3rd icH&Hpsy 2017

3rd International Conference on Health and Health Psychology

CHRONIC ILLNESS STIGMA AND WELL-BEING IN YOUTH: THE MEDIATING ROLE OF SUPPORT

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Abstract

A considerable amount of stigma-related health research has been conducted in school-aged and university students, yet few studies involved young people enrolled at further education colleges. The present study aims to investigate the role of social support on the consequences of stigma on general health and social functioning in students in Colleges of Further Education (CFE) living with chronic illness. Participants of this study (n = 55) were students in CFE in Ireland aged 18-25 years diagnosed with a chronic illness. Self-report measures were used to assess stigma, social support, social functioning and general health. Using Structural Equation Modeling (SEM) with 2000 bootstrapped samples a model was constructed and tested to answer the research questions of the study. SEM revealed a good model fit to data (χ^2 = 2.12, df = 2, p = .33). Stigma negatively predicted general health and social functioning in youth living with chronic illness. The bootstrapped mediational model showed that social support from family, friends and a significant other partially mediated the influence of stigma on social functioning but not on general health. Stigma is an important element that negatively influences aspects of well-being in young adults living with chronic illnesses. Youth that perceive their environment to be more supportive tend to have less self-stigma attitudes and better functioning. Understanding how stigma operates in students in CFE can be used to design effective interventions.

Keywords: Stigma, social support, social functioning, health, youth, chronic illness.

1. Introduction

Chronic health illnesses are categorized by the World Health Organisation (WHO; Nolte & McKee, 2008) as conditions that require continuous management over a long period of time. These include cardio-vascular conditions, diabetes, cancer, respiratory conditions, long-term viral conditions such as Hepatitis C, and some communicable diseases, for example HIV/AIDS, which were previously considered rapidly deteriorating but are now controllable health conditions. The definition of chronic conditions also encompasses mental health disorders. The Centers for Disease Control and Prevention (CDC, 2017) also includes musculoskeletal, neurological ilnesses and obesity in their definition. The Chronic Illness Framework outlined by the Health Service Executive (HSE, 2008) focuses more clearly on the features of a chronic condition, noting that chronic conditions have multiple and complex causes, occur across the life span and share common risk factors. This framework also recognises the burden chronic illnesses place on the individual, leading to deterioration of quality of life.

In Ireland, national estimates of the prevalence of chronic disorders in late adolescence show that 20-30% experience a chronic condition, with over 10% reporting that their condition has a significant negative impact on their quality of life (Yeo & Sawyer, 2005). These rates are likely to increase with age, particularly in the case of mental health problems, of which a majority develop by the age of 18 years (Kessler et al., 2007). Verhoof and colleagues highlight that as treatment and prognosis for chronic illnesses improve, more affected children and adolescents reach adulthood. These young people encounter the same developmental milestones as their peers such as going to college, leaving home and finding a job (Verhoof, Maurice-Stam., Heymans, Evers, & Grootenhuis, 2014). This may be more challenging for young people with chronic conditions as it can be difficult for them to fully participate in certain activities.

Research has shown that young adults with chronic conditions may be at risk for poorer developmental and social outcomes as they struggle with the impact of their condition (Stam, Hartman, Deruloo & Grootenhuis, 2006). Significant variations in functioning are seen even within the same chronic illness. Severity of illness symptoms cannot fully account for these variations in adverse impacts on functioning (Verhoof, et al., 2014). Thus, when trying to understand the impact of chronic illnesses the need to examine the influence of psychosocial factors on health outcomes has been highlighted (Boot, Heijmans, van der Gilden & Rijken, 2008). One psychosocial aspect of the experience of chronic illnesses that may contribute to this disparity is stigma.

1.1. Chronic Illness Stigma

Stigma theorists have offered different dimensions of the term that help clarify stigma's impact. Public stigma, or enacted stigma, is the perception held by a large group or society that an individual, based on some criteria, is socially unacceptable and is often accompanied by stereotyping, prejudice and discrimination (Vogel, Wade, & Haake, 2006; Molina, Choi, Cella & Rao, 2013). When individuals with chronic illnesses internalize negative public beliefs, this is self-stigma, or internalized stigma. Self-stigma then is the detriment to an individual's self-esteem or self-worth caused by self-identifying as someone deemed by society to be socially unacceptable. Quinn and colleagues examined the impact of stigma on psychological distress and illness symptoms in individuals with stigmatised chronic illnesses suggesting

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that stigma produced negative outcomes in terms of psychological and physical wellbeing (Quin et al., 2014).

Stigma research with a variety of specific chronic illnesses including HIV/AIDS (Smith, Rosetto & Peterson, 2008), obesity (Puhl & King, 2013) and mental health disorders (Hinshaw & Stier, 2008) has illustrated negative effects on self-esteem, physical outcomes, psychological distress, self-efficacy and adherence to treatment. In a systematic review of the impact of stigma on wellbeing in patients with inflammatory bowel disease (IBD), Taft and Keefer (2016) found that those who experienced high levels of stigma experienced reduced quality of life and higher levels of social withdrawal. Bower and colleagues (2012) found that young people cited fear of embarrassment and stigma as the primary barriers to help seeking. Increased psychological distress caused by stigma places a significant burden on sufferers who may feel their symptoms are exacerbated and their quality of life is doubly burdened. However, stigma does not occur in isolation and may be affected by other factors. Within chronic health research, the effects of stigma have been found to be mediated by factors such as social support (Bautista, Shapovalov & Shoraka, 2015).

1.2. Social Support

Social support can be understood as the reassurance, information and help that a person receives from others (Sarason, 2013). Social support has been found to influence the relationship between stigma and quality of life in serious mental illness (Chronister, Chou & Liao, 2013) and chronic diseases (Earnshaw, Quinn, Kalichman, & Park, 2013). Those with lower perceived social support tend to report greater experiences of stigma and diminished quality of life. These findings are in line with the buffering hypothesis which postulates that social support has a protective function during conditions of high stress that are detrimental to health (Penninx et al., 1997).

An important distinction that has emerged in social support literature is that of perceived social support versus the actual social support received. Perceived social support is defined by Kang, Park and Wallace (2016) as the perception by an individual that they are in receipt of affective and attitudinal assistance and the availability of instrumental support. Received social support is described as the frequency with which supportive behaviours are actually received (Dour et al., 2014). This distinction is crucial given the body of research which suggests that perceived social support is more consistently linked to positive health outcomes than that of received social support (e.g. Uchino, 2004). The effects of perceived social support on physical health outcomes in individuals have been investigated for a number of chronic conditions, typically involving samples of older adults (e.g., Lyyra, & Heikkinen, 2006; Strom & Egede, 2012).

1.3. Non-Traditional University Students

Although traditional university students are one of the most studied population group in the social science literature (Henrich, Heine, & Norenzayan, 2010), there is a dearth of literature investigating non-traditional university students, such as those attending colleges of further education. These institutions are reported to differ from traditional universities in terms of demographic, culture and rates of mental health difficulties (Eisenberg, Hunt & Speer, 2013; Katz & Davison, 2014). In a recent nationwide survey (N =

4,312), Eisenberg and colleagues found that the prevalence rates were higher in non-traditional university students attending Community Colleges, with 49% of students reporting experiencing either anxiety or depression (Eisenberg, Goldrick-Rab, Ketchen-Lipson & Broton, 2016). This higher prevalence rate had been observed in conjunction with fewer institutional mental health resources when compared with traditional universities (Katz & Davison, 2014). Research into the challenges facing community college students in relation to mental health difficulties is in its infancy and even less is known about the levels of physical health difficulties among students in such institutions. The positive effects of social support on adjustment to student life have been explored in traditional universities (Credé & Niehorster, 2012). However, to date there are no studies conducted in Colleges of Further Education.

2. Problem Statement, research questions and purpose of the study

2.1 Problem Statement

As discussed previously, improvements in treatment options for those with chronic illnesses have resulted in an increased number of youth surviving into adulthood and thus perusing third level or further education (Barakat & Wodka, 2006). Royster and Marshall (2008) note that those with chronic illnesses may face more limited post-secondary education possibilities as the typical 3 or 4 year University path may prove difficult to manage. Eisenberg et al. (2016) highlight that community colleges may provide an option to bridge the gap between post-secondary education and University and may be more accessible. Students in such colleges are likely to represent a broader range of backgrounds, particularly in terms of socio-economic status. In order to develop comprehensive programmes to deal with the impact of stigma in this vulnerable population, it is necessary to explore these concepts in context. While considerable research has focused on the experience of chronic health problems in adults, few studies have investigated the impact of stigma on chronic health conditions in young people and particularly in students attending further education settings.

2.2 Research Questions

The present study aimed to answer the following research questions: a) Is stigma associated with social functioning and general health in students in Colleges of Further Education (CFE)? b) Does social support mediate the relationship between stigma, social functioning and general health?

2.3 Purpose of the Study

Research suggests that students in further education settings encounter more mental health problems than students attending traditional university settings (e.g. Eisenberg et al., 2016). However, there is limited or no knowledge on chronic illnesses rates in this population. Stigma has been previously associated with a number of adverse outcomes on different aspects of well-being and quality of life. One possible explanation is that individuals who experience stigma are less likely to seek professional help or support (Schnyder, Panczak, Groth, & Schultze-Lutter, 2017). This may contribute to accessing less resources that could ameliorate their physical or/and psychological well-being. Furthermore, as a result of facing stigma people may think of themselves as inferiors or as burden to others, which often leads to their isolation and social exclusion (Green, 2009). To date no studies have examined the links between

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stigma, well-being and social support in CFE students living with a chronic illness. The present study aimed to shed light in this field by examining the effects of stigma on well-being and the role of social support in young adults enrolled at further education settings. We hypothesized that stigma will exert a negative impact on social functioning and general health and that social support will mediate this relationship.

3. Research Methods

3.1. Participants

Participants of this study were students aged 18-25 years (mean age = 20.2, *SD* = 2.22) enrolled at Colleges of Further Education in the Republic of Ireland (*n* = 55). The inclusion criterion to participate in the study was to have been formally diagnosed and live with a physical or/ and mental chronic illness. Table 1 presents the sample distribution accounted for by gender, ethnicity and type of chronic illness. As shown in Table 1, the majority of the participants were females, white Irish and were diagnosed with a mental chronic illness.

Table 01. Demographics about gender, ethnicity and diagnosed chronic illness (*n* = 55)

Gender	N	Frequency (%)
Males	12	21.8%
Females	40	72.7%
Do not identify oneself as male or female	3	5.5%
Ethnicity		
White	54	98.2%
Black/Black Irish	1	1.8%
Chronic Illness		
Mental	27	49.1%
Physical	11	20.0%
Both	17	30.9%

3.2. Measures

Chronic Illnesses. Participants were presented with a definition of chronic illness, which was developed by combining the definitions provided by WHO, CDC and HSE. Then they were asked to indicate if they were formally diagnosed with a physical or/and mental chronic illness by a health or mental health care professional.

Social Support. To assess social support participants completed the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988). MSPSS, a 12-item self-report questionnaire. This scale was constructed to measure three sources of social support: family, friends and a significant other. Each of these sources is a subscale consisting of four items. Each item is rated on 7-point scale ranging from 'strongly disagree' (1) to 'strongly agree' (7). The score is calculated by averaging the item scores. MSPSS showed good reliability and validity in patients living with chronic

physical and mental illnesses and is recommended for use in clinical populations (Hardan-Khalil & Mayo, 2015). Cronbach's alpha for the present sample was excellent ($\alpha = .88$).

Chronic Illness Stigma. Stigma was assessed using the Stigma Scale for Chronic Illnesses 8-item version (SSCI-8) developed by Molina and colleagues (Molina, et al., 2013). This brief scale measures internalized and enacted stigma in individuals living with chronic conditions. Each item is rated on a 5-point Likert scale ranging from *'Never'* to *'Always'*. The total score derives by summing up all items. The tool has demonstrated adequate internal consistency and validity associated with psychological well-being and functioning (Molina et al., 2013). Cronbach's alpha for the present sample showed an excellent internal consistency ($\alpha = .86$)

Social Functioning and General Health. The Social Functioning and General Health scales of the 36-Item Short Form Survey (SF-36) were used to assess these two domains of quality of life. The SF-36 is a brief self-report questionnaire that has been widely used in health research to assess quality of life (Ware, Snow, Kosinski, & Gandek, 1993). In total there are eight scales measuring eight different dimensions of health: Vitality, Bodily Pain, Role limitations due to physical problems, Role limitations due to emotional problems, Emotional Well-being, General Health, Social Functioning and Physical Problems. The tool has been proven valuable in assessing quality of life in patients living with chronic illnesses. The usefulness of SF-36 spans across a wide range of applications both in research and clinical practice (Pan & Barnhart, 2016; Ware, 2000). For the purposes of the present study only the Social Functioning and General Health scales of the survey were used demonstrating excellent reliability (Cronbach's alpha: $\alpha = .85$ and $\alpha = .93$ for Social Functioning and General Health respectively). The scales were scored following the developers' guidelines by averaging the items of each scale after recoding them. The scores represent percentages ranging from 0-100 with higher scores indicating better social functioning and better general health.

3.3. Procedure

Data collection for this study was conducted using Qualtrics software (Qualtrics, Provo, UT) after creating an online version of the survey. Participants were recruited entirely online via snowball sampling. Prior to their participation, they were presented with an electronic information sheet and consent form. All responses were anonymous. The Human Research Ethics Committee - Humanities of University College Dublin granted ethical approval for the study.

3.4. Data Analysis Overview

Data analyses included two tiers. At Tier 1 zero order correlations were applied in order to examine the relationships among all the study variables using SPSS version 20. At Tier 2 Structural Equation Modeling (SEM) was conducted to test the hypothesized mediation model using AMOS version 20. The following fit indices were used in order to determine fitting-data adequacy: chi-square (χ^2) statistic (when non-significant indicates good fit); Root Mean Square Error of Approximation (RMSEA) and Standardized Root Mean Square residual (SRMR) with values <.08 indicating a good fit and values

$\leq$. 05 indicating an excellent fit; Goodness of Fit Index (GFI), Adjusted Goodness of Fit Index (AGFI) and Comparative Fit Index (CFI) with values > .90 indicating a good fit and values >.95 indicating an excellent fit (Hu & Bentler, 1999).

The total, direct and indirect effects were calculated using bootstrapping with bias-corrected (BC) confidence interval (CI) procedures. Bootstrapping is a resampling method suggested as a superior alternative of the product of-coefficients approach (Sobel test), because it overcomes the normal distribution assumption of the indirect effect (Hayes, 2009). The 95% CIs of the total, direct and indirect effects were calculated using 2000 bootstrapped resamples drawn from the initial sample (n = 55). There were no missing values.

4. Findings

4.1. Descriptives and interrecorrelations

Descriptive statistics and correlations among study variables are presented in Table 2. All correlations were statistically significant. As shown in Table 2 stigma demonstrated a moderate to strong negative correlation with social support, social functioning and general health. As expected social support, social functioning and general health were all positively associated.

Table 02. Descriptives and intercorrelations among all study variables (n = 55).

Variable	Mean	SD	1	2	3	4
1.Stigma	18.5	6.87	-			
2.Social Support	4.9	1.16	-.34[*]	-		
3.Social Functioning	47.1	28.6	-.46[**]	.40[**]	-	
4.General Health	47.4	25.4	-.55[**]	.34[*]	.31[*]	-

[*] p < .05, [**] p < .01

4.2. Structural Equation Modeling

The findings of SEM showed that hypothesized model fitted very well the current data. The chi- square was not significant (χ^2 = 2.12, df = 2, p = .33) with RMSEA and SRMR values were .04 and .05 respectively. CFI, GFI and AGFI values were .99, .98 and .91 respectively. Stigma accounted for 11% of the variance in social support and 30% of the variance in general health. Together stigma and social support accounted 28% of the variance in social functioning.

Chronic illness related stigma negatively predicted social support (β = -.34, SE = .12, p = .008, CI = -.52-.13), social functioning (β = -.37, SE = .12, p = .01, CI = -.52-.13) and general health (β = -.55, SE = .09, p = .001, CI = -.69-.37). Social support exerted a significant positive impact on social functioning (β = .27, SE = .12, p = .04, CI = .05-.46). However, social support did not significantly predicted general health during the first time the model was tested, thus it was decided to fix this path to zero in order to achieve a better model structure. Hence, social support was tested as a mediator of the association between stigma and social functioning. The indirect effect of stigma on social functioning through social support was significant (β = -.09, SE = .06, p = .02, CI = -.21-.02), indicating that social support partially mediated the impact of stigma on social functioning.

5. Conclusions

The findings of the present study showed that chronic illness related stigma has a strong negative influence on social functioning and on general health in students of CFE living with a chronic illness. These findings are consistent with other studies showing the negative consequences of stigma on well-being in individuals living with chronic illnesses. For example, Taft and Keefer (2016) found that the internalisation of stigma was associated with the highest levels of psychological distress and exacerbation of physical symptoms. Similar negative consequences of stigma have been found in young adults suffering from narcolepsy (Kapella, et al, 2015). Thus, our study expands this literature showing that chronic illness related stigma is a crucial element in the lives of students attending CFE because aspects of well-being such as general health and social functioning are affected. This becomes increasingly important considering that these young adults are in a transitional life stage facing major challenges such as successfully completing their studies, starting a career and establishing a life plan. Living with a chronic illness coupled with the adverse outcomes of stigma imposes a huge burden on these young people, which significantly deteriorates their quality of life.

Our findings showed that perceived social support from family, friends and a significant other mediates the negative impact of stigma on social functioning but not on general health. Stigma inhibits the social life of people who are the recipients of false beliefs and lack of understanding of others. This often leads people to limit or even avoid social interactions in an effort to protect themselves from stigma (Armentor, 2015). The buffering role of social support was evident in other studies with people living with chronic illnesses. For example, Xiao and colleagues showed that social support was a significant factor related to the coping strategies employed by people living with a chronic illness (Xiao, Li, Qiao, Zhou, & Shen, 2017). In another study, Ravert, Russell and O'Guin (2017) found that peer support was one of the most important resources for college students living with chronic conditions.

Social support from family and friends has been asserted as an important element of coping strategies employed to counter the burden of a chronic illness (Williams, 2016; Yohannes, 2013). Because living with a chronic illness is very often accompanied with stigma, our findings have important implications in the light of designing prevention and intervention programs that will tackle stigma by raising awareness on and promoting the vital role of social support. Sources of social support such as health professionals and self-help groups have also been reported as positive assets for different population groups living with a chronic illness (Garcia-Sanjuan, Lillo-Crespo, Sanjuan-Quiles, Gil-Gonzalez, & Richart-Martinez, 2016). Future research should be oriented in examining the potential impact of these support resources in relation to stigma in students of continuing education settings who live with a chronic illness.

5.1. Limitations

Despite the strengths of the present study there are some limitations that should be considered. We assessed two aspects of well-being, social functioning and general health. Firstly, although these two aspects are important indicators of one's quality of life, other domains should be also explored for being affected by stigma such as emotional well-being. Secondly, although we evaluated stigma attached to chronic illness, we did not measure the different facets of stigma. Hence, results of the present

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investigation should be interpreted without making inferences about the effects of different facets of stigma on young adults' well-being. Lastly, the majority of the participants were female students, which did not allow to examine for gender differences across the study variables.

Acknowledgments

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