HHS Public Access

Author manuscript

Health Commun. Author manuscript; available in PMC 2016 February 01.

Published in final edited form as:

Health Commun. 2016 February ; 31(2): 150–160. doi:10.1080/10410236.2014.940671.

Keeping Secrets or Educating Others: A Dyadic Analysis of Group Entitativity's Influence on Spouses' Label Management Connected to AATD

Rachel A. Smith,
The Pennsylvania State University

Roxanne L. Parrott, and
The Pennsylvania State University

Sara E. Wienke
Pathway Genomics

Abstract

Goffman (1963) argued 50 years ago that forming a group based on shared stigma may provide benefits. However, there is no empirical research on whether perception that a separate, unique, coherent group exists (i.e., group entitativity) influences coping, such as educating others or secrecy, for the stigmatized individual or his/her spouse. Further, little is known about how spouses influence each other in terms of promoting the education of others about a stigmatizing condition, especially when it comes to the role of believing that stigma-based groups, to which they may both belong, exist. This study provides a step toward bridging this gap in the research by applying the Label Management model in efforts to understand coping for couples in which one spouse is diagnosed with genetic mutations leading to alpha-1 antitrypsin deficiency (AATD). This study included 50 married couples, in which one spouse is diagnosed with genetic mutations leading to alpha-1 antitrypsin deficiency (AATD). We found that group entitativity related to those with AATD counter-balanced the influence of genetic stigma on spouses' intentions to keep the diagnosis secret or to educate others about it. Intrapersonal and interpersonal influences appeared among spouses. Attention is needed on the power of creating groups for stigmatized persons and their relatives. Indeed, people live within a dynamic world of group entities, and multiple social identities including spousal and familial. While attention has been paid to the diffusion of stigmas to loved ones, less has been paid to the uplift of group entities for them.

Keywords

Label management; genetics; couples; group entitativity; dyadic analysis; secrecy; education

Authors' Note: Rachel A Smith (PhD, Michigan State University) is an Associate Professor in Communication Arts & Sciences and Human Development & Family Studies, The Pennsylvania State University, University Park, PA (ras57@psu.edu). Roxanne L Parrott (PhD, University of Arizona) is a Distinguished Professor in Communication Arts & Sciences and Health Policy & Administration, The Pennsylvania State University, University Park, PA (rlp18@psu.edu). Sara E Wienke (MS, University of North Carolina, Greensboro) is the Genetic Counselor for Pathway Genomics (sewienke@gmail.com).

In his seminal work on stigma, Goffman (1963) wrote extensively about three kinds of people in a stigmatized person's life: potential stigmatizers (i.e., “normals,” p. 5), close connections who accepted the stigmatized person (i.e., “wise,” p. 19), and those who shared the same stigma (i.e., “the own,” p.30). And yet, very little attention has been paid to how social interactions or cognitions associated with either the “wise” or “the own” influence strategic coping. Goffman (1963) wrote of the Wise as “persons who are normal but whose situation has made them intimately privy to the secret life of the stigmatized individual” (p. 28); unmarked spouses meet this definition. The Own could provide information on how to live and cope with the stigma as well as emotional support and acceptance. His argument aligns those behind self-help and social-support groups, which attempt to provide resources for people to gain control over their lives and promote their wellbeing (e.g., Braithwaite, Waldron, & Finn, 1999).

In 2010, Smith and Hipper proposed label management (LM) theory (2010), which integrated sociological theories of coping (modified labeling theory, MLT, Link, 1987; Link et al., 1989) and courtesy stigma (Goffman, 1963), with communication theories of management, communication privacy management (CPM, Petronio, 2002), and stigma communication (Smith, 2007). LM makes predictions about the strategies stigmatized persons, Goffman's the “own,” *and* their unlabeled confidants, Goffman's “wise,” use to cope, such as secrecy or educating others. This study explores the interpersonal, and individual, mutual influences that may appear between a stigmatized person--in this case, someone testing positive for a genetic mutation, with genetic testing itself setting tested individuals apart from others and positive test results long acknowledged to be a way to mark some one as outside the scope of normal--and his/her spouse.

The growing number of acknowledged genetic mutations associated with chronic health conditions aligns with an increase in the number of advocacy groups in the U.S. It also affords the opportunity for the formation of group entitativity, the perception that a separate, unique, coherent group exists, in relation to a genetic condition (Campbell, 1958; Yzerbyt, Judd, & Corneille, 2004). Group entitativity has been largely examined from an outsider's perspective, such that one's perceptions that a unique entity exists comingles with one's views about how to interact with members of the group, leading to stereotyping and enactment of stereotypes (Grzesiak-Fedlman & Suszek, 2008). As a step toward understanding how group entitativity affects coping with one spouse's genetic condition, we consider couples in which one spouse is diagnosed with genetic mutations leading to alpha-1 antitrypsin deficiency (AATD), and their reported enactment of education and secrecy coping strategies.

Alpha-1 Antitrypsin Deficiency and Label Management

The genetic mutation leading to AATD appears in the *SERPINA1* gene located on chromosome 14 (14q31-32. 3) (Laurell & Eriksson, 1963; Sharp et al., 1969). AATD-related symptoms look similar to other conditions like asthma; these similarities can lead to a five to eight year lag time between onset of symptoms and an AATD diagnosis (Stoller et al., 2005). AATD predisposes affected individuals to adult-onset diseases such as chronic obstructive pulmonary disease (COPD), emphysema, cirrhosis, and lung or liver cancer

(Laurell & Eriksson, 1963; Sharp, Bridges, Krivit, & Freier, 1969). The prognosis for AATD varies widely: some people with two deleterious mutations may not get symptoms, while carriers can develop serious symptoms through environmental exposure (e.g., pollutants) or health behaviors (e.g., smoking; Tanash, Nilsson, Nilsson, & Pitulainen, 2010). It is often the combination of genotype and environmental exposures that leads to clinical presentation.

Stigmas are normalized, diffused, pervasive stereotypes of the disgrace of a particular group of people (Smith, 2007, 2011). A model of label management (LM; Smith & Hipper, 2010) drawing upon modified labeling theory (Link et al., 1989; Link, Yang, Phelan, & Collins, 2004), communication privacy management (CPM, Petronio, 2002), courtesy stigma (Goffman, 1963), and stigma communication (Smith, 2007). LM (Smith & Hipper, 2010) makes predictions about the strategies stigmatized persons and their unlabeled confidants use to cope with anticipated stigmatization.

Genetic stigmas focus on those with shared genetic mutations. Goffman's (1963) work on stigmas highlighted that the devaluation is so severe as to consider the person no longer human. Genetic stigmas resonate with Goffman's definition of a tribal stigma (e.g., race) “that can be transmitted through lineages” (p. 4); distinguishing people based on their shared mutations provides a biological basis by which to question their inclusion as humans. Genetic stigmas typically differ from other stigmas in that people are *born* into their membership into the stigmatized group, and are thereby marked by their genes, which they cannot control. Experiments varying whether health conditions are attributed to genetic mutations or not show that people perceived health conditions with genetic attributions (versus environmental) as more serious, held stronger stigmas about it, and believed there to be a greater likelihood that the condition would persist (Phelan, 2005).

People with AATD face genetic stigmatization (Klitzman, 2010), especially as a person moves from asymptomatic to symptomatic; symptomatic AATD displays respiratory symptoms similar to those associated with smokers, possibly leading to causal attributions and blame (Berger, Kapella, & Larson, 2011). Studies of non-smokers diagnosed with lung cancer, for example, have shown a pattern of blame and stigma due to having a cancer associated with smoking (Chapple, Ziebland, & McPherson, 2004). Symptoms, then, may add additional layers described by Goffman as defects of the body and blemished character. AATD also has a documented association with genetic discrimination, with Terri Seargent being fired after her employer learned of her genetic testing results, and she began taking expensive medication for AATD (Jones & Sarata, 2008).

LM (Smith & Hipper, 2010) assumes that stigmas are socialized throughout a community (Link et al., 1989; Scheff, 1966; Smith, 2007). A person who has a condition that could categorize them as a member of a stigmatized group (i.e., labeled) will often anticipate that others will judge them to be responsible, categorize them, and label them (Link, 1987; Link et al., 1989). Drawing on CPM (Petronio, 2002; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004), LM posits that labeled persons and their unlabeled confidants may use the socialized stigma to form expectations about how others may devalue them and discriminate against them (Goffman, 1963; Link, 1987; Link et al., 1989). Consequently, labeled persons

(Herek, 1996; Link, 1987; Link et al., 1989, Miller & Major, 2000) and their confidants (Smith & Hipper, 2010; Smith, 2007, 2011) engage in coping strategies aimed at preventing negative reactions: withdrawal, secrecy, and education (Link et al., 1989). This study focuses on secrecy and education. Secrecy is defined as action taken to conceal distinguishing marks that categorize one in a stigmatized group (e.g., Goffman, 1963; Jones et al., 1984; Link et al., 1991; Smith, 2007). Education is defined as "preventative telling" (Link et al., 1991, p. 304) or providing information in the hope of generating acceptance and warding off social rejection (e.g., Link et al., 1991). According to LM, greater perceived stigma predicts more coping, thus more secrecy and more educational activities. The following hypothesis is posed:

H1: Genetic stigma is positively related to (a) secrecy and (b) education activities.

Group Entitativity and Coping with AATD

Group entitativity is the perception of a group as a real and coherent entity (Campbell, 1958; Yzerbyt, Judd, & Corneille, 2004). This vague definition has been expanded to include cues of "groupy-ness," including appearing similar to each other, sharing common goals, functioning in a coordinated way, and appearing to have a boundary (Hamilton, Sherman, & Spencer-Rodgers, 2004). Entitativity, then, is the difference between perceiving a group as a unique social entity, and perceiving it as just a collection of people (Spencer-Rodgers, Williams, Hamilton, Peng, & Wang, 2007). Notably, group entitativity, the focus of this paper, is not the same as group identification. Entitativity is a necessary prerequisite: one needs to perceive a social group as existing, before one can identify as a member of it. Group identification is a form of self-categorization, in which a person belongs to a group and this belonging informs one's self-concept (Hogg, Sherman, Dierselhuis, Maitner, & Moffitt, 2007). For example, some people with AATD refer to themselves as Alphas (Klitzman, 2010); the label and its self-reference are likely associated with group identification. The two concepts are related, as people tend to identify with highly entitative groups (Hogg et al., 2007). Notably, there are COPD support groups and AATD support groups; by focusing on the AATD community, we place attention on the commonality of the genetic mutations instead of disease.

Group entitativity based on a shared stigmatized condition has been argued to be problematic, because it may exacerbate perceived differences from society and lead to more secrecy (Corrigan & Watson, 2002). This argument may relate to findings such as those that reveal group entitativity directly relates to stereotypes associated with Jews, Germans, Arabs and homosexuals, with each regarded to consist of a collection of persons bonded in a homogenous way (Grzesiak-Fedlman & Suszek, 2008). Individuals united by a common genetic diagnosis and condition who regard themselves to be part of a unique group linked by their diagnosis may fear such group stereotyping and thus keep their status secret. Group entitativity may thus be one explanation for individuals' reticence to disclose a positive genetic test result, even to their romantic partners (Keenan, Simpson, Miedzybrodzka, Alexander, & Semper, 2013).

The existing research on stigmas and group entitativity has focused on stigmatized persons, not their loved ones. As noted earlier, perceiving that a stigma-based group exists could

make the stigma salient, thus increasing loved ones' sense of difference from the general community, thus predicting more secrecy (Corrigan & Watson, 2002). The one study that focused on group entitativity, however, found that among 85 persons with mental illness, stronger group entitativity was not related to intentions to keep their mental illness secret (Rüsch et al., 2009). We thus considered the following question:

> RQ1: Does group entitativity relate to use of secrecy as a coping strategy for diagnosed AATD patients or for their spouses?

A reasonable claim is that stronger perceptions of a group existing based on the stigma may lead people to educate others as a strategy to cope with stigmatization, instead of secrecy (Rüsch et al., 2009). Group identity research based on race, gender, age, and sexual orientation finds that stronger identification with the stigmatized group is associated with stronger self-esteem in stigmatized people (Corrigan, Larson, & Rüsch, 2013). The one study that focused on group entitativity found that among 85 persons with mental illness mentioned previously found that stronger group entitativity directly related to greater intentions to educate members of the public about mental illness, help others with mental illness, and participate in anti-stigma initiatives (Rüsch et al., 2009).

Group entitativity may, bolster a sense of belonging that fosters educational activities, a proposition associated with belief that the ability to resist others' stereotyping depends upon more direct refutation (Rüsch et al., 2009). The ability to enact such explicit counterargument to stereotyping may, however, depend upon support enacted from relatives linked to stigmatized persons. Relatives of stigmatized persons have been found to feel emboldened to fight stigmatization and structural discrimination by lobbying and protesting, and encouraging the stigmatized family member to do the same (Angermeyer, Schulz, & Dietrich, 2003). Whether these actions co-exist with the perception that a unique entity exists for relatives (i.e., Alpha-Spouses) is not known. These are important issues to consider in an era of ever-growing emphasis on personalized medicine, with recognition of a greater number of genetic mutations associated with adult-onset medical conditions, the case for AATD. Thus it predicted that:

> H2: Group entitativity is positively related to diagnosed AATD patients' and their spouses' efforts to educate others about AATD as a coping strategy.

Dyadic Influences on Coping with AATD

Drawing upon CPM (Petronio, 2002), LM presumes that when a person discloses his/her labeling condition to an unlabeled confidant, the two become co-owners of this information. Co-owners (Petronio, 2002) share the knowledge of the discloser's labeled status, regulation of this knowledge, as well as its consequences. As the threat of a labeled group becomes more personally relevant for unlabeled confidants, they have more reason to learn about the devaluation and discrimination facing labeled persons. They must learn to abide by the community's edicts to avoid their own categorization into the group as a labeled member or as a sympathizer (i.e., courtesy stigma; Goffman, 1963). Courtesy stigma suggests that confidants may co-own not just the information of one's labeled status, but its consequences as well. Courtesy stigma occurs when a community treats both labeled persons and their supporters as though they all have been labeled (Goffman, 1963).

Spouses often exhibit some level of similarity in their beliefs, attitudes, and actions. There are two common reasons for such interdependence: common fate and interpersonal influence (Kenny, Kashy, & Cook, 2006). When spouses both are socialized to, anticipate, and experience the stigma of AATD, then this common fate creates similarities between them. Spouses may influence each other's distress (Mays et al., 2003) or how each other copes (Lewis et al., 2006); this is interpersonal influence. The relation between group entitativity and secrecy, as well as education, is more likely to be from interpersonal influences, rather than common socialization (e.g., through media messages). Disclosers may tell their confidants not to share their test results with anyone else (Petronio, 2002; Petronio et al., 2004). Instead of presuming that labeled persons decide on coping strategies alone, LM (Smith & Hipper, 2010) argues that confidants may advise labeled persons to engage in secrecy or education to help the labeled person avoid future problems.

In studies of couples coping with lung cancer, sharing tasks and seeking support from shared networks were forms of relational maintenance, and they predicted less distress over time (Badr & Taylor, 2008). People diagnosed with AATD may perceive that there is a group of Alphas in existence, but their spouses, because they are not in-group members, may not (Rüsch et al., 2009). We may find the reverse for the group, Alpha-spouses: spouses and registered members may not have strong similarities in their perceptions of whether such a relatives-group exists. On the other hand, we may find projection effects: if one member of the couple perceived that there is a self-relevant group, they may perceive a reference group for their spouse as well. Last, we may find interpersonal influences: the group entitativity perceptions of one's spouse may predict one's decisions to cope through secrecy or education. The following research questions are posed:

RQ2: How similar are spouses in their perceptions of group entitativity of Alphas and Alpha Spouses?

RQ3: Do spouses' perceptions of group entitativity influence each other's secrecy or education about AATD?

Methods

Participants and Procedures

An institutional review board approved the study. Participants were recruited through the Alpha-1 Research Registry located at Medical University of South Carolina (MUSC) in August of 2012. The registry includes 1788 members (ARR members) who provided email addresses and indicated willingness to be contacted for research. The recruitment invitation (provided via email) told registered members that the study was interested in married couples' experiences with the AATD test results, and provided the link to access our online questionnaire. Of the 1788 members, 179 members started the survey, and 130 completed it, including 40 who did not meet the marital status requirement. After giving consent, participants were asked whether they had a partner who could also complete the survey. Those without partners (n = 40 ARR members) were sent to a thank you page, and did not answer questions in the survey.

Married participants were asked to report their marriage date and then state where they currently reside, which was used to link couples' responses. We do not know how many of the ARR members are married, but the response rate (179/1788 or 10%) is likely an underestimate of how many married ARR members completed this survey. Fifty-eight spouses of ARR members also completed the survey. Of the 130 ARR members and 58 spouses, 50 couples could be matched.

Participants were asked to complete measures related to genetic stigma, genetic testing, couple communication, emotions related to testing positive for AATD, and perceived stress, marital quality, diagnosed health conditions, and demographics. Participants, on average, completed the survey in 20 minutes, which is similar to our pilot test results. Another article drawing on different variables in this dataset exists (Smith, Wienke, & Coffman, 2014).

Measures

Genetic stigma—Eight items (adapted from the devaluation-discrimination scale; Link et al., 1989) were used to measure genetic stigma beliefs (e.g., *Most people would feel that being diagnosed with a genetic mutation is a sign of personal failure;* 1 = *strongly disagree* to 5 = *strongly agree*). Responses were averaged into one score (α = .86, registered member; α = .84, spouse), with higher scores indicating more belief that AATD is a stigmatized condition.

Alpha and Alpha-spouse entitativity—For Alpha entitativity, five items (adapted from Spencer-Rodgers, Williams, Hamilton, Peng, & Wang, 2007) were used to measure the degree to which people appraise Alphas as a distinct social entity (e.g., *How intact is this group?*, *To what extent does this group qualify as a group?*, and *To what extent do you think that Alphas feel that they are part of a group?* 1 = *not at all*, 5 = *very much*), see the Appendix for all the items and instructions. The instructions preceding the items were "Some groups have the characteristics of a "group" more than others do. When you answer this question, please think about people diagnosed with Alpha-1 as a group." Responses were summed into one score (α = .89, registered member; α = .84, spouse), indexing Alpha entitativity. The same questions were asked again referring to Alpha Spouses as a distinct social entity (e.g., *To what extent do you think that those married to Alphas—Alpha Spouses—feel that they are part of a group?* 1 = *not at all*, 5 = *very much*). Responses were summed into one score (α = .94, registered member; α = .89, spouse), indexing Alpha entitativity.

Secrecy—Seven items (adapted from Link et al., 1989) were used to measure the use of secrecy to cope (e.g., *I keep the Alpha-1 diagnosis secret;* 1 = *strongly disagree* to 5 = *strongly agree*). Responses were summed into one score (α = .83, registered member; α = .88, spouse), with higher scores indicating more secrecy.

Education—Three items (adapted from Link et al., 1989) were used to measure the use of education to cope (e.g., *I take it upon myself to educate those who are uncomfortable with Alpha-1 about it;* 1 = *strongly disagree* to 5 = *strongly agree*). Responses were summed into one score (α = .79, registered member; α = .70, spouse), with higher scores indicating more education.

Results

Descriptive Statistics

On average, the couples perceived that Alphas were a distinct, social entity (M = 3.64, SD = 0.94 for the entire sample), but most did not believe that Alpha-spouses had group entitativity (M = 2.51, SD = 1.12 for the entire sample). Overall, participants did not keep the Alpha-1 diagnosis secret (M = 2.05, SD = 0.75 for the entire sample). Participants varied in reporting that they educated others about Alpha-1 to reduce stigmatization; some agreed that they did so, while others disagreed (M = 3.29, SD = 0.85 for the entire sample).

Within-couple Comparisons

To conduct the comparisons and estimate intraclass consistency, the data were set up in a dyad structure (one couple per row), distinguishing participants as either the registered member (R) or the spouse (S; Kenny et al., 2006). Using paired-sample t tests, the mean levels of the key variables were compared between registered members and their spouses (see Table 1). Couples reported similar levels of secrecy, education, and Alpha Spouse entitativity; however, registered members reported higher group entitativity for Alphas than did their spouses.

Hypothesis Testing

Intrapersonal influences and interpersonal influences in couples' answers were assessed using *Pearson-r* correlations (Kenny et al., 2006). The results appear in Table 2.

Genetic stigma, secrecy, and education—H1a posited a positive relation between genetic stigma and secrecy about the Alpha-1 diagnosis. For both registered members and their spouses, there was a statistically significant, positive, intrapersonal relation between genetic stigma and secrecy, r (48) = .37, $p < .05$ and r (48) = .28, $p < .05$ respectively. H1a was supported. H1b posited a positive relation between genetic stigma and education to reduce stigmatization. None of the intrapersonal relations were statistically significant; H1b was not supported.

Group entitativity and secrecy—RQ1 explored the relation between group entitativity and secrecy. The relation between Alpha entitativity and secrecy was negative for registered members, r (48) = -.41, $p < .05$, and for spouses, r (48) = -.54, $p < .05$. For Alpha entitativity, H3 was supported. The relation between Alpha-Spouses entitativity and secrecy was negative for registered members, r (48) = .25 and for spouses, r (48) = -.09, but neither was statistically significant. The findings suggest an intrapersonal effect of group entitativity on secrecy, only for Alphas, but not for Alpha-spouses.

Group entitativity and education—H2 posted a positive relation between group entitativity and education. The correlations showed intrapersonal influences. For registered members, the relation between Alpha entitativity and education was positive, r (48) = .48, $p < .05$. The relation between Alpha-Spouses entitativity and education was positive, r (48) = .30, $p < .05$. H2 was supported, intrapersonally.

Intracouple Consistency and Interpersonal Influences

RQ2 explored the similarity in spouses' perceptions of the group entitativity of Alphas and Alpha-Spouses. Intraclass consistency in couples' answers was assessed using *Pearson-r* correlations (Kenny et al., 2006). The results appear in Table 2; the intraclass coefficients are shaded. Couples had statistically significant intraclass coefficients for Alpha entitativity (.57) and Alpha-spouses entitativity (.32). The answer to RQ1, then, was that spouses are similar in their perceptions of group entitativity. Their scores were also more consistent with each other than we expect to occur with a randomly assigned person (e.g., a stranger). That said, the intraclass coefficient (.32) is not very strong. In addition, spouses reported similar mean levels of entitativity for Alpha Spouses, but registered members reported stronger entitativity for Alphas than did their spouses (see Table 1).

Of note, couples also showed statistically significant intraclass coefficients for genetic stigma (.31) and secrecy (.61), but not for education (.23).

RQ3 explored the interpersonal influences of group entitativity on secrecy and education. Registered members' secrecy was associated with their spouses' perceptions of Alpha entitativity, r (48) = -.35, $p < .05$. Spouses' secrecy was not associated with registered members' perceptions of Alpha-Spouses entitativity, r (48) = -.20, *ns*. The interpersonal effect of group entitativity on secrecy was only statistically significant for registered members. The opposite pattern appeared for education. Registered members' education was not associated with their spouses' perceptions of Alpha entitativity, r (48) = .26, *ns.* $p < .05$. Spouses' education was associated with registered members' perceptions of Alpha-Spouses entitativity, r (48) = .28, $p < .05$. The interpersonal effect of group entitativity on education was only statistically significant for spouses.

Post Hoc: Projections in Group Entitativity

The correlations also showed strong associations in self-other perceptions of group entitativity. Notably, registered members' perceptions of Alpha entitativity was strongly associated with perceptions of Alpha-Spouses entitativity, r (48) = .71, $p < .05$. The projection for spouses was smaller, r (48) = .47, $p < .05$. These findings suggest that as one spouse perceived higher group entitativity for their group, they perceived it for their partner's group too.

Post Hoc: Actor-Partner Interdependence Models

Multilevel modeling was used to estimate actor-partner interdependence models. Data were set up in an individual structure: each person has a row, and each row contains both person and partner's data. Variables were created to distinguish each couple and each individual's position in the couple (effect coded: registered member = 1; spouse = -1). Using SPSS syntax, distinguishing variable and interactions were modeled; the multilevel model was run, allowing for compound symmetry (Kenny et al., 2006).

Two separate regressions were estimated: one for secrecy and one for education. The two variables were regressed on the same intrapersonal and interpersonal variables: genetic stigma, partner's genetic stigma, Alpha entitativity, as well as the couple position (member

or spouse), and interactions among the variables and the couple position. The results appear in Table 3.

Secrecy was predicted by intrapersonal and interpersonal variables (*pseudo* R^2 = .28). Married adults who perceived a stronger genetic stigma and less Alpha entitativity reported more secret-keeping of the Alpha-1 diagnosis. There were significant interactions for couple position (registered member or spouse) and the partner's perceptions of genetic stigma. The interaction reflects that spouses' secret-keeping was more strongly influenced by registered members' genetic stigma, than registered members' secret-keeping was by their spouses' genetic stigma.

Education was also predicted by intrapersonal and interpersonal variables (*pseudo* R^2 = .28). Married adults reported educating others more about Alpha-1 in order to reduce stigmatization as they personally perceived a stronger genetic stigma, but their partners perceived a weaker genetic stigma. They educated more as they personally perceived stronger group entitativity for Alphas, and their partner perceived stronger entitativity for Alpha spouses. There were two significant interactions between couple position (registered member or spouse) and genetic stigma as well as Alpha entitativity. These interactions reflect that registered members engaged in more education as they perceived a stronger genetic stigma and Alpha entitativity. The spouses, in contrast, engaged in less education if they perceived a stronger genetic stigma and had a weaker association between education and Alpha entitativity.

Discussion

This study provides the first empirical study of group entitativity associated with a genetic condition, AATD. Further, this study included married couples in which one member was diagnosed with a genetic mutation leading to AATD, providing additional needed insights into dyadic influences in couples (Lewis et al., 2006). The rise of advocacy groups affiliated with AATD was fueled by a need to bring attention to the under-recognized (Stoller et al., 2005) but common, inherited, monogenic disorder (Stoller & Aboussouan, 2012), to raise funds for clinical research, and to support Alphas and their families (e.g., Alpha Spouses). The diagnosed members and their spouses with membership in the Alpha-1 Research Registry who participated in this research reveal the importance of group entitativity on coping strategies adopted while living with AATD.

In this context, registered members have one group relevant to their lives, called Alphas, and their spouses have another, Alpha-spouses. The results showed that registered members and their spouses perceived group entitativity for Alphas. In other words, they perceived that such a group existed as a distinct social entity. Notably, registered members perceived stronger entitativity of Alphas than did their spouses. The findings further revealed that personal perceptions of Alpha entitativity were associated with married adults' reports of keeping the Alpha-1 diagnosis secret and educating others to cope with the diagnosis. Intrapersonal and interpersonal influences appeared, highlighting the complex, interdependent nature of coping.

Secrecy and Education

Couples had the strongest intraclass coefficients for secrecy, indicating the most interdependence appeared in secret-keeping. In contrast, they showed the least interdependence in their education efforts. Communication theories on privacy management (i.e., communication privacy management, CPM; Petronio, 2002) emphasize the coordinated nature of keeping boundaries around information. Indeed, CPM posits that once people disclose information to another, the two co-own that information and the responsibilities to regulate who else gets to know it (Petronio, 2002, Petronio et al., 2004). The strong interdependence in secret-keeping aligns with this argument.

It is interesting, however, that education efforts do not. Education poses potential risks, because one inherently discloses or aligns oneself with the potentially stigmatized condition (Link et al., 1989; Smith & Hipper, 2010). For married adults, if one person engages in educational efforts, they may expose not only themselves to this risk, but also their spouse. The couples in this study reported engaging in education efforts; future research is needed to understand how much coordination goes into such efforts, and the consequences of coordinated (or not) efforts on the couple.

Group Entitativity: Investigating the “Own”

Goffman's seminal book (1963) started a lively, robust effort to further social science understanding of stigmas as a concept and as an experience. Interestingly, the book places much attention on different kinds of supporters; less attention has been paid to supporters. Many kinds of groups associated with stigmas exist such as those constituted by others who share the stigmatized condition, those attempting to fight the stigma (whether they are marked or not), and for those who are connected to stigmatized persons. While these groups exist, there is no empirical research on how perceiving that a group exists influences basic associations, such as stigma and secrecy.

This study showed that couples were consistent in their perceptions of Alphas as a distinct, social entity. Registered members reported even higher entitativity for Alphas than did their spouses. This coincides with the argument that in-group members likely group entitativity likely to be higher for in-group members than for others (Rüsch et al., 2009). Couples showed weaker perceptions of (and less consistency) Alpha-spouses. Alpha entitativity was associated with both secrecy and education efforts. The basic correlations showed that intrapersonally and interpersonally, stronger entitativity for Alphas predicted more engagement in education efforts and less secrecy for registered members and their spouses. The mixed-level models showed that both genetic stigma and Alpha entitativity predicted secrecy and education. While genetic stigma was positively associated with both secrecy and education, stronger entitativity for Alphas was associated with less secrecy and more education. These findings support the arguments that group entitativity may promote education and not secrecy (Rüsch et al., 2009).

Alpha-spouse entitativity may have been less present, because it may not be central to the advocacy efforts of the Alpha-1 community. Alternatively, how families take advantage of or leverage relatives' groups to access coping resources may not be well understood. As

noted in the literature review, a previous study of loved ones who were all involved in a relatives' group reported very little about what role their group played in coping strategies. In this study, the associations between Alpha-spouse entitativity and education were all interpersonal. The only significant association between spouses' entitativity perceptions of Alpha-spouses was with registered members' educational efforts. In addition, registered members' perceptions were significantly associated with spouses' education efforts. The presence of interpersonal influences without intrapersonal ones is striking, and needs to be better understood in order to facilitate effective relatives' groups.

Couples' Coping

While attending to group entitativity is the first contribution from this study, the second is studying these relations within couples. The correlations showed intrapersonal and interpersonal associations among variables, which also appears in relations between communication about genetic tests and distress in parenting dyads (Mays et al., 2013). The mixed-level model showed interesting complexities for both secrecy and education.

As married adults personally perceived more genetic stigma and less Alpha entitativity, they engage in more secrecy. Furthermore, for spouses, the registered member's perception of genetic stigma also positively influenced their secret-keeping. These findings show that genetic stigma may affect the actions of those with the stigmatized condition as well as their loved ones, which provides support for the interpersonally-based model of label management (Smith & Hipper, 2012). It also highlights the potential power-dynamics within couples, as one person's feelings may have more weight in one spouse's decision-making in comparison to the other. The spouse, for example, may feel a chilling effect (Afifi & Olson, 2005; Afifi et al., 2005; Cloven & Roloff, 1993) from the patient's stigma perceptions. These findings also provide additional insights into the unique needs spouses may have in providing support (Badr & Taylor, 2008), and an opportunity to design interventions to assist partners (Cohrane & Lewis, 2005) and couples (Lewis et al., 2006).

For education, married adults engaged in greater education efforts as they personally perceived more genetic stigma and stronger Alpha entitativity, and their partners perceived lesgenetic stigma and stronger entitativity for Alpha-spouses. The significant interactions showed that genetic stigma and Alpha entitativity were interpersonal contributors for registered members' education efforts. These findings call for more consideration of the ramifications of patient-based education efforts, and ways to integrate families into these efforts. Indeed, future studies should investigate how partners feel about finding themselves in a stigmatized situation, and how does the development affect the marital relationship and influence the way they personally and collectively cope with it.

Limitations

The findings are limited by the small sample and use of the registry. The small sample limited statistical power. Using a registry to recruit participants provided us contact with persons with the relevant genetic mutations, but it may also represent a selection bias of those willing to join a registry. Indeed, the findings represent people with homozygous (ZZ) more than heterozygous (e.g., MZ) results. People considered carriers may be less likely to

be involved in registries. Further, those more likely to engage in educational efforts, in general, may be involved in registries as a means to actively further science for their health condition and may thus feel less stigmatized. In addition, one of the items in the group entitativity scale “to what extent do you think that Alphas feel that they are part of a group?” reflects perceptions of a unique social entity, but may also relate to identification (even attributed from outsiders) with that group. This item brings up concerns around separating these two perceptions and ways to measure each well. The findings from this study should be treated cautiously until they have been replicated.

Conclusion

Stigmas involve categorizing a certain set of people into a discredited group, which can have negative consequences for stigmatized persons. As stigmatized people form social cognitions around a group based on the shared condition they may gain multiple benefits. This study showed that perceptions of group entitativity counter-balanced the influence of genetic stigma on coping through secrecy or through education. More attention on the power of creating groups for stigmatized persons and their loved ones is needed. Indeed, people live within a dynamic world of group entities, and multiple social identities including spousal and familial. While attention has been paid to the diffusion of stigmas to loved ones, less has been paid to the uplift of group entities for them.

Acknowledgments

This project was supported by an ELSI grant with the Alpha-1 Foundation and Award Number P50-DA010075-16 from the National Institute on Drug Abuse.

We want to thank Donna Coffman, Mary Poss, Marisa Greenberg, and Ryan Chestnut for their feedback on earlier drafts of the paper. Most importantly, we are grateful to the members of the Alpha-1 Research Registry and their spouses for sharing their thoughts with us. Corresponding author is Dr. Rachel Smith, W-252 Millennium Science Complex, The Pennsylvania State University, University Park, PA, 16802. Telephone: 1(814)867-4651. Fax: N/A. Email: ras57@psu.edu.

Appendix

Some groups have the characteristics of a “group” more than others do. When you answer this question, please think about people diagnosed with Alpha-1 as a group.

	Very much	Moderately	Somewhat	A little	Not at all
To what extent do you think that Alphas feel that they are part of a group?					
To what extent does this group qualify as a group?					
Overall, how similar are Alphas to each other?					
How united is this group?					
How intact is this group?					

References

Angermeyer MC, Schulz B, Dietrich S. Courtesy stigma: A focus group study of relatives of schizophrenia patients. Social Psychiatry and Psychiatric Epidemiology. 2003; 38:593–602.10.1007/s00127-003-0680-x [PubMed: 14564387]

Badr H, Taylor CL. Effects of relationship maintenance on psychological distress and dyadic adjustment among couples coping with lung cancer. Health Psychology. 2008; 27:616–627.10.1037/0278-6133.27.5.616 [PubMed: 18823188]

Berger BE, Kapella MC, Larson JL. The experience of stigma in chronic obstructive pulmonary disease. Western Journal of Nursing Research. 2011; 33:916–932.10.1177/0193945910384602 [PubMed: 20940446]

Braithwaite DO, Waldron VR, Finn J. Communication of social support in computer-mediated groups for people with disabilities. Health Communication. 1999; 11:123–151. [PubMed: 16370973]

Campbell DT. Common fate, similarity, and other indices of the status of aggregates of person as social entities. Behavioural Science. 1958; 3:14–25.

Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: A qualitative study. The British Medical Journal. 2004; 328:1470–1475.10.1136/bmj.38111.639734.7C [PubMed: 15194599]

Corrigan PW, Watson AC. The paradox of self-stigma and mental illness. Clinical Psychology: Science and Practice. 2002; 9:35–53.10.1093/clipsy.9.1.35

Goffman, E. Stigma: Notes on the management of spoiled identity. Englewood Cliffs, NJ: Prentice-Hall; 1963.

Grzesiak-Fedlman M, Suszek H. Conspiracy stereotyping and perceptions of group entitativity of Jews, Germans, Arabs and homosexuals by Polish students. Psychological Reports. 2008; 102:755–8. [PubMed: 18763447]

Hamilton, DL.; Sherman, SJ.; Spencer-Rodgers, J. Perceiving the groupness of groups: Entitativity, homogeneity, essentialism, and stereotyping. In: Yzerbyt, V.; Judd, C.; Corneille, O., editors. The psychology of group perception: Contributions to the study of homogeneity, entitativity, and essentialism. Brighton, United Kingdom: Psychology Press; 2004. p. 39-60.

Herek, GM. Why tell if you're not asked? Self-disclosure, intergroup contact, and heterosexuals' attitudes toward lesbians and gay men. In: Herek, GM.; Jobe, J.; Carney, R., editors. Out in force: Sexual orientation and the military. Chicago: University of Chicago Press; 1996. p. 197-225.

Hogg MA, Sherman DK, Dierselhuis J, Maitner AT, Moffitt G. Uncertainty, entitativity, and group identification. Journal of Experimental Social Psychology. 2007; 43:135–142.10.1016/j.jesp.2005.12.008.

Jones, EE.; Farina, A.; Hastorf, AH.; Markus, H.; Miller, DT.; Scott, RA. Social stigma: The psychology of marked relationships. New York: W. H. Freeman and Company; 1984.

Jones, NL.; Sarata, AK. Report for Congress. Genetic information: Legal issues relating to discrimination and privacy. 2008. Retrieved from http://biotech.law.lsu.edu/crs/RL30006_20080310.pdf on January 22, 2013

Keenan KF, Simpson SA, Miedzybrodzka Z, Alexander DA, Semper J. How do partners find out about the risk of Huntington's Disease in couple relationships? Journal of Genetic Counseling. 2013; 22:336–344.10.1007/s10897-012-9562-2 [PubMed: 23297124]

Kenny, DA.; Kashy, DA.; Cook, WL. Dyadic data analysis. New York, NY: The Guilford Press; 2006.

Klitzman R. Views of discrimination among individuals confronting genetic disease. Journal of Genetic Counseling. 2010; 19:68–83.10.1007/s10897-009-9262-8. [PubMed: 20054623]

Laurell CB, Eriksson S. The electrophoretic alpha-1 globulin pattern of serum in alpha-1 antitrypsin deficiency. Scandinavian Journal of Clinical Laboratory Investigation. 1963; 15:132–140.

Lewis MA, McBride CM, Pollak KI, Puleo E, Butterfield RM, Emmons KM. Understanding health behavior change among couples: An interdependence and communal coping approach. Social Science & Medicine. 2006; 62:1369–1380.10.1016/j.socscimed.2005.08.006 [PubMed: 16146666]

Link BG. Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. American Sociological Review. 1987; 52:96–112.

Link BG, Cullen FT, Struening EL, Shrout PE, Dohrenwend BP. A modified labeling theory approach to mental disorders: An empirical assessment. American Sociological Review. 1989; 54:400–423.

Link BG, Yang LH, Phelan JC, Collins PY. Measuring mental illness stigma. Schizophrenia Bulletin. 2004; 30:511–541. [PubMed: 15631243]

Mays D, DeMarco TA, Luta G, Peshkin BN, Patenaude AF, Schneider KA, Tercyak KP. Distress and the parenting dynamic among BRCA1/2 tested mothers and their partners. Health Psychology. 2013 Advance online publication. 10.1037/a0033418

Miller, CT.; Major, B. Coping with stigma and prejudice. In: Heatherton, TF.; Kleck, RE.; Hebl, MR.; Hull, JG., editors. The social psychology of stigma. New York: Guilford Press; 2000. p. 243-272.

Nuffield Council on Bioethics. Genetic screening: A supplement to the 1993 report. Nuffield Council on Bioethics; London: 2006.

Petronio, S. Boundaries of privacy: Dialectics of disclosure. New York: State University of New York Press; 2002.

Petronio S, Sargent J, Andea L, Reganis P, Cichocki D. Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. Journal of Social and Personal Relationships. 2004; 21:33–52.

Phelan JC. Geneticization of deviant behavior and consequences for stigma: The case of mental illness. Journal of Health and Social Behavior. 2005; 46:307–322. [PubMed: 16433278]

Rüsch N, Corrigan PW, Wassel A, Michaels P, Olschewski M, Wilkniss S, Batia K. Ingroup perception and responses to stigma among persons with mental illness. Acta Psychiatrica Scandinavica. 2009; 120:320–328.10.1111/j.1600-0447.2009.01403.x [PubMed: 19485961]

Scheff, TJ. Being mentally ill: A sociological theory. Chicago: Aldine; 1966.

Sharp H, Bridges R, Krivit W, Freier E. Cirrhosis associated with alpha-1 antitrypsin deficiency: A previously unrecognized inherited disorder. Journal of Laboratory and Clinical Medicine. 1969; 73:934–939. [PubMed: 4182334]

Smith RA. Language of the lost: An explication of stigma communication. Communication Theory. 2007; 17:462–485.

Smith RA, Hipper T. Label management: Investigating how confidants encourage the use of communication strategies to avoid stigmatization. Health Communication. 2010; 25:410–422. [PubMed: 20677045]

Smith RA, Wienke SE, Coffman DL. Alpha-1 couples: Interpersonal and intrapersonal predictors of spousal communication and stress. Journal of Genetic Counseling. 2014; 23:212–220.10.1007/s10897-013-9639-6 [PubMed: 23934327]

Spencer-Rodgers J, Williams MJ, Hamilton DL, Peng K, Wang L. Culture and group perception: Dispositional and stereotypic inferences about novel and national groups. Journal of Personality and Social Psychology. 2007; 93:525–543.10.1037/0022-3514.93.4.525 [PubMed: 17892330]

Stoller JK, Aboussouan LS. A review of α_1-Antitrypsin deficiency. American Journal of Respiratory and Critical Care Medicine. 2012; 185:246–259. [PubMed: 21960536]

Stoller JK, Sandhaus RA, Turino G, Dickson R, Rodgers K, Strange C. Delay in diagnosis of alpha-1 antitrypsin deficiency: A continuing problem. Chest. 2005; 128:1989–94. [PubMed: 16236846]

Yzerbyt, VY.; Judd, C.; Corneille, O., editors. The psychology of group perception: Perceived variability, entitativity, and essentialism. New York, NY: Psychology Press; 2004.

Table 1

Descriptive statistics for variables and similarities within the couple (N = 50 couples)

	Registered Member		Spouse		
	M	***SD***	***M***	***SD***	**Paired-sample *t***
Genetic Stigma	2.45	0.70	2.48	0.60	-0.29
Alphas Entitativity	3.77	0.93	3.51	0.94	2.13*
Alpha Spouses Entitativity	2.55	1.16	2.46	1.09	0.51
Secrecy	2.04	0.76	2.05	0.74	-0.06
Education	3.39	0.89	3.20	0.81	1.25

Table 2

Correlations among Variables Associated with Registered Members and their Spouses (N = 50 couples)

	1	2	3	4	5	6	7	8	9
1. S Genetic Stigma									
2. S Alphas Entitativity	-.15								
3. S Alpha-spouses Ent.	.00	.47*							
4. S Secrecy	.28*	-.54*	-.09						
5. S Education	-.12	.23	.21	-.07					
6. Genetic Stigma	.31*	.00	.09	.28*	.00				
7. Alphas Entitativity	-.09	.57*	.28*	-.41*	.26	-.13			
8. Alpha-spouses Ent.	.12	.40*	.32*	-.20	.28*	-.16	.71*		
9. Secrecy	.11	-.35*	-.18	.61*	-.07	.37*	-.41*	-.25	
10. Education	-.16	.26	.38*	-.20	.23	.12	.48*	.30*	-.34*

Notes. *S* = Spouses' answers. The data were set up in a dyadic structure for the Pearson r correlations. The shaded boxes represent the intraclass coefficients for the five key variables.

Table 3
Actor-Partner Interdependence Models Using Multilevel Modeling

	Secrecy		Education	
	estimate	***se***	**estimate**	***se***
Intercept	2.83*	0.66	1.64*	0.81
Genetic stigma	0.42*	0.14	0.28†	0.17
Alpha entitativity	-0.30*	0.16	0.53*	0.19
Alpha-spouse entitativity	0.12	0.12	-0.04	0.15
P Genetic stigma	-0.12	0.17	-0.31*	0.17
P Alpha entitativity	-0.15	0.13	-0.20	0.16
P Alpha-spouse entitativity	-0.06	0.10	0.26*	0.12
Registered member	-0.02	0.67	1.00	1.10
Genetic stigma* RM	-0.31	0.24	-0.50*	0.28
Alpha entitativity * RM	-0.11	0.22	-0.49*	0.25
Alpha-spouse entitativity * RM	-0.02	0.16	0.11	0.19
P Genetic stigma* RM	0.37†	0.24	0.41†	0.28
P Alpha entitativity * RM	-0.03	0.22	0.23	0.25
P Alpha-spouse entitativity * RM	0.16	0.16	-0.09	0.19
Intraclass correlation	.48		.07	
Pseudo R^2	.28		.16	

Notes. P denotes the partner's answers. RM = registered member. Of note, the intraclass correlation computed from the multilevel model estimates controls for the effects of the independent variables (Kenny, Kashy, & Cook, 2006).

† $p < .10$

* $p < .05$