text{model1}} = 0.28$). The addition of baseline felt stigma to the model did not improve predictive power ($F_{\text{change}}[1,69] = 2.22, p = 0.141; R^2_{\text{model2}} = 0.30$).

Predictive validity of stigma concealment on anxiety. We predicted that greater stigma concealment at baseline would predict greater anxiety at follow-up, controlling for baseline

anxiety. Hierarchical regressions revealed that baseline stigma concealment did not significantly predict anxiety at follow-up, after controlling for baseline anxiety (see model 1 results above for the predictive value of baseline anxiety to follow-up anxiety; $F_{\text{change}}[1,68] = 3.23, p = 0.08$; $R^2_{\text{model2}} = 0.45$).

Predictive validity of stigma concealment on depression. We predicted that greater stigma concealment at baseline would predict greater depressive symptoms at follow-up, controlling for baseline depressive symptoms. Hierarchical regressions revealed that baseline stigma concealment did not significantly predict depressive symptoms at follow-up, after controlling for baseline depressive symptoms (see model 1 results above; $F_{\text{change}}[1,68] < 0.01, p = 0.958$; $R^2_{\text{model2}} = 0.49$).

Predictive validity of stigma concealment on abdominal pain. We predicted that greater stigma concealment at baseline would predict greater abdominal pain at follow-up, controlling for baseline abdominal pain. Hierarchical regressions revealed that baseline stigma concealment did not significantly predict abdominal pain at follow-up, after controlling for baseline abdominal pain (see model 1 results above; $F_{\text{change}}[1,67] = 0.06, p = 0.804$; $R^2_{\text{model2}} = 0.26$).

Predictive validity of stigma concealment on GI symptoms. We predicted that greater stigma concealment at baseline would predict greater GI symptoms at follow-up, controlling for baseline GI symptoms. Hierarchical regressions revealed that baseline stigma concealment did not significantly predict severity of GI symptoms at follow-up, after controlling for baseline GI symptoms (see model 1 results above) ($F_{\text{change}}[1,69] = 0.05, p = 0.829$; $R^2_{\text{model2}} = 0.28$).

Predictive validity of stigma concealment on pain interference. We predicted that greater stigma concealment at baseline would predict greater pain interference at follow-up, controlling for baseline pain interference. Hierarchical regressions revealed that baseline stigma concealment did not significantly predict pain interference at follow-up, after controlling for baseline pain interference (see model 1 results above; $F_{\text{change}}[1,69] = 0.05$, $p = 0.820$; $R^2_{\text{model2}} = 0.28$).

In sum, the hypothesized prospective relations between baseline stigma constructs and measures of mental health, physical health, and pain interference at follow-up were not supported. Baseline values of health-related outcomes strongly predicted values at follow-up, accounting for 26-49% of the variance for all measures. Neither felt stigma nor stigma concealment significantly increased the power of baseline scores to predict follow-up scores on mental health, physical health, or pain interference. Sensitivity analyses were conducted to determine whether baseline internalized stigma significantly predicted health-related outcomes at follow up, as internalized stigma was hypothesized to correlate more strongly with health-related outcomes compared to anticipated stigma. Controlling for baseline anxiety symptoms, baseline internalized stigma significantly predicted anxiety symptoms at follow-up ($F_{\text{change}}[1,68] = 5.54$, $p = 0.021$; $R^2_{\text{model2}} = 0.47$). There was no significant effect for any other outcome assessed. Details of these analyses are reported in Supplementary Appendix C.

CHAPTER 4

DISCUSSION

An Overview

The current study had two aims. The first was to develop and validate a measure of psychological stigma constructs relevant to adolescents with FAP. A theory-driven approach was utilized to improve upon existing stigma measures and to clarify the psychological stigma facets relevant to this population. We constructed a measure designed to capture three stigma facets (anticipated stigma, internalized stigma, and concealment) hypothesized to affect health outcomes in adolescents with FAP. We used a rigorous approach, employing exploratory rather than confirmatory factor analysis to determine whether items hypothesized to represent these three constructs would independently emerge as distinct factors (DeVellis, 1991). Consistent with hypotheses, items thought to represent stigma concealment emerged as a distinct factor. Theory and prior research led us to hypothesize that concealment would be particularly distinct from other stigma facets. While other psychological facets of stigma represent internal processes (beliefs and emotions), concealment represents a behavioral response to those processes, and both adults and adolescents with chronic illness appear to more frequently endorse concealment compared to other psychological stigma constructs (M. P. Jones et al., 2009; Westbrook et al., 1992). EFA did not support the hypothesized differentiation between anticipated stigma and internalized stigma, suggesting the utility of the term “felt” stigma (comprising elements of both perceived and internalized stigma; Brohan et al., 2010) in the current sample. The revised two-factor Health-Related Stigma and Concealment Questionnaire had good internal consistency.

Predicted cross-sectional relations between felt stigma and measures of mental health, physical health, and functioning were confirmed, demonstrating good construct validity. With a few exceptions, all hypothesized relations were also statistically significant for stigma concealment. Stigma concealment was not significantly related to self-efficacy, nausea, or non-GI somatic symptom severity. The lack of significant relation between stigma concealment and measures of upper GI (nausea) and non-GI symptoms is somewhat consistent with study predictions (we had anticipated that stigma constructs would be most strongly associated with lower GI symptoms as these are the symptoms most likely to elicit disgust). Indeed, although relations between felt stigma and these two variables (nausea; non-GI symptoms) were statistically significant, they were small in magnitude. Also consistent with study hypotheses, both felt stigma and stigma concealment were significantly higher among participants who met symptom-based criteria for IBS compared to those who did not.

Exploratory analyses indicated that greater felt stigma was significantly associated with greater mental health service utilization. Although these data are cross-sectional and directionality cannot be determined, one interpretation of this finding is that individuals experiencing higher degrees of felt stigma are more likely to seek mental health services to address emotional distress related to FAP. Another possibility is that individuals receiving mental health services are more likely to have a mental health disorder that increases the perception and internalization of stigma. Consistent with either of these interpretations, both felt stigma and mental health service utilization were significantly associated with greater mental health symptom severity (anxiety and depression) as well as with maladaptive cognitions (catastrophizing, elevated pain threat).

Stigma concealment, by contrast, was not significantly related to mental health service utilization. At first glance, this may be surprising; stigma concealment, like felt stigma, was associated with mental health symptoms and maladaptive cognitions that would be expected to correlate with mental health treatment utilization. However, this result makes sense if one considers that the stigma concealment scale used in the current study does not specify *from whom* the participant conceals their FAP. Attempts to conceal one's FAP from *everyone*, including healthcare providers, would clearly be expected to *decrease* mental health treatment utilization.

Roughly a quarter of the participants in the present sample endorsed felt stigma related to their FAP and roughly half reported concealing their FAP from others. Rates among those who met criteria for IBS were slightly higher – 29% for felt stigma and 59% for stigma concealment. These findings parallel the results of a previous study conducted with adolescents with epilepsy (Westbrook et al., 1992). In that study, about a third of participants (31-40%) endorsed feeling stigmatized, yet almost twice that many (69-70%) reported concealing their epilepsy from others (Westbrook et al., 1992). Similar results were found in a study of 49 adults with IBS (M. P. Jones et al., 2009). Again, roughly a third of participants (31%) endorsed perceived stigma (i.e., believing that others think their IBS is “all in their head”) while roughly twice as many (63%) reported limited disclosure of their IBS (M. P. Jones et al., 2009). Although this pattern may seem counterintuitive (why would individuals conceal their stigma, if not because of anticipated rejection?), such behavior makes sense within a risk assessment framework. That is, survey participants may deny anticipating rejection from others if they estimate that the chances of such rejection are small. However, even a highly improbable event is expected to affect behavior if the consequences of such an event are sufficiently severe. That is, even an adolescent who

estimates that her peers would be unlikely to reject her due to learning of her FAP may still be expected to conceal her FAP if she anticipates that such rejection would be devastating. Another possibility is that adolescents are more able to accurately report on external (behavior) as compared to internal (cognitions and emotions) processes. This interpretation is consistent with the finding that while stigma concealment was similar across age groups, reports of felt stigma significantly increased with age. Meta-cognition, or the ability to think about one's own thoughts, has been shown to improve between the ages of 11 and 17 (Weil et al., 2013), and emotional awareness is a developmental process similar to that described by Piaget for cognition in general (Bajgar, Ciarrochi, Lane, & Deane, 2005). It is also possible that older adolescents in our sample genuinely perceive and internalize more FAP-related stigma compared to younger adolescents, but that they do not engage in greater stigma concealment for some other reason.

Although a two-factor solution was used for the majority of analyses in the current study, there may still be some value in distinguishing anticipated vs. internalized stigma. Support for their differentiation comes from a-priori theory and the stronger relation between mental health symptoms and internalized vs. anticipated stigma. Cronbach's alphas were acceptable for the six item internalized stigma scale and the three item anticipated stigma scale. Future researchers using the HR-SCQ may benefit from exploring both a two-factor and a three-factor scale, as the utility of these psychological stigma constructs is likely to vary by population and research question.

The second aim of the current study was to explore possible mechanisms by which stigma affects health-related outcomes in adolescents with FAP. Contrary to study hypotheses, baseline data did not support a model in which concealment mediates the effect of felt stigma on physical health and functioning. By contrast, inspection of a correlation matrix reveals that

health-related outcomes were more strongly associated with felt stigma than stigma concealment. Sensitivity analyses using only anticipated stigma items as the predictor variable also failed to produce significant indirect effects, suggesting that this null result is not due to the inclusion of internalized stigma items in the predictor (a construct expected to be more strongly related to outcomes compared to anticipated stigma). Another possible explanation for the lack of significant indirect effects is that stigma concealment is so infrequent in adolescents with FAP as to limit the predictive power of stigma concealment. Evidence against this hypothesis comes from the lack of significant mediation observed even among those participants with IBS (who reported higher rates of felt stigma and stigma concealment compared to the full sample). Research on adolescents with epilepsy (Westbrook et al., 1992) and adults with IBS (M. P. Jones et al., 2009) suggests that rates of concealment are similar in those populations. However, the current mediational model drew heavily from studies of adults with HIV. Rates of concealment may be significantly higher in that population. For example, in a study of 260 HIV seropositive adults in Nigeria, 95% stated that they had never disclosed their HIV status to a friend (Ebuenyi et al., 2014). In another study of Latina women with HIV, 75% reported never having disclosed their diagnosis to a friend (Comer, Henker, Kemeny, & Wyatt, 2000). In a study of 22 HIV seropositive pregnant women, 67% reported never having disclosed their HIV status to a friend (Lester, Partridge, Chesney, & Cooke, 1995). These rates of concealment are higher than those observed in the current study.

A third possible explanation for the lack of significant indirect effects is that adolescents may have less control over the extent to which their stigma is concealed compared to adults. Parents may reveal their child's diagnosis to teachers or parents of their child's friends, such that adolescents' effort to conceal their stigma may be ineffective. A fourth consideration is that the

response of the individual to whom the stigma is revealed profoundly impacts whether the disclosure is beneficial. Models highlighting the potential for stigma disclosure to elicit a “corrective emotional experience” (Alexander & French, 1946; Pachankis, 2007) and enhance well-being should also consider the adaptive role of concealment in hostile environments. Stigma disclosure does not always elicit a supportive response, and a growing literature indicates that the reaction of the confidant is perhaps the most important factor in predicting the effect of disclosure on the stigmatized individual (Chaudoir & Quinn, 2010). For example, in a longitudinal study of women with a history of first trimester abortion, women who disclosed their abortion to a close other and perceived that other as less than wholly supportive exhibited greater psychological distress compared to women who had not disclosed at all (Major et al., 1990). Results of experimental studies similarly suggest no benefit of disclosure when confidant reactions are negative or neutral (Lepore, Ragan, & Jones, 2000; Rodriguez & Kelly, 2006). This suggests that the proposed mediational relationship between anticipated stigma, stigma concealment, and positive health outcomes only holds true when the response of the confidant is supportive – a case of moderated mediation. It is possible that the individuals to whom adolescents with FAP disclose are, on average, less supportive than the individuals to whom adults with stigmatizing conditions such as HIV disclose. Alternatively, it may be that adolescents are less skilled than adults at predicting which individuals will be supportive. Either of these possibilities could account for the null findings in the current study.

A fifth possible explanation for the lack of significant indirect effects is that there is some other characteristic of adolescents with FAP that makes disclosure less beneficial compared to adults with stigmatizing conditions. The Disclosure Processes Model (DPM; Chaudoir & Fisher, 2010) posits that individual differences in the discloser (e.g., reasons for disclosing,

communication ability, and coping skills) each affect the response of the individual to whom the stigma is revealed. For example, “ecosystem” motivations for disclosure – motivations that reflect a relational concern for how the disclosure will affect both self and other – predict more positive responses to disclosure (Chaudoir & Quinn, 2010). Individual differences would also presumably affect the ability of the stigmatized individual to cope with responses that are less than fully supportive. In one study of 176 women with HIV from three major ethnic groups, ethnicity significantly moderated the effect of disclosure on mental health symptoms (Comer et al., 2000). Specifically, disclosure was unrelated to mental health outcomes in African American and Caucasian American women, but associated with higher levels of depressive symptoms and psychological distress in Hispanic American women. Alternatively, there may be characteristics of life-threatening, infectious stigmatizing conditions such as HIV that make concealment more directly detrimental to health outcomes than it is in FAP.

Yet another explanation for the lack of significant indirect effects is that the outcome measures utilized in the current study – particularly those used to assess functional impairment – may not be sufficiently sensitive to detect the adverse impact of concealment in adolescents with FAP. The finding that concealment did not significantly mediate the effect of anticipated stigma on functional impairment was especially surprising, as research suggests that attempts to conceal one’s stigma frequently result in the avoidance of situations that might lead to discovery and rejection (Pachankis, 2007). The pain interference scale used in the current study assesses the extent to which pain affects adolescents’ physical functioning (standing, walking, running), mood, sleep, concentration and schoolwork. These may not be the types of activities that are most strongly impacted by concealment of FAP. Although the FDI includes three items thought to be of particular relevance to adolescents with FAP (i.e., “being at school all day”; “doing

something with a friend”; “eating regular meals”), the remaining seven items focus on physical functioning and schoolwork. Other areas of functioning that may be more impacted by concealment in adolescents with FAP include transportation, attending a sleepover, eating meals with friends, using the restroom at school, choice of clothing, and dating. Indeed, research on adults with IBS suggests that patients’ attempts to control and conceal their symptoms impacts their ability to tolerate long car trips, their wardrobe, their diet, and their employment, in addition to their romantic and other close relationships (Dancey & Backhouse, 1993; Patrick, Drossman, Frederick, Dicesare, & Puder, 1998). Future research should attempt to identify the situations and activities in which adolescents with FAP experience the most impairment in order to determine whether concealment further impairs functioning in those domains.

Finally, it is important to note that the heterogeneity of FAP may have affected results. Symptoms vary significantly across individuals meeting criteria for FAP, such that each study participant would have interpreted HR-SCQ items in relation to a different symptom pattern. Stigma may be more prevalent in some manifestations of FAP than others, as evidenced by (1) the stronger associations between stigma constructs and lower GI symptoms compared to upper and non-GI symptoms and (2) the higher degrees of felt stigma and stigma concealment among participants who met criteria for IBS. Although mediational models were not supported among the subset of participants with IBS, power calculations were not conducted in anticipation of these sensitivity analyses. Future researchers may wish to use eligibility criteria with a higher degree of diagnostic specificity (e.g., enrolling only adolescents with IBS or even only adolescents with diarrhea-predominant IBS) in order to increase precision in exploring the relation between psychological stigma and health-related outcomes in those populations.

Exploratory analyses were conducted using the three-factor version of the HR-SCQ to test for originally hypothesized relations between anticipated stigma, internalized stigma, and health-related outcomes. Baseline data were consistent with a model in which internalized stigma significantly mediated the effect of anticipated stigma on symptoms of depression, anxiety, abdominal pain, GI symptoms, and pain interference. Indirect effects of internalized stigma did not reach statistical significance for functional disability. These results generally support predicted relations between anticipated stigma, internalized stigma, and measures of physical and mental health, and suggest that internalized stigma could be an important target of psychotherapy for adolescents with FAP. Further, these findings lend support to the differentiation of anticipated vs. internalized stigma, despite EFA results.

Exploratory analyses indicated that both felt stigma and stigma concealment were fairly stable from pre-post treatment, regardless of treatment group. The lack of main effect of time and lack of group X time interaction suggest that the CBT protocol utilized in the current study did not significantly lower the psychological stigma constructs assessed.

As a whole, predictive relationships were not supported. It is possible that baseline levels of the chosen health-related constructs so strongly predicted follow-up levels of those constructs that there was little variance left to be accounted for by other factors. The exception to this was that baseline internalized stigma significantly predicted anxiety symptoms at follow-up, after controlling for baseline anxiety. Again, these results indicate the possible utility of a three-factor solution to the HR-SCQ and support the hypothesis that internalized stigma may be a promising target for psychotherapeutic intervention.

Limitations

It is important to note a few limitations regarding the interpretability and generalizability of the present findings. First, model testing used baseline data only. As such, it is important to reiterate that the direction of observed effects is unknown. For example, it is possible that internalized stigma mediates the effect of mental health symptoms on anticipated stigma, rather than the effect of anticipated stigma on mental health symptoms. Studies using longitudinal designs are needed in order to determine the directionality of these effects. Furthermore, studies with sufficient power to use structural equation modeling will allow for the modeling of complex dependencies and latent variables, which was not possible in the current study. Another limitation is the racial and ethnic homogeneity of the current sample. The majority of participants in the current study were White, preventing the investigation of potential ethnic differences in perceptions of stigma, degree of stigma concealment, and effect of concealment in adolescents with FAP.

Future Directions

In addition to using longitudinal designs, future studies should investigate the processes by which adolescents decide whether to disclose a stigmatizing condition to others. Models of disclosure decision-making have been tested in various adult populations, including those with mental illness (Pahwa, Fulginiti, Brekke, & Rice, 2017; Venetis, Chernichky-Karcher, & Gettings, 2017), nonvisible health conditions (Greene et al., 2012), and a variety of other concealable stigmatized identities (Chaudoir & Quinn, 2010). However, little attention has been given to how adolescents make decisions regarding disclosure, with the exception of adolescents with HIV (Hogwood, Campbell, & Butler, 2013; Lee, Yamazaki, Harris, Harper, & Ellen, 2015; Thoth, Tucker, Leahy, & Stewart, 2014). Future research should investigate whether these

models can be generalized to adolescents with FAP and other FGIDs. It will also be important to determine the most common responses to stigma disclosure among adolescents, the effect these responses have on health-related outcomes, and individual differences that moderate these effects. Each of these lines of research will inform recommendations for whether, how, and to whom adolescents with stigmatizing conditions should disclose their stigma to others.

Conclusion

The proximal goal of the current study was to improve upon existing measures of psychological stigma and validate this measure in a sample of adolescents with FAP. We hope that the HR-SCQ will help advance research on health-related stigma in adolescents with FAP and other chronic health conditions by allowing for more precise assessment of psychological stigma constructs. The ultimate goal of examining the mechanisms by which psychological stigma results in poor outcomes for youth with FAP is to identify novel targets for psychotherapeutic intervention. Currently, there is insufficient evidence to suggest that stigma concealment accounts for the detrimental effects of anticipated stigma on mental health, physical health, or functioning in this population. By contrast, cross-sectional data were consistent with a theory-based model in which internalized stigma mediates the effect of anticipated stigma on these outcomes. Although more research is needed, findings from the current study suggest that internalized stigma may be a good target for psychological intervention. In sum, psychotherapies for adolescents with FAP may do better to challenge what these adolescents say to themselves about their condition than what they say to others.

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APPENDIX A

Results of Mediation Analyses Using Anticipated Stigma as the Predictor Variable

Sensitivity Analyses

Concealment as a mediator of the effect of anticipated stigma on mental health. We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on anxiety (original hypothesis 1). The direct effect of anticipated stigma on anxiety was 3.62 (SE = 1.19). This effect was significantly different from zero, $t(124) = 3.03, p = 0.003$. The indirect effect of anticipated stigma on anxiety via concealment was 0.28 (Boot SE = 0.81). This effect was not significantly different from zero (95% CI = -1.46-1.76). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on depression (original hypothesis 2). This hypothesis was first tested using the Promis depression measure. The direct effect of anticipated stigma on Promis depressive symptoms was 4.48 (SE = 1.15). This effect was significantly different from zero, $t(124) = 3.90, p < 0.001$. The indirect effect of anticipated stigma on depression via concealment was -0.16 (Boot SE = 0.72). This effect was not significantly different from zero (95% CI = -1.70-1.18). The presence of direct vs. indirect effects was also investigated using CDI depressive symptoms. The direct effect of anticipated stigma on CDI score was 0.28 (SE = 0.07). This effect was significantly different from zero, $t(124) = 3.90, p = 0.002$. The indirect effect of anticipated stigma on CDI score via concealment was < 0.01 (Boot SE = 0.05). This effect was not significantly different from zero (95% CI = -0.10-0.09). Thus, baseline data did not support the proposed model in which concealment mediates the effect of anticipated stigma on mental health.

Concealment as a mediator of the effect of anticipated stigma on physical symptoms.

We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on abdominal pain (original hypothesis 3). The direct effect of anticipated stigma on abdominal pain was $b = 0.17$ (SE = 0.10). This effect was not significantly different from zero, $t(124) = 1.74$, $p = 0.084$. The indirect effect of anticipated stigma on abdominal pain via concealment was $b = 0.06$ (Boot SE = 0.06). This effect was not significantly different from zero (95% CI = -0.07 - 0.18). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on GI symptoms (original hypothesis 4). The direct effect of anticipated stigma on GI symptoms was $b = 0.15$ (SE = 0.08). This effect was not significantly different from zero, $t(124) = 1.87$, $p = 0.064$. The indirect effect of anticipated stigma on GI symptoms via concealment was $b = 0.05$ (Boot SE = 0.05). This effect was not significantly different from zero (95% CI = -0.04 - 0.16). Thus, baseline data did not support the proposed model in which concealment mediates the effect of anticipated stigma on physical symptoms.

Concealment as a mediator of the effect of anticipated stigma on functional impairment. We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on functional disability (original hypothesis 5). The direct effect of anticipated stigma on functional disability was $b = 0.18$ (SE = 0.08). This effect was significantly different from zero, $t(124) = 2.29$, $p = 0.024$. The indirect effect of anticipated stigma on functional disability via concealment was $b = 0.04$ (Boot SE = 0.05). This effect was not significantly different from zero (95% CI = -0.05 - 0.15). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of anticipated stigma on pain interference (original hypothesis 6). The direct effect of

anticipated stigma on pain interference was $b = 4.86$ ($SE = 1.49$). This effect was significantly different from zero, $t(124) = 3.25$, $p = 0.002$. The indirect effect of anticipated stigma on pain interference via concealment was $b = 0.74$ (Boot $SE = 1.01$). This effect was not significantly different from zero (95% $CI = -1.27 - 2.68$). Thus, baseline data did not support the proposed model in which concealment mediates the effect of anticipated stigma on functional impairment.

APPENDIX B

Results of Mediation Analyses Among Participants with IBS

Sensitivity Analyses

Physical symptoms. We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on abdominal pain (revised hypothesis 3). This hypothesis was not supported in the full sample of participants; analyses were repeated using data from only the subset of participants meeting criteria for IBS. Among participants with IBS, the direct effect of felt stigma on abdominal pain was $b = 0.14$ (SE = 0.10). This effect was not significantly different from zero, $t(73) = 1.36$, $p = 0.177$. The indirect effect of felt stigma on abdominal pain via concealment was $b = 0.01$ (Boot SE = 0.06). This effect was not significantly different from zero (95% CI = -0.09 - 0.15). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on GI symptoms (revised hypothesis 4). Among participants with IBS, the direct effect of felt stigma on GI symptoms was $b = 0.21$ (SE = 0.09). This effect was significantly different from zero, $t(73) = 2.44$, $p = 0.017$. The indirect effect of felt stigma on GI symptoms via concealment was $b < -0.01$ (Boot SE = 0.05). This effect was not significantly different from zero (95% CI = -0.09 - 0.10). Thus, the proposed model (in which concealment mediates the effect of felt stigma on physical symptoms) was not supported among the subset of participants with IBS.

Functional impairment. We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on functional disability (revised hypothesis 5). Among participants with IBS, the direct effect of felt stigma on functional

disability was $b = 0.09$ (SE = 0.10). This effect was not significantly different from zero, $t(73) = 0.91$, $p = 0.368$. The indirect effect of felt stigma on functional disability via concealment was $b = 0.06$ (Boot SE = 0.07). This effect was not significantly different from zero (95% CI = -0.04 - 0.21). We hypothesized that baseline data would be consistent with a model in which concealment mediates the effect of felt stigma on pain interference (revised hypothesis 6). Among participants with IBS, the direct effect of felt stigma on pain interference was $b = 5.22$ (SE = 1.62). This effect was significantly different from zero, $t(73) = 3.22$, $p = 0.002$. The indirect effect of felt stigma on pain interference via concealment was $b = 0.52$ (Boot SE = 1.15). This effect was not significantly different from zero (95% CI = -1.57 - 3.02). Thus, the proposed model (in which concealment mediates the effect of felt stigma on functional impairment) was not supported among the subset of participants with IBS.

APPENDIX C

Results of Prospective Analyses Using Internalized Stigma as a Predictor Variable

Anxiety

We hypothesized that greater internalized stigma at baseline would predict greater anxiety at follow-up, controlling for baseline anxiety. Hierarchical regressions revealed that baseline anxiety significantly predicted follow-up anxiety ($F[1,69] = 50.72, p < 0.001, R^2_{\text{model1}} = 0.42$). Consistent with study hypotheses, the addition of baseline internalized stigma to the model significantly increased predictive power ($F_{\text{change}}[1,68] = 5.54, p = 0.021; R^2_{\text{model2}} = 0.47$).

Depression

We hypothesized that greater internalized stigma at baseline would predict greater depressive symptoms at follow-up, controlling for baseline depressive symptoms. Hierarchical regressions revealed that baseline depression significantly predicted follow-up depression ($F[1,69] = 66.05, p < 0.001, R^2_{\text{model1}} = 0.49$). The addition of baseline internalized stigma to the model did not improve predictive power ($F_{\text{change}}[1,68] = 0.76, p = 0.388; R^2_{\text{model2}} = 0.50$).

Abdominal Pain

We hypothesized that greater internalized stigma at baseline would predict greater abdominal pain at follow-up, controlling for baseline abdominal pain. Hierarchical regressions revealed that baseline abdominal pain significantly predicted follow-up abdominal pain ($F[1,68] = 23.72, p < 0.001, R^2_{\text{model1}} = 0.26$). The addition of baseline internalized stigma to the model did not improve predictive power ($F_{\text{change}}[1,67] = 0.99, p = 0.324; R^2_{\text{model2}} = 0.27$).

GI Symptoms

We hypothesized that greater internalized stigma at baseline would predict greater GI symptoms at follow-up, controlling for baseline GI symptoms. Hierarchical regressions revealed that baseline GI symptoms significantly predicted follow-up GI symptoms ($F[1,70] = 26.77, p < 0.001, R^2_{\text{model1}} = 0.28$). The addition of baseline internalized stigma to the model did not improve predictive power ($F_{\text{change}} [1,69] = 0.87, p = 0.353; R^2_{\text{model2}} = 0.29$).

Pain Interference

We hypothesized that greater internalized stigma at baseline would predict greater pain interference at follow-up, controlling for baseline pain interference. Hierarchical regressions revealed that baseline pain interference significantly predicted follow-up pain interference ($F[1,70] = 26.75, p < 0.001, R^2_{\text{model1}} = 0.28$). The addition of baseline internalized stigma to the model did not improve predictive power ($F_{\text{change}}[1,69] = 2.00, p = 0.162; R^2_{\text{model2}} = 0.30$).