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Identity Concealment and Chronic Illness: A Strategic Choice

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The research presented here investigates potential psychological and health consequences of concealing a chronic illness. Data were collected from 2,500 individuals living with multiple sclerosis (MS), as part of an ongoing longitudinal research project. Questions on identity concealment and psychosocial reserve (a broad measure of well-being) were embedded in a semi-annual national survey. Responses were linked to each participant's concurrent responses to questions about their disability status, and prospectively to the same measure of disability status 1 year later. Just over 16% of respondents indicated that it was mostly true to very true that they actively concealed their MS and most indicated at least some degree of concealment. For people at lower levels of disability, decisions to conceal or disclose were not related to their levels of psychosocial reserve. However, with rising disability, concealment predicted lower levels of psychosocial reserve. Concealment was also associated with improved disability status 1 year later. A mediation analysis suggests that this may be in part because people who concealed were more likely to be employed. Taken together, the current research

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adds to the evidence that consequences of concealment often may be multifaceted and depend on a variety of moderators, including degree of disability.

Introduction

Multiple sclerosis (MS) is a chronic, immune-mediated neurological disorder. Although its exact cause is unknown, MS is thought to develop when genetically susceptible individuals are exposed to possible environmental agents. In people with MS, the immune system attacks and damages myelin, an insulating sheath surrounding the axons of many nerve cells. Myelin has a protective role and helps to increase the speed at which nerve impulses travel. If myelin becomes damaged, the speed of nerve impulses is slowed and nerve cells can become dysfunctional and die. As this happens, symptoms of the disease become apparent. Symptoms can be severe and debilitating (Rejda, Jackson, & Giovannoni, 2010) and include sensory disturbance; visual and cognitive impairment; difficulty with balance; weakness; fatigue; bowel, bladder and sexual dysfunction; pain; and depression (Stüve & Oksenberg, 2011). However, the course of MS is somewhat unpredictable. Most commonly, people have “relapse-remitting” MS (around 85% of cases), characterized by acute attacks followed by full or partial recovery (Rejda et al., 2010). As a result, many people with MS may be able to hide their illness if they choose.

People conceal parts of themselves when they are concerned that disclosure may make them a target of stigma. Stigma occurs when people with a given characteristic are seen as separate from and lower in status than others and thus, as legitimate targets of discrimination (Link & Phelan, 2001). People with chronic illness often anticipate and experience stigma (Earnshaw & Quinn, 2012). Sometimes chronic illness stigma is confounded with socially stigmatized behaviors that lead to disease transmission, such as HIV infection due to sexual activity between men. However, chronic illness presents a stigma even for a disease like MS (Clement & Klueger, 1998; Cook, Germano, & Stadler, 2016; Grytten & Måseide, 2005, 2006; Joachim & Acorn, 2000; Vickers, 2010) that is not communicable and not directly caused by behavioral choices. Simply being different (“separate”) can make others uncomfortable and thus strain interpersonal relationships, particularly as disease symptoms emerge (Joachim & Acorn, 2000; Jones et al., 1984). Because of the stigma associated with MS, people often try to conceal their diagnosis (Cook et al., 2016).

Consequences of Concealment

Research on the consequences of concealment is limited. In general, the psychology literature suggests that concealment should be associated with negative outcomes. Concealing an important aspect of oneself requires tracking complex

social information, maintaining a public persona that deviates from private, and regularly searching the environment for signs that concealment may have been compromised (Quinn, 2006). Understandably then, concealment can be cognitively demanding (Sedlovskaya et al., 2013; Smart & Wegner, 1999), create feelings of inauthenticity (Kelly, 2002), and decrease people's sense of belonging and social engagement (Lattanner & Richman, 2017; Moore & Tangney, 2017; Newheiser & Barreto, 2014; Newheiser, Barreto, & Tiemersma, 2017).

However, given that people often do conceal stigmas, including chronic illness, they must sometimes perceive that benefits outweigh costs. Psychologically, being able to choose whether, when, and how to disclose provides a form of personal control (Kelly & McKillop, 1996), which has been identified as an innate (Ryan & Deci, 2000) and core (Fiske, 2004) social need. Concealment may offer particular psychological advantages for people who are dispositionally concerned with social rejection (Cole, Kemeny, & Taylor, 1997). Moreover, in some situations concealment may help reduce the salience of an identity, which can prevent underperformance from stereotype threat (Quinn, Kahng, & Crocker, 2004). Successful concealment can also prevent discrimination (Chaudoir & Fisher, 2010; Cole et al., 1997; Gupta & Jürges, 2012; Quinn & Chaudoir, 2009), and thus help with career advancement and other self-relevant goals requiring external approval. Thus, considering situational variability and individual differences, there are reasons to expect that benefits of concealment do, in fact, sometimes outweigh costs (Pasek, Filip-Crawford, & Cook, 2017).

Much of the work on concealment has focused on stigmatized identities besides chronic illness, often homosexuality, leaving questions about whether the consequences of concealment found in previous research generalize across different types of stigma. We can easily imagine how the consequences of concealing a sexual minority identity (for example) may differ from concealing a chronic illness like MS. For instance, sexual orientation is fraught with public debates about controllability and morality (Cook, Calcagno, Arrow, & Malle, 2012). These factors are less relevant in MS, as its cause is considered to be outside of individual control (Grytten & Måseide, 2005). Understanding the consequences of concealment requires research on a wider variety of identities, including chronic illness, as investigated here. Such research can ultimately help reveal which consequences of concealment apply across identities, which apply across chronic illnesses (but may differ from other identities), and which vary across chronic illnesses and are thus idiosyncratic to a particular disease.

Moderators and Mediators of Concealment Outcomes

The research literature becomes particularly sparse when focusing on the lived consequences of concealment and the ways people presumably learn to manage concealment and disclosure decisions repeatedly over long periods of time. To

our knowledge, Cole and colleagues (Cole et al., 1997; Cole, Kemeny, Taylor, & Visscher, 1996a, 1996b) remain the only group to have examined the longitudinal health consequences of concealment. They studied disease progression among HIV-positive gay men who varied in how much they concealed their sexual orientation. Initial results showed that concealing sexual orientation was associated with accelerated disease progression (Cole et al., 1996a). However, results published later showed that consequences of concealment depended on individual differences in participants' sensitivity to rejection because of their sexual orientation. For men low in rejection sensitivity, concealment was associated with accelerated disease progression, but for men high in rejection sensitivity, concealment was associated with *slower* disease progression (Cole et al., 1997). This suggests that the consequences of concealment may depend on individual differences not routinely studied.

One individual difference that could moderate the consequences of concealment for people with a chronic illness is their level of disability. Concealment may make the most sense when people are asymptomatic, and thus, there is little reason that others would suspect an illness. At this low level of disability, benefits of concealment in terms of bolstering core aspects of psychological well-being or retaining employment may be perceived to outweigh risks. Concealment may become more difficult and costly with moderate disability when the disease takes a more unavoidable role in people's everyday experiences. Rising disability may provoke anxiety about being unable to conceal, increasing the psychological costs of concealment and preventing opportunities for support and accommodation. Concealment largely loses its meaning at advanced stages of disability when overt debilitating symptoms would be difficult or impossible to conceal even if one tried to conceal the cause of symptoms.

The foregoing discussion suggests that any consequences of MS concealment could vary by disability level. Consistent with this, we test in the current study whether disability moderates any potential associations between concealment and two study outcomes: (1) psychosocial reserve, a measure of psychological well-being assessed concurrently with concealment at Time 1 (henceforth T1), and (2) participants' disability status 1 year later (Time 2; henceforth T2). Within a range where concealment makes sense (i.e., low-to-moderate disability), we hypothesized that concealment may be relatively benign for people without disability but more problematic as disability increases. We also test psychosocial reserve and employment as possible mediators of any long-term effects. To the extent that concealment is associated with T2 disability status, it could be from the more proximal association between concealment and psychosocial reserve, and/or because concealment helps people to stay employed (e.g., by reducing the possibility of discrimination; Sweetland, Riazi, Cano, & Playford, 2007).

Study Overview

This study uses a large, national sample of individuals living with MS to investigate psychological and longitudinal health consequences for participants of concealing chronic illness. Questions on identity concealment and other psychological constructs were embedded in a semi-annual survey and tied to participants' responses from their enrollment survey, their concurrent responses to questions about their mental and physical health (T1), and prospectively to their physical health 1 year later (T2).

Method

Participants and Procedure

Data were collected in conjunction with a semi-annual, large-scale survey of MS patients administered by the North American Research Committee on Multiple Sclerosis (NARCOMS). NARCOMS maintains and operates a voluntary registry for adults with MS to confidentially report on a wide range of health-related topics. Registry participants first complete an enrollment form and are then asked to update their information twice a year. In addition to routine questions on health and disease activity, each update survey focuses on a special topic of current interest. The registry database has over 38,000 enrollments, primarily from the United States, and each update survey yields about 8,000 responses. Although the NARCOMS sample is self-selected, it is diverse with respect to patient disease severity and socio-demographic characteristics (NARCOMS documentation, September 2011) and demographic data are similar to the representative National Health Interview Survey (Marrie, Cutter, Tyry, Campagnolo, & Vollmer, 2008).

In the spring 2013 update survey (T1), we included several psychological items assessing MS concealment and psychosocial reserve. These were labeled as questions about "possible thoughts and experiences related to living with MS." To reduce overall response burden to registry participants, the number of items that could be included was limited. Data from T1 were linked to participants' enrollment survey, which assessed demographic information, and to the spring 2014 update survey, administered 1 year later (T2), when disease status (but not our psychological variables) was assessed again.

Data were available from 6,572 registry participants who completed measures of disability at T1 and T2. Because of our focus on concealment, we excluded 3,498 individuals whose T1 disability was sufficiently severe (e.g., using an assistive device or being bedridden) that concealment would be difficult or impossible. An additional 48 individuals were excluded because they had missing data on their education level ($n = 47$) or race ($n = 1$), which were used as statistical covariates in the analyses. This yielded a starting sample of 3,026.

An additional 526 individuals did not complete our psychological items assessing concealment and psychosocial reserve at T1 (524 did not complete any concealment or psychosocial reserve items and another 2 completed enough items to calculate one, but not the other scale). There were no differences between participants who did and did not complete these items as a function of race, $\chi^2(3, N = 3,026) = 0.89, p = .83, \phi_c = .02$, T1 disability status, $t(3,024) = -0.56, p = .58, \eta_p^2 < .001$, or T2 disability status, $t(3,024) = -1.50, p = .13, \eta_p^2 = .001$. However, a few small demographic differences emerged. A slightly higher proportion of women (18%) than men (15%) did not respond to the psychological items, $\chi^2(1, N = 3,026) = 3.20, p = .07, \phi_c = .03$. In addition, participants who responded to the psychological items were about a year younger ($M = 54.99, SD = 10.13$) than those who did not ($M = 56.00, SD = 8.91$), $t(3,024) = -2.12, p = .03, \eta_p^2 = .001$. Responders and nonresponders also differed in educational attainment, $\chi^2(2, N = 3,026) = 8.63, p = .01, \phi_c = .05$, with analysis of adjusted residuals indicating a lower response rate among people with less education (i.e., a high school diploma or less).

Excluding the 526 individuals who did not complete the items assessing concealment and psychosocial reserve, the final sample in the analyses that follow was comprised of 2,500 individuals with an average age of 55 years at T1 ($M = 54.99, SD = 10.13$) who had been living with MS for an average of 17 years since diagnosis ($M = 16.86, SD = 8.55$).¹ The overwhelming majority was female (82%) and White, non-Hispanic (91%). A relatively small number identified as Black/African American (2%) or Hispanic/Latino (1%), with the remaining 6% belonging to one of several other possible racial groups or identifying their race as mixed. Approximately 27% of participants indicated at enrollment that their highest level of education was a high school diploma or less, 47% indicated having a technical, associate's, or bachelor's degree, and 26% had completed postgraduate education.

Nearly all participants had some type of health insurance at T1 (97%), with relatively few (2%) indicating no insurance (the remaining 1% did not respond). Consistent with patterns reported elsewhere (Rejdak et al., 2010), most participants (81%) had a relapse-remitting course of MS (including benign, clinically isolated, and unconfirmed diagnoses). Progressive MS, which is characterized by steadily increasing disease progression with little or no remission (Lublin et al., 2014), was reported by 8% (e.g., primary progressive, secondary progressive, progressive relapsing). The remaining 11% indicated that they were unsure or did not answer. Approximately 64% of participants reported that they were taking a disease modifying therapy (DMT) approved for the treatment of MS, while 36% indicated that they were not or did not answer. Most participants (87%) did not

¹Excludes 21 with missing data on their age at MS diagnosis.

smoke cigarettes, while 11% reported being regular or occasional smokers and 2% did not answer.

Materials

Disability status. Participants' level of disability at T1 (spring 2013) and T2 (spring 2014) was measured with the *Patient Determined Disease Steps* (PDDS) (Hohol, Orav, & Weiner, 1999; Learmonth, Motl, Sandroff, Pula, & Cadavid, 2013; Marrie & Goldman, 2007), a measure that is included in each NARCOMS survey administration. Participants in the sample analyzed here had T1 scores of 0 (*normal*, $n = 712$), 1 (*mild disability*, $n = 751$), 2 (*moderate disability*, $n = 370$), and 3 (*gait disability*, $n = 667$). As previously mentioned, participants with PDDS scores from 4 to 8 were excluded, because the severity of their symptoms would generally preclude concealment. An elaborated description accompanied each anchor. For instance, the description accompanying *moderate disability* is, "I don't have any limitations in my walking ability. However, I do have significant problems due to MS that limit daily activities in other ways."

Concealment. Concealment was computed by averaging participant responses to three items: "In general, I tend to conceal my MS from others," "I am very careful who I tell that I have MS," and "Telling someone I have MS is risky." Responses were provided on a fully anchored scale from 1 (*not at all true*) to 5 (*very true*). Reliability was adequate ($\alpha = .86$).²

Psychosocial reserve. Psychosocial reserve was computed by averaging three items measuring overall belonging ("I feel like I belong"), agency ("I am able to advocate for my needs"), and social support ("There are people I can count on to support me"). These constructs were selected because they are thought to be fundamental psychological concerns (Cohen & Hoberman, 1983; Fiske, 2004; Ryan & Deci, 2000). Responses were provided on a fully anchored scale from 1 (*not at all true*) to 5 (*very true*). Reliability in this sample was adequate ($\alpha = .77$).

Demographics and health status. Demographic data were collected from participants' NARCOMS enrollment survey. Participants indicated their sex and year of birth, which was used to calculate their T1 age. They also reported their age at diagnosis, which was used to determine their disease duration at T1. Because of missing data from 21 people on years since diagnosis, and because of a moderately high correlation between age and years with MS ($r = .52$), we formed a single composite "Years" variable to use as a covariate by averaging age and years with

²If individual items were missing, scales were calculated as the average of available responses.

Table 1. Descriptive Statistics and Intercorrelations of Primary Study Variables

<i>N</i> = 2,500	<i>M</i>	(<i>SD</i>)	1	2	3	4
1. Conceal ^a	2.41	(1.25)	1			
2. Psychosocial Reserve ^b	4.05	(1.01)	-.04*	1		
3. T1 disability ^c	1.40	(1.16)	-.09***	-.14***	1	
4. T2 disability ^d	1.52	(1.34)	-.11***	-.15***	.75***	1

^aRange from 1 to 5; higher scores = greater concealment. ^bRange from 1 to 5; higher scores = greater psychosocial reserve. ^cRestricted by design to scores from 0 (*normal*) to 3 (*gait disability*). ^dObserved range from 0 to 7.

* $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$.

MS after first standardizing each. For individuals with missing data on years with MS, this variable was simply their standardized age score.³ Participants also selected their race/ethnicity from one of ten possible categories. Based on response frequencies, we reduced this to four categories (Non-Hispanic White/Caucasian, Black/African American, Hispanic/Latino, and Other). Participants also indicated their education level. As part of the T1 survey, participants indicated if they smoked (missing data for 52), had health insurance (missing data for 20), whether they were taking a DMT and their MS type. They also indicated if they were employed full-time, part-time, or not at all (missing data for 14). Coding of all variables is described below.

Results

Overall, participants reported high levels of psychosocial reserve and moderate efforts at concealment. On a scale from 1 to 5, with higher scores indicating greater psychosocial reserve, the sample mean was 4.05 ($SD = 1.01$), just above an average rating of *mostly true* in response to the individual scale items. On a scale from 1 to 5, with higher scores indicating greater efforts at concealment, the mean concealment in the sample was 2.41 ($SD = 1.25$), roughly between *slightly true* and *somewhat true*. Just over 16% of respondents had a concealment scale score between 4 and 5, indicating that it was *mostly true* to *very true* that they actively concealed their MS. Table 1 presents descriptive statistics and intercorrelations of the key variables.

Differences in Concealment by Demographic and Health Status Variables

There were no differences in concealment as a function of sex ($p = .93$), race/ethnicity ($p = .52$), health insurance status ($p = .24$), or use of DMTs

³Results are substantively unchanged if age is used instead of the years composite.

($p = .68$). However, greater concealment was associated with being younger, $r(2,498) = -.17$, $p < .001$, and with fewer years since MS diagnosis, $r(2,477) = -.07$, $p < .001$. Concealment also differed by education level, $F(2, 2,497) = 16.84$, $p < .001$, $\eta_p^2 = .013$. Contrast analysis revealed concealment to be linearly associated with education level ($p < .001$), rising from high school diploma or less ($M = 2.19$, $SD = 1.17$), to a technical, associate's, or bachelor's degree ($M = 2.44$, $SD = 1.25$), to postgraduate education ($M = 2.58$, $SD = 1.29$). There was no evidence of a quadratic trend ($p = .29$). In addition, nonsmokers ($M = 2.44$, $SD = 1.25$) concealed more than smokers ($M = 2.19$, $SD = 1.21$), $F(1, 2,446) = 10.31$, $p = .001$, $\eta_p^2 = .004$, and people who were employed full- or part-time ($M = 2.67$, $SD = 1.31$) concealed more than those who were not employed ($M = 2.13$, $SD = 1.11$), $F(1, 2,484) = 122.37$, $p < .001$, $\eta_p^2 = .047$.

Differences in concealment also emerged as a function of MS type, $F(2, 2,497) = 6.73$, $p = .001$, $\eta_p^2 = .005$. Tukey's post hoc comparisons revealed concealment to be lower among people with a progressive course of MS ($M = 2.11$, $SD = 1.09$) than those with a relapse-remitting course ($M = 2.43$, $SD = 1.26$) and those who were unsure or did not answer ($M = 2.49$, $SD = 1.24$) ($p \leq .003$). The latter two categories did not differ from each other ($p = .76$).

Analysis Strategy

In the analyses that follow, we examine the association of concealment with two outcomes: (1) psychosocial reserve at T1 and (2) disability status at T2. We used a common hierarchical multiple regression approach to examine both outcomes. In Step 1, we tested the association between concealment and each outcome, controlling only for T1 disability status. In Step 2, we added the interaction of concealment and T1 disability status. We retained the interaction if it was statistically significant and removed it if not (to more accurately estimate the concealment coefficient across levels of disability status). In Step 3, we added demographic and health status covariates to determine if any associations between concealment and the outcomes remained after accounting for potentially competing explanations. In an exploratory, Step 4, we added psychosocial reserve and T1 employment status as two putative mediating variables that may account for any health associations attributed to concealment. That is, people's concealment decisions may affect disability status through their effects on psychosocial reserve and/or employment status. Since psychosocial reserve was also an outcome, Step 4 was only appropriate for modeling T2 disability. All coefficients reported below are unstandardized.

Covariates in regression models were coded as follows. The primary predictor of interest was concealment, which was centered at the sample mean. T1 disability status, years, and psychosocial reserve (when modeling T2 disability) were entered without any centering transformation (i.e., on their original scale). Sex was contrast

coded ($-1 = \text{female}$, $+1 = \text{male}$), as was use of DMT ($-1 = \text{no}$, $+1 = \text{yes}$). Race/ethnicity was included as three dummy variables comparing participants identifying as non-Hispanic White (reference category) to those identifying as (1) Black/African American, (2) Hispanic/Latino, and (3) all other racial/ethnic groups. MS type was entered as two dummy variables comparing people with a relapse-remitting course (reference category) to (1) people with a progressive course and (2) people who were unsure or did not answer. Education was also entered as two dummy codes, comparing participants with a technical, associate's, or bachelor's degree (reference category) to (1) those with a high school diploma or less and (2) those with postgraduate education.

Smoking status, health insurance status, and employment status had missing data, which were coded as a separate category to avoid listwise deletion. Smoking formed two dummy-coded variables, comparing nonsmokers (reference category) to (1) smokers and (2) those with missing data. Health insurance formed two dummy-coded variables, comparing people with health insurance (reference category) to (1) those without health insurance and (2) those with missing data. Participants' employment status formed two dummy-coded variables, comparing unemployed individuals (reference category) to (1) those employed full- or part-time and (2) those with missing data. Associations involving covariates are generally not discussed further, but results involving them can be found in Tables 2 and 3.

Association between Concealment and Concurrent Psychosocial Reserve

In Step 1, controlling for T1 disability, concealment was associated with a lower sense of psychosocial reserve, $b = -0.04$, $t(2,497) = -2.77$, $p = .006$, $\eta_p^2 = .003$, 95% CI ($-0.076, -0.013$). In Step 2, the interaction of concealment with T1 disability status was also significant, $b = -0.07$, $t(2,496) = -4.70$, $p < .001$, $\eta_p^2 = .009$, 95% CI ($-0.092, -0.038$) (see Table 2). Simple effects tests revealed a positive, but nonsignificant, association between concealment and psychosocial reserve for participants without overt disability (i.e., normal; PDDS = 0), $b = 0.04$, $t(2,496) = 1.58$, $p = .12$, $\eta_p^2 = .001$, 95% CI ($-0.009, 0.083$). However, among participants with relatively advanced disability (i.e., gait disability; PDDS = 3), concealment was associated with lower psychosocial reserve, $b = -0.16$, $t(2,496) = -5.45$, $p < .001$, $\eta_p^2 = .012$, 95% CI ($-0.213, -0.100$). Thus, concealment was associated with lower psychosocial reserve only for participants with a higher level of disability.

In Step 3, after adding the demographic and health status variables, the interaction between concealment and T1 disability status remained significant and similar in magnitude, $b = -0.06$, $t(2,482) = -4.41$, $p < .001$, $\eta_p^2 = .008$, 95% CI ($-0.087, -0.034$). The overall model explained only 5.40% of the variance in psychosocial reserve, suggesting (as might be expected) that a variety of other

Table 2. Regression Coefficients Predicting Psychosocial Reserve for Steps 1–3

Variable	Step 1			Step 2			Step 3		
	B	SE (b)	CI (95%)	b	SE (b)	CI (95%)	b	SE (b)	CI (95%)
Intercept	4.049***	0.020	4.010, 4.088	4.041***	0.020	4.002, 4.080	4.032***	0.038	3.957, 4.107
Conceal ^a	-0.044**	0.016	-0.076, -0.013	-0.053***	0.016	-0.085, -0.022	-0.067***	0.016	-0.099, -0.035
T1 disability ^b	-0.123***	0.017	-0.156, -0.089	-0.123***	0.017	-0.157, -0.090	-0.110***	0.018	-0.144, -0.075
Conceal × T1 disability				-0.065***	0.014	-0.092, -0.038	-0.061***	0.014	-0.087, -0.034
Years ^c							-0.072**	0.025	-0.121, -0.023
Sex ^d							0.037	0.026	-0.015, 0.088
Education D1 ^e							-0.001	0.048	-0.096, 0.094
Education D2							0.216***	0.048	0.122, 0.311
Race D1 ^f							0.256	0.152	-0.042, 0.554
Race D2							-0.118	0.216	-0.542, 0.306
Race D3							-0.193*	0.080	-0.350, -0.035
MS type D1 ^g							-0.097	0.075	-0.245, 0.050
MS type D2							-0.004	0.069	-0.140, 0.132
Insurance D1 ^h							-0.264	0.143	-0.545, 0.016
Insurance D2							-0.300	0.224	-0.739, 0.139
Smoke D1 ⁱ							-0.094	0.064	-0.219, 0.030
Smoke D2							0.146	0.142	-0.134, 0.425
DMT ^j							0.034	0.022	-0.009, 0.078
N = 2,500									
									R ² = .054***

Note. R² change between steps significant at $p < .001$. ^aMean centered. Higher scores = greater concealment. ^bFrom 0 (normal) to 3 (gait disability). ^cComposite of standardized age and years since diagnosis. ^d-1 = female, +1 = male. ^eEducation dummy codes compare participants with a technical, associate's, or bachelor's degree (0) to (D1) those with a high school diploma or less and (D2) those with postgraduate education. ^fRace dummy codes compare non-Hispanic Whites (0) to (D1) Blacks/African Americans, (D2) Hispanics/Latinos, and (D3) all others. ^gMS type dummy codes compare people with relapse-remitting MS (0) to (D1) those with progressive MS and (D2) those unsure/no answer. ^hHealth insurance dummy codes compare people with (0) to (D1) those without and (D2) those with missing data. ⁱSmoking dummy codes compare nonsmokers (0) to (D1) smokers and (D2) those with missing data. ^jUse of disease modifying therapies: -1 = No (or no answer), +1 = Yes. * $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$.

Table 3. Regression Coefficients Predicting T2 Disability for Steps 1–4

Variable	Step 1			Step 2			Step 3			Step 4		
	<i>b</i>	<i>SE</i> (<i>b</i>)	CI (95%)	<i>b</i>	<i>SE</i> (<i>b</i>)	CI (95%)	<i>b</i>	<i>SE</i> (<i>b</i>)	CI (95%)	<i>b</i>	<i>SE</i> (<i>b</i>)	CI (95%)
Intercept	1.520***	0.018	1.485, 1.555	1.521***	0.018	1.486, 1.556	1.459***	0.034	1.392, 1.527	1.751***	0.081	1.592, 1.910
Conceal ^a	-0.044**	0.014	-0.072, -0.016	-0.044**	0.014	-0.072, -0.016	-0.031*	0.014	-0.059, -0.002	-0.025	0.015	-0.053, 0.004
PDDS-T1 ^b	0.855***	0.015	0.825, 0.886	0.855***	0.015	0.825, 0.886	0.834***	0.016	0.803, 0.865	0.819***	0.016	0.787, 0.850
Conceal × PDDS-T1				0.003	0.012	-0.021, 0.027						
Years ^c				0.056*		0.011, 0.100				0.027		-0.018, 0.073
Sex ^d				-0.022		-0.068, 0.025				-0.012		-0.059, 0.034
Education D1 ^e				0.074		-0.012, 0.159				0.057		-0.028, 0.142
Education D2				-0.024		-0.109, 0.062				-0.006		-0.091, 0.080
Race D1 ^f				-0.156		-0.424, 0.111				-0.164		-0.431, 0.103
Race D2				-0.279		-0.660, 0.102				-0.300		-0.680, 0.079
Race D3				0.023		-0.118, 0.164				0.002		-0.139, 0.143
MS type D1 ^g				0.361***		0.228, 0.494				0.346***		0.214, 0.478
MS type D2				0.005		-0.117, 0.127				0.001		-0.121, 0.123
Insurance D1 ^h				0.042		-0.210, 0.293				0.014		-0.237, 0.265
Insurance D2				0.385		-0.009, 0.779				0.687*		0.129, 1.245
Smoke D1 ⁱ				0.007		-0.105, 0.119				-0.003		-0.115, 0.108
Smoke D2				0.199		-0.052, 0.451				0.193		-0.057, 0.443
DMT ^j				-0.007		-0.046, 0.033				-0.004		-0.043, 0.035
Psychosocial Reserve ^k										-0.049**		-0.085, -0.014
Employment D1 ^l										-0.155***		-0.233, -0.078
Employment D2										-0.623		-1.285, 0.039
<i>N</i> = 2,500				<i>R</i> ² = .557***			<i>R</i> ² = .557***			<i>R</i> ² = .567***		

Note. *R*² change *p* < .001 between steps, except between Steps 1 and 2 (n/s). ^aMean centered. Higher scores = greater concealment. ^bFrom 0 (normal) to 3 (gait disability). ^cComposite of standardized age and years since diagnosis. ^d-1 = female, +1 = male. ^eEducation dummy codes compare participants with a technical, associate's, or bachelor's degree (0) to (D1) those with a high school diploma or less and (D2) those with postgraduate education. ^fRace dummy codes compare non-Hispanic Whites (0) to (D1) Blacks/African Americans, (D2) Hispanics/Latinos, and (D3) all others. ^gMS type dummy codes compare people with relapse-remitting MS (0) to (D1) those with progressive MS and (D2) those unsure/no answer. ^hHealth insurance dummy codes compare people with (0) to (D1) those without and (D2) those with missing data. ⁱSmoking dummy codes compare nonsmokers (0) to (D1) smokers and (D2) those with missing data. ^jUse of disease modifying therapies: -1 = No (or no answer), +1 = Yes. ^kHigher scores = greater reserve. ^lEmployment dummy codes compare people unemployed (0) to (D1) those employed full- or part-time and (D2) those with missing data. **p* ≤ .05, ***p* ≤ .01, ****p* ≤ .001.

variables not measured in the current study also contribute to psychosocial reserve (see Table 2 for all coefficients). As before, the association between concealment and psychosocial reserve was positive and nonsignificant for participants with no reported disability, $b = 0.02$, $t(2,482) = 0.73$, $p = .47$, $\eta_p^2 < .001$, 95% CI $(-0.029, 0.064)$. The same association was negative and statistically significant for participants at the highest levels of disability within the selected range, $b = -0.16$, $t(2,482) = -5.72$, $p < .001$, $\eta_p^2 = .013$, 95% CI $(-0.221, -0.108)$.⁴ Thus, controlling for all covariates, concealment continued to be associated with lower psychosocial reserve only for participants with more advanced disability.

Analysis of residuals from Step 3 revealed 50 cases with studentized deleted residuals between -3 and -3.41 , suggesting possible outliers. No cases had values greater than $+3$. To ensure that these 50 cases were not spuriously driving effects, we conducted sensitivity analyses, excluding these cases and re-examining the pattern of coefficients. Their removal had little effect and the concealment \times T1 disability interaction remained significant, suggesting it was not due to outlying cases.

Prospective Association between Concealment and T2 Disability

In Step 1, controlling for T1 disability status, concealment was associated with lower T2 disability status (i.e., fewer symptoms), $b = -0.04$, $t(2,497) = -3.09$, $p = .002$, $\eta_p^2 = .004$, 95% CI $(-0.072, -0.016)$. Adding the interaction between T1 disability and concealment in Step 2 did not improve model fit, $b = 0.003$, $t(2,496) = 0.25$, $p = .80$, $\eta_p^2 < .001$, 95% CI $(-0.021, 0.027)$. Thus, the interaction was removed in Step 3 in order to facilitate estimation of the concealment coefficient across disability levels. After adding the block of demographic and health status variables in Step 3, concealment continued to predict lower T2 disability, $b = -0.031$, $t(2,483) = -2.13$, $p = .03$, $\eta_p^2 = .002$, 95% CI $(-0.059, -0.002)$. Table 3 displays coefficients.

After adding psychosocial reserve and employment status in Step 4, the association between concealment and T2 disability no longer reached statistical significance, $b = -0.025$, $t(2,480) = -1.69$, $p = .09$, $\eta_p^2 = .001$, 95% CI $(-0.053, 0.004)$ (see Table 3). This is consistent with the possibility that these variables play a mediating role. Psychosocial reserve in this model was associated with lower T2 disability, $b = -0.05$, $t(2,480) = -2.73$, $p = .006$, $\eta_p^2 = .003$, 95% CI $(-0.085, -0.014)$. Also, people who were employed at T1 had lower T2

⁴Adding employment status did not alter this pattern. In this model, being employed was associated with greater psychosocial reserve than being unemployed, $b = 0.32$, $t(2,480) = 7.31$, $p < .001$, $\eta_p^2 = .021$, 95% CI $(0.232, 0.403)$. There was no difference in psychosocial reserve between those who were unemployed and those with missing data ($p = .63$).

disability than those who were unemployed, $b = -0.16$, $t(2,480) = -3.92$, $p < .001$, $\eta_p^2 = .006$, 95% CI (-0.233, -0.078).

Four cases from the Step 4 model had studentized deleted residuals less than -3 (smallest value = -3.29) and 34 cases had studentized deleted residuals greater than +3 (including six greater than +4 and five greater than +5; largest value = +5.63). Temporarily removing all 38 of these potential outliers did not change the pattern of results.⁵

The smaller concealment coefficient in Step 4 and the significant coefficients for psychosocial reserve and employment suggest that the prospective association between concealment and T2 disability status may be due to differences in psychosocial reserve and employment. To more formally examine this and better understand the pattern of results, we tested whether psychosocial reserve and employment status mediated the association between concealment and T2 disability status. We simultaneously modeled both mediators and, as above, included T1 disability status as a moderator of the association between concealment and psychosocial reserve. Predictors of employment were concealment, T1 disability, and the same set of demographic and health status covariates used for all outcomes (i.e., sex, race, years, MS type, insurance status, education, smoking status, DMT use). We estimated the mediation model with Mplus 7 (Muthén & Muthén, 1998–2015), which uses a robust weighted least squares procedure to estimate coefficients in models with dichotomous mediator variables. We requested 5,000 bootstrapped results to estimate confidence intervals around mediation estimates. Figure 1 displays path coefficients for key variables.

Psychosocial reserve mediated the association between concealment and T2 disability, but only for people with more advanced T1 disability. Among participants without overt disability at T1 (i.e., PDDS = 0), there was no evidence of mediation, $M = -.001$, 95% CI (-0.005, 0.001), largely because as reported above, concealment did not predict psychosocial reserve for these individuals. However, among people with relatively advanced T1 disability (i.e., PDDS = 3), psychosocial reserve mediated the relation between concealment and T2 disability, $M = 0.010$, 95% CI (0.003, 0.019). Thus, for more disabled participants, concealment was associated with lower psychosocial reserve, which was prospectively associated with greater T2 disability.

Being employed (versus not) also mediated the association between concealment and T2 disability, $M = -.016$, 95% CI (-0.028, -0.008). The dummy code comparing unemployed people to those with missing data did not mediate this relation, $M = -.042$, 95% CI (-0.130, 0.043). People who concealed, regardless

⁵Because T2 disability could be considered an ordinal variable rather than continuous, we also tested these models using ordinal logistic regression. The pattern of results was unchanged.

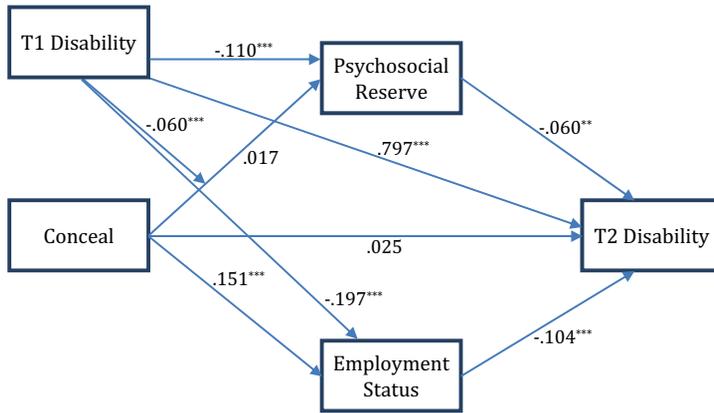


Fig. 1. Path Model Predicting T2 disability from concealment, psychosocial reserve, employment status, and T1 disability. T1 disability from 0 (normal) to 3 (gait disability). Coefficients and significance tests based on robust weighted least squares estimation. Concealment was centered at the sample mean (higher scores = greater concealment). For psychosocial reserve, higher scores indicate greater reserve. Employment status was coded as 0 = unemployed, 1 = employed full- or part-time. Not shown, but included as a mediator, was the second employment dummy code (comparing unemployed to those with missing employment data), which did not mediate. The usual block of covariates (i.e., sex, race, years, MS type, insurance status, education, smoking status, DMT use) was also included as predictors of all endogenous variables. [Color figure can be viewed at wileyonlinelibrary.com]

of their T1 disability level, were more likely to be employed, and being employed was associated with lower T2 disability level.⁶

Discussion

This study is the first to describe concealment and its potential consequences for people living with MS using a large longitudinal sample. Thus, it provides a starting place for examining how concealment of chronic illness relates concurrently to psychological well-being and prospectively to disability status. As part of the ongoing NARCOMS project, participants' disability status was assessed twice, separated by 1 year. At the first assessment (T1), we included measures of concealment and psychosocial reserve to capture psychological health.

With respect to psychosocial reserve, results suggest that for people at lower levels of disability, the psychological consequences of concealment are negligible;

⁶Reversing the causal order, concealment did not mediate between employment status or psychosocial reserve and T2 disability, regardless of T1 disability level. We also estimated a model using employment status from T2 instead of T1; results were substantively unchanged.

decisions to conceal or disclose were not related to psychosocial reserve. However, with rising disability, the psychological costs of concealment mount, as increasing levels of concealment were associated with lower levels of psychosocial reserve. This result was robust to the inclusion of a number of relevant demographic and health status variables. The association of concealment with lower psychosocial reserve for people with more advanced disability is consistent with the idea that identity salience (i.e., experiencing MS symptoms) predicts lower well-being when people conceal (Quinn & Earnshaw, 2013).

Disability results suggest that concealment was associated with self-reports of slightly *lower* disability (i.e., improved health) 1 year later. This result was robust to the inclusion of relevant demographic and health status variables, including T1 disability level. However, unlike the association between concealment and psychosocial reserve, this relation did not vary as a function of T1 disability. Thus, in this sample, concealment prospectively predicted small health benefits.

A mediation analysis revealed that psychosocial reserve and employment status helped account for the association between concealment and disability but in different directions. For individuals beginning to show overt signs of disability at T1, concealing was associated with lower psychosocial reserve, which predicted greater disability. However, employment status also emerged as a significant mediator. Regardless of T1 disability level, people who concealed were more likely to be employed and being employed was associated with lower prospective disability.

Taken together, this research adds to the evidence that consequences of concealment often may be multifaceted. Concealment may sometimes be a reasonable individual decision to help people cope with stigma from their illness in a way that makes the most sense for them. Here, concealment was associated with lower prospective disability, which was partly explained by the fact that people who concealed were more likely to be employed. In addition, concealment did not undermine psychosocial reserve for people without overt disability. This latter effect is consistent with Cole et al. (1997), who found that consequences of concealment may depend on individual differences. More research is needed to uncover additional moderators of concealment. At minimum, results here suggest that concealment of chronic illness in real-world settings is neither uniformly unhealthy nor uniformly healthy.

Results here also raise the possibility that consequences of concealment may vary across group memberships. Very few studies have looked prospectively at health or other outcomes related to concealment and even fewer have examined concealment of chronic illness. It may be the case that concealment of some group memberships, like sexual orientation, has different implications than concealing others, like chronic illness. Even within chronic illness, choices to conceal and implications of that may vary. For instance, concealment related to an illness associated with personal responsibility may differ from concealment of an illness like MS. Additional research is needed to examine these possibilities.

With respect to MS, results join other research in suggesting that concealing is common among people with low-to-moderate degrees of disability. The association of concealment with employment is consistent with the idea that people living with MS fear employment discrimination. The degree to which discrimination leads to unemployment or underemployment in people with MS is unclear, but given the pattern reported here, concealing at work may sometimes be a protective strategy.

Limitations

This research has many advantages for investigating the consequences of concealing chronic illness, most notably a large sample and a longitudinal design. However, limitations should be noted. For instance, given that concealment, psychosocial reserve, and employment status were assessed at the same time, the direction of causality between these variables is uncertain. It is possible that psychosocial reserve and employment predict concealment rather than the opposite. That a path analysis found evidence of mediation only when concealment was an exogenous predictor, not when it was a mediator (see Footnote 6), provides some reassurance of the specified causal order, but alternatives cannot be ruled out. Also, the study design prevented the use of longer psychological scales with better established psychometric properties. Although we carefully selected items with high face validity and verified reliability of scales, it is possible that using other measures of psychosocial reserve or concealment may have yielded different results.

The observed effect sizes in the current research were relatively small, leading to questions about the practical importance of concealment as a predictor of illness outcomes. Clearly more research is needed to understand both the consequences of concealment and its relative importance. Because changes in MS disability over a single year are typically modest, it is possible that effects may become more pronounced over longer periods of time.

Conclusions and Implications

Concealment of chronic illness can be a strategic choice with a cost–benefit ratio that may change over time depending on characteristics of individuals and their environments. To the extent that people are able to retain employment or other desirable outcomes, benefits of concealment may sometimes outweigh potential costs. Of course, it would be preferable if people did not feel the need to conceal their illness in order to retain employment. Moreover, as symptoms develop, concealment is associated with lower psychosocial reserve, which is associated with greater disability. Employers in the United States are required to make accommodations for employees based on disability and many offer support beyond what is

legally required. When people conceal, they potentially forgo such opportunities for support and accommodation. A potential policy implication is that employers should implement and communicate equitable policies related to chronic illness and other concealable stigmas. This could encourage disclosure, which could be a win/win scenario. Individuals living with MS would not have to worry as much about trying to conceal their use of new and effective MS treatments early in the disease course and could benefit from needed work accommodation as disability progresses. For employers, appropriate accommodations may help with retention and productivity of employees with chronic illness. At the same time, employer policies that promote acceptance and disclosure can enhance the visibility of illnesses like MS and help reduce stigma as people become more familiar with the illness. Any policy efforts that promote disclosure would also need to be accompanied by educational outreach to reduce bias toward people living with MS and other chronic illnesses.

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