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Anticipated stigma and healthcare utilization in COPD and neurological disorders☆,☆☆

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ABSTRACT

This descriptive correlational study explored the experience of anticipated stigma and its association with health-seeking behavior in individuals with COPD or a neurological disorder. Participants with COPD (n = 38) or neurological disorders (n = 39) were recruited from specialty practices. The Chronic Illness Anticipated Stigma Scale (CIASS) and Healthcare Access Measure (HAM) were used to measure stigma and healthcare utilization in this population. Socio-demographic and illness-related data were entered into a hierarchical regression analysis to identify variables that contribute to anticipated stigma from three sources. The mean scores of anticipated stigma by family and friends, coworkers, and healthcare workers were low to moderate at 7.96, 11.68 and 7.94 respectively. Mean score on the HAM was 12.94, indicating moderate delay, in healthcare utilization. The HAM was correlated with anticipated stigma by family and friends and healthcare provider subscales (r = .293, p = .010; r = .449 p = .000), indicating a relationship between higher levels of anticipated stigma in these areas and lower levels of healthcare utilization. Anticipated stigma by coworkers was correlated with neurological disorders (r = .257, p = .048). In a final model, 20%, 35.4% and 16.8% of the variance of anticipated stigma from 3 sources can be explained in the final model. Findings from this study describe low to moderate levels of anticipated stigma from three sources is experienced in individuals with COPD and neurological disorders and lends new understanding about the association of stigma to healthcare utilization behavior in this population. Strategies are needed to mitigate the effects of stigma on healthcare utilization.

1. Introduction

Sixty percent of individuals in the United States (U.S.) have one or more chronic health conditions (Buttorff, Ruder, & Bauman, 2017). Chronic illness can lead to long-term disability, reduced health related quality of life (HRQoL) and death. Chronic obstructive pulmonary disease (COPD) and Parkinson's disease (PD) are currently the 3rd and 14th leading cause of death in the U.S. and along with other neurological disorders have a high morbidity rate (American Lung Association, 2013; Frandsen, Kjellberg, Insen, & Jennum, 2014). Effective chronic disease management can reduce the morbidity impact, however adequate self-management that includes follow up with healthcare services for disease monitoring and acute illness management is essential (CDC, 2009). Stigma has been identified in the literature as one reason patients delay, or avoid, using healthcare services (Earnshaw & Quinn, 2011; Weiss, Ramakrishna, & Somma, 2006) resulting in poor disease management and HRQoL (Earnshaw, Quinn, & Park, 2011).

2. Background and significance

Stigma, as defined by Goffman (1963), is the social devaluation of an individual based on physical characteristics, disabilities or behaviors incongruent with established social norms. Stigma can be experienced (enacted), or anticipated (internalized) (Weiss et al., 2006). The diagnosis of a chronic illness often becomes the marker for stigmatizing behavior by self and others (Earnshaw, Quinn, Kalichman, & Park, 2013) and can increase the burden of illness (Weiss et al., 2006). Experienced and anticipated stigma associated with chronic illness is often influenced by whether the illness is believed to be caused by controllable (high-risk behaviors), or uncontrollable factors (Johnson, Campbell, Bowers, & Nichol, 2007). Tobacco related illnesses are frequently associated with self-blame and experienced stigma by family

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and healthcare providers (Berger, Kapella, & Larson, 2011; Halding, Heggdal, & Wahl, 2011). Self-blame increases internalized stigma, and when internalized stigma is coupled with experienced (perceived or enacted) stigma the risk of anticipated stigma is increased (Earnshaw & Quinn, 2011). Whether intentional or unintentional, stigma impacts the health and well-being of individuals with chronic illness (Earnshaw & Quinn, 2011; Halding et al., 2011).

The association between stigma and delay, or avoidance, in accessing healthcare services is prominent in the HIV and mental health disorder literature. Only recently has stigma associated with other chronic illness been more thoroughly investigated. Earnshaw and Quinn (2011) explored internalized, experienced (enacted) and anticipated stigma associated with chronic illness and noted that participants who internalized stigma (self-blame), or who had experienced stigma during healthcare encounters, anticipated stigmatization by healthcare providers more often and were less likely to access healthcare for routine or urgent health management. Anticipated stigma from family and friends, coworkers and healthcare providers also contributes to poorer healthcare utilization and reduced HRQoL (Earnshaw et al., 2011).

A systematic review of stigma-related experiences in individuals with respiratory disease identified negative physical, psychosocial, quality of life, employment, treatment and clinical outcomes (Rose, Paul, Boyes, Kelly, & Roach, 2017). Blame from family and others correlated with self-blame. In patients with COPD, anticipated stigma and self-blame were linked to poorer health status and longer delay in seeking treatment (Rose et al., 2017). In asthma, anticipated stigma was reported to be associated with poorer self-efficacy and subsequent self-management. Illness-related factors were moderately correlated with stigma (Andrews, Jones, & Mullan, 2013). Anticipated stigma by family and friends and coworkers have been reported in individuals with PD (Burgener & Berger, 2008; Hermann, 2013; Maffoni, Giardini, Pierobon, Ferrazzoli, & Frazzitta, 2017; Rao et al., 2009) and chronic migraines (Young, Park, Tian, & Kemper, 2013) and is associated with poorer HRQoL. Demographic characteristics, illness related factors and depression were moderately correlated with stigma in individuals with chronic migraines (Young et al., 2013).

The impact of stigma contributes to the disease burden of chronic illness on many levels, but delay in healthcare seeking is of particular concern for chronic illness management and health outcomes (Quinn & Earnshaw, 2013; Weiss et al., 2006). The literature exploring anticipated stigma in individuals with COPD and neurological disorders is limited. Additionally, the association between anticipated stigma and healthcare utilization has not been described in this population.

3. The study

The purpose of this study was to explore the experience of anticipated stigma in individuals with COPD and neurological disorders, and examine the relationship between anticipated stigma and healthcare utilization. It was our goal to better understand the impact anticipated stigma has on healthcare utilization in individuals with COPD and a subset of neurological disorders in order to develop interventions to reduce stigma-related delays in accessing healthcare services. The research questions were: (a) What are the levels of anticipated stigma by friends and family, coworkers, and healthcare workers experienced by individuals living with COPD or a neurological disorder? (b) What is the relationship between anticipated stigma and healthcare utilization in individuals with COPD or a neurological disorder? (c) What are the predictors of anticipated stigma by friends and family, coworkers, and healthcare workers in individuals with COPD or a neurological disorder?

3.1. Theoretical framework

The Individual and Family Self-Management Theory [IFSMT] (Ryan & Sawin, 2009), a mid-range theory that considers the contextual process and outcome factors that influence self-management, informed this study. Specifically, the social facilitation process, which includes the dimensions of social influence, social support and negotiated collaboration (patient, family, healthcare providers) was perceived by the researchers to be most relevant to the association between anticipated stigma and healthcare utilization, an important component of self-management.

According to the theory, social influence is the advice given to an individual by a healthcare provider (HCP) that encourages them to engage in specific self-management behaviors, social support includes emotional and informational support provided by the HCP to facilitate an individual's engagement in self-management, and negotiated collaboration is the unification of clinician expertise and individual preferences to determine treatment goals, responsibilities and strategies. In this study, anticipated stigma by HCPs was expected to reduce healthcare utilization resulting in reduced opportunities for social influence and social support from healthcare providers. This potentially can negatively impact collaborative illness management.

3.2. Design, sample and setting

A cross-sectional descriptive correlational design was used in this study. A convenience sample of patients with a confirmed diagnosis of COPD or a neurological disorder, who were able to read and write in English and received follow up care at a pulmonology or neurology office within a regional healthcare system, was obtained for this study. Based on a literature review of stigma in populations similar to those under investigation in the current study, a medium effect size by convention was expected. To achieve a power of 0.80 with an alpha of 0.05 and effect size of 0.15, a minimum of 97 participants were required for this regression analysis with 6 predictor variables (Cohen, 1992).

3.3. Research instruments

3.3.1. Demographic and chronic illness data collection tool

Demographic data collected included age, gender, race, marital status, level of education and family income. Participants also reported the number of years since their diagnosis and the extent to which their chronic illness affected life enjoyment on a scale of 1 (not at all) to 5 (all the time).

3.3.2. The Chronic Illness Anticipated Stigma Scale (CIASS)

The CIASS (Earnshaw et al., 2013) was used to measure anticipated stigma. This 12-item scale consists of 3 subscales that measure the extent individuals anticipate stigma from family and friends, coworkers and healthcare providers. Each subscale contains 4 items on a 5-point Likert scale of 1 (very unlikely) to 5 (very likely). Items on each subscale are averaged to create a score for each area of anticipated stigma. Subscale scores range from 1 to 5 with higher scores indicating greater anticipated stigma. Psychometric evaluation of this tool demonstrated good internal consistency ($\alpha = 92, 0.95, 0.95$ for subscales 1–3 respectively) and test-retest reliability ($r = 0.82$, $p < .001$) (Earnshaw et al., 2013). In this study Cronbach's alpha was calculated and subscale reliabilities were 0.851, 0.922 and 0.900 respectively. Permission for use of this scale was obtained from the instrument developer.

3.3.3. The Healthcare Access Measure (HAM)

The HAM (Earnshaw & Quinn, 2011) is a 6 item Likert scale that measures healthcare utilization behavior on a 4-point scale from “strongly disagree” (1) to “strongly agree” (4), indicating whether participants should have accessed healthcare services earlier in a variety of clinical situations. Averaging the 6 item responses provides a total HAM score ranging from 1 to 4. Higher scores indicate poorer healthcare utilization. In this study Cronbach's alpha was 0.730. Permission for use of this measure was obtained from the instrument

developer.

3.3.4. Mental Health Index (MHI-5) of the 36-item SF health survey (SF-36)

The MHI-5 (Ware & Sherbourne, 1992) was used to screen for depression. This abbreviated instrument has a reported Cronbach's alpha of 0.74. Scores < 52 (0 − 100) are suggestive of the presence of significant depressive symptoms (Berwick, Kapella, & Larson, 1991).

3.4. Data collection procedures

After receiving Institutional Review Board (IRB) approval participants were recruited from the specialty practice offices. Participants were informed of the study through flyers displayed in the office waiting areas. Interested participants were directed to request a study packet from the office staff. Each packet contained a study information sheet, a consent form, data collection tools and a stamped, pre-addressed envelope for return of documents to the PI at the university. Participants were directed to read the study information sheet and consent form enclosed in the packet. To maintain anonymity, the participant retained the consent form. Return of the data collection tools implied consent for participation. An additional form and envelope were supplied for provision of a contact number if the participant wished to be entered into a raffle for a Kindle Reader.

3.5. Data analysis

Data were entered into SSPS software. Demographic data were analyzed using descriptive statistics to categorize the sample population. Pearson correlation analysis was conducted to explore associations between stigma and healthcare utilization behavior. Hierarchical regression was used to analyze the relationships among demographic and clinical variables on anticipated stigma in each area explored in the CIASS.

4. Results

4.1. Participant characteristics

A total of 77 participants completed and returned study packets. Although the study was powered for 97 participants, all efforts to recruit additional participants were exhausted. All pulmonology and neurology practices in the healthcare system that agreed to allow recruitment of participants for the study in their office were reminded to have study flyers visible and study packets available. Offices were visited once monthly. After a 3 months period with no further study packets returned, data collection was halted.

Demographic and clinical characteristics are presented in Table 1. Thirty-eight participants (49.4%) reported a diagnosis of COPD and 39 (50.6%) participants reported a neurologic diagnosis. The sample was predominantly white (n = 73, 95%), married (n = 42, 54.5%) females (n = 53, 68.8%) with a mean age of 61.1 (range 20–91, *SD* = 16.33).

Table 1
Demographic, clinical characteristics and mean score of CIASS and HAM (N = 77).

Characteristic	*M* ± *SD* (range)
Age (years)	61.1 ± 16.3 (20–91)
Years with diagnosis	10.7 ± 9.37 (1–39)

Characteristic	n %
Gender	
Male	24 (31.2%)
Female	53 (68.8%)
Marital status	
Single	14 (18.2%)
Married	42 (54.5%)
Widowed	12 (15.6%)
Divorced	9 (11.7%)
Education	
Less than high school	10 (13.0%)
High school	16 (20.8%)
Some college	21 (27.3%)
Associate degree	5 (6.5%)
Bachelor degree	14 (18.4%)
Graduate degree	11 (14.5%)
Income	
< 15,000	12 (15.5%)
15,000–35,000	18 (23.4%)
36,000–55,000	17 (22.1%)
56,000–75,000	13 (16.9%)
> 75,000	17 (22.1%)
Diagnosis	
COPD	38 (49.4%)
Neurological disorder	39 (50.6%)
Migraine	8
Parkinson	12
Other	19

Scale scores	*M* ± *SD* (range)
CIASS subscale 1	2.0 ± 0.98 (1–4.75)
CIASS subscale 2 (workers only n-60)	2.6 ± 1.14 (1–5)
CIASS subscale 3	2.2 ± 0.96 (0.75–4.5)
HAM	2.2 ± 0.57 (1–3.5)

Table 1 shows the participants' mean scores for the study variables of anticipated stigma and healthcare access. The results indicate that study participants experienced a greater amount of anticipated stigma from coworkers (*M* = 2.6, *SD* = 1.14) than by friends and family (*M* = 2.0, *SD* = 0.98) or healthcare providers (*M* = 2.2, *SD* 0.96). Participants also reported reduced healthcare utilization on the HAM (*M* = 2.2, *SD* = 0.57).

4.3. Bivariate analysis of correlations among study variables

Correlation coefficients indicate that anticipated stigma from friends and family (subscale 1) and healthcare providers (subscale 3) was significantly correlated with poorer healthcare utilization behavior. Anticipated stigma from coworkers (subscale 2) was significantly correlated with medical history (*r* = 0.257, p .048), years with diagnosis (*r* = −0.273, p .038) and greater impact of illness on enjoyment of life (*r* = 0.326, p .011). The correlations between subscales of the CIASS, HAM, demographic and clinical variables are displayed in Table 2.

4.4. Multivariate regression analysis of anticipated stigma

The hierarchical regression results are displayed in Table 3. Two models are presented for each CIASS subscale (1, 2, 3) outcome variable. In the first step of each model patient-related factors were entered to determine the influence of gender, age and marital status on anticipated stigma. These variables accounted for 18% of the variance in anticipated stigma from friends and family, 15% of the variance in anticipated stigma from co-workers and 15.9% of the variance in anticipated stigma from healthcare providers. However, only gender contributed significantly to the variance in anticipated stigma by friends and family (subscale 1) and coworkers (subscale 2), and only age contributed significantly to the variance in anticipated stigma by healthcare providers (subscale 3). In step 2 of each model, illness-

Table 2
Bivariate Pearson correlation matrix.

	Age	Gender	Marital status	Medical history	Years with diagnosis	Subscale 1	Subscale 2 n = 60	Subscale 3	HAM	MHI
Age	1***									
Gender	−0.076	1								
	0.523									
Marital status	.428**	0.171	1							
	0.000	0.139								
Medical history	−.437**	−0.047	−0.196	1						
	0.000	0.683	0.089							
Years with diagnosis	0.086	0.099	0.195	0.102	1					
	0.481	0.403	0.098	0.389						
Subscale 1	−276*	.249*	0.002	0.105	−0.014	1				
	0.018	0.029	0.986	0.363	0.906					
Subscale 2	−315*	.230*	−0.122	.257*	−.273*	.459**	1			
	0.015	0.045	0.357	0.048	0.038	0.000				
Subscale 3	−335**	0.136	−0.085	.0.185	0.092	.527**	.440**	1		
	0.004	0.238	0.464	0.108	0.435	0.000	0.000			
HAM	−0.241	0.285	−0.117	.283*	0.112	.293*	0.127	.449**	1	
	0.071	0.013	0.318	0.013	0.346	0.010	0.338	0.000		
MHI-5	.328**	−0.008	.243*	−0.040	0.130	−.297**	−.343**	−0.188	−0.178	1
	0.005	0.943	0.034	0.729	0.269	0.009	0.007	0.101	0.123	

* p < .05.
** p < .01.
*** p < .001.

related factors were entered to determine the influence of illness diagnosis, length of time since diagnosis and MHI-5 score on anticipated stigma. Medical history and years since diagnosis were significant predictors of variance in anticipated stigma by coworkers (subscale 2). There were no significant illness-related predictors of variance in anticipated stigma by friends and family (subscale 1) or healthcare providers (subscale 2). The final models indicated that 20%, 35.4% and 16.8% of the total variance in anticipated stigma by friends and family, coworkers and healthcare providers respectively, is explained by personal-related and illness-related factors.

5. Discussion

This study investigated the experience of anticipated stigma in individuals with COPD and a subset of neurological disorders that include PD (30.8%) and chronic migraines (20.5%). The relationship between anticipated stigma and healthcare utilization was also explored. Participants reported low levels of stigma from family and friends and healthcare workers with only 20–36% reporting that stigma was somewhat likely, likely, or very likely to occur on the CIASS subscales. This is consistent with findings by Rao et al. (2009) and Hermann (2013) in which 10% and 40% of participants with PD reported being stigmatized by family and friends. Qualitative studies by Berger et al. (2011) and Halding, Heggdal, and Wahl (2011) uncovered participant experiences of stigmatization by family, friends and healthcare workers in participant's with COPD, however the number of reports were not quantified. Anticipated stigma by coworkers was captured on CIASS subscale 2 with 45–70% of participants reporting that stigma was somewhat likely, likely, or very likely to be experienced. This is consistent with findings from other studies in which participants with chronic migraines anticipated stigma by colleagues due to missed work time (Young et al., 2013) and by participant's with PD due to inability

Table 3
Hierarchical regression analysis predicting relationship of patient-related and illness-related variables on CIASS subscales.

	CIASS subscale 1			CIASS subscale 2			CIASS subscale 3		
	Friends and family			Coworkers			Healthcare workers		
	n = 77			n = 60			n = 77		
	B	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Step 1									
Patient-related factors									
Age (years)	−0.054	0.033	−0.232	−0.013	0.043	−0.047	−0.072	0.032	−.325*
Gender	2.508	0.975	.302*	3.79	1.33	.351*	1.62	0.944	0.205
Marital status	0.394	0.418	0.122	−0.024	0.553	−0.006	0.114	0.405	0.037
R^2	.180**			.150*			.159*		
$R^{2\ change}$									
Step 2									
Illness-related factors									
Medical history	0.063	0.966	0.008	3.31	1.29	.352**	0.100	0.935	0,014
Years since diagnosis	−0.012	0.046	−0.030	−0.167	0.057	−.355**	0.035	0.045	0.094
MHI-5 score	−0.006	0.005	−0.146	−0.039	0.029	−0.164	−0.004	0.023	−0.021
R^2	0.200			.354**			0.168		
$R^{2\ change}$	0.020			0.204			0.009		

* p < .05.
** p < .01.

to perform work duties because of symptoms (Maffoni et al., 2017). The literature also reports that individuals with COPD anticipate stigma by coworkers because of their frequent illness-related absenteeism and also out of fear of the impact of their illness on insurance rates (Berger et al., 2011). A higher level of depression was also correlated with higher levels of anticipated stigma by coworkers, however the nature of this relationship is not known.

Healthcare utilization was moderately reduced with 30–63% of individuals reporting avoiding, or delaying, necessary healthcare services. HAM scores were significantly correlated with medical history (neurological disorders) ($p = .013$). Anticipated stigma by friends and family and healthcare workers were also correlated with poorer routine and urgent healthcare utilization (< 0.01, < 0.001). This has been reported in the literature to be associated with internalized (self-blame) and enacted stigma leading to anticipated stigma and subsequent avoidance of healthcare encounters (Berger et al., 2011; Chin, 2017; Earnshaw & Quinn, 2011; Halding et al., 2010).

According to the IFSMT (Ryan & Sawin, 2009) individuals are more likely to engage in recommended health behaviors, including healthcare follow-up for routine and urgent care, if they experience social facilitation during their healthcare encounters. Social facilitation includes receiving advice and support as well as engaging in negotiated collaboration to facilitate illness self-management. On the anticipated stigma by healthcare providers subscale of the CIASS, 28.6% of participants thought that a healthcare provider would blame them for not getting better, 20.8% thought a healthcare provider would think they were a bad patient and 36.4% thought a healthcare provider would be frustrated with them. Anticipated stigma by healthcare providers negatively impacts healthcare utilization (as indicated by HAM results) and disengages individuals from the social facilitation process, potentially resulting in poor health outcomes.

Regression analysis demonstrated that patient related-factors contributed most of the variance in anticipated stigma by family and friends (gender) and by health care providers (age), however illness-related factors (medical history, years since diagnosis) contributed a greater amount to the variance in anticipated stigma by co-workers. The literature supports that individuals with chronic migraines and COPD experience frequent absenteeism because of their illness, and individuals have difficulty with performing job tasks because of their symptoms, which explains the higher contribution of illness-related factors to the total variance in anticipated stigma by coworkers. Patient-related factors of age and gender contributed significantly to the variance in anticipated stigma by family, friends and healthcare providers, however illness-related factors do not contribute substantially to the total variance in these sources of anticipated stigma. No conclusions have been drawn from this.

5.1. Implications

Interventions need to be developed for patients, families, employers and healthcare providers to reduce the impact of stigma on healthcare utilization, employment and overall HRQOL. Strategies that increase awareness of anticipated stigma and stigmatizing behaviors are needed, especially among healthcare workers. An important opportunity also exists to increase sensitivity to individuals with chronic disease to reduce stigma in the workplace.

5.2. Limitations

The main limitations in this preliminary study if anticipated stigma and healthcare utilization are the inclusion of multiple neurological disorders in the sample and the overall sample size, which was underpowered limiting generalizability. In future studies it would be recommended to limit recruitment to a single neurological disorder, or increase the sample size in each disorder subset. Additionally, this study used self-report measures and participant diagnosis was not validated with medical records. Although confidentiality and anonymity were ensured and data was returned directly to the researcher at the university, the packets were distributed in physician offices and participants may not have been honest regarding their experience of stigma from healthcare workers. This may also have impacted participation resulting in the researcher's inability to obtain the powered sample. On the contrary, this population also may have had a satisfactory relationship with their healthcare providers, which may not be typical of the larger population of patients receiving these specialty services. The older, educated, white, female characteristics of participant's further limit generalizability.

6. Conclusions

The findings of this study describe the experience of anticipated stigma in individuals with COPD and neurological disorders by family and friends, coworkers and healthcare workers. It also lends new understanding about the relationship of stigma to healthcare utilization behavior in individuals with COPD and a subset of neurological disorders. Anticipated stigma from family and friends and healthcare workers was associated with poorer routine and emergent healthcare utilization, and potentially can contribute to morbidity in this population. Having a neurological disorder was associated with higher levels of anticipated stigma by coworkers. Strategies need to be developed to mitigate the effects of anticipated stigma on employment enjoyment, healthcare seeking behavior and overall HRQoL.

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