THE ROLE OF STIGMA IN THE RELATIONSHIP BETWEEN ILLNESS INTRUSIVENESS AND DEPRESSION/ANXIETY IN COLLEGE STUDENTS: A PATH MODEL

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Abstract: Objective: Adolescents/Young Adults (AYAs) with a chronic illness display elevated risk for poor psychosocial outcomes. This has been well-documented among AYAs attending college, yet relatively little is known about factors that place these individuals at risk. Illness intrusiveness (i.e., perceived illness-induced impediments to engaging in routine activities) is a known predictor of negative psychosocial outcomes in AYAs. Illness-related stigma, an understudied concept in this population, may also be a key contributor to increased intrusiveness. The present study investigated the hypothesis that higher levels of illness-related stigma would be associated with higher levels of depressive and anxious symptoms in AYAs, and that this relationship will be mediated by illness intrusiveness. Methods: College students with a chronic illness completed measures of illness intrusiveness, illness-related stigma, and depressive and anxious symptoms. Results: A path model was estimated to test the above hypothesis. Overall, the model yielded good fit to the data, CFI (.99), SRMR (.02), and RMSEA (.10), and yielded a significantly better model fit than a model where illness-related stigma and illness intrusiveness were estimated as independent predictors. Stigma was significantly related to illness intrusiveness, and illness intrusiveness was significantly related to depressive and anxious symptoms. Both the stigma → intrusiveness → depression, and the stigma → intrusiveness → anxiety indirect paths were significant. Conclusions: Findings support previous research indicating relationships between stigma, illness intrusiveness, and negative psychosocial outcomes. Results implicate illness intrusiveness as a possible mediator between illness-related stigma and depressive and anxious symptoms in AYAs. Illness intrusiveness may be a potential mechanism by which illness-related stigma leads to negative psychosocial outcomes.

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CHAPTER I

INTRODUCTION

Many chronic illnesses are diagnosed in childhood, and as medical treatments improve, more chronically ill children are living into adulthood. As such, there is a growing need to assess the many unique challenges and stressors associated with coping with a chronic illness during the transitional period between childhood and adulthood (Abraham, Silber, & Lyon, 1999; Pfeffer, Pfeffer, & Hodson, 2003; Verhoof, Maurice-Stam, Heymans, Evers, & Grootenhuis, 2014). It is well-documented that adolescents/young adults (AYAs) with a chronic illness display an elevated risk for the development of maladaptive psychosocial outcomes, including depression, anxiety, and lower quality of life, but much less is known about how this risk develops, including those factors that enhance the likelihood of negative psychosocial outcomes (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Ferro, Gorter, & Boyle, 2015; Herts, Wallis, & Maslow, 2014; Mackner & Crandall, 2006; Pao & Bosk, 2011; Wilder Smith et al., 2013). This risk is likely due, in part, to the increased risk that the AYA age group has for adjustment difficulties in general. Factors that are more specific to the stress and burden of coping with a chronic illness, such as illness-related stigma, are also likely to play an important role (Dancey, Hutton-Young, Moye, & Devins, 2002; Pinquart & Shen, 2011a, 2011b; Stewart-Brown et al., 2000).

Stigma

Stigma is broadly defined as perceived or enacted disapproval, discrimination, or rejection associated with an attribute or characteristic that is different or undesirable (Link & Phelan, 2006). Illness-related stigma, the experience of stigma as a result of a medical condition, has been studied in various illness populations such as HIV and epilepsy, and has proven to be an especially important predictor of negative psychosocial outcomes in adults with chronic health conditions (Quinn & Chaudoir, 2009). Although there is a relatively large body of research assessing illness-related stigma in adulthood, research on younger populations is quite limited (Cianchetti et al., 2015; Jenerette & Brewer, 2010).

Adolescents/Young Adults (AYAs) with Chronic Illness

Compared to younger children or older adults with chronic illnesses, AYAs are likely to be particularly vulnerable to socially driven forces like illness-related stigma. Adolescence and young adulthood is a time of great change, and AYAs are faced with many new demands and situations such as navigating dating relationships, shifting peer groups, and pressure to attain educational/career success and assert independence as they move away from home (Arnett, 2001). Moreover, this developmental period is critical for social network establishment, and peer relationships are considered to be of the utmost importance (Arnett, 2000). AYAs who are also suffering from a chronic medical condition must confront the additional challenges associated with the experience of illness-related stigma (e.g., actual or perceived negative peer evaluation), while simultaneously coping with stressors related to their health and medical management of their condition (Abraham et al., 1999; Bleyer, Barr, Ries, Whelan, & Ferrari, 2017). This added burden carries the potential to disrupt an AYA’s social network.

AYAs attending college may be particularly vulnerable, as college is a time of great social transition and peer networks may be constantly evolving. Indeed, studies of college students with chronic illnesses have revealed general deficits in social support (Herts et al., 2014). This is problematic as deficits in social support have been linked to negative outcomes such as poor adherence to medical regimens, negative psychosocial outcomes such as depression and anxiety, and poorer health related quality of life in multiple illness populations (e.g., cancer, diabetes, and inflammatory bowel disease; DiMatteo & Robin, 2004; Kemp, Griffiths, & Lovell, 2012; Skinner, John, & Hampson, 2000; Warner et al., 2016). Indeed, research on AYAs with epilepsy and irritable bowel disease has demonstrated associations of stigma to decreased self-esteem and self-efficacy, limited disclosure about illness, and social withdrawal (Cianchetti et al., 2015; Taft, Ballou, & Keefer, 2013; Taft, Keefer, Artz, Bratten, & Jones, 2011). Further, Casillas and colleages (2010) have identified illness-related stigma as a substantial barrier to survivorship care in Latino AYA survivors of pediatric cancer.

Illness-Related Stigma

Although much of the early stigma research linked belonging to a stigmatized group with negative psychosocial outcomes, recent work has shown that there is substantial variability in how different people perceive and cope with stigma (Allport, 1954; Erickson, 1956; Major, 2006). Simply belonging to a stigmatized group is not the strongest predictor of negative psychosocial outcomes. Instead, outcomes are highly variable based on the amount of stigma perceived, the saliency of the stigmatized identity to the individual, and the extent to which the identity is central to the individual's self-perception (Quinn & Chaudoir). For individuals with a chronic illness, whose illness serves as a *concealable stigmatized identity* (i.e., an identity that can be kept hidden but still carries socially undesirable qualities) levels of perceived stigma and its' impact are likely to be especially variable (Crocker, Major, & Steele, 1998; Quinn & Chaudoir, 2009). Research in adult populations has shown that increased perceptions of illness-related stigma is linked to increased negative psychosocial outcomes including depression and anxiety (Duffy, 2005; Quinn & Chaudoir, 2009; Taft & Keefer, 2016; Vanable, Carey, Blair, & Littlewood, 2006). This is consistent with previous research on illness-related stigma in AYAs, which has indicated that although stigma is a predictor of negative psychosocial outcomes, the effect and experience of stigma differs between individuals, even within the same illness group (Dancey et al., 2002; Jenerette & Brewer, 2010; MacLeod & Austin, 2003). These findings are supported by Stevelink and colleagues' (2012) model of stigma, in which negative psychosocial outcomes result from an affected individual experiencing, perceiving, and anticipating negative social reactions (See Figure 1). These stigma experiences then lead to the internalization of stigma, which is evidenced by negative feelings about one's self, transformations in one's identity, and maladaptive behaviors. These manifestations of the internalized stigma are then theorized to lead to negative psychosocial outcomes such as depression and anxiety.

Theoretical Model

Given the observed variability of perceived stigma, and its relationship with negative psychosocial outcomes, it is important to assess possible modifiable mediators which may link the experience of illness-related stigma to negative psychosocial outcomes. In fact, Stevelink et al.'s (2012) model indicates that there are likely mediators to the effects of stigma. Specifically, they predict that an individual who perceives or expects stigma from others will engage in "maladaptive behaviors," which can include avoiding typical activities. *Illness intrusiveness*, an established predictor of psychosocial distress in adult and AYA populations, may be an important construct to assess as a mediator, as it is defined as the extent to which one's illness is believed to induce disruptions in lifestyle, activities, values, and interests (Devins, 2010; Mullins et al., 2017). Illness intrusiveness is believed to negatively affect quality of life and psychosocial outcomes by reducing positive experiences associated with valued activities, and by decreasing perceived control over one's experiences (Devins et al., 1996). Further, illness intrusiveness is hypothesized to result from an individual's perception of their illness and their environment, and may be magnified by negative cognitions about one's self, such as illness related-stigma (Dancey et al., 2002). Indeed, two previous studies have identified illness intrusiveness as a mediator between illness-related stigma and negative psychosocial outcomes (Dancey et al., 2002; Devins, Stam, & Koopmans, 1994). Importantly, neither of these studies were in pediatric or AYA populations, and neither used contemporary statistical analyses. Thus, there is much to gain from understanding how varying levels of perceived illness-related stigma may serve as a precursor to the disruption of daily activities that is captured by illness intrusiveness.

Study Aims

To this aim, the current study seeks to evaluate the relationship of perceived illness-related stigma and negative psychosocial outcomes of depression and anxiety in a sample of AYA college students. Specifically, this study aims to expand on the existing literature that has linked perceptions/expectations of stigma with negative psychosocial outcomes by assessing the extent to which illness intrusiveness serves as a mediator of this relationship. It is hypothesized that stigma will be associated with higher levels of illness intrusiveness. Further, it is predicted that a model in which illness intrusiveness is a mediator will yield better fit to the data than a model which assesses illness intrusiveness and stigma as independent predictors of depressive and anxious symptoms.

CHAPTER II

REVIEW OF THE LITERATURE

Adolescence and Young Adulthood

Typically developing adolescents and young adults (AYAs) are faced with numerous changes, transitions, and new experiences such as navigating dating relationships, shifting peer groups, pressure to perform well in school and plan for future careers, moving away from home, and facing their newly found independence (Arnett, 2001; Eiser, Penn, & Katz, 2009). AYAs experience changes in their self-perception, the roles that they serve in their environment, and biological changes, which can make them vulnerable to negative psychosocial outcomes (Arnett, 2015; Orth, Robins, & Roberts, 2008; Robins, Fraley, Roberts, & Trzesniewski, 2001). Modern theories about the unique challenges of adolescence and young adulthood were sparked by Erik Erikson's seminal work in characterizing psychosocial life stages of development. According to Erikson's theory of psychological development, identity formation and social relationships are the two most vital areas of development during this stage (Erikson, 1956).

The research which has followed Erikson's work has identified that the transition to adulthood is highly dependent upon culture, and the cultural expectations that exist for individuals of this age (Arnett, 2015; Schwartz, Zamboanga, Luyckx, Meca, & Ritchie, 2013). Over the past half-century, there has been a dramatic shift in cultural expectations (Bynner, 2005; Schwartz, Côté, & Arnett, 2005). Now, instead of quickly shifting from adolescence to adulthood at the age of 8, the process is prolonged. The adolescence/young adulthood age is an extended period where individuals are no longer children, but also not quite adults, and going to college and postponing the initiation of careers and families has become socially normative. Currently, AYAs in the United States increasingly tend to place high importance on social aspects of their lives, such as their status compared to peers, the perception that their peers have of them, and their relationships with peers (Montgomery, 2005).

This age group, coined "emerging adulthood" by many developmental psychology researchers, can be characterized by five elements: assertion of independence, instability, self-focus, feeling in-between, and possibilities (Arnett, 2015). Further, research has shown that AYAs across ethnic groups self-identify establishing independence and forging relationships to be among the most important aspects of transitioning to adulthood (Arnett, 2003). Thus, adolescence appears to be a critical time period for establishing new peer relationships as their environment changes and they assert their independence, now more than ever before. Arnett and colleagues have argued that these five unique elements, which characterize the AYA period are specifically linked to mental health risks (Arnett, Žukauskienė, & Sugimura, 2014). For example, the instability of changing environments might put AYAs at risk for loss of various social supports, which would leave them more vulnerable to depression and anxiety.

Unfortunately, despite a recent shift towards focusing more research on the AYA population, relatively limited research has been devoted to understanding the unique developmental risk for negative psychosocial outcomes at this age (Schulenberg, Sameroff, & Cicchetti, 2017). What is known is that AYAs are at an increased risk for developing untoward psychological outcomes as compared to their younger or older peers (Schulenberg & Zarrett, 2006). A 2005 epidemiological review indicated that the 12-month prevalence of any psychiatric condition in individuals aged 18-29 was 40%, which was higher than for any other age range (Kessler et al., 2005). Importantly, the development of psychopathology during the AYA time period is also associated with an increased risk for life-long issues with poor psychosocial outcomes (Kim-Cohen et al., 2003). Thus, the study of risk and resiliency factors in AYAs is critical, particularly for those who face additional stressors, such as having a chronic illness.

Coping with Chronic Illness as an Adolescent/Young Adult

A chronic illness is defined as a condition which is not yet curable or is highly resistant to treatment and has been present for longer than three months, or will likely last longer than three months, or has occurred three or more times in a year and will likely reoccur (Mokkink, Van Der Lee, Grootenhuis, Offringa, & Heymans, 2008). Many such conditions develop during early childhood, and as a result of medical advancement, many children are surviving illness and aging into adulthood. Thus, it is imperative to understand how the stress of coping with a chronic illness impacts AYAs as they encounter developmental changes in the process of reaching adulthood (Abraham, Silber, & Lyon, 1999; Pfeffer, Pfeffer, & Hodson, 2003; Verhoof, Maurice-Stam, Heymans, Evers, & Grootenhuis, 2014). According to national data collected between 2011-2012, roughly 17.5% of youth between the ages of 12-17 years have one chronic health condition, and roughly 13.3% have two or more chronic conditions, indicating that almost one third of youth have at least one chronic condition (Child and Adolescent Health Measurement Initiative, 2012). Data collected by the American College Health Association indicates that among youth who go on to attend college, roughly 19.7% report having an allergic condition, 9.1% report having asthma or asthma-related illness, and 5.2% report having another chronic condition such as diabetes, cancer, or inflammatory bowel disease (Hoban & Leino, 2013).

Research specific to psychosocial outcomes of Adolescents/Young Adults (AYAs) with a chronic illness is relatively new, with dedicated research on this population only beginning in the past two decades. The emerging literature suggests that the majority of AYAs, as well as children and adults, who have a chronic illness appear to cope well and are thus resilient. However, there also appears to be a notable subset who experience significant psychological distress or difficulties in adjustment (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Clarke & Currie, 2009; Pao & Bosk, 2011; Pinquart & Shen, 2011a, 2011b, 2011c). Adolescents who are coping with a chronic illness are not only more likely to experience internalizing and externalizing symptoms than their healthy peers, but the trajectories of their psychological symptoms are also worse as they age into young adulthood (Ferro, Gorter, & Boyle, 2015). A series of meta-analyses conducted by Pinquart and Shen (2011) found small but significant effect sizes when comparing levels of depressive symptoms, anxious symptoms, and behavior problems of healthy adolescents with their chronically ill peers. Additionally, Pinquart and Shen found that larger effect sizes existed for studies with more girls than boys, which suggests that female AYAs may be at particular risk for psychological distress.

Given the unique risk associated with the AYA age range (see section Adolescence/Young Adulthood), it is thus likely that AYAs coping with a chronic illness are uniquely vulnerable to negative psychosocial outcomes. Additionally, the presence of negative psychosocial outcomes may be especially concerning as the development of psychopathology at this age is associated with long-term psychosocial risk (Hampel, Rudolph, Stachow, Laß-Lentzsch, & Petermann, 2005). As mentioned previously, adolescence and young adulthood is a time that is accompanied by many new stressors and challenges such as gaining independence, dating, and moving away from home. AYAs with a chronic illness must tackle each of these challenges in addition to many illness-specific stressors, such as adhering to treatment protocols (e.g., taking medication, monitoring physiological data such as glucose, dietary restrictions), attending doctor visits, and learning to manage their own care. The compounded stress of coping with typical stressors faced by AYAs, in addition to illness-specific stressors, may contribute to the elevated psychosocial distress that is seen in this population (Abraham et al., 1999; Bleyer, Barr, Ries, Whelan, & Ferrari, 2017). Further, the psychological distress potentially experienced by an AYA with a chronic illness during this vital time for social development may be harmful to AYAs' ability to successfully meet developmental milestones. For instance, depression is associated with social withdrawal and lack of interest. Such symptoms may inhibit AYAs from engaging with peers and forging intimate peer relationships (Rubin, Coplan, & Bowker, 2009).

For AYAs with a chronic illness, social withdrawal as a result of depressive symptoms may be especially harmful as social support has been shown to be an important contributor to resiliency among AYAs coping with chronic illness.

Deficits in social support and lack of social engagement have indeed been linked to more anxious and depressive symptoms in AYAs, and are also related to poorer adherence to medical regimens and reduced health-related quality of life (DiMatteo & Robin, 2004; Skinner, John, & Hampson, 2000; Warner et al., 2016). Specifically, DiMatteo and colleagues' (2004) meta-analysis uncovered substantial effect sizes between social support and adherence to medical regimens, with the largest effects on adherence being from familial social support. Research has also shown that psychological distress is associated with poorer adherence to treatment protocols, which are vitally important to medical health outcomes (Rapoff, 2010). Research on samples of youth with inflammatory bowel disease, asthma, HIV, and diabetes have demonstrated that a link exists between anxious and depressive symptoms and adherence (Bender, 2006; Gonzalez et al., 2008; Gray, Denson, Baldassano, & Hommel, 2012; Murphy et al., 2005; Williams et al., 2006). Grey and colleagues' (2012) analyses even indicated that the link between barriers to adherence and adherence itself was mediated by psychological distress, indicating the importance of psychosocial outcomes on medical outcomes such as treatment adherence. Thus, the presence of psychological distress in individuals with chronic illness at this sensitive time in development should be considered distinctly concerning.

In sum, AYAs with a chronic illness show an increased vulnerability for developing negative psychosocial outcomes as compared to their healthy peers, and they are more likely than healthy peers to have escalating trajectories of distress as they age into adulthood. Additionally, AYAs with a chronic illness who experience negative psychosocial outcomes are less likely to adhere to their medical regimens and are thus at an increased risk for adverse physical health risks, increased disease severity and course, and mortality. Thus, AYAs with a chronic illness are an especially vulnerable population and increased research attention to understanding risk factors for developing negative psychosocial outcomes is greatly needed. One such risk factor is that of illness-related stigma, a construct that has been understudied in this population, but for which a great deal of evidence exists in the adult illness literature (Stevelink, Wu, Voorend, & van Brakel, 2012).

Illness-Related Stigma

Illness-Related Stigma Framework

Stigma is defined as the disapproval, discrimination, or rejection associated with a socially undesirable trait or characteristic (Link & Phelan, 2006). Stigma can be either enacted (i.e., a person's actions are directly motivated by, and displaying, disapproval, rejection, or discrimination towards another individual) or perceived (i.e., an individual suspects that a person is disapproving, discriminating, or rejecting of an individual). Although stigma is typically thought of in reference to traditionally observable traits such as ethnicity or gender, there is considerable research to suggest that individuals with chronic medical conditions are also subject to stigma. Individuals with chronic medical conditions possess *concealable stigmatized identities*, identities which can be hidden, but still possess socially undesirable characteristics (Crocker, Major, & Steele, 1998; Quinn & Chaudoir, 2009). It has historically been thought that due to the lack of inherent visibility, there may be some benefits to having a concealable stigmatized identity, such as better psychosocial outcomes (Allport, 1954; Erikson, 1956). However, research has indicated that the visibility or type of stigmatized group that an individual belongs to is not necessarily the most important predictor of psychological distress. Rather, the strongest predictors of psychosocial outcomes in individuals with stigmatized conditions are the extent to which an individual perceives others to view their trait or characteristic with stigma, the extent to which the stigmatized identity is salient to the individual, and the extent to which the stigmatized identity is central to the individual's view of themselves (Major, 2006). Thus, individuals with concealable stigmatized identities in the context of a chronic illness, are believed to have variable levels of psychological distress, as the experience of stigma appears to be vastly different across individuals.

Given the concealability of chronic medical conditions, individuals have the option to disclose their illness to others or keep it hidden. However, the option to disclose comes with its own sources of stress. According to a model proposed by Joachim & Acorn (2000), individuals with concealable stigmatized identities face a great deal of stress even if they do not disclose their illness to others. This is because the stress of hiding their condition and attempting to be “normal” may present a great number of challenges. These individuals will also experience additional stress and stigma if they are “caught in the lie” of pretending to be without an illness. Research also shows that when individuals with a concealable stigmatized identity attempt to conceal their condition, they report lower levels of belongingness and their peers actually rate them as having poorer social skills in social interactions (Newheiser & Barreto, 2014). Interestingly, studies reveal that over half of individuals with chronic illness prefer not to disclose their illness or prefer to disclose their illness to very few people (Herts, Wallis, & Maslow, 2014; Newheiser & Barreto, 2014).

To understand the processes by which stigma may relate to negative psychosocial outcomes in adults with chronic health conditions, Stevelink and colleagues (2012) outlined a model based on the findings of Livingston & Boyd’s (2010) meta-analysis of mental illness-related stigma. According to this model, individuals with chronic illness perceive stigma through experiencing negative social interactions, perceiving negative social interactions, and expecting negative social interactions. These perceptions of stigma then result in *internalized stigma* (i.e., negative perceptions about one’s own illness and own worth as a result of their condition), which drives negative feelings about one’s self, identity transformation, and maladaptive behaviors. These negative feelings, identity transformation, and maladaptive behaviors are then proposed to lead to negative psychosocial outcome variables such as psychological distress, guilt, shame, embarrassment, exclusion, isolation, withdrawal, and others. In Livingston & Boyd’s (2010) meta-analysis, internalized stigma was associated not only with negative psychosocial outcomes but also with poorer treatment adherence. Support for Stevelink and colleagues' (2012) model comes from reviews of other adult illness populations (Link & Phelan, 2001; Logie & Gadalla, 2009; Mak, Poon, Pun, & Cheung, 2007; Van Brakel, 2006).

Illness-Related Stigma in Adult Populations

Illness-related stigma has been studied for the most part in adult populations, with a great deal of literature specifically focusing on the stigma experiences of adults with HIV/AIDS, epilepsy, tuberculosis, and mental disorders (Bharat, 2011; Juniarti & Evans, 2011; Van Brakel, 2006; Weiss, Ramakrishna, & Somma, 2006). Indeed, much of the emphasis on stigma in the context of chronic medical conditions began with research involving the HIV/AIDS population (Mahajan et al., 2008). The treatment and prevention of HIV/AIDS presented a unique challenge to healthcare providers as the stigma surrounding the disease was immense. The effects of this stigma led affected individuals to either attempt to hide or deny their illness, or else be shunned and ostracized. Further, the stigma associated with possibly being HIV positive left people in fear of getting tested, delaying their access to treatment and allowing the further spread of disease. Since the AIDS epidemic began in 1981, a great deal of progress has been made to reduce stigma, and improve access to healthcare, screenings, and prevention efforts (Mahajan et al., 2008).

Overall, research on individuals with chronic illnesses such as HIV/AIDS, epilepsy, tuberculosis, cancer, diabetes, and inflammatory bowel disease has demonstrated that a substantial subset of individuals with these concealable stigmatized medical conditions report mild, moderate, or severe perceptions of stigma from their environment which ranges from perceiving that others view their illness as unappealing, to perceiving that others actively shun or reject them as a result of their illness (Chapple, Ziebland, & McPherson, 2004; Weiss et al., 2006). Further, research consistently shows that the degree of stigma perceived is linked to psychosocial outcomes, such that those who experience higher levels of perceived stigma display poorer psychosocial outcomes such as depression, anxiety, or global psychological distress (Duffy, 2005; Quinn & Chaudoir, 2009; Taft & Keefer, 2016; Vanable, Carey, Blair, & Littlewood, 2006). In a qualitative study examining stigma perceived by individuals with type 2 diabetes, individuals often endorsed feeling “blamed by others for causing their own condition,” “being subject to negative stereotyping,” and “being discriminated against or having restricted opportunities in life” (Browne, Ventura, Mosely, & Speight, 2013). Further, these individuals identified that the stigma that they perceived came from not only cultural sources such as the media, but also their family, friends, colleagues, and even healthcare professionals. Browne and colleagues (2013) also reported that the individuals in the study reported themes of experiencing significant psychological distress in relation to the stigma that they perceived.

The stigma associated with chronic medical conditions can also present physical health risks for those affected. Researchers have found that chronic stress, which can be the result of chronic stigmatization, can cause additional medical problems (Kumari, Ram, Haque Nizamie, & Goyal, 2009; Link & Phelan, 2006; Pascoe & Smart Richman, 2009; Taft & Keefer, 2016). This can include increased risk for high blood pressure, cardiovascular disease, respiratory conditions, diabetes, and obesity. Thus, the stress of stigma may be especially damaging as it is associated with additional stress-related health problems, which may worsen the course of the original condition. Research on individuals with inflammatory bowel disease has also demonstrated that not only is perceived stigma associated with negative psychosocial outcomes, but is also associated with decreased health-related quality of life, suggesting that there is a notable association between stigma and health (Taft, Ballou, & Keefer, 2013; Taft, Keefer, Artz, Bratten, & Jones, 2011). Further, in cases where individuals perceive a particularly high level of stigma, individuals may avoid or postpone medical treatment, which may also impact health outcomes (Duffy, 2005; Pascoe & Smart Richman, 2009).

Findings which suggest a link between stigma and negative outcomes such as psychological distress and reduced quality of life are consistent throughout the literature.

However, recent research has also begun exploring resiliency factors associated with stigma. Taft and colleagues (2013) assessed the impact of stigma internalization, the extent to which a person believes the negative stigmatizing thoughts about themselves and their condition in a cohort of individuals with inflammatory bowel disease. They found that almost 40% of their sample experienced internalized stigma and that this stigma was significantly related to poorer psychosocial outcomes and health-related quality of life. However, they also found that almost 90% of their sample endorsed *stigma-resistant* thoughts and behaviors, such as thinking "living with IBD has made me a tough survivor." Taft and colleagues found that stigma resistance served as a protective factor against stigma and was associated with better psychosocial outcomes. Such findings suggest that individuals with chronic illness may be able to develop a positive view of their illness, and that this positive perception is related to better psychosocial outcomes, thus shedding light on possible areas for intervention. Stigma resistance as a construct has also been studied in populations of individuals with schizophrenia and HIV/AIDS, showing similarly promising results (Poindexter & Shippy, 2010; Sibitz, Unger, Woppmann, Zidek, & Amering, 2011).

Illness-Related Stigma in Pediatric and Adolescents/Young Adults Populations

Although there is considerable research on illness-related stigma in adults, there is a relatively limited amount of research in AYA or even pediatric populations (Cianchetti et al., 2015; Jenerette & Brewer, 2010). To date, stigma has been studied in pediatric and AYA populations such as epilepsy, sickle cell disease, cancer, facial differences, and mental disorders (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Casillas, Kahn, Doose, Landier, & Bhatia, 2010; Elkington et al., 2012; Funderburk, McCormick, & Austin, 2007; Herts et al., 2014; Jacoby, 2002; Jenerette & Brewer, 2010; MacLeod & Austin, 2003; Masnari et al., 2013). Among these studies, those which assessed psychosocial outcomes (i.e., Austin et al., 2004; Funderburk, Mccormick, & Austin, 2007; Jenerette & Brewer, 2010; Masnari et al., 2013), found a link between perceived stigma and psychological distress. A small number of pediatric and AYA studies have also assessed health-related quality of life in relation to illness-related stigma. Herts et al. (2014) found stigma to be negatively associated with health-related quality of life, as did MacLeod and Austin's (2003) review of the pediatric epilepsy literature. Casillas and colleagues (2010) also identified illness-related stigma as a barrier to receiving survivorship care in young adults who experienced pediatric cancer, further emphasizing the risk that illness-related stigma has on health.

In general, the experience of illness-related stigma appears to be similar in a number of ways for children/AYAs and adults with chronic health conditions. Specifically, the pediatric and AYA studies of illness-related stigma found that simply belonging to a stigmatized group did not mean that individuals invariably perceived stigma, rather, levels of stigma reported were variable within individuals of the same illness group. Funderburk, McCormick, and Austin (2007) found that children who perceived elevated levels of illness-related stigma also held negative attitudes toward their condition, suggesting that pediatric populations may be at risk for the internalized stigma that is seen in adult populations.

According to the adult literature, individuals who feel stigmatized tend not to disclose their illness (Joachim & Acorn, 2000). Among pediatric and AYA studies, a number have also found that many or most children and AYAs prefer not to disclose their illness to others. Studies of children with epilepsy found that children preferred to keep their epilepsy a secret, such that almost 60% of children reported concealing their condition from others and 70% reported rarely or never talking about their epilepsy with others (Austin et al., 2004; MacLeod & Austin, 2003). A qualitative study of children with IBD found similar patterns of preference towards non-disclosure (Barned, Stinzi, Mack, & O'Doherty, 2016). Additionally, Herts and colleagues (2014) found that among college freshmen with chronic illness, roughly half report having disclosed their condition to less than five of their peers. According to Jenerette and Brewer (2010), children with epilepsy reported that they were anxious about disclosure because of the possibility of negative peer evaluation associated with being different.

In sum, illness-related stigma has garnered research support in adults with chronic illness since the AIDS epidemic in the early 1980s. Illness-related stigma has shown to have detrimental effects on the psychological and physical health of adults coping with chronic illness. Indeed, the limited research which does exist in pediatric and AYA populations indicates that the experience of illness-related stigma in childhood, adolescence, and young adulthood may be similar to the experience in adulthood. However, due to important developmental differences among these different age ranges, there are likely many distinctive differences between pediatric/AYA and adult illness-related stigma which have yet to be uncovered. Additionally, it is important to understand the paths by which stigma may affect negative psychosocial outcomes. As such, an established predictor of psychological distress in both adult and AYA populations, illness intrusiveness, may be an important variable to assess in relation to stigma. Illness intrusiveness is hypothesized to result from an individual's perceptions about their illness, environment, and situation, and thus may be greatly affected by an individual's perception of stigma from their peers.

Illness Intrusiveness

Illness intrusiveness is defined as the extent to which an individual perceives their daily or valued life activities to be disrupted as a result of illness (Devins, 2010). According to the theory of illness intrusiveness, the disruption created by illness is associated with negative psychosocial outcomes by two pathways: 1) the disruption reduces or eliminates positive reinforcement that would be achieved by participating in a valued activity, and 2) the disruption reduces feelings of control over one's life and activities (e.g., Devins, 1994, 2010). The study of illness intrusiveness has roots in adult populations with chronic illness and disability (Devins et al., 1996). This research largely indicates that illness intrusiveness is robustly associated with negative psychosocial outcomes such as depression and anxiety, as well as related outcomes such as physical health, fatigue, and marital satisfaction (e.g., Devins, 2010; Mullins et al., 2001; Shawaryn, Schiaffino, LaRocca, & Johnston, 2002).

Studies in pediatric populations have found that children who report greater illness intrusiveness also indicate poorer psychosocial outcomes (Wagner et al., 2003). Carpentier, Mullins, and Van Pelt (2007) found that, among college students with asthma, illness intrusiveness significantly predicted depressive and anxious symptoms as well as missed school days. A recent study of AYAs in college similarly found that illness intrusiveness was a significant predictor of depression and anxiety (Mullins et al., 2017). Additionally, in a study of young and middle-aged adults with ulcerative colitis, Maunder and colleagues (2007), found that younger age and single marital status were both risk factors for experiencing elevated levels of illness intrusiveness, indicating that AYAs may be at an elevated risk for illness intrusiveness.

Research has also shown illness intrusiveness to be associated with disease severity, symptom severity, treatment side effect severity, and variability of treatment regimens (Devins, 2010). However, illness intrusiveness is believed to primarily result from an individual's subjective response to and appraisal of their illness, treatment, and environment. It is believed to be more associated with cognitive appraisals of one's illness than objective data about one's illness and treatment. This is consistent with the majority of literature on psychosocial outcomes in illness populations, suggesting that objective data about illness factors is consistently less predictive of psychosocial outcomes as compared to cognitive appraisal variables such as illness intrusiveness or others like illness uncertainty (Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017).

To date, illness intrusiveness has been implicated as a mediating mechanism between stigma and negative psychosocial outcomes in at least two previous studies. Devins, Henderikus, and Koopmans (1994) found that, in adult patients who had recently received a laryngectomy, illness intrusiveness served as a mediator between perceived illness-related stigma and negative psychosocial outcomes. Dancey and colleagues (2002) similarly found illness intrusiveness to mediate the relationship between perceived illness-related stigma and quality of life in adults with irritable bowel syndrome. Importantly, neither of these studies assessed this mediational relationship using contemporary statistical analyses of mediation, nor was this relationship assessed in a pediatric or AYA population.

Summary

In sum, adolescents and young adults (AYA) are at an elevated risk for negative psychosocial outcomes such as depression and anxiety. This is likely due to the transitional nature of adolescence and young adulthood, as well as the many biological and social factors associated with this developmental stage. AYAs who are coping with additional stressors, such as chronic illness, are likely to be at an increased risk for negative psychosocial outcomes. Adolescence and young adulthood is a time for transition in many domains; however, social transitions and social changes seem to be of vital importance for AYAs. Thus, the stress of coping with a chronic condition, and the stigma which may be associated with it, may carry the potential to disrupt typical social development.

Stigma, specifically, has been identified as an important predictor on negative psychosocial outcomes in adults with chronic illness. Further, a small, but growing, number of studies have assessed illness-related stigma in pediatric and AYA populations. Such studies have similarly found stigma to be an important predictor of negative psychosocial outcomes. Frameworks for understanding stigma in adult populations have identified a number of important mediators in the relationship between stigma and negative psychosocial outcomes, which include: negative feelings about one’s self, identity transformation, and maladaptive behaviors.

Illness intrusiveness, the extent to which an individual perceived their illness to keep them from engaging in daily or valued activities, may be an important mediator to assess in AYA illness populations. Illness intrusiveness has consistently been linked to negative psychosocial outcomes. Illness intrusiveness may serve as a maladaptive mechanism, such that individuals who perceive more stigma may be less likely to engage in daily or valued activities as a result of their anticipation or fear of stigma from others when engaging in such activities.

Presently two vital gaps exist in the illness-related stigma literature. First, stigma is understudied in AYAs, a group for which stigma may be especially notable. Second, while illness intrusiveness has been speculated to mediate the relationship between illness-related stigma and psychosocial outcomes, no study has yet assessed this relationship using modern statistical techniques. The study proposed here will serve to better define the effects of stigma in populations of AYAs with chronic illness. Further, the proposed study will use modern statistical techniques to assess the extent to which illness intrusiveness may mediate the relationship between illness-related stigma and psychosocial outcomes.

CHAPTER III

METHODOLOGY

Procedures

Participants were collected as part of an ongoing study assessing psychosocial functioning in college students with and without a chronic illness. All participants were recruited from a large Midwestern university. Participants who completed the survey of questionnaires via an online portal were compensated with course credit, a requirement for many undergraduate courses, including psychology courses. To be included in this study, participants must have a self-reported chronic illness (e.g., diabetes, asthma, inflammatory bowel disease), be between the ages of 18-24 years, and be presently enrolled as an undergraduate student. Participants were not excluded if they reported a chronic psychiatric condition (e.g., major depressive disorder, attention deficit/hyperactivity disorder), but participants must have reported at least one chronic illness which was not psychiatric in nature.

Measures

Demographic characteristics.

Demographic information collected includes age, sex, ethnicity, education level, and type of chronic illness.

Perceived severity and controllability of illness.

Participants rated perceived severity and controllability of their illness on single-item 7-point Likert scales ranging from “mild” to “very severe” and “entirely uncontrollable” to “entirely controllable”, respectively.

Stigma Scale-Revised (SS-R)

The Stigma Scale-Revised (SS-R) is an 8-item self-report questionnaire which assesses perceived illness-related stigma on a 5-point Likert scale, with higher scores indicating more perceptions of stigma (Austin, 2004). The SS-R is a revised version of Austin’s (2004) Stigma Scale (SS), which was initially designed to assess perceived stigma related to an individual’s epilepsy. The SS-R used in the present study is an adapted version of the measure assessing perceived illness-related stigma related to an individual’s “chronic illness.” The scale asks about the extent to which individuals feel that others will be uncomfortable around them because of their chronic illness, how much others will view them differently, and how often they disclose their condition to others. Previous research indicates that the SS has good internal consistency (α = .81; Austin, MacLeod, Dunn, Shen, & Perkins, 2004). In the present study, internal consistency was excellent (α = .94).

Illness Intrusiveness Rating Scale (IIRS)

The Illness Intrusiveness Rating Scale (IIRS) is a 13-item self-report measure assessing the extent to which one’s illness interferes with one’s ability to carry out daily life activities such as work, maintaining relationships, and involvement in the community (Devins, 1983). The items are on a 7-point Likert scale, with higher scores indicating higher levels of illness intrusiveness. Previous research indicates that the IIRS has good to high internal consistency (α = .81-.97; Devins, 2010). In the present study, internal consistency was excellent (α = .92).

Center for Epidemiological Studies – Depression Scale (CES-D)

The Center for Epidemiological Studies – Depression Scale (CES-D) is a 20-item self-report measure assessing current depressive symptoms on a 4-point Likert scale (Radloff, 1977). The items ask about domains of depression such as sadness, loss of interest, loss of appetite, difficulties sleeping, difficulty thinking/concentrating, guilt, tiredness, and movement. Higher scores on the scale indicate higher levels of depressive symptomatology. Scores of 16 or more are considered to be clinically concerning (Lewinsohn, Seeley, Roberts, & Allen, 1997). Previous research indicates that the CES-D has good internal consistency (α = .85-.90; Radloff, 1977). In the present study, internal consistency was excellent (α = .95).

Zung Self-Rating Anxiety Scale (SAS)

The Zung Self-Rating Anxiety Scale (SAS) is a 20-item self-report measure assessing current anxiety symptoms on a 4-point Likert scale (Zung, 1971). The items reflect domains of anxiety such as worry, physiological sensations, and nervousness. Higher scores on the scale indicate higher levels of anxiety symptoms. Scores of 36 or more are considered to be clinically concerning (Zung, 1971). Previous research indicates that the SAS has good internal consistency (α = .81; Olatunji, Deacon, Abramowitz, & Tolin, 2006). In the present study, internal consistency was good (α = .89).

Overview of Analyses

Bivariate correlations initially were conducted to assess the presence of relationships between variables. Path analysis, a specific type of structural equation modeling (SEM), using M*plus* version 7.4, was used to test the relationship between illness-related stigma and both depressive and anxious symptoms, through illness intrusiveness as a mediator. Full information maximum likelihood was used to handle missing data (Ender, 2010). Stigma was entered as an exogenous variable, and illness intrusiveness, depression, and anxiety were entered as endogenous variables. Demographics were estimated for all endogenous variables, including: age, sex, education level, and ethnicity, which was dichotomized due to sample size. Additionally, to control for illness-related factors, self-reported controllability and severity of one's illness were estimated on all endogenous variables. The model was evaluated by model indicators including the chi-square fit to the data, CFI, TLI, RMSEA, and SRMR. The indirect paths of stigma →

intrusiveness → depression and stigma → intrusiveness → anxiety were evaluated, with significant results being indirect paths with $p < .05$.

An additional, alternative model was tested where stigma and illness intrusiveness were put in the model as independent predictors of depression and anxiety, such that no mediational path was tested. This model was compared to the mediational model using the Akaike and Bayesian criteria to test comparative model fit, to identify if the mediational model provides superior model fit to the alternative model (Posada, Buckley, & Thorne, 2004). Lower scores on the Akaike and Bayesian criteria indicate better model fit to the data.

The presently tested mediational model contains 10 manifest variables and 28 freely estimated parameters. Recommendations by Bentler and Chou (1987) suggest that to have adequate power to detect an effect, between 5-10 cases are needed per parameter. Thus, the present study required between 140-280 participants in order to have adequate power to detect an effect.

CHAPTER IV

RESULTS

Descriptive Statistics

Of the 285 college students who completed the study, 275 completed all four measures of interests, and thus were included in the present analyses. Participants in the sample were predominantly Caucasian (77.5%), female (76.5%), and freshmen in college (50.2%). All descriptive statistics are reported in Table 1. On average, participants reported their illness to be between moderate and severe (M = 3.99, SD = 2.15) and between mostly controllable and somewhat uncontrollable (M = 4.23, SD = 1.66). Participants reported significant distress, with 43.2% reporting depressive symptoms above the clinically-concerning cut-off, and 68.4% reporting anxious symptoms above the clinically concerning cut-off. Depressive and anxious symptoms were significantly correlated (r = .80, p < .001), and 53.7% of those reporting clinically concerning depressive symptoms also reported clinically concerning anxious symptoms. Means and standard deviations of variables of interest can be found in Table 2.

Preliminary Analyses

Bivariate correlations revealed significant relationships between demographic and endogenous variables, including sex and anxiety (r = .20, $p < .01$) and grade level and depression (r = -.12, $p < .05$). Significant relationships were found between severity of illness and both stigma (r = .13, *p* < .05) and illness intrusiveness (r = .18, *p* < .001), but not depression or anxiety. Significant relationships were found between controllability of illness and stigma (r = -.21, *p* < .01), illness intrusiveness (r = -.26 *p* < .001), depression (r = -.16, *p* < .01), and anxiety (r = -.23, *p* < .001). Stigma, illness intrusiveness, depression, and anxiety were all significantly correlated with each other (*p*s < .001). The full correlation matrix can be found in Table 3.

Path Analysis

Path analysis was used to test the mediational model with 10 manifest variables and 28 freely estimated parameters. Demographic variables including age, sex, education level, and ethnicity were estimated on all endogenous variables. The model was bootstrapped to 5000. The estimated model yielded good fit to the data as indicated by the CFI (.99), SRMR (.02), and RMSEA (.10). The chi-square test of model fit yielded significant results ($\chi 2$ (2) = 8.0, p < .05), suggesting sub-optimal model fit, and the TLI did not meet acceptable levels (>.90) of model fit (TLI = .88). However, there is evidence to suggest that the chi-square test is not the best indicator of model fit as it is often significant in sample sizes greater than 200, and the TLI is simply a transformation of the chi-squared (Hooper, Coughlan, & Mullen, 2008). Thus, it is believed that the model fit is still good. All anticipated direct paths were significant. Stigma was significantly related to illness intrusiveness (B = 1.18, SE = .09, *p* < .001). Illness intrusiveness was significantly related to both depressive (B = .43, SE = .05, p < .001) and anxious symptoms (B = .37, SE = .03, *p* < .001). Thus, higher perceptions of stigma were related to more illness intrusiveness, which, in turn, were related to increased depressive and anxious symptoms. Further, the indirect paths between stigma and both depression (B = .50, SE = .07, *p* < .001) and anxiety (B = .44, SE = .05, *p* < .001) were significant, indicating that illness intrusiveness was a significant mediator of the relationship. Akaike and Bayesian comparative fit indices were AIC = 6128.95, BIC = 6230.22. Overall, this model accounted for 44% of the variance in illness intrusiveness, 40% of the variance in anxious symptoms, and 29% of the variance in depressive symptoms. See Figure 2 for a depiction of the mediational model.

The alternative path model was estimated with 10 manifest variables and 29 freely estimated parameters. Demographic variables including age, sex, education level, and ethnicity were estimated on all endogenous variables. The model was bootstrapped to 5000. The estimated model yielded significantly poorer fit to the data, with the Akaike (AIC = 6246.49) and Bayesian (BIC = 6351.38) comparative fit indices indicating poorer model fit as compared to the mediational model. As such, the model in which illness intrusiveness was considered as a mediator yielded improved fit to the data as compared to the model in which stigma and illness intrusiveness are considered separately.

CHAPTER V

DISCUSSION

Study Review

The present study examined the relationships between illness-related stigma, illness intrusiveness, and depressive and anxious symptoms in a population of college student AYAs. These results align with previous findings which suggest both illness-related stigma and illness intrusiveness to be important predictors of negative psychosocial outcomes (i.e., depression and anxiety; Devins, 2010; MacLeod & Austin, 2003). Importantly, while a small number of studies have assessed the relationship between illness-related stigma and negative psychosocial outcomes in pediatric populations (e.g., Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Funderburk, McCormick, & Austin, 2007; Masnari et al., 2013), illness-related stigma is a novel predictor in AYA illness populations. The present study is the first known to assess the relationship between illness-related stigma and negative psychosocial outcomes in an AYA population, with previous pediatric studies assessing children only up until the age of 16 (Austin et al., 2004; Funderburk et al., 2007; Masnari et al., 2013). To build upon this previous research, the present study also sought to theoretically understand how illness-related stigma may lead to these negative psychosocial outcomes. According to Stevelink and colleagues' (2012) model, which is specific to illness-related stigma in adults, the primary means by which illness-related stigma affects psychosocial outcomes is through behavioral manifestations, including maladaptive behaviors and cognitions. Thus, the present study sought to test illness intrusiveness as a possible behavioral mechanism by which illness-related stigma may influence psychosocial outcomes.

Illness intrusiveness has been widely implicated as a contributor towards negative psychosocial outcomes in pediatric, adult, and AYA populations, and across a range of illness populations (Devins, 2010). Most recently, Mullins and colleagues (2017) conducted a related study of college student AYAs, finding that illness intrusiveness was a particularly important predictor of both depressive and anxious symptoms, even when controlling for self-reported severity and controllability of illness. The current findings further identified illness intrusiveness as a significant mediator between illness-related stigma and both depressive and anxious symptoms. Importantly, comparative model fit analyses revealed that the model assessing illness intrusiveness as a mediator yielded better fit to the data than a model in which illness-related stigma and illness intrusiveness were considered as independent predictors. Thus, our results support previous studies which have identified illness-related stigma as a mediator between illness-related stigma and negative psychosocial outcomes (Dancey et al., 2002; Devins et al., 1994). Yet, the present study adds considerably to our understanding of this relationship, as previous studies which have assessed these constructs together were tested only in adult populations, and in limited illness populations (i.e., laryngectomy and irritable bowel syndrome).

Most studies of illness intrusiveness have evaluated the construct as an independent predictor of negative psychosocial outcomes (Devins, 2010). However, we tested the importance of illness intrusiveness as a possible mechanism by which illness-related cognitions and perceptions (i.e., illness-related stigma) may lead to negative psychosocial outcomes such as depression and anxiety. Theoretical models of illness intrusiveness posit that the intrusion of illness leads to negative psychosocial outcomes by reducing positive reinforcement from one's environment and reducing one's sense of control over their environment (Devins, 2010). Although illness intrusiveness may be partially driven by objective intrusions of illness into one's abilities to engage in valued activities, the present analyses would suggest that illness intrusiveness may be partially driven by negative cognitions, such as stigma, which result in an individual withdrawing from valued activities despite objective abilities to engage in these activities. Thus, illness intrusiveness may actually serve as a manifestation of stigma, as per Stevelink and colleagues' (2012) model. With this model in mind, it may be that individuals who perceive and expect stigma might actually withdraw from valued activities *in anticipation* that their illness may be noticeable and negatively evaluated if they engage in these activities. In this manner, illness intrusiveness may serve as an important mechanism by which stigma leads to negative psychosocial outcomes.

Clinical Implications

The present study has multiple implications for potential systemic and clinical interventions. Most notably, the rates of depressive and anxious symptoms reported by AYAs in this sample were markedly elevated. Thus, there appears to be a great need for universities to provide appropriate screening and interventions to address psychosocial distress in college students with chronic illnesses, as they may be at particularly elevated risk for these negative psychosocial outcomes. Additionally, these results reveal multiple areas for intervention which may be helpful in addressing negative psychosocial outcomes. First, system-wide interventions aimed at reducing stigma are likely to be especially useful in alleviating perceptions of stigma in AYAs with chronic illnesses. Previous research has demonstrated that, with increased awareness about specific health conditions, perceptions of stigma are lowered (Vaughan & Hansen, 2004). As such, projects which aim to raise awareness about chronic illnesses on college campuses, or via social media may be especially useful in preventing or reducing perceptions of stigma across a large number of AYAs. Second, individual interventions which target distorted cognitions about illness-related cognitions, such as Cognitive Behavioral Therapy (CBT), or interventions which promote acceptance of things that cannot be changed, such as Acceptance and Commitment Therapy (ACT) may be useful in reducing perceived stigma and its effects on an individual level (Halliburton & Cooper, 2015; Hofman, 2013). Finally, interventions which target illness intrusiveness, such as Behavioral Activation, may be particularly helpful in reducing negative psychosocial outcomes (McCauley et al., 2016).

Future research is needed to test the applications of the aforementioned interventions in order to determine their efficacy in reducing stigma and its deleterious effects on mental health. Additional studies are also needed to replicate the present findings in other AYA samples. Further, given that AYAs with chronic illnesses have reduced social support as compared to their healthy peers, and that both stigma and illness intrusiveness are inherently social constructs, future research would benefit from the addition of social support to this model. Serial mediation could also be used to test additional models, as reductions in social support may be secondary to the observed intrusion of illness in this population, and reduction in social support may also help explain the occurrence of negative psychosocial outcomes.

Limitations

The findings of the present study should be interpreted in light of a number of limitations. Most notably, the present study is cross-sectional in nature, which means that causality cannot be inferred from these analyses. Future research would benefit from the longitudinal analysis of these variables to better determine the temporal nature of these phenomena. Additionally, the present findings may have limited generalizability as the AYAs included in this sample were not particularly ethnically diverse and include disproportionately more females than males. Additionally, only AYAs enrolled in a university were included in the analyses, and thus these findings may not generalize to AYAs who did not go on to attend college. Finally, given the self-report nature of the measures included, findings may be artificially bolstered by common method variance. However, in light of these limitations, the present study is believed to be an important contribution to our limited understanding of illness-related stigma in AYAs with a chronic illness.

Conclusions

In sum, the present results validate previous findings that both illness-related stigma and illness intrusiveness are related to negative psychosocial outcomes (i.e., depressive and anxious symptoms). Further, these findings are the first to examine this relationship in an AYA population. Additionally, these analyses revealed that illness intrusiveness may be a valuable mediator of the relationship between illness-related stigma and negative psychosocial outcomes. These findings have multiple implications for interventions to help alleviate negative psychosocial outcomes in AYAs with chronic illnesses, which may be particularly relevant for universities seeking ways to address student mental health

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APPENDIX A. TABLES

Table 1. Demographic Characteristics (*N* = 285)

Characteristic	*N (%)*
Ethnicity	
Caucasian	222 (77.9)
African American	9 (3)
Hispanic	10 (3.5)
Native American	19 (6.7)
Asian	6 (2.1)
Multi-Racial	17 (6.0)
Not reported	2 (1)
Age – Mean (SD)	20 (3.13)
Sex	
Female	218 (76.5)
Grade Level	
Freshman	143 (50.2)
Sophomore	67 (23.5)
Junior	37 (13)
Senior+	38 (13.3)
Chronic Medical Conditions Reported	
Asthma	118
Gastrointestinal Disorders (i.e., Inflammatory Bowel Disease, Irritable Bowel Syndrome)	63
Type 1 Diabetes	19
Other (e.g., epilepsy, obesity, juvenile rheumatoid arthritis)	258

Table 2. Average Total Scores and Standard Deviations

Measures	Mean	SD	Range
SS	18.28	8.80	8-40
II	34.74	17.48	13-84
CES-D	20.58 †	14.34	0-60
SAS	42.14 †	11.24	21-76

Note: SS = illness-related stigma, II = illness intrusiveness, CES-D= depressive symptoms scale, SAS = anxiety symptoms scale

† Above screening clinical cut-off

Table 3. Correlation Matrix

Variables	1	2	3	4
1. Stigma	-			
2. II	.63***	-		
3. CES-D	.42***	.51***	-	
4. SAS	.49***	.61***	.80***	-
5. Severity	.13*	.18***	.02	.08
6. Controllability	-.21**	-.26***	-.16**	-.23***
7. Age	.07	.11	-.03	.05
8. Sex	.07	.11	.06	.20**
9. Ethnicity	.02	.02	.09	.03
10. Grade Level	.01	.10	-.12*	-.02

Note: CES-D= depressive symptoms scale, SAS = anxiety symptoms scale, II = illness intrusiveness
*$p < .05$, **$p < .01$, ***$p < .001$

APPENDIX B. FIGURES

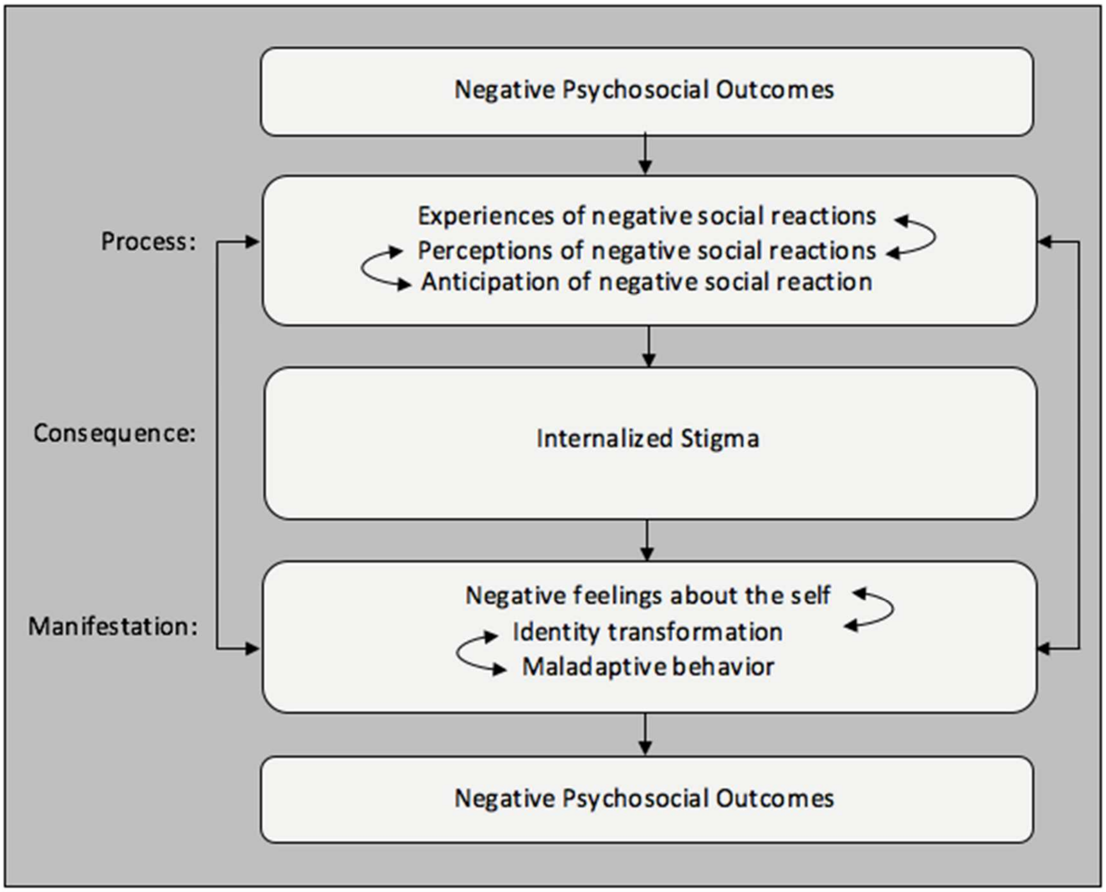


Figure 1. Adapted framework for the impact of illness-related stigma (based on Stevelink et al., 2012)

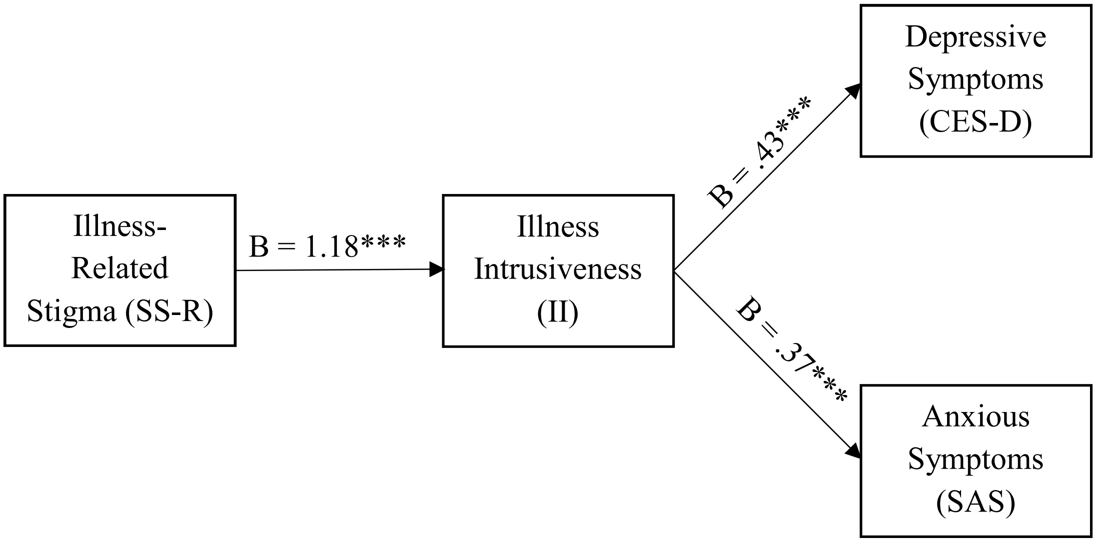
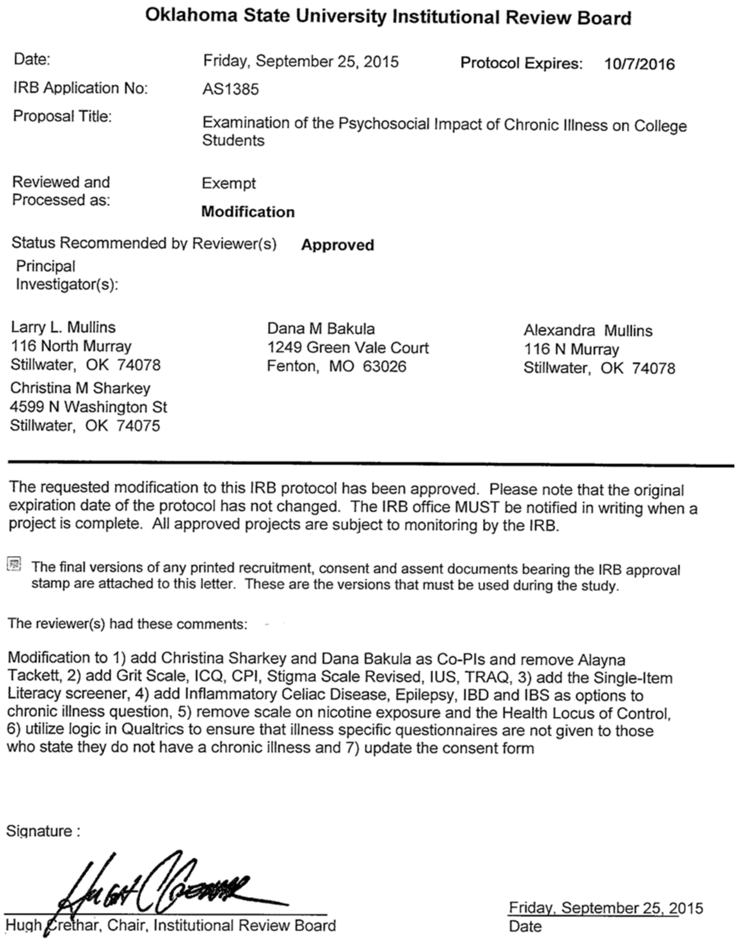


Figure 2. Path Analysis Model.
Note. Demographic variables (i.e., age, sex, ethnicity, education level) were controlled for in the model, but are not depicted.
Note. ***$p < .001$



Oklahoma State University Institutional Review Board

Date: Friday, September 25, 2015 **Protocol Expires:** **10/7/2016**

IRB Application No: AS1385

Proposal Title: Examination of the Psychosocial Impact of Chronic Illness on College Students

Reviewed and Processed as: Exempt

Modification

Status Recommended by Reviewer(s) **Approved**

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The requested modification to this IRB protocol has been approved. Please note that the original expiration date of the protocol has not changed. The IRB office MUST be notified in writing when a project is complete. All approved projects are subject to monitoring by the IRB.

☑ The final versions of any printed recruitment, consent and assent documents bearing the IRB approval stamp are attached to this letter. These are the versions that must be used during the study.

The reviewer(s) had these comments:

Modification to 1) add Christina Sharkey and Dana Bakula as Co-PIs and remove Alayna Tackett, 2) add Grit Scale, ICQ, CPI, Stigma Scale Revised, IUS, TRAQ, 3) add the Single-Item Literacy screener, 4) add Inflammatory Celiac Disease, Epilepsy, IBD and IBS as options to chronic illness question, 5) remove scale on nicotine exposure and the Health Locus of Control, 6) utilize logic in Qualtrics to ensure that illness specific questionnaires are not given to those who state they do not have a chronic illness and 7) update the consent form

Signature :

Hugh Crethar, Chair, Institutional Review Board

Friday, September 25, 2015
Date

VITA

DANA MARIE BAKULA

Candidate for the Degree of

Master of Science

Thesis: THE ROLE OF STIGMA IN THE RELATIONSHIP BETWEEN ILLNESS INTRUSIVENESS AND DEPRESSION/ANXIETY IN COLLEGE STUDENTS: A PATH MODEL

Major Field: PSYCHOLOGY

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Society of Clinical Child & Adolescent Psychology – APA Division 53
Society for a Science of Clinical Psychology
American Psychological Association of Graduate Students (APAGS)
Society of Rehabilitation Psychology – APA Division 22