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Internalized and Anticipated Stigmatization in Patients With Gout

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Objective. To investigate the relationship between stigma perception and demographic, clinical, and psychosocial variables.

Methods. A sample of 50 patients with gout and prescribed urate-lowering medication (84% were males, mean serum urate 0.34 mmol/l) completed questionnaires on internalized and anticipated stigma, demographics, clinical gout-related variables, and psychosocial variables (illness perceptions, illness-related disability, illness-related body satisfaction, intentional nonadherence). Serum urate level was obtained from the most recent blood test.

Results. In this sample, 26% experienced internalized stigma, 26% expected to be stigmatized by friends or family members, and 14% by health care workers. Univariate regression analyses showed that younger age, ethnicity other than New Zealand European, increased severity of gout pain, cognitive and emotional illness perceptions, greater illness-related disability, and increased intentional nonadherence to urate-lowering medication were associated with increased internalized and anticipated stigma. Younger age, emotional illness response, and intentional nonadherence were the only variables explaining incremental variance of the experience of anticipated stigma in a multivariate regression model.

Conclusion. Internalized and anticipated illness-related stigma was reported by a subgroup of patients with gout. The experience of stigma is associated with younger age, a negative emotional illness response, and intentions to not adhere with a medical treatment.

INTRODUCTION

Gout is a common rheumatic disease characterized by acute, intermittent, and very painful episodes of inflammatory arthritis. It is caused by elevated urate levels, leading to chronic deposition of monosodium urate crystals within joints and other tissues (1). Although risk factors for gout include genetic variants and specific types of pharmacotherapy, lifestyle factors, such as the excessive consumption of alcohol and rich food, are often perceived as the only causes (1). These perceptions regarding the nature of gout may increase the risk of associated social stigma.

Stigma is defined as social devaluation due to a given mark or attribute (2). Self or internalized stigma occurs when an individual perceives that sociocultural beliefs about an undesirable condition apply to them (2). Past research has demonstrated that individuals who experience internalized stigma also experience anticipated stigma, where they expect to be stereotyped by others in the future (2).

Stigmatization is evident in patients with various chronic medical conditions, including epilepsy, HIV infection, asthma, multiple sclerosis, and dermatological diseases. The experience of stigma has been associated with a number of outcomes, including demographic variables (eg, age, education, sex, cultural background) (3,4), clinical variables (eg, symptom severity, general physical health status) (4), and psychosocial variables (eg, illness perceptions, sense of mastery, coping strategies, social support, illness-related disability) (3). Perceived stigma has also been found to negatively interfere with outcomes associated with illness adjustment, such as seeking less health care, poorer treatment adherence, and increased social withdrawal (2).

Although the pathogenesis of gout is well defined, various stereotypes remain associated with the medical condition. The lay population often perceives gout as a humorous,

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SIGNIFICANCE & INNOVATIONS

- Internalized and anticipated stigma are experienced by a subgroup of gout patients.
- Stigma perception is associated with younger age, ethnicity, pain severity, negative illness perceptions, illness-related disability, and intentional nonadherence to urate-lowering medication.
- Younger age, negative emotional illness response, and intentional nonadherence account independently for variance in perceptions of stigma.

self-inflicted, and benign disorder. Attributes of other socially stigmatized illnesses, such as controllability, preventability, visibility, and unpredictability may also apply to gout (5). Qualitative studies assessing the experiences of individuals living with gout suggest that patients often feel embarrassed about seeking help and can be reluctant to accept or act upon their diagnosis (6). This study aims to investigate the strength of association between a set group of variables and stigma in patients with gout. We chose demographic, clinical, and psychosocial variables that have been demonstrated to be related to the experience of stigma in patients with other chronic medical conditions (see brief summary of previous study results above).

METHODS

Participants and procedure. Participants were recruited between August and December 2017 using community advertising in primary and secondary care clinics within Auckland, New Zealand. Participants were included if they had previously been diagnosed with gout by a physician, were 18 years of age or older, were able to complete forms in English and provide written informed consent, and were currently prescribed urate-lowering medication. The study was approved by the University of Auckland Human Participants Ethics Committee. During the study session at the University of Auckland Clinical Research Centre, participants underwent an assessment to confirm gout according to the American College of Rheumatology/European League Against Rheumatism Collaborative Initiative (ACR-EULAR) classification criteria (7) and completed questionnaires.

Measures. *Stigma*. Internalized stigma was assessed using six items from the Internalised/Self-Stigma subscale (current sample Cronbach's α = 0.93) of the Stigma Scale for Chronic Illness (SSCI) (8) that apply well to the condition gout. Anticipated stigma was assessed with the Family Member/Friend (α = 0.81) and Healthcare Worker subscales (α = 0.95) of the Chronic Illness Anticipated Stigma Scale (CIASS) (5). Items from both scales were adapted by replacing the term "illness" with "gout." Table 1 provides information about the scoring of both scales.

Assessing demographic and clinical correlates of stigma. Participants also self-reported demographic variables including age, sex, ethnicity, and years spent in the educational system. Gout history and symptoms (number of flares over the past year, time since first and last gout flare), type of gout medication, duration of urate-lowering therapy (in years), and health care utilization (number of visits to rheumatologist or general practitioner in past year) were assessed using self-report. Subjective general health was assessed with an 11-point numerical rating scale. Pain severity during and between gout episodes was assessed using visual analogue scales. Participants' serum urate level was used to provide an objective biological measure of adherence to urate-lowering medication. Target serum urate level was considered 0.36 mmol/l (7).

Assessing psychosocial correlates of stigma. Illness-related disability was assessed using the disability index of the Health Assessment Questionnaire-II (HAQ-II; α = 0.95) (9). Illness perceptions (consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response) were measured with the Brief Illness Perception Questionnaire (BIPQ) (10). The Resisting Illness (α = 0.96) and Testing Treatments subscales (α = 0.96) of the Intentional Non-Adherence Scale (INAS) (11) were administered to assess intentional nonadherence to urate-lowering medication. Items were adapted to ask participants about "urate-lowering/gout medication." Illness-related body image was assessed with the Brief Satisfaction with Appearance Scale (Brief-SWAP; α = 0.97) (12). Items in the Subjective Dissatisfaction subscale address body parts rarely affected by gout. Items were therefore reworded to ask participants how satisfied they were with the appearance of their feet and ankles.

Statistical analyses. A power analysis revealed that a minimum of 44 participants was required to achieve a moderate effect of $r = 0.40$ with 80% power and an $\alpha = 0.05$ significance level. Statistical analyses were conducted using SPSS version 25. First, univariate linear regression analyses were performed in order to explore whether psychosocial, clinical, and demographic variables were associated with internalized and anticipated stigma.

Second, a multivariate hierarchical linear regression model was applied with each type of stigma as a dependent variable. Variables identified as significant correlates of stigmatization in the univariate analyses were entered as independent variables in the multivariate models to test for incremental variance (level 1: demographic variables; level 2: clinical variables; level 3: psychosocial variables). We assessed some of the independent variables with subscales of one measure (eg, two subscales of the INAS). In the case that two or more independent variables, assessed with the same measure, correlated significantly with one dependent variable, we would check their intercorrelation first. In case of significantly intercorrelated variables ($P > 0.05$), we would add to the

Table 1. Demographic and clinical characteristics and baseline questionnaire mean scores of the sample (N = 50)

Independent Variable	Mean (SD) or N [%]	Min-Max
Demographic variables		
Age (y)	67.77 (9.85)	36-89
Years spent in education	13.62 (4.54)	3-21
Male	42 [84%]	
Ethnicity		
New Zealand European	41 [82%]	
Māori/Pacific Islander	6 [12%]	
Asian	3 [6%]	
Clinical gout-related variables		
Number of gout flares in past year	3.00 (8.78)	0-60
Time since first episode (y)	20.65 (12.54)	1-51
Time since last gout flare (mo)	33.84 (40.42)	0-216
Treatment length (y)	13.49 (12.37)	0-44
Pain during gout flares (VAS)[a]	7.54 (2.25)	0.2-10.0
Pain between gout flares (VAS)[a]	1.58 (2.52)	0.0-10.0
Subjective health rating (NRS)[b]	6.54 (2.48)	0-10
Number of GP & rheumatologist visits in past year	1.22 (1.72)	0-6
Presence of tophi	16 [32%]	
ULT medication		
Allopurinol[c]	48 [96%]	
Febuxostat[d]	2 [4%]	
Serum urate level <0.36 mmol/l	31 [62%]	
Serum urate level (mmol/l)	0.34 (0.09)	0.18-0.64
Psychosocial variables		
Anticipated stigma-family members/friends (CIASS)[e]	0.62 (0.73)	0.00-2.75
Anticipated stigma-health care worker (CIASS)[e]	0.57 (0.76)	0.00-3.00
Internalized stigma (SSCI)[f]	0.71 (0.93)	0.00-2.83
Perceived illness consequences of gout (BIPQ)[b]	2.80 (3.30)	0-10
Perceived illness timeline of gout (BIPQ)[b]	7.64 (3.73)	0-10
Perceived personal control over gout (BIPQ)[b]	7.26 (3.03)	0-10
Perceived treatment control over gout (BIPQ)[b]	8.80 (2.00)	2-10
Perceived gout symptoms/identification with gout (BIPQ)[b]	3.34 (3.16)	0-10
Perceived gout-related concerns (BIPQ)[b]	4.72 (3.59)	0-10
Perceived understanding of gout (BIPQ)[b]	8.00 (2.27)	1-10
Perceived emotional response to gout (BIPQ)[b]	2.52 (3.46)	0-10
Illness-related body dissatisfaction (SWAP)[g]	3.32 (2.23)	0.00-6.00
Illness-related disability (HAQ-II)[h]	0.72 (0.75)	0.00-2.40
Intentional nonadherence – testing treatment (INAS)[k]	0.32 (0.69)	0.00-3.00
Intentional nonadherence – resisting illness (INAS)[k]	0.42 (0.75)	0.00-3.29

Abbreviation: BIPQ, Brief Illness Perception Questionnaire; CIASS, Chronic Illness Anticipated Stigma Scale; GP, general practitioner; HAQ-II, Health Assessment Questionnaire-II; INAS, Intentional Non-Adherence Scale; NRS, numerical rating scale; SSCI, Stigma Scale for Chronic Illness; SWAP, Brief Satisfaction with Appearance Scale; ULT, urate-lowering therapy; VAS, Visual Analogue Scale.
[a]VAS: no pain versus worst possible pain. [b]Eleven-point numerical rating scale. [c]Range of dosage: 100-800 mg/d. [d]Range of dosage: 80-120 mg/d. [e]Five-point Likert scale (0 = very unlikely, 4 = very likely). [f]Five-point Likert scale (0 = never, 4 = always). [g]Seven-point Likert scale (0 = strongly disagree, 6 = strongly agree). [h]Four-point Likert scale (0 = without any difficulty, 3 = unable). [k]Five-point Likert scale (0 = strongly disagree, 4 = strongly agree).

multivariate analysis the one variable that reveals the highest correlation with the dependent variable in order to avoid multicollinearity.

RESULTS

Participant characteristics. Demographic and clinical characteristics of the current sample (N = 50) as well as baseline outcomes from the clinical interview and questionnaires are summarized in Table 1. The majority of participants were men (84%), were of New Zealand European ethnicity (82%), were taking allopurinol (96%), and were aged between 55 and 75 years (74%). The duration of urate-lowering therapy was 13 years. The mean serum urate was 0.34 (SD = 0.09), and 62% of participants had a serum urate below 0.36 mmol/l.

Frequency and extent of stigmatization experience in patients with gout. The evaluation of the CIASS (Likert scale: 0 = very unlikely, 1 = unlikely, 2 = somewhat likely, 3 = likely, 4 = very likely) showed that participants reported low average levels of anticipated stigma by both family members and

friends (mean = 0.62, SD = 0.73) and by health care workers (mean = 0.57, SD = 0.76). They also showed low average levels of internalized stigma (mean = 0.71, SD = 0.93) on the SSCI (Likert scale: 0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = always). A mean internalized stigma score of 1 or more was met by 13 participants (26%). Similarly, an average score greater than 1 was reported by 13 participants (26%) on the Family Member/Friends subscale and by 7 participants (14%) on the Health Care Workers subscale of the CIASS. The single items of the anticipated stigmatization scales (CIASS) were rarely answered with "likely" or "very likely" (family and friends: 0 to 4 participants; health care worker: 0 to 3 participants). The only exception was the item describing the expectation that family members or friends blame patients for gout to be their fault: 10 participants (20%) answered this item with "likely" or "very likely." The number of participants who answered items of the internalized stigma scale (SSCI) with "often" or "always" ranged between 2 and 9.

Univariate relationships between gout-related stigma and demographic, clinical, and psychosocial variables. Univariate linear regression analyses revealed similar patterns of significant associations with demographic, clinical, and psychosocial variables for both, anticipated and internalized stigma (see Table 2). Individuals who experienced increased levels of both types of stigma were more likely to be an ethnicity other than New Zealand European and reported higher pain scores during and between gout flares. They felt their life was more affected by gout (BIPQ Consequences), reported a greater emotional response to their gout (BIPQ Emotional Response), experienced symptoms as more severe (BIPQ Identity), and were more concerned about their gout

Table 2. Univariate linear regression analyses of associations between different types of stigma perception in gout patients and demographic, clinical, and psychosocial variables (N = 50)

Independent Variable	Internalized Stigma (SSCI)	Anticipated Stigma – Family Members & Friends (CIASS)	Anticipated Stigma – HC Worker (CIASS)
Demographic variables	β	β	β
Age (y)	−0.35*	−0.38**	−0.21
Years spent in education	0.05	0.07	0.04
Sex[a]	0.09	0.02	−0.01
Ethnicity[b]	0.28*	0.29*	0.28*
Clinical variables			
Number of gout flares in past year	−0.14	−0.16	−0.15
Time since first episode (y)	−0.07	−0.12	−0.09
Treatment length (y)	−0.03	−0.06	0.00
Time since last gout flare (mo)	−0.12	−0.12	−0.02
Subjective health rating (NRS)	−0.21	−0.24	−0.19
Pain during gout flares (VAS)	0.31*	0.33*	0.29*
Pain between gout flares (VAS)	0.52***	0.49***	0.45**
Number of GP & rheumatologist visits in past year	0.21	0.20	0.19
Presence of tophi	0.14	0.08	0.20
Serum urate level (mmol/l)	0.25	0.21	0.30*
Psychosocial variables			
Perceived illness consequences of gout (BIPQ)	0.45**	0.51***	0.43**
Perceived illness timeline of gout (BIPQ)	−0.00	0.08	−0.00
Perceived personal control over gout (BIPQ)	−0.07	−0.16	−0.17
Perceived treatment control over gout (BIPQ)	−0.18	−0.24	−0.17
Perceived gout symptoms/identification with gout (BIPQ)	0.32*	0.39**	0.39**
Perceived gout-related concerns (BIPQ)	0.44**	0.43**	0.48***
Perceived understanding of gout (BIPQ)	−0.35*	−0.25	−0.34*
Perceived emotional response to gout (BIPQ)	0.63***	0.64***	0.67***
Illness-related body dissatisfaction (SWAP)	−0.06	−0.12	−0.11
Illness-related disability (HAQ-II)	0.39**	0.38**	0.40**
Intentional nonadherence – testing treatment (INAS)	0.37**	0.35*	0.27
Intentional nonadherence – resisting illness (INAS)	0.41**	0.35*	0.55***

Abbreviation: BIPQ, Brief Illness Perception Questionnaire; CIASS, Chronic Illness Anticipated Stigma Scale; GP, general practitioner; HAQ-II, Health Assessment Questionnaire-II; HC, health care; INAS, Intentional Non-Adherence Scale; NRS, numerical rating scale; SSCI, Stigma Scale for Chronic Illness; SWAP, Brief Satisfaction with Appearance Scale; ULT, urate-lowering therapy; VAS, Visual Analogue Scale.
[a]1 = female, 2 = male. [b]1 = New Zealand European, 2 = ethnicity other than New Zealand European. *P < 0.05, **P < .001, ***P < 0.001.

(BIPQ Concern). Additionally, these participants also experienced more illness-related disability and expressed greater illness resistance as a reason for being nonadherent to their medication.

Experiencing internalized stigma was additionally associated with younger age, more intentional nonadherence in the form of testing treatment, and less perceived understanding of gout. Participants who expected to be stigmatized by friends or family members were also younger and more likely to be intentionally nonadherent to test the treatment. Participants who anticipated being stigmatized by health care workers reported decreased understanding of their gout (BIPQ Understanding) and had higher serum urate levels.

Incremental variance of stigma explained by demographic, clinical, and psychosocial variables. Age and ethnicity were entered as independent variables in the first step of the hierarchical regression analyses, as they were the strongest demographic correlates of both internalized and anticipated stigma by friends and family in the univariate analyses. In the first step of the hierarchical regression analysis, including anticipated stigma by health care workers, only ethnicity was included as an independent variable. Pain between and during gout flares was added in the second step of all three multivariate analyses. In the regression analysis that included anticipated stigma by health care workers as a dependent variable, we additionally entered the serum urate level as a clinical variable. Four psychosocial correlates were selected as independent variables in the third step of the multivariate analyses. Of all BIPQ items, Emotional Response revealed the highest correlation with the dependent variable in the univariate analyses and was therefore entered in our multivariate analyses. We did not include BIPQ Consequences, Identity, and Concern to the multivariate analyses because they significantly intercorrelated with BIPQ Emotional Response ($0.44 \leq r \leq 0.61$, $P < 0.01$). BIPQ Understanding was not intercorrelated with BIPQ Emotional Response ($r = -0.25$, $P = 0.084$) and was therefore entered in the multivariate regression analyses that included internalized stigma and anticipated stigma by health care workers as a dependent variable. We also added level of illness-related disability (HAQ-II) and the Resisting Illness INAS subscale score as independent variables to all three multivar-

Table 3. Multivariate hierarchical linear regression models of associations between different types of stigma perception in gout patients and demographic, clinical, or psychosocial variables (N = 50)

Independent Variables	Internalized Stigma (SSCI)	Anticipated Stigma - Family & Friends (CIASS)	Anticipated Stigma - HC Worker (CIASS)
Step 1: Demographic variables	$R^2_{adj} = 0.123^{*}$	$R^2_{adj} = 0.144^{*}$	$R^2_{adj} = 0.065^{*}$
	β	β	β
Age	-0.30^{*}	-0.33^{*}	...
Ethnicity[a]	0.20	0.19	0.29^{*}
Step 2: Clinical variables	$R^2_{adj} = 0.319^{***}$ $\Delta R^2 = 0.216^{**}$	$R^2_{adj} = 0.321^{**}$ $\Delta R^2 = 0.198^{**}$	$R^2_{adj} = 0.289^{**}$ $\Delta R^2 = 0.263^{**}$
	β	β	β
Age	-0.27^{*}	-0.31^{*}	...
Ethnicity[a]	−0.07	−0.07	0.07
Pain between gout flares	0.44^{**}	0.39^{**}	0.40^{*}
Pain during gout flares	0.23	0.26^{*}	0.18
Serum urate level (mmoles/l)	...	...	0.33^{*}
Step 3: Psychosocial variables	$R^2_{adj} = 0.488^{***}$ $\Delta R^2 = 0.197^{**}$	$R^2_{adj} = 0.434^{***}$ $\Delta R^2 = 0.138^{*}$	$R^2_{adj} = 0.589^{***}$ $\Delta R^2 = 0.309^{***}$
	β	β	β
Age	−0.20	-0.24^{*}	...
Ethnicity[a]	−0.06	−0.03	0.09
Pain between gout flares	0.27	0.20	0.16
Pain during gout flares	0.07	0.09	−0.03
Serum urate level (mmol/l)	...	...	0.02
Perceived understanding of gout (BIPQ)	−0.19	...	−0.11
Perceived emotional response to gout (BIPQ)	0.24	0.33^{*}	0.34^{*}
Illness-related disability (HAQ-II)	0.14	0.14	0.13
Intentional nonadherence - resisting illness (INAS)	0.21	0.16	0.36^{**}

Abbreviation: BIPQ, Brief Illness Perception Questionnaire; CIASS, Chronic Illness Anticipated Stigma Scale; HAQ-II, Health Assessment Questionnaire-II; HC, health care; INAS, Intentional Non-Adherence Scale; SSCI, Stigma Scale for Chronic Illness.

[a]1 = New Zealand European, 2 = ethnicity other than New Zealand European. $^{*}P < 0.05$, $^{**}P < 0.01$, $^{***}P < 0.001$.

iate analyses. The Testing Treatment INAS subscale was not included because it significantly intercorrelated with the other INAS subscale (r = 0.70, P < 0.01) but had lower univariate associations with the dependent variables compared with the other INAS subscale.

Results of the hierarchical multivariate regression analyses are summarized in Table 3. The third and final regression model revealed that age, emotional illness response, and intentional nonadherence related to resisting illness were the only independent variables that explained incremental variance, but only in anticipated stigma. Individuals who were more emotionally affected by gout and who were younger experienced stronger anticipated stigma by friends and family, after controlling for other demographic, clinical, and psychosocial variables. Individuals who were more emotionally affected by gout and those with greater nonadherence related to illness resistance experienced more anticipated stigma by health care workers.

In the following, we report means and standard deviations in order to quantify the level of emotional illness response and intentional nonadherence in participants who did experience anticipated stigma compared with participants who did not. The descriptive values confirm the findings of the regression analyses. Participants who experienced anticipated stigma by their family and friends or by health care workers showed, on average, a greater emotional illness response ($M_{\uparrow CIASS\text{-}family/friends}$ = 4.85, $SD_{\uparrow CIASS\text{-}family/friends}$=4.04, n=13; $M_{\uparrow CIASS\text{-}HCworkers}$=7.57, $SD_{\uparrow CIASS\text{-}HCworkers}$ = 2.76, n = 7) compared with those who did not ($M_{\downarrow CIASS\text{-}family/friends}$ = 1.70, $SD_{\downarrow CIASS\text{-}family/friends}$ = 2.87, n = 37; $M_{\downarrow CIASS\text{-}HCworkers}$ = 1.70, $SD_{\downarrow CIASS\text{-}HCworkers}$ = 2.82, n = 43). Participants who experienced anticipated stigma by health care workers reported, on average, greater nonadherence relating to illness resistance ($M_{\uparrow CIASS\text{-}HCworkers}$ = 1.13, $SD_{\uparrow CIASS\text{-}HCworkers}$ = 1.17, n = 7) compared with those who did not experience these types of stigma ($M_{\downarrow CIASS\text{-}HCworkers}$ = 0.31, $SD_{\downarrow CIASS\text{-}HCworkers}$ = 0.61, n = 43).

DISCUSSION

This study aimed to examine the relationship between demographic, clinical, and psychosocial variables and the experience of internalized and anticipated stigma. An important finding of our study highlighted a pattern of variables that are associated with the experience of stigma, which is similar to correlative patterns identified in other patient groups with chronic medical conditions. In the current study, younger age was associated with higher stigma, a finding also evident in patients with epilepsy (4). The onset of gout tends to occur later in life (1), similar to other chronic medical conditions, which means that the condition may be considered more normative and therefore potentially less stigmatizing at an older age. The finding that ethnicity was associated with stigma experience is of special interest. Our results showed that Māori and Pacific Islander patients experienced more internalized and anticipated stigma. The most recent result of the New Zealand Health Survey showed a significantly increased prevalence of gout in Māori as well as Pacific Islander patients compared with other ethnicities in New Zealand (13). Māori and Pacific Island patients were demonstrated to experience more severe levels of the disease with higher flare frequency and higher levels of illness-related disability (14).

Perceiving an increased pain severity during and between flares was associated with increased stigma. Qualitative work with gout patients has highlighted that pain is the most predominant and severely debilitating gout symptom (6). Therefore, it is clinically relevant to consider that patients who are the most disabled by the experience of pain are also likely experiencing greater stigma, which may subsequently affect their psychosocial functioning.

Additionally, certain illness perceptions, illness-related disability, and intentional nonadherence were identified as psychosocial correlates of stigma experience in the current sample of patients with gout. A strong positive association between symptom-related disability and stigma experience has also been demonstrated in a large sample of adults with different chronic medical conditions (3).

A final important result showed that younger age, emotional response to gout, and intentions of nonadherence related to illness resistance were the only associated factors of stigma experience that independently accounted for variance of anticipated stigma. Studies of patients with different chronic diseases have demonstrated that perceiving illness-related stigma is associated with a negative emotional response to illness and to poorer illness adjustment, particularly in regards to treatment adherence (15). Therefore, although the subgroup of patients identified in the current sample who experience stigma is relatively small compared with other chronic conditions, it is important to consider how emotionally affected these patients feel by their gout symptoms and that the stigma experience probably interferes with their disease management. The finding that young gout patients in our study seem to have an increased risk of anticipating stigmatization could be explained by characteristics of our sample. A substantial proportion of subjects in this study had lived with a gout diagnosis for quite some time (mean duration of disease was 21 years). A more intense experience of stigma in our younger participants could be explained by the fact that patients who suffer from a medical condition over a longer period of time have learned to adapt better to their condition. They are probably better educated about gout, are more experienced in managing their illness, and probably have better control over the disease process with urate-lowering medication.

The limitations of the current study should be considered when interpreting these findings. Our sample was highly selective, where the majority of participants were New Zealand European, male, of older age, and were currently taking urate-lowering medication. This sample is therefore not necessarily representative of

the general population of gout patients. The external validity of our findings is probably limited, and the probability of gout-related stigma experience could be underestimated in our sample. Second, this study was only a pilot trial. We wanted to investigate whether we could quantify the level of stigma experience in gout patients with measures of stigma that were used in previous studies of samples with chronic medical conditions other than gout. Because of limited resources, we could assess only a set number of variables as potential correlates of stigma experience. There are additional variables that have been demonstrated to be correlates of illness-related stigma perception (eg, social support, psychological well-being, and quality of life) and that should be investigated in future studies. Moreover, we had to apply a cross-sectional design that does not allow the causal interpretation of findings in terms of directional relationships between stigma and the assessed outcomes.

To conclude, this study identified that some patients with gout experience illness-related stigma and that stigma is associated with a heightened negative emotional response toward the illness and greater intentional nonadherence toward medical treatment. Future research should utilize longitudinal designs that allow mediation and path analyses to better understand the relationship between perceived stigma and demographic, clinical, and psychosocial variables. For example, it would be important to understand if a stigma experience predicts nonadherence with urate-lowering medication and other health behaviors that are relevant for a successful gout treatment (eg, adherence to a specific diet). In the case that stigma experience predicts nonadherence, it would be important to investigate whether this relationship is moderated by variables such as negative stigma-related emotions (eg, feelings of embarrassment) for example. Future research should also attempt to understand the overall prevalence of gout-related stigma in a broader group of patients, including those who are recently diagnosed and are not on urate-lowering therapy. Our results emphasize that perceived stigma and the associated psychosocial variables are important issues that should be considered and explored by clinicians who treat patients with gout.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Kleinstäuber had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Kleinstäuber, Petrie, Dalbeth.
Acquisition of data. Kleinstäuber, Wolf.
Analysis and interpretation of data. Kleinstäuber, Jones, Petrie, Dalbeth.

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