



Stigma, Expressed Emotion, and Quality of Life in Caregivers of Individuals with Dementia

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Expressed emotion (EE) is a measure of a caregiver's critical and emotionally overinvolved (EOI; e.g., intrusive, self-sacrificing) attitudes and behaviors toward a person with a mental illness. Mounting evidence indicates that high levels of these critical and EOI attitudes and behaviors (collectively termed high EE) in family members are associated with a poorer course of illness for people with a range of disorders, including dementia (Nomura et al., 2005). However, less is known about factors that might trigger high EE and how high EE might impact dementia caregivers' own mental health. In this study we propose that caregivers who perceive stigma from their relative's illness may be more likely to be critical or intrusive (high EOI) toward their relative in an attempt to control symptomatic behaviors. We further hypothesized that high EE would partially mediate the link between stigma and quality of life (QoL) as there is some evidence that high EE is associated with poorer mental health in caregivers themselves (Safavi et al., 2015). In line with study hypotheses and using a sample of 106 dementia caregivers, we found that greater caregiver stigma was associated with both high EE (for criticism and EOI) and with poorer QoL. Mediation analyses further confirmed that high EE accounts for much of the association between stigma and poorer QoL. Study results suggest that addressing caregiver stigma in therapy could reduce levels of high EE and indirectly therefore improve caregiver QoL. Intervening directly to reduce high EE could also improve caregiver QoL.

Keywords: Expressed Emotion; Quality of Life; Dementia; Caregivers

Fam Proc x:1–13, 2017

Currently 5.3 million people suffer from Alzheimer's disease and other age-related dementias.^{1,2} If no cure or prevention is found, the prevalence is expected to triple by 2050 (Alzheimer's Association, 2015). This illness takes a major toll not only on those

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This study was supported by the Provost Research Award from the University of Miami. We thank the patients and families who participated in this randomized trial.

¹Dementia refers to a variety of conditions that develop when nerve cells in the brain no longer function properly or die off (Thies & Bleiler, 2012).

²The *Diagnostic and Statistical Manual of Mental Disorders 5th ed. (DSM-5)*; American Psychiatric Association, 2013) has moved to use the term neurocognitive disorders when referring to conditions commonly affecting younger individuals (e.g., traumatic brain injury). However, *DSM-5* continues to use the term dementia for degenerative conditions primarily affecting older adults. This study is focused on caregivers of individuals aged 60 years and older with neurocognitive impairment, thus, we continue to use the term dementia in this study.

afflicted but on their caregivers as well. In 2014, an estimated 16 million caregivers provided 18 billion hours of unpaid care to those with Alzheimer's and other dementias (Alzheimer's Association, 2015). In the United States, 85% of dementia caregivers are family members (Gitlin & Schulz, 2012). Caregiving for a mentally ill family member can result in high degrees of depression, anxiety, and burden, due to the financial and physical aspects of caregiving along with the considerable demands on one's time (Kahn, Wishart, Randolph, & Santulli, 2016; Suro & Weisman de Mamani, 2013). Caregiving demands can be far reaching and include assisting with activities of daily living (showering, dressing, shaving), driving patients to appointments, and handling patients' financial and personal affairs (Martins Gratao et al., 2010; Weisman de Mamani et al., 2014). The burden of caring for a family member with dementia is often further compounded by the presence of symptoms that may appear rude, inappropriate, or bizarre to others who are unaware of the person's illness. For example, patients may become agitated or combative, spew obscenities, make off-color jokes, and/or wear clothing that is soiled or unusual (Comer, 2015). Not only are these behaviors likely difficult for a caregiver to manage, they may also be embarrassing, causing caregivers to feel stigmatized, particularly if observers are unaware that the behaviors are caused by a neurological disorder.

Despite substantial gains in public awareness of dementia, both dementia patients and their caregivers continue to report feeling stigmatized (Kahn et al., 2016). As a result, dementia caregivers may engage in activities such as criticizing the patient or excessively involving themselves in the patient's care in an attempt to control or reduce stigmatizing behaviors. Although an understandable reaction, a large body of research examining a construct called expressed emotion (EE) indicates that critical (and related negative attitudes and emotions, e.g., anger, irritation) and emotionally overinvolved behavior (termed high EE) toward a mentally ill person is associated with a poorer course of illness for the patient. This association was first found in schizophrenia by Brown, Monck, Carstairs, and Wing (1962) and has since been replicated in a range of other disorders (e.g., depression, bipolar disorder, eating disorders) and appears to be a valid and robust finding (see Butzlaff & Hooley, 1998; Hooley, 2007; and Weintraub, Hall, Carbonella, de Weisman Mamani, & Hooley, 2017, for reviews of this literature). This link has also been examined in dementia. In a longitudinal study of caregivers of nondepressed Alzheimer patients, Vitaliano, Young, Russo, Romano, and Magana-Amato (1993) found that high EE in caregivers was linked to increased negative behaviors (such as being uncooperative, threatening, physically abusive, or ungrateful behavior) exhibited in patients at 15- to 18-month follow-ups.

In addition to being detrimental to mentally ill patients, a smaller body of research suggests that high EE attitudes may also be linked to poorer psychological well-being in caregivers who express them. For example, a study of Alzheimer's caregivers with comorbid depression found that high EE was related to higher levels of depression and burden in the caregivers themselves (Wagner, Logsdon, Pearson, & Teri, 1997). Despite these findings, the literature on the effect of EE on caregivers themselves is sparse and little is known about factors that might trigger high EE and how high EE might impact dementia caregivers' own mental health. Pinpointing factors that might lead to high EE could have direct benefits to both dementia patients and their caregivers alike.

Prior research indicates that guilt and shame proneness are associated with high EE. For example, Wasserman, Weisman de Mamani, and Suro (2012) found that higher levels of both shame and guilt/self-blame about having a relative with schizophrenia predicted high EE in caregivers. Hasson-Ohayon et al. (2012) further found that proneness to shame in patients with mental illness was associated with increased risk of experiencing self-stigma. Another study conducted with caregivers of patients with schizophrenia in China (Phillips, Pearson, Li, Xu, & Yang, 2002) found that perceived stigma was associated with

high EE attitudes toward the patient. In this study, coders also rated the perceived impact of stigma on the quality of caregivers' lives using a one-item measure with four anchor points (ranging from 0 = no effect to 3 = severe effect; Phillips et al., 2002). Although the authors reported finding a link between greater caregiver stigma and greater life impact, it is important to note that life impact ratings were derived from coders' intuitions based on caregivers' responses to the stigma items. Thus, they may not be a valid reflection of caregivers' own perceptions. Moreover, stigma and life impact scores cannot be viewed as independent ratings because they were derived from the same instrument and impact ratings were inferred directly from participants' responses to the stigma items. Thus, in line with Phillips et al. (2002), we propose that stigma may be one factor that precipitates high EE attitudes and behaviors. However, it will be important to assess how stigma relates to caregiver quality of life (QoL) using a more global and independent rating of stigma that clearly taps caregivers' own perceptions.

In this study, we hypothesize that dementia caregivers who perceive greater stigma from their relative's illness will also be more likely to be critical, angry, self-sacrificing, or intrusive (higher EE) toward their relative in an attempt to control symptomatic behaviors. In addition, expanding upon Wagner et al.'s (1997) finding linking high EE to greater depression and burden in caregivers, we also hypothesize that higher EE behaviors in dementia caregivers will be associated with poorer reported overall QoL. We further expect that greater caregiver stigma will be linked to poorer QoL in caregivers. Finally, although never yet tested empirically, we hypothesize that high EE will indirectly influence the link between stigma and QoL. Specifically, we hypothesize that caregivers who experience stigma will respond by trying to control the embarrassing behavior by criticizing the patient and becoming overly involved to reduce them. Subsequently, we assert that being critical of a loved one with a serious illness is likely to result in self-reproach, and self-sacrificing and other EOI behaviors are likely to result in exhaustion, collectively reducing caregivers QoL.

METHOD

Participants

Participants included 106 dementia caregivers recruited throughout the United States through a series of Craigslist and Google advertisements posted nationally. We also placed calls to various agencies throughout the country that service elderly populations to let them know about our study and to provide contact information. As assessments took place via telephone, caregivers could participate from anywhere within the United States. We did not systematically record the city/state from which participants were calling. However, we did have fairly balanced representation throughout the United States, including the East and West coasts, the Northern and Southern regions, and the Midwest. Respondents were family members who served as unpaid, live-in caregivers to relatives who were 60 years or older and had received a prior diagnosis of dementia or age-related memory impairment (confirmed through the Dementia Clinical Rating Scale in our study). The relationships between the caregiver and the person with dementia were as follows: 55 adult offspring, 15 spouses, 19 grandchildren, 9 nieces/nephews, 6 children in-law, and 2 siblings.

Table 1 provides a breakdown of caregiver gender, ethnicity, marital status, education, and income. Although this study is focused primarily on caregivers, demographic information on patients' age, gender, ethnicity, marital status, and education were collected and are provided in Table 2. General exclusion criteria were caregivers being below age 18, not living with the person with dementia, being a paid, professional caregiver (e.g., nurse

TABLE 1
Caregiver Demographic Information (n = 106)

Category	Frequency	Percentage
Gender	Male: 20	18.9
	Female: 86	81.1
Ethnicity	White = 57	53.8
	Black = 30	28.3
	Hispanic = 7	6.6
	Asian-American = 2	1.9
	Other = 10	9.4
Marital status	Married = 44	41.5
	Divorced = 21	19.8
	Single = 34	32.0
	Separated = 6	5.7
	Widowed = 1	0.9
Education	Advanced degree = 21	19.8
	College degree = 41	38.7
	Some college = 40	37.7
	High school = 3	2.8
Annual family income	Some H.S. = 1	0.9
	Less than \$25,000 = 29	27.4
	\$25,000–\$50,000 = 31	29.2
	\$51,000–\$75,000 = 23	21.7
	\$75,000–\$100,000 = 15	14.2
	\$100,000+ = 7	6.6
	Declined to report = 1	0.9
Caregiver age range = 25–83; $M = 50.73$, $SD = 12.73$		

TABLE 2
Patient Demographic Information (n = 106)

Category	Frequency	Percentage
Gender	Male: 33	31.1
	Female: 73	68.9
Ethnicity	White = 58	54.7
	Black = 30	28.3
	Hispanic = 8	7.5
	Asian-American = 3	2.8
	Other = 7	6.6
Marital Status	Married = 25	23.6
	Divorced = 14	13.2
	Single = 11	10.4
	Widowed = 56	52.8
Education	Advanced degree = 10	9.4
	College degree = 18	17.0
	Some college = 17	16.0
	High school = 42	39.6
	Some H.S. = 10	9.4
	Grade 8 = 4	3.8
	Below grade 8 = 4	3.8
	Missing data = 1	0.9
Patient age range = 60–96; $M = 79.21$, $SD = 8.98$		

or home health aide), not being fluent in English, or the person with dementia being below age 60.

Procedure

The protocol used in this study was approved by the Institutional Review Board of the authors' home university. The study was telephone based and conducted nationwide. All participant contact occurred via telephone. Participants were read an IRB-approved consent script, and if they agreed, consented orally, prior to participating. When potential participants contacted our laboratory, they were first screened using the Dementia Clinical Rating Scale to confirm that they had a family member who met criteria for dementia. If deemed eligible, they were then administered the remainder of the instruments. All study questionnaires were administered via telephone by trained graduate students or undergraduate research assistants who entered participant responses into a secured computer network file.

Measures

Confirmation of dementia diagnosis and assessment of cognitive impairment

The Clinical Dementia Rating Scale (CDR; Hughes, Berg, Danziger, Coben, & Martin, 1982) was used to confirm dementia diagnosis and to evaluate cognitive impairment in patient functioning. The CDR is a semistructured interview that rates impairment in the following domains: Memory, Orientation, Judgment and Problem Solving, Community Affairs, Home and Hobbies, and Personal Care. Five-point ratings are used to assess each area, with 0 indicating "none", .5 indicating "questionable", 1 indicating "mild", 2 indicating "moderate", and 3 indicating "severe" (Morris, 1993). From these category ratings, a global CDR score which utilizes an identical rating scale (0 = "none", .5 = "questionable", 1 = "mild", 2 = "moderate", 3 = "severe") is attained using a computer algorithm developed by the Alzheimer's Disease Cooperative Study (Morris, 1997). To be eligible for this study, the individual with dementia had to meet criteria for a global CDR score of 1 or greater.

All interviewers completed an online training and reliability protocol that was developed by John Morris at the Knight Alzheimer's Disease Research Center Memory and Aging Project, and fulfilled the requirements for certification as a CDR rater. Coders first studied the online training materials, which consisted of videotaped interviews of participants and a detailed videotaped review of the scoring criteria corresponding to each interview. They then rated six training tapes. Coders could miss no more than one Global CDR score to be deemed CDR certified. If coders did not become reliable on the first round, additional scoring modules and training tapes could be assigned. However, all coders in this study achieved a minimum reliability of 83–100% agreement with the gold standard raters on the first attempt. For more details regarding the scale and training details, see Morris (1993).

Expressed emotion

Expressed emotion was assessed using the 20-item Family Questionnaire (FQ; Wiedemann, Rayki, Feinstein, & Hahlweg, 2002). This measure asks participants to rate, on 4-point Likert scales, the degree to which they identify with a range of statements concerning the family environment. The responses are further broken down into two subscales, Emotional Overinvolvement (EOI; e.g., "I have given up important things in my life in order to help him/her"; "I have to keep asking him/her to do things") and Criticism (CC/hostility; e.g., "I am often angry with him or her"; "He/she irritates me"). Each subscale

ranges from 0 to 40, with low scores representing low EOI and/or CC/hostility. The FQ has demonstrated adequate internal consistency (all Cronbach's $\alpha > .79$; Wiedemann et al., 2002) in prior research with categories correlating highly with those from the gold standard measure of EE: the Camberwell Family Interview (Vaughn & Leff, 1976). In this study, Cronbach's α for the EOI and CC/hostility subscales in this sample were .76 and .88, respectively. The reliability for the full scale was .88.

Quality of life

Caregiver's QoL was measured with 22 items from the Quality of Life Inventory (QOLI; Frisch, Cornell, Villanueva, & Retzlaff, 1992). This inventory has been shown to be related to other measures of subjective well-being and to have negative correlations with measures of general psychopathology (Frisch et al., 1992). Respondents are asked to rate the perceived importance of certain life domains and their satisfaction with these domains (i.e., health, self-esteem, love, etc.). Importance items are evaluated on a 3-point Likert-type scale that ranges from 0 ("not important") to 2 ("extremely important"). Satisfaction items are assessed on a 6-point Likert-type scale that ranges from 0 ("very dissatisfied") to 5 ("very satisfied"). Total scores were obtained by multiplying the importance and satisfaction rating for each domain and then averaging ratings across all 11 domains. A sample item includes, "How satisfied are you with your goals and values?" In this study, Cronbach's α for the QOLI was .86.

Caregiver stigma

Perceived stigma was measured with a variation on Fife and Wright's (2000) Stigma Impact Scale, originally developed to measure stigma toward people with HIV/AIDS. Burgener and Berger (2008) revised the scale to make the wording relevant for measuring stigma toward people with dementia. The revised scale was later adapted by Liu, Buckwalter, and Burgener (2014) to measure perceived stigma among caregivers of people with dementia. Liu et al. (2014) reported excellent internal reliability (Cronbach's $\alpha = .92$). The Caregiver Stigma Impact Scale, Caregiver Version, comprises four subscales: Social Rejection (nine items), Financial Insecurity (three items), Internalized Shame (five items), and Social Isolation (seven items). The instrument consists of 24 items with scores that are rated on a 0- to 4-point Likert-type scale. Scores can range from 0 to 96 with higher scores indicating higher perceived stigma. A sample scale item is "I encounter embarrassing situations as a result of my family member's illness." Internal consistency (Cronbach's α) in the current study was .93.

Statistical Analyses

Analyses were conducted with SPSS version 22 (IBM Corp, 2013). Primary variables were first examined for normality by assessing their skew and kurtosis. Skewness values between -1 and 1 and kurtosis values between -2 and 2 were considered acceptable (Bulmer, 2012; George, 2011; Joanes & Gill, 1998). Because greater patient symptom severity is likely to be associated with greater caregiver stigma, higher EE, and poorer caregiver QoL, we controlled for this variable in all analyses on theoretical grounds. We also think it is important to examine age, gender, and ethnicity as potential covariates because these variables could impact the caregiver experience. For example, the physical demands of caregiving may be harder on older caregivers and females and when the patient is male, as males generally weigh more and are harder to maneuver (Pinquart & Sörensen, 2006). Furthermore, some studies indicate that Caucasian caregivers, relative to ethnic minorities, demonstrate more negative outcomes related to caregiving including increased levels of burden, depression, and global role strain (Farran et al., 2007; Skarupski, McCann,

Bienias, & Evans, 2009; Suro & Weisman de Mamani, 2013). Thus, we examined the relationships between QoL and the following potential demographic covariates: caregiver age, patient age, patient gender, caregiver gender, patient ethnicity, and caregiver ethnicity. Pearson correlation coefficients were used for continuous variables (i.e., patient and caregiver age), *t*-tests were used to assess gender, and ANOVAs were used to assess ethnicity. We then examined the relationship of all primary variables (the Stigma Impact Scale, the Family Questionnaire subscales, and the QOLI) using Pearson correlation coefficients to determine whether hypothesized associations were significant. Finally, the PROCESS macro within SPSS was used to test EE as a partial mediator in the relationship between stigma and QoL (Hayes, 2013). This method of testing for mediation uses a bootstrapping approach, which is a random resampling process by which a confidence interval for the strength of the indirect effect is provided. When the confidence interval does not contain zero, there is evidence for a significant indirect effect. For this study, 5,000 bootstrap samples were performed.

RESULTS

Preliminary Analyses

Missing data and normality

Missing data were very minimal in this study. Two participants had incomplete data on one scale each (the QOLI and the Criticism subscale of the FQ). Missing data in these two instances were addressed using list-wise deletion. The skew and kurtosis statistics of all variables were examined and found to be within normal limits. Thus, no transformations were necessary.

Covariates

The relationship between other potential demographic covariates and QoL was examined next. Patient age and caregiver age were marginally related to QoL such that older ages were associated with decreased QoL ($r(105) = -.19, p = .052$; $r(105) = -.18, p = .062$, respectively). In addition, patient gender was significantly related to QoL such that caregiver QoL was higher for caregivers of male patients relative to caregivers of female patients ($t(103) = -2.54, p = .013$). Thus, patient age, caregiver age, and patient gender were used as covariates in the primary regression analyses below. There were no significant relationships between QoL and caregiver gender, patient ethnicity, caregiver ethnicity, caregiver education, family income, marital status, or relation to patient. Although patient symptom severity did not relate to QoL, as noted above, we also controlled for this variable in all primary analyses for theoretical reasons.

Primary Results

As hypothesized, greater caregiver stigma was positively associated with criticism ($r(103) = .372, p < .001$) and EOI ($r(104) = .398, p < .001$). In addition, both criticism and EOI were associated with poorer QoL in caregivers ($r(104) = -.345, p < .01$; $r(105) = -.349, p < .01$, respectively). EE total scores (i.e., the sum of the criticism and EOI subscales) were also significantly correlated with stigma ($r(103) = .434, p < .01$) and with QoL ($r(104) = -.393, p < .01$).

We began by examining whether high EE (criticism + EOI) significantly accounts for the indirect relationship between stigma and QoL. First, QoL was regressed upon stigma, while controlling for patient dementia symptom severity, patient and caregiver age, and patient gender. Stigma significantly related to QoL such that greater stigma was associated with poorer QoL ($b = -.43, SE = .13, p = .002$). QoL was regressed on stigma and

EE, and EE was regressed on stigma. Covariates in this analysis included patient dementia symptom severity, patient and caregiver age, and patient gender. Stigma significantly related to EE such that greater stigma was associated with higher levels of EE ($b = .29$, $SE = .06$, $p < .001$). EE significantly related to QoL such that greater EE was associated with poorer QoL ($b = -.60$, $SE = .22$, $p = .007$); however, stigma was only marginally related to QoL ($b = -.26$, $SE = .14$, $p = .079$). The indirect effect of stigma on QoL through EE was also significant, as the confidence interval did not contain zero ($b = -.18$, $SE = .07$, CI: -0.34 to -0.06). See Figure 1.

Next, we examined whether the indirect effect of EE in the relationship between stigma and QoL differed by subtype. QoL was regressed on EOI and stigma, and EOI was regressed on stigma (controlling for the same aforementioned variables). Stigma significantly related to EOI such that greater stigma was associated with higher levels of EOI ($b = .13$, $SE = .03$, $p = .03$). EOI significantly related to QoL such that greater EOI was associated with poorer QoL ($b = -1.03$, $SE = 0.43$, $p = .019$). Stigma also related to QoL ($b = -.30$, $SE = .14$, $p = .04$). The indirect effect of stigma on QoL through EOI was also significant, as the confidence interval did not contain zero ($b = -.13$, $SE = .06$, CI: -0.69 to -0.17). See Figure 1.

Criticism was examined next. QoL was regressed on criticism and stigma, and criticism was regressed on stigma (controlling for the same aforementioned variables). Stigma significantly related to criticism such that greater stigma was associated with higher levels of criticism ($b = .16$, $SE = .04$, $p < .001$). Criticism significantly related to QoL such that greater criticism was associated with poorer QoL ($b = -.79$, $SE = .34$, $p = .02$). Stigma also related to QoL ($b = -.30$, $SE = 0.14$, $p = .03$). The indirect effect of stigma on QoL through criticism was also significant, as the confidence interval did not contain zero ($b = -.13$, $SE = .07$, CI: -0.30 to -0.03). See Figure 1.

DISCUSSION

This study examined the interplay among stigma, EE, and QoL in caregivers of individuals with age-related dementia. Specifically, we hypothesized a model whereby caregivers

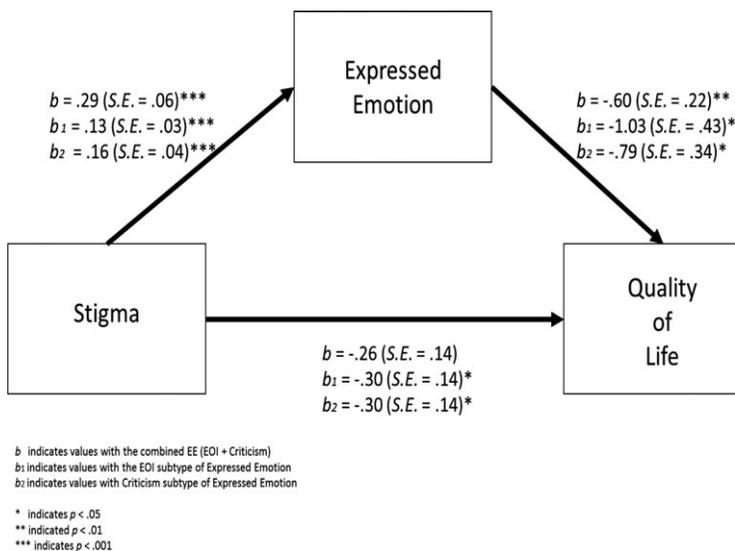


FIGURE 1. Path Diagram in Relationship Among Stigma, Expressed Emotion, and Quality of Life (Paths Represent Direct Effect of Relationships Between Variables).

who are prone to experience stigma may become angry at or criticize their mentally ill relative and/or intrude in their affairs or take over in a self-sacrificing manner (EOI) as an attempt to control symptomatic behaviors that are perceived as stigmatizing. In turn, although we did not specifically examine guilt in this study, caregivers may feel guilty for being critical of an ill family member, and depleted due to all the self-sacrificing and intrusive behaviors, which ultimately detract from their overall QoL.

In line with expectations and with the results of Phillips et al. (2002) in a schizophrenia sample, in this study we found that greater stigma was associated with higher EE. Also as expected, and consistent with findings of Wagner et al. (1997), we found that higher EE (both criticism and EOI) was associated with poorer QoL in caregivers. Finally, results of this study suggest that greater caregiver stigma is linked to poorer QoL and the pathway whereby stigma influences QoL is at least partially mediated by EE. In other words, it appears that caregivers who feel greater stigma engage in higher EE behaviors, which in turn negatively affects their QoL. It is important to underscore that both types of high EE (criticism and EOI) are linked to greater stigma and poorer QoL. Although our study is cross sectional, it is not difficult to see how stigma might lead to both subtypes of high EE and how in turn this might result in poorer QoL in caregivers. In Table 3 we provide a case example that might help illustrate the model tested and supported in this study.

Results from this study suggest that researchers and clinicians should formally assess stigma and EE as part of a standard test battery or work-up with dementia caregivers, as these factors appear to be strongly linked to QoL. Moreover, study findings point to a strong need to combat caregiver stigma and high EE attitudes. How might this be done? In some respects, high EE attitudes and behaviors are an understandable, often visceral response to patients' behaviors that are perceived as stigmatizing, embarrassing, or annoying. Nonetheless, prior studies have shown a link between the attributions family members make regarding the cause of a relative's illness and the associated symptoms and emotional reactions that they have toward this relative. For example, several studies (Weisman & López, 1997; Weisman, López, Karno, & Jenkins, 1993; Weisman,

TABLE 3
Case Example

Sue is a 52-year-old live-in caregiver for her mildly to moderately demented, 83-year-old, father, Dan.

Overall, Dan can still carry on simple conversations and is able to take care of primary activities of daily living (e.g., eating, bathing, and walking). However, Dan has become very forgetful lately, asking the same set of questions repeatedly and engaging in behaviors that have the potential for danger (e.g., leaving the stove on; getting lost on walks around the neighborhood). As a result, Sue is hesitant to leave him home alone and has begun taking him with her on errands and to events whenever no other family member is available to care for him. Recently, Sue brought her father to a work-related holiday party at her boss's house. Sue was looking forward to the party as she enjoys her co-workers and rarely has a chance to socialize since becoming a caregiver 2 years ago.

Once at the party, however, Sue quickly became embarrassed and frustrated by her father's behaviors.

Soon after they arrived, Sue was having a pleasant conversation with her boss when she noticed that her father was piling too much food on his plate and spilling some of it on his clothing and on her boss's floor. Fearing that the host would judge her for her father's behavior and for bringing him to the party (stigma), she quickly approached Dan saying, "Dad please stop making a pig of yourself and spilling food everywhere" (high EE-crit). For the rest of the evening, she kept Dan within an arm's length. In conversations, Sue answered questions that were posed to her father. When Dan reached for food, she insisted on getting it for him, even feeding him herself with a fork to ensure that he did not spill it (EOI). Not surprisingly, Sue left the party exhausted and depleted. Furthermore, she began feeling bad about herself for being short with her father for behaviors that she knew, intellectually at least, he cannot control. This chain of events led to a more general decline in her overall QoL that spilled over to the rest of the weekend and into the following week.

Nuechterlein, Goldstein, & Snyder, 1998) have shown that when family members make external attributions toward a mentally ill person's symptomatic behaviors, they are less likely to hold high EE and other negative attitudes and emotions (e.g., frustration, anger) toward them. Teaching caregivers to make more accurate, external attributions toward their loved one's symptomatic behaviors through education about dementia (e.g., focusing on the biological aspects of the disease) could gradually help to reduce high EE attitudes. This in turn could improve caregiver QoL and improve patient prognosis.

At the societal level, awareness campaigns may be one avenue to reduce the stigma associated with having or caring for someone with dementia. In January 2013, the Alzheimer's Society of Canada launched a nationwide campaign called, "See me, not my disease. Let's talk about dementia." Although results are not yet available, the overarching goals of the campaign are to address myths about dementia, shift attitudes, and make it easier for people to understand and talk about dementia (Alzheimer Society Canada, 2013).

Large-scale campaigns like the one mentioned in the previous paragraph are likely to have some impact on addressing stigma around dementia at the societal level. However, they are costly to implement and may take years to have an impact. Furthermore, as Phillips et al. (2002) astutely point out, stigma and discrimination are usually experienced and interpreted at the level of the individual, rather than the community. In other words, depending on personality, prior experiences, etc., every caregiver will react differently to actual or perceived stigma. Thus, a more proximal route for researchers and clinicians is to develop programs that encourage caregivers to externalize stigma as reflecting societal ignorance about dementia, rather than internalizing it as one's own shortcoming, which could aid in this regard. Educating caregivers about the links among stigma, EE, and QoL may also be helpful.

It is important to point out that a few family educational programs already exist to educate dementia caregivers. For example, the Alzheimer's Association (2017) offers programs for family caregivers and individuals facing Alzheimer's disease that are designed to explain the disease and prognosis, understand the symptoms and care needs, learn ways to maximize safety and prepare for emergencies, and to explain some of the legal and financial aspects of the illness. A qualitative study at the Stanford University Medical Center (Ghatak, 2011) also examined a comprehensive program to educate dementia caregivers about the care and safety of their relatives suffering from dementia and support them in the day-to-day coping with the disease. Results indicated that the large majority of participants (over 90%) reported that they felt like they had achieved better acceptance and understanding of their loved one's illness, and learned more adaptive coping skills, after attending the program. Results of this study suggest that integrating components directly aimed at reducing caregiver stigma and high EE into these educational programs may further enhance the efficacy of existing interventions.

CONCLUSION, STUDY LIMITATIONS, AND FUTURE DIRECTIONS

Study findings suggest that targeting perceived stigma associated with dementia may be one route to reducing high EE attitudes thereby indirectly improving QoL. This study is limited by the cross-sectional nature. Longitudinal studies are necessary to assess whether stigma does indeed precede high EE attitudes and whether high EE results in poorer QoL over time.

It would also be helpful to address other potential factors that could influence the development of dementia caregivers' stigma and impact their QoL in future research. For example, are caregivers who are predisposed to experiencing guilt and shame more likely to feel stigmatized in response to dementia in a loved one, and are these emotions linked to caregiver EE and QoL? Studies that examine shame and guilt proneness using the Test of

self-conscious emotions (Tangney, Wagner, & Gramzow, 1989) might be helpful in this aim. Furthermore, in this study we did not assess the quality of the relationship between patients and caregivers prior to the onset of dementia. It would be interesting to see in future research whether premorbid relationship quality had an impact on caregiver QoL postdementia or whether relationship quality moderated any of the other patterns examined in this study.

The study is also limited by the use of a self-report scale to measure EE. While, as noted earlier, the FQ has good concordance with interview measures of EE (Vaughn & Leff, 1976; Wiedemann et al., 2002), some of the items assess constructs in an indirect manner (e.g., inferring criticism based on the expression of anger and annoyance toward the patient rather than counting the number of critical comments actually expressed toward the patient). In future studies it would be helpful to replicate the findings in this study with interview measures of EE and/or develop self-report scales that tap EE in a manner that maps more directly on to the existing interview approaches.

Prospective intervention studies that attempt to reduce stigma and EE through cognitive remediation and then examine the effect of this on caregivers' QoL over time are clearly warranted. Research using methodologies such as daily diary experience sampling and other momentary sampling approaches whereby caregivers are asked in real time about their loved one's current symptomatic behaviors and the attributions, attitudes, and emotions these symptoms trigger may also be helpful in obtaining a more concrete and accurate understanding of how stigma, EE, and QoL interact.

A final consideration is that our sample was marked by heterogeneity in the relationship among caregivers and patients. It is possible that the interplay among EE, stigma, and QoL would differ based on the nature of the relationship (e.g., child vs. spouse vs. sibling). Unfortunately, our subgroup samples were not large enough to examine this question empirically. However, it will be important in future research to assess whether the nature of the relation between patients and caregivers has an impact on caregiver stigma and EE toward the patient and/or whether the impact of caregiver stigma and EE on patient QoL varies by relationship status (e.g. marital vs. parental).

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